Research Centre

Research Project Summaries

CAG*2023*

Research Centre

Impact-oriented applied health services research and evaluation

To forever impact how people live and age at home, across Canada and around the world.

Our Purpose:

To respond to the needs of people, their caregivers, and health and social care providers with evidence-based solutions to tough health and social care problems in partnership with experts-by-lived experience.

Our Goal:

To synthesize, generate, translate, adapt and mobilize scientific evidence in the co-design, implementation, and evaluation of person and family-centred health and social care services.

Areas of Focus:

 Aging in Society

 Dying, Death and Grief

 Models of Care Delivery

 Health and Care Experiences

What makes us different is that our research centre is embedded in a learning health system. We are committed to participatory, community-driven and action-oriented research to facilitate positive health system change.

SCAN to read about our researchers

Contents

The Reflection Room®: Creating Space for Pausing, Reflecting, and Storytelling at the End-of-Life

The COVID-19 pandemic created a tremendous amount of collective loss and grieving that requires care and support.[1] This was as true in residential long-term care (LTC) homes, which continue to experience pandemic-related challenges, as in hospitals and among the general public.[2] Through the Reflection Room® project, our interdisciplinary team of researchers partnered with LTC homes in Ontario to create physical spaces to pause, reflect, connect, and process grief. The Reflection Room uses quiet reflection and storytelling to generate open dialogue about dying, death, and grief in a way that is accessible, anonymous, and adaptable to community needs.

The Reflection Room® is an evidence-based, participatory art installation that provides an immersive space for visitors to read stories written by others and write and share their own stories on the topic of dying, death, and/or grief. Visitors are invited to "pause, reflect, and share" although engagement with the Room is self-directed and open-ended.

Project Overview

Many LTC home communities were seriously affected by COVID-19.[3] On top of the stress from COVID-19 infections and deaths, staff have experienced burnout and low morale,[4] and some homes with outbreaks must continue to restrict residents' movements, isolate residents in their rooms, and limit activities such as social functions to reduce risk of spread.[5] Many within these communities have reflected on the trauma[3] the

pandemic has caused. Ontario's Long-Term Care COVID-19 Commission Final Report[6] has recommended reforms and counselling services. However, with the immense levels of grief, and feelings of helplessness, regret, and sadness, there is also a need for innovative and timely support for LTC communities.

The Reflection Room pilot project was created in 2016 by the SE Research Centre, led by Dr. Paul

Holyoke from the Centre and Dr. Barry Stephenson from Memorial University of Newfoundland. The goal of the project was to support people in community and health care settings to talk about dying and death.[7] A research study from 2016-2018 evaluated the impact of 25 Reflection Room installations across Canada. We found the installations created space for expressing emotions (e.g., love and regret) and making sense of experiences related to dying and death such as making meaning of the mystery of mortality; dying and death; and feeling that connections with the soul/spirit/memories can continue after physical death.[7]

Adapting to COVID-19

During the pandemic, the Reflection Room project was adapted to address experiences of loss and grief in LTC homes in Ontario, Canada. The pilot version of Reflection Room project was found to increase visitors' comfort talking about dying and death,[7] and we thought it might be possible to invite reflections on experiences during the pandemic. The idea behind this is that people able to name their experiences with grief and loss are often able to process and transform their grief.[8] With grief being under-supported in most areas, it was important to find an innovative and engaging way to support grief and loss in LTC homes.

In this version of the Reflection Room project, an easy-to-set-up 'kit' was designed that incorporated instructions and materials (e.g., Reflection Cards, a red curtain to display Reflection Cards, candles, etc.) at no cost, so that LTC homes could install a Reflection Room adapted to their space. The invitation to visitors was to "*write about your experiences or thoughts about what has happened for you over the course of the pandemic*".

Supported by Ontario Health's Central Region, Family Councils Ontario and Saint Elizabeth Foundation, a Reflection Room was installed in 32 LTC homes across Ontario, with 19 more still hoping to install a Room.

To understand how a Reflection Room might support pandemic-related grief, we analyzed data from 1) Reflection cards written by people in LTC homes; 2) a survey from staff, residents, and caregivers; and 3) interviews and surveys from staff who set up the Room.

Feasibility and Adaptability

We found that the Reflection Room as designed for this iteration was feasible and adaptable. The Room took little time for staff of LTC homes to set up, promote, and maintain. It was also reported that the Room was adaptable to the various settings, and was installed in various creative places within LTC homes (e.g., chapel, recreation room, meeting room, solarium) and integrated into existing services such as memorials for those who had died.

Pandemic Related Grief Stories

Reflection Cards written by LTC home community members shared stories about the pandemic, including stories about overload (e.g., burnout), loss (e.g., loss of meaningful activities), and restoration (e.g., wanting to return to normal). Additionally, they shared stories about pandemic-related learnings (e.g., the importance of time together), and gratitude (e.g., for receiving good care).

Support for Grieving

Most staff, residents, and caregivers (n=98) recommend the Reflection Room to others because it supports grieving and well-being. These communities felt the Reflection Room was helpful by 1) Offering a quiet restful place; 2) Providing an outlet for thoughts and emotions; 3) Allowing people to reflect and process; 4) Providing additional support; 5) Supporting community building and connection; and 6) Supporting wellbeing for individuals and communities.

What are we doing now?

The research portion of this project has ended, yet dissemination of the work continues. The Saint Elizabeth Foundation is working with various Canadian organizations to distribute Reflection Room "kits" so there can be installations of this

arts-based storytelling initiative that supports grieving and well-being for Canadians, especially in a post-pandemic future.

What will be the (anticipated) impact?

The expectation is that installation of the Reflection Room in various spaces will support communities to grieve and cope together through pausing, reflecting, and sharing stories. The Room may also increase peoples' understanding of grief and activities that can support their grieving through end-of-life journeys.

Visit TheReflectionRoom.ca to read reflections from our installations across Canada:

How was the research funded?

The evaluation of the Reflection Room was funded by the Saint Elizabeth Foundation.

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Research Centre

How personal support workers (PSWs) set and maintain safe and respectful limits with clients

Personal Support Workers (PSWs) are often asked to perform tasks that go beyond the stated care plan or to accommodate client preferences. Some of these tasks have the potential to compromise PSW safety. This study explored compassionate strategies used by PSWs to set limits to prevent exploitation, harassment, or injury.

PSWs and their supervisors identified key strategies and phrases used to establish and maintain limits in common but challenging situations. These include setting appropriate client expectations, responding to reinforce a boundary when it is challenged or to prevent problematic situations from recurring. Online and in-person training programs are being developed to teach these strategies.

Project Overview

Personal support workers (PSWs) often work alone in the community. The care provided to clients is guided by a care plan, but how it is provided, which activities are prioritized, and when additional helpful activities can be completed are negotiated between the provider and client. Choosing when to set limits on how or what care is provided, and how to do so successfully, is a challenge for many PSWs. However, failure to establish boundaries can put PSWs at risk for exploitation or harassment and may lead to injury for the PSW or their client.

Some PSWs are very skilled at setting limits with clients and their families, while maintaining a positive relationship. To explore how these "positive deviants" establish and maintain boundaries, PSWs were asked to share how they manage boundary negotiations. Supervisors were included in these

conversations, as their support is important for reinforcing PSWs' limits.

The goals of our study were: 1) to identify strategies that highly skilled PSWs and their supervisors use to set and maintain appropriate boundaries with clients; and 2) to develop training materials to share these strategies with others.

What did we do?

PSWs and supervisors from 3 regions in Southern Ontario participated in the study workshops.

Participants were presented with common care scenarios in which a PSW might feel pressured to perform a task unrelated to planned care. For each care scenario, participants identified the boundary they would establish or enforce, and the specific strategies and phrases they would use. All vignettes were based on real situations that emerged during

the study of PSW Safety in the Community, conducted at SE Health in 2016-2017. A summary of that project is available [here](#).[1]

What did we find?

Setting expectations: A core strategy identified by PSWs and supervisors was to establish expectations early and reinforce these as needed. Both PSWs and supervisors stated this should first be done at the supervisor's initial visit with the client to develop a care plan. This ensures the client has accurate information regarding services, visit duration, or scheduling. PSWs should then review expectations at their initial client visit, or if a limit is challenged.

