

Research Project Summaries





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.





Contents

E,	riday Octobor 21, 2022	
	Aging In Place (11:15-12:45) Mobilizing expertise in aging at home: engagement of older adults, caregivers and health and social care providers in the development of the "Long-term Life Care at Home" model	 3
	Improving Aging Care (14:00-15:30) How do we successfully integrate health and social care? Learnings from efforts in a resource-poor neighbourhood	 7
	Older Adults During The Pandemic (16:00-17:30) Addressing pandemic-related grief and loss in long-term care homes: The Reflection Room®	 9
Sa	aturday, October 22, 2022	
•	Health Education (08:00-09:30) Evaluation of a training package for social care workers to support increased access to palliative care for persons experiencing homelessness	 11
•	Poster Session V (08:00-09:30) Mobilizing & Addressing Aging and Mental Health Research Priorities for Aging Canadians: The Canadian Aging, Action, Research and Education for Mental Health Group	 13
•	Operationalizing a Holistic Health Definition as a Framework to Guide Comprehensive Assessment at the Point of Care: A Modified eDelphi Study	 15
•	Resource utilization groups in transitional home care programs: Validating the RUG-III/HC case-mix classification system in a novel population of home care clients	 17
•	Poster Session IX (13:30-15:00) Developing an item pool for measuring client experience of merging models of integrated home and community care	 19







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 residential long-term care (LTC) beds. To make the quality of life of older Canadians a priority, we need services to meet their life care needs across the health care system. 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 over 200,000 Ontario home care assessments and a survey of over 40 home care providers. We used the results to develop a model called *Long-term 'Life Care'* at *Home* to meet the 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 older adult care to the community.

Project Overview

Although 96% of Canadians want to live, age and receive care at home long-term¹, the long-term care (LTC) system in Canada continues to prioritize residential care settings. For example, the Ontario government is currently working to create 8,000 and re-develop 12,000 residential LTC beds², yet wait times for admission continue to grow³. With the population of Canadians 85 years+ set to triple in the next 30 years⁴, we will have to look beyond building residential LTC to meet the demand.

Meanwhile, Canadian home care is funded for task-based care delivery, often for short periods following a hospital stay⁵ and inadequate availability of services⁶. In addition,

it is not designed to support social or mental health needs^{7,8} and relies heavily on caregivers⁹.

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) hospital alternate level of care (ALC); and 4) residential LTC. Currently, none of these LTC options are adequately meeting people's needs¹⁰⁻¹⁸.

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 home capacity for those who have needs that are best served in those settings¹⁹.

What did we do? 19

- Reviewed over 200,000 home care assessments to categorize the Ontario home care population into groups based on known risk factors of residential LTC admission;
- 2. Analyzed each group to describe the dominant medical, functional and social life care needs;
- Conducted a six-week survey consensus process (or modified eDelphi) with 40+ home care providers to identify packages of care/services to meet life care needs;
- Completed a feasibility assessment by comparing life care needs and average daily costs of care between emerging model and the existing 4 types of LTC beds; and
- 5. Facilitated workshops with 67 older adults, family caregivers and health/social care providers to validate and refine the model and care packages.

What are we finding so far?

- The Ontario home care population can be divided into 6 groups based on known risk factors for LTC admission including social frailty, caregiver distress, chronic disease management, cognitive impairment and behaviours, and geriatric syndromes (Table 1).
- Medical, functional and social 'life care' needs can be described using the 6 dimensions of the Pillars for Positive Health which include: bodily functions, mental wellbeing, meaningfulness, quality of life, social & societal participation and daily functioning²⁰.
- 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).

