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Client and Caregiver Experience Evaluation of Home and Community Care Services

A rapid review and jurisdictional scan of
existing surveys

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

WRITTEN BY

S. Shearkhani, J. Im, R. Abdelhalim, S. Jopling,
J. M. Li, & W. P. Wodchis

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Health System Performance Research Network

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Health System Performance Research Network

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. Housed at the Institute of Health Policy, Management and Evaluation (IHPE) at the University of Toronto, HSPRN includes investigators, visiting scholars, post-doctoral fellows, graduate students, and research staff. HSPRN has a long history in performance measurement and improvement in Ontario. The network has expertise in many areas of health system performance measurement, including clinical quality, financial management, patient safety, and patient satisfaction. Academic disciplines represented include health economics, epidemiology, finance, health informatics, health services research, nursing, organizational management, and statistics.

Authors

Sara Shearkhani, MAE, PhD Student – IHPE, University of Toronto, and HSPRN trainee

Jennifer Im, HBA, MSc Student – IHPE, University of Toronto, and HSPRN trainee

Reham Abdelhalim, MD, MSc, CPHQ, PhD Student – IHPE, University of Toronto, and HSPRN trainee

Sydney Jopling, HBSc, MSc Student – IHPE, University of Toronto, and HSPRN trainee

Joyce M Li, HBSc, MSc Candidate – IHPE, University of Toronto, and HSPRN Research Assistant

Walter P Wodchis, BMath, MA, MAE, PhD – IHPE, University of Toronto Professor and HSPRN Principal Investigator

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KEY MESSAGES

Question

- What survey tools are being used in jurisdictions across the world to capture the experiences of clients and caregivers receiving home and community care?
- What aspects of the patient and caregiver experience are being measured?
- How are these tools being developed and validated?

Importance of the issue

- The challenges in home and health care delivery cascade down to the quality of services that are provided to clients and families, which further impacts their experience of care. As such, the assessments of service delivery can help to identify areas of strength as well as areas of improvement as perceived by recipients of care.

Findings

- For the client experience review, a total of 64 references were included (34 were peer-reviewed sources and 30 were from the grey literature search).
- For the caregiver experience review, a total of 76 references were included (47 were peer-reviewed sources and 29 references were from the grey literature search).
- The articles identified in the peer-reviewed search of both client and caregiver experience measures included a mix of program evaluation studies, survey validation studies for the home and community care services, as well as qualitative studies examining the effectiveness of home or community care programs.
- The client grey literature search included 30 documents consisting of a combination of survey tools and reports from healthcare organizations, with nearly half of the included tools assessing patient satisfaction as opposed to patient experience with home and community care.
- The caregiver grey literature search included 29 documents consisting of a combination of policy papers, organization reports, executive summaries, policy briefs, working group reports, and survey reviews.
- The literature review team identified domains measuring client and caregiver experience from the peer-reviewed and grey literature searches. The findings from each of the rapid reviews were synthesized through a concept mapping exercise undertaken by the team. Domains common to both clients and caregiver domains include Quality of Care, Communication & Information, and Client Involvement. Two additional caregiver domains extracted were Support and Preparedness/Willingness to Care for Client.

ACRONYMS & ABBREVIATIONS

AHCCES	Health Quality Council of Alberta Home Care Client Experience Survey Tool
BCCHC	Black Creek Community Health Centre
CCEE	Client and Caregiver Experience Evaluation
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CNAP	Community Navigation and Access Program
H&CC	Home and Community Care
HCSM	Home Care Satisfaction Measure
HCSQ	Health Care Satisfaction Questionnaire
HHCAHPS	Home Health Care Consumer Assessment of Healthcare Providers and Systems
HQO	Health Quality Ontario
HSCS	British Columbia Home Support Client Survey
HSPRN	Health System Performance Network
iCOACH	Integrating Care for Older Adults with Complex Health Needs
IC-PREMs	Intermediate Care-Patient Reported Experience Measures
IHI	Institute for Healthcare Improvement
IHPME	Institute of Health Policy, Management and Evaluation
IOM	Institute of Medicine
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning
MEDLINE	Medical Literature Analysis and Retrieval System Online
MeSH	Medical Subject Headings
MOHLTC	Ministry of Health and Long-Term Care
NBHC	New Brunswick Health Council
PAIEC	Patient Assessment of Integrated Elderly Care Survey
PES	Participant Experience Survey Tools
VOICES	Views of Informal Carers-Evaluation of Services

