COMPARING QUALITY INDICATOR RATES FOR HOME CARE CLIENTS RECEIVING PALLIATIVE AND END-OF-LIFE CARE BEFORE AND DURING THE COVID-19 PANDEMIC

COMPARING QUALITY INDICATOR RATES FOR HOME CARE CLIENTS RECEIVING PALLIATIVE AND END-OF-LIFE CARE BEFORE AND DURING THE COVID-19 PANDEMIC

by

JULIA KRUIZINGA, RN, BNSc

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TITLE:	Comparing Quality Indicator Rates for Home Care Clients Receiving Palliative and End-of-Life Care Before and During the COVID-19 Pandemic
AUTHOR:	Julia Kruizinga, RN, BNSc
SUPERVISOR:	Dr. Sharon Kaasalainen, RN, BScN, MSc, PhD
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Abstract

Background. The consensus among Canadians with regards to end-of-life preferences is that with adequate support the majority prefer to live and die at home.

Purpose. To compare quality indicator (QI) rates for home care clients receiving palliative and end-of-life care prior to and after the onset of the COVID-19 pandemic.

Methods. A retrospective population-based cohort design was used. Sixteen QIs informed by existing literature and a preliminary set of QIs recently evaluated by a modified Delphi panel were compared. Data were obtained from the over 280-item interRAI PC instrument for Ontario home care clients for two separate cohorts: the pre-COVID (January 14th, 2019 to March 16th, 2020) and COVID cohort (March 17th, 2020 to May 18th, 2021). A propensity score analysis was used to match on 21 covariates, resulting in a sample size of 2479 unique interRAI PC assessments per cohort. Alternative propensity score methods were explored as part of a sensitivity analysis.

Results. After matching the pre-COVID and COVID cohorts (using nearest neighbour matching), five of the 16 QIs had statistically-significant differences in the QI rates. The two alternative propensity score methods produced slightly different results with fewer statistically-significant differences between the cohorts. However, in examining the effect sizes, the results of all propensity score methods were found to be not clinically meaningful. High rates of the prevalence of shortness of breath with activity, no advance directives, and fatigue were observed in both cohorts and across all three propensity score methods.

Discussion. This study is the first to examine differences in QI rates for home care clients receiving palliative and end-of-life care before and during COVID in Ontario. Key limitations in interpreting the results include a limited understanding of the typical variation in QI rates over time and reliance on the comparison of a single proportion (the QI) in judging potential differences in quality. Importantly, a strength of this study was that these QIs focused on outcomes of care and were mainly symptom-focused as aspects of high-quality care valued by home care clients and families and in contrast to previous studies focusing on structure and processes of care. These QIs also indicated how frequently quality concerns may be occurring for those receiving palliative and end-of-life home care.

Conclusion. It appears that QI rates did not change over the course of the pandemic in this population. Future work should be directed to understanding the temporal variation in these QI rates, risk-adjusting the QI rates for further comparison among jurisdictions, provinces, and countries and in creating benchmarks to project acceptable rates of different QIs.

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List of Abbreviations

ACP:	Advance Care Planning
ADL:	Activities of Daily Living
CCAC:	Community Care Access Centre
CHESS	Changes in Health, End-Stage Disease and Signs and Symptoms
COVID:	Corona Virus Disease
EOL:	End of Life
HCP:	Healthcare Provider
interRAI:	international Resident Assessment Instrument
IADL:	Instrumental Activities of Daily Living
LHIN:	Local Health Integrated Network
NCP:	National Consensus Project
NNM:	Nearest Neighbour Matching
OPCN:	Ontario Palliative Care Network
PC:	Palliative Care
PEoLC:	Palliative and End-of-Life Care
PSW:	Personal Support Worker
interRAI HC:	international Resident Assessment Instrument – Home Care
interRAI PC:	international Resident Assessment Instrument – Palliative Care
SD:	Standard Deviation

Declaration of Academic Achievement

This thesis reports the original research that I have conducted under the supervision of Drs. Sharon Kaasalainen, Kathryn Fisher, Dawn Guthrie, and Melissa Northwood since September 2020. The supervisory committee members provided their expertise towards: the study design and research methodology, research proposal and protocol, Hamilton Integrated Research Ethics Board and Wilfrid Laurier University's Research Ethics Board application, and all chapters of the thesis dissertation (i.e., introduction, literature review and conceptual framework, research methodology, results, and discussion). Statistical analyses were completed by myself, with expert consultation and verification of results from Dr. Kathryn Fisher.

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CHAPTER 1: INTRODUCTION

Palliative Home Care

Demands for home care services are reflected by projections that show by 2046 the people in need of home care will be twice the number of people that will receive home care (Government of Canada, 2019; Home Care Sector Study Corporation, 2003). In Ontario, publicly-funded home care includes nursing, personal support workers (PSWs), occupational and physical therapy, counselling, physicians, and nurse practitioners (Health Quality Ontario, 2019). Home care is designed to promote well-being and independence for recipients while building health system capacity (Home Care Ontario, 2018) and includes palliative and end-of-life care (PEoLC).

PEoLC can be defined as the last six months to one year of life (Griebeler Cordeiro et al., 2020). The consensus among Canadians with regards to PEoLC preferences is that with adequate support the majority prefer to live and die at home (Brazil et al., 2004; Gomes et al., 2013). PEoLC is an essential part of home care and has been shown to be associated with outcomes of improved symptom management (Gomes et al., 2013), increased likelihood of having a home death (Maetens et al., 2019), improved caregiver burden (Davis et al., 2015), and satisfaction with healthcare (Brian Cassel et al., 2016) for persons with life-limiting illnesses (World Health Organization, 2018). However, the quality of palliative and end-of-life *home care* has been reported to vary substantially for home care clients who are dying, such as across geographical regions and by type of illness (Health Quality Ontario, 2016, 2019). With a shifting focus on the home care sector among a rapidly aging population with increasing PEoLC needs, better quality of and access to PEoLC is a major priority for Canadians (Fowler & Hammer, 2013; Government of Canada, 2019, 2020).

Clients who receive PEoLC home care are allowed more hours and care by specialized palliative healthcare workers (Health Quality Ontario, 2019). In a retrospective population-level observational study it was found that less than 10% of Ontario decedents had record of a PEoLC home visit and over half of these visits occurred in the last month of life (Tanuseputro, 2017). Though improvements have been made in home-based care, the proportions of those receiving PEoLC or any home care in the last month of life remains low (Health Quality Ontario, 2019).

Challenges in Home Delivery of Palliative and End-of-Life Care

Providing quality PEoLC in the last weeks and months of life and in the environment of the home care sector is challenging. Providing high-quality palliative and end-of-life home care is challenged by several factors limiting equitable and integrated home-based care. For example, communication and navigating interprofessional relationships can impact healthcare team members' ability to provide care throughout the illness trajectory (Austin et al., 2000; Meier et al., 2016). Further, the quality of PEoLC can be influenced by many organizational attributes, including the home environment, timing of care initiated, philosophy and culture, service collaboration, and community equipment suppliers (Austin, 2011; Marcella & Kelley, 2015; Xia & Kongsuwan, 2020). In addition, inequities exist in the delivery of PEoLC in home care, where it is reported that those in wealthier neighborhoods or urban areas are more likely to receive PEoLC (Health Quality Ontario, 2019). Receiving PEoLC earlier on increases the likelihood that an individual will die at home (Costa, 2014), though it is reported that in the last month of life only one quarter of people living in the community received palliative and end-of-life-specific home care (Health Quality Ontario, 2019). Many of these challenges exist because of funding and workforce shortages, under-resourcing of PEoLC services, late initiation of PEoLC and a lack of PEoLC trained professionals (Canadian Society of Palliative Care Physicians, 2016). For individuals with life-limiting illnesses wishing to remain in their home, receiving the necessary supports in order to promote quality of care is difficult (Health Quality Ontario, 2016).

COVID-19 Pandemic and the Quality of Home Care

Health systems and services have been significantly disrupted because of the corona virus disease (COVID) pandemic which began in 2019, highlighting existing and ongoing challenges in the delivery of quality home-based care for individuals with serious or life-limiting illnesses. The political and policy context following the COVID-19 pandemic dramatically shaped the quality of home care (Health Canada et al., 2021). For example, home care coordinators and other practitioners were unable to do home visits at the beginning of the pandemic and much of the care delivered was shifted to virtual care (Canadian Institute for Health Information, 2020; Sinn et al., 2022). Major legislative changes occurred to authorize virtual care for healthcare professionals. While there were successes with virtual care, there were limitations in developing therapuetic relationships, assessing illness severity, and with connectivity and training, particularly in rural and remote areas (Health Canada et al., 2021). In terms of the healthcare workforce, the pre-existing shortage of PSWs was further exacerbated when restrictions were imposed to limit them to working in one facility or setting which resulted in less availability of PSWs to work in home care. Clients or their families also began to cancel essential services out of fear of the virus and many home care services were put on hold. As a result, the quality of home care was threatened and the impacts on the quality of care and for clients receiving palliative and end-of-life home care remains largely unknown, thus demanding further research (Lapid et al., 2020).

The home care sector has also been severely affected during the COVID-19 pandemic as many individuals chose to remain home to receive care because of visitor restriction policies in healthcare settings and out of concerns for safety with the virus (Canadian Nurses Association, 2020). This shift has placed a major burden on the home care sector which is shouldering an unprecedented weight of care and in which services are sadly stretched beyond limits (Health Canada et al., 2021). Many visiting hospice care programs, community respite programs, home care services and volunteer care services have faced challenges in adapting safe and effective care provision. Delays in supply delivery and shortages in staff, medications, and personal protective equipment have also affected the timeliness and ability to provide quality care, of which long-term impacts and outcomes are still largely unknown (Arya et al., 2020; Health Canada et al., 2021). The quality of PEoLC has been threatened due to increasing social isolation for individuals living at home, adaptation to virtual care further isolating clients receiving care at home and difficulties accessing services (Flint et al., 2020; Lebrasseur et al., 2021). Yet, the home care sector was insufficiently organized and funded to support quality PEoLC long before the COVID-19 pandemic as demonstrated by issues of disjointed care, resource inefficiencies, and an overall poor investment in PEoLC (Canadian Society of Palliative Care Physicians, 2016; Health Quality Ontario, 2016, 2019).

During the COVID-19 pandemic the quality of PEoLC within home care has received little attention when compared to the hospital and long-term care sectors and represents a critical time period to evaluate (Health Canada et al., 2021). While there has been significant pivoting to create innovative ways to provide care and connection for individuals receiving PEoLC, the impacts of COVID on the quality of PEoLC are largely undetermined (Ritchey et al., 2020). Home-based care is critical and has been emphasized throughout the pandemic given the potential for surging rates of hospital admissions related to COVID-19 during each wave (Shoukat et al., 2020), as well as its role in essential pain and symptom management, advance care planning, and grief and bereavement supports (Bowers et al., 2020; Lapid et al., 2020). Therefore, measuring and monitoring the quality of home-based PEoLC services is essential to improving the quality of PEoLC for home care clients and their families (Lapid et al., 2020).

Importance of Engaging in Continuous Quality Improvement in Home Care

Over the past decade, efforts to improve PEoLC began with the Ontario Ministry of Health and Long-Term Care's action plan which recognized PEoLC as a strategic priority (Ontario Ministry of Health and Long-Term Care, 2015). Part of these recommendations in the action plan included achieving better health outcomes and quality of care (Ontario Ministry of Health and Long-Term Care, 2015). Several major reports and leading organizations have also consistently cited the need to improve the quality of palliative and end-of-life home care (Canadian Institute for Health Information, 2018; Canadian Society of Palliative Care Physicians, 2016; Health Quality Ontario, 2016, 2019; Sleeman et al., 2021) as individuals continue to face challenges with receiving quality PEoLC (Health Quality Ontario, 2019). The establishment of the Ontario Palliative Care Network (OPCN) in 2016 has been key along with its partnership with Health Quality Ontario in revitalization around developing quality indicators (QI) and quality standards for PEoLC (Health Quality Ontario, 2016). Most recently, the OPCN has identified action plan priorities for 2021/22, with measuring and reporting on quality in PEoLC being an area of focus, as well as enabling the adoption of quality standards (Ontario Palliative Care Network, 2020).

To understand the quality of PEoLC for individuals receiving home care, there must be regular measurement, monitoring, and evaluation of care (Canadian Cancer Society, 2016). The EOL period, though sometimes synonymous with PEoLC, can be defined as the last weeks of life with care directed to persons in the final phase of life, whereas PEoLC involves those with a life-limiting illness earlier on in the illness trajectory and includes treatment and control of symptoms to improve quality of life (Figure 1) (Krau, 2016). The last days to weeks of life are particularly significant for home care clients receiving PEoLC as their psychological, physical, and financial needs concurrently rise as they become closer to death (Conen et al., 2021; Schulz et al., 2016; Seow et al., 2020, 2021). Yet with earlier integration of PEoLC, there is an opportunity to alleviate symptom burden, lessen acute care use (Qureshi et al., 2019; Seow et al., 2018) and improve the quality of life for individuals with life-limiting illnesses and their families (Paetkau et al., 2011). Due to the expanding knowledge and research around managing and improving PEoLC and the concern for patient-centered care, measuring the quality of care for home care clients with PEoLC needs is important (National Consensus Project, 2004).

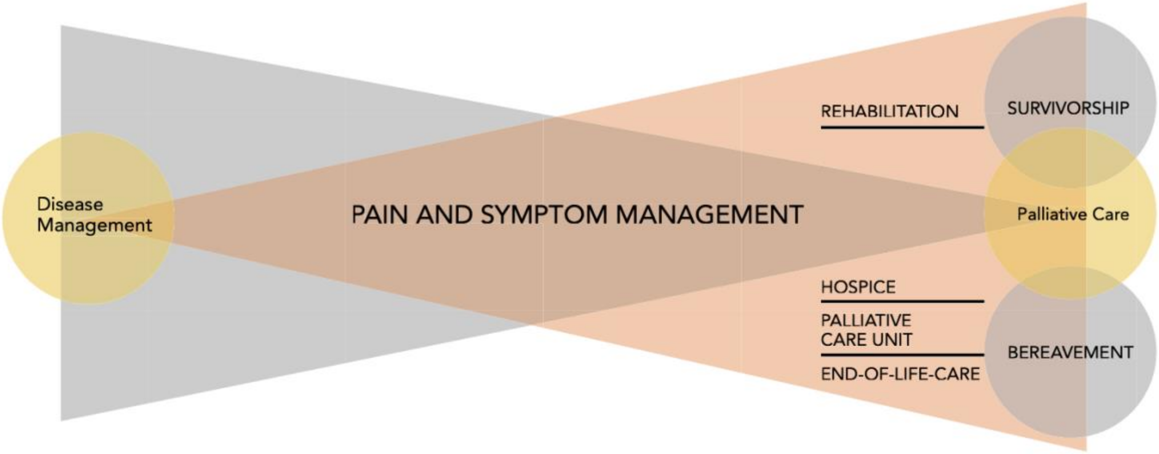

Figure 1. Hawley, P. H. (2014). The Bow Tie Model of 21st Century Palliative Care. *Journal of Pain and Symptom Management, 47*(1), 2-5.

Despite the call for quality improvement in the home care sector, a quality assurance mechanism to measure, monitor, and benchmark across jurisdictions is lacking. Progress in quality measurement and evaluation is a crucial step necessary to inform healthcare system decision-making and wide-spread planning of PEoLC and to identify areas to improve the quality of PEoLC for individuals living at home (Canadian Society of Palliative Care Physicians, 2016; Health Quality Ontario, 2019). Chronic underfunding in this sector has led to inequities in care and challenges to delivering the services home care clients may require (Yakerson, 2019). Such quality assurance mechanisms exist in long-term care and in the acute care sector in Ontario (Agency for Healthcare Research and Quality, 2014; Health Quality Ontario, 2012); however, there is a need for a quality assurance process to likewise be embedded in the home care sector (Canadian Institute for Health Information, 2021a). In order to advance the quality of palliative and end-of-life home care, quality improvement initiatives are needed to both understand the inequities in care and inform efforts to improve palliative and end-of-life home care, targeting the most significant issues impacting home care clients receiving PEoLC. There is therefore a need for agreed-upon QIs for palliative and end-of-life home care to support a mechanism for ongoing quality improvement in home care.

Palliative Care Quality Indicators: Development and Measurement

QIs are defined as "quantitative measures that provide information about the effectiveness, safety and/or people-centredness of care" (Quentin et al., 2019, p. 33) and are one way to gauge how a system is performing (Health Quality Ontario, 2013). QIs are explicitly defined measurable items of healthcare quality and reflect structure, processes, or outcomes of care (Campbell et al., 2003; De Roo et al., 2013; Donabedian, 1988). QIs can further be used to compare structure, process, and outcomes within a population and between settings, providers, or regions (Health Quality Ontario, 2013). A set of Canadian QIs is thus necessary to support decision-making and quality improvement for palliative and end-of-life home care (Claessen et al., 2011; Guthrie et al., 2022).

While there are currently no universally adopted QIs by organizations or at a provincial level for regular monitoring of home care clients receiving PEoLC, 23 home care QIs are endorsed for general home care clients by interRAI, a non-profit collaborative network of international researchers, policy makers, and clinicians (Morris et al., 2013; Smith et al., 2010). However, this broader set does not focus on PEoLC and there is no current mechanism to measure, monitor, and benchmark these QIs for home care clients receiving PEoLC (Canadian Institute for Health Information, 2021). While there is research summarizing QIs for home care (Morris et al., 2013; Wagner et al., 2020) and PEoLC more broadly (Barbera et al., 2015a, 2015b; Claessen et al., 2011; De Schreye et al., 2017; Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008; Henson et al., 2020; Johnston & Burge, 2002; Leemans et al., 2015; Miyashita et al., 2008; Raijmakers et al., 2012; Schenck et al., 2010), there is a paucity of research identifying specific QIs for home care clients receiving PEoLC (Guthrie et al., 2022).

