



DESIGNING TECHNOLOGY THAT CARES

BARRIERS TO CARERS' TECHNOLOGY ADOPTION

Written by Jacquie Eales, Janet Fast & Jennifer Boger, on behalf of DATCares Team

BARRIERS



Lack of Awareness



Failure to Solve Carers' Problems



Affordability



Lack of Internet Access



Lack of Support



Inadequate Digital Skills



Impact on Relationships

STRATEGIES

- Provide information and education from trusted sources and establish searchable repositories of technologies available for carers with ratings and reviews by carers.
- Address carers' perceived problems through empathic design, linking carers with product designers and developers and involving carers from the beginning in a co-design process.
- Enhance affordability by enhancing existing financial assistance to carers who are experiencing financial hardship and by considering multiple payment models that could include third party payers.
- Ensure equitable internet access by continuing to develop infrastructure in all communities, and ensuring fees for internet access are affordable for most Canadians, including carers.
- Enhance digital literacy by improving access to digital literacy education and training programs and designing technologies that are easy to use by carers with basic digital literacy skills.
- Facilitate AT adoption and continued use by providing opportunities to trial new products before committing to purchase, and providing post-purchase support, including from a real person.
- Develop technology that supports relationships by using an empathic design process and protecting and making transparent privacy of personal information collected when using technologies.

Funding provided by:



Canadian Institutes of Health Research
Instituts de recherche en santé du Canada





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KEY MESSAGE

Care provided by family members and friends to those with chronic, acute or age-related health problems is foundational both to care needs being met and to sustainability of publicly funded health and continuing care systems. Yet many family carers are under duress because of their caring responsibilities and at risk of becoming the poor, isolated and lonely elders of tomorrow. Assistive technologies have the potential to support carers, but only if they are appropriate, accessible, and sustainable. There are a number of barriers that prevent carers from accessing, adopting and integrating technologies that meet their unique needs: lack of awareness; failure of AT to solve carers' problems; affordability; lack of internet access; lack of capacity to engage with technologies; lack of ongoing support through the adoption process; and resistance from their care receivers.

FAMILY/FRIEND CAREGIVING IS A 'WICKED PROBLEM'

Increasing longevity and rising rates of disability are creating a 'perfect storm' in which the demand for care is outstripping the supply of care, both by paid care workers and family/friend carers¹. The more than 1 in 4 Canadians who were family/friend carers in 2012 collectively spent 15.5 billion hours that year caring for someone with a long term health problem, physical or mental disability, or aging-related needs². Family/friend carers juggle care with other aspects of their busy lives, including paid employment, education and job training, intimate relationships and child rearing³. While many Canadians who take on care responsibilities reportedly benefit from a strengthened relationship with the person for whom they are caring and personal growth through the care journey⁴, carers often also report a wide range of health⁵, social⁶, employment⁷ and financial⁸ consequences. To replace carers' labour would cost the Canadian health and social care system a conservatively estimated \$66.5 billion⁹ — equivalent to 1/3 of the total expenditures on formal health care services in the same year¹⁰. Prime Minister Trudeau has recognized carers' valuable contributions and identified several ways that public policies and programs are changing to better support carers¹¹. For example, in 2017-18 the federal government extended the Compassionate Care program and simplified the caregiver tax credit system. But there is a role for all stakeholders, including governments, carers, NGOs, product developers, designers, producers, and retailers, in creating a sustainable care system.

WHAT ARE ASSISTIVE TECHNOLOGIES FOR CARERS?

Technology alone cannot provide adequate care, but it has a role to play in creating a sustainable care system. While assistive technologies (AT) cannot replace the human touch, carer-specific or common market devices, products or services have the potential both to support those with care needs to live independent and active lives, and to assist those providing care¹². Small tools can make a big difference in carers' lives. For example, care coordination technologies can facilitate care planning, communication and records management. Remote monitoring technologies can provide carers with peace of mind when it comes to safety of the person for whom they are caring and alert carers to situations that need immediate attention. And social networking technologies can enhance carers' social relationships and link them to peer support.

BARRIERS TO CARERS' TECHNOLOGY ADOPTION

There are a number of challenges to overcome to facilitate the uptake of assistive technologies to better support family/friend carers, reduce negative impacts of caring on their lives and enhance their overall well-being. Below we identify seven barriers and offer potential strategies to address them.

Lack of Awareness



Failure to Solve Carers' Problems

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1. Lack of Awareness



Carers need the right product or service at the right time. The care journey is new, unfamiliar, and dynamic territory for most carers. Most don't know how or where to access resources, information, products or services that can help them and must rely on their own resourcefulness to compensate for lack of easily accessible information¹³. They may not even know what they need until confronted with an immediate challenge¹⁴. And other life demands leave little time to research and find products and services that can make a real difference in their lives. Carers' top desire is to know what they need to know before they need to know it¹⁵. There are risks to relying on vendors, motivated as they are by profit, for information rather than government agencies and NGOs whose mandate is to serve the public good. Pre-purchase information and education from trusted sources would help carers navigate the overwhelming amount of information available on the internet.

