



RESEARCH ON THE RUN

Person and Family Centred Care

Striking a balance between self-care, family caregiving, and formal home care

This research focused specifically on the perspectives and experiences of older people using home care services.

Key learnings

Older people with impairments and chronic health conditions want to find a balance between formal home care, family caregiving, and self-care.

A balance in care can enable older people to have a sense of independence and autonomy.

It is more difficult for people with limited financial means and little family support to find a balance between sources and forms of support.

Project overview

Older people with chronic health conditions and impairments often receive care from both formal care providers and family/friend caregivers. At the same time, they continue to care for themselves to maintain their own health and well-being. Yet, there is little knowledge of the ways older home care clients experience the relationship between self-care, family/friend caregiving, and formal home care.

This research addressed the following questions:

- How do clients experience the relationship between self-care, family caregiving, and formal home care?
- How does self-care and family caregiving shape experiences and expectations of home care services?

Through these questions, this research aims to support person-centered care (PCC). Key aspects of PCC include sharing power among individuals involved in care relationships; respecting and accommodating clients' needs, perspectives, and interests; and involving clients in decision-making.

What did we do?

Interviews were conducted with 34 people in the Greater Toronto-Hamilton Area who were using home care. The interviews focused on:

- The support participants received from formal care providers and family/friends
- The relationships participants had with caregivers
- The ways participants took care of themselves

Here is some information about the 34 interview participants

- Age: 65-100, average 81
- Gender: 26 women, 8 men
- Living environment: Owned home (19), rental apartments (4), subsidized seniors' housing (5), assisted living/

retirement communities (4)

- Living arrangement: Lived alone (21), with family (13)
- Home care use: Public (25), private (3), both (5)
- Health conditions: Varied physical impairments and chronic health conditions (people with dementia excluded)

What did we find?

Older people want to find a balance between formal home care, family caregiving, and self-care. This balance can enable them to have a sense of autonomy, even while they are experiencing chronic health conditions and impairments.

The following themes describe participants' experiences:

- **Minimizing reliance:** Participants practiced self-care as much as possible and did not want to rely on others. When they did need extra help, participants turned to formal care. They wanted to avoid asking family members for too much help
- **Developing partnerships:** Participants expressed a sense of interdependence between self-care, family caregiving, and formal home care. Even though they needed support from others, participants felt empowered in their caregiving relationships. They often had wide networks of support
- **Filling in gaps:** Participants felt that they did not receive enough home care. They struggled to care for themselves, or felt guilty about placing demands on family. These participants expressed a sense of powerlessness and vulnerability. This often occurred when participants had limited financial means and little social support.

Innovative approach:

These findings help to understand clients' experiences and expectations of home care.

Developing strategies to recognize and respond to these different situations can contribute to person-centered care

IMPACT: How are we moving Knowledge to Action?

- Conducted a workshop for care providers to share findings and their applications to practice.
- Presented at academic conferences.
- Publications being prepared for research journals.
- Blog post for Hamilton Council on Aging:
<https://hamiltoncouncilonaging.wordpress.com>

Who are our collaborators?

Rachel Barken received an Award for Home Care Research Award from Saint Elizabeth to carry out this research, which fulfilled a portion of the requirements of her doctoral degree at McMaster University. Rachel is currently a postdoctoral fellow in the Department of Sociology at York University

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For more information about this project, please see our PFCC webpage:

www.saintelizabeth.com/pfcc

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About the Saint Elizabeth Research Centre

Saint Elizabeth Health Care has made a strategic commitment to research — \$10 million over 10 years.

At the Saint Elizabeth Research Centre, we study the needs of people, their caregivers, and health care providers to develop innovative solutions to improve health and care experiences across the continuum/ more effective approaches to care. The Research Centre has four areas of focus: integrated care and transitions, end of life care, caregivers and person and family centred care.

Our goal is to improve people's health and care.

We work on innovative solutions for tough problems.

We see possibilities everywhere.