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

Group 1 Social Frailty	Group 2 Caregiver Distress	Group 3 Chronic Disease Management	Group 4 Cognitive Impairment + Behaviours	Group 5 Medical Complexity	Group 6 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 sy mptoms 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	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**

IADLs: Instrumental Activities of Daily Living; ADLs: Activities of Daily Living; PSW: personal support worker; OT: occupational therapist; PT: physiotherapist; RD: registered dietitian; SLP: speech language pathologist. *Providers listed from highest to lowest involvement. Primary nurse responsibilities include care integration as well as the delivery of direct nursing care. **Average daily total care and coordination hours across home care team.

- 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 our new model of Long-term Life Care at Home are lower in cost than current hospital ALC rates; and many are lower in cost than private room residential LTC.
- Feedback from workshop participants suggests opportunities for model refinement in three categories: factors that will influence the operationalization of the model, changes and additional considerations, and support for design principles (Figure. 1)

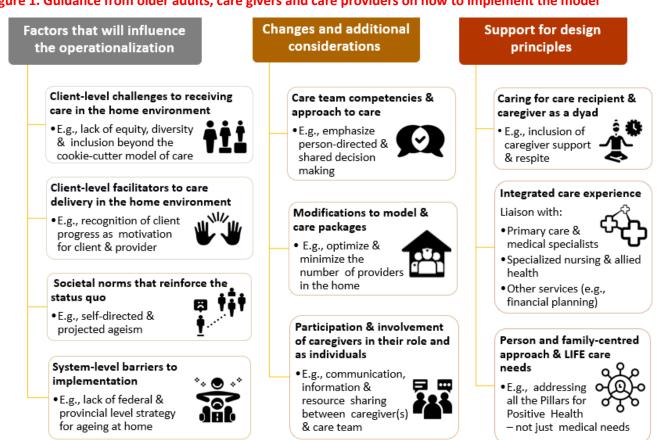
 Inclusion of older adults, caregivers and health/social care providers as experts-by-experience in the development of new models of care is critical to ensure they are acceptable and responsive to the needs and preferences of aging Canadians.

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.

Figure 1. Guidance from older adults, care givers and care providers on how to implement the model



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Getting to integrated, team-based home and community care

Fragmentation and silos within and across sectors of the Ontario health care system has led to suboptimal client and provider experiences, health outcomes and costs. A small neighbourhood-based program was developed and implemented in a resource-poor area of Toronto to move towards a collaborative, integrated approach to home and community care. We conducted a retrospective evaluation to examine barriers and facilitators to integration.

As Ontario Health Teams work towards improved integration and coordination to support aging at home, there is opportunity to share and learn from previous integrated care initiatives and models and apply learnings in the future. Our analysis of the experiences of a neighbourhood care team integrating care revealed the importance of various factors for successful integration: intra-team familiarization, direct-care providers' perspectives, a focus on individual clients' needs and preferences, management support, and tools and policies for communication and coordination.

Project Overview

Ontario's vision to deliver coordinated care across providers and organization was prompted by criticisms of a siloed system that contributed to inequitable patient experiences and outcomes. Ontario Health Teams (OHTs) have been created to deliver care that brings together health and social care providers and organizations to work as one coordinated team to improve patient outcomes. It is important for OHTs to apply learnings from previous initiatives to achieve transformative change in the system.

Before the pandemic, a neighbourhood program was developed and successfully implemented in a resource-poor neighbourhood of Toronto to move towards a more collaborative, integrated approach to care. The team leading this program worked to emphasize client and caregiver autonomy and share decision-making, while creating strong linkages within and across care sectors. This team's work offered some learnings that may benefit OHTs as they move forward.

What did we do?

We conducted a retrospective evaluation to examine barriers and facilitators to integration encountered during the neighbourhood care team implementation. We analyzed the detailed minutes from 25 meetings of the neighbourhood care team that included members from 10 provider organizations. In our review, we looked for developments and changes that occurred in the conceptualization and implementation of the home and community care team, with analysis guided by the frameworks of Peckham et al. (2018)¹ and Calancie et al. (2021)². The goal was to uncover learnings that could be shared with OHTs to inform sustainable integration across the system.

