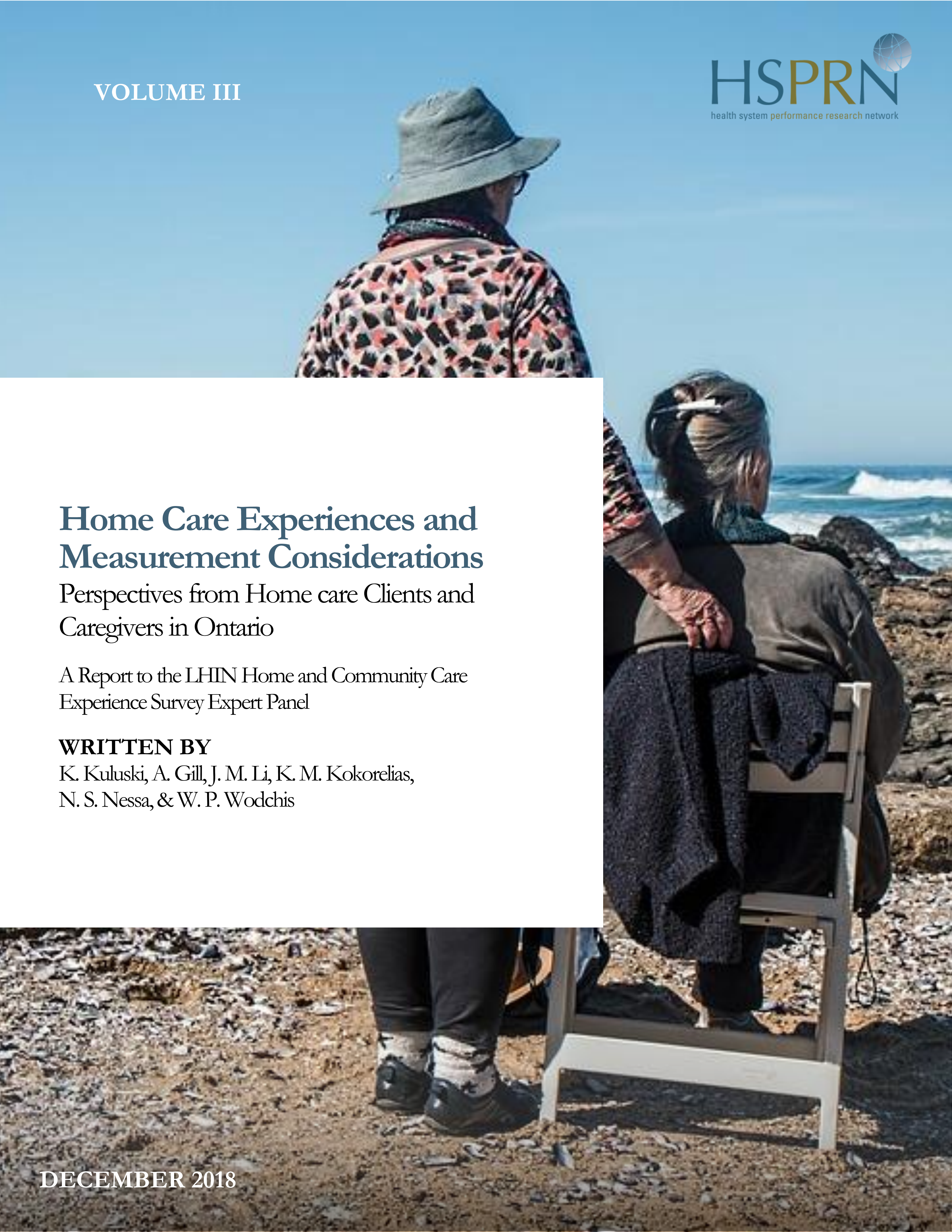

VOLUME III

HSPRN
health system performance research network

Home Care Experiences and Measurement Considerations

Perspectives from Home care Clients and Caregivers in Ontario

A Report to the LHIN Home and Community Care Experience Survey Expert Panel

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Home Care Experiences and Measurement Considerations: Perspectives from Home Care Clients and Caregivers in Ontario

The Health System Performance Research Network (HSPRN) is a multi-university and multi-institutional network of researchers who work closely with policy and provider decision-makers to find ways to better manage the health system. HSPRN consists of scientists, visiting scholars, post-doctoral fellows, graduate students, and research associates. HSPRN is recognized for its research on individuals with complex health and social care needs, its' commitment to performance measurement and its' rigorous developmental evaluations of quality improvement efforts focused on improving health outcomes, experience of care and costs for patients in Ontario's health system. The network has expertise in many areas of health system performance measurement, including clinical quality, financial management, and patient safety and experience. Academic disciplines represented include health economics, epidemiology, finance, health informatics, health services research, nursing, organizational management, and statistics

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ACRONYMS & ABBREVIATIONS

ADL	Activity of Daily Living
CCEE	Client and Caregiver Experience Evaluation
CF	Change Foundation
H&CC	Home and Community Care
HQO	Health Quality Ontario
HSPRN	Health System Performance Network
HSSO	Health Shared Services Ontario
IADL	Instrumental Activity of Daily Living
IHPME	Institute of Health Policy, Management and Evaluation
LGBTTQI	Lesbian, Gay, Bisexual, Transgender, Two-Spirited, Queer/Questioning, and Intersex
LHIN	Local Health Integration Network
MOHLTC	Ministry of Health and Long-Term Care
OHIP	Ontario Health Insurance Plan
PSW	Personal Support Worker
RHO	Rainbow Health Ontario

OVERVIEW

Over the last decade, there has been a growing imperative across health systems to better understand health care experiences [1, 2]. Understanding care experiences can be achieved through the use of surveys that capture patient reported outcomes and experiences. Experience surveys typically include a mix of closed and open-ended questions that aim to capture *what care is like* from the perspective of the user, often within a specific sector like the hospital or home care. Ideally, the data collected are then analyzed, aggregated, and used as a source of information to improve care. A key issue is that performance measures, in general, are seldom developed *with* clients or caregivers. Instead, survey content is typically developed and derived by input from researchers, care providers and decision makers, which provide important perspectives, but an incomplete picture [3]. Another issue is that data collected may not be actionable (lacking the needed detail to address identified problems).

The purpose of this report is to share findings from engagement meetings that took place over six months with home care clients and caregivers across Ontario, Canada. Researchers from the Health System Performance Research Network (HSPRN) led the engagement work, to support a broader project on home care experience survey re-design with Health Quality Ontario (HQO) and Health Shared Services Ontario (HSSO). In our engagement meetings with clients and caregivers, we had two key objectives: a) to learn about their home care experiences and needs, and b) seek feedback on the type of content/questions that should be included in two home care experience surveys (one for home care clients, the other for caregivers of home care clients).

A home care client survey already exists in Ontario and the content was analyzed by our team prior to the engagement sessions [4, 5]. The in-depth meetings we had with home care clients and caregivers that followed provided a foundation of knowledge to inform the design of meaningful questions for the new surveys which will be cognitively tested and field-tested in preparation for a formal roll out.

