Effectiveness and impacts of assistive technologies in supporting informal caregivers

Visions for Change Policy Challenge 2024-2025

AGEWELL
Canada's technology and aging network

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Executive Summary

This policy report aims to explore which assistive technologies (AT) are effective in supporting friends and family caregivers and what is their impact on burden and wellbeing outcomes, while highlighting caregivers' needs and preferences. These technologies range from simple devices like medication reminders, to more sophisticated systems that monitor health issues and offer remote assistance.

A scoping review was conducted, a method of choice that involves searching various databases and sources to describe the breadth and depth of a field of complex topics[1]. The review findings indicate a lack of consensus on the classification of Assistive Technology (AT), ranging from assistive to adaptive and accessible technology, hindering accurate generalizations about its impact on caregivers. The scarcity of caregiver-specific AT underscores a market gap, neglecting unique needs and challenges faced by caregivers. While AT is commonly designed for dementia patients, its impact on caregivers' burden and wellbeing remains inconclusive. Existing research reveals a need for comprehensive, long-term studies to assess AT's effects on caregivers, encompassing mental health, stress levels, and overall quality of life. This crucial information is essential for providing caregivers with adequate support and resources. In addition, the review found that supports for friends and family caregivers in Canada differ between provinces and territories, making their availability uneven and variable. In the face of this dilemma, AT may play a pivotal role in empowering older adults and their friends and family caregivers.

This policy report outlines one recommendation that policymakers can implement to help organizations across Canada transition to AT, while reaching a mutual understanding of specific AT that support friends and family caregivers. Considering that most people will at some point become caregivers, the healthcare system must be prepared for the surge in demand for AT and friends and family caregivers' support.

Policy Question

Which assistive technologies have demonstrated effectiveness in supporting informal caregivers and what is their impact?

Assistive Technologies:

"any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." [2]

Informal Caregivers

"family and friends who provide unpaid assistance with tasks such as transportation and personal care—help seniors[a] remain in their homes, thereby reducing demands on the health care system." [3]

[a] The statement was reported as described by the OECD; therefore, the term "senior" was preserved, but we acknowledge that the targeted community prefers "older adults", which is the term used in this report.

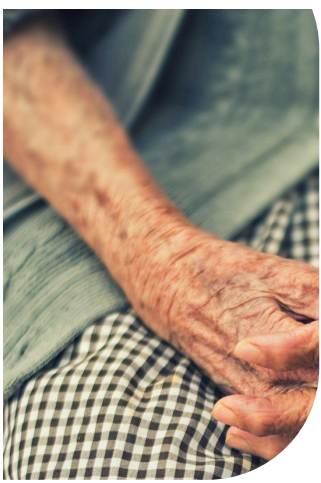
Background

An overview of existing services and programs in Canada for friends and family caregivers is needed to better understand current care arrangements and how AT is introduced to them. This section presents firstly the assistive technologies available to older adults and provides secondly an overview of the existing services and programs for friends and family caregivers, while highlighting the key findings and gaps in the literature.

1. Aging population and assistive technologies

About 46% of Canadians aged 15 years and older have provided care for a family member or friend with an aging need, a disability, or a long-term health condition[4]. While it is predicted that the number of elderly people in need of care will double by 2030[5], there is a lot of promise in leveraging AT to maximize their autonomy and, most significantly, to support caregivers.

Innovation in technology has immense potential to help people with aging needs and disabilities[6]. Over the past few decades, there has been a notable acceleration in the development of sensors, artificial intelligence, robotics, and information and communication technology[6]. Although numerous terms are used to present AT in Canadian policy and legislation, Wang & Wilson, (2022)[7] specified that AT encompass wheelchairs, medication reminders, or symptom management apps, and



products for the general population including computers and software for teleconferencing, smart home systems, and mobile scheduling apps. AT clearly covers a wide range of tools and solutions to meet different needs, demonstrating its adaptability and capacity to deal with various challenges in caregiving contexts.

