DESIGNING TECHNOLOGY THAT CARES

CAREGIVERS' EXPERIENCES DRIVE THE DESIGN PROCESS

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

KEY MESSAGE

Designing assistive technologies that support family caregivers' holistic needs starts by using their experiences to drive the design process. Understanding caregivers' unique needs and complicated lives is critical to developing successful strategies for the development, communication and adoption of technologies to effectively support family caregivers – a market of more than 8.1M Canadians[1]. Caregiver-centred empathic design is a process that integrates caregivers in such a way that their experiences and expertise drive the design, solving their real life problems to improve their well-being and ultimately, to succeed in the marketplace. Key components of this approach are: co-creating better or innovative solutions; actively listening to and empathizing with caregivers' stories; developing a shared representation of the design problem; evaluating external sources of inspiration or potential solutions; and allowing adequate time, resources and flexibility.

FAMILY/FRIEND CAREGIVING IS A 'WICKED PROBLEM'

In 2012 more than 1 in 4 Canadians (8.1 million of them) had cared for a family member or friend with a long term health problem, disability or age-related condition within the last year. But nearly half (46%) had **ever** provided care to a loved one[1]. And these numbers are forecast to continue to grow as the population continues to grow older and disability rates continue to increase[2]. This is a substantial market.

Collectively, caregivers spend 15.5 billion hours annually caring for a loved one[3], often juggling care with other responsibilities such as paid work and child rearing. Canadians who take on care responsibilities do so willingly but often at a personal cost, reporting a wide range of social[4], health[1], employment[5] and financial[6] consequences.

Policymakers and practitioners concerned about risks these negative consequences of care pose to the sustainability of the family care sector, and their spill-over effect on the formal health care sector, are seeking solutions. Some are turning to assistive technologies (AT) as one such solution. The literature shows that, while technological innovations have the potential to support caregivers, caregivers are concerned that AT could add to their burden[7], especially those designed for care receivers[8]. New products and services that fail to meet caregivers' real needs (for example, because they ignore the realities of caregivers' lives), that are unaffordable, that are too complicated to use, or are invisible in the marketplace, will not be adopted by those for whom they are intended. Understanding caregivers' unique needs and complicated lives is critical to developing successful strategies for the development, communication and adoption of technologies to effectively support family caregivers.

Some designers propose an approach to designing new products and services that is more likely to meet users' needs—in the case at hand, caregivers' needs—to make their lives easier and enhance their well-being. Variously referred to as user-centred, human-centred or UeX design, the basic principle of caregiver-centred empathic design is that caregivers must be integrated fully into the design process from the outset. Understanding caregivers' unique needs and complicated lives is critical to developing successful strategies for the development, communication and adoption of technologies to effectively support caregivers.

WHAT IS CAREGIVER-CENTRED, EMPATHIC DESIGN?

Caregiver-centred empathic design is a process that integrates caregivers in such a way that their experiences and expertise drive the design, solving their real life problems to improve their well-being and, ultimately, to succeed in the marketplace. This is a paradigm shift from a more typical approach in which designers drive the design, assuming that they know what caregivers need and want, and that "if you build it, they will come".

Underlying a caregiver-centred empathic design approach is a steadfast belief that caregivers are experts and hold the necessary situation-specific knowledge about a complex problem like caring for a loved one with a long term health problem, disability or age-related condition. As the primary beneficiaries of the intended product or service, the process supports caregivers to share their knowledge with product designers. The success of the whole design process lies in the satisfaction of caregivers' needs, but bridging the gap between caregivers' experiences and designers' understandings is crucial to meeting the real needs of caregivers.

WHY ENGAGE IN CAREGIVER-CENTRED EMPATHIC DESIGN?