Reinforcing boundaries: PSWs emphasized the importance of maintaining a positive tone and staying 'on the client's side' when reinforcing set boundaries. This is accomplished by emphasizing what they *can* do to address client concerns. For example, providing care in different ways, connecting with a supervisor to seek additional services or supports, and reminding the client that they can address further 'extras' and spend more time together during the next visit.

Making exceptions: In situations where PSWs choose to make exceptions to established boundaries, they remind clients of the limit and inform their supervisor of the exception. Keeping supervisors informed about exceptions or persistent client/family requests for 'exceptions' allows them to understand changing client needs and promotes safety for the full complement of PSW team.

Self-awareness: Beyond specific strategies to set boundaries, participating PSWs and supervisors emphasized the importance of PSWs knowing their own core values, having a clear vision of their role, and understanding the importance of self-care. These insights were helpful in enabling PSWs to continue to work well and enjoy their lives and relationships outside of work.

What is the impact?

In addition to planned publications, the outcomes from this study form the basis for a training program being developed for PSWs. This program will be made available both online and in-person.

Modules for the program will cover:

- different types of boundaries;
- situations where these may be tested;
- clear and compassionate strategies for establishing boundaries;
- appropriate responses when they are challenged; and
- reinforcing boundaries for future visits.

Additional resources to support PSWs and supervisors in maintaining appropriate boundaries will also be made available.

The effectiveness of the two training delivery methods will be evaluated in a future study.

How was the research funded?

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Aging and Mental Health:
How can we destigmatize and build resilience through conversations in home & community care?

The COVID-19 pandemic has raised concerns about the mental well-being of older adults, who often face two stigmas: ageist attitudes and negative attitudes about mental health. These stigmas create barriers to accessing necessary mental health support, care, and treatment. More intentional conversations about mental health, prompted by home and community care providers, could help to better meet older adults' holistic health and social care needs and build a more resilient health system for the future.

We are acting on _aging and mental health research priorities_[1] identified by Canadians during the pandemic, including that research should prioritize skill-building for community-based providers and the need for broad application of user-friendly tools to identify signs of positive and poor mental health. The goal of this project is to co-design and test an evidence-based approach to mental health conversations between home and community care providers and older adults during routine care interactions in rural and urban settings across Canada.

Project Overview

The COVID-19 pandemic has reinforced a mental health crisis in Canada, which has disproportionately impacted older adults because they are more likely to experience systemic ageism and mental health stigma in the health and social care system and society overall.[2] As a result, older adults are at a higher risk of social isolation, loneliness, and substance use and addictions,[3] and often experience barriers in accessing needed mental health support, care, and treatment.

To address the wider impacts of COVID-19 on older adults across Canada, we need to find opportunities to destigmatize and encourage more conversations about mental health–our "positive sense of well-being, or our capacity to enjoy life and deal with the challenges we face"[4]–with aging Canadians who are already accessing the health care system for physical health care needs.

Acting on research priorities identified by Canadians

The SE Research Centre and Canadian Mental Health Association (CMHA) National office partnered with older adults, caregivers, and health and social care providers during the early phases of the pandemic to identify priorities for aging and mental health research. Top priorities according to aging Canadians were:

1. **Skill-building in community health and social care providers who are not mental health specialists; and**

***** *Prior to the pandemic, older adults expressed feeling uncomfortable talking about mental health issues with*

health care providers.[5] Older adults' mental health needs are more likely to be under-reported or misdiagnosed due to the prioritization of physical health concerns.[6]

2. Application of user-friendly tools to identify signs of positive and poor mental health

*The Mental Health Continuum (MHC) Model uses a multiple-domain, colour-coded scale to promote self-reflection and self-monitoring by using common and destigmatizing language to demonstrate that a person's mental health is dynamic on a spectrum.[7] The MHC Model requires adaptation for use with older adults in community and health and social care settings.

Partnering with experts-by-experience

Guided by the Participatory Research to Action Framework,[8] we will partner with experts-by-experience in all phases of the research. Our project Working Group includes older adults, caregivers, and health and social care providers from across Canada. They will advise on the project direction, support diverse community engagement in research activities (e.g., help sharing recruitment materials), help to create data collection tools and do data analysis, and participate/ guide the creation of summaries, reports, papers and other communications about the project and results with participants, other researchers, health decision makers and the broader public.

Project goal

The overall goal of this project is to co-design and test an evidence-based approach to mental health conversations between home and community care providers and older adults during routine care interactions in rural and urban settings across Canada.

3 phases over 3 years

Phase 1, a two-stage process, consisted of online workshops and an online survey. Phase 2 consists of 7 in-person co-design sessions in 3 rural and 3 urban communities across 3 Canadian provinces. We have completed 5 co-design sessions and anticipate having Phase 2 completed by January

2024. Phase 3 is anticipated to be completed by September 2024.

Phase 1—Year 1

Using a modified ADAPTE process,[9] 59 older adults, caregivers, and health and social care providers from across Canada participated in 4 online English workshops and 2 online French one-on-one interviews. Participants provided their input on how to adapt the MHC Model[6] for use with older adults in community health and social care settings.

Content analysis of the workshops and one-on-one interviews revealed two major findings:

1. There was consensus a visual model depicting mental health as complex with many components was helpful to guide conversations between older adults, caregivers, and health and social care providers.

2. The visual model needed to be adapted to promote conversations in home and community care settings using more neutral and action-oriented language; more culturally inclusive colours; re-naming model components; adding aging-relevant signs and signals; and reflecting potential change over time.

The analysis led to an adapted visual model called the *Mental Health Continuum for Aging Canadians* (See Figure below).

Using an online survey, older adults, caregivers, and health and social care providers from across Canada were asked to state their level of agreement with each of the adaptations of the *Mental Health Continuum for Aging Canadians* using a 5-point Likert scale (1 – strongly disagree to 5 – strongly agree). The online survey contained 12 questions about adaptations of the *Mental Health Continuum for Aging Canadians* and one open-ended question for additional feedback. Eleven survey questions received an endorsement of 83% or higher (>3 on a 5-point Likert scale) with only one adaptation related to colour receiving a 76% endorsement from 1,068 survey respondents. The usefulness of the *Mental Health Continuum for Aging Canadians* to

	All Good (No immediate follow-up)	Take Notice (Continue to monitor)	Find Support (Encourage engagement with support network/ community services)	Seek Care (Refer or link to mental health care provider/ clinicians)
	Has there been a change from usual?	Has the change become a pattern?	Is the pattern causing anyone concern?	
Thoughts, Feelings & Emotions	• Easy going • Calm • Positive outlook	• Frustration • Nervous/worried • Indifference	• Anger • Stressed/afraid • Negative outlook	• Furious • Panic/paranoia • Hopeless/despair
Daily Routine & Activities	• Active (work, home, volunteer) • Basic needs are met (e.g., food, clothing, shelter) • Self-care/personal hygiene maintained	• Choose to be less active • Basic needs are sometimes missed • Skipping some usual self-care/ personal hygiene tasks	• Not active due to loss • Difficulty meeting basic needs (e.g., bills unpaid, access to food) • Self-care and personal hygiene tasks are rare	• No desire to be active • Not able to meet basic needs (e.g., loss of housing, no winter clothing) • Self-care/personal hygiene completely neglected
Sleep Experience	• Getting enough sleep for needs • Minimal sleep disruptions • Comfortable/safe sleep location	• Sleeping more/less than desired • Occasional sleep disruptions (e.g., nightmares) • Sometimes alternate sleep location (e.g., couch)	• Sleeping too much/little for needs • Mostly disrupted sleep (e.g., bathroom trips, noise) • Sleep location is mostly not ideal (e.g., recliner, wheelchair)	• Always sleeping/never sleeping • Cannot stay asleep (e.g., health condition, intrusive thoughts, behaviours) • No comfortable or safe sleep location
Physical Observations	• Consistent body weight • No pain • Able to rest/be still	• Minor gradual weight loss/gain • Well-managed pain • Fidgeting (e.g., restless legs, wringing hands, tapping)	• Major gradual weight loss/gain • Increased or new unmanaged pain • Nervous behaviours (e.g., scratching, picking, pacing)	• Major sudden weight loss/gain • Debilitating chronic pain • Injuries or unexplained marks/ bruises
Relationships, Participation & Connection	• Satisfied with personal/provider relationship(s) • Satisfying involvement in community (e.g., shopping, religious, online) • Feeling connected/companionship (e.g., someone with shared interests, doing things together)	• Some dissatisfaction with personal/ provider relationship(s) • Less involvement in community than desired (e.g., seasonal weather) • Less connection/companionship than desired (e.g., nobody to share meal with socially)	• Major loss of personal/provider relationship(s) (e.g., death, move) • Difficulty with involvement in community (e.g., transportation, digital literacy) • Sometimes lonely/seeking attention (e.g., online)	• Negative/harmful or lack of meaningful relationship(s) • No sense of belonging to a community • Chronically lonely or socially vulnerable
Habits & Coping Strategies	• Use/consumption of products does not impede & may improve daily routine (e.g., alcohol, medications, drugs, tobacco, food) • Engagement in hobbies/interests/ leisure does not impede or may improve daily routine (e.g., gaming, shopping, collecting, exercise, gambling, social/traditional media) • Talks openly about habits & coping strategies (e.g., balance/recovery)	• Use/consumption of products is making daily routine difficult • Engagement in hobbies/interests/ leisure is making daily routine more difficult • Hides/covers-up use of habits & coping strategies (e.g., pill bottles)	• Use/consumption of products has led to major life changes/self-harm • Engagement in hobbies/interests/ leisure has led to major life changes/ self-harm • Lies or denies habits and coping strategies	• Use/consumption of products is unsustainable/dangerous to life • All-consuming engagement hobbies/ interests/leisure is unsustainable/ dangerous to life • Extreme measures taken to continue habits & coping strategies (e.g., theft)