In a recent report, Carers UK, (2018) [8] argues that while technology cannot offer enough care on its own, it may be incorporated into larger systems to improve or augment current care arrangements. For instance, online platforms and mobile applications can provide a centralized hub for information on available respite services, making it easier for family and friends caregivers to locate and access these services. By incorporating technology into the respite care system, family and friends caregivers may also benefit from improved coordination of care, as digital tools can facilitate communication and collaboration between different healthcare providers and support networks. One bottleneck to consider when using AT with older adults is that they usually require human support to use them since they are often inexperienced with them or are unable to use them on their own. This reliance on human support can be both a benefit and a challenge. On one hand, the presence of a caregiver can ensure that the older adult is able to effectively use the technology [9,10]. On the other hand, it could place an additional burden on the caregiver, who may already be overwhelmed with other responsibilities [11,12]. It is then important to identify which AT are effective in supporting friends and family caregivers and what is their impact on burden and wellbeing.

2. Existing services and programs

Respite care is the main program in Canada that specifically targets friends and family caregivers, and even then, eligibility is usually determined by the requirements of the older adults rather than the caregiver[13].

In cases where respite services are offered, friends and family caregivers often have little knowledge about them[14], perceive them as costly, or encounter challenges in locating and using them[15]. Similarly, research by the AARP (2020)[16] (previously known as the American Association of Retired Persons) revealed that the lack of knowledge about respite care options led to underutilization of these services.

While caregiver tax credits are offered by all provinces and territories, most are nonrefundable, income-tested, and subject to the same qualifying requirements as federal tax credits. There are some exceptions, such as the means-tested but refundable primary caregiver tax credit in Manitoba and the means-tested but refundable caregiver and respite care tax credits in Quebec[6,17]. Most caregivers are ineligible for the Quebec caregiver tax credit and its upgrades since only a fraction of caregivers live with the person they care for17.

Moreover, key disparities exist amongst friends and family caregivers, as some benefit more than others from caregiver support programs. Higher-income earners gain more financially than lower-income earners, for instance, because financial benefits (e.g. tax credits or income supplements) are determined as a percentage of wages[18]. Similarly, higher-income earners benefit more from nonrefundable tax credits compared to lower-income earners[18].

In conclusion, the aging population leans heavily on unpaid caregiving, and emerging assistive technology offers a potential solution. However, existing caregiver support primarily centers around respite and tax incentives rather than technological advancements. Technologies can support individuals with activities of daily living (ADLs), medication management, social connectedness and more and provide autonomy, independence, and peace of mind. There is great potential for assistive technologies to support both individuals who require care and their caregivers.

Research Approach

A scoping review of published reviews was performed following Arksey and O'Malley recommendations [1]. Grey literature was also reviewed to extract any policy reports relevant to the research question. Our approach included:

1. Identifying the research question
2. Identifying the scope of AT and their impacts on informal caregivers
3. Selecting the most relevant reviews
4. Collecting and charting the data according to the key questions
5. Summarizing the findings and analyzing patterns within the data.

The data charting was conducted using a standard form. When information was missing in the included studies, the first author attempted a contact with study's investigators to obtain and confirm data. The results were synthesized and grouped per characteristics of studies included and characteristics of AT (type of technology, indicators of caregivers supporting) and experiences and outcomes of caregivers. The outcomes were mapped out to the conceptual framework of outcomes for caregivers of AT users to better understand the impact of AT on caregivers in term of quality of life, psychological health factors, physical health and participation [19]. More information about the research method is described in Appendix 1.

Key findings

(See Appendix 2 for further details)

The following findings are extracted from relevant studies and 4 literature reviews published between **2017** and **2022**, each of which reported between 10 to 56 studies results related to the impact of AT on friends and family caregivers.

No agreement on the classification of AT available to users

The definitions vary from assistive technology [20], adaptive technology [21] to accessible technology [22]. This lack of consensus makes it difficult to accurately generalize about the impact of AT on caregivers. Additionally, the wide range of AT options further complicates the issue, as different technologies may require varying levels of support from caregivers.

Caregiver-specific AT was notably less common, as just one review[10] reported these technologies.

This limited availability of caregiver-specific AT highlights a gap in the market, as caregivers often have unique needs and challenges that could be addressed through specialized technology.

AT are commonly designed for patients with dementia, particularly GPS trackers, motion sensors, and medication reminders [9–11].

While these AT were widely viewed as valuable by users and their friends and family caregivers, the effect on caregivers' burden, satisfaction, or wellbeing outcomes was not significant.

The review by Sriram et al., (2019)[9] showed that among 16 included studies in which AT were reported as 'somewhat' or 'very useful', no significant changes in caregivers' well-being or burden outcomes were reported.