BACKGROUND

As outlined in the *Aging with Confidence: Ontario's Action Plan for Seniors* Report by the Ministry of Health and Long-Term Care (MOHLTC), the vision for the government of Ontario is to make the province “a place where seniors feel supported in living independent, healthy and active, safe and socially connected lives” [1]. In Ontario, over 90% of older adults aged 65 years and older reside in a private household [1]. A commonly held value of older adults is to be able to live independently [1, 2]. The services provided by the Home and Community Care (H&CC) sector play a major role in ensuring that this vision and value are achieved.

Currently, improving coordination of care is a major challenge in the H&CC sector and the Ontario health system writ large. Improving system coordination entails also improving related aspects of care such as communication and training of healthcare providers. All of these challenges cascade down to the quality of services that are provided to clients and families, which further impacts their experience of care. Assessments of service delivery can help to identify areas of strength as well as areas of improvement as perceived by recipients of care. However, the value added of such assessments depends on its ability to capture the experience of care that is truly important for clients and caregivers.

To capture the experience of care among clients and caregivers of the H&CC sector, Health Quality Ontario (HQO) is redeveloping the existing Client and Caregiver Experience Evaluation (CCEE) surveys. To complete this task, HQO is working with the Health System Performance Research Network (HSPRN) to conduct the following:

- i) an analysis of the existing CCEE survey instruments;
- ii) rapid reviews of existing client¹ and caregiver experience measures in the H&CC sector (the focus of this report);
- iii) client and caregiver engagement sessions;
- iv) development of new CCEE survey instruments; and
- v) piloting of the CCEE survey instruments.

The findings included in this review will be discussed with client and caregiver advisory members through engagement sessions. These phases of the project will inform the development of the final CCEE surveys for pilot testing.

This report outlines the methodology and findings from the rapid review of the literature on currently existing measures that assess the experience of client and caregivers receiving H&CC services. A team for client measures and a team for caregiver measures each conducted two reviews, one of the peer-reviewed literature and one of the grey literature for both client and caregivers. The rapid reviews were conducted to support the development of the new CCEE surveys for the H&CC sector. The reviews were driven by an over-arching goal to develop surveys that can capture important aspects of care as perceived by client and caregivers.

METHODS

Rapid reviews were conducted to identify domains and measures for the client experience and caregiver experience surveys. To identify domains, measures and items for the new H&CC surveys, four rapid reviews were undertaken:

1. A review of the peer-reviewed literature on client experience measures
2. A jurisdictional scan of the grey literature on client experience measures
3. A review of the peer-reviewed literature on caregiver experience measures
4. A jurisdictional scan of the grey literature on caregiver experience measures

¹ In some cases, papers and reports use the terms “patient experience”. In this report, we exclusively use the term “client” to refer to any source of information regardless of whether the original source used the term patient.

Peer-Reviewed Literature Search

The peer-reviewed searches were performed in the Medical Literature Analysis and Retrieval System Online (MEDLINE) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) using a combination of the following key terms: “patient experience”, “client experience”, “care experience”, “care* adj experience”, “care* adj satisfaction”, “patient perspective”, “patient reported experience”, “patient reported experience measures”, “patient satisfaction”, “patient participation”, “home care services”, “home care services, hospital-based”, “house calls”, “home nursing”, “homecare”, “home care”, “home based”, “home visits”, “hospital at home”, “intermediate care”, “community care”, “community health services”, “surveys”, “questionnaires”, “evaluation studies”, “evaluation”, “instrument”, “validat*”, “develop*” “measur*”, “tool”, “assess*”, “aging”, “adult”, “Aged”, “aged, 80 and over”, “older adults”, “elderly”, “caregivers”, “caregiv*”, “carer”, “informal adj1 care”, “unpaid adj care*”, “family adj care*” (see Appendices A-D). Restrictions were added to the searches to limit the search results to return articles that were written in English and published after 2008. The latter restriction was added based on the rationale of the Institute for Healthcare Improvement (IHI)’s Triple Aim Framework, having been published in 2008, in order to screen a feasible number of search hits. Additional articles were identified through a search of the references of included articles.