POTENTIAL STRATEGIES TO PROVIDE INFORMATION AND EDUCATION FROM TRUSTED SOURCES:

- Establish searchable repositories of technologies available for carers, backed by large, reputable and trustworthy organizations (governments or non-governmental advocacy and service organizations such as Alzheimer Society, Canadian Association of Retired Persons (CARP), Carers Canada). Alternatively, governments may fund establishment and maintenance of such a system. Ideally, an online system would include product reviews and ratings by carers as valued users and trusted experts themselves.
- Improve system navigation (including creating system navigation technologies and secure sharing of health information) to reduce the burden on carers who must way-find across multiple providers, systems and sectors, repeatedly providing the same information to different providers.

BARRIERS TO CARERS' TECHNOLOGY ADOPTION

2. FAILURE OF AT TO SOLVE CARERS' PROBLEMS



Assistive technologies are increasingly beneficial, IF the design process is based on a comprehensive understanding of end-users' needs and context. Carers are often not involved in establishing the challenge or design problem the technology is intended to address. Carers clearly stated their reluctance to invest their limited time in AT that addresses minor annoyances, require too much effort to use and integrate in their busy lives, add to their burden or do not adapt to changing needs. A DATCare family carer who reviewed an app that facilitates care circle communication remarked: "While the information in the app is important, my family already has a shared calendar and group message system. New systems are time consuming to switch over and set up. This app would have to be worthwhile to change my family's current strategies."

POTENTIAL STRATEGIES TO ADDRESS CARERS' PERCEIVED PROBLEMS:

- Improve the ability of AT to meet carers' needs by linking carers, product designers and developers in a co-design process. One DATCares participant said: "We have to get a true understanding of the problem and challenges to truly design good AT." HUDDOL, Canada's first bilingual collaboration network, creates a space where people can seek out carers' wisdom and contribute to a pool of insight to help carers achieve better health and wellness outcomes along their care journeys.
- Encourage product and service standards writers (such as the Canadian Standards Association and the Canadian General Standards Board) to address the AT design process ensuring that it adheres to user-centred design principles.

3. AFFORDABILITY



According to one DATCares carer, "Caregiving is expensive, not just time consuming". More than 40% of carers in Canada incur care-related out of pocket expenditures, 18% of whom experience financial hardship as a result, often using or deferring savings to cover these extra costs⁸, putting their own financial futures at risk. AT must be affordable for carers who often balance price with [or against] effectiveness. While AT, such as wheelchairs and other mobility aids, are often subsidized by governments for eligible care receivers, carers are not considered 'clients', making them ineligible for subsidies for technologies that would support their needs. As a result, they incur the full cost. It should be noted that, if carers were eligible for subsidies for supportive technologies, they would still be subject to the same constraints as technologies for care receivers such as long wait lists, funding delays, delayed procurement, and insufficient coverage¹³.

POTENTIAL STRATEGIES TO ENHANCE AFFORDABILITY:

- Consider multiple payment models that could include third party payers such as governments, insurance companies and employers and build the business case for them. This may include:
 - Amending health care policies to make carers eligible for products and services in their own right.
 - Working with private insurers and employers to encourage subsidies for carer AT.
- Offer/enhance existing financial assistance to carers who are experiencing financial hardship because of their care-related expenditures (e.g. caregiver tax credits; carer benefit, pension credits for carers).

BARRIERS TO CARERS' TECHNOLOGY ADOPTION

4. LACK OF INTERNET ACCESS



Over 85% of Canadians are internet users and nearly all Canadians under the age of 45 use the internet every day¹⁶. Many digital technologies available today rely on having a computer, tablet or smartphone and internet access. Carers' interest in using technology to enhance their care is high¹⁷. Yet access to the internet is not affordable for some, and not reliable for others who live in rural or remote parts of the country. While living in a rural community is not a significant predictor of carers' ability to use and understand digital information, it does predict their internet use¹⁸.

POTENTIAL STRATEGIES TO ENSURE EQUITABLE INTERNET ACCESS:

- Continue developing infrastructure in all communities, especially rural and remote regions. For example, the federal government's Connecting Canadians program is extending and enhancing broadband infrastructure to reach previously underserved communities in rural and remote parts of the country, some for the first time¹⁹.
- Enhance or extend internet access through public libraries to support those without personal computers or a data plan.
- Ensure that fees for internet access are affordable for most Canadians. Compared to other countries, Canadians pay among the highest rates for home internet and mobile wireless access²⁰.
- Offer internet access subsidies for people who are recognized carers to facilitate access to information and resources and prevent social isolation.