There are four key components to this report: first, we outline the background and rationale for the project, including the importance of designing surveys with input from clients and caregivers; second, we outline the methods used to conduct our engagement sessions where we captured home care experiences and insights for survey design; third, we outline our key findings in relation to home care experiences and survey re-design; and fourth, we discuss our key findings in relation to previous work and outline recommendations for moving forward.

BACKGROUND & RATIONALE

Improving care and experiences for people and their caregivers is a key priority for the Ontario government, as outlined in its *Patients First* agenda [6]. In order to improve care and understand unmet needs, it is important to measure experiences appropriately and ask questions that are relevant to clients and caregivers. Too often, measurement tools are developed without the input of the user, and thus, run the risk that the content captured misses the things that matter most to people.

Measuring the quality of home care, in particular, is important, as increasing numbers of people need and use home care, and more will require this service in the future. As people age, more and more individuals require (and often prefer) to receive care in their homes, instead of going to a care facility (long-term care) [7]. Home care services are intended to help people age successfully in their homes, for as long as possible. Many types of providers deliver home care services, including paid professionals: nurses, occupational therapists, physiotherapists, dieticians and speech language pathologists, as well as personal support workers (PSWs) who provide support with activities of daily living (ADLs) such as eating, bathing, toileting, dressing, and other personal hygiene activities. While anyone is eligible for a home care assessment, eligibility criteria must be met in order to qualify for publicly funded services (e.g., some level of functional and/or cognitive impairment that precludes people from performing ADLs). In Ontario, service caps and volume restrictions limit the amount of care that can be received. Needless to say, unpaid family members and friends provide much of home care, alongside the publicly funded home care services, and fill important gaps [8], particularly the provision of instrumental activities of daily living (IADLs) (i.e., housekeeping, preparing meals, transportation, household maintenance, paying bills, and social recreation activities) which tend to fall outside publicly funded entitlements. Services to support IADLs are typically provided by an array of community based, grassroots community service organizations or by family. While the focus of this report is on publicly funded home care, there is some attention paid to the role of community service organizations, given that the services provided are critically important in helping people age successfully in their homes. We refer to the broad array of services as Home and Community Care (H&CC).

In Ontario, a home care survey is currently in use, with information captured by telephone with a randomized group of clients, each year. The current survey was developed based on input from care providers, not patients and caregivers. The survey consists of 48 questions about the quality of care with the various providers and organizations that provide it. Home care clients within each of Ontario's 14 Local Health Integration Networks (LHINs) are invited to complete the current survey at defined periods. It is unclear if the information asked is relevant to clients and caregivers, and if it provides sufficient detail to act on the results (through service changes and improvements). Survey results to date (from the current home care survey) suggest high satisfaction with home care services, with little variation across Ontario. Feedback from the research and practice community suggests that the results do not reflect the true client experience. Furthermore, the needs and experiences of caregivers are not included, unless they respond on behalf of the client. Even then, the focus is on the client's experience and not the caregiver's. As a result, there is a need for a caregiver experience survey, as well as a client experience survey.

To address these gaps, the overarching research questions that guided our study was, "How can we best measure the home care experiences of clients and caregivers?" Sub questions include:

i) "What matters most to home care clients and caregivers?"
ii) "What questions do we need to ask to understand the needs and experiences of home care clients and their caregivers?" In other words, what questions/concepts are most important to clients and caregivers to measure and improve on?

METHODS

We hosted 13 engagement sessions (small group meetings); a combination of two in-person and 11 over-the-telephone between May and October 2018. While the intention was to conduct all sessions in person, it was difficult to coordinate multiple schedules amongst interested clients and caregivers. Feedback from caregivers, in particular, noted that it was much more convenient to phone into a meeting than attend in person. Following ethics approval from the University of Toronto Ethics Review Board, engagement sessions were organized.

The engagement sessions were run as focus groups (guided, small group discussions) with clients who were current or recent (within the last 12 months) home care clients and caregivers of these type of clients.

Recruitment

We started by reaching out to participants of home care in Ontario who, previously, took part in a recent study conducted by members of the University of Toronto research team. These participants had agreed to be re-contacted following the initial study. We then worked with the *Client and Caregiver Experience Evaluation* (CCEE) *Expert Panel* (assembled to guide this project) to recruit other participants from their network. The CCEE Expert Panel is comprised of 13 people—home care clients and caregivers, members of policy think tanks, executive directors of LHINs, directors at the Ministry of Health and Long-Term Care (MOHLTC), quality improvement leads, clinicians, implementation specialists, and researchers. Directors of home care in the northern LHINs helped connect us to caregivers and clients in small towns and rural areas, along with Franco-Ontarian populations. Members of various Patient and Family Advisory Councils of Ontario's LHINs were also invited. The lead author on this report also sought advice from the Indigenous Health Consultant for the Toronto Central LHIN and the Executive Director at Rainbow Health Ontario (RHO). RHO shared an extensive study which captured home care experience and was done with the LBGTTQI population [9], and agreed to be re-contacted during the pilot testing phase to ensure the questions were sensitive to LGBTTQI populations, experiences, and needs. Earlier in the project, HQO and HSSO met with MOHLTC's Urban Indigenous Table, and the First Nations Home and Community Care Advisory Committee to discuss a potential longer-term engagement strategy so that the indigenous community can inform how best to measure home care experience in a way that is culturally appropriate.

To aid with recruitment, a participant flyer and one-page lay language information sheet was used for email correspondence with prospective participants. These materials were also translated in French.

Inclusion criteria for clients were:

a) over the age of 18;
b) current recipient of provincially funded home care services or recent recipient (within the last 12 months);
c) cognitively capable to participate in a focus group and able to give informed consent; and
d) residing in the province of Ontario.

Inclusion criteria for caregivers were:

a) over the age of 18;
b) caregiver of a current recipient (pediatric, adult or senior) of provincially funded home care services or caregiver of a recent recipient (within the last 12 months);
c) cognitively capable to participant in a focus group and able to give informed consent; and
d) residing in the province of Ontario.

Interested participants were identified by our aforementioned stakeholders and were followed up by two members of the research team by phone or email to provide study details, share logistics, and review the consent process. Participant background sheets and consent forms were distributed to those who agreed to participate.

At the end of the focus groups, participants were all asked if they were willing to be re-contacted to review potential survey questions and/or review the newly constructed surveys during the cognitive testing phase (where questions will be reviewed for comprehension and clarity). Twenty-two participants agreed to be re-contacted.

Data Collection

A research team member led each focus group (with the first few conducted by pairs of researchers to ensure consistency in process). Following that, the sessions were divided up between three researchers (KK, AG & NSN). The focus group length was typically between 90 minutes and two hours.

The focus group was divided into broad content areas/questions with several probes:

1) Tell me about your experience with home care.
   [Probes: reflect on a positive home care experience. What was happening to make it positive? What was your relationship with the care providers like? How did they make you feel? Reflect on a negative home care experience, what was happening to make it negative? What was your relationship with care providers like? How did they make you feel?]

2) What is most important about home care?
   [Probe: what things need to happen to enable a good experience?]