Jurisdictional Environmental Scan

To perform the jurisdictional scans, a combination of open Google searches and targeted searches of specific organizations and survey tools, as informed by prior knowledge and peer-reviewed literature, were used. A combination of the following key terms were used for the search: “patient”, “client”, “carers”, “informal carers”, “unpaid carers”, “caregiver education”, “caregiver support groups”, “experience”, “satisfaction”, “home support”, “home support workers”, “home support services”, “home support surveys”, “personal support”, “community care”, “community support services”, “home health care”, “home care”, “home based care”, “paid home care”, “transition to home”, “social care”, “hospice”, “respite”, “adult day care”, “Extra-Mural Program”, “nonmedical home support services”, “home Assistance”, “questionnaires”, “survey”, “surveying”, “experience of care”, “psychometrics”, “measure”, and “tool” (see Appendices E and F). Full texts of the tools were obtained directly from database search when available or through requests of information from researchers or holding organizations (CCEE survey, Health Care Satisfaction Questionnaire (HCSQ) survey and British Columbia Home Support Client Survey (HSCS)). When reviewing the open Google search engine results, the first 20 pages were reviewed or when new tools stopped appearing. No restrictions were added to the grey literature searches.

Criteria for Screening

The first phase of the rapid review entailed screening the titles and abstracts of the search results. Articles that were deemed relevant were retrieved to be reviewed in full-text. The screening process was guided by the following inclusion criteria:

- i) captures the client or informal caregiver perspective;
- ii) specific to client or informal caregiver experience/satisfaction; and
- iii) relevant to home care or social care services.

The screening process for client experience measures used an additional inclusion criteria:

- iv) focus on survey/tool development or validation.

Studies and reports were excluded if the articles were unavailable in full-text. For the grey literature review, documents were also excluded if the full survey was not available for review. The screening process for caregiver experience measures was less restrictive due to the smaller number of existing surveys and tools focusing on the caregiver experience as compared to the client experience. Information from relevant articles and reports were extracted to synthesize the findings.

RESULTS

Overview

For the client experience review, a total of 64 references were included. Thirty-four of these references were peer-reviewed sources and the remainder of the 30 references were identified through the grey literature search. For the caregiver experience review, a total of 76 references were included. Forty-seven articles reviewed were peer-reviewed sources and the remainder of 29 references were identified through the grey literature search. The rapid reviews included articles predominantly from Canada, United States, United Kingdom, Australia, Sweden, and the Netherlands.

Peer Reviewed Literature

Clients

The scholarly database searches yielded a total of 1701 articles to review. After screening the titles and abstracts of the search results, 66 articles were included to be reviewed in full-text. From this subset, 34 articles were included for synthesis of findings. The studies were conducted in Sweden (n=8), United States (n=6), Canada (n=5), the Netherlands (n=5), United Kingdom (n=4), Australia (n=3), Greece (n=2) and Italy (n=1).

The articles reviewed in the peer-reviewed search included a mix of program evaluation studies, survey validation studies for H&CC services, as well as qualitative studies that provided useful insights on important aspects of care for older adults receiving H&CC services. Program evaluation studies most often used survey items that had been previously validated [3-10]. Studies that reported on the development and validation of surveys were typically based on literature reviews, qualitative evidence and/or expert panel discussions followed by piloting and testing the survey through various factor-analysis [11-19]. The majority of the studies measured patient satisfaction as opposed to specifically patient experience [3-5, 7, 9-16, 19-23]. There were a few exceptions to this such as the Home Health Care Consumer Assessment of Healthcare Providers and Systems (HHCAHPS) survey [24], and the Italian version of the Intermediate Care-Patient Reported Experience Measures (IC-PREMs) questionnaire [25], which was based on IC-PREMs survey from the United Kingdom to evaluate home-based or facility-based community care services [18]. The remainder of the studies which focused on patient experience with using H&CC services were qualitative in design [6, 26-31] or were studies that provided relevant information for the review [8, 32-36].

Caregivers

Searches of the scholarly databases yielded a total of 2341 articles to review, 1941 from MEDLINE and 400 from CINAHL. Following screening of the search results, 47 peer-reviewed articles were selected to be reviewed in full-text and included for synthesis of findings. The studies were conducted in the United States (n=9), Australia (n=9), Canada (n=6), the United Kingdom (n=6), Germany (n=2), the Netherlands (n=2), Sweden (n=2), Israel (n=2), Belgium (n=1), Denmark (n=1), Italy (n=1), Hong Kong (n=1), Japan (n=1), Korea (n=1), Taiwan (n=1), and Saudi Arabia (n=1). Additionally, one of the studies was a European multi-national study conducted in France, Germany, Poland, Spain, and Scotland.