What did we find?

Facilitators supporting integration within the neighbourhood care team included:

- Efforts to familiarize the members of the team with each other and to develop an understanding of their scopes and philosophies of practice facilitated negotiations towards a shared frame of reference for working together, and the development of trusting working relationships
- Client-centred discovery and familiarization around specific clients' needs (including incorporating clients' preferences for certain providers) advanced the integration of care
- Direct-care and managerial representation at team meetings provided opportunities to incorporate the valued input from direct-care providers to guide the implementation and the processes and policies that enable integration of care
- Community engagement provided unique opportunities to understand client experiences and inform the development of a shared vision and model of care. As an added benefit, community

engagement help embed the care team within the community, bolstering its credibility

Barriers to integration included:

- Misaligned worldviews across sectors and interagency competition¹ persisted as barriers to integration but were incrementally reduced through pressure and persuasion from the direct-care members of the team
- Lack of clarity and transparency from leadership and decision-makers threatened group cohesion.
 Insufficient support for model development and implementation led to frustrations and doubts about the perceived value of continuing collaboration and the use of limited resources
- Challenges around the compatibility of information technology and the policies and processes that govern their use (e.g., consent, privacy and confidentiality policies) persisted. Through the assistance of technology and privacy experts, most organizations were able to continue collaborating, although some in less capacity
- Team raised concerns regarding equitable contribution, especially concerning funding mechanisms. A partnership agreement that outlined roles, responsibilities, and terms of involvement for each funding application has potential to protect partners and discourage passive or exploitive membership

What could the impact be?

As OHTs work to develop local innovative integrated care programs to support aging at home in Ontario, there is opportunity to share and learn from previous integrated care initiatives and models and apply learnings to build on success and learn from challenges as we collectively work towards a more integrated care experience for aging Canadians.

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How was this research funded and supported?

This research was funded and supported by: SE Health,

one of Canada's largest social enterprises.

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The Reflection Room®: Creating Space for Grief, Bereavement, Community and Healing in Long-Term Care Homes

The global COVID-19 pandemic has prompted worldwide experiences of grief and loss. In Canada, as in other countries, the human impact of the pandemic - in terms of mortality and negative physical, emotional and psychological outcomes - has been especially devastating in long term-care homes (LTCHs). As we move towards a post COVID-19 future, finding new ways to address grief and loss in LTCH communities is important. The Reflection Room® uses storytelling to generate open dialogue about dying and death without reluctance and fear. The project has also highlighted opportunities to engage in wider conversations about grief, regret and gratitude, especially given the social challenges of the COVID-19 pandemic.



The Reflection Room® engages people in thinking and talking about dying, death, and grief. The Reflection Room® has shown that a space for storytelling can be used as part of a grieving process for people, or as part of remembering, celebrating, teaching, learning, and connecting.

Project Overview

The Reflection Room® is an evidence-based art installation that was developed by researchers from the SE Research Centre and Memorial University in 2016. As storytelling has demonstrated a healing effect on storytellers and listeners, the researchers hypothesized that creating a calming physical space for people to write stories about dying, death and grief and read

those of others would generate open reflection about these topics and thereby support coping. Over a five-year period, 62 Reflection Room® installations were set up across Canada. Over a thousand collected reflections showed that storytelling served as part of a grieving process for people, and as part of remembering, celebrating, teaching, learning, or connecting.

October 2022 DDG 425

In response to the pressing need for grief and bereavement supports in LTCH communities, who have been hit hard by the COVID-19 pandemic, we introduced Phase 3 of the Reflection Room®.

The Reflection Room's® focus on dying and death was pivoted to address grief flowing from multiple losses, including death, loss of social contact, and loss of freedom. LTCH across Ontario are invited to host a Reflection Room®, at no cost, with the aim of offering a dedicated space for residents, caregivers, and staff to process their experiences throughout the pandemic, connect as a community center in their LTC home, and move towards collective healing.