start mental health conversations and 6 categories of the model received the highest endorsements and the colour blue received the lowest endorsement. Qualitative feedback from 435 of 1,068 survey respondents was analyzed using content analysis and revealed further support and feedback for the model and ideas about its applications.

Phase 2—Year 2

We will conduct 7 action-oriented in-person co-design sessions at 6 sites (3 urban and 3 rural) in the following provinces:

- British Columbia (Penticton; Similkaneen Valley/Osoyoos);
- Ontario (Toronto; Peterborough); and
- Nova Scotia (Halifax; Antigonish).

Each co-design session will include 9-15 health and social care providers working in home and community care. Through gamestorming methods such as empathy-mapping and bodystorming,[10] we will develop site-specific process maps to guide the implementation of destigmatized mental health conversations between older adults and health and social care providers during routine care interactions using the *Mental Health Continuum for Aging Canadians*. We will compare and contrast these process maps to identify both consistent and unique factors to implementation by geography, ethnocultural, linguistic diversity and other demographic characteristics.

Phase 3—Year 3

We will conduct pilot and feasibility testing of the new co-designed mental health conversations with the same 6 sites and providers who participated in Phase 2. Up to 30 older adults will be engaged in these conversations at each site. Surveys and key-informant interviews will be conducted with older adults, caregivers, and health and social care providers to understand the feasibility and preliminary outcomes regarding older adult help-seeking behaviour and enhanced provider confidence.

What will be the impact?

The anticipated outcome of this research is enhanced individual, collective and health system resilience. Key indicators of success include:

More holistic care: better integration between physical and mental health care during routine home and community care interactions;

Enhanced system access: more direct linkages to needed mental health support, care and treatment

made by community health and social care providers;

Reduced stigma: increased help-seeking behaviours and enhanced provider skills and confidence through better understanding of and more conversations about mental health.

For more information about the project and/or how you can get involved please contact:

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Funding and Ethics

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In the Media

- Waterloo Project Aims to Improve Mental Health Care for Seniors[11]
- New funding targets stigma of aging and mental health[12]

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Canadian Aging Action, Research, & Education (CAARE) for Mental Health Group

The CAARE Group is a group of experts-by-lived-experience who are committed to mobilizing knowledge and influencing positive change for aging and mental health support, care and treatment in Canada.

> The CAARE Group's work is grounded in the priorities identified by older adults, caregivers, and health/social care providers from across Canada. Our three goals are to: 1) build and sustain authentic partnerships to advance mental health; 2) support research and action-oriented projects on the priority questions; and 3) advocate and/or apply for funding to support the priorities and activities of the group.

Project Overview

Mental health is our "positive sense of well-being or the capacity to enjoy life and deal with the challenges we face"[1]. Our mental health is not a static state of being 'healthy' or 'ill'. Instead, it ranges along a continuum and can change over time. For example, aging-related changes like declining health, retirement or experiencing the loss of friends/family can impact overall mental health and well-being. However, there are major gaps in our knowledge of how mental health interacts with aging. Older adults may experience both ageism and negative attitudes towards mental health, making it more difficult to access needed support, care, or treatment.

In partnership with the Canadian Mental Health Association (CMHA) National office and a steering group of experts-by-lived-experience, the SE Research Centre developed a project to learn more about the needs of the diverse and growing population of older adults in Canada. Over a 3-year period, starting in Fall 2019 and continuing through the COVID-19 pandemic, we identified priority unanswered research questions on aging and mental health according to older adults, caregivers, and health/social care providers living in Canada.[2] More information about the priority questions is available on our website.

In Fall 2021, the Canadian Aging Action, Research, and Education (CAARE) for Mental Health Group was formalized and included members from the original project's steering group and interested members of the public.

Who are we?

The CAARE Group is a group of experts-by-lived-experience from across Canada. Our members include older adults, family and friend caregivers of older adults, health and social care providers who work with older adults, and members of organizations who focus on mental health. We recognize the importance of authentic partnerships and CAARE strives to challenge the traditional definitions of 'experts' and 'allies' in mental health research. Our goal is to be inclusive, equitable, and

non-hierarchical, with a diverse representation of the many perspectives of aging Canadians.

What are our goals?

The goal of CAARE is to promote awareness of and action on the top 10 unanswered questions on aging and mental health *as well as* the answered questions. Specifically, we are working to:

1. Build and sustain authentic partnerships between researchers, health and social care providers, older adults, family/friend caregivers, funders and policymakers interested in working together to advance aging and mental health care, support, and treatment in Canada;
2. Support the co-design and completion of research and action-oriented projects on the top 10 unanswered questions as well as the answered questions identified by older adults, family/friend caregivers, and health and social care providers;
3. Advocate and/or apply for funding to support the priorities and activities of the group.

The CAARE Group meets quarterly, and our activities include:

- Creating opportunities to incorporate the perspectives of experts-by-lived-experience in aging and mental health initiatives;
- Providing practical and strategic advice to research scientists on the design and implementation of mental health research and action projects;
- Identifying opportunities for collaboration with researchers, funders, policymakers, etc. on the questions on aging and mental health that Canadians have identified; and
- Promoting aging and mental health projects (e.g., recruitment, uptake of knowledge, etc.) with local communities and contacts.

What are we doing?

We were supported by a CIHR – Institute of Aging Voluntary Sector Knowledge Mobilization Support Grant between 2022-2023 to: formalize the group (e.g., establish a group name, logo, member honoraria); start recruiting additional members; and begin preliminary knowledge mobilization activities (e.g., developing an information video about the group and priority questions).

Our planned activities in 2023-2024, with funding support from SE Health, include:

- Leveraging the CAARE Group's lived experiences with collaborating organizations by providing feedback, support, etc. on upcoming older adult mental health initiatives;
- Recruiting more individuals to the CAARE Group who are representative of Canada's diversity; and,
- Expanding on the SE Research Centre's existing webpage for aging and mental health initiatives, while establishing a 'resource hub' of information related to the priority questions.

How can you get involved?

If you are interested in joining the CAARE for Mental Health Group, sharing our materials with your network, or learning more about us in general, you can contact Elizabeth Kalles at elizabethkalles@sehc.com.

The CAARE Group is committed to inclusive and equitable practices and working with you to remove any barriers you or others may experience. Some examples we have implemented include mailed materials in advance of gathering, honoraria in recognition of the time involved, flexible scheduling, phone and video support for meetings, translation of materials into French, and synchronous and asynchronous opportunities to provide input and share ideas and feedback.

Scan the QR code to watch a brief (2.5 min) video and learn how you can get involved with the CAARE Group.

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How is this research funded and supported?

This research is funded and supported by: SE Health, one of Canada's largest social enterprises and a CIHR Institute of Aging Voluntary Sector Knowledge Mobilization Grant.

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Our Dementia Journey Journal: A co-designed tool to support partnerships among persons living with dementia, their caregivers and care providers

Unpaid caregivers and care providers of persons living with dementia (PLWD) told us they want a tool to help them communicate with each other and support their individual and joint roles for working together in dementia care.