Although measuring the quality of PEoLC has evolved, it can be helpful to draw upon work done using administrative databases and existing measurement tools. Traditionally, measuring the quality of PEoLC has been accomplished by use of administrative data, for example capturing emergency department visits or the number of days spent in hospital (Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008). Using administrative data to generate QIs can generally be less time-consuming and more economical when compared to using medical records or conducting chart reviews or patient surveys (Earle et al., 2003; Grunfeld et al., 2006). Administrative data also allows for the generation of large amounts of data which can then be applied to different populations and in a variety of settings (Earle et al., 2003; Grunfeld et al., 2006). While some proposed QIs for PEoLC exist in Canada (Barbera et al., 2006; Gagnon et al., 2015; Grunfeld et al., 2006), these QIs rely strictly on hospital administrative data or on data captured in acute care settings. Internationally, PEoLC QI sets do exist (Leemans et al., 2015, 2017); however, there is not a common set being widely used in Canada. The limitations when using administrative data for QIs is that they can often be limited to the structures and processes of care and may miss other important aspects of high-quality PEoLC such as pain and symptom management, advance directives, or communication, which are not typically captured in administrative databases (Earle et al., 2003).

interRAI and New Developments of Palliative Care Quality Indicators

More recently, several QIs for seriously ill home care clients have been proposed by Harman et al. (2019) and Guthrie et al. (2019) using the international Resident Assessment Instrument for Home Care (RAI HC). There is also current work underway to develop a set of new PEoLC QIs for the home and community sector based on existing interRAI home care and PEoLC data (Guthrie et al., 2022; Luymes et al., 2021; Williams et al., 2021). interRAI as an organization has been working to develop, test, and validate QIs dating back to the 1990s and several QIs have been established for the quality of home care (Morris et al., 2013). Both the interRAI HC and international Resident Assessment Instrument for Palliative Care (interRAI PC) are validated clinical assessment instruments that have the potential to generate QIs that can then be used to flag potential quality issues among clients receiving home-based PEoLC (Landi et al., 2000, 2001; Luymes et al., 2021; Morris et al., 2009; Williams et al., 2021).

Progress towards a valid and reliable set of QIs for individuals receiving PEoLC using the interRAI PC instrument began with a multi-stage study that took place from 2017 to 2021. The multi-stage study included a workshop to gain qualitative input from key stakeholders (Williams et al., 2021), qualitative interviews and focus groups with caregivers and Knowledge Users (Luymes et al., 2021) and a modified Delphi panel

(Guthrie et al., 2022). A set of 27 potential QIs were defined using feedback from the workshop, interviews and focus groups, and were later reduced to 22 QIs after further consideration through the Delphi panel (Guthrie et al., 2022). These QIs can be classified under two categories, "follow-up prevalence" QIs and "failure to improve" QIs (Guthrie et al., 2022). Nineteen researchers, clinicians, or decision makers across Canada and internationally (US, Belgium) made up the research team that actively contributed to the development of these QIs. Future work is taking place to test and validate this set of QIs, although the rigorous process of developing and defining these QIs has lent to the clinical importance, validity, and usability of the QIs (Guthrie et al., 2022). With consensus, these newly proposed PC QIs with the interRAI HC and interRAI PC can be embedded into existing systems to support PEoLC providers and policy makers in using real-time data to evaluate patient outcomes (Guthrie et al., 2022).

More broadly, QIs for PEoLC can be generated using different databases, such as interRAI assessment data or administrative data. Administrative data has strengths in measuring data from acute care, but is poor in measuring patient outcomes (Earle et al., 2003; Grunfeld et al., 2006). The strengths of interRAI data are in generating QIs reflecting outcomes of care and aspects of high-quality care valued by home care clients and families that cannot always be captured by administrative data (Harman et al., 2019), but can be limited by the recommended frequency of assessments and the timeframes for QIs (Smith et al., 2010). Depending on the province in Canada, some instruments are mandatory (e.g., interRAI HC in Ontario, Newfoundland and Labrador and Yukon) and others are voluntary (Canadian Institute for Health Information, 2021b). Although measuring the quality of care has evolved, there is a need to build upon this work to monitor and evaluate PEoLC using QIs and against existing frameworks and strategies to improve the quality of care for people receiving palliative and end-of-life home care (Canadian Institute for Health Information, 2018). This study will build upon this work in summarizing current literature around PEoLC QIs and comparing QI rates for home care clients receiving PEoLC prior to and during COVID, thereby supporting decision-making and measures aimed at quality improvement (Guthrie et al., 2022).

Chapter 2: Literature Review

A literature review summarizing the development, measurement, and evaluation of QIs for PEoLC will be presented, followed by a critique of these QIs and synthesis of the proposed QIs for this study. The literature review was conducted to assess existing knowledge of the topic and to describe and summarize QIs pertaining to PEoLC. These QIs could then be used to inform QIs relevant to this retrospective cohort study and able to be operationalized using variables in the dataset used in this study (interRAI PC). The search strategy will first be described, followed by inclusion and exclusion criteria and the conceptual framework that will organize the QIs extracted. A summary of the extracted QIs will be presented along with a brief critical analysis of the existing QIs, including how they are measured and evaluated. Most importantly, this review will highlight the apparent lack of QIs endorsed for home care clients receiving PEoLC as well as the opportunity to borrow well-established QIs from other sectors or patient populations. Finally, the research question and methodology for this study will be described.

Search Strategy

Embase, Medline, PsycInfo, and CINAHL were searched as formal databases using the search terms summarized in Table 1. These databases were searched from 1946 until May 2021.

Table 1

Search terms utilized

1) Quality indicator* OR Quality standard* OR Quality measure*

and

2) Palliative care OR End of life care OR Terminal care OR Terminally ill OR Serious* ill* or Terminal* ill*

not

3) Pediatric* OR Child*

Inclusion/Exclusion Criteria

Articles selected for review needed to first meet the following inclusion criteria: 1) English-language studies; 2) the QIs were applicable to the context of PEoLC as defined in the literature as measurable in the last six months to one year of life (Griebeler Cordeiro et al., 2020); 3) population of adults aged 18 and older; 4) the article described the development process and/or characteristics of QIs developed; and 5) the QI included a numerator(s) and denominator(s), or the numerator(s) and denominator(s) could be deduced directly from the descriptions of the QIs (De Roo et al., 2013). Exclusion criteria included editorials, letters to the editor, comments, and narrative case reports. Publications applying existing QIs to clinical practice or reviewing existing QIs without new developments were excluded. Additionally, articles that included indicator sets or QIs specific to a defined setting and not generalizable to home care, such as intensive care units or inpatient PEoLC units, were excluded.

Results yielded 1641 English studies for review after 1000 duplicates were removed. Of these, 15 independent articles met the inclusion criteria (see below) and were included for final review (Appendix B). A summary table with extracted information relevant to the selected articles can be found in Appendix C. Information such as country, methodology, description of QIs, limitations and strengths of QIs, critical appraisal and population/setting of interest are described in more detail (Appendix C).

Prior to discussion of these specific QIs for PEoLC, an understanding of the development of QIs as well as their role in quality improvement and advancement will be detailed, which will be preceded by an explanation of the conceptual framework guiding QI extraction from the literature review.

Conceptual Framework

It is important to consider an overarching understanding of how quality is defined and the various elements of PEoLC important to the healthcare provider, family or caregiver and recipient of care. Donabedian's conceptual model for quality assessment has been widely accepted as the standard approach in assessing the quality of healthcare services and improvements to them (Donabedian, 1966, 2005). This model is divided into the three categories of structure, process, and outcome, where it is understood that improvements in structure can lead to improvements in the processes of care, which can eventually be seen as improved client outcomes (Donabedian, 1966, 2005). Structural measures assess healthcare provider's capacity and the systems to provide high-quality care (e.g., staffing, certification/training, equipment), process measures reflect what services are being delivered to maintain or improve health (e.g., diagnostics, treatments, best practice guidelines) and outcome measures consider the impact of an intervention or service on the individual (e.g., re-hospitalizations, complications, mortality) (Agency for Healthcare Research and Quality, 2015). The National Consensus Project (NCP) further expands on this model, focuses on PEoLC, and includes the following eight key domains: structure and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious, and existential aspects of care;

cultural aspects of care; care of the imminently dying; and ethical and legal aspects of care (Ferrell et al., 2018). These NCP domains overlap, though not exclusively, with Donabedian's model, where the NCP framework contains a distinct domain for structure and processes of care and the other NCP domains are focused on specific structure, processes, and outcomes of care (Ferrell et al., 2018). The NCP framework will be applied in this study to summarize and describe the QIs extracted from the literature review as the framework relates directly to PEoLC (Ferrell et al., 2018).

Overview of Quality Indicators for Palliative and End-of-Life Care

As part of the literature review, 15 key published articles explain and propose 372 QIs for PEoLC which will be described in greater detail (Barbera et al., 2015a, 2015a; Claessen et al., 2011; De Schreye et al., 2017; Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008; Harman et al., 2019; Henson et al., 2020; Johnston & Burge, 2002; Leemans et al., 2015; Miyashita et al., 2008; Peruselli et al., 1997; Raijmakers et al., 2012; Schenck et al., 2010). These QIs ranged in the associated purpose and stage of development, the target populations, the associated database they were developed from, and what types of domains and aspects of quality they are associated with. For example, the purposes for QI development ranged from informing policy and programs (Johnston & Burge, 2002), examining regional variation in the quality of EOL care (Barbera et al., 2015a, 2015b), enhancing standardized evaluation of care and services (Leemans et al., 2015), and measuring inappropriate and appropriate healthcare use (De Schreye et al., 2017). While some QIs have been rigorously tested and developed with a broad range of input from clients, caregivers, and experts (Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008;

Leemans et al., 2015), others are in their earlier stages of development and require additional validity, reliability, or feasibility testing (De Schreye et al., 2017; Harman et al., 2019; Raijmakers et al., 2012).

The majority of QIs were developed and applied to individuals with cancer (Barbera et al., 2015a; Earle et al., 2003; Grunfeld et al., 2006, 2008; Raijmakers et al., 2012), though several articles included individuals with any illness (Harman et al., 2019; Johnston & Burge, 2002; Leemans et al., 2015; Schenck et al., 2010). It is important to note that only two articles exclusively reported on QIs developed for home care clients (Harman et al., 2019; Peruselli et al., 1997). However, the findings from this literature review are still appropriate and relevant to palliative and end-of-life home care as the QIs broadly capture domains of care applicable to anyone receiving PEoLC regardless of the setting. It is also of note that some QIs were identified and reported on in several articles for specific populations, such as cancer decedents or for a particular geographic region (Barbera et al., 2015a, 2015a; Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008). A summary table further organizes the extracted QIs according to the most appropriate domain using the NCP framework as well as further subdomains (Appendix D). Therefore, these extracted QIs from the literature review will be described to demonstrate the diversity in how quality can be assessed in the context of PEoLC.

In the fifteen studies, 372 QIs were identified and described, though significant overlap and duplication exists. There is also much disagreement and debate as to the quality construct used to define the QI and how generalizable they may be based on their intended purpose. These QIs were commonly mapped against Donabedian's model of quality (1966) and the NCP's (2004) quality PEoLC domains. While some QIs distinctly fit into one of the NCP's domains, there was variation in the literature as some QIs were overlapping and found to satisfy more than one domain, though all belonged to at least one domain and as such will be described below (De Roo et al., 2013; Ferrell et al., 2018). Notably, there is an overall cited lack of QIs around spiritual and cultural aspects of care (Claessen et al., 2011; Leemans et al., 2015; Miyashita et al., 2008) (n=10) and satisfaction with healthcare (Peruselli et al., 1997) (n=1), especially in contrast to the number of QIs around physical aspects of care (n=124) or structure and processes of care (n=105) (De Roo et al., 2013; Henson et al., 2020; Pasman et al., 2009) as a result of many of the QIs being derived from administrative data. QIs from this literature review will be described in detail, followed by a critical analysis of their associated strengths and limitations.

Structure and Processes of Care

Healthcare service use and healthcare professional involvement.

The majority of QIs identified across studies involved measuring and evaluating service use and healthcare professional involvement. Healthcare professional involvement included the frequency of different types of healthcare professionals delivering PEoLC services and were further specified by the format of these interactions. These QIs could be defined as either a poor or good indicator of quality PEoLC depending on the QI. For example, in terms of poor quality of PEoLC, QIs were described by emergency department visits (Barbera et al., 2015a, 2015b; De Schreye et al., 2017; Earle et al., 2003; Grunfeld et al., 2006, 2008), intensive care unit admissions (Barbera et al., 2015a, 2015b; De Schreye et al., 2017; Earle et al., 2003; Grunfeld et al., 2006, 2008) and hospital admissions (De Schreye et al., 2017; Earle et al., 2003; Grunfeld et al., 2006, 2008) towards the EOL. Other QIs included a low proportion of hospice referrals and referral to hospice in the last few days of life (Earle et al., 2003). Alternatively, QIs that were representative of good quality PEoLC included home care visits before death (Barbera et al., 2015a, 2015b; Peruselli et al., 1997; Raijmakers et al., 2012), multidisciplinary medical consults (De Schreye et al., 2017; Leemans et al., 2015), communication from healthcare professional with patient and/or family (Peruselli et al., 1997; Raijmakers et al., 2012) and physician home visits or house calls (Barbera et al., 2015a, 2015b; Grunfeld et al., 2006, 2008; Leemans et al., 2015; Peruselli et al., 1997). Home visits were further defined by the type of healthcare professional, such as nurses, PSWs and physicians (Barbera et al., 2015a, 2015b). These QIs often reflected the process domain and were thus classified under the NCP's structure and processes of care domain.

Medications.

QIs about medications described and measured medication use and were defined as either inappropriate or appropriate care. For example, QIs for inappropriate medication use included initiation of a new anti-depressant (De Schreye et al., 2017), use of statins (De Schreye et al., 2017), anti-hypertensives (De Schreye et al., 2017), calcium or vitamin D (De Schreye et al., 2017), oral anticoagulants (De Schreye et al., 2017), and receiving medications not wanted (Leemans et al., 2015). QIs for appropriate medication use were described as having a prescription for pain (De Schreye et al., 2017; Miyashita et al., 2008) or dyspnea medications (Miyashita et al., 2008), opioid use (De Schreye et al., 2017; Schenck et al., 2010), neuropathic medications when receiving morphine (De Schreye et al., 2017) and receiving anti-emetics during chemotherapy (De Schreye et al., 2017). These QIs were often reflective of a specific population or cohort in which medication use would be expected or initiated, influencing the appropriateness or inappropriateness of the medication described. For example, receiving anti-emetics during chemotherapy was applied to the population of cancer decedents who had received chemotherapy and the numerator and denominator were reflective of this.

Treatments and investigations.

Treatments or investigations were described through many QIs as potential indicators of poor quality of PEoLC. QIs were identified as the interval between last chemotherapy and death (Grunfeld et al., 2006), chemotherapy use (Barbera et al., 2015a, 2015b; De Schreye et al., 2017; Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008; Leemans et al., 2015; Raijmakers et al., 2012), radiation therapies (Grunfeld et al., 2008; Schenck et al., 2010), artificial fluids and/or nutrition (Leemans et al., 2015), blood transfusions (De Schreye et al., 2017), receiving intravenous or feeding tubes (De Schreye et al., 2017), diagnostic testing (De Schreye et al., 2017), and surgery (De Schreye et al., 2017). These therapies were often described in the context of cancer care at EOL, but several were also defined for other life-limiting illnesses, such as Alzheimer's disease or chronic obstructive pulmonary disease (De Schreye et al., 2017). In the context of PEoLC, these QIs were considered a potential marker of poorer quality of care relating to structure and processes of care.

Physical aspects of care.

Several QIs presented were defined around common symptoms for those receiving PEoLC and included measures around disruptive or severe pain (Claessen et al., 2011; Harman et al., 2019; Miyashita et al., 2008; Schenck et al., 2010), having a pain assessment (Leemans et al., 2015; Miyashita et al., 2008), inadequate medication to control pain (Harman et al., 2019; Raijmakers et al., 2012), shortness of breath (Miyashita et al., 2008; Schenck et al., 2010), constipation (De Roo et al., 2013; Harman et al., 2019; Peruselli et al., 1997; Raijmakers et al., 2012), and fatigue (Claessen et al., 2011; Peruselli et al., 1997). Uncontrolled or poorly managed symptoms were potential flags of poorer quality of PEoLC and these QIs were described as indicators relating to physical aspects of care.

Psychological and Psychiatric Aspects of Care

A limited number of QIs described the outcomes of psychological and psychiatric aspects of care. These QIs were related to anxiety or depression and included the prevalence of negative mood (Harman et al., 2019), depression (Claessen et al., 2011), patients screening positive for depression with follow-up (Schenck et al., 2010), anxiety (Claessen et al., 2011; Miyashita et al., 2008), and assessment of anxiety (Leemans et al., 2015). Other related QIs included the extent of support when feeling anxious or depressed (Claessen et al., 2011) and feeling that life is worthwhile (Claessen et al., 2011). Several QIs related to the presence of delirium or agitation (Leemans et al., 2015; Miyashita et al., 2008) or treatment of delirium (Leemans et al., 2015). A subcategory of QIs focused on the caregiver or family's psychological well-being and included support with preparations for saying goodbye (Claessen et al., 2011), acceptance of patient nearing death (Claessen et al., 2011), having a peaceful death reported (Claessen et al., 2011) and caregiver distress or anxiety (Harman et al., 2019; Peruselli et al., 1997).