This highlights the need for more comprehensive research that examines the long-term effects of AT on caregivers, including their mental health, stress levels, and overall quality of life. Without this information, caregivers may continue to struggle with the challenges of caregiving without the necessary support and resources.

Main Policy Recommendations

A consensus-building body should revisit the terms used to describe AT specific for older adults and caregivers.

How ?

This could imply creating standardized guidelines for the classification and evaluation of AT while emphasizing caregiver-specific AT. This process would involve engaging educators, institutions, and stakeholders in discussions to ensure that the terms used accurately reflect the needs and experiences of older adults and caregivers. In addition, several organizations that could potentially lead implementation of this recommendation, such as Health Canada, the Canadian Medical Association, or the Health Standards Organization.

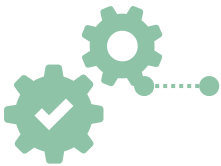
Additionally, this recommendation could be implemented within the framework of continuing education programs accredited by professional organizations for healthcare professionals. Training content could be revised and co-created in collaboration with caregivers and AT older adults to capture their needs and experiences.

Benefits of implementing this recommendation

- Consistency in classification facilitates shared understanding in communication among policymakers, researchers, and health professionals.
- Standardization enables a more precise measurement of AT's impact on caregiver well-being and burden, and may improve the quality of research, potentially leading to more informed conclusions.
- Recognizing caregiver-specific AT emphasizes caregivers' individual needs in the care trajectory. Training friends and family caregivers improves home care by giving them the skills and knowledge they need to use effectively AT.

Challenges

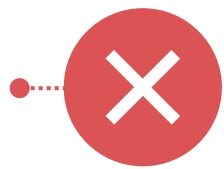
- Implementing new standardized norms requires time and resources.
- Educational institutions may need financial and human resources to update courses and provide additional training.
- Training within care settings for continuing education requires additional time under an already strained system.



Feasibility

- ***Government:*** Relies on political will to spend money on developing guidelines.
- ***Economic:*** Implementation costs may be offset by improved research quality and more informed policy decisions.
- ***Key stakeholders*** should identify any additional training needs for educators or health professionals to effectively deliver content related to AT.

Sources of Potential Risk and Mitigation



- **Risk:** Opposition from industry interests.
- Mitigation: To obtain a balanced approach, include industry representatives in the drafting of recommendations.
- **Risk:** Inadequate researcher and health professionals' adoption.
- Mitigation: Provide researchers with training and incentives to follow the rules.

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APPENDIX 1: Description of the Research Method

Effectiveness of assistive technologies in informal caregivers of adults with disabilities: A scoping review

Six-Stage Framework

- A scoping review is the method of choice to describe the breadth and depth of a field of research that is complex (Arksey & O'Malley, 2005; Levac et al., 2010)
- PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines.

Stage 1 — Identifying research question

Which assistive **or social technologies** have demonstrated effectiveness in supporting **unpaid caregivers friends/ family** and what **is their impact?**

- Which assistive technologies have demonstrated effectiveness in supporting informal caregivers ?
- To which extent supportive technologies impact the experiences and outcomes of informal caregivers ?

Stage 2 — Searching for relevant studies

- **Inclusion criteria:** quantitative/ qualitative studies published in English or French in peer-reviewed scientific journals; in accordance with each of the following statements: (1) The study addresses the assistive technology as a primary research topic (2)The study includes informal or natural caregivers (3)The assistive technology is primarily used by adults (> 18 years old) with physical (eg, traumatic brain injury, stroke) or cognitive disabilities (eg, dementia)
- **Exclusion criteria:** Studies that don't encompass informal caregivers (eg, family, friends, etc.). Studies that don't include outcomes or experiences of caregivers.

Electronic Search Strategy-2013 January 1st -2023

Scopus: (TITLE-ABS-KEY (caregiver*) AND TITLE-ABS-KEY ("self help device*"))
EMBASE: exp self help device/ AND exp caregiver/
MEDLINE: ("Self-Help Devices"[Mesh] AND "Caregivers" [Mesh]))

Stage 3 — Selecting studies

The **title** and **abstract** of each article will be inspected by one of the authors to identify those meeting the selection criteria. If this was unclear, then the full paper will be examined.