What have we done?

In the first phase of the project, we found that where and how the Reflection Room® created space and time for people was important. In an extension of the original Reflection Room® research project, we created longer-term Reflection Room® installations across Canada. Installations were designed to create an immersive, welcoming, and relaxing environment with elements in the room connecting to the themes that emerged from an earlier spirituality research project.

By analyzing the stories shared on the Reflection Cards, we have observed several themes:

- Experiences remain in our hearts even though years or decades have passed.
- Relationships are at the center of the stories.
- Expressions of gratitude for people, experiences, memories are central.
- Feelings of regret run deep.
- Real appreciation for the invitation to reflect and remember.

What will we do next?

With the goal to increasing the reach of the Reflection Room® in Phase 3, we hope to determine whether the

Reflection Room® is scalable and spreadable to address pandemic-related grief, and if so, in what circumstances. Loss and grief may be a direct result of COVID-19 related deaths or other forms of loss such as changes to normal routines and ability to socialize with family and friends. Participating LTCH will receive kits to install a Reflection Room. Since June 2021 forty-seven LTCHs have already chosen the Reflection Room® as a resource to help their communities reflect on their grief and heal from the pandemic together.

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



What will be the (anticipated) impact?

The expectation is that the installation of the Reflection Room® will provide an opportunity for residents, family and friend caregivers, and long-term care home staff to express and share their reflections on their experiences of grief, including loss-oriented and restorationoriented stressors, and address some of the grief that has accumulated as a result of Covid-19-related deaths and other forms of loss.

So far, the LTCHs that have participated in Phase 3 have said that for many, reading and writing reflections in the Reflection Room® brings up feelings of gratitude, sadness, and peace. All visitors who completed surveys said they would recommend the Reflection Room® because it is soothing, supports the community to heal together, and provides a peaceful space for needed reflection.

How was this research funded and supported?

This research was funded and supported by: SE Health, one of Canada's largest social enterprises.

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Evaluation of the PA2Care training package for social care workers

Access to palliative care is especially difficult for persons who are experiencing homelessness, given the discrimination they face and the stigma they encounter in usual health care settings. Social care workers who support persons experiencing homelessness are trusted, but are not necessarily skilled in palliative care issues. The PA2Care (Palliative Approach to Care) training package is for those social care workers to build their knowledge, skill, and confidence in assisting people to gain access to palliative care. We evaluated the delivery of the training package to 191 social care workers at 3 sites across Canada: Toronto, Calgary and Thunder Bay.

Social care workers reported increases in their knowledge, attitudes, skills and confidence. They reported that the training package was useful and relevant to their work due to its principled approach, structure, content and flexibility. The training package is freely available for others who work with people who are experiencing homelessness.

Project Overview

Many people who are experiencing homelessness have chronic or life limiting conditions. However, because of social stigma, people experiencing homelessness are often unable or unwilling to access health care, including palliative care.

Workers who support people who are experiencing homelessness ("social care workers") are able to build trusting relationships and therefore have an opportunity to use these relationships to directly improve access to palliative care. However, these social care workers generally know little about palliative care.

The PA2Care training package was developed to enable social care workers to better address the palliative care needs of people experiencing homelessness. Building on the design activities in Phase I¹, Phase II evaluated the acceptability and relevancy of the final PA2Care training package, which was delivered at 22 workshops across 9 sites in Toronto, Calgary, and Thunder Bay.

What did we do?

Surveys were collected at 3 time points from the social care workers who participated in the training. The surveys collected self-reported data on knowledge,

October 2022 DDG 365

attitudes, skills, and confidence before, immediately after, and three months after participating in the training course. Semi-structured interviews were conducted with course facilitators to obtain feedback on the aspects of the training package that worked well and areas for improvement.



What did we find?