Social Aspects of Care

Social aspects of care reflect the environment and social factors that affect the patients' and families' function and quality of life (Ferrell et al., 2018). Assessment and ongoing care for the family was reflected by QIs around family's preference of care (Miyashita et al., 2008), family's insight of disease (Miyashita et al., 2008; Peruselli et al., 1997), family's expectations and preferences (Miyashita et al., 2008; Schenck et al., 2010), and discussion with family around goals of care (Miyashita et al., 2008). Screening and assessment of the patient and/or family and their quality of life and well-being included a QI around the prevalence of social isolation or interaction (Harman et al., 2019; Peruselli et al., 1997). Communication through the form of conversations around goals of care (Leemans et al., 2015; Miyashita et al., 2008), insight of disease (Miyashita et al., 2008), medical condition or diagnosis/prognosis (Claessen et al., 2011; Leemans et al., 2015; Miyashita et al., 2008) and patient's preferences or expectations (Claessen et al., 2011; Miyashita et al., 2008) were also reflected by these QIs.

Spiritual, Religious, and Existential Aspects of Care

The domain of spiritual, religious, and existential aspects of care was under-represented with a limited number of QIs identified and described (De Roo et al., 2013). These included having a priest or spiritual counsellor available (Claessen et al., 2011; Leemans et al., 2015), documentation of spiritual discussion (Miyashita et al., 2008), respect for spiritual well-being (Claessen et al., 2011), regularly talking about spirituality and religion in an understanding way (Leemans et al., 2015), respect for philosophy of life (Leemans et al., 2015), documentation of patient's religion (Miyashita et al., 2008), and spiritual well-being (Leemans et al., 2015).

Cultural Aspects of Care

There was only one QI identified for cultural aspects of care. This QI was defined as the provision of interpreters or translators for non-English–speaking individuals or those with hearing loss (Schenck et al., 2010). The domain related to cultural aspects of care is defined as incorporating cultural assessments and tailoring care to the patient's and family's culture, including language, beliefs and values, and rituals (De Roo et al., 2013). While there may be some overlap with the QIs previously identified under spiritual, religious and existential and social aspects of care as these domains share aspects of culture, these QIs were not distinctly defined under cultural aspects of care. This domain remains an area for future development and generation of more QIs.

Care of the Patient Nearing the End of Life

The domain of caring for the patient nearing EOL includes "recognizing and documenting the transition to the active dying phase; ascertaining and documenting patient/family wishes about the place of death; [and] implementing a bereavement care plan" (De Roo et al., 2013, p. 559). Few QIs were indicative of this domain and overlap with other domains existed. For example, overlap with structure and processes of care was found with QIs around documenting patient's and family's preference of place of care (Miyashita et al., 2008), death in the location of preference (Claessen et al., 2011) and receiving a home visit on the day of the patient's death (Peruselli et al., 1997). These QIs were more often defined under the structure and processes of care domain, although there was variation in the literature (De Roo et al., 2013; Ferrell et al., 2018). An overlap was found with the domain related to physical aspects of care with a QI defined as moderate to severe pain in the last week of life (Schenck et al., 2010). Four distinct QIs were representative of care of the patient nearing the EOL, including explanation of impending death (Miyashita et al., 2008; Schenck et al., 2010), caregiver support after the patient's death, caregiver being informed about aftercare and a final conversation to evaluate care and treatment (Claessen et al., 2011).

Place of care/death.

One common QI across numerous studies was place of death. Place of death was described in several ways, such as deaths in hospital (Barbera et al., 2015a, 2015b; De Schreye et al., 2017; Earle et al., 2003), site of death (Grunfeld et al., 2006) and deaths at home (De Schreye et al., 2017; Johnston & Burge, 2002; Peruselli et al., 1997). Other related QIs included patient's preference of place of care (Miyashita et al., 2008) or death in the location of preference (Claessen et al., 2011), which overlapped with care of the patient nearing EOL. Place of death was commonly related to care of the patient nearing the EOL.

Ethical and Legal Aspects of Care

There were several QIs under ethical and legal aspects of care that focused on either ethical principles or advanced care planning. QIs that reflected ethical principles included respect for autonomy (Claessen et al., 2011) and respect for privacy (Claessen et al., 2011; Leemans et al., 2015). An example of a QI representing poor ethical behaviour was defined as receiving treatments against the patient's wishes (Leemans et al., 2015). For advanced care planning, these QIs included documentation of an advanced directive or discussion of an advanced directive (Grunfeld et al., 2008; Schenck et al., 2010), documentation concerning the desired care and treatment at EOL (Claessen et al., 2011; Schenck et al., 2010), percentage of those with a do-not-resuscitate code known to the caregiver (Leemans et al., 2015; Miyashita et al., 2008) and documentation of a substitute decision-maker (Miyashita et al., 2008; Schenck et al., 2010).

Limitations of Evaluating and Measuring Quality Indicators for Palliative and End-of-Life Care

In order for quality structure, processes, and outcomes to be achieved within the home care context, there needs to be standardized QIs and strategies for measuring and monitoring PEoLC at the local, provincial, and national levels (Canadian Society of Palliative Care Physicians, 2016). Several key research reports have brought to light the need to identify QIs of home-based PEoLC, especially to standardize QIs and report on them consistently (Canadian Society of Palliative Care Physicians, 2016; Health Quality Ontario, 2016, 2019). The main concern is that currently there is no standard set of QIs for home care clients receiving PEoLC and these are needed before there can be progress in the measurement and evaluation of the quality of home-based care (Harman et al., 2019). There are established QIs for PEoLC which can be applied to home care, such as examining place of death, acute care use and aggressive treatment at EOL which signal gaps in PEoLC and suboptimal quality of care; however, measuring and accessing these and other data are challenging (Canadian Cancer Society, 2016). For example, in accessing some databases measurement limitations exist in the inability to distinguish whether an emergency department visit was planned or unplanned or in capturing patient preferences for care. Another major limitation in the literature is that most of the work on QIs has focused on individuals with cancer (Barbera et al., 2006, 2015a, 2015b; Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008; Henson et al., 2020; Miyashita et al., 2008), limiting the extension of existing QIs to individuals with other serious and life-limiting illnesses.

Based on this literature review and similar literature reviews, there are evident gaps in identifiable and measurable QIs around spiritual, religious, and existential aspects of care (n=10), cultural aspects of care (n=1), ethical and legal aspects of care (n=17) and care of the patient nearing EOL (n=5) (Claessen et al., 2011; De Roo et al., 2013; Henson et al., 2020; Leemans et al., 2015; Miyashita et al., 2008; Pasman et al., 2009; Schenck et al., 2010). Despite these limitations, there is a substantial base of evidence in the literature around validated QIs that have been used for close to two decades (Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008). Organizations such as Health Quality Ontario (2016) and the Canadian Cancer Society (2016), among others, have endorsed the use of administrative data to examine service use such as home care visits, acute care use, and location of death. A main limitation to these QIs is that they are restricted to the structure and processes domains and lack outcomes pertaining to the care recipient. Emerging literature supporting newly proposed QIs for home care clients addresses this limitation by proposing QIs that reflect the physical, psychological, and social domains (Harman et al., 2019) and there are promising developments with a preliminary set of QIs rigorously evaluated by a modified Delphi panel (Guthrie et al., 2022), though these QIs rely on data from non-administrative sources (e.g., interRAI).

Problem Statement

Home care has long been identified as a priority and has the potential for the delivery of a broad range of high-quality PEoLC services with adequate funding, staffing and continuous quality improvement support (Ganann et al., 2019). By strengthening this sector there is opportunity to support home care clients receiving PEoLC to achieve the best care until death through the delivery of high-quality PEoLC (Ganann et al., 2019). The COVID-19 pandemic and consequent disruption of home care services may have impacted the provision of PEoLC and thus the quality of care and related patient outcomes. Exploring this impact from a quantitative perspective will supplement published qualitative research (Health Canada et al., 2021) and is important in order to inform on-going quality assessments and continuous quality improvement in this sector. Therefore, there is a need to examine and evaluate the quality of PEoLC received by home care clients before and during the COVID-19 pandemic using existing QIs. The **purpose of this study** was to compare QI rates for home care clients designated to receiving PEoLC prior to and after the onset of the COVID-19 pandemic. Specifically, this study addresses the following research question: What are the differences in PEoLC quality indicator rates among home care clients aged 18 years and older receiving palliative and end-of-life home care services before and during the COVID-19 pandemic?

Chapter 3: Methods

Study Design

A retrospective population-based cohort design (Barrett & Noble, 2019; Earle & Ayanian, 2006) was used to compare QI rates generated from interRAI PC assessment data for home care clients designated to receiving PEoLC in Ontario, Canada prior to and during the COVID-19 pandemic (see Appendix E for more details). Retrospective analysis is an efficient and time-effective approach for monitoring and evaluating PEoLC, particularly over time periods and to compare across jurisdictions and demographic groups (Earle & Ayanian, 2006). Further, using a retrospective design is optimal when examining care shortly before death (Earle & Ayanian, 2006) and has been frequently used to monitor and evaluate QI rates for PEoLC (Barbera et al., 2015a; Grunfeld et al., 2006; Soares et al., 2020; Sudat et al., 2018).

Context

The scope of this research study was to focus specifically on those who received an interRAI PC assessment in Ontario, Canada and who are receiving palliative and end-of-life home care services. Ontario represents a region made up of 42 Ontario Health Teams within six Ontario Health Regions (Ontario Ministry of Health and Long-Term Care, 2021). These Ontario Health Regions were previously distinguished as fourteen Local Health Integrated Networks which through a new governance process have been in transition to a more integrated and patient-centred model with the newly proposed Ontario Health Regions and Teams (Government of Ontario, 2021b). The home care setting provides a unique context for PEoLC to be provided as it occurs in one's home, often with limited resources, and primarily by informal caregivers (Field et al., 1997). The COVID-19 pandemic also provides an opportunity in which to analyze the difference in QI rates because the pandemic has disrupted many aspects of the healthcare system and how home care has been delivered (Arya et al., 2020; Ritchey et al., 2020).

Roughly 470,000 individuals receive publicly-funded home care in Ontario each year (Canadian Institute for Health Information, 2021b). In order to receive publicly-funded home care services, a self- or provider-initiated referral is made in which eligibility is determined by a case manager as to who receives care, for how long, and the level of care required (Government of Ontario, 2021a). Eligibility for PEoLC services is often determined by estimated prognosis and the presence of a life-limiting illnesses (Home Care Ontario, 2015). Service provider agencies deliver home care services in Ontario, which are overseen by the newly initiated Ontario Health Teams. Palliative and end-of-life home care often includes increased hours of service, after-hours service, and access to care by palliative designated-nursing or specialized PEoLC clinicians (Health Quality Ontario, 2019).

Study Cohort

This study involved the comparison of two groups of home care clients aged 18 years and older receiving palliative and end-of-life home care in Ontario, Canada. The first group (pre-COVID) was home care clients with an interRAI PC assessment, which was not an admission assessment, between January 1st 2019 to March 16th 2020, and the second group (COVID) were similarly assessed between March 17th 2020 to May 18th 2021. The two cohorts were further restricted to follow-up assessments as admission assessments likely do not reflect the quality of care during the time of the assessment (Guthrie et al., 2022). Where duplicates (individuals in both cohorts) existed, those in the COVID cohort were retained because there were fewer assessments in this time frame. In cases where multiple non-admission assessments were available for an individual, the most recent assessment was kept.

Cohort Periods

The COVID-19 pandemic was announced as a state of emergency by the Ontario provincial government on March 17th, 2020 (Rodrigues, 2020). The time periods for each cohort were selected based on when COVID was initially declared a pandemic in Ontario and for the duration of time data were available for this study. interRAI PC data were available until May 18th, 2021 and so a timeframe of 60 weeks was available and applied to the COVID cohort. The same timeframe was applied to the pre-COVID cohort.

Quality Indicators

The 372 QIs identified from the literature review were pared down by first removing QIs that were disease specific (n=93), QIs that were already defined by the cohort of interest (n=15), QIs not measurable or conceptually defined in the interRAI PC tool (n=163), and QIs with overlapping constructs (n=45). QIs that described a change or failure to improve, such as related to a particular symptom (n=42), were not included due to sample size considerations and discretionary completion. For example, a QI for worsening or improvement of pain or worsening or improvement of shortness of breath would be restricted to individuals within the cohort that experiences these changes. In addition to the QIs excluded, one additional QI, the prevalence of sleep problems, was added to the final set of QIs based on a study not yet published during the time of the literature review (Guthrie et al., 2022). QIs that were disease-specific were removed because the cohort of interest is any home care client receiving PEoLC, thereby not limiting the sample to those with only cancer or another life-limiting illness. See Appendix F for a detailed flow chart outlining the steps taken to arrive at the final QIs that were used for this study and Appendix G to see the QIs mapped to the individual studies.

While there were various ways to define the QIs in terms of their numerators and denominators and given the significant overlap of constructs for these QIs, the final definitions (i.e., the numerator and denominator) were selected using available interRAI PC data elements and in reference to a recent published study of validated QIs based on an ongoing multi-stage study (Guthrie et al., 2022) (Appendix H). This final set included 16 QIs for home care clients aged 18 years and older receiving PEoLC, and is further described in Appendix H. These QIs are summarized in previous reports and journal articles and represent input from experts, caregivers, family members, policy makers, and clients. Several of these QIs have also been endorsed by Health Quality Ontario as indicators of quality PEoLC, such as emergency department visits and hospital admissions (Health Quality Ontario, 2016, 2019). These QIs formed the basis for evaluating the quality of PEoLC for home care clients and met the criteria of being measurable, reflecting broadly the domains of the NCP framework (Ferrell et al., 2018), and in use to some extent in quality improvement and research initiatives. The QIs were all proportions and are listed as follows: the prevalence of hospitalizations in the last 90 days of life, the prevalence of emergency department visits in the last 90 days of life, prevalence of falls, prevalence of disruptive or intense daily pain, prevalence of severe or excruciating pain that is inadequately controlled by medication, prevalence of constipation, prevalence of shortness of breath at rest, prevalence of shortness of breath upon exertion, prevalence of caregiver distress, prevalence of negative mood, prevalence of no advance directive, prevalence of stasis/pressure ulcers, prevalence of a delirium-like syndrome, prevalence of nausea or vomiting, prevalence of fatigue, and prevalence of sleep problems.

Data Sources

The interRAI PC is a standardized clinical assessment instrument used to inform care planning and is designed for adults aged 18 and older with EOL needs (Smith et al., 2010). It was developed by a multinational research consortium as part of a suite of interRAI instruments and while it is not mandated for use in Ontario, it is frequently used for those receiving PEoLC (Wagner et al., 2020). While the interRAI HC was another dataset that could have been used and includes those who may be receiving PC, it requires an algorithm to designate them under PEoLC (Harman et al., 2019), which introduces additional uncertainty. The advantages of using assessment data from the interRAI PC database are that to receive an interRAI PC assessment, home care clients must be receiving PEoLC, which is directed to two groups of persons: those with a terminal illness and those without a terminal illness but with symptoms that limit their functional capacity and impair well-being (Smith et al., 2010). In a recent cross-sectional analysis of interRAI PC assessment data, some key distinctions of this home care population were that 64.1% had a prognosis of less than six months versus 35.9% with a prognosis of greater than six months, and cancer was identified as the most prevalent diagnosis at 83.2% (Williams et al., 2021).

The interRAI PC instrument has established validity and reliability for its measures, with at least 50 percent of the questions having a kappa score of 0.8 or higher and an average kappa ranging from 0.76 to 0.95 for each of the eight domains (Steel et al., 2003). Information is collected through a semi-structured interview process about clients' strengths, needs, and preferences to primarily guide care planning and service delivery. Data from the assessments are also used to generate health index scales (clinical and functional status), and measures of functional and cognitive performance and mental health (Canadian Hospice Palliative Care Association, 2013). interRAI PC assessments are completed by trained professionals (usually a registered nurse) using a software application and these electronic assessments are shared with the relevant agency providers as part of the home care health record (Cook et al., 2013). Data are self-reported by home care clients and/or their caregiver along with trained professionals who conduct the assessment and verify the data. The data are anonymized by Ontario Health Shared Services, and then stored at the University of Waterloo on a secure server for use by interRAI Canada Fellows and their students for research and quality improvement purposes. The availability of the data is important in evaluating the progress, quality, and outcomes of PEoLC (Canadian Institute for Health Information, 2018).

Statistical Analyses

All statistical analyses were completed on a remote secure server set up through the University of Waterloo. Statistical analyses included descriptive statistics, where means and standard deviation (SD) values for continuous variables and percentages for categories were reported for baseline characteristics. Prior to examining differences in QI rates, propensity score matching was used to create matched cohorts based on demographic variables and other key covariates (Austin, 2008). Following propensity score matching, the differences in QI rates between cohorts were analyzed using a chi-squared test (=z test of 2 proportions) and additional measures such as odds ratio and effect size. Odds ratios (ORs) and effect sizes were generated to help in judging the clinical significance of group differences, as these measures are not driven by sample size (Sullivan & Feinn, 2012). Where statistical significance indicates the probability that the results are due to chance, clinical significance indicates whether the results obtained are clinically meaningful. The question of clinical significance is only asked when statistical significance exists. All statistical analyses were completed using R Version 4.1.2. A two-tailed alpha level of 0.05 was used to identify statistically-significant differences.