18 months of co-design work led to the development of a prototype tool for supporting unpaid caregivers and care providers of PLWD. We call it *Our Dementia Journey Journal.* With funding from the Public Health Agency of Canada and SE Health, we have spent the last 3 years adapting the tool to reflect the diverse needs of people in a variety of communities across Canada.

Project Overview

As of 2020, there were approximately 597,000 Canadians living with dementia, with numbers expected to rise to almost a million by the year 2030.[1] In turn, Canada's 2022 Dementia Strategy calls for increased capacity to care for persons living with dementia (PLWD) with an emphasis on integrated, person-centred, quality care.[2]

Person- and family-centred care (PFCC) means actively involving PLWD in their own care throughout the dementia journey[3] and has been described by PLWD, their unpaid caregivers and care providers as "promoting a continuation of self and normality".[4]

In a collaborative project exploring PFCC in dementia care with the Alzheimer's Society of Canada we heard from unpaid caregivers and care providers of PLWD that the dementia journey is full of changes–in mental and physical function, in care settings, and in the number and types of care providers. We have also heard that the roles of unpaid caregivers and care providers change over time, including their roles in providing "clinical" versus more "emotional, relational" care. They told us they would like to have a tool to help them communicate with each other and support their individual and joint roles for working together in dementia care.

In response, over the course of 18 months, we held 6 co-design workshops with 26 unpaid caregivers and care providers of PLWD in an Ontario long-term care home community to develop a prototype paper-based tool for unpaid caregivers and care providers to be active, informed, collaborative caregivers of PWLD. We call this tool *Our Dementia Journey Journal* (ODJJ).

Considering the diverse experiences of PLWD, their unpaid caregivers, and care providers there remained questions about whether the content,

focus and structure of the ODJJ would be relevant to other communities who differ based on their access to health resources (e.g., geographic location), culture, race and/or language.

What have we done?

We completed community-based consultations and workshops with PLWD, their unpaid caregivers and care providers with two First Nations and one urban Indigenous community in Northern Ontario (n=34), a group in British Columbia (n=5) and members of South Asian communities in Ontario and Alberta (n=10). Participants were invited to review the paper prototype of the ODJJ and provide commentary and suggestions for ensuring cultural safety and for its usefulness in their relationships especially during changes along the dementia journey.

Through these consultations and workshops, we received considerable feedback on the look and content of the prototype. Feedback included the need for culturally relevant imagery as depicted by the medicine wheel in Figure 1 which is part of the Northern Ontario First Nations version of the ODJJ; the request for a digital version of tool; and changes to layout like including more room for writing questions. At the same time, we heard from participants that they believed the core components of the *Journal* would be helpful to improve the care of PLWD.

Since then, we have revised the prototype and developed community-specific versions of the ODJJ. Furthermore, we have translated these adapted versions into French, Punjabi, and Hindi and have also created e-versions that offer an alternative to the paper format.

Following adaptation, we provided revised versions of the ODJJ (in both paper and e-version format) to 10 members from the British Columbia and First Nations communities involved. Participants were asked to complete a survey before and after using the *Journal* for a minimum period of three months. Participants found the ODJJ useful in different ways

including to connect with others in the circle of care and to reflect through journaling.
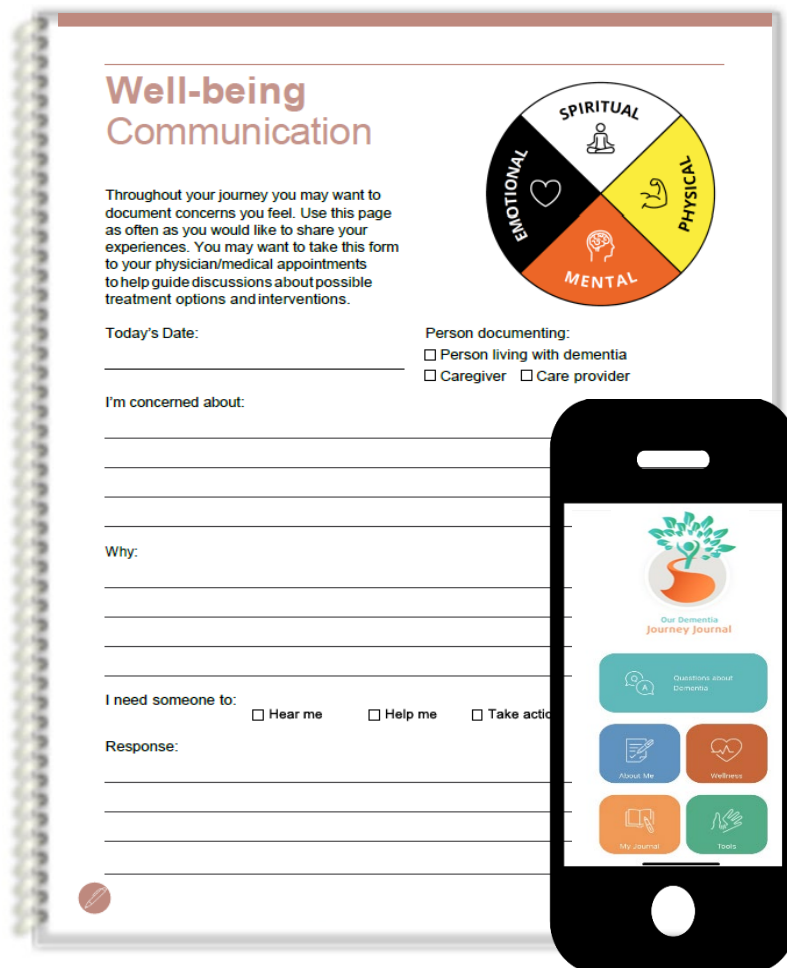
Figure 1. The image above, is an excerpt of one of the pages of Our Dementia Journey Journal, adapted for the Northern Ontario First Nations communities. The image on the right, is a screenshot of the home screen of Our Dementia Journey Journal mobile

What are we doing?

We are currently working on optimizing the South Asian version of the ODJJ through further co-design with community members. This version will be made available in English, Punjabi, and Hindi.

In addition, we have been developing a mobile application 'generic' version of the ODJJ, as requested by participants. It is hoped that the mobile application will increase the tool's reach across Canada.

Lastly, as a part of new Public Health Agency of Canada (PHAC) funding, we began the deployment of the ODJJ paper, e-version and app in facility-based continuing care in Alberta, First Nations communities across Canada, and South Asian communities in Southern Ontario in the fall of 2023. This project will focus on the evaluation and sustainability planning of the tool so that it can be used more widely and beyond the funding by PHAC.

What is the intended impact?

We hope that our work on *Our Dementia Journey Journal* will strengthen relationships among the dementia circle of care enhancing the quality of dementia care in different settings across Canada.

How is the research funded?

This research was and is funded by the Public Health Agency of Canada under its Dementia Community Investment Program, and by SE Health, one of Canada's largest social enterprises.

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Long-term LIFE care at home: the future of aging-focused care in Canada

Most Canadians want to live, age, and receive care at home, yet the health care system continues to prioritize building more hospital and long-term care (LTC) facility beds. To make older Canadians' quality of life a priority, we need to consider and provide services that meet their 'life care' needs. Improving home and community care will give older Canadians more options for where to live and receive care as they age.

We completed a review of Ontario home care assessments, engaged home care providers in a consensus building process, facilitated workshops with older adults, family caregivers and health and social care providers, and conducted interviews with health and social care decision makers. Together, these results were used to inform the development of an innovative model of home care called *Long-term Life Care at Home* which considers the broad range of health and social care needs of aging Canadians. Overlap in needs across LTC and home care populations, and initial price comparisons across settings show that there can be both short-term and long-term benefits to shifting more long-term older adult care to the community.

Project Overview

Although 96% of Canadians want to live, age, and receive care at home long-term,[1] the long-term care (LTC) system in Canada continues to prioritize facility-based care settings. For example, the Ontario government is currently working to create 8,000 LTC beds and re-develop another 12,000,[2] yet wait times for admission continue to grow.[3] With the population of Canadians 85 years+ set to triple in the next 30 years,[4] we have to look beyond building LTC facilities to meet the demand for care.