There are a number of advantages of adopting a caregiver-centred empathic design approach:

- When caregivers help define the problem and create the solution, the product is more likely to meet their holistic needs.
- A product or service that is more likely to meet the needs of caregivers will be more likely to be adopted, make a meaningful difference in caregivers' lives and enhance their well-being.
- As a result, the probability of uptake and integration of the product into caregivers' lives, and ultimately its commercial success, is greater.

HOW DO YOU ENGAGE IN CAREGIVER-CENTRED EMPATHIC DESIGN?

While this concept is not necessarily ground breaking, putting the details together for the problem space is. To really understand the caregiving context, designers need to hear first-hand from the people who are living it and involve caregivers in developing solutions that impact their lives. Several key components of employing a caregiver-centred empathic design approach emerged from the Designing Assistive Technology that Cares workshop that brought together multi-sectoral and transdisciplinary stakeholders to challenge traditional design approaches. These key components, with exemplar quotes from workshop participants, are explained below.

Co-create better or innovative solutions – Too often caregivers own needs are ignored, often superseded by the needs of the person for whom they are caring. The success of the caregiver-centred empathic design process lies in a profound commitment to embed caregivers as experts, with their experiences informing the entire product development and design process, beginning with problem identification and definition, through to product testing in situ. Through this inclusive, caregiver-centred, empathic design process, caregivers' holistic needs are assimilated into the design discussions and development of solutions that will better meet their needs and enhance its integration into their busy, complicated lives.

"Caregivers is synonymous with human tenderness and human connection. There is a place for assistive technologies (AT), but AT doesn't replace compassion, human empathy and dignity." ~Community Organization Partner

Actively listen to caregivers' stories – Empathic design entails design practitioners observe or meet directly with the intended user group[9]. Caregivers, and their caring journeys, are diverse. Ordinary lives are transformed by the experience, and feelings of being overwhelmed, frustrated and challenged are common. If designers haven't been a caregiver, listening first-hand to caregivers' stories simulates "walking a mile in their shoes." Listening with intent to a day in the life of a caregiver develops awareness about their experiences (including challenges and supports), and helps to build trust and mutual respect among stakeholders in the design process. This is a critical step in developing solutions that will address caregivers' very real challenges while accounting for the complexity of their lives.

"Hearing the stories of the caregivers and the challenges they face... helps to make the problem more real to me." ~Product Designer

Develop a shared representation of the caregiver goal – Working with an empathy map[10], a design tool adapted specifically for caregivers, encourages them to describe in-depth their current situation, their wishes, goals, challenges, feelings and influences. Through a series of guiding questions about each of these topics and the rich dialogue that ensues, designers and product developers realize a comprehensive understanding of the messiness of caregivers' real life situations, their holistic needs, and the complexity of their relationships with significant others (e.g., care receivers, family members, friends and care staff) toward a shared representation of the design problem. While some of the problems that caregivers have cannot be easily solved by AT, the empathetic design process supports caregivers to identify those that can be, and defines the barriers (problems and challenges) that need to be overcome in the design process to achieve caregivers' goals.

"Caregiving is not health care – this is my life!" ~Caregiver

HOW DO YOU ENGAGE IN CAREGIVER-CENTRED EMPATHIC DESIGN?

"We have to get a true understanding of the problem and challenges to truly design good AT." ~Developer

Evaluate external sources of inspiration or potential solutions – External sources of inspiration or potential solutions are introduced after caregivers' stories are shared. In this way, caregivers' experiences drive the solutions rather than starting with a technology first. A collection of photographs of existing technologies, including those provided by caregivers, allows stakeholders to assess whether or not a given technology is able, or can be adapted, to address one of the caregivers' challenges or goals. This design discussion, supported by photographs as analogies or external frames of reference, stimulates divergent creative inspiration and identifies desirable features and shortcomings of existing technologies. Gathering transdisciplinary perspectives through this discussion enables a more complete analysis of the situation.