3) What questions should be included in a home care experience survey?
   [Probes: what do we need to know to understand your home care experience?] Note: For this question, participants were provided with sample questions drawn from our previous rapid review[5].

At the beginning of the focus group, the facilitator sought verbal consent from all participants (if by phone) or collected consent forms (if in person). Participant information sheets were also collected for in-person meetings. Participants who phoned in had the option of returning their consent form using pre-paid postage or emailing it to the lead author. All participants were reminded about the purpose of the focus group and that they could leave at any time or skip any questions without repercussions.

Each focus group was audio recorded with the permission of the participants. In cases where the focus groups had two facilitators, one member took notes as a supplement to the audio-recordings.

Data Analysis

The audio-recordings were sent to a transcriptionist using a secure online server (used and approved by previous University of Toronto ethics protocols) who transcribed the audio recording verbatim. A member of the research team checked the transcripts against the audio-recordings to ensure accuracy. Names and other identifying information were removed.

To become familiar with the data, three researchers (KK, AG & KMK) chose two similar transcripts to analyze independently by reading the text line by line and making notes to capture core ideas. The three researchers reconvened to discuss content and decide on how to categorize the transcripts for the fuller analysis. It was decided that the team would divide up the transcripts and capture three core content areas (similar to the structure of the focus groups):

1) participant background (key demographic characteristics and type of home care services used);
2) information on care experiences; and
3) information to inform survey redesign.

Emergent concepts were also discussed to ensure that pertinent items were not overlooked, nor missed. From there, the team divided up the transcripts and summarized information into the three core categories and identified sub-categories. The lead author, subsequently, reviewed all of the sub-categories and merged similar concepts resulting in key categories to eliminate redundancy. Additional members of the research team (four researchers) then re-reviewed all transcripts to ensure no content was missed. The core categories were further refined. The anonymized transcripts were uploaded to NVivo version 10 (a qualitative data analysis software) to support the coding process.

FINDINGS

Participant Characteristics

The research team engaged with 28 participants; five clients, 20 caregivers and three who identified as both client and caregiver. Ages ranged from 35 to over 80 years old, and the male to female ratio was 1:9. While some clients were receiving (or had received) short-term post-acute home care, most were using (or caring for someone) using ongoing (long-term) home care services. Client disease and symptom characteristics included various forms of dementia, Parkinson's disease, stroke, multiple sclerosis, diabetes, urinary retention, congestive heart failure, arthritis, cancer, joint replacements, and spinal cord injury. Symptoms were also wide ranging, including pain, mobility restrictions (requiring the use of mobile aides), cognitive impairment (sometimes accompanied by delirium), and depression. Some clients, particularly children with complex care needs, were using various forms of life sustaining technology, including ventilators, had tracheostomies and required gastrostomy tubes (G-Tubes) for feeding. Caregivers were mostly relationally linked to the client (predominantly spouse/partner or parent caregivers), while others were friends or neighbours of the client. As noted, caregivers were caring for clients who had a variety of care needs, ranging from full time, pediatric, technologically dependent children to older adults with multimorbidity and dementia. Among those who reported years of caregiving, the time duration ranged from six months to 26 years. Participants were from various regions across urban and northern/rural Ontario (as far south as Toronto, and as north as Dryden and Chapleau). Most identified as North-American White, while others identified as East Asian, Caribbean Black, and/or European.

We summarize qualitative findings in two broad sections. First, we outline the important components of home care; second, we outline key measurement considerations (i.e., general considerations for survey design). All data presented are drawn directly from the suggestions of client and caregiver participants with supplementary quotes. Since all engagement sessions typically had a mix of clients and caregivers, we have presented their findings together.

SECTION 1: IMPORTANT COMPONENTS OF HOME CARE

SUMMARY TABLE OF FINDINGS

Key Component	Sub-Components	Definitions
Organization of Care	Coordination, Continuity and Scheduling	Knowing who to contact when questions arise, knowing when providers will show up and having consistent providers.
	Knowing What's Available and What to Expect	Knowing what services are available, what is publicly funded and knowing how to support self/loved ones (particularly following a hospital stay).
	Access	Having providers that are available, including someone to fill in when cancelations occur. Getting timely responses to questions.
Quality of Care	Variability in Care Quality between Providers	Having respectful care providers who are competent in their skills.
	Variability in Care Quality between Home Care Programs	Having continuity of care across home care programs.
	Variability in Care Quality between Regions	Equitable and consistent access to a wide range of programs and care continuity, regardless of health region (i.e., LHINs).
	Training and Accountability	Providers that have the training to meet specialised needs (e.g., managing dementia behaviors, use of ventilators, etc.). A system that holds people accountable to provide good care, to communicate with teams and follow-up.
Relevancy of Care	Alignment of Services with Personal Needs and Preferences	Greater flexibility in service offerings and timing of visits/programs.
Personal Impact of Care	Personal Costs	Support for out-of-pockets costs, which can be high, even when private insurance coverage is available. Caregiving, in particular, is characterized by emotional strain and burnout, due to limited respite and from providing around-the-clock support.
	Advocacy/Willingness to Give Feedback Stigma/Privacy/Respect	Feeling safe and confident in providing feedback without getting reprimanded for it (or being labeled as 'difficult'). Respect for lifestyle preferences and cultural sensitivity.

1. ORGANIZATION OF CARE

Coordination, Continuity and Scheduling

The logistics associated with organizing home care services is challenging, as ongoing coordination issues were shared by many participants. It was not always clear whom to contact if questions arose about services, whom to reach out to if appointments had to be rescheduled, whom to connect to if needs arose and what time providers would show up. It seemed that schedules, at times, were organized around the convenience of the provider and not around that of the client and caregiver. A caregiver for his wife with Parkinson's disease shared the following:

> "…*my regular worker for my wife is unavailable today, so they want to push someone at 08:30; well 08:30 is no good to me. So, I told them to look for someone for six o'clock. I've yet to hear back from them.*"

Having a reliable person to directly contact (without leaving multiple voicemails), and from whom getting quick responses from was desired; however, as a caregiver noted, the notion of having a *sole* coordinator was a bit of a myth. Participants referred to many different people who provided a coordinating function. A caregiver who was caring for both her parents and in-laws noted that having a core team would be helpful:

> "*But let's say there's a team of, it doesn't matter the number, but, for instance—like, you know how they have it in a lot of medical professions, they have four doctors, right? But if your doctor is not in that day, you see another doctor. There's always the four and you get to know them, and you feel more comfortable. Maybe something like that, and then, so, you have that same case team with you the whole time.*"

There were unique coordination issues articulated by participants from northern communities, who noted a disconnection between people scheduling home care visits with those providing the care:

> "*They* [schedulers] *have no clue what [city in Northern Ontario] is like. So again, I don't know about you, but they have these poor women and men running, they could be in [small community A] and expect to be from [small community A] to my brother's place. That's a 45-minute drive. They've got him scheduled for 10-minute drive* [sic]. *They have no clue.*"