Meanwhile, home care is underfunded, resulting in task-based care delivery, often for short periods following a hospital stay[5] and inadequate availability of services.[6] In addition, home care has not been designed to support social or mental health needs[7,8] and relies heavily on caregivers.[9]

If we broaden our thinking about LTC to a system-wide perspective, we can consider four types of LTC "beds": 1) at home without care; 2) at home with care; 3) in hospital alternate level of care (ALC); and 4) in LTC facilities. Currently, none of these LTC options are adequately meeting people's needs.[10-18]

Our position is that a solution that focuses on meeting the long-term needs of people in their own homes and beds will not only better match care to the preferences of all Canadians, but it will also reserve hospital and LTC facility capacity for those who have needs that are best served in those settings.[19]

What did we do? [19]

1. Reviewed 205,000 home care assessments to categorize Ontario's home care population into groups based on known risk factors of LTC facility admission;
2. Analyzed each group to describe their dominant medical, functional and social 'life care' needs;
3. Conducted a six-week survey consensus process with 42 home care providers to identify packages of care/services to meet life care needs;
4. Completed a feasibility assessment by comparing life care needs and average daily costs of care between the emerging *Long-term Life Care at Home* model and the existing 4 types of LTC "beds";
5. Facilitated workshops with 67 older adults, family caregivers and health and social care providers to validate and refine the model and care packages; and
6. Conducted interviews with 10 health and social care decision makers to explore their perspectives on positioning the *Long-term Life Care at Home* model within the Ontario healthcare context, including mapping a potential referral process.

Table 1. Six groups of older adults based on Ontario home care assessment data & preliminary care packages

| Group A: Social Frailty	Group B: Caregiver Distress	Group C: Chronic Disease Management	Group D: Cognitive Impairment + Behaviours	Group E: Medical Complexity	Group F: Geriatric Syndromes
Maya Jones • Lives alone • Requires IADL support & ADL supervision • Unsteady gait • Living with daily pain • Some cognitive decline	**Frank Santos** • Lives with spouse • Signs of caregiver distress • Requires support with IADLs & ADLs • Unsteady gait • Living with daily pain • Continence concerns • Cognitive impairment • Indicators of depression	**Helen Yoon** • Lives with granddaughter • Signs of caregiver distress • Requires support with IADLs & ADLs • Unsteady gait • Mild health instability • Living with daily pain • Cognitive impairment	**Priya Laghari** • Lives with son's family • Signs of caregiver distress • Requires support with IADLs & ADLs • Unsteady gait and falls • Continence concerns • Cognitive impairment • Indicators of depression • Exhibiting behaviours	**Annette Moreau** • Lives with daughter • Moderate health instability • Cardiorespiratory symptoms • Living with daily pain • Multiple medications • Requires support with IADLs & ADLs • Continence concerns • Indicators of depression • Cognitive impairment	**Gloria Drakos** • Lives with daughter • Signs of caregiver distress • Requires support with IADLs & ADLs • Weight loss • Unsteady gait and falls • Living with daily pain • Continence concerns • Indicators of depression • Cognitive impairment
Care team*: PSW, Therapy Assistant, Visiting Nurse, Primary Nurse, OT, PT	**Care team*:** PSW, Visiting Nurse, Therapy Assistant, Social Worker, Primary Nurse, PT, OT	**Care team*:** PSW, Visiting Nurse, Social Worker, Primary Nurse, Therapy Assistant, SLP, OT, PT, RD	**Care team*:** PSW, Visiting Nurse, Social Worker, Primary Nurse, Therapy Assistant, SLP, OT, PT, RD, Spiritual Care Provider	**Care team*:** PSW, Visiting Nurse, Social Worker, Primary Nurse, Spiritual Care Provider, PT, OT, RD	**Care team*:** PSW, Visiting Nurse, Primary Nurse, PT, SLP, RD, OT
3.1 hours/ day**	4.6 hours/day**	5.7 hours/day**	7.3 hours/day**	8.1 hours/day**	5.9 hours/day**

What are we finding so far?

- Ontario's home care population can be divided into 6 groups based on known risk factors for LTC admission (Table 1, Row 1).
- Medical, functional, and social 'life care' needs can be described using the 6 dimensions of the Pillars for Positive Health including: bodily functions, mental wellbeing, meaningfulness, quality of life, social & societal participation and daily functioning.[20]
- There are 65 types of care and support services that can be considered to support the life care needs of older adults at home and in the community.
- Care packages which meet the life care needs of the 6 patient groups at risk of LTC admission range from 3.1 - 8.1 hours per day including both direct care and coordination (Table 1, Rows 3-4).
- Overlap in the life care needs of older adults currently receiving home care and LTC in Ontario suggests the potential to shift the setting of care for more older adults to their homes.

- All care packages in the new *Long-term Life Care at Home* model are lower in cost than current hospital ALC rates; and many are lower in cost than a private room in a LTC facility.
- Feedback from workshop participants (older adults, caregivers and care providers) suggests opportunities for model refinement in three categories: factors influencing model operationalization, changes and additional considerations, and support for design principles (see Figure 1 below).
- Feedback from interviews with health and social care decision makers highlighted the potential for *Long-term Life Care at Home* to supplement existing services and emphasized the significance of a person-centred and integrated approach to care.

Inclusion of older adults, caregivers, health/social care providers and decision makers as experts-by-experience in the development of new models of care is critical to ensure they are acceptable and responsive to the needs and preferences of aging Canadians.

Figure 1. Guidance from older adults, care givers and care providers on how to implement the model
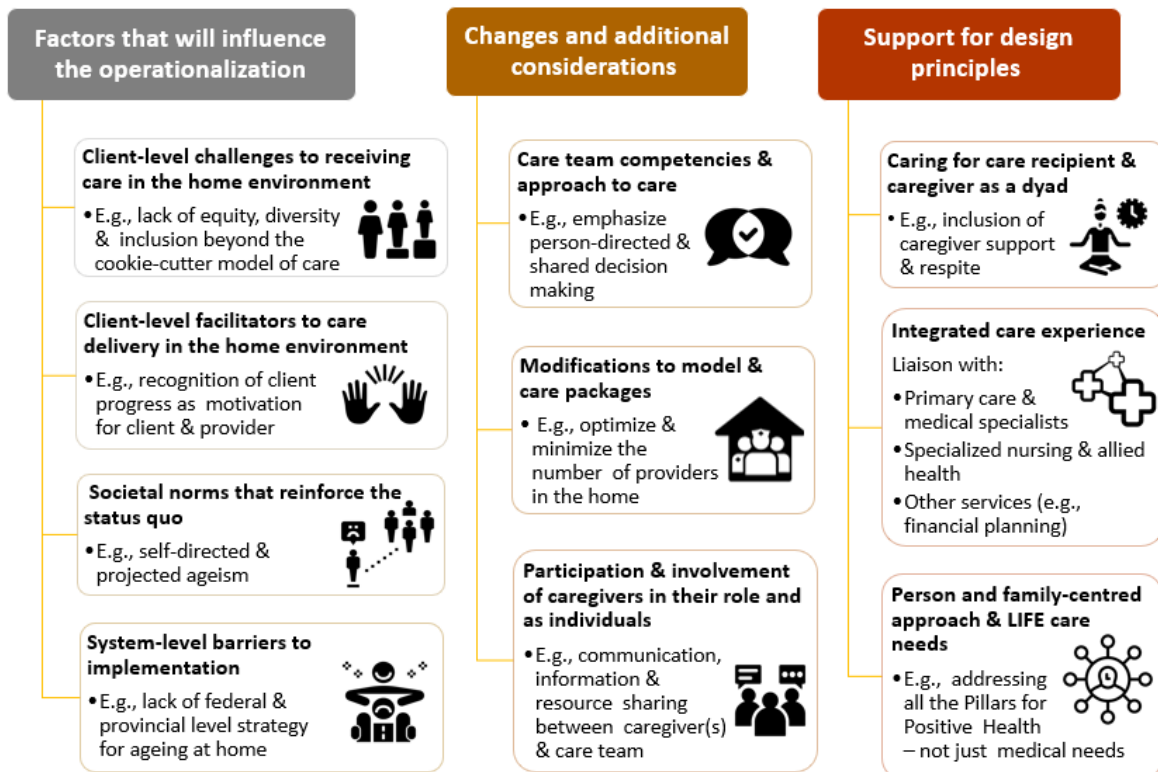
What is the anticipated impact?

A new model of care to meet the life care needs of older adults at home long-term is anticipated to:

- Restore and increase the volume and range of home care services available to older adults and preserve their autonomy and choice around where to live, age and receive care; and
- Help shift our LTC system in Canada to focus less on bricks and buildings and more on people and communities.