Social care workers reported a high level of general knowledge about palliative care prior to participating in the training. However, they reported lacking specific knowledge and practices, including the difference between a palliative approach and what they know as a harm reduction approach in their work. After the eLearning module, social care workers generally reported an increase in their knowledge, attitudes, and skills across all topics. After the in-person workshop, which provided opportunities for discussion and sharing among peers, the knowledge, skills and attitudes self-reported scores also generally increased.

The key features of the training package participants reported as most helpful were: ways to identify available legal and financial resources for the clients as they are dying, and strategies for talking about end of life with their clients. Social care workers reported

these strategies helped them to feel better prepared to discuss with clients their wishes and priorities for their end of life care. The participants also found the activity about handling their own grief when their clients die helpful for their personal well-being.

The positive, interactive, and non-judgemental sharing of experiences as part of the in-person workshop was very well received by social care workers. The opportunity to share strategies and hear stories from colleagues was reported as especially valuable both in learning new techniques and fostering a sense of connection to the wider community. Guest speakers from local palliative outreach programs were also reported as a favourite part of the training, as they provided valuable information on locally available resources.

Feedback from course facilitators was similarly largely positive. However, they made some suggestions for changes to the training package's format. Specifically, facilitators wanted flexibility to tailor some activities based on their sense of how participants were responding. For example, some groups preferred discussion over role play, and facilitators wanted the opportunity to accommodate these preferences.

What is the impact?

Based on the feedback from the participants and facilitators, the PA2Care training package was revised, and is available online, free of charge, at pa2care.ca. The package and other resources are freely accessible to interested individuals, social care workers, and organizations working with people who are experiencing homelessness.

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Who were our collaborators?

Partnerships with local organizations included Hospice Toronto, Hospice Northwest and Calgary Allied Mobile Palliative Program (CAMPP) advocates who work closely with people experiencing homelessness and their social care providers.

How was this research funded and supported?

This research was funded and supported by: SE Health, one of Canada's largest social enterprises.

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

The CAARE Group is a collective 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, the "positive sense of well-being or the capacity to enjoy life and deal with the challenges we face" is an important part of our overall well-being and the health of older adults. Mental health or mental well-being can be conceptualized as a continuum we move across throughout our life, rather than a static state of 'healthy' or 'ill'3. However, there are major gaps in our knowledge of how mental health interacts with aging across the life course. Older adults may experience dual stigmas related to mental health and ageist attitudes, which can pose barriers to accessing appropriate 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 Canada⁴.

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 collective 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,

October 2022 AIS 485

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:

- Advising on opportunities to incorporate the perspectives of experts-by-lived-experience in aging and mental health initiatives;
- Providing practical and strategic advice 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 with local community and contacts.

What are we doing?

We have several upcoming activities:

- 1. Recruiting ~20 new members outside of Ontario to better represent the diverse perspectives of aging Canadians. We will do this through targeted recruitment with our collective network connections.
- 2. Mobilizing knowledge of CAARE and the top 10 unanswered questions through a series of videos.
- 3. Presenting at academic conferences, including the Canadian Association on Gerontology's annual conference.
- 4. Planning a webinar to explain the top 10 unanswered questions and the process we took, with a target audience of non-academic individuals and organizations.

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.

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AIS 485 **14** October 2022



Operationalizing a holistic health definition as a framework to guide dialogue-based assessment at the point-of-care

Comprehensive assessment of client needs is an important component of the care planning process. Unfortunately, existing assessment tools (e.g., the interRAI Home Care assessment) are not always used as intended to support comprehensive care planning at the point-of-care. The reasons for this are not clearly understood, but it is possible that the comprehensiveness of these assessment tools from a documentation perspective could make conducting the assessment as a person-centred and conversational process challenging for both the assessor and the client. To address this challenge, we aim to map the items from the comprehensive assessment tool to a holistic health definition that could support dialogue-based care planning and goal-setting in home care.