The studies reviewed for the caregiver search were classified into three broad categories (with some overlap), those measuring

- i) caregivers' satisfaction with their caregiving role and/or formal care and services (n=22);
- ii) caregivers' experience caring for the patient and/or with formal care and services (n=20); and
- iii) caregiver outcomes (e.g., burden, strain), preparedness, and/or needs (n=13).

Study designs varied, including 20 qualitative, 19 quantitative, and 8 mixed methods studies. A number of quantitative studies were concerned with the design, development and/or validation of new or existing survey tools [14, 37-45]. Only one caregiver experience tool, the Views of Informal Carers-Evaluation of Services (VOICES) survey, was identified in multiple studies [39, 46, 47]. Other quantitative and mixed methods studies used existing tools to examine the effectiveness of H&CC programs and interventions [48-60]. One study used

a mixed methods design to develop a home nursing quality scale informed by qualitative data collected through interviews with caregivers [61]. The quantitative and mixed methods studies used a variety of methods to validate the tools, including measuring validity [14, 40-42, 50, 56-58], triangulating with focus groups and survey data [48], and user pilot testing [49]. Qualitative studies explored experience and satisfaction with the caregiving role [62-64], with formal care and services delivered at home or in the community [28, 47, 65-72], perceptions of quality of care [73, 74], and needs and preferences [30, 64, 75-77]. Themes that emerged from these studies were used to validate and supplement domains from the quantitative surveys and tools.

In Practice/Grey literature

Clients

The grey literature search yielded 50 hits. After screening of titles, 30 documents were included. The tools included in this search come from eight countries: Canada (n=17), UK (n=4), the Netherlands (n=1), Greece (n=1), Australia (n=1), Sweden (n=1), Ireland (n=1) and the United States (n=4).

The documents reviewed consisted of a combination of survey tools and reports from healthcare organizations. Certain details about the development and validation of surveys (e.g., concept mapping, factor analysis, etc.) [78, 79] were available for only eight tools (Health Quality Council of Alberta Home Care Client Experience Survey Tool (AHCCES) [80], CCEE [81], HHCAHPS [82], Home Care Satisfaction Measure (HCSM) [83], HCSQ [79], Questionnaire to measure satisfaction with home care in Greece [11], Client Satisfaction with Home Health Care Nursing [78], and the Patient Assessment of Integrated Elderly Care Survey (PAIEC)[36]).

Nearly half of the included tools assessed patient satisfaction as opposed to patient experience with H&CC. Those which looked at patient experience were: HHCAHPS [82], AHCCES [80], CCEE [81], New Brunswick Health Council (NBHC) Home Care Survey [84], HSCS [85], Nova Scotia Mental Health and Addictions Patient Experience Survey [86], Black Creek Community Health Centre (BCCHC) Client Experience Survey [87], Waypoint Centre for Mental Health Care Third Annual Inpatient and Community Client Experience Survey [88], Western Health Community Health and Family Services Client Experience [89], East End Community Health Centre Client Experience Survey [90], Community Navigation and Access Program (CNAP) Client Experience Survey Report [91], Parkdale Queen West Community Health Centre Client Experience Survey [92], Participant Experience Survey Tools (PES) [93], and Domiciliary Care Survey [94].

Comparing the Canadian tools to ones available from international jurisdictions reveals that Canadian tools cover many domains concerning patient experience with H&CC, e.g., the NBHC Home Care Survey [84] and AHCCES [80]. These tools can provide a foundation for the development of a comprehensive tool for measuring client experience in Ontario. It is also worth mentioning that certain Canadian surveys also included items that are particularly relevant to the Ontario context given its diverse population. These items relate to the ethnic and gender diversity of clients when receiving home care services, which can impact the experience of care (e.g., Unison Health & Community Services survey [95] and NBHC Home Care Survey [84]).

Caregivers

The caregiver grey literature search yielded a total of 36 documents to review and after screening, 29 relevant documents with instruments were included. This literature came out of the following jurisdictions: Canada (n=13), United Kingdom (n=8), United States (n=3), the Netherlands (n=1), and Australia (n=4).