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How is this research funded and supported?

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Getting to integrated, team-based home and community care

Fragmentation across Ontario's health system has contributed to poor client and provider experiences, health outcomes, and higher costs. This is particularly true for older adults with complex health and social needs. We are exploring how organizations in Ontario are taking a collaborative, integrated approach to home and community care for older adults. We first identified lessons learned from a previous neighbourhood-based initiative, and now aim to see how these lessons can be applied in the context of Ontario Health Teams.

As Ontario Health Teams move towards improved integration and coordination to support aging at home, there are opportunities for learning across current and past integrated care initiatives in the province. In the first part of our research, we analyzed experiences of a care team in a resource-poor urban neighbourhood and found that home and community care organizations were able to collaborate when they had a shared vision for their collaboration, as well as processes for sharing information and resources. Integration was further supported by engagement of community members, clients, and point-of-care staff; strategies to overcome policy barriers and competitive relationships among organizations; and a clear role within the broader health system, along with openness to bottom-up innovation.

Project Overview

Ontario's vision to deliver coordinated care across providers and organizations was prompted by criticisms of a siloed system that contributed to poor patient experiences and outcomes. Ontario Health Teams (OHTs) have been created to deliver care that brings together coordinated teams of health and social care providers and organizations to improve patient outcomes. OHTs can learn from previous initiatives and from each other, to avoid duplication and achieve transformative change in the system.

Before the pandemic, an integrated care team was developed and implemented in a resource-poor urban neighborhood. This team aimed to move towards a more collaborative, integrated approach to home and community care for older adults with complex needs. The team leading this program worked to emphasize client and caregiver choice and shared decision-making, while creating strong linkages within and across care sectors. This team's work offers learnings that may benefit OHTs as they move forward.

What did we do?

The neighbourhood care team ceased operations in

2020, due in part to the effects of provincial policy shifts as well as the challenges posed by the pandemic. However, lessons can still be learned from its work. We analyzed detailed minutes from 25 meetings of the neighbourhood care team. These meetings included members from 10 provider organizations. We examined how the team's collaboration was affected by contextual factors, including the community and clients served, the participating organizations themselves, and the broader health system. The goal was to uncover learnings that could be shared with OHTs to inform sustainable cross-sectoral integration. We then tested our emerging analysis through interviews with five participants who were involved in the neighbourhood care team.

What did we find?

Our preliminary analysis found clinical- (micro), organizational- (meso), and system- (macro) level facilitators and barriers of integration within the neighbourhood care team. In the text that follows, facilitators and barriers are bolded; strategies that the neighbourhood care team used to apply facilitators or cope with barriers are italicized. These complex inter-relationships are also represented in a diagram on the following page.

At an organizational) level, facilitators of integration included:

- Norms (or values and beliefs) including a **shared vision and purpose** and **open discussion and conflict resolution**.
- Functions (or processes) including a **broad membership, learning and evaluation, sharing resources,** and **inter-organizational communication**.

These facilitators were also influenced by other parts of the health system, including micro-level factors like **community engagement, client-centred planning processes,** and **frontline staff engagement**. Several strategies linked these clinical-level factors to organizational integration:

- **Community engagement** and **client-centred planning** were used to strengthen the team's **shared vision and purpose**, as centering on client and community perspectives helped organizations—and individual staff—to *bridge worldviews*.
- **Client-centred planning** also supported **learning and evaluation**, as *aligning outcomes* with client goals helped to ensure the team was measuring what mattered.
- **Point-of-care staff engagement** contributed to **inter-organizational communication**, through *involving frontline managers* to act as a conduit between clinical and strategic processes.

System-level facilitators included **a clear role within the health system, receptive system leadership,** and **infrastructure and policy enabling communication and resource distribution across organizations**. While these factors were not always present throughout the work of the neighbourhood care team, various strategies were used or suggested to cope with the resulting barriers:

- **A clear role within the health system** and **receptive system leadership** underpin a **shared vision and purpose** at an organizational level, by creating space in which organizations can bring their shared vision to life. This requires system-level decisionmakers to collaborate with organizational leaders to *enable bottom-up innovation*.
- When **infrastructure and policy** created barriers to **resource sharing** and **inter-organizational communication**, organizations created *Terms of Reference* to ensure that those benefitting from collaboration are also accountable to contributing. *Privacy experts* were engaged to develop appropriate workarounds.

Across every level, a consistent set of principles were important. These were:

- **Time** to build relationships and develop strategies and structures;
- **Trust** and **Transparency** among the varying people, communities, and organizations involved; and
- **Tailoring** of strategies to local and current needs.

What could the impact be?

As OHTs work to develop local integrated care programs to support aging at home in Ontario, there is an opportunity to share and learn from previous integrated care initiatives and models. Learnings from the neighbourhood care team may be particularly important to OHTs as they navigate the complex context of the home and community care.
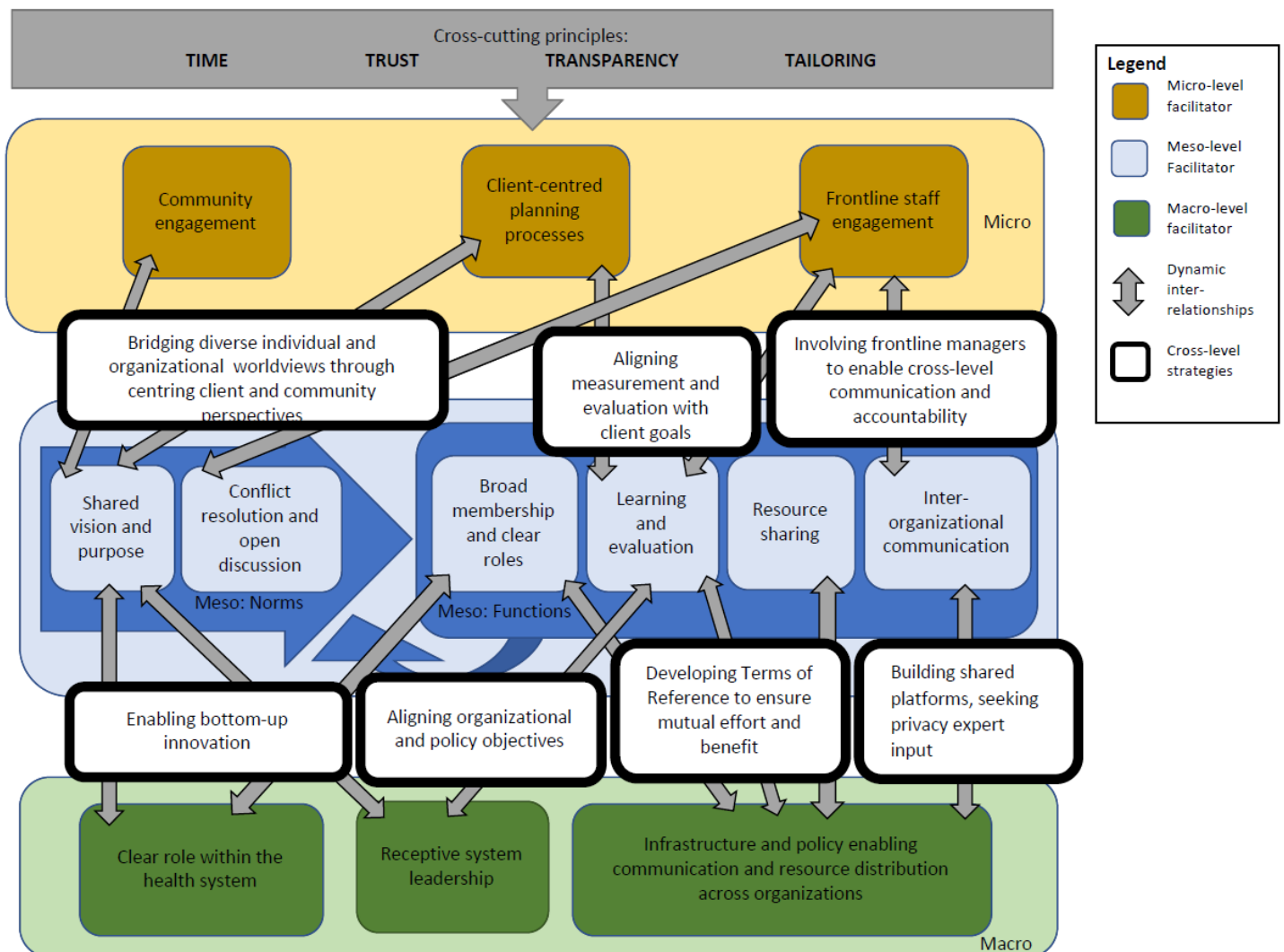
How was the research funded and supported?