This study explored the use of the Pillars for Positive Health¹, a holistic definition of health developed by researchers in the Netherlands as a tool to guide a more person-centred and conversational point-of-care assessment process in home care. This was done by inviting a group of home care experts to conduct a series of surveys aimed at mapping the Pillars for Positive Health, with elements of the interRAI Home Care assessment tool². We anticipate that the results from this study could be used to develop a conversation guide for comprehensive assessment in home care to complement existing comprehensive assessment tools and support a more consistent, person-centred and dialogue-based approach to care planning.

Project Overview

How health is defined across population groups is important as it, to a large extent, informs the delivery of care for these groups. Thus, a robust yet operationalizable definition of health suited to the health demands of individuals across a range of settings is vital to the creation of programs tailored towards addressing holistic care needs. The World Health Organization's (WHO) health definition, given its focus on "completeness", has been described as ill-suited to

meeting the health demands across population groups¹. To address the deficiencies of the WHO's definition, researchers in Netherlands proposed a conceptual health definition that emphasizes the human ability to adapt to changing health states, termed the Pillars for Positive Health (PPH)². This definition, given its robustness, practicality and ability to reflect current epidemiological realities, has the potential to guide the dialogue-based and person-centred point-of-care

MCD 466 October 2022

assessment approach that is needed in home and community care. To facilitate its use as a framework to guide care assessment conversations, however, there is a need to operationalize the PPH in accordance with the interRAI Home Care (HC) tool, currently used in Canada by point-of-care providers to evaluate the needs of home care clients³. Mapping the items of the interRAI HC tool to the PPH will inform our understanding of the potential for the integration of this definition to support more individualized and holistic care planning at the point-of-care in home care⁴.

We sought to operationalize the Pillars for Positive Health as a framework to link a comprehensive assessment instrument with dialogue-based goal setting and interdisciplinary care planning at the point-of-care in home care.

What did we do?

We conducted a two-stage modified eDelphi study with a team of home care experts that included researchers, clinicians, older adults and caregivers. In the first stage, the experts complete a series of mapping exercise via a series of online surveys. In these surveys, the expert panel were asked to map the interRAI HC tool to the 6 PPH categories (i.e., bodily functions, daily functioning, societal participation, quality of life, meaningfulness, and mental wellbeing). In the second stage, we asked the experts to provide suggestions regarding unmapped elements from the interRAI HC assessment tool and the PPH categories. The team were then asked to rate their agreement with these suggestions.

What did we find?

Of the 201 interRAI assessment elements considered in this mapping exercise, 80 items (32%) mapped to bodily functions, 32 (16%) to each Daily Functioning and Mental Wellbeing, 24 (12%) to Quality of Life, 10 (5%) to Participation and 1 to Meaningfulness. Ten (5%) items were considered to have No Pillar of Best Fit and 12 (6%) elements did not reach consensus. The experts also proposed a range of suggestions for additional assessment elements in the underrepresented domains (i.e., Participation and Meaningfulness) and additional descriptors to expand on the scope covered by each of the PPH domains.

What will be the impact?

It is anticipated that the findings of this study will be used to develop a conversation guide to complement existing comprehensive assessment tools and support a more consistent, person-centred and dialogue-based approach to care planning. Key indicators of success will include:

Holistic Health Assessment: Helping clinicians to approach the holistic health assessment process in a person-centred and conversational way to ensure that it reflects health needs across all relevant health domains.

Dialogue-based care planning: Ensures client experience and engagement in care planning is enhanced, resulting in more person-centred goals for action.

Make the assessment process less challenging: The mapping process done in the first stage of the study will be useful in reconciling the comprehensive assessment as a conversation and documentation exercise, thus making the care planning process less arduous for assessors and clients, concomitantly leading to improved outcomes.