The two cohorts were matched on the following covariates: sex, age, Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) score (Hirdes et al., 2003), marital status, Local Health Integrated Network (LHIN) identifier, living arrangement, time since last hospital stay, number of days and total minutes in last week of formal care (e.g., home health aides, home nurse), individual instrumental activities of daily living (e.g., meal preparation, ordinary housework, managing medications) and individual activities of daily living (e.g., bathing, personal hygiene, walking, locomotion, transfer toilet, toilet use, and eating) (Appendix I). These covariates were identified based on current literature, the availability of interRAI data elements and consensus among the supervisory committee. Where several options for a similar construct were available, only one was kept. For example, there were several measures for health instability (e.g., CHESS score, chronic conditions count), and CHESS score was kept because it is a strong predictor of mortality in persons receiving health care in the community and can be reliably generated from interRAI items (Hirdes et al., 2003, 2014).

As part of the statistical analysis, propensity score matching was used to reduce the effect of confounding variables between the two cohorts, thereby creating a more equivalent comparison cohort (Austin, 2008). To assess how well matching worked, a threshold of 0.1 of the standardized mean difference, that measures the difference in each covariate, was used (Stuart et al., 2013). Nearest neighbour matching (NNM) was chosen as the primary propensity score method and a sensitivity analysis was used to explore weighted and overlap weighted propensity score methods, all of which met the 0.1 threshold.

NNM is the most common form of matching used in propensity score analysis (Austin et al., 2021). It is a matching method based on a distance measure and can employ a caliper. A caliper "can be thought of as a ring around each unit that limits to which other units that unit can be paired" (Greifer, 2022, pg. 11). The method involves random selection of a treatment unit (COVID assessment) which is then matched to a control unit (pre-COVID assessment) that falls within the caliper and the process stops when all treatment units are matched. If a treatment unit is not matched, it is dropped.

The distance (caliper) was set to 0.2 for this study, which has been shown in prior research to be suitable for a variety of settings and regarded as optimal, thus it was used for this study (Austin, 2011). The effect of using a larger caliper, or not using a caliper at all, would be to increase the sample size, but this typically results in poorer covariate balance. Matching without replacement (also called 1:1 matching) was another methodological decision made where each control unit is only matched to one treatment unit (Austin & Cafri, 2020).

In terms of the additional propensity score methods, weights are employed to reflect the importance assigned to propensity scores and covariate balance during matching. The aim is to use more of the sample using multiple controls per treatment unit and weighted composites of controls, unlike NNM which uses paired-matching. Matching weight and overlapping weight were the two weighted methods used. The matching weight method was proposed by Li and Greene (2013) and is comparable to one to one pair matching without replacing; however, instead of discarding unmatched treatment units, no unit is ever rejected entirely but instead is down-weighted so that multiple controls can be matched with the weight distributed among these units where a fraction of the unit is contributing. As units are weighted so that they contribute less to the sample than with unweighted units, the effective sample size may be lower than with paired matched (Griefer, 2022). The overlapping weight method proposed by Li et al. (2018) is another weighting method that matches on propensity score as well as the covariates. The method works similarly to the matching weight method, but the weights are based on both the propensity score and covariates which results in the exact balance on the means of all the covariates included. As a result, units are automatically down weighted with extreme propensity scores. As there are additional constraints in the overlap weights method, such as including covariates and propensity score in the matching process, a smaller sample size can be expected. The best practice for selecting propensity score methods is to try multiple methods and explore all those that meet the pre-established criteria for acceptability, as there is no universally-superior method (Garrido et al., 2014; Griefer, 2022). In this study, the pre-established criteria for acceptability were adequate covariate balance (below the 0.1 threshold noted above) and sample size sufficiency. If the methods met these two criteria, they were considered equally valid for use in the analysis, (Griefer, 2022).

Ethics

The study protocol was approved by the Research and Ethics Committees of the following Research Ethics Boards: Hamilton Integrated Research Ethics Board (HiREB), #13960 (Appendix J) and Wilfrid Laurier University's Research Ethics Board, #6003004 (Appendix K).

Chapter 4: Results

Cohorts

In the pre-COVID cohort (January 14th, 2019 to March 16th, 2020), 27,625 assessments were completed and in the COVID cohort (March 17th, 2020 to May 18th, 2021), 13,320 assessments. In creating the cohorts, records were assigned to the two timeframes defined by the time periods of interest (pre-COVID and COVID) as well as by a process of eliminating duplicate assessments for the same individual and across time periods as previously described. Records were then sorted in ascending order and where multiple assessments existed for the same client identifier in each cohort, only the most recent assessment was kept. From the pre-COVID cohort, 3,480 duplicate client identifier assessments were removed and 3,074 from the COVID cohort, leaving 24,145 unique assessments in the pre-COVID cohort and 10,246 records in the COVID cohort.

The majority of assessments completed during the pre-COVID cohort were admission (first) assessments (58.5%), followed by routine reassessments (36.1%), return assessments (2.8%) and significant change assessments (2.7%). A similar pattern was noted in the COVID cohort, with first assessments (68.3%) making up the majority, followed by routine reassessments (27.3%), return assessments (1.8%) and significant change assessments (2.7%). A table outlining the pattern of these assessments as well as a breakdown of how many repeated assessments were completed for home care clients for each cohort can be seen in Appendix L.

Next, only assessment types that were routine reassessments, return reassessments and significant change in status reassessments were kept. The final pre-COVID and

COVID cohorts included 6,346 unique assessments and 3,231 unique assessments respectively, meeting the criteria listed above to be included in the final cohorts. For the pre-COVID cohort, the breakdown of records were 83.8% (n=5321) routine reassessments, 7.3% (n=466) return assessments, and 8.8% (n=559) significant change in status reassessments. For the COVID cohort, the breakdown of records were 83.8% (n=2709) routine reassessments, 6.2% (n=201) return assessments, and 9.9% (n=321) significant change in status reassessments. For a more detailed breakdown of records kept and discarded at each step, see Appendix M and N.

Table 2

Breakdown of type of assessment for pre-COVID and COVID final cohorts

Cohort	**Type of Assessment**			
	Routine Reassessment (A2)	**Return Assessment (A3)**	**Significant change (A4)**	**Total**
pre-COVID	5321	466	559	6346
COVID	2709	201	321	3231

Missing data

In the process of creating matched cohorts, a small number of assessments were eliminated due to missing covariate data. Any observations with missing data on the covariates were excluded prior to propensity score analysis which included 214 records from the pre-COVID cohort and 159 records from the COVID cohort. Missing data was linked to the following covariates: CHESS score (n=214 pre-COVID, n=159 COVID), meal preparation (n=208 pre-COVID, n=156 COVID), ordinary housework (n=208 pre-COVID, n=156 COVID) and managing medications (n=208 pre-COVID, n=156

COVID). There was no pattern as to the missing data being related to a particular home care jurisdiction, type of PEoLC program or reason for assessment. Multiple imputation was not attempted as the number of observations were too small to meet the threshold commonly cited in literature (<5%) (Schafer, 1999).

When calculating the outcomes (QI rates), missing data were only encountered for the pain measure used to calculate prevalence of severe or excruciating daily pain (n=6) and prevalence of severe or excruciating pain that is not controlled by therapeutic regimen in the pre-COVID cohort (n=6) after matching the cohorts using NNM.

Propensity Score Analysis

Propensity score analysis was then used to match the cohorts on 21 covariates (Appendix O). Firstly, the propensity scores were created and the following covariates had SMDs greater than the threshold (0.10): home care jurisdiction (SMD=1.403), living arrangement (SMD=0.101), time since last hospital stay (SMD=0.132), IADLs – meal preparation (SMD=0.123), ordinary housework (SMD=0.110), managing mediations (SMD=0.107), and ADLs – bathing (SMD=0.130), personal hygiene (SMD=0.151), walking (SMD=0.149), locomotion (SMD=0.151), transfer toilet (SMD=0.161), toilet use (SMD=0.163), and eating (SMD=0.107). As these covariates had SMDs greater than the threshold, there was the need to match on the basis of the propensity score using different propensity score methods (e.g., matching, weighting).

After running the propensity score analysis, all three propensity score analysis methods (NNM, weights and overlapping weights) produced acceptable SMDs (<0.1) for each of the covariates (Appendix P-R). With the NNM method, SMDs ranged from 0.002

to 0.062 with the cohort size as 2,479 for both pre-COVID and COVID cohorts. The SMDs for the two other propensity score methods were even smaller than with the NNM methods. For the weighted propensity score method, the SMDs ranged from <0.001 to 0.018, and the sample sizes were 2,389.9 (pre-COVID) and 2,383.2 (COVID). Finally, for the overlapping weights propensity score method, the SMDs ranged from <0.001 to 0.017 and the cohort sizes were 1,453.1. For the subsequent analysis, it was decided to use the NNM propensity score method as the primary approach for the results as it retained the largest sample size, and the other two propensity score methods were explored in a sensitivity analysis.

Once the final matched cohorts were created using propensity score analysis, the final step was to calculate the rates of the 16 QIs and compare these between pre-COVID and COVID cohorts using several statistical tests of difference. Each QI was defined as a dichotomous variable (i.e., those in the cohort that met the condition that the QI was capturing among those who were eligible to trigger on the QI). For example, all of those with shortness of breath at rest were coded as a 1, meeting the criteria for the QI, and those without shortness of breath at rest (absent at rest, present with moderate activities, or present with normal day-to-day activities) were coded as a 0. The sum of those with a 1 for shortness of breath was used as the numerator in the QI, and the denominator was all those assessed. QI rates were then compared between the propensity score matched pre-COVID and COVID cohort. See Table 3 for the rates calculated for each QI as well as the tests for statistical analysis of difference.

Table 3

QI Statistical Results – NNM Method

QI#	QI Description	Pre-COVID Cohort (%) N=2479	COVID Cohort (%) N=2479	Statistical Analysis of Difference				
				X^2 (z)[a]	QI Diff (95% CI)[b]	X^2 (z) p-value[b]	OR (p-value) (95%CI)[c]	Effect Size[d]
QI 1	Prevalence of severe or excruciating daily pain	16.70	14.40	4.98 (2.23)	-0.02 (-0.005, -0.08)	**0.03**	0.86 (0.03) (0.76, 0.98)	-0.08
QI 2	Prevalence of severe or excruciating pain that is not controlled by therapeutic regimen	6.75	5.81	1.87 (1.37)	-0.009 (-0.10, 0.02)	0.17	0.86 (0.17) (0.69, 1.07)	-0.08
QI 3	Prevalence of emergency department visits	20.40	18.26	3.51 (1.87)	-0.02 (-0.07, 0.002)	0.06	0.90 (0.06) (0.80, 1.01)	-0.06
QI 4	Prevalence of hospital admissions	24.89	22.71	3.23 (1.80)	-0.02 (-0.06, 0.003)	0.07	0.91 (0.07) (0.83, 1.01)	-0.05
QI 5	Prevalence of falls	24.06	23.00	0.73 (0.85)	-0.01 (-0.05, 0.02)	0.39	0.96 (0.39) (0.86, 1.06)	-0.02
QI 6	Prevalence of constipation	18.15	16.42	2.61 (1.62)	-0.02 (-0.07, 0.007)	0.11	0.90 (0.11) (0.80, 1.02)	-0.06
QI 7	Prevalence of shortness of breath at rest	15.21	15.89	0.44 (0.66)	0.007 (-0.03, 0.05)	0.51	1.05 (0.51) (0.92, 1.19)	0.03

QI #	QI Description	Pre-COVID Cohort (%) N=2479	COVID Cohort (%) N=2479	Statistical Analysis of Difference				
				X^2 (z)[a]	QI Diff (95% CI)[b]	X^2 (z) p-value[b]	OR (p-value) (95%CI)[c]	Effect Size[d]
QI 8	Prevalence of shortness of breath when performing moderate / normal day-to-day activities	49.50	51.27	1.56 (1.25)	0.02 (-0.01, 0.05)	0.21	1.04 (0.21) (0.98, 1.09)	0.02
QI 9	Prevalence of caregiver distress	24.10	21.36	5.26 (2.29)	-0.03 (-0.005, -0.07)	**0.02**	0.89 (0.02) (0.80, 0.98)	-0.06
QI 10	Prevalence of negative mood	8.43	6.21	8.99 (3.00)	-0.02 (-0.03, -0.14)	**0.003**	0.74 (0.003) (0.60, 0.90)	-0.17
QI 11	Prevalence of no advance directives	44.90	46.43	1.17 (1.08)	0.02 (-0.01, 0.04)	0.28	1.03 (0.28) (0.97, 1.10)	0.02
QI 12	Prevalence of ulcers	12.53	11.74	0.71 (0.84)	-0.008 (-0.06, 0.03)	0.40	0.94 (0.40) (0.81, 1.09)	-0.03
QI 13	Prevalence of a delirium-like syndrome	5.17	3.32	10.43 (3.23)	-0.02 (-0.04, -0.18)	**0.001**	0.64 (0.001) (0.49, 0.84)	-0.25
QI 14	Prevalence of nausea or vomiting	19.65	17.43	4.04 (2.01)	-0.02 (-0.0003, -0.07)	**0.04**	0.89 (0.04) (0.79, 1.00)	-0.06
QI 15	Prevalence of fatigue	40.74	41.51	0.30 (0.55)	0.008 (-0.02, 0.04)	0.58	1.02 (0.58) (0.95, 1.09)	0.01

QI #	**QI Description**	**Pre-COVID Cohort (%) N=2479**	**COVID Cohort (%) N=2479**	**Statistical Analysis of Difference**				
				X^2 (z)[a]	**QI Diff (95% CI)[b]**	**X^2 (z) p-value[b]**	**OR (p-value) (95%CI)[c]**	**Effect Size[d]**
QI 16	Prevalence of sleep problems	35.74	35.26	0.13 (0.36)	-0.005 (-0.03, 0.02)	0.72	0.99 (0.72) (0.92, 1.06)	-0.01

[a] $z^2 = \chi^2$, used frequencies from 2x2 table obtained using proportions, χ^2 obtained from R (see note [b]):

[b] QI Diff= COVID-Pre-COVID, 95% obtained from R [res<-prop.test(x=c(407, 2072), n=c(857, 4101))

[c] OR stats from online calc: https://www.medcalc.org/calc/relative_risk.php

[d] *d* = LogOddsRatio x ($\sqrt{3}/\pi$) = Ln(OR) x 0.551328

In comparing the QI rates between the pre-COVID and COVID cohorts with the first propensity score analysis method (NNM) using the chi-squared test (or z test of proportions), there was a statistically-significant difference of QI rates between the pre-COVID and COVID cohorts for the following QIs: decrease in prevalence of severe or excruciating daily pain pre-COVID to COVID (p=0.03, effect size= -0.08), decrease in prevalence of caregiver distress pre-COVID to COVID (p=0.02, effect size= -0.06), decrease in prevalence of negative mood pre-COVID to COVID (p=0.003, effect size= -0.17), decrease in prevalence of a delirium-like syndrome pre-COVID to COVID (p=0.001, effect size= -0.25) and decrease in prevalence of nausea or vomiting pre-COVID to COVID (p=0.04, effect size= -0.06).

In considering the effects sizes for each QI difference, they were all found to be well below the threshold for clinical significance (0.2) except for prevalence of a delirium-like syndrome which would still be considered a small difference based on Cohen's guidelines for interpreting effect size (0.2-0.499) (Cohen, 1988). For example, a decrease in effect size for depressed mood pre-COVID to during COVID would not be considered a clinically significant finding given the very small effect size (effect size= -0.17). When running the sensitivity analysis (Appendix S and T) to examine QI rates and measures of statistical analysis of difference using the two alternative propensity score analysis methods (weights, overlapping weights), these differences in QI rates were found to be no longer statistically-significant in the weights method (e.g., prevalence of severe or excruciating daily: p=0.65, prevalence of caregiver distress: p=0.86, prevalence of a delirium-like syndrome: p=0.60) and overlap weights method (e.g., prevalence of severe or excruciating daily: p=0.60, prevalence of caregiver distress: p=0.88, prevalence of a delirium-like syndrome: p=0.78 and prevalence of nausea or vomiting: p=0.06). Importantly, all three propensity score methods were in agreement in that no clinically meaningful differences between the cohorts were observed (e.g., effect size for prevalence of negative mood: -0.15 and prevalence of nausea or vomiting: -0.10 for the weights method and effect size for prevalence of negative mood: -0.16 for the overlap weights method).

The cohorts were in agreement with the lowest and highest prevalence rates for the following QIs: prevalence of a delirium-like syndrome - 5.17% (pre-COVID) and 3.32% (COVID), prevalence of severe or excruciating pain that is not controlled by therapeutic regimen - 6.75% (pre-COVID) and 5.81% (COVID), prevalence of negative mood - 8.43% (pre-COVID) and 6.21% (COVID), prevalence of ulcers - 12.53% (pre-COVID) and 11.74% (COVID), prevalence of shortness of breath when performing moderate/normal day-to-day activities - 49.50% (pre-COVID) and 51.27% (COVID), prevalence of no advance directives - 44.90% (pre-COVID) and 46.43% (COVID), prevalence of fatigue - 40.74% (pre-COVID) and 41.51% (COVID) and prevalence of sleep problems - 35.74% (pre-COVID) and 35.26% (COVID).

