Research Centre

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,

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?

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

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