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Resource utilization groups in transitional home care programs: Validating the RUG-III/HC casemix classification system in a novel population of home care clients

Home care program planning requires a broad understanding of client needs and resource utilization patterns. This project applied the RUG-III/HC case-mix system to a novel population of home care clients in Ontario – transitional hospital-to-home programs - to understand patterns of resource utilization among clients.

Case-mix indices can be used to evaluate trends in care client resource utilization within and across home care programs.

The RUG-III/HC case-mix system suggests that clients in transitional hospital-to-home care programs differ substantially from traditional long-stay home care clients. Clients in transitional care programs are more clinically complex and tend to have a lower degree of functional limitation. However, there is considerable variation in client needs across hospital-to-home programs.

Project Overview

The determinants of health service needs and utilization in home care settings are complex and multifaceted, and can be influenced by a client's health status, their functional ability and level of autonomy, as well as the availability of paid and unpaid care¹. There is a need to support informed care decision-making and resource allocation in home care settings.

Case-mix systems that classify clients into groups based on their clinical profile can be used to understand trends

in client care needs and resource utilization. The Resource Utilization Groups version III for Home Care (RUG-III/HC) case-mix system is a classification algorithm that was developed to describe the care utilization patterns of long-stay home care clients^{2,3}.

The RUG-III/HC uses data from routine client assessments (i.e., interRAI Home Care [interRAI-HC]) to classify home care clients into one of seven hierarchical groups: 1) Special Rehabilitation, 2) Extensive Services,

October 2022 MCD 476 17

3) Special Care, 4) Clinically Complex, 5) Impaired Cognition, 6) Behaviour Problems, and 7) Reduced Physical Functions, based on their clinical characteristics, with 23 sub-groups reflecting the degree of limitations with activities of daily living (ADL) and instrumental activities of daily living (IADL). The hierarchical groups reflect historical patterns of health human resource use in long-stay home care settings.

We aimed to 1) evaluate the fit and relevance of the RUG-III/HC case-mix system in a new form of home care in Ontario – transitional hospital-to-home care programs – and 2) evaluate patterns of relative resource utilization across RUG-III/HC groups in this novel client population.

What did we do?

Using patient-level data from interRAI-HC assessments conducted on admission to a multi-week hospital-to-home care program, we classified care clients into groups based on their clinical characteristics using the RUG-III/HC algorithm.

We then used billing records from each client's care episode to explore patterns of resource utilization within and across RUG-III/HC groups by calculating casemix indices that capture differences in the relative cost and time of paid care alone as well as combined paid and unpaid care.

What did we find?

The RUG-III/HC case-mix system demonstrates that clients in transitional hospital-to-home care programs differ substantially from those in traditional long-stay home care. Clients in hospital-to-home care programs are more clinically complex, tend to have a lower degree of functional limitations, and are less likely to have impaired cognition.

Relative resource utilization of clients in the RUG-III/HC groups follows a decreasing hierarchical pattern of care time and cost both within and across groups, suggesting that the RUG-III/HC accurately describes patterns of relative resource use in this population.

This hierarchical trend is particularly evident when accounting for combined paid and unpaid care, reflecting the importance of unpaid caregiving in home care populations.

There is considerable variation in client needs and resource utilization across hospital-to-home programs, particularly with respect to the need for rehabilitation and special care services.

What's next?

We will be exploring adaptations to the RUG-III/HC to provide a more nuanced case-mix system for transitional home care programs and validating our findings with clinical & financial stakeholders.

How can this impact home care?

Case-mix indices can be leveraged to evaluate resource allocation within & between client populations as well as across home care programs.