"I was surprised at how innovative caregivers are themselves." ~Industry Partner

Support the process by allowing adequate time, resources and flexibility – Those who adopt a caregiver-centred design process must allow adequate (and often additional) time for the co-creation process; be open and responsive to caregivers' expertise; and be flexible, nimble and agile in the directions this process can take. Caregivers need to be supported to be integrated in ways they wish to be; their involvement needs to be voluntary and cannot be forced. Finally, there are many demands on caregivers' time. Respecting their time, compensating them for their expertise or providing respite from their care responsibilities facilitates their involvement.

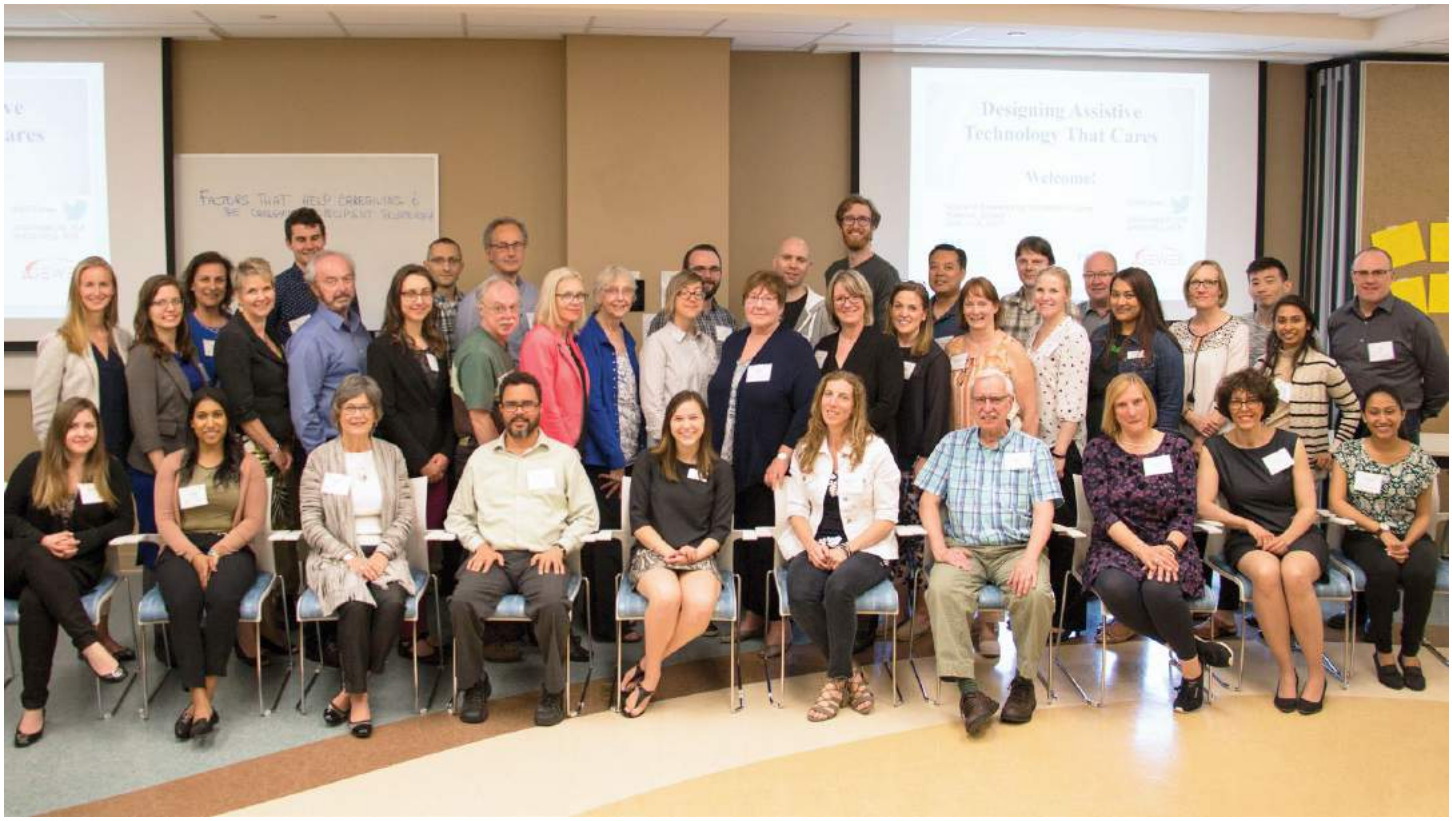
"AT doesn't solve all problems and should only be applied where it adds value, otherwise it makes caregivers' lives even more difficult." ~Researcher