The documents reviewed consisted of a combination of policy papers, organization reports, executive summaries, policy briefs, working group reports, and survey reviews. Most of these were used to assess the landscape of H&CC from the caregivers' perspective with the remaining specifically used for program evaluation purposes. The search generated studies that could be categorized into three broad categories: those measuring the caregivers' experience with the caregiving role and/or the services provided to them and their loved ones (n=11); those measuring the caregivers' satisfaction with the caregivers' experience with the

caregiving role and/or the services provided to them and their loved ones (n=8); and caregiver cost and outcomes, such as burden and stress (n=1).

There were no documents identified in this search that specifically focused on survey development or validation. Instead, all of the quantitative studies or studies with quantitative components applied existing measures in order to gain a better understanding of the caregiver role, their needs, experience and/or satisfaction [96-99]. A select number of studies focused on program evaluation, assessing either specific interventions or the overall effectiveness of H&CC programs and whether they met the needs of the caregivers they were servicing [100-103]. Several documents utilized a mixed-method three-pronged approach, using a combination of quantitative measures, semi-structured interviews and focus/engagement groups to get a well-rounded understanding of the caregiver role and experience [104-106]. This approach gave caregivers a platform to elaborate on the services currently being provided to them and their loved one, shortcomings and what supports or improvements they feel would benefit their experience and/or satisfaction.

Domains

The findings from each of the rapid reviews were synthesized through a concept mapping exercise undertaken by the literature review team. Each team (for client and caregiver experience measures) conducted concept-mapping exercises to group domains and subdomains. The caregiver team had identified outcomes (e.g., caregiver burden, strain) as a domain, but it is not an experience measure and was left out of the final set of domains. However, since a large proportion of the literature included outcomes when measuring caregiver experience, the outcomes domain will be presented to caregivers during engagement sessions for further review. The teams then came together to identify areas of overlap between the client and caregiver results and further condense and collapse domains and subdomains into coherent categories. At this stage, the definition of domains and allocation of subdomains were informed by the Institute of Medicine (IOM) definitions and frameworks, as described below. The teams identified three domains common to both patients and caregivers: Quality of Care, Communication & Information, and Client Involvement. An additional two domains, Support and Preparedness/Willingness to care for the patient, were unique to the caregiver results (Table 1). Each of the domains are described in detail below, with Tables 2-4 providing examples of questions for each domain and sub-domain from the client experience review.

Table 1. Resulting Domains from the Literature Review

Client Domains	Caregiver Domains
1) Quality of Care <ul style="list-style-type: none"> a) Service Delivery b) Client-centredness c) Professionalism d) Staff skills & Competency e) Safety 	1) Quality of Care <ul style="list-style-type: none"> a) Service Delivery b) Client-centredness c) Professionalism d) Staff skills & Competency
2) Communication & Information	2) Communication & Information
3) Client Involvement	3) Client & Caregiver Involvement
	4) Support <ul style="list-style-type: none"> a) Direct support for caregivers b) Support with care of patients
	5) Preparedness/Willingness to Care for Client

Definition of Domains

- 1) **Quality of Care** – The IOM defines quality of care as "the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." [107] Along with this definition, they provide six quality domains of healthcare quality in the IOM Framework: safe, effective, patient-centered, timely, efficient, and equitable. We used this framework as a guide to create sub-domains that reflect the findings from the literature review on client experience for H&CC clients for the Ontario context.

- a. *Service Delivery* – This sub-domain reflects the activities that are undertaken by providers to improve delivery of services through care planning, providing appropriate levels of care to meet client’s needs, that is accessible and available to the client.
 - b. *Client-Centeredness* – This sub-domain of care delivery depends on the providers' behaviour or organizational culture. It focuses on the extent to which client preferences are considered when planning and delivering care services.
 - c. *Safety* – The IOM Framework defines safety as freedom of error [108]. However, this definition needed to be broadened to reflect other aspects such as stigma (especially for clients with mental health and addiction issues, those belonging to the LGBTQ community, as well as clients who have experiences with the justice system), privacy and reporting complaints. These aspects reflect a more holistic approach when looking at safety and is more reflective of the home and community setting as compared to the hospital setting where feeling safe is mostly about freedom of error.
 - d. *Professionalism* – This sub-domain relates to the way in which service providers interact with clients and their families when delivering care.
 - e. *Staff Skills & Competency* – This sub-domain captures the degree to which clients have confidence in and trust the expertise of their services providers.
- 2) **Communication & Information** – This domain reflects the way in which information flows within the client’s team of home care providers and between providers and clients and their families.
- 3) **Client and Caregiver Involvement** – This domain stems from the concept of treating clients and families as partners, engaging them actively in the design and implementation of care and not as passive recipients of care, e.g., involved in decisions about care/treatment, involved in goal setting.
- 4) **Support** – This domain involves two main concepts of support: direct support to the caregivers through support networks, education and training, etc. or indirectly through supporting their loved ones.
- 5) **Preparedness/Willingness to Care for Patient** – This domain mainly looks at how ready caregivers are to take over the role of caregiving as well as how satisfied are they with this role.

Table 2: Domains, sub-domains and examples from the client experience review

Domains & Sub-domains	Aspects	Sample Questions	Response Categories	References
Service Delivery	Access	Suitability of scheduled days and hours of visits	5-point Likert scale	[11]
	Availability	Professional Home Care services met my needs with [remaining at home]	Yes/Partly/No, I did not need this/I don't know	[80]
	Reliability	I was able to reach my [home care provider] when I needed him/her	Yes/Partly/No, I did not need this/I don't know	[80]
	Safety	Do you know who to contact if you want to make a complaint about your home care services?	Yes/No/Do not know/Do not remember/ Not applicable	[84]
		Feel safe receiving care and services	Excellent, Very good, Good, fair and poor	[95]
		Do you or your family members believe that you were harmed because of an error or mistake as a result of home care services?	Yes/No/Do not know/Do not remember/Not applicable	[80]
Professionalism	Treatment	My home care professional staff treated me with courtesy and respect	Yes, Partly, No, I don't know	[80]
	Interaction with client	Staff informs [client] if it is going to arrive late	5-point Likert scale format	[11]
Staff Knowledge & Skills	Expertise of staff	My home care professional staff knew what kind of care I needed and how to provide it	Yes, Partly, No, I don't know	[80]
	Cautious	The staff is careful and orderly	7-graded scale (from 1 = very dissatisfied)	[5]
Communication	Among providers	In the last 2 months, how often have you received conflicting or different information from different home support workers?	Never/Sometimes/Usually/Always/Do not know/Do not remember/Not applicable	[84]
	With clients	When you first started getting home health care from this agency, did someone from the agency tell you what care and services you would get?	Yes/No/Don't remember	[24]
Information	Care planning	My [care team] follows through with the care plan it creates with me	5-point Likert scale	[19]
	Access to information	My family or friends who help with my care were given the information that they wanted when they needed it	Strongly disagree/Disagree/Neutral/Agree, Strongly Agree/Do not know/Do not remember/Not applicable	[84]
Client Involvement	Inclusion of clients	I get enough opportunity to say what kind of care I need	5-point Likert scale	[20]
	Decision-making	Involved in decisions about care/treatment	5-point Likert scale format	[25]

Table 3: Domains, sub-domains and examples from the caregiver experience review

Domains & Sub-domains	Aspects	Sample Questions	Response Categories	References
Service Delivery	Availability	Help is available when most needed	4-point Likert scale	[60]
	Continuity (Transition)	Help is provided by the same care worker each time	4-point Likert scale	[60]
Professionalism	Treat with respect	Care workers treat carers with dignity and respect	4-point Likert scale	[60]
Staff Knowledge & Skills	Trust	Her (his) nursing skill makes me feel reassured	4-point Likert scale	[80]
Communication	Information	Do professionals provide sufficient information about care? (e.g., options for home care, available services)	Never/Sometimes/Mostly/Always/Not applicable/I don't know	[109]
Involvement	Recognition of caregiver role and responsibility	How often have you found you feel enough participation in your relative's HC?	7-point Likert scale (1=never)	[44]
Preparedness/Willingness to Care for Patient	Readiness	How well prepared do you think you are for the stress of caregiving?	5-point Likert scale	[45]
	Satisfaction with role	How often have you found you can do what is most important to you?	7-point Likert scale	[44]
Support	Direct support for caregivers	Do professionals pay sufficient attention to changes in your health?	Response category always to never	[58]
	Support with care of patient	Do professionals provide sufficient emotional support to your loved one?	Response category always to never	[58]

Table 4: An amalgamation of domains, sub-domains and examples from the client and caregiver experience reviews

Domains & Sub-domains	Aspects	Sample Questions	Response Categories	References
Client-centeredness	Care planning	My [care team] follows through with the care plan it creates with me	5-point Likert scale	[19]
	Appropriateness	Suitability of scheduled days and hours of visits	5-point Likert scale	[11]
	Access/Availability	Professional Home Care services met my needs with [remaining at home]	Yes/Partly/No, I did not need this/ I don't know	[80]
Safety	Issues with Service	Her (his) nursing skill makes me feel reassured	4-point Likert scale	[84]
	Privacy	Has your home support worker or the agency ever given information to your family or friends that you did not agree for them to have?	Yes/No/Do not know/Do not remember/Not applicable	[84]
	Error	Do you or your family members believe that you were harmed because of an error or mistake as a result of home care services?	Yes/Partly/No/I don't know	[84]
	Stigma	Feel safe receiving care and services	Excellent, Very Good, Good, Fair and Poor	[95]
Professionalism	Treatment with respect	My home care professional staff treated me with courtesy and respect	Yes, Partly, No, I don't know	[80]
	Punctuality	Staff informs [client] if it is going to arrive late	5-point Likert scale	[11]
Staff skills and competency	Expertise	My home care professional staff knew what kind of care I needed and how to provide it	Yes, Partly, No, I don't know	[80]
		Her (his) nursing skill makes me feel reassured	4-point Likert scale	[61]
	Cautious	The staff is careful and orderly	7-graded scale (from 1 = very dissatisfied)	[5]
Communication & Information	Informed providers	In the last 2 months, how often have you received conflicting or different information from different home support workers?	Never, Sometimes, Usually, Always, Do not know/Do not remember/Not applicable	[84]
	Informed clients and caregivers	Do professionals provide sufficient information about care? (e.g., options for home care, available services)	Never, Sometimes, Mostly, Always, Not applicable/I don't know	[109]
	Patience	Staff listens carefully to what the enrollee has to say	5-point Likert scale	[11]
Client & Caregiver Involvement	Inclusion of clients	I'm given enough opportunity to help decide how the care is provided	5-point Likert scale	[20]
	Inclusion of caregivers Decision-making	The staff include my family, (if I wish) in planning my care Involved in decisions about care/treatment	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree 5-point Likert scale	[110] [25]

<i>Caregiver Specific</i>				
Support	Direct support for caregivers	Do professionals pay sufficient attention to changes in your health?	Response category always to never	[58]
	Support with care of client	Do professionals provide sufficient emotional support to your loved one?	Response category always to never	[58]
Preparedness/ Willingness to Care for Client		How well prepared do you think you are for the stress of caregiving?	5-point Likert scale	[45]
		How often have you found you can do what is most important to you?	7-point Likert scale	[44]

CONCLUSION

This review consisted of four separate literature reviews of both the peer-reviewed and grey literature. These reviews yielded five domains overall (Quality of Care, Communication/Information, Client Involvement, Support, and Preparedness/Willingness to provide care), two of which are specific to caregivers (Support, and Preparedness/Willingness to Provide Care). These domains will be shared with the larger HSPRN team whom are working on the redevelopment of the CCEE surveys for Ontario to inform the final set of domains, sub-domains, aspects and questions. The findings will be compared with knowledge that has been produced from the Integrating Care for Older Adults with Complex Health Needs (iCOACH) program of research by Dr. Kerry Kuluski *et al.* These findings will also be shared with clients and caregivers participating in engagement sessions to further shape the final CCEE surveys.

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APPENDICES

Appendix A: Overview of patient experience search in MEDLINE

Database:	MEDLINE
Search date:	17-Mar-18
Search combination: (tw = textword search (title and abstract); kf = author's keywords; mp = multipurpose search; otherwise, MeSH terms)	
["patient satisfaction" OR "patient participation" OR (patient satisfaction or patient experience or client experience or care experience or patient perspective or patient reported experience).tw,kf.]	
AND	
["home care services" OR "home care services, hospital-based" OR "house calls" OR "home nursing" OR (homecare or home care or home based or home visits or hospital at home or intermediate care).mp. OR (community care).tw,kf OR "Community Health Services/ec, sn, ut [Economics, Statistics & Numerical Data, Utilization]"]	
AND	
["surveys and questionnaires" OR "evaluation studies" OR (survey or questionnaire or evaluation or instrument or validat* or develop* or measur* or tool or assess*).tw,kf.]	
AND	
["aging" OR "adult" OR Aged" OR "aged, 80 and over" OR (older adults or elderly or aged or aging).mp]	
Hits:	2443
Limited to English, 2008-present	1362

Appendix B: Overview of patient experience search in CINAHL

Database:	CINAHL
Search date:	17-Mar-18
Search combination:	
(patient experience or patient satisfaction) OR client experience OR care experience OR (patient participation or patient involvement) OR patient reported experience measures	
AND	
(home care services or home health care or home healthcare) OR (house calls or home visits) OR home based care OR hospital at home OR home nursing OR community health services OR community care OR intermediate care	
AND	
adults OR (older adults or elderly or seniors or geriatrics)	
AND	
surveys and/or questionnaires OR (tools or instruments) OR (evaluation or assessment) OR (validation studies or validation scales or instrument validation) OR measur*	
Hits:	
Limited to full text, English, and 2008-present	233
Additional searches ran:	
"patient experience survey"	93
"patient reported experience measures"	13

Appendix C: Overview of caregiver experience search in MEDLINE.

Database:	MEDLINE
Search date:	20-Mar-18
Search combination: (tw = textword search (title and abstract); kf = author's keywords; mp = multipurpose search; otherwise, MeSH terms)	
exp CAREGIVERS/ OR caregiv*.mp. OR carer.mp. OR (informal adj1 care*).mp. OR (unpaid adj care*).mp. OR (family adj care*).mp. OR (care* adj experience).mp. OR (care* adj satisfaction).mp.	
AND	
exp Aging/ or exp Adult/ or exp Aged/ or exp "Aged, 80 and over"/ or exp Middle Aged/	
AND	
["home care services" OR "house calls" OR "home nursing" OR "home care services, hospital-based" OR "exp Community Health Services/ec, sn, ut [Economics, Statistics & Numerical Data, Utilization]"OR (homecare or home care or home based or home visits or hospital at home or community care or intermediate care).tw,kf.] OR "respite" OR "adult day care" OR (care* adj support).mp. OR (care* adj education).mp.	
AND	
["surveys and questionnaires" OR "evaluation studies" OR (survey or questionnaire or evaluation or instrument or validat* or develop* or measur* or tool or assess*).tw,kf.]	
Hits:	4184
Limited to human, English and 2008-present	1941

Appendix D: Overview of caregiver experience search in CINAHL

Database:	CINAHL
Search date:	23-Mar-18
Search combination:	
(MH "caregivers+") OR caregiv* OR "carer" OR (informal N care*) OR (unpaid N care*) OR (family N care*) OR (care* N experience) OR (care* N satisfaction)	
AND	
"home care services" OR "house calls" OR "home nursing" OR "home care services, hospital-based" OR (homecare or home care or home based or home visits or hospital at home or community care or intermediate care) OR (MH "Community Health Services/UT/SN/EV/EC+") OR "respite" OR "adult day care" OR (care* support) OR (care* education)	
AND	
"surveys and questionnaires" OR "evaluation studies" OR (survey or questionnaire or evaluation or instrument or validat* or develop* or measur* or tool or assess*)	
AND	
(MH "Adult+") or (older adults or elderly or aged or aging)	
Hits:	1139
Limited to Human, English and 2008-present	400

Appendix E: Overview of client experience search in the grey literature

Database:	Google
Search date:	16-Apr-2018
Search combination:	
home support, home support workers, home support services, home support surveys, personal support, community support services, home health care, home care, home based care, paid home care, social care, Extra-Mural Program, nonmedical home support services, home Assistance.	
AND	
questionnaires, surveys, surveying, experience of care, psychometrics, and satisfaction	
* In some cases the names of specific tools were also searched.	
Relevant Hits:	50

Appendix F: Overview of caregiver experience search in the grey literature

Database:	Google
Search date:	17-Mar-2018
Search combination:	
caregivers, informal caregivers, unpaid caregivers, carers, informal carers, unpaid carers	
AND	
experience, satisfaction	
AND	
home care, community care, hospice, respite, adult day care, caregiver education, caregiver support groups, transition to home	
AND	
survey, measure, tool	
Relevant Hits:	36