The RUG-III/HC case-mix system can be used within hospital-to-home care settings to support:

- Care planning
- Predicting health human resource needs
- Resource allocation
- Comparing care programs & institutions
- Quality improvement
- Pricing care programs

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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 focused on medical and personal care, with community-based social care and services such as friendly visiting, meals and transportation.^{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 Additionally, studies have found that the current home care system in Ontario is underfunded, understaffed, and inequitable in access resulting in clients not receiving the full care they need.2,8,9

HCE 478 **19** October 2022

To address these challenges, the Ontario Ministry of Health and Long-term Care recently 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 also strengthening client and caregiver participation in care planning.¹⁰

One care delivery model that integrates home and community care is SE Health's Home Opportunity People Empowerment (H.O.P.E.) Approach to Care. This model builds on the evidence-based primary nursing model instituted in other health care sectors and positive experiences of this model in home and community care.

Clients receiving care from H.O.P.E. are supported to meet their goals by self-managing teams of nurses that:

- 1. address client and family needs by creating care plans based on client and caregiver life priorities;
- 2. ensure care provider continuity;
- 3. provide comprehensive life care that addresses the social determinants of health while supporting clients' self-management capabilities; and
- 4. leverages community and neighbourhood supports by integrating community services and social networks into care delivery.

What have we done?

To develop and validate a PREM for the client experience of new and emerging models of home and community care, such as the H.O.P.E. Approach to Care we first outlined the foundational principles of innovative home care models and created an item pool (a pool of potential concepts and questions), which can be refined through face and content validation and psychometric testing.11

Clarify Foundational Principles

The new PREM will be organized around the principles of equity, life care, and continuity. Evidence suggests these principles are crucial to effectively deliver home and community-based care that reduces costs, improves population health, enhances healthcare experience, and improves healthcare provider wellbeing.^{2,12,13}

The principle of equity aims to reduce the impact of multiple and intersecting forms of racism,

discrimination, and stigma (e.g., chronic illnesses, nonconforming gender and sexual identities, age, etc.) on people's access to services and their experiences of care. For clients and their caregivers, equity means, a) perceiving care to be supportive and appropriate to their needs, b) being comfortable in seeking care, and c) having confidence that the care they receive will be helpful to them.4,14

The principle of life care encompasses both a scope of care that involves bodily functions, mental well-being, meaningfulness, daily functioning, participation, and quality of life, and a process of care that is personcentred. For clients and their caregivers having their life care needs met means they will, a) be asked about all aspects of life care, b) perceive care to be personcentred, c) collaboratively develop life care goals with healthcare workers, and d) co-create care plans with healthcare workers. 13,15

The principle of continuity is "the degree to which a series of discrete healthcare events are experienced as coherent and connected and consistent with the client's medical needs and personal context". 16(p.1221) For clients and their caregivers, continuity means, a) perceiving that providers know what has happened before, b) that different providers agree on a management plan, and c) that a provider who knows them will care for them in the future.16

Item Pool Development

We conducted a literature review of PREMs in community healthcare. PREMs were included if they captured patient experience and had been used in practice or undergone psychometric testing. The research team reviewed 171 existing PREMs and 3,000+ items. Items from eligible PREMs were deductively coded into domains and then inductively categorized. The research team removed duplicative and not applicable items by voting consensus. Healthcare leader experts (n=5) were interviewed about the relevance and coverage of the items and domains.

Preliminary analysis found client experience of innovative home and community care is well captured by four domains (equity, continuity, life care, and overall experience) encompassing 14 categories (e.g., respect, collaboration, and person-centered care planning). Categories contain 75 meaningful item concepts to measure (e.g., adapted care to lifestyle, primary

provider, care goals discussion). Healthcare leader experts agreed these domains, categories, and item concepts are robust and align with intended experience outcomes of innovative care models.¹¹

What will we do next?

Over the next six months we will work with health and social care providers, home care clients, and caregivers of home care clients to further fine and then test the new PREM. Activities include having clients, caregivers, and providers rate the appropriateness and relevance of the item concepts to ensure they capture the full

client experience; refining and scaling the items and psychometrically testing the PREM with clients. 11

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. This new PREM will ensure the right type of data is collected that can accurately measure health system performance, improve quality, and inform optimization of innovative home and community care models.

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