KEY DESIGN PRINCIPLES CAREGIVERS NEED

Key design principles of better or innovative technologies for caregivers that emerged from our own caregiver-centred empathic design process included: 'apparent simplicity' in form and function; familiarity arising from similarities to other technologies caregivers already use; accessibility; affordability; safety; and privacy. Caregivers also want technologies to be flexible and adaptable so that they can evolve as the caring context changes over time, such as when the care receiver's condition changes or as care networks change.

"Sometimes the most simple AT solutions can lead to the greatest changes."
~Researcher

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 caregivers, 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 Aging and Technology Network). Driven by caregivers' experiences, the workshop explored how AT could be designed to better support the holistic needs of family caregivers, enhance relationships between the caregiver and care receiver, and how the design process itself can better involve caregivers 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.

DESIGNING TECHNOLOGY THAT CARES

CAREGIVERS' EXPERIENCES DRIVE THE DESIGN PROCESS

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

References

[1] Sinha, M. (2013). Portrait of caregivers, 2012 . Ottawa ON: Statistics Canada, Ministry of Industry. Available http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm

[2] Keefe, J., Légaré, J., & Carrière, Y. (2007). Developing new strategies to support future caregivers of older Canadians with disabilities: Projections of need and their policy implications. Canadian Public Policy, 33 (Supplement 1), S65-S80.

[3] Hermus, G., Stonebridge, C., Theriault, L., & Bounajm, F. (2012). Home and Community Care in Canada: An Economic Footprint . Ottawa: Conference Board of Canada.

[4] Keating, N. & Eales, J. (2017). Social consequences of family care: A scoping review. International Journal of Care and Caring , 1 (2), 153-173.

[5] Keating, N., Fast, J., Lero, D., Lucas, S. & Eales, J. (2014). A taxonomy of the economic costs of family care to adults. Journal of the Economics of Aging, 3 , 11-20.

[6] Duncan, K., Shooshtari, S., Roger, K., Fast, J., & Han, J. (2018, February). The cost of caring: Out-of-pocket expenditures and financial hardship among Canadian carers. Paper presented at the Financial Planning Foundation 2018 Canadian Academic Research Forum, Arlington, VA.

[7] Marasinghe, K. M. (2015). Assistive technologies in reducing caregiver burden among informal caregivers of older adults: a systematic review. Disability and Rehabilitation: Assistive Technology , 11 (5), 353-360.

[8] Mortenson, W. B., Demers, L., Fuhrer, M.J., Jutai, J.W., Lenker, J. & DeRuyter, F. (2012). How assistive technology use by individuals with disabilities impacts their caregivers: A systematic review of the research evidence. American Journal of Physical Medicine & Rehabilitation , 91 (11), 984–998.

[9] Thomas, J. & McDonagh, D. (2013). Empathic design: Research strategies. Australasian Medical Journal, 6 (1), 1-6. http//dx.doi.org/10.4066/AMJ.2012.1575

[10] Boag, P. (2015). Adapting empathy maps for UX design . Available at https://boagworld.com/usability/adapting-empathy-maps-for-ux-design/

Funding provided by: AGEWELL CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada RIA Research Institute for Aging, Schlegel Centre for Learning, Research and Innovation in Long-Term Care TENA