This research was funded by SE Health as part of its social innovation mission.

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Developing the Participatory Research to Action (PR2A) framework

Patients, caregivers, and other knowledge users are increasingly involved in health services research. The SE Research Centre team identified the need for a framework to guide involvement of experts-by-experience. The framework needed to be flexible enough to encompass a range of contexts and methodologies—but structured enough to embed involvement across the complete continuum of applied health services research, from identifying a problem to disseminating and evaluating solutions.

The Participatory Research to Action (PR2A) framework brings together concepts from service design, co-design, and integrated knowledge translation to articulate a six-stage process for participatory applied health services research. We describe three cases representing stages in the development of the PR2A framework: a stroke care project that highlighted gaps in off-the-shelf approaches to involving experts-by-experience; the participatory development of the PR2A framework itself; and the successful application of the new framework in a study with caregivers of persons living with dementia.

Project Overview

Patients, caregivers, and other experts-by-experience are increasingly recognized as important partners in health research. Participation of experts-by-experience has been argued to improve the relevance and quality of research.[1]

One approach to patient participation is experience-based co-design, which uses observation, video prompts, and workshops to explore and respond to health services issues.[2] Another approach is integrated knowledge translation which involves knowledge users like clinicians and policymakers, with the goal of closing gaps between research knowledge, and its uptake in practice and policy.[3]

However, researchers at the SE Research Centre found that these approaches did not fully meet the needs of both researchers and experts-by-experience engaged in their studies. The range of methods used was too limited, often relying on traditional interview- and focus group-based approaches, and decision-making still lay largely with researchers rather than experts-by-experience.

To address these shortcomings, the SE Research Centre team introduced an additional approach: service design, which engages people in open-ended creative processes.[4] The team then drew on these three approaches–experience-based co-design, integrated knowledge translation, and

service design–in the development of a new, action-oriented framework that balanced creativity and structure.

What did we do?

We use three cases to describe the development of the PR2A framework. First, we describe a project prior to the formal development of the PR2A framework, in which the SE Research Centre team members encountered limitations of approaches described in the literature at the time. Next, we describe the participatory development of the PR2A framework itself. Finally, we describe an early example of the framework's application.

What did we find?

Case 1: Identifying the need for a new framework

In 2017, the SE Research Centre was engaged by a large teaching hospital to help improve a coordinated care pathway for cardiac surgery patients. The researchers had previously used experience-based co-design and integrated knowledge translation methods and found them too prescriptive to fluidly engage with experts-by-experience as authentic research partners throughout. They decided to use a service design approach instead. Service design uses "generative methods," which explore not only what people say and do, but also what they *make* when encouraged to participate creatively. The process led to the successful design of an ecosystem of supports for cardiac patients and their unpaid caregivers.

However, the team encountered several challenges. First, service design approaches are intentionally unstructured at the start, to maximize creativity. This was difficult to balance with the need for transparent, structured and step-wise research protocols. Second, while service design methods offered guidance for ideating on and prototyping interventions or tools, it did not offer guidance for implementing or evaluating these. The proposed ecosystem of supports was never fully put into practice or evaluated.

Case 2: Developing a new framework

Through reflection on experiences including the project described above, the SE Research Centre team decided to formally develop a tailor-made approach to participatory research, customized to applied health services research and evaluation studies. Workshop sessions were held to identify concepts and strategies from relevant bodies of literature. Next, these concepts and strategies were mapped onto the complete cycle of research, from study conception to implementation and evaluation. These findings were synthesized into a framework that addressed how participation could be embedded in six stages of a research cycle: *assess readiness, discover, define, develop, deliver,* and *measure* (see Figure below). This framework offers guidance for who to involve, when to involve them, and how to involve them in each of these stages. In doing so, the framework balances the generative potential of creativity with the rigor of a structured research process.

Case 3: Applying the new framework

The PR2A framework has since been applied in several projects. One early example was a project to explore and respond to the experiences of unpaid caregivers of persons living with dementia, initiated in 2018. Following the *readiness assessment*, the *discovery* phase included literature reviews, environmental scans, and diaries and photos produced by caregivers. Qualitative analysis of these materials was used to *define* the problems faced by caregivers. Co-design workshops with caregivers and care providers were used to *develop* a prototype for a paper-based tool that could help caregivers and care providers to collaboratively navigate the dementia journey. *Delivery* and *measurement* lead to iteration and expansion into both an analogue and a digital tool. This tool is now available in culturally adapted and multilingual versions.

What was the impact?

The PR2A framework has been applied successfully in a wide range of SE Research Centre projects. For

example, the team is co-designing and testing an approach to have conversations about mental health between home and community care providers and older adults during routine care interactions; developing and evaluating a training package for social care workers to support persons experiencing homelessness through the end of life; and proposing a model of long-term life care at home that can meet the health and social care needs of aging Canadians.

The balance of flexibility and structure within the PR2A framework has influenced the culture of the SE Research Centre, building capacity for managing the uncertainty of participatory work—such as the need for iterative protocol development and sustainable relationship building with experts-by-experience. Given its track record of successful application, this framework will be of interest to other researchers seeking to engage in participatory, applied health services research.

How was this research funded and supported?

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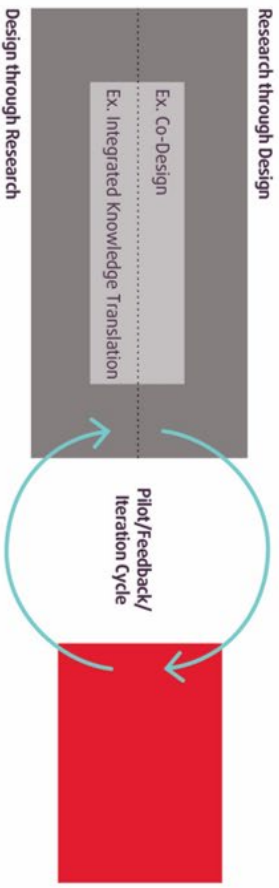**Paul Holyoke LLB MSc(Econ) PhD**
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Research through Design

Ex. Co-Design
Ex. Integrated Knowledge Translation

Pilot/Feedback/ Iteration Cycle

Design through Research

	READINESS	DISCOVER	DEFINE	DEVELOP	DELIVER	MEASURE
	Assess fit	**Exploration:** Understanding Context	**Reflection:** Synthesize & Translate	**Co-Creation:** Ideation, Prototyping & Iteration	**Planning:** Piloting & Implementation, Translation to Action	**Outcome/Engagement/ Measurement**
Supported by methods/tools such as:	Kick off meetings; Project planning	Literature Reviews; Diaries	Qualitative Analysis; Creative artifacts	Journey Maps; Gamestorming	Role Play; Feedback interviews	Surveys; Focus Groups

End-users/Community Members

Other possible supports
Innovators
Research

Marketing/Communications
Information Technology/Web
Human Resources/Operations
Clinical Practice

Evaluation

The influence of integrated home and community care programs on Quadruple Aim and Health Equity outcomes across the health care system

Health system transformation requires an understanding of how each sector within the system interacts and influences other settings and the broader system. As Canada looks to transform health care to better meet the needs of its aging population, it is crucial to understand the influence of integrated home and community care programs on the health system.

We are conducting a scoping review to map the quantity and type of evidence about the influence of integrated home and community care on various components of the health system including acute care, emergency medical services, primary care, informal care, and facility-based long-term care. Through this review, we hope to better understand if, and how, integrated home and community care programs influence Quadruple Aim (population health, care experience, cost of care, provider well-being) and Health Equity outcomes across the health system and identify any potential gaps in the knowledge base.

Project Overview

As the aging population continues to grow, the health system must recognize the changing care needs of society, such as an increasing number of people are requiring continuing care for chronic and medically complex conditions. Countries with publicly funded health systems, such as Canada, are looking to transform their health and social care systems to ensure their citizens receive the right care, at the right time, in the right place, ensuring available resources are maximized. The expansion of home and community care has been identified as a key driver for system transformation that can support the provision of medical, functional, cognitive, and psychosocial care, while meeting the desire of the aging population to live, age, and receive care at home.