Chapter 5: Discussion

This study is the first study to examine differences in QI rates for home care clients receiving PEoLC before and during COVID in Ontario. It appeared that QI rates did not change over the course of the pandemic in this population. Several QIs were found to have statistically-significant differences between the pre-COVID and COVID cohorts, though effect sizes from the statistical analysis were small and thus, the differences were not clinically meaningful. There are a number of other considerations (e.g., temporal variation, interpreting single QI rates and methodological choices) that will be discussed in order to interpret these findings.

These QIs and the comparison of them across the cohorts should be interpreted with caution for several reasons. Firstly, any single number or QI rate cannot directly indicate that poor quality of care was delivered (Barbera et al., 2015b; Earle & Ayanian, 2003). Rather, QIs serve as a proxy to the quality of care delivered and can provide valuable information on the state of PEoLC (Canadian Cancer Society, 2016; Williams et al., 2021). QIs can provide a sense of how frequent an issue or problem is occurring, but not directly conclude whether poor quality of care is being delivered (Barbera et al., 2015b; Earle et al., 2003). It is important to recognize that QIs alone cannot determine whether poor care is provided and each must be interpreted with caution and be subject to further investigation (Earle et al., 2003; Krakauer et al., 1995). Additionally, a single QI rate captures the effect of a range of service/quality-related changes, and those changes cannot be explored via the analysis of a single number. As part of the analysis, the QI rates for each home care client were reduced to one QI rate for each QI in the two cohorts, and by reducing the information on a relationship or comparison to a single number for each cohort, there is a loss in statistical power. Though these QIs have undergone rigorous development, there is still work being done to refine their definitions and to develop risk adjusters to ensure the QIs are capturing the quality constructs as intended and enable fair comparison across regions and home care providers (Dalby et al., 2005; Guthrie et al., 2022). As a result, these QIs may still be changing to reflect the best knowledge and expertise. Additionally, the temporal variation in rates is unknown and needs to be explored as there are likely statistically-significant differences in the rates over time and within the same cohort. Though the pre-COVID cohort provided a suitable comparator cohort, variation of these rates over time is largely unknown and statistical differences between the cohorts may reflect natural variation in QI rates over time (not cohort differences).

In terms of statistical significance, there appeared to be differences in several QIs (e.g., prevalence of severe or excruciating daily pain, prevalence of caregiver distress, prevalence of negative mood, prevalence of nausea or vomiting and prevalence of a delirium-like syndrome) from the first propensity score analysis method, NNM. However, the few statistically-significant differences were inconsistent across the three propensity score methods (all of which met acceptability criteria), and there were no clinically meaningful differences between the cohorts when examining the effect sizes. These discrepancies can be explained by methodological issues between the methods which resulted in different sample sizes and therefore differences in the assessments kept when matching on covariates. NNM was thus used for the primary analysis, and the weighted methods were explored as part of a sensitivity analysis. While there are advocates for different propensity score methods, such as weighting or matching methods, the empirical evidence for any singular method is varied and does not often achieve better performance despite the theoretical or conceptual defence (Greifer, 2022).

In interpreting the results of this study, a p-value is not sufficient alone to interpret the differences between these QI rates as it does not account for sample size (Sullivan & Feinn, 2012). Subsequently, effect sizes and odds ratios were explored and aided in interpreting the results of this study. Additionally, p values were not adjusted for because there were no consistent statistically-significant and clinically-meaningful results, though this step would have been necessary if that was not the case in order to adjust for multiple comparisons. As the results were compared across the three propensity score methods, the majority of the statistically-significant findings were inconsistent and thus this adjustment of the p value was deemed unnecessary.

The severity of outcome can also be a helpful descriptor when interpreting the magnitude of effect size as there is caution to using generic descriptions solely in interpreting effect sizes (Valentine & Cooper, 2003). For example, some QIs measure more severe outcomes, such as severe pain uncontrolled by medications or caregiver distress and clinically speaking, may be more meaningful or amenable to change. Therefore, each of the QIs should not be considered of equal weight in comparing them among fellow QIs.

While there may not have been clinically meaningful differences in any QI rates, it is also important to note that there were some concerning rates regardless of time period for several QIs. Several QIs had high overall rates when compared against other QI rates regardless of pre-COVID or COVID time periods warranting further attention. Other QIs had lower rates when compared to other QI rates in this study which are also important to examine. For example, on the lower side of QI rates during COVID were the prevalence of negative mood (NNM - 6.21%, Weights - 7.31%, Overlap - 7.17%), prevalence of severe or excruciating pain that is not controlled by therapeutic regimen (NNM - 5.81%, Weights - 6.76%, Overlap - 6.81%), and prevalence of a delirium-like syndrome (NNM - 3.32%, Weights - 4.33%, Overlap - 4.32%). Though these rates are lower compared to other QI rates, it is also important to consider the frequency of assessments and whether these clinical issues are able to be detected given how often the interRAI PC is required for use. For example, the sensitivity to detect clinical issues such as delirium-like syndrome or depression among home care client receiving PEoLC may be challenging as symptoms fluctuate and may not be as easily captured based on the timing of the assessment done.

On the higher side of QI rates during COVID were prevalence of shortness of breath when performing moderate/normal day-to-day activities (NNM - 51.27%, weights - 51.43%, overlapping weights - 51.18%), prevalence of no advance directives (NNM - 46.43%, weights - 44.60%, overlapping weights - 44.17%) and prevalence of fatigue (NNM - 41.51%, weights - 40.70%, overlapping weights - 40.67%). It is important to note that while the QIs cannot indefinitely determine whether poor quality of care was delivered, they can provide an indication as to where issues may be occurring (Earle et al., 2003). As previously mentioned, the home care sector was insufficiently organized and funded to support quality PEoLC long before the COVID-19 pandemic and high QI rates may reflect this long-standing problem (Canadian Society of Palliative Care Physicians, 2016; Health Quality Ontario, 2016, 2019). Further, little work has been done to create benchmarks around acceptable rates of these QIs, and how they should be interpreted. Regardless, the fact that several of these QIs were experienced by almost half of the population should warrant further attention as these QIs reflect outcomes of care that may be amendable to change.

In examining differences in these QIs, it is first important to note that there were significantly less assessments overall in the COVID cohort (n=3231) than the pre-COVID cohort (n=6346). This finding was consistent with other research that examined patterns and changes in home care assessments during the first wave of COVID where there was noted to be a 25% decrease in screening assessments and a 44% decrease in full assessments (Canadian Institute for Health Information, 2020). While there were less assessments during COVID and this speaks to an aspect of quality, a large proportion of the COVID assessments were still retained for analysis (n=2479). While the decrease in assessments overall does not necessarily infer services were not being provided, it can be concluded that the home care system was not operating as it was prior to COVID (Canadian Institute for Health Information, 2020). Given that many of the QIs were symptom focused, the aspect of structural quality may not have been as apparently captured through the QIs examined and thus resulted in lower QI rates than expected due to assessments being completed less frequently.

Similarly, in a study about patterns of home care assessments and service provision before and during COVID in Ontario, it was found that there were significantly less home care admissions, discharges, and standardised assessments (Sinn et al., 2022). As a result, perhaps fewer routine assessments resulted in little differences observed between the QI rates. In other reports it was highlighted that many service providers faced significant staffing challenges, and services were put on hold at the request of families and patients to limit contact (Bandini et al., 2021; Giebel et al., 2020; Rowe et al., 2020; Weeks et al., 2021). In recognizing the disruption to the home care system, as evidenced by significant reductions in standardized assessments, these changes may have led to individual- and system-wide effects not necessarily captured by these QIs that were more symptom focused (Sinn et al., 2022). For example, a missed assessment could have led to a failure to recognize health changes and adjust home care services, especially for those nearing EOL, where care needs may be changing more frequently than someone more stable and receiving home care (Sinn et al., 2022). Also, there may have been an increased burden on patients and families with home care services being cancelled or limited due to service capacities. These individuals may not have been captured in the data which may have resulted in no meaningful differences between the pre-COVID and COVID cohorts.

Finally, though not as explicitly reported on in the literature, there were reports that home care clients or their families were cancelling or discontinuing visits due to limiting exposure of COVID (Giebel et al., 2020). The decision as to who was kept on service or how home care clients were being triaged can be found in the report by the

OPCN (2022), but the extent to how this was being followed in practice is absent from the data examined in this study. In a qualitative study on those receiving home care during COVID, the reason for service cancellation was due to home care workers testing positive for COVID, home care workers working in nursing homes and multiple home care workers being assigned to a client (Weeks et al., 2021). With perhaps fewer home care clients to track due to discontinued or paused services, more efforts from home care agencies may have been able to be diverted to those clients who were still receiving palliative and end-of-life home care. As observed during propensity score analysis, covariates of formal care such as number of days and minutes in the last week with home health aides or home nurses were relatively similar before and after adjusting with propensity score analysis. However, the frequency of how often home care clients were being assessed and whether there were delays in routine assessments is beyond the scope of this research project, but an important question in understanding the potential causal effects between structure, processes, and outcomes of care during COVID as well as who was being assessed and whether that is reflected in the cohort of those living at home and receiving PEoLC during COVID.

In examining the different QIs, no single QI provides the full picture of describing quality of care provided. Multiple QIs were selected and examined that captured several domains of PEoLC, including structures and processes of care, physical aspects of care, psychological and psychiatric aspects of care, and ethical and legal aspects of care. However, not all of the domains are captured in the QIs derived from the interRAI instrument and there is a need for ongoing development around additional QIs. As described in Ferrell's framework (2018), eight domains of PEoLC exist, yet few validated QIs exist within cultural aspects of care, spiritual, religious and existential aspects of care and social aspects of care. The 16 QIs that were examined in this study reflect a range of domains of PEoLC as previously mentioned; however, they are not reflective of all domains. The QIs reported on are largely symptom focused (e.g., pain, nausea, vomiting, sleep problems, fatigue, negative mood etc.) and outcomes of care. When considering Donabedian's model of quality, it is important to have measures that capture structure, processes, and outcomes of care. As noted from the literature review, the large majority of QIs summarized reflected structure and processes of care (41.1%) and have been often reported on in the literature (Barbera et al., 2015b; Earle & Ayanian, 2006). In looking at the QIs examined, and the literature search conducted, it is evident that there requires more development around a robust set of QIs. While the QIs used in this project cover several domains of PEoLC, there remains more work to be done to develop QIs around spiritual, religious, and existential aspects of care, cultural aspects of care, and social aspects of care. These QIs are often underreported in the literature and there is certainly opportunity to develop QIs that reflect these domains.

Additionally, from the flow chart in Appendix F, several QIs were disregarded as they were not measurable with the interRAI PC instrument, those being place of death, communication between person, family and healthcare provider, access to resources/services, extent to which care wishes are met, timeliness of care, satisfaction with healthcare and specific treatments for certain issues. While these QIs were recognized as important and measures identified in the literature (Barbera et al., 2015a, 2015b; Claessen et al., 2011; De Schreye et al., 2017; Earle et al., 2003; Grunfeld et al., 2006; Johnston & Burge, 2002; Miyashita et al., 2008; Peruselli et al., 1997), they are not captured in any data elements in the interRAI PC instrument. When looking at quality of care, it is important to consider and examine multiple QIs, rather than individual QIs as each reflects different aspects of care and domains of PEoLC, as identified in this study. Perhaps if these QIs were developed and examined, there may have been differences in these aspects of quality care.

Another consideration to this study is in recognizing that the interRAI PC instrument itself is not universally used. This was evident when examining differences in the home care jurisdiction covariate where some regions appear to use the tool more frequently than others. While there are data that reflect the current population that is being assessed using the interRAI PC (Williams, Hermans, et al., 2021), little consensus across jurisdictions as to guidelines for using the interRAI PC instrument exist. In order to examine the QIs comprehensively, it is important to make sure those with PEoLC needs are being regularly assessed and that the interRAI PC instrument is consistently being used across different regions and patient populations. Many studies that aim to capture individuals receiving PEoLC encounter difficulties defining that population well because of differences in coding practices, limits to inclusion criteria that restrict PEoLC services or the uncertainty in prognosis in certain life-limiting illnesses (Borgsteede et al., 2006; Health Quality Ontario, 2016; McNamara et al., 2006), and so efforts to more fully integrate the interRAI PC and ensure those who are receiving PEoLC are being assessed with it would help with subsequent reporting on QIs and aspects of quality care.

Of consideration to the quality of data and though not possible to distinguish from this study and the assessments completed, it is important to recognize that many home care assessments were also being done virtually during the initial months of the COVID-19 pandemic. Assessment methods were mostly conducted virtually to reduce close contact and some home care clients and their families' put services on hold for similar reasons (Canadian Institute for Health Information, 2020). How this alteration in mode of assessment changed the quality of assessments is uncertain. For example, with in-person assessments there may be more than one source of data available (e.g., family, home care client) when compared to virtual methods making it easier to retrieve additional information or make sense of differing answers. There is certainly mixed data on the benefits and risks of virtual care. For example, some cited pros are increased access for those living in rural or remote areas, increased efficiency, particularly in the settings of home visits and reduced wait time for patients (Allen Watts et al., 2021). However, challenges exist such as in the difficulty of gathering data from physical assessments, the reduced ability to recognize nonverbal cues, and technological difficulties (Allen Watts et al., 2021). The difference in virtual versus in-person methods for obtaining quality assessment data is undetermined and worthwhile to explore as to which standard processes should guide assessing home care clients receiving PEoLC. Such evidence may be warranted should another system-level crisis occur. Though not able to be explored in this study, such differences in assessment practices could have resulted in why there were rather few differences in QI rates.

Chapter 6: Strengths, Limitations, and Implications

In this chapter, the strengths and limitations of this study will be described and how they may influence the generalizability of the findings. Following this, the implications of this research will be explored in relation to clinical practice, nursing education, policy, and future research.

Strengths

There are several strengths in relation to this study. As to the author's knowledge, this is the first study comparing these QI rates for home care clients receiving PEoLC across time periods, and also, the first study to examine these QI rates during the COVID-19 pandemic. Oftentimes QIs in the literature have been reported as rates and examined with subgroup analyses, comparing between those with or without cancer or between organizations or settings of care. These QI rates have not been examined over time nor have they been looked at to see the impacts with disruption in care or interventions aimed to improve the QI rates.

As previously described, these QIs are based on the interRAI PC, a standardized clinical assessment instrument used in Ontario. The interRAI PC instrument has established validity and reliability for its measures (Steel et al., 2003) and has strengths in the completeness and comprehensiveness of the data collected. The breadth of the data captured from the interRAI PC allowed for a variety of QIs to be generated that capture key domains of interest in PEoLC, such as processes of care, physical aspects of care, psychological and psychiatric aspects of care, and ethical and legal aspects of care. These QIs are not only important to assessing the quality of PEoLC and reflect a diversity in what domains they capture, but they are also relevant to what patients and families value in terms of the quality of PEoLC (Cohen & Leis, 2002; Heyland et al., 2006; Singer et al., 1999). While previous studies have made use of administrative data to report on QI rates, these studies have often been limited to examining structures or processes of care and rarely examine patient outcomes (Barbera et al., 2015b; Earle et al., 2003, 2005). The strength of many of the QIs used in this study is that they focus on symptoms and patient-reported outcomes which are less frequently reported in the literature. Therefore, the advantage of the interRAI PC instrument and in this study was the ability to examine several QIs that reflect patient outcomes such as pain and other symptoms and the well-being of caregivers.

Further, there were several strengths with regards to how the cohorts were created and the statistical approaches used. A rigorous cohort definition was adopted and purposeful use of assessment records that were not intake assessments helped to accurately examine the QI rates and offer a fair comparison as admission assessments do not reflect the quality of care during the time of the assessment (Guthrie et al., 2022). The cohorts were also not limited to those with only a cancer diagnosis, as often reported in previous studies examining QIs (Barbera et al., 2015a, 2015b; Earle et al., 2003, 2005; Grunfeld et al., 2006, 2008; Miyashita et al., 2008; Raijmakers et al., 2012). As noted in a previous study profiling the demographics of those in the interRAI PC database, around 82.3% of those assessed with the interRAI PC had a cancer diagnosis and while they overwhelmingly make up those in the interRAI database, there are those with other life-limiting illnesses represented (Williams, Hermans, et al., 2021). This fact is important because home-based PEoLC should not be limited to only those with a cancer diagnosis. A rigorous statistical approach was also adopted, where propensity score matching was used to reduce the influence of numerous covariates on the QI rates, multiple matching methods (e.g., NNM, weights, overlap weights) were explored to look at the changes in QI rates over time and multiple statistical measures were compared (e.g., chi-square test, odds ratio, effect size).

Furthermore, these QIs are designed for a large cohort of individuals receiving PEoLC, namely those living at home, and have undergone rigorous testing and evaluation by a modified Delphi panel (Guthrie et al., 2022). While future work is taking place to further test this set of QIs, the rigorous process of developing and defining these QIs has lent to the clinical importance, validity, and usability of the QIs (Guthrie et al., 2022). These QIs are among few that are specific to the setting of home care, where the focus has previously been hospital and acute care settings. Among this fact, few studies have examined the impact of the COVID-19 pandemic on palliative and end-of-life home care and the health and well-being of home care clients receiving PEoLC and their caregivers (Sinn et al., 2022). To this knowledge, this study is of the first to examine the use of QIs for home-based PEoLC using interRAI data during the COVID-19 pandemic and to compare the QI rates between time periods.