5. INADEQUATE DIGITAL SKILLS TO ENGAGE WITH TECHNOLOGY



Technologies are often designed based on inaccurate assumptions about carers' digital literacy or their capacity to engage with it. Many carers lack the expertise needed to interact with digital technologies, leaving them frustrated and products abandoned. Older carers' digital literacy skills can be lower than their younger counterparts', but other factors play a bigger role in their ability to access, use and comprehend digital information and tools: lower educational attainment and income, and being unemployed or a landed immigrant¹⁸. ICT literacy also has been shown to reduce care-related employment impacts, including labour force exit¹⁸.

POTENTIAL STRATEGIES TO ENHANCE DIGITAL LITERACY:

- Design technologies that are easy to use by carers who have a wide range of digital literacy skills; seek out carers with lower digital literacy skills to pilot new technologies.
- Improve access to digital literacy education and training programs, especially for marginalized groups (such as those with lower educational attainment or incomes, those who are unemployed or not born in Canada, or those who are older).

BARRIERS TO CARERS' TECHNOLOGY ADOPTION

6. LACK OF ONGOING SUPPORT THROUGH THE ADOPTION PROCESS



For some, using new technology may not be a natural or normal part of everyday life and way of interacting with others. In addition to the capacity question, technology adoption also requires that users – in this case, carers – have the time, ability, and desire to invest in learning how to use new technologies and to integrate it into their busy lives. For some, the learning curve is steep and setbacks are inevitable. Lack of technological support at time of adoption and beyond has been flagged as a significant deterrent to adoption and as a contributor to the decision to abandon technologies post-purchase¹⁷.

POTENTIAL STRATEGIES TO FACILITATE AT ADOPTION AND CONTINUED USE:

- Provide opportunities to trial new products before committing to purchase (ability to rent technologies of interest or read carers' reviews).
- Provide access to comprehensive point-of-purchase training, support, and technical information.
- Provide post-purchase support, preferably from a real person.

7. IMPACT OF TECHNOLOGY ON CARE RELATIONSHIPS



Caregiving is not just about 'doing care'; by its very nature care is relational, interdependent and involves linked lives²¹. As one DATCares caregiver aptly stated: "Caregiving can bring together families or tear them apart." Individuals in need of care may want to use a technology to enhance their independence, but its use may add to carers' burden or out-of-pocket expenses. Alternately, carers may be willing to use AT to support their own well-being or improve the efficiency or effectiveness of their care, but the person they are supporting may fear (or know) that technology could reduce or replace their 'face time' with the carer²². DATCares workshop participants expressed concerns about privacy, dignity, autonomy and the impersonal nature of technology. One said: "My wife fears technology and is not open or receptive to being taught."

POTENTIAL STRATEGIES FOR TECHNOLOGY TO SUPPORT RELATIONSHIPS:

- Recognize that technology cannot solve all problems. As one DATCares participant concluded: "There is a place for AT, but AT doesn't replace compassion, human empathy and dignity." Co-designing technologies with carers can help ensure that new products respect the relational nature of care.
- Enable more informed choice by strengthening policy and practice that protects and makes transparent privacy of personal information collected in the course of searching for, purchasing and using technologies (e.g. tracking and monitoring technologies; internet search engines; online shopping sites).
- Strengthen policy and practice that ensures care receivers' dignity and autonomy is preserved without further burdening carers (e.g. codes of conduct/practice for health care professionals and institutions).



DESIGNING ASSISTIVE TECHNOLOGY THAT CARES WORKSHOP (#DATCares)



DATCares Workshop Participants (June 7, 2017)

Held June 7-8, 2017 in Waterloo ON at the Schlegel-UW Research Institute on Aging, the #DATCares workshop brought together 40 people from across Canada and Sweden, including family/friend carers, researchers, government, community and industry representatives. Led by Dr. Jennifer Boger, the multi-sectoral workshop was a joint initiative of a sub-set of members of the AGE-WELL NCE network (Canada's Technology and Aging Network). Driven by carers' experiences, the workshop explored how AT could be designed to better support the holistic needs of family/friend carers, enhance relationships between carers and the people they support, and how the design process itself can better involve carers as experts. Workshop funding and/or in-kind support was received from: AGE-WELL NCE, Canadian Institute of Health Research (CIHR), SCA/TENA, the Schlegel-University of Waterloo Research Institute for Aging (RIA), and Réseau Québécois de Recherche sur le Vieillissement (RQRV). This briefing note is one of several knowledge mobilization products arising from the #DATCares workshop.



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