The Quadruple Aim is an internationally recognized framework which takes a multi-faceted approach to system redesign and improvement. According to the Quadruple Aim, improvement efforts should focus on the following four goals:

1. improving population health;
2. enhancing the care experience for both clients and caregivers;
3. reducing the costs of care; and
4. improving the work life of care providers.

More recently, Health Equity was added as a guiding principle to ensure that improvement efforts benefitted all individuals, regardless of their socioeconomic or demographic characteristics.

What are we doing?

We are conducting a scoping review of the published research literature to better understand what the evidence tells us about the influence of integrated home and community care programs on acute care, emergency medical services, primary care, informal care and facility-based long-term care.

We started by searching three databases to gather literature using keywords relevant to home and community care, health system settings, and the Quadruple Aim and Health Equity outcomes. Then, we hand searched major integrated care journals to identify any articles that may have been missed during database searching.

We assessed 5,656 titles and abstracts and 568 full text articles for inclusion in our review. Currently, we are summarizing and analyzing the findings of included articles, and we plan to consult with study collaborators for feedback following completion of data analysis and completion of the review.

What will we find?

Preliminary findings are showing:

1. Most articles investigated effects of integrated home and community care on hospital or emergency medical service utilization (i.e., readmission rates, length of stay, and emergency department visits) with few articles including cost details.
2. Most articles report population health outcomes, with few articles investigating economic, patient/ provider experience or equity outcomes.

What is the anticipated impact?

Findings from this scoping review are anticipated to:

- Increase the understanding of the influence of integrated home and community care programs on the health system
- Identity gaps in the quantity and types of evidence assessed in existing research to inform future research on integrated home and community care programs

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How was the research funded?

Measuring client experience of emerging models of integrated home and community care

People want to live well, with dignity and safety, in their homes and communities for as long as possible.[1,2] To support this, some home care services in Ontario are restructuring to integrate home care (e.g., medical and personal care) with community-based social care and services (e.g., friendly visiting and meals).[1,3,4] Measures of client experience, referred to as 'patient-reported experience measures' (PREMs) are important for guiding health system improvements, yet current tools are insufficient for measuring client experience of these new models of home and community care.[5,6]

> This study will develop a new PREM that can be used to accurately identify, monitor, and address the concerns and priorities that matter most to clients of integrated home and community care. This new measure will be implemented to evaluate innovative models at SE Health and will also be made available to other organizations and teams in Ontario to support the design and measurement of positive changes in home and community care through Ontario Health Teams and beyond.

Project Overview

Home care is an important part of any healthcare system because it allows clients to receive care and live full, meaningful lives at home while remaining in the communities to which they belong.[1,2] However, the need for home care services has grown due to an aging population, increasing numbers of people having multiple complex chronic illnesses, and faster hospital discharge practices.[7] Studies have found the current home care system in Ontario is underfunded, understaffed, and inequitable in access resulting in clients not receiving the level of care they need.[2,8,9]

To address these challenges, the Ontario Ministry of Health and Long-term Care introduced Bill 175, the *Connecting People to Home and Community Care*

Act. This Act aims to more fully integrate home and community care to deliver better care centred around client's needs that ensures stability and continuity of care while strengthening client and caregiver participation in care planning.[10] One example of this new model of home and community care is SE Health's Home Opportunity People Empowerment (H.O.P.E.)® approach to care. This is a primary nurse-led model that addresses client and caregiver life care needs by leveraging community supports and services as well as clients' self-management capabilities.[11]

Patient-reported experience measures (PREMs) are important for guiding the development of new care

models. However, existing PREMs do not align with these emerging home and community care models.

We are developing a new PREM that captures the experience of people receiving integrated home and community care.

What have we done?

First, we outlined **the foundational principles** of innovative home care to map the types of relevant questions to this client experience.[12] Existing evidence suggests the principles of **equity, life care, relational caring, and continuity** (see details of these principles below) are crucial to enable delivery of home and community-based care that meets the quintuple aims of achieving health equity, reducing costs, improving population health, enhancing healthcare experience, and improving healthcare provider well-being.[2,13,14]

Equity: Is about measuring if people have access to care, feel safe and respected during care, and feel they are treated fairly.[4,15]

Life care: Is about measuring if clients receive care that meets their holistic needs such as bodily functions, mental well-being, meaningfulness, participation, and quality of life.[14,16]

Relational caring: Is about measuring if care happens between people within relationships that are attentive, collaborative, and supportive of growth and well-being.[16]

Continuity: Is about measuring if care feels connected, continuous, and coherent in that care providers know what happened to clients before and what the plan is now.[18]

PREM Development & Testing

Phase 1: Item Pool Development

In the summer of 2022, we conducted a literature review of PREMs in community healthcare. PREMs were included if they captured client experience and had been used in practice or there was

evidence the PREM produced reliable and valid data. The research team reviewed 171 existing PREMs and 3,000+ items. Items from eligible PREMs were coded into domains and then categorized. The research team removed duplicative and not applicable items by voting consensus.

Preliminary analysis found client experience of innovative home and community care was well captured by three domains (equity, life care, and continuity) encompassing 14 categories (e.g., respect, collaboration, and person-centred care planning). Categories contained 72 meaningful item concepts to measure (e.g., adapted care to lifestyle, having a primary provider, care goals discussion).

Healthcare leader experts (n=6) were interviewed about the relevance and coverage of these items and domains. They agreed these domains, categories, and item concepts were robust and aligned with intended experience outcomes of innovative care models.[12]

Phase 2: Content and Face Validity

In the Fall of 2022, we worked with health and social care providers (n=15), and home care clients and family/friend caregivers (n=17) to refine and test the proposed PREM items. Clients and caregivers engaged in focus groups, and care providers were individually interviewed. Both groups rated the appropriateness and relevance of the 72 item concepts, discussed what was missing, and how to improve relevance of concepts.[12]

The primary recommendations focused on

1. recognizing the responsibility of primary providers in delivering well organized care; and

2. shifting from a focus on self-management to having needed supports, and collaborative care planning. Participants excluded several item concepts due to being vague or not meaningful, such as asking, "my providers understood my needs".

Based on analysis of recommendations and how providers mapped item concepts to domains an additional domain was added, 'relational caring', resulting in our PREM having four domains (equity,

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life care, relational caring, and continuity). Item concepts were reorganized within the PREM, moving several from life care and equity into relational caring, and one new item was created (i.e., "My care provider(s) was kind to me"). We then developed the item concepts into PREM items with response options for further testing.

Phase 3: Cognitive Testing

In the Winter of 2023, we engaged clients and caregivers (n=11) with diverse gender expressions, racial backgrounds, abilities, and socioeconomic status in one-to-one interviews to identify issues related to answering the questions on our newly developed PREM.[12] The 39 items are scaled on a 6-point Likert scale: strongly disagree, disagree, neutral, agree, strongly agree, and not applicable. PREM instructions and demographic questions were developed and included.

Interview participants were engaged in a "thinking aloud" process to understand how items were being interpreted, if the items were clear, and if the scale options made sense.[11] From this cognitive testing, several adaptations were made to the PREM:

1. instructions were adapted to be role-specific (i.e., client vs. caregiver vs. substitute decision maker);
2. the definition of "care provider" was clarified (i.e., anyone who provides public or privately-funded care in the home);
3. the first question was re-ordered to make orientation to the survey easier by beginning with the concept of listening vs. holistic assessment;
4. 19/40 items in the PREM were amended to improve clarity;
5. scaling of non-response options were collapsed into a 'No answer' option;
6. the content of one question was amended to capture the concept of appropriate care, felt to be missing by participants; and
7. two questions about involvement in decision-making were collapsed as people answered them the same way.

Scan the QR code below to view the PREM's 4 domains and 39 items.

What will we do next?

We have tested the PREM with 191 home and community care clients and are currently conducting reliability and validity tests. We will determine if the PREM measures what it is meant to and if it produces the same results on different occasions.[12] From this information, we will refine the items and scale.

What will be the impact?

It is anticipated that this study will result in a measure that is reliable and valid for use with home care clients in Ontario. Applying this new PREM in practice will support a more accurate evaluation of home care experience that can be used to improve quality and inform optimization of innovative home and community care models.

How was the research funded?

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