Poor care continuity was noted in some cases due to high staff turn-over or last-minute cancellations. In other cases, providers left a home care visit early, or failed to show up at all. A friend caregiver of an elderly woman, who had vision and hearing impairments, noticed that the home care visits seemed to be getting shorter and certain tasks were often uncompleted:

> "*Comme elle est la patiente, elle doit signer un rapport à tous les jours, après la visite. Bon, bien, moi, je me suis aperçue là, les visites sont écourtées, surtout dans l'après-midi. On fait au plus vite parce qu'on a… ce sont des emplois à temps partiels et on a un contrat avec quelqu'un d'autre et je sais pas* [sic] *quelle méthode de paiement qu'ils ont. Je sais pas si c'est à l'heures, au client, je n'ai aucune idée. Mais on s'aperçoit que la visite est écoutée et puisque c'est elle qui signe et elle a de la difficulté* […] *faut lui dire où mettre la ligne, elle peut pas* [sic] *vérifier l'horloge.* […] *Pour les visites d'une heure, des fois, on a 30 minutes, des fois, on a 20 minutes. On s'aperçoit aussi que certaines choses sont pas faites. Des fois, on est sensé faire le petit ménage ; on y touche pas du tout.*" [Since she is the client, she has to sign a report each day, after the visit. So, me, I noticed that the visits are shorter, especially in the afternoon. It is done as fast as possible, because these are part time jobs, and they have a contract with someone else, and I don't know what compensation model they have. I don't know if it's by the hour, by client, I have no idea. But we are noticing that the visits are shortened, and since she is the one who signs, and she has difficulty […], you have to tell her where to sign on the line, she can't check the clock. […] For visits that are an hour, sometimes we just get 30 minutes, sometimes we have 20 minutes. We are also noticing that certain things aren't getting done. Sometimes, they are supposed to do light cleaning, but it's completely untouched.]

A lack of care continuity had an impact on the caregiver who had to fill the gaps, as well as orient new people to client routines. Interfacing with changing providers meant that people had to keep re-telling their story and often referred to themselves as the "book keepers" or "administrative support" for managing their care—adding to the many roles that caregivers and clients must adopt when managing the reception of services within H&CC.

Having a consistent care provider not only made things easier logistically, but was more comfortable for clients, particularly for those with dementia, highly complex medical needs, and for those who required help with personal care, like bathing. This client from Northern Ontario appreciated having one consistent person give her a bath. Since she was able to know her provider and they got along well, it seemed the bath was less a task and more of a social visit:

> "*At the start, I had* […] *so many different people. So, me, I don't this. I'm not always going to undress myself fully naked in front… in front of the whole gang.* […] *So now, that's been taken care of, so it's always the same one who comes for my bath."* She further went on to say. "*She's nice because we can talk about whatever.*"

Similarly, a client with multiple sclerosis, who had received different types of home care services for the past ten years, discussed the vulnerability associated with personal care and the importance of consistent care providers:

> "*…when [providers] see you the way they do, and help treat you the way they do, and if they're giving you personal care, then they're going to see you more than—in ways which are more than anybody else it would be possible* [sic]. *Possibly your partner, but nobody else sees you that way and it's more than just being naked, it's just like being naked in your nakedness.*"

If clients ended up in hospital, once discharged back home, they would receive *new* home care staff and schedules, even if they had already become accustomed to their original care providers before their hospital admission. This participant, who was both a client of home care and a caregiver, noted the following:

> "*…when you get back in the community, you have to start off with all these new people again coming in and we had to, kind of, marry it so—like, we were getting this one lady and we really liked her, and we're like, 'What do you do during the week?' She's like, 'Well, my last client just was hospitalized, so I'm free', so we literally called with her in the room and said can she be our permanent? And then, he was hospitalized again for the amputation, so she's gone now.*"

Clients and caregivers developed their own workaround solutions that made coordination a bit more manageable. A caregiver for her child with complex care needs contacted each of the home care staff directly to stay on top of scheduling, and she was mindful that she was not following protocol:

> "*We go around protocols. I'm not supposed to have the telephone numbers of every single one of my nurses, but I do because I'm the one who texts them to say, 'Are you coming tonight? I didn't see anyone on my shift. Did you switch off?' Or they text me and say, 'Just so you know, I'm taking vacation next week. Make sure they have someone to back me up.' And that goes around standard protocols. It shouldn't be like that.*"

All in all, it seemed that continuity, coordination and scheduling largely fell to caregivers (i.e., unpaid family members and friends) of home care clients, adding additional stress to their role.

Knowing What is Available and What to Expect

Participants wanted greater transparency as to what services were available. They did not know what to expect when managing care at home and felt inadequately prepared when transferring from hospital back to home. It was difficult to mobilize services quickly once discharged home, leading to immense pressure on caregivers to fill the gaps. Some people felt mislead about what to expect when leaving hospital, only to arrive home to face significant challenges and delayed initiation of home care services.

> *"I think that when the hospital sends you home with all their lists and instructions and everything, that I think it's their responsibility to make sure that when you get home that they call within 24 hours to make sure that a) home care showed up, b) you feel comfortable, you know, playing the role of the caregiver."*

Clients and, in particular, caregivers were not clear if they were doing things right and wished that they had someone to connect with, in a timely manner to seek advice and support. A home care client with multiple sclerosis noted:

> *"Yeah. Like, even though we might say, 'No, everything's great,' like, that's one thing. But maybe you're going to call us and just say, like the pharmacist did, 'How you're feeling?', 'Well actually I'm a little overwhelmed right now, I don't know if I'm doing the right thing, the infection keeps coming back, the intestinal this, the home care this', whatever the problem may be."*

Caregivers want to be better informed about clients' care and want to be included in discussions. This caregiver from Northern Ontario, who was caring for her elderly parents, noted the following:

> "*Yeah, and to make sure that we are sharing information. Not just with clients, but with the family and we understand that you need the client's consent. But once it's done, to continue with the communication.*"

A lack of transparency was noted as it related to the 'care plan', something that this caregiver knew nothing about:

> *"I know in the survey it talks about assume you have a care plan in place. I just want to point out that I was not made aware that there was a care plan for the longest time. No one ever did a care plan with me; no one even said there was one. It was only when I sort of pushed back, they went, 'Well, that's not part of the care plan.' I'm going, 'What care plan?' So, that is a huge thing, because I think right off that, that was, especially when you're going through the emerge thing, or even when you're going into another facility, they should sit down with you, set up the care plan, and discuss things, and then review it every year, every six months, whatever."*

A caregiver was caring for her husband with multiple fluctuating chronic conditions and had five emergency department visits before finding out about a community care program aimed at people like her husband. She noted that:

> "*I just want you to know that we need more education. We need more assistance to* [sic] *people who do not necessarily know what's available, and we need to educate the care coordinators and the hospital staff and the primary care staff to help people find what they need for their particular situation.*"

There was concern that home care services would not be adaptable or available over time. This was particularly concerning for caregivers of children with ongoing complex care needs. Two types of future concerns were articled: first, the services, as they currently stood, were *just enough* to get by, and should anything shift, the 'barely hanging together' structure would fall apart. A young caregiver for her pediatric son appreciated the care she had, but also pointed to the fragility of the situation:

> "*We have been very, very lucky and we have had good nurses that have been with us for four years. We know them, they know us. It's worked well. The system has run well for us. There are times where we have gaps, and people don't show up, and that's a problem, but if I get a phone call and you tell me how—I'll be like 'Yeah, it's good. I got sleep last night. We're good.' But it's not until it falls apart that you're like 'Whoa, this doesn't work.'*"

Second, a father with a teenage son with Downs Syndrome, expressed concern, as he wanted to make sure care was in place for his son in the long term after he is no longer able to support him:

> "*Especially if I'm not going to be around. I'm not planning to die, but I can read mortality tables and you don't live forever. And he's going to outlive me. So, I have to have something in place. And home care will be a big part of it probably* [...] *So, it's going to be important for me, and I've looked into it already, to know what can be expected, what can be available, and what falls back on to the family to provide.*"

A mother of a young girl with significant complex care needs, who wondered what would happen when her daughter turned 21 years of age, shared a similar concern:

> "*Now she's a child and she's getting hours and I'm very grateful for that, but the minute she hits 21, it's all gone. Her care hasn't changed; she's going to need even more care, but there's nothing, the nursing stops, everything stops when she's 21.*"

Access

Participants shared concerns about the availability and timeliness of services. Particularly problematic in northern and rural communities was a shortage of skilled home care providers. If a home care worker was unable to make it to the participant's home, at times, there was no one available to fill the gap. It was particularly difficult to get care on weekends, even when participants were willing to pay. A caregiver who was caring for her disabled brother shared the following:

> "*There's nobody to replace them. So, I'll get a phone call and again, with my brother's disability, his choking hazard risk. So, he has to be seen at supper time. So, there's many times I will get a phone call at quarter to five saying, 'There will be nobody to do that.' So, I drop everything that I'm doing and I run to his house to put on his meal. I already provide his meals. I don't do meals on wheels.*"

Some services were unavailable all together. A caregiver could not access respite care at night for her mother, who had kidney failure, heart failure and chronic pain, even though she was willing to pay:

> "*There was no respite available for night-time, so it was either my father getting up with her, you know, to help her to the washroom or reposition and get comfortable. Or, if he was worried, he'd be calling me literally in the middle of the night to come help her. So, that was a really difficult three or four months as she was declining. Home and community care, I guess at the time 'access centre,' didn't have hours to support overnight care, and when we looked into hiring privately for some respite options, there was nobody to hire.*"

Finally, as an extension to the examples shared in the above theme, when questions or concerns arose, participants wanted *timely* responses to avoid continuously tracking people for answers.

2. QUALITY OF CARE

Variability in Care Quality between Providers

While some home care providers were described as 'going the extra mile,' others were described as 'doing the bare minimum.' There was variability on several factors, ranging from interpersonal skills (i.e., how providers made clients and caregivers feel and how they interacted with them), to knowledge and professional skills (i.e., proficiency in completing tasks and holding the necessary knowledge to do things in a way that demonstrated competence and expertise). The latter was particularly important for the home care services of young children with complex care needs and adults with dementia.

Quality of communication was also important. In this case, a caregiver, caring for her elderly parents, noted the value of having a client and care provider that could communicate in the same language:

> "*Moi, j'ai vu la différence quand mon père recevait les services du personnel qui était unilingue Anglophone. C'était simplement : rentre, fait le ménage, c'est tout. Il y a pas* [sic] *de conversation, il y a* [sic] *rien de plus. C'est important,*

> *les services en français, même si c'est pour faire le ménage parce que la personne est capable de communiquer* […] *est capable de s'asseoir faire une partie de son heure avec des visites amicales.* " [I saw the difference when my father used to receive services from staff that was unilingual Anglophone. It was simply: get in, clean up, that's it. There is no conversation, there is nothing more. It is important to have services in French, even if it's just to do the cleaning because the person is able to communicate. […] can sit down and make a part of their hour a friendly visit.]

A caregiver, caring for her six-year-old daughter with significant complex care needs, shared an insight that emphasizes that everyone plays a part in fostering a high-quality relationship:

> "*…because of the relationship I have with them* [home care nurses]. *We get along extremely well. I take very good care of my nurses in the sense that I never take advantage. You know, we have a working relationship, but also, I appreciate them and I'm constantly thanking them and recognizing what they do.*"

Variability in Care Quality between Home Care Programs

Participants who had experienced a specific type of home care service, such as palliative home care, noted the difference compared to regular home care services. With palliative home care, care seemed to be more continuous, staff turnover was lower, and people had access to greater support for both health and social needs. A participant, who was both a caregiver and client of home care, shared the following about her mother-in-law:

> "*When she was diagnosed with pancreatic cancer, as I mentioned, that's when the home care kicked in. She was immediately transferred over to the palliative care side of [the home care agency] … As a caregiver, I found there was one point of contact. The [home care agency] case manager was very, very much available, easy to reach. There were all different services offered like dietary services, the whole gamut. You could tell that it was [a] very specialized type of home care.*"

A home care client, who had access to direct funding to hire her own staff, noted the difference it made when she was able to select and work with a consistent team of providers and develop relationships with them:

> "*…now that I'm Direct Funding it seems much easier because those are the rules that I write. So yes, I think it's absolutely necessary that you develop a relationship with your worker.*"

Variability in Care Quality between Regions

It was recognized that not all regions (i.e., LHINs) were created equal when it came to H&CC. Not only were different levels and types of services available, variability in overall quality was noted. A caregiver for his aging parents and in-laws noted the following:

> "*I found the [Region A] far superior with home care. Yeah, just far superior. You know, some of your survey questions, if I had to answer them all for the three different ones* [regions] *for [region A] I would say, 'Yes, we felt respected. Yes, they called us when they weren't going to be able to come. Yes, they kept us informed.' I can't say the same for the other two [regions].*"

This caregiver also went on to say that this particular region A had lower turnover of staff.

Training and Accountability

Participants were concerned about staff that appeared to lack the required skills and expertise to support people with complex care issues (such as the use of technology or supports for behavioural and cognitive challenges). Caregivers, in these cases, did not trust that the provider knew what to do. Additional training of home care staff was recommended:

> "*But it also depends on, like, there's no certification; there's no subspecialties for nursing in some of these areas that home care is required, right? So, you have a sub specialty in nephrology if you're going to do home dialysis, and stuff like that. You'll have wound care subspecialty, but there's not a pediatric subspecialty, or a mental health subspecialty, or dementia subspecialty. You can't ask for their training and experience if there's no training and experience in that area.*"

A caregiver, living with and caring for her mother, who suffered multiple strokes, talked about the variability between providers:

> "*Basically, is* [sic] *that people are not trained properly. There should be some sort of government standard for training and there isn't. And some girls have the knack—some people have the knack for it. Other people—it's no different than being a teacher: some people are good teachers; some people are not.*"

Another caregiver who had previously cared for her husband with Alzheimer's disease shared a similar experience:

> "*So the bottom line is—and again, the other quality is they're not trained well enough. They have no idea what their illness is and how to deal with it. So, my husband, when he had his Alzheimer's, was stubborn. So, because he was stubborn, I had home care people that would come in and because he wouldn't—they couldn't let him upstairs to shower right away. They left him unattended, went back and said, 'The client's stubborn.' Well, that's part of Alzheimer's. They had no clue.*"

Family caregivers also desired training for themselves in order to feel more confident in supporting their loved ones in the home setting. This was particularly important following hospitalization and managing a specific need or symptom (e.g., wound care and changing dressings), or following a new diagnosis. A caregiver for a child with medically complex conditions noted the following:

> "*…you have to learn to do everything yourself too because a lot of us are not in the medical field. So, you have to remember that, we have no training, like medical training. So, we've learned what we've had to learn through hospitalizations, through the nursing company at some level, and then whatever additional stuff, the training we've had to get in-between, and we're expected to take care of these children that are medically fragile, and we have no medical background.*"

There also appeared to be no accountability when it came to following the care plan. While some were not familiar with the care plan, others noted that it was not followed, stating, "*[providers] don't even follow the profiles [care plan]*" and "*don't have time [to read them].*"

3. RELEVANCY OF CARE

Alignment of Services with Personal Needs and Preferences

Participants spoke of the rigidity of service offerings, which did not always correspond with their preferences and needs. Unmet service needs included IADLs or social supports (such as housekeeping, meal preparation, transportation, social visits) and respite care, services that generally fall outside the scope of publicly funded home care entitlements. A caregiver for her son and mother-in-law noted the following with regards to care being accommodating to one's culture:

> "*And, it's something as simple too as: if you're Muslim and you're fasting. does the care come during the day or after? You can't have—that's a spiritual and cultural value of that household and it's huge. Do you feed someone in the middle of the day if the rest of the house is fasting because the PSW shows up at a certain time? Like, it's basic as that as much as everything else, there's basic cultural issues, right?*"

Service volumes and duration seemed inflexible and applied uniformly across different patient types and patient needs. A client who had a hip fracture injury, and required home physiotherapy appointments, noted the following:

> "*You know, normal hip recovery, it's pretty quick, but I was given home physio, to begin with, but under OHIP* [Ontario Health Insurance Plan] *you only get six visits and there's no facility for doctors to prescribe longer initial visits. It's like everybody gets to six* […] *there should be the facility for doctors to say, 'this person has an underlying medical condition. Six visits is* [sic] *not going to be enough.' I want 20 or, you know, ten or whatever the number is.*"

Participants appreciated when visits could be accommodated to align with their preferences. A caregiver from northern Ontario, who was looking after her mother in her home, noted the following:

> "*…twice a day, I switched to half an hour. And then, twice a week, I'm supposed to get respite for 3.5 hours. So, the half an hour though, the girls that I have now, the ones that do come here are super. They are just like—they're my pride and joy. They are so good. We can get her finished up in probably 15 to 20 minutes.*"

People who were caring for clients with medically complex needs also wanted a greater volume of services, as even maximum hours were not enough.

When care plans were put in place, it was important that they were flexible enough to evolve; otherwise, they quickly became irrelevant, as noted by this caregiver who was caring for her parents and in-laws:

> "*…that's why it becomes crisis to crisis, because you have a care plan set up in this moment in time. This moment in time, the person is still mobile; the person still seems to be functioning okay. A person can have a fall; all of a sudden, they're not as mobile anymore. They're traumatized by it, they're so frightful and fearful, then they lose a lot of cognitive ability because they just can't think straight. So, all of a sudden, the care plan that you originally had does not work anymore.*"

For caregivers, respite services, or home care generally, was lacking and was not flexible enough to experience a true break. A caregiver for her mother with dementia shared the following:

> "*…and in regards to my respite, I mean, they try to dictate to me when I can use my respite, but I said no. That's because, you know, respite is not—like, you're not really helping me if you're telling me when I should be using it. I'm going to use it when I need it and when I want to use it, right…*"

4. PERSONAL IMPACT OF CARE

Personal Costs

Participants discussed costs in terms of stresses and frustrations, as well as financial—out-of-pocket costs for services that were not publicly funded. For some, such out-of-pocket costs were burdensome. Caregivers spoke about expenses generated from purchasing needed equipment and supplies, having to pay for services like transportation, and supplementing home care with private care for additional respite. While some people managed to pay out-of-pocket costs, a patient advocate, who also had caregiving experience, noted that through his work of being a collective voice for others using health care, out-of-pocket costs can be a real issue:

> "*I think most families have done that where they're able to, but then there's half the people that can't afford to do that, so they bear the brunt of not being able to, but again not having the help they need.*"

Participants faced many competing demands and made continuous trade-offs. A caregiver of a child with neurodegenerative conditions requiring 24-hour, life-sustaining support, shared the multiple competing demands that she and her husband faced.

> "*And my husband and I, both, work full-time. So, I finish work and then I've got [to] rush back. We have another daughter, a 13-year-old, so then I have to rush back home and help out with her and then, you know, make dinner, everything else, and then take over with my daughter. My husband gets up for his nightshift and then he also, you know, helps with her dinner, gets everything going, and then goes off to work at 10 o'clock at night or—well I guess it's around 11, and then the nurses come at 11 when she's at school. So then, we have a night nurse when she's in school. So then, they're there from 11:00 p.m. until 7:00 a.m.*"

She went on to say:

> "*Like we just—you know, like I said, we're both working full-time because we need our benefits in order to pay for a lot of her stuff because it's very expensive, even just equipment wise and supply. Like everything is really expensive.*"

The multiple stresses and impacts felt by caregivers were articulated by the following:

> "*What kills you the most isn't doing the work, isn't the sleepless nights, it's seeing them suffer. That's what causes me the most stress. The most stress. So at least, if I knew I had a plan in place that could reduce the suffering to the best of my abilities. I don't expect to be perfect, but there's always this thing, especially when something goes sideways, you think, 'What I could have done more?' or, 'Why didn't I know about this before?' You know, you start blaming yourself.*"

Advocacy/Willingness to Give Feedback

Many participants, both patients and caregivers, were at times reluctant to give feedback related to complaints and concerns for fear that they, or the people they cared for, would be ignored or reprimanded. Caregivers, at times, felt they had no choice, as advocating for their loved one was their highest priority to ensure their needs were met. In doing so, one caregiver noted that one risks gaining 'a label'. In the excerpt below, she noted that she was judged for being an advocate for her husband during his cancer appointments:

> "*I stood up for him. And I didn't accept their answers as being what was best for him. It may have been what the standard of care was, but it wasn't necessarily what was best for him. And so, because I accompanied him, and I stood up for him, and I asked a lot of questions, I had a label. I wasn't there to make friends. I was there to care for him, period.*"

One caregiver noted that she was *encouraged* by a care coordinator to provide honest feedback, which opened the door for her to safely share her concerns.