Limitations

The study has several limitations, particularly by means of timeline, sample size sufficiency, the QIs themselves, the cohort studied and the types of QIs able to be examined. One major limitation is in comparing QI rates at different timepoints without any sense of temporal variation in the measure. In terms of methodology, while state-of-the art techniques were used to balance the cohorts (PSM), this technique could only capture covariates available in the interRAI PC. There are also likely to be important covariates missing in the analysis, such as income, ethnicity, highest level of education or rurality (Maetens et al., 2019), that could not be balanced.

There were also limitations as to which QIs could be generated due to the data elements available in the interRAI PC instrument. For example, QIs around place of death, communication between person, family, and healthcare provider, access to resources/services, extent to which care wishes are met, timeliness of care, spiritual aspects of care, satisfaction with healthcare and specific treatments for certain issues are difficult to generate due to lack of data availability for these constructs from the interRAI PC instrument. Regardless, QIs used for this study are based on the best available evidence and literature to date around what is known about QIs for PEoLC and what can be captured by the interRAI PC instrument by building upon current work that has been done to identify conceptually valid QIs for PEoLC (Guthrie et al., 2022; Williams et al., 2021). Another set of QIs that were excluded were those requiring multiple assessment timepoints or what has been defined as "change" QIs. Change QIs were not considered due to the frequency of reassessments completed and discretionary completion. Due to the need to define the cohort differently as those with multiple assessments during the time period of interest, variability in subsequent assessments and constraints of the thesis timeline, these QIs were not included, though identifiable in the literature (Guthrie et al., 2022).

Another limitation was with regards to sample size sufficiency. Given the uncertainties around how to define QIs, how they vary over time, and how or if they respond to practice changes, a sample size was not hypothesized in relation to an expected change in effect size. With many of the QIs studied, an effect size of between two to three percent was observed and given sample sizes for statistical tests of proportions are often required to be very large, it was unknown if the sample size used for this study was sufficient. Therefore, how representative the observed differences were given the sample size in this study remains unknown and is an area for future research.

There were also limitations around the domains of PEoLC able to be examined, those being social aspects of care, spiritual, religious, and existential aspects of care and cultural aspects of care. Consistent with the literature, there are few validated and agreed upon QIs that relate to these domains; however, it is still a limitation (Brook et al., 2000; Seow et al., 2009). Nonetheless, different QIs reflect various aspects of care and were interpreted with caution recognizing that any single QI does not reflect poor quality of care (Canadian Cancer Society, 2016).

Another limitation is regarding the specific QIs used. For QIs such as emergency department visits or hospitalizations, there may be limitations as they do not account for personal preferences and the ability to examine planned or unplanned service use that could be deemed appropriate. While unable to be distinguished in the data, there are appropriate instances when a client living at home may need to be transferred to hospital, the emergency department, or another setting; however, most emergency department visits are considered to be potentially avoided (Health Quality Ontario, 2019).

Lastly, assessors using the interRAI PC assessment form may use their discretion as to when and how to use the instrument, meaning that not all home care clients receiving PEoLC were captured in the data. Though variations in PEoLC across different regions are evident in the literature (Health Quality Ontario, 2016, 2019), propensity score analysis was used to control for this covariate. The population of those receiving PEoLC is difficult to define and not well defined in the literature as previously described. For the purposes of this study, those with an interRAI PC assessment formed the basis for inclusion to the cohort, yet the population itself may not be generalizable to all home care clients receiving PEoLC. However, from what is known about the population of those being assessed with the interRAI PC instrument (Williams et al., 2021), this population has representation of those with or without a cancer diagnosis and both a shorter (<6 months) and longer prognosis (>6 months), reflecting the broader definition used in this study of PEoLC (Griebeler Cordeiro et al., 2020).

Implications

Policy

In terms of the use of the interRAI PC, in order to accurately gauge PEoLC use and the quality of care, it is important that the tool be adopted universally and consistently. In order for this to happen, the interRAI PC should be mandated for use in Ontario and with a clearly defined population of home care clients receiving PEoLC. Parameters around when to initiate the use of the interRAI PC instrument and how often to assess are needed as home care clients receiving PEoLC may have varied needs compared to more stable home care clients. Further, the population of those receiving PEoLC is difficult to define and not well described in the literature. This remains a topic for further discussion, clarification in the literature and standardization of parameters around the use of the interRAI PC instrument from a policy perspective.

As ongoing work is being done to improve the quality of PEoLC services, these QIs can serve as a starting point to identify areas of focus and benchmarks for developing quality standards and indicators for home-based PEoLC and services. Given that these assessments are standardized and routinely collected using existing software, these QIs can be easily generated from the data and compared across regions, provinces and countries collecting interRAI PC data. As mentioned in the literature review, several organizations are working to strengthen PEoLC in Ontario and with further work to examine differences among regions and for different types of life-limiting illnesses, these QIs can serve as decision-support tools to identify areas for quality improvement. Then with targeted interventions, these QI rates can be monitored over time using a similar methodology as presented in this study.

Education

Typically, assessors using the interRAI PC assessment form may use their discretion as to when and how to use the instrument, meaning that not all home care clients receiving PEoLC will be captured in the data. With the onset of COVID, assessment practices varied and the need to accommodate for virtual assessments became normalized in practice. Education in terms of how to conduct virtual assessments may be helpful if such use becomes a norm or alternative for practice beyond COVID and in considering jurisdictions serving clients in remote or rural areas. In order to preserve the quality of assessment data, virtual care may require more sensitive assessment skills and direction guided by current literature (Tieman et al., 2016).

Practice

Importantly, these QIs can be adopted and used regionally for practice. The focus of this study was to examine QI rates from a provincial standpoint, but there would certainly be utility in examining these QIs over time for a specific organization or region as there may be variability that exists. Once these QIs are finalized and appropriately risk-adjusted, they can be built into software so that individual organizations and home care agencies can generate the rates themselves. Given the difference in assessments pre-COVID and COVID, there would be value in selecting a few QIs to focus on and allowing those to guide future QI initiatives and work in different practice settings, such as those mentioned with higher rates from this study (prevalence of shortness of breath when performing moderate/normal day-to-day activities, prevalence of no advance directives, and prevalence of fatigue). While these QIs are not definitive measures of quality, they can serve as a gauge for areas that may require further investigation and attention from home care clinicians, management, and decision-makers (Earle et al., 2003).

Research

Ongoing work and progress are still needed to refine a set of QIs to be universally adopted and examined routinely. For example, there is still work being done to risk-adjust these QIs (Guthrie et al., 2022). Though beyond the scope of this project, risk-adjustment is an important step because it allows for comparison between regions and attempts to control for the differences in risk profiles of different populations that may exist (De Schreye et al., 2017). Then benchmarks in terms of acceptable or guided direction to improvement in QI rates would also be helpful to identify acceptable rates (De Schreye et al., 2017; von Eiff, 2015). Next steps in research would be scaling up the QIs to compare between provinces and for use internationally in other countries where the interRAI PC is being used.

Conclusion

The purpose of this retrospective population-based cohort study was to compare QI rates for home care clients designated to receiving PEoLC prior to and after the onset of the COVID-19 pandemic. Sixteen QIs informed by an extensive literature review and recent developments towards a set of QIs as part of a multi-stage study (Guthrie et al., 2022; Luymes et al., 2021; Williams, Boumans, et al., 2021) were used to examine the quality of PEoLC. It appeared that QI rates did not change over the course of the pandemic in this population, though considerations of temporal variation, interpreting single QI rates and methodological choices aided in interpreting these findings. While several QIs were found to have statistically-significant differences between the pre-COVID and COVID cohorts, effect sizes from the statistical analysis were small and thus, the differences were not clinically meaningful. Future work should be directed to examining variation in these QI rates and their expected stability over similar time increments, risk-adjusting the QI rates for further comparison among jurisdictions, provinces and countries and establishing benchmarks or thresholds to determine acceptable rates of different QIs. The interRAI PC should also be mandated for use in assessing home-based PEoLC. This work will further support better interpretation and understanding of QI rates for home care clients receiving PEoLC and the need for ongoing monitoring and evaluation of home-based PEoLC.

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Appendices

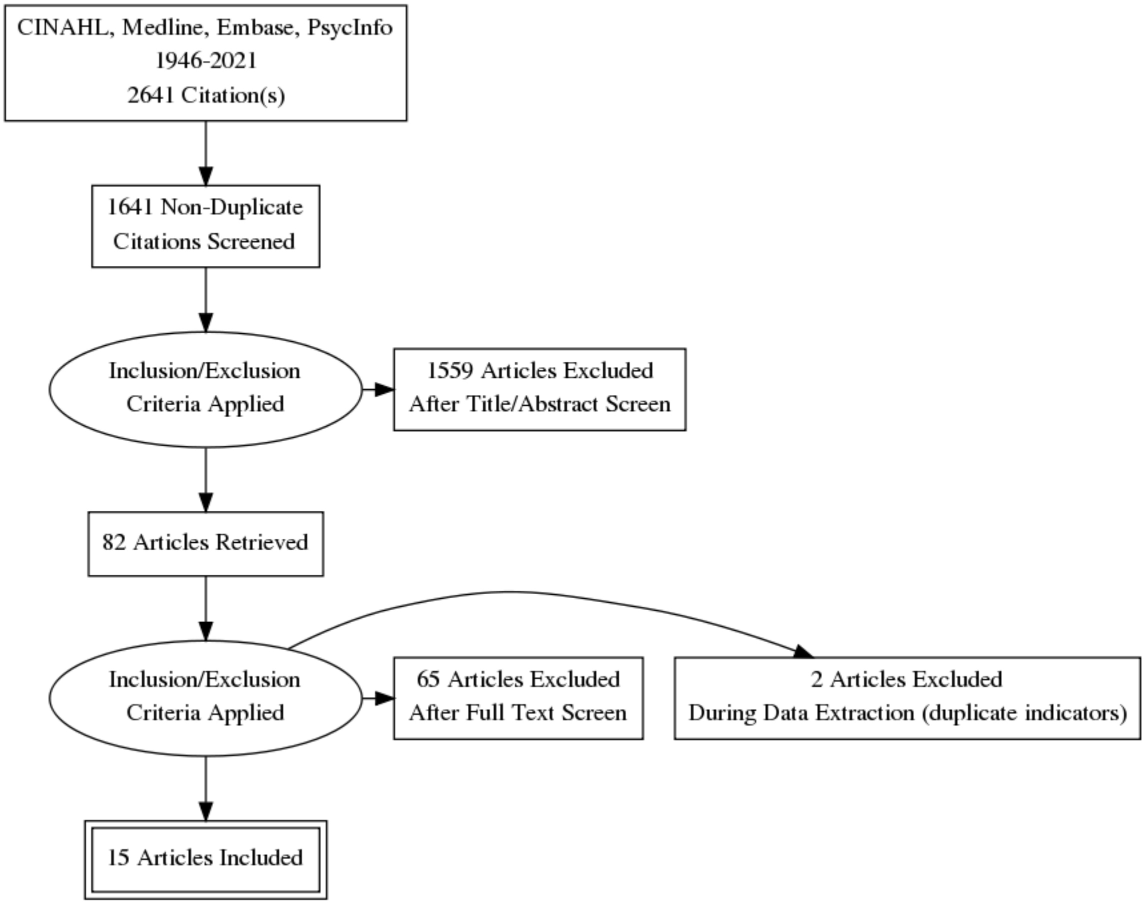
Appendix A

Glossary

Term	Definition
Community and home care	"services designed to help individuals receive care in their homes and to live as independent as possible in their community" (Government of Canada, 2016, p. 20).
Palliative and end of life care	Typically refers to the last six months to one year of life (Krau, 2016).
Home care	"An array of health and support services provided in the home, retirement communities, group homes, and other community settings to people with acute, chronic, palliative, or rehabilitative health care needs" (Canadian Home Care Association et al., 2016, p. 1).
Palliative care	Aims to relieve suffering and improve "the quality of living and dying, using a holistic approach" for those living with a life-limiting illness and their families (Health Quality Ontario, 2019, p. 2); *Palliative care* is also defined by the World Health Organization (WHO) as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (2002, p. 84).
Quality indicators	QIs are "explicitly defined measurable items" of health care quality and reflect structure, processes, or outcomes of care (Campbell et al., 2003; De Roo et al., 2013, p. 557; Donabedian, 1988)

Appendix B

Flowchart of Included Studies



Appendix C

Chart with Appraisal of Included Studies and Characteristics

Author & Year	Country	Population / Classification of Cohort	Method	Description of Indicators	Strengths / Limitations	Critical Appraisal
Harman, L., Guthrie, D., Cohen, J., Declercq, A., Fisher, K., Goodridge, D., Hirdes, J. & Seow, H. (2019) Potential quality indicators for seriously ill home care clients: a cross-sectional analysis using Resident Assessment Instrument for Home Care (RAI-HC) data for Ontario	Canada	Seriously ill home care clients aged 65 and older (2006-2013) defined as having a prognosis of less than six months or a CHESS score of four or greater	Cross-sectional secondary analysis of RAI-HC data for Ontario	From a potential list of 17 quality indicators that would be operationalized with the RAI-HC, seven final quality indicators were proposed and given operational definitions in terms of the numerator and denominator: • Prevalence of falls • Prevalence of disruptive or intense daily pain • Prevalence of caregiver distress • Prevalence of negative mood • Prevalence of inadequate medication to control pain • Prevalence of social isolation • Prevalence of constipation	Strengths Quality indicators determined through expert analysis and review of the literature. Indicators were adjusted for client-level risk. These are the first indicators developed explicitly for home-based palliative care and based on routinely collected home care data and a tool used internationally. Limitations Limited by only including input from experts and indicators are missing perspectives from clients, families. And policymakers. Quality indicators were restricted to those for which interRAI home care data were available which limited a number of potential quality indicators that are important to patients/clinicians.	All proposed indicators are based on items from the RAI-HC tool which is a standardized assessment in Ontario. Additionally, quality indicators are operationally defined and applicable to those with and without cancer. Indicators do not have a proposed timeline for measurement (i.e., at one month or three months prior to death) as they are measured variably for different clients. All quality indicators focus on symptoms and would be classified as outcomes of care and under the domains of physical and psychosocial aspects of care.
Peruselli, C., Marinari, M., Brivio, B., Castagnini, G., Cavana, G., Centrone, G., Magni, C., Merlini, M., Scaccabarozzi, G. & Paci, E. Evaluating a Home Palliative Care Service: Development of Indicators for a Continuous Quality Improvement Program (1997)	Italy	Patients receiving care primarily in their home from a local health authority delivering palliative care	Descriptive	53 quality indicators were proposed after evaluating current literature and measurement as well using the Therapy Impact Questionnaire (TIQ) and Support Team Assessment Schedule (STAS) which are currently being used by the service. Proposed indicators were mapped to the following domains: • Structure and process (n=9) • Physical aspects of care (n=22) • Social aspects of care (n=15) • Psychological and psychiatric aspects of care (n=6) • Other – satisfaction (n=1)	Strengths The indicators are mapped to domains of quality, quality dimensions (i.e., effectiveness, competence, appropriateness) and contain a quality standard or dimension to be achieved (i.e., 75% or 95%). Limitations In terms of methodological considerations, the quality indicator set has a low scientific evidence base to support use and involved little stakeholder involvement in the development.	Quality indicators mapped to Donabedian's model of quality: structure, process and outcome. Indicators are relevant to home care but may be limited in generalizability due to tools used and a relatively small population examined in one country.
Barbera, L, Seow, H., Sutradhar, R.,	Canada	Patients with cancer-related cause of death	Retrospective cohort study	• Death in acute care hospital or bed	Strengths	Challenges in merging data sources across provinces and a

Chu, A., Burge, F., Fassbender, K., McGrail, K., Lawson, B., Liu, Y., Pataky, R. & Potapov, A. (2015a)
Quality of end-of-life cancer care in Canada: a retrospective four-province study using administrative health care data
		between 2004 and 2009 in British Columbia, Alberta, Ontario and Nova Scotia > 19 years with a valid provincial health card number		• Hospitalization within 30 days of death
				• With intensive care unit admission
				• Emergency department visit within 2 weeks of death
				• Home visit within 6 months of death
				  ◦ By a registered nurse
				  ◦ By a personal support worker
				  ◦ For palliative care
				• Physician house call within 2 weeks of death
				• Chemotherapy within 2 weeks of death
					The study used a retrospective population-based cohort identified using a common method. The populations spanned the settings of inpatient, ambulatory, and community settings. Efforts were made to ensure that the indicators represent fair comparisons given different data sources were used for the quality indicators.
					Limitations
					Some limitations existed for different quality indicators due to data availability and different source availability based on provinces. For example, ED visits were not available for all provinces and thus inpatient hospitalization data was used as an alternative. Additionally, indicators such reflect where a patient spent their time at end of life.
						focus on indicators in health service mostly reflecting process quality indicators. Well defined indicators that have been used commonly and defined several indicators as specific to individuals who would be receiving home care at end of life.