- The reference list of the included articles will be reviewed to identify any existing studies relevant to the topic.
- Schematic diagram of the literature search
- *Nbr. eliminated articles*
- *Nbr. Unclear abstracts*
- *Nbr. selected articles, etc.*

Stage 4 — Charting the data

- The data charting will be conducted by the first author (DRA) using a calibrated form.
- The form will be reviewed by two of the co-authors prior to starting the charting process (SA and ?). When information was missing in the included studies, the first author will attempt a contact with the study's investigators to obtain and confirm data.

Stage 5 — Collating, summarizing and reporting the results

- The results will be synthesized and grouped per:
1. Characteristics of studies included (population and assistive technology used)
2. Indicators of effectiveness and impact on caregivers (indicators of supporting recieved and experiences and health- related outcomes)

	Population (Caregiver and assistive technology user)	Assistive technology	Indicators of effectiveness in supporting the caregivers	Experiences and Outcomes relevant to caregivers
Authors; Year of publication				

Stage 6: Incorporating consultation with stakeholders to validate study findings

Discuss with stakeholders the implications of study findings to practice, research and **policy**.
Findings will be translated into evidence informed policy recommendations following APEASE criteria as reported by West and colleagues (2019)

APEASE criteria can be used to draft recommendations or help policy makers identify factors that may influence the intended outcome when applying the recommendation.

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APPENDIX 2: Table of Key Findings

Author (Year)	Studies included (n, date)	Population	AT for users and informal caregivers	Effective AT	Experiences and Outcomes relevant to informal caregivers
(D'Onofrio et al., 2017)	26 studies published between 2000 and 2015	Patients with dementia and their formal and informal caregivers	"Application of information and communication technologies" **Older adult** "electronic applications providing reminders (e.g., medication management prompting devices), social contact (e.g., cell phones, online chat groups), safety (e.g., alarm systems and action triggered lighting), and daily activities (e.g., music players)." **Informal caregiver:** "a customized computer–telephone integration system that provides a psychoeducational intervention; video monitoring; text-based chat forums and web-based video conferencing."		- Better caregiver wellbeing -decreased caregiver burden and depression -strengthen family caregivers' confidence in caring for persons with dementia - improved communication and behavior management and ease of use
(Sriram et al., 2019)	56 published between 2000 and 2017	Patients with dementia and their informal caregivers	**User:** the electronic medication reminders; tracking devices and home safety devices; supporting memory and orientation; social interaction and leisure activities devices **Informal caregiver:** not reported	GPS tracker : Enable people to participate in meaningful activities; tracking as a secondary intervention; ADL gateway with alarm button, sensors: useful if dementia deteriorates Telecare (Videoconferencing) and sensors: useful PAL4 BV - agenda for the day, diary, two-way video contact: considered the system useful and user friendly Unattended autonomous surveillance system : very useful	Relationships: - AT strengthened social bonds, aiding leisure, memory, and interaction. - Became a valued member of the broader social network. - fear to replace the 'person' component of caring Autonomy: - AT provided an alternative to controlling methods, fostering independence. - Balanced personal time and space for caregivers. -fear from the AT may reduce social care Safety: - AT, including tracking devices, ensured safety and independence. -Quality of Life: - AT improved mental well-being, easing worries and burdens. Competence: - AT enhanced independence for individuals with dementia

					and benefited caregivers personally. -lack of unfamiliarity with AT -AT created more dependence of the person with dementia on the carer,
(Björg Thordardottir et al., 2019)	30 published between 2007 and 2014	People diagnosed with mild cognitive impairment (MCI), or advanced or severe dementia or Alzheimer Disease (AD), their formal and/or their informal caregivers.	Older adult: devices related to support memory social contact; sensor technology; lost seeking devices; social assistive robot; etc.	The Automatic Night & Day Calendar; The Lost Item Locator; The Automatic Night Lamp; The Gas Cooker Device; The Picture Button Telephone: perceived as useful	While some informal caregivers were less anxious after accepting to use AT, others reported a decrease in their quality of life.
(Marasinghe et al., 2022)	10 published between 2010 and 2015	Older adults with all conditions and informal caregivers	Older adult : an assistive robot; standard and intelligent power wheelchair; in-home monitoring and communication.	Caregivers found that Intelligent wheelchairs decreased risks of accidents while care recipients are participating in social activities.	-Decreased caregiver burden and helped to maintain the quality of life of caregivers (e.g. reducing time, levels of assistance, anxiety and fear) - Some participants reported that AT could add to caregiver burden (e.g. by making the caregivers more accessible through AT that allows virtual communication and monitoring and bringing further worrying and stress to the family members)