> "*One instance I had a very, very good experience of someone reinforcing with me '[name], if you're concerned about anything'—this was one of the managers* [care coordinator]— *'if you're concerned about anything, please let me know. We won't think badly of you. We're here to help you. We're here to help ensure that everything's working well, okay?' That was very—that experience was very, very, very encouraging and affirming that it was all right if there were concerns. Other instances… I wouldn't have dared to have said anything for fear that it might impact the care my dad was receiving.*"

Stigma/Privacy/Respect

In a few cases, participants, particularly younger patients and caregivers, felt judged by staff, or were worried about what home care staff would think about their lifestyles. At times, assumptions were made about how people should live in their homes. A young patient, who also cared for her partner, shared a negative interaction with a care provider:

> "*[The provider said] 'Well we don't feel comfortable with you staying in the same bed', I'm like but it's my house, so like, then you need to find a new nurse or a new attendant to come in because that's not something I should have to change, right?*"

A young caregiver, whose son required 24-hour care, appreciated the ongoing support from a home care nurse in the evenings and nights, but felt that her life lacked privacy:

> "*If my husband and I get into a fight at night because we're looking at the insurance bills, do I not fight because there's someone in my house? What does that mean for personal, family existence…?*"

Finally, when it came to the concept of respect, one participant described it as encompassing multiple factors:

> "*Yeah, it's about: does the person respect your preferences with your care? Whether it's cultural related* [sic]*, or a timing issue, or anything.*"

HOME CARE EXPERIENCES SUMMARY

In summary, patients and caregivers want reliable services that are tailored to their needs, including supports for daily living, and not just disease management and bathing. They want to know who to call if they have questions or concerns and feel confident that the person at the other end will respond to them and provide support. They want their expectations managed regarding what services are available, when they can be provided, and where to look for information. If things change (e.g., timing or type of services), they want to be informed in a timely manner, and have a backup plan in place. If they feel uncomfortable with a service or provider, they want to be able to report it without feeling guilty and feel confident that something will be done to address it. Given the range of complexity and variability of care needs that people present with, participants want to see tailored and specialized training among their home care staff. Caregivers want to feel prepared for the task of providing care, particularly for medically complex children, or following a care transition, as they feel enormous pressure to do things correctly, so they do not harm their loved ones. Clients and caregivers appreciate kindness from staff, which went hand in hand with comfort, trust, and openness to care. They observe the constraints that providers are working in and recognize those that willingly do more. Caregivers, while needing a break, first and foremost, want their family members and friends to receive optimal care from core staff. Clients and caregivers don't expect a perfect system, but a respectful system that makes their day-to-day life managing their health a bit easier. The gaps in home care are seen most prominently through the out-of-pocket costs for supplemental care, which for some people have significant consequences.

SECTION 2: MEASUREMENT CONSIDERATIONS

During engagement sessions, we also asked participants to provide measurement advice, and review example survey questions. The findings of this part of the discussion are organized here.

Things to keep in mind when constructing surveys: Who, What, When, Why, and How?

WHO *are people assessing?*
Home care clients and caregivers highlighted that many people are involved in their care including coordinators, various PSWs and professional staff (e.g., nursing, occupational therapy, etc.) who may turnover frequently. When asking to share experiences with home care providers, it will be important to clarify to whom we are referring to, or whether a general experience is sufficient. A 'sandwich caregiver' (who was caring for her son and mother-in-law, simultaneously) noted the following:

> "*So, if you were to survey me, I would ask you in the survey, 'Well, who are you asking me about?' The management? The [home care] case coordinator? The individual RN, RPN? The wound care nurse versus the overnight shift nurse? Like, I can divide it up for you.*"

WHOSE *perspective are we capturing?*

Caregivers and clients pointed out that some are in dual roles—both clients and caregivers or, changing between. Therefore, we need to be clear what perspective we are capturing.

WHAT *will we do with the information we collect?* ***WHY*** *are we asking people to do this?*

The purpose of the surveys needs to be clear and stated at the very beginning. Home care clients and caregivers stressed the importance of asking questions that could be acted on. Questions that were too broad, or overarching, would leave a decision maker or provider with lack of clarity on how to move forward. The purpose of the questions is to get a sense of where the gaps are, and how to address them and not just to generate data. A former home care client and patient/caregiver advocate stated that:

> "*…part of the survey should be 'and here's what we're doing with it,' to go look at those gaps and see if we can do anything about them. Don't survey just for surveying.*" He went on to say: "*The only reason I would fill out a survey is, I would hope that there's a group of people, including patients and caregivers, that are looking at the data to improve the gaps. So, I don't want to do any surveys that are self-fulfilling and say look, I've got a 78% satisfaction level because of this one case manager, whatever. That's irrelevant to me.*"

Following up with open-ended questions for clarity was recommended by participants to capture needed context. Furthermore, questions may require further probing to get the needed context to make them actionable. A caregiver commented on a particular question and provided suggestions for improvement:

> "*But it's not deep enough* [referring to question about providers explaining things in a way that was easy to understand], *because maybe I didn't understand, because it wasn't in my mother tongue. Maybe I didn't understand because the doctor was speaking too quickly and didn't make eye contact. You know what I mean? It's not rich enough. They're too simplistic, I guess, overall, each one. That was just one example. Because the question itself is a good question, because if you don't understand and we're finding that the trend is most people aren't understanding what they're being told, we need to make a change. Well, what change is that?*"

WHAT *do we ask?*

Some participants encouraged the use of open-ended questions to capture a fuller experience, before drilling down to specific questions:

> "*There needs to be an overall and open-ended question on, 'How satisfied are you with your caregiving experience?' and not filtered to a set of questions on only a piece of that experience measured on a scale of 1-5 or whatever you use. The second and third questions should be, 'In your experience, what were the gaps you saw in your home care journey?' and 'In your experience, what were the excellent services/support that most helped you through your journey?'*"

A caregiver, caring for his son, recommended a series of straightforward questions:

> "*Did you get what you expected?*
> *'What was your expectation?*
> *'Was the person nice?*
> *'Was the person qualified?*
> *'Overall, how was your experience?*"

He went on to say:

> "*When I see a questionnaire with 25 questions, I'm tired before I start. In your discussions, you might see certain themes being repeated by different groups and 10 questions is the right [amount to] ask. I think that's the goal* […] *say, here's eight themes that we hear, if we can deal with those eight issues and we solve 75% of the problems in that sector…*"

In line with this caregiver's recommendation, the questions in the survey will stem from the core categories of experience detailed in Table 1 as these reflect what is most important in home care from the client and caregiver perspective. While not every aspect of care can be captured, all survey components will be examples of things that have been identified as meaningful and important by home care clients and caregivers in our study.

Participants also mentioned the importance of both positive and negative feedback. Simply asking, *"What's working for you?"* will yield important data and point to areas of success that should continue to be resourced.

WHEN *is the appropriate time point to get information?*

Home care clients and caregivers were unclear as to what time point they would refer to when filling out/responding to a survey. For example, is the home care survey meant to be formative or summative? Perhaps it should be both? In our sample, some caregivers were new to home care and reflected on an important experience (of waiting for an assessment and services to be put in place) versus those that were 'seasoned,' or previous home care users who have experience and reflected on a journey, an experience which was immensely valuable, but ever-changing.