Barbera, L., Seow, H., Sutradhar, R., Chu, A., Burge, F., Fassbender, K., McGrail, K., Lawson, B., Liu, Y., Pataky, R. & Potapov, A. (2015b) Quality Indicators of End-of-Life Care in Patients with Cancer: What Rate is Right?	Canada	Patients with cancer-related cause of death between 2004 and 2009 in British Columbia, Alberta, Ontario and Nova Scotia > 19 years with a valid provincial health card number	Retrospective cohort study	• Emergency department visit in the last 30 days • Received physician home visit in the last 2 weeks • Intensive care unit admission in the last 30 days • Received palliative home care by a nurse or personal support worker in the last 6 months • Deaths in hospital	Strengths The study used a population-based cohort making up 65% of Canadians across four provinces. The quality indicators were compared against empiric benchmarks that were defined using indicator rates from top-ranked regions. Indicators were adjusted based on age and sex. Indicators were defined as supportive care or aggressive care. Limitations Excluded those outside the four provinces of interest, <19 years and benchmarks are limited in generalizability beyond Canada.	May be bias for some indicator definitions and limited by what data sources provide i.e., defined intensive care unit admission indicator with all cancer deaths as the denominator and location of death may be less accurate compared to preferred place of death. Indicators lacking are those related to patient satisfaction or patient perspective.
Claessen, S., Francke, A., Belarbi, H., Pasman, R., van der Putten, M. & Deliens, L. (2011) A New Set of Quality Indicators for Palliative Care: Process and Results of the Development Trajectory	Netherlands	Adult patients applicable for all settings in which palliative care is being provided	Phased approach	A set of 33 quality indicators were developed and 10 addition indicators for support of relatives surrounding a patient's death. Quality indicators were subdivided into the following categories for patients: 1. Management of pain and other physical symptoms 2. Care for psychosocial well-being 3. Care for spiritual well-being 4. General aspects Relatives: 5. Care for psychosocial and spiritual well-being of relatives	Strengths Final indicators determined through interviews with patients, family caregivers and relatives; drafts were then tested among experts. Indicators are applicable to all setting where palliative care is delivered and generalizable to many patient groups as recipients of palliative care. Limitations The authors are of the opinion that outcome indicators are more representative of quality care for care users though they may be more difficult and expensive to extract. No indicators of structure	Indicators are applicable to all settings of palliative care and for multiple patient groups. This indicator set uniquely addresses physical, psychosocial and spiritual domains as well as aftercare. Feasibility and usability of indicators was reported on.

				6. General aspects 7. Aftercare (Care of the Patient Nearing the End of Life)	were presented. The indicator set was tested in a small sample of care organizations.	
De Schreye, R., Houttekier, D., Deliens, L. & Cohen, J. (2017) Developing indicators of appropriate and inappropriate end-of-life care in people with Alzheimer’s disease, cancer or chronic obstructive pulmonary disease for population-level administrative databases: A RAND/UCLA appropriateness study	Belgium	Individuals with Alzheimer’s disease, cancer or chronic obstructive pulmonary disease at the population level	Modified RAND/UCLA appropriateness method	Indicator sets were developed for each life-limiting illness: • Alzheimer’s disease (n=28) • Cancer (n=26) • Chronic obstructive pulmonary disease (n=27)	Strengths Used a widely accepted consensus method to determine appropriateness of measures and expert interviews. Authors believe that this indicator set may have broader international relevance and applicability due to data availability in other countries. Limitations Administrative level data is limited in the ability to examine treatment and medication rather than consider other quality aspects, for example communication, patient satisfaction or psychosocial well-being. Diverse perspectives such as patients and families were not included in the consensus process.	Indicators developed through literature review and expert interviews and address a variety of domains including “aggressiveness of care, pain and symptom treatment, specialist palliative care, place of care and place of death and coordination and continuity of care” (p. 932). No current benchmarks exist for this quality indicator set and validity, acceptability and feasibility need to be established.
Earle, C., Park, E., Lai, B., Weeks, J., Ayanian, J. & Block, S. (2003) Identifying Potential Indicators of the Quality of End-of-Life Cancer Care From Administrative Data	United States	Cancer patients at end of life, population level	Literature review, focus groups and expert panel using modified Delphi approach	Three major concepts of poor quality of end-of-life cancer care were presented that captured 8 indicators in total: • Institution of new anticancer therapies or continuation of ongoing treatments very near death may indicate overuse • A high number of emergency room visits, inpatient hospital admissions, and days spent in the ICU near the end of life may indicate poor-quality care • A high proportion of patients never referred to hospice, only referred in the last few days of life, or death in an acute-care setting, may indicate poor-quality care	Strengths Diverse perspectives including patients with cancer, family members, and an expert panel. There was a sufficient evidence base provided and indicators were assessed by ranking meaningfulness and importance of potential quality indicators. Limitations Unable to capture domains such as access to psychosocial or multidisciplinary services and pain and symptom management given existing limitations of data systems. Participants may not have been a highly representative pool for focus groups and expert panels.	Authors recommend a feasible approach of determining cohort from deaths to evaluate care with the flexibility of choosing a time period based on period of time empirically deemed. All quality indicators must be interpreted with caution, particularly administrative level data which may eliminate important clinical data though they provide a practical and economic tool to screen problems with care. In a further study, benchmarks for these measures are proposed in addition to assessing their validity and reliability (Earle et al., 2005).
Earle, C., Neville, B., Landrum, M., Souza, J., Weeks, J., Block, S., Grunfeld,	United States	“Decedents representing all Medicare eligible patients over age 65 who were identified on the death certificate as	Literature review, focus groups and expert panel using	Three major concepts of poor quality of end-of-life cancer care were presented that captured 8 indicators in total: • Institution of new anticancer therapies or continuation of ongoing	Strengths Reports on validity, accuracy and associated benchmarks for quality indicators.	Identified candidate quality indicators to be applied to administrative data for cancer decedents and their end-of-life care. This study reports on

E. & Ayanian, J. (2005) Evaluating claims-based indicators of the intensity of end-of-life cancer care		having died from lung, breast, colorectal, or other gastrointestinal cancers, diagnosed while residing in one of the 11 SEER areas between January 1, 1991 and December 31, 1996" (p. 506)	modified Delphi approach	treatments very near death may indicate overuse • A high number of emergency room visits, inpatient hospital admissions, and days spent in the ICU near the end of life may indicate poor-quality care A high proportion of patients never referred to hospice, only referred in the last few days of life, or death in an acute-care setting, may indicate poor-quality care	Limitations Utility of these indicators depends on the understanding and perception of the quality of care at end of life by patients, families, healthcare providers, policymakers and the public.	benchmarks and the quality indicator's associated validity and accuracy.
Grunfeld, E., Lethbridge, L., Dewar, R., Lawson, B., Paszat, L., Johnston, G., Burge, F., McIntyre, P. & Earle, C. (2006) Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology	Canada	All females who died of breast cancer from January 1st 1998 to December 31st 2002 in Nova Scotia or Ontario	Retrospective cohort in two Canadian provinces	An initial 19 quality indicators were chosen from the literature and narrowed down to an indicator set of seven feasible and measurable indicators on Nova Scotia and Ontario: • Interval between last chemotherapy and death • Site of death • Frequency of ER visits • Hospital days near the end of life • ICU days near the end of life • Continuity of care • Time and location of care • Adverse events	Strengths Administrative data has the strengths of being an efficient and unbiased population-based method to monitor the quality of care. Limitations Limited by the scope of provincial data collection. Disadvantages of administrative data are the lack of data reflective of patients', families' and providers' needs such as pain and symptom management, psychosocial care, multi-disciplinary treatment and spiritual well-being. Difficulties using administrative data are in linking databases, aggregating data and the usefulness of data.	Authors present population-based indicators of quality end-of-life care for a specific population of decedents with breast cancer. Validity, reliability and feasibility was acceptable for using administrative databases. Population-level data may be limited in capturing other information important to patients, families and providers, for example, spiritual well-being, advanced directives or pain and symptom management.
Grunfeld, E., Urquhart, R., Mykhalovskiy, E., Folkes, A., Johnston, G., Burge, F., Earle, C. & Dent, S. (2008) Toward Population-based Indicators of Quality End-of-Life Care: Testing Stakeholder Agreement	Canada	Quality indicators for end-of-life cancer care potentially measurable from population-based administrative health databases	Modified Delphi	10 quality indicators and two quality indicator subsections were agreed upon as use for quality end-of-life care. Quality indicators demonstrating agreement and acceptability: • Radiation therapy for uncontrolled bone pain for patients with painful bony metastases • Potent antiemetic treatment for highly emetogenic • Frequency of emergency room visits • Intensive care unit days near the end of life • Enrollment in palliative care within 6 months of death • Enrollment in palliative care within 3 days of death • Multidisciplinary care • Time and location of care at monthly visits	Strengths Consensus of indicators determined through a modified Delphi methodology using multidisciplinary panels of cancer care healthcare workers. Limitations Administrative level indicators may be limited in interpretability when considering preferences and local resources for end-of-life care.	Authors assess stakeholder acceptability of quality indicators of end-of-life care potentially measurable by administrative health databases at a population level. Quality indicators assessed for acceptability by multidisciplinary panels consisting of cancer care health professionals and focus groups of patients and bereaved family caregivers.

				• Access to care • Access to palliative care • Regular palliative care assessments • Advance care directives (ethical and legal aspects of care) • Assessment of financial and caregiving resources		
Johnston, G. & Burge, F. (2002) Analytic Framework for Clinician Provision of End-of-Life Care	Canada	Persons receiving care at end of life	Stepwise fashion for developing an analytic framework	Ten quality indicators were mapped to the following dimensions of end-of-life care: Clinician-patient continuity • Percent of patients dying with at least one clinician visit • No. of visits per patient (log transformation) • No. of clinicians providing care to each patient Timing and location of care • Percent of visits occurring in last two weeks of life • Ratio of office to home visits decreases as death nears • Percent of visits during evenings, night, and on weekends Community-centred services • Percent of days spent at home vs. hospital • Percent of patients dying at home • No. of visits to emergency room Multidisciplinary care (Structure/processes of care) • Percent of patients registered in palliative care unit, receiving palliative radiotherapy, etc. *Investigator must specify the length of end-of-life period, must select a clinician or group of clinicians of particular interest	Strengths The principles underlying these indicators are useful for decision making, feasible data collection, reasonable cost, reliable and valid measures, and a balanced overview. These indicators require retrospective data analysis as populations are identified through a group of decedents yet can also be applied in prospective studies. Indicators are thought to be transferrable to other countries with existing administrative databases and indicators are applicable to a range of life-limiting illnesses. Limitations Investigators must specify time period of interest and diverse perspectives from patients and family members not included.	Indicators focused on home care from a primary care perspective and at a population-level and were established based on Canadian literature and previous knowledge.
Leemans, K., Deliens, L., Francke, A., Stichele, R., Van Den Block, L. & Cohen, J. (2015)	Belgium	Patients 18 years and older living and those who died 6 weeks to 6 months earlier, home care population specified	Mixed methods including quantitative cross-	• 84 indicators as a part of three modules and titles reported for each indicator • Numerator and denominator information is available upon request from the authors	Strengths Measurement procedure was found to be feasible by caregivers. Quality indicators were described as valid, feasible, discriminative and useful. Indicators can be generalizable to home care teams,	Mapped to structure, process and outcome domains as well as "(1) physical, psychosocial and spiritual aspects of care; (2) communication and care

Quality indicators for palliative care services: Mixed-method study testing for face validity, feasibility, discriminative power and usefulness		as having at least one face-to-face contact	sectional application		palliative care units and care homes. Indicator consensus process involved representative of multiple perspectives including patients, family members, professional caregivers and policy makers. Limitations Study is limited by the sample of palliative care services where feasibility cannot necessarily be generalized. Response bias may not be able to be fully excluded.	planning and (3) coordination of care" (p. 73).
Miyashita, M., Nakamura, A., Morita, T. & Bito, S. (2008) Identification of Quality Indicators of End-of-Life Cancer Care From Medical Chart Review Using a Modified Delphi Method in Japan	Japan	End-of-life cancer care	Modified delphi method	Thirty quality indicators identified and were mapped to the following domains: • Symptom control (n=8) • Decision making and preference of care (n=5) • Family care (n=11) • Psychosocial and spiritual concern (n=6)	Strengths Quality indicators are generalizable to general wards, palliative care units and home care. Indicators were rated and assessed by multi-professional specialists. Limitations Feasibility is not established by actual measurement and the relationship between outcome measures and quality indicators remains unclear. Limited diverse perspectives on quality indicators included, such as patients and family members.	Quality indicators covered the domains of symptom control, decision-making and preferences, family care and psychosocial and spiritual concerns. In a further study, reliability of the quality indicators is presented (Sato et al., 2008). Feasibility and appropriateness of each indicator was reported.
Raijmakers, N., Galushko, M., Domeisen, F., Beccaro, M., Hagelin, C., Lindqvist, O., Popa-Velea, O., Romotzky, V., Schuler, S., Ellershaw, J. & Ostgathe, C. (2012) Quality Indicators for Care of Cancer Patients in Their Last Days of Life: Literature Update and Experts' Evaluation	Argentina, Italy, Germany, the Netherlands, New Zealand, Slovenia, Sweden, Switzerland and the United Kingdom	Patients with cancer in their last days of life	Literature review and electronic questionnaire	Thirty-four quality indicators were included in which there needed to be a numerator, denominator, and cut-off point. After expert analysis, 18 additional topics for quality indicators for care of dying patients were suggested resulting in 55 additional quality indicators described as 18 structure quality indicators, 21 process quality indicators, and 16 outcome quality indicators. Six quality indicators were included in the final round: • More than 90% of all families served by home palliative care services should have received a home visit on the week following patient's death to provide support during the mourning process	Strengths Quality indicators reviewed by an international panel of multiprofessional palliative care experts and quality indicator development experts in palliative care. Quality was assessed by whether the indicator was a good descriptor and how applicable in was to the last days of life. Indicators were based on perspectives of a large international expert panel. The response rate was reasonable (58%), and efforts were made to include a multiprofessional representation. Limitations Potential validity issues of the survey results given the length and increase in missing values towards the end. This study did not attempt to validate or assess psychometric properties of any measures.	Parsimonious quality indicator set given a strict definition for quality indicators that represents international opinion and consensus but is lacking diverse perspectives from patients and family members. Indicators are relevant to the final days and weeks of life and applicable to multiple settings. Further validation and assessment of psychometric properties is needed.

				• Fewer than 10% of patients who died from cancer received chemotherapy in the last 14 days of life. In at least 75% of all patients during the last week of life no or limited need is present for the following topics: • Pain control • Global score for gastrointestinal symptoms • Global score for pain • Communication from professional to patient and family		
Schenck, A., Rokoske, F., Durham, D., Cagle, J. & Hanson, L. (2010) The PEACE Project: Identification of Quality Measures for Hospice and Palliative Care	United States	Hospice and palliative care recipients	Literature review and Technical Expert Panel	174 measures were initially identified and reviewed and 88 were deemed appropriate to the setting of hospice and palliative care. Of the final 34 PEACE indicators recommended, they were each mapped to the following domains of palliative care: • Physical aspects of care (n=16) • Structure and process (n=4) • Psychological aspects of care (n=3) • Spiritual aspects of care (n=1) Social aspects of care (n=2) • Care of the imminently dying (n=2) • Cultural aspects of care (n=1) • Ethical and legal issues (n=4) • Adverse events (n=1)	Strengths Quality indicators mapped against National Consensus Project domains and cover all domains parsimoniously. Quality indicators were rated based on importance, scientific soundness, feasibility and usability. Limitations Measures that capture access to hospice and palliative care, undesired hospitalization or aggressive treatments and length of stay in hospice are not included. Clinically meaningful lengths of stay in hospice have not been determined and with the challenge of not being able to distinguish patient preference for acute care use, the authors decided to not incorporate hospitalizations or intensive treatment though recognized it can be considered an indicator of poor quality.	A critical review and synthesis of quality indicators established through expert consensus, though lacking the perspectives of patients and family members. Indicators were developed to be applicable to a diverse range of healthcare settings delivering hospice and palliative care and covered all domains established by the National Consensus Project with higher recommendations for the physical domain. Indicators still require further evidence of feasibility, established reliability and sensitivity. These indicators are overall focused on process of care rather than clinical outcomes.

