



RESEARCH ON THE RUN

Aging in Society

Co-designed tools for strong partnerships with caregivers, people with dementia and care providers

Saint Elizabeth and the Alzheimer Society of Canada (ASC) are partnering to develop tools that will enable meaningful partnerships between caregivers of persons with dementia and professional care providers. Using a creative co-design process, caregivers, persons with dementia and care providers will contribute to the creation of tools and processes that allow all stakeholders to be active and equal members of the care team.

Key Considerations

The line between the family caregiver and professional care provider roles is infinitely flexible. Further, the extent of the family caregiver's role is not well-understood and an equitable sharing of roles has not been established.

There is a need to meaningfully negotiate care roles between family caregivers and care providers. This inherently entails exploring the tensions between medical vs. psychosocial care and clinical vs. relational tasks. It is not yet clear which roles are meant to be taken up by family caregivers and which roles should be taken-on by care providers.

There is a need to establish a definition of 'dementia care' and what it entails. This includes understanding both task-based and emotional work, who is responsible for the different types of work, and understanding how the 'place' of care factors in.

Project overview

The resemblance of LTC homes to hospitals, along with the emphasis on the medical model, makes it is easy for staff to forget that they are working in someone's home, so the focus is often on tasks that need to get done, rather than on the person and on making the environment feel like a home.

The growth in the aging population, alongside with consumer advocacy, have contributed to a growing emphasis for person and family-centered care (PFCC) in both LTC and home care. The ultimate goal of PFCC is to create partnerships among care home staff, people with dementia and their families to enhance the quality of care of people living with dementia. A core principle of PFCC is person and family engagement.

The gradual shift from a medical model to a PFCC approach has tended to create some tension between care providers, caregivers and persons with dementia, as they learn to create partnerships to enhance the quality of care provided to residents. Therefore it is crucial to explore what can be done to enable strong and equal partnerships amongst caregivers, persons with dementia, and care providers.

What we are doing

We are conducting up to six co-design workshops with caregivers, persons with dementia, and care providers (home and long-term care). Through these workshops, the researchers and stakeholders will co-create tools and processes that will enable meaningful partnerships between all members of the 'dementia care triad'.

What we have found so far

An environmental scan was conducted and discussions with caregivers and persons with dementia were held. These discovery steps suggested that there is a need for care roles to be negotiated between caregivers, persons with dementia and care staff. There also needs to be a clearer definition of what "dementia care" entails and how the place of care influences equal partnerships between all stakeholders. These topics will be explored further during the co-design workshops.

Innovative approach:

Co-design approaches are, by nature, done by, for, and with the people who will be using or most directly impact by the outcomes, and can be particularly useful for designing tools to enhance collaboration. Through co-design, participants are given the opportunity to share, select, and prototype ideas; reframe opportunities and constraints; and determine which ideas are viable for user-friendly tools and/or processes. Through co-design, family caregivers, people living with dementia and care providers who have the expertise and experiences, are able to be involved in imagining and shaping new possibilities of building strong and equal partnerships

IMPACT: How will we move Knowledge to Action

The primary deliverables will be user-friendly tools for caregivers and people living with dementia to support a person-centered team approach and relationship building with care providers. Tools/resources for care providers may also be developed.

Who are our collaborators?

The Alzheimer Society of Canada

About our researchers

Dr. Marina B. Wasilewski, Postdoctoral Fellow, SE Research Centre, marinabastawrousasilewski@saintelizabeth.com

Dr. Paul Holyoke, Director, SE Research Centre, paulholyoke@saintelizabeth.com

Justine Giosa, MSc, PhD(c), Manager of Research Operations, SE Research Centre, justinegiosa@saintelizabeth.com

How was this research funded?

This research is being funded by Saint Elizabeth and the Alzheimer Society of Canada.

About the Saint Elizabeth Research Centre

Saint Elizabeth has made a strategic commitment to research – \$13 million over 13 years. The Saint Elizabeth (SE) Research Centre conducts impact-oriented health services research and evaluation to synthesize, generate, translate, adapt and directly apply scientific evidence in the design, delivery and evaluation of person- and family-centred health and social care services.

At the Saint Elizabeth (SE) Research Centre, we study the needs of people, their caregivers, and healthcare providers, to develop innovative solutions to tough health and social care problems.

The SE Research Centre has four fields of research and evaluation: *Aging in Society; Dying, Death and Grief; Health and Care Experiences; and Models of Care Delivery.*

We see possibilities everywhere.