HOW *will we collect our information?*

While telephone surveys are one way to capture information, participants noted that multiple modalities may work better, particularly since some people with complex care needs, might not be able to reach the phone. A homebound patient asked us if *"people answer the calls when [they're] in a bad way"* reminding us that, through telephone surveys, we will lose an opportunity to connect with some people.

HOW *people respond will depend on the level of comfort and expectations of the system instead of sharing what they really want/need?*

How people respond to any survey will be dependent on both their level of expectations of the system and comfort in sharing information. If expectations are low, they may not even bother asking for more optimal care, as they are grateful *"just to have a body in the house"*. Comfort in sharing, i.e., a relational aspect, is an important factor that accompanies data collection. Whoever collects the data needs to create an open and comfortable space for discussion.

See Supplemental Table 1 for additional details on measurement considerations.

DISCUSSION & FUTURE DIRECTIONS

As we endeavour to develop home care experience surveys for clients and caregivers, it is important that we not only consider what is meaningful (addressing the core components of home care) but what is actionable (detailed enough to allow a funder, or provider, to respond).

Measuring what matters to people *and acting on it* can be illustrated in several ways. For example, asking about unmet need will point to services that can be considered as part of the publicly funded range of services in the future. Inquiring about the nature of communication issues (e.g., language barriers) can be matched to a strategy that supports connecting people to linguistically compatible providers or translators. As noted earlier, the value of the provider and client speaking the same language means that a home care visit can be social as opposed to just task oriented, creating a more meaningful and comfortable experience and potentially better outcomes.

Measuring and addressing one core component of home care can also have spillover effects to other areas. For example, developing a clear line of communication—so every client and caregiver has a 'point person' or 'point people' who are responsive, open to feedback, and non-threatening means that clients and caregivers may feel more confident about getting information when they need it, have expectations managed and share concerns without fear of being reprimanded.

Addressing what clients and caregivers identify as important can provide an opportunity to strengthen the sector so that it works better, not only for the user, but for the provider as well. With the growing complexity of care needs among clients; providers are facing increasingly unpredictable situations in the home, and require ongoing support, tools and training to be best prepared for their roles. Thus, measuring care quality and competency, as perceived by clients and caregivers can provide an opportunity to strengthen the home care workforce. Caregivers observed the poor conditions that providers work in and the need to provide adequate compensation to enhance the status of home care work and address high turnover.

Importantly, participants continually reminded us that home care is only one segment of the system they interact with. Many participants were using various sectors and providers (e.g., hospitals, emergency rooms, primary care, specialist care, community support services and social services). Any care plan or coordinating function needs to bring these various players together in some form (such as through improved communication platforms) so that clients and caregivers can experience 'one team' as opposed to various disjointed parts. In other words, improving home care needs to occur in conjunction with improving its links to these other 'systems.'

Our findings corroborate findings from many other large-scale studies that have been conducted recently in the province of Ontario. We reflect on four of these studies. First, Kiran *et al.* [10], as part of her embedded Scientist role at HQO, engaged over one thousand Ontarians to learn about their experiences transitioning from hospital to the home. Several key findings (which align with the findings from our engagement work) were the need for timely access to home care, including someone to help with logistics; education around what to expect and whom to contact with questions; and timely follow-up.

Second, members of our team conducted a multi-jurisdiction study (in Ontario, Quebec and New Zealand) [11], of 172 ethnically diverse clients and caregivers (most of whom were receiving home care services), including Maori indigenous, non-English speaking and new immigrant populations. These participants shared needs that align with the findings in our engagement work, including the need for a key point person who was responsive and connected to a broader array of resources; access to both health and *social* care (including respite services, and lighter supports in the home), in addition to a greater volume of support, with attention to complex clinical needs (wound management and support for people with dementia). The caregivers in this multi-jurisdiction study had no breaks, even with services in place. They felt unrecognized, had high out-of-pocket costs, and were yearning for greater clarity and education around what was available to them and how to access it [12].

Third, the Change Foundation (CF), an Ontario-based policy think tank, has been leading several initiatives to engage with, and support, caregivers within the health care system. Their initial engagement work, spanning the province of Ontario, demonstrated that caregivers often felt unrecognized and excluded from the care team [13]. The CF is currently working with health care organizations to build tools and supports for caregivers. The new caregiver experience survey to be created from our work is another important step in helping this overlooked population gain recognition and access to supports in the future.

Finally, the Report of the Expert Group on Home and Community Care, led by Dr. Gail Donner, entailed consultation with decision makers and providers, along with a review of hundreds of peer reviewed and gray literature reports. The findings of the expert panel, similar to our work, included a need for: greater supports for caregivers; the addition of 'lighter' instrumental supports in the range of home care services; and greater accountability in the system, among other things [8].

Some themes in our findings were less prominent, but this could be a product of our sample. For example, only younger participants noted experiences of stigma during home care visits. While not a prominent theme in our data, this was a core finding in a large program of research on the home care experiences of LGBTTQI home care clients conducted by Daley *et al.* in partnership with RHO [9], particularly among the transgender population who experienced or feared judgment from home care staff. Many home care clients were unaware of what services were available. These important findings should not be overlooked and must be considered in any home care reform, particularly training of staff on cultural safety, which the LGBTTQI study found to be lacking. Questions about comfort with home care staff, and the reasons driving discomfort, may help to capture this important component of home care.

Our engagement work supports previous work and extends it in important ways. Our engagement work picked up on a core theme identified by participants, who expressed reservations, and sometimes fear and guilt, about sharing concerns for fear that it would compromise their services. Some, based on their expectations of the system, did not see the point in getting involved and continued to have unmet need. Level of engagement and expectation of system improvement will likely affect their willingness to respond to any experience surveys in the future. A clear statement of purpose and accountability to respond to findings was articulated several times and may ameliorate some of the reservations captured in our work. Having a survey that is succinct in overall length, while also specific and actionable was recommended. Finally, the important context captured through our engagement sessions point to the importance of building continuous engagement into future measurement strategies. While telephone or paper-based surveys are cost efficient and have greater reach, there is value in bringing people together to share their stories and ideas for change. Recognizing the limitations of conducting surveys alone, the Toronto Central Community Care Access Centre (prior to merging with the LHIN) added qualitative and quantitative evaluation interviews with clients and caregivers, as a supplement to the provincial survey, to better understand experiences. This provided important data to understand which strategies were working based on their experience.

Moving forward, perhaps our greatest challenge is capturing the variability in quality in a short survey. Variability is shaped by several factors, including geographic location, provider training, as well as interpersonal characteristics. While some people are pleased with aspects of their care and with some providers, they are unhappy with others. To that end, learning from success is just as important as understanding challenges. Designing a survey tool to capture these distinctions is critical but will require a multi-pronged measurement strategy and ongoing partnerships with research. Finally, bringing people together for these engagement sessions to share experience seemed to have therapeutic value by providing a sense of shared experience and support, which should be considered when a formal roll-out of the new surveys takes place.

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