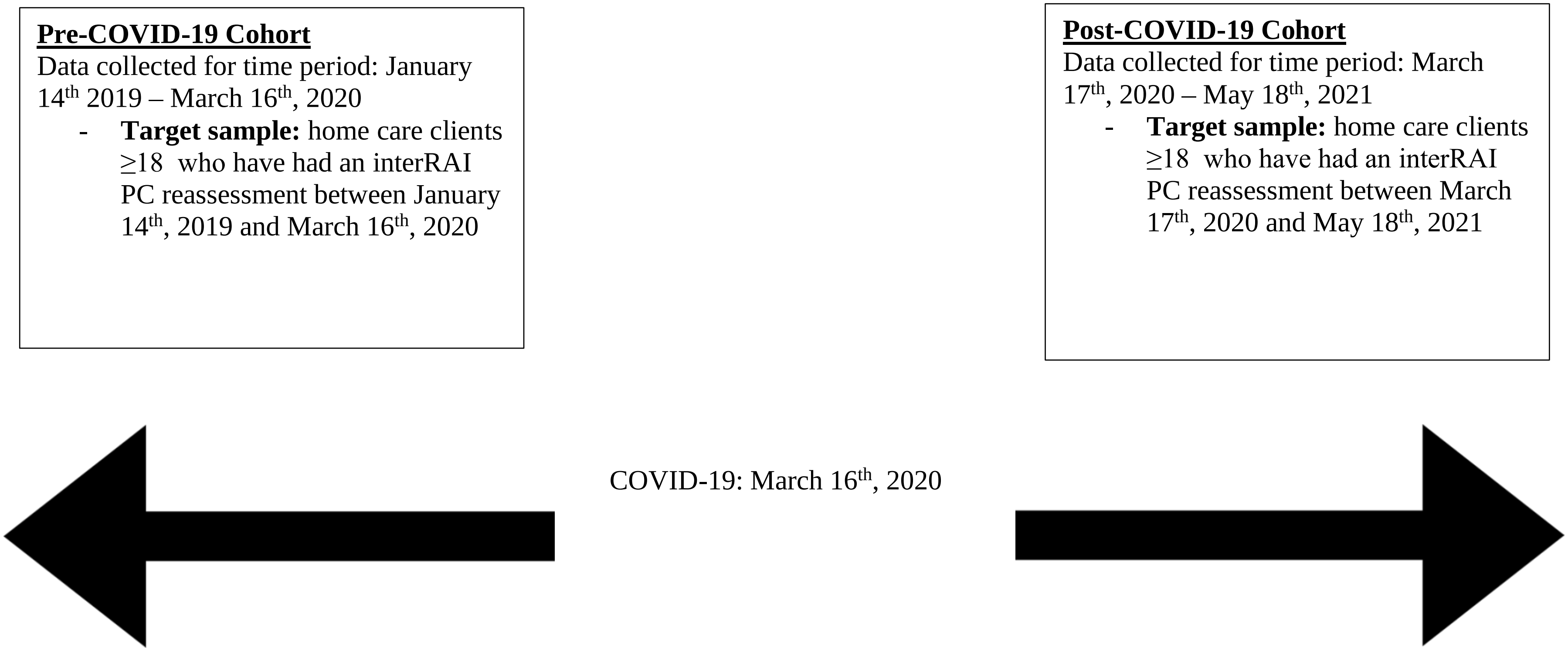
Appendix D

Summary of Quality Indicators Mapped to the National Consensus Project Framework

Domain and Subdomain	Number	Percentage (%)
Structure and Processes of Care		
Healthcare service use	37	9.9
Healthcare professional involvement	42	11.3
Treatments and investigations	35	9.4
Medication	24	6.5
Other	15	4.0
Physical Aspects of Care		
Pain	21	5.6
Other symptoms	27	7.3
Adverse events	3	1.0
Other	14	3.8
Psychological and Psychiatric Aspects of Care		
Delirium	6	1.6
Depression/Anxiety	12	3.2
Caregiver/Family	46	12.4
Other	15	4.0
Social Aspects of Care	30	8.0
Spiritual, Religious, and Existential Aspects of Care	10	2.7
Cultural Aspects of Care	1	0.27
Care of the Patient Nearing the End of Life	5	1.3
Place of death	11	3.0
Ethical and Legal Aspects of Care		
Advanced care planning	11	3.0
Ethical principles	7	1.9
Total	372	100

Appendix E

Cohort Definition and Timeline



Pre-COVID-19 Cohort

Data collected for time period: January 14th 2019 – March 16th, 2020

- **Target sample:** home care clients ≥18 who have had an interRAI PC reassessment between January 14th, 2019 and March 16th, 2020

Post-COVID-19 Cohort

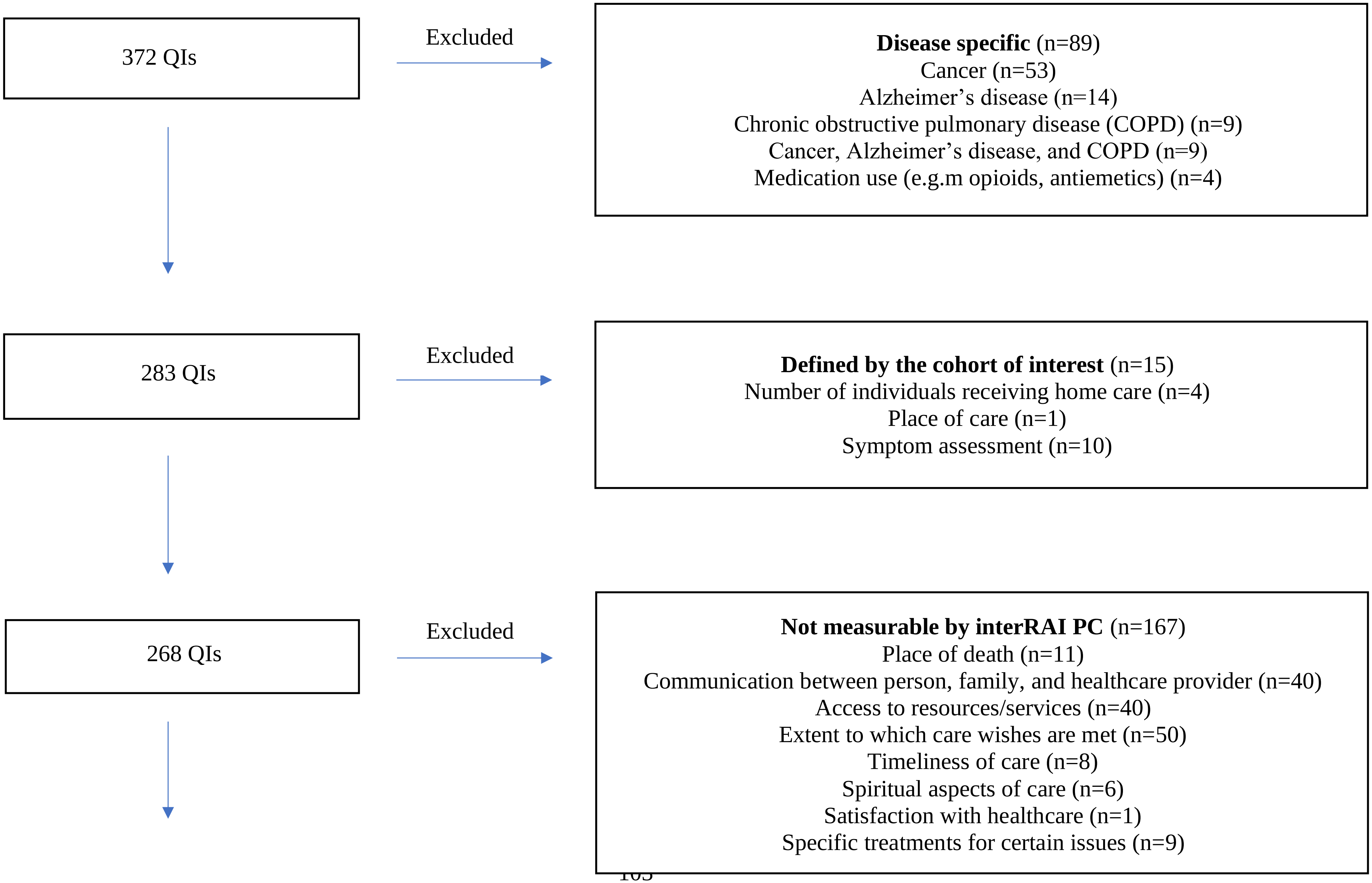
Data collected for time period: March 17th, 2020 – May 18th, 2021

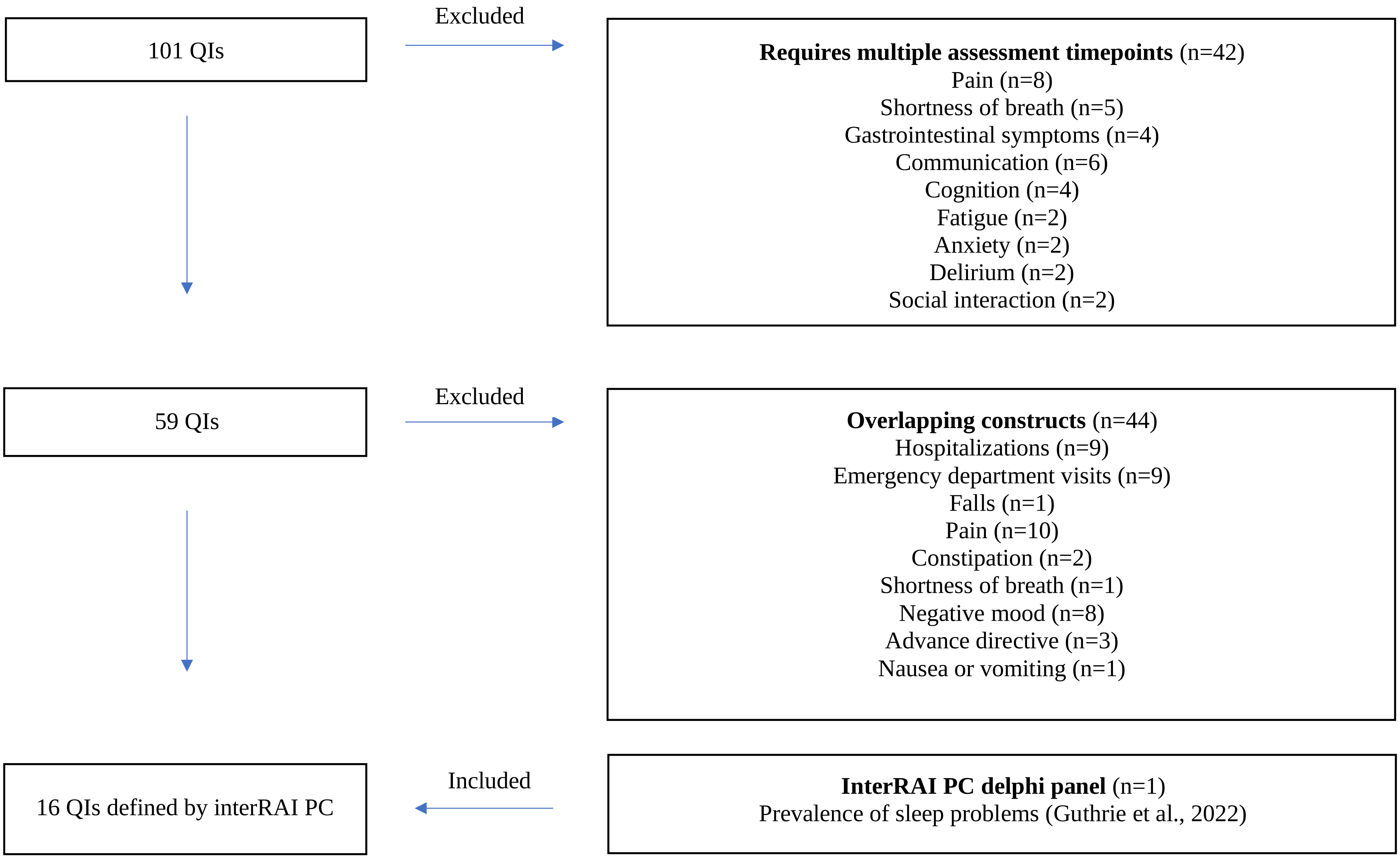
- **Target sample:** home care clients ≥18 who have had an interRAI PC reassessment between March 17th, 2020 and May 18th, 2021

COVID-19: March 16th, 2020

Appendix F

Flow Chart of Final Quality Indicators




101 QIs
Excluded
Requires multiple assessment timepoints (n=42)
Pain (n=8)
Shortness of breath (n=5)
Gastrointestinal symptoms (n=4)
Communication (n=6)
Cognition (n=4)
Fatigue (n=2)
Anxiety (n=2)
Delirium (n=2)
Social interaction (n=2)
59 QIs
Excluded
Overlapping constructs (n=44)
Hospitalizations (n=9)
Emergency department visits (n=9)
Falls (n=1)
Pain (n=10)
Constipation (n=2)
Shortness of breath (n=1)
Negative mood (n=8)
Advance directive (n=3)
Nausea or vomiting (n=1)
16 QIs defined by interRAI PC
Included
InterRAI PC delphi panel (n=1)
Prevalence of sleep problems (Guthrie et al., 2022)

Appendix G

Table Describing Quality Indicators

Indicator				
Title	**Numerator** (*interRAI item number included following each descriptor in brackets)	**Denominator**	**Associated Database/Question**	**National Consensus Project Domains of Palliative Care**
Prevalence of emergency department (ED) visits within the last 90 days of life[1,2,3,4,5,6]	Home care clients* who had ≥1 ED visit in the last 90 days of life (M3b≥ 1)*	All home care clients on re-assessment	**interRAI-PC** **Section M: Treatments and Procedures** 3. Hospital and emergency room use b) Emergency room visit (not counting overnight stay), Code is for number of times during the last 90 days (or since last assessment if < 90 days)	**Structure and Processes of care**
Prevalence of hospital admissions within the last 90 days of life[1,2,3,4,5,7]	Home care clients who had ≥1 hospitalization in the last 90 days of life (M3a≥ 1)	All home care clients on re-assessment	**interRAI-PC** **Section M: Treatments and Procedures** 3. Hospital and emergency room use a) In-patient acute hospital with overnight stay, Code is for number of times during the last 90 days (or since last assessment if < 90 days)	**Structure and Processes of care**
Prevalence of Falls[5,8,9]	Home care clients who recorded a fall on a follow up assessment (1+ falls in last 90 days (C4=1, 2, 3 or more as 0= no falls in last 90 days, 1=1 fall, 2=2 falls) and J2g= 0, 1, 2, 3, 4, 5)	All home care clients on re-assessment not completely dependent on bed mobility in cohort	**interRAI PC** **Section C: Health Conditions** 4. Falls: ≥1 (1=fall 31-90 days ago, 2=one fall in last 30 days, 3=two or more falls in last 30 days) **Section J: Functional Status** 2. g) Bed mobility: how moves to and from lying position, turns from side to side, and positions body while in bed (0=independent, 1-independent set up help only, 2=supervision, 3=limited assistance, 4=extensive assistance, 5=maximal assistance, 6=total dependence)	**Physical Aspects of Care**

Prevalence of Disruptive or Intense Daily Pain[6,7,8,9,10, 11,12]	Home care client is having daily pain (C1a=2, 3) -AND- It is severe or excruciating pain (C1b=3, 4)	All home care clients on re-assessment	**interRAI PC** **Section C: Health Conditions** 1. Pain Symptoms a) Frequency with which person complains or shows evidence of pain (=2, 3) b) Intensity of highest level of pain present (=3, 4)	**Physical Aspects of Care**
Prevalence of Severe or Excruciating Pain that is Inadequately Controlled by Medication[6,7,8,12]	Home care client has severe or excruciating (C1a=3, 4) daily pain (C1b=2, 3) -AND- pain is uncontrolled by medications (C1g=4, 5)	All home care clients on re-assessment	**interRAI PC** **Section C: Health Conditions** 1. Pain Symptoms a) Frequency with which person complains or shows evidence of pain frequency is daily (=2, 3) b) Intensity of highest level of pain present (=3, 4) g) Pain control – adequacy of current therapeutic regimen to control pain (from person's point of view) (=4, 5)	**Physical Aspects of Care**
Prevalence of Constipation[7,8,9,10]	Home care client has no bowel movement in 3 days (C6d= 2, 3, 4)	All home care clients on re-assessment	**interRAI PC** **Section C: Health Conditions** 6. Problem Frequency – GI Status d) Constipation: no bowel movement in 3 days or difficult passage of hard stool (2, 3, 4)	**Physical Aspects of Care**
Prevalence of Shortness of Breath at rest[6,9,10]	Client experiences shortness of breath at rest (C2=3)	All home care clients on re-assessment	**interRAI PC** **Section C: Health Conditions** 2. Dyspnea (=1 Absent at rest, but present when performed moderate activities, =2 Absent at rest, but present when performed normal day-to-day activities, =3 Present at rest)	**Physical Aspects of Care**
Prevalence of Shortness of Breath upon exertion[6,9,10]	Client experiences shortness of breath when performing moderate or normal day-to-day activities (C2=1, 2)	All home care clients on re-assessment	**interRAI PC** **Section C: Health Conditions** 2. Dyspnea (=1 Absent at rest, but present when performed moderate activities, =2 Absent at rest, but present when performed normal day-to-day activities, =3 Present at rest)	**Physical Aspects of Care**

Prevalence of Caregiver Distress[8]	Home care client's primary caregiver experiences feelings of distress, anger or depression (O4c=1)	All home care clients on re-assessment who have a primary caregiver	**interRAI-PC** **Section O: Social Supports** 4. Informal Helper Status c) Primary informal helper expresses feelings of distress, anger, or depression (=1)	**Psychological and Psychiatric Aspects of Care**
Prevalence of Negative Mood[8]	Home care client has signs/symptoms of depression (Depression Rating Scale [DRS] score ≥3)	All home care clients on re-assessment	**interRAI PC** **Section H. Mood** 1. Indicators of Possible Depressed, Anxious, or Sad Mood a) Made negative statements b) Persistent anger with self or others c) Expressions, including nonverbal, of what appear to be unrealistic fears d) Repetitive health complaints e) Repetitive anxious complaints / concerns (non-health related) f) Sad, pained, or worried facial expressions g) Crying, tearfulness Depression Rating Scale [DRS] score 3+, DRS scores range from 0 to 14	**Psychological and Psychiatric Aspects of Care**
Prevalence of no Advance Directive[6,9,11]	Home care client has no advance directives for avoiding common medical treatments (e.g., no directive for resuscitation nor for hospitalization) N2a=0, N2b=0, N2c=0, N2d=0, N2e=0, N2f=0)	All home care clients on re-assessment	**interRAI-PC** **Section N: Responsibility / Directives** 2. Advance Directives 0 = Not in place 1 = In place a. Advance directives for not resuscitating b. Advance directives for not intubating c. Advance directives for not hospitalizing d. Advance directives for not sending to emergency department e. Advance directives for not tube feeding f. Advance directives for medication restriction	**Ethical and Legal Aspects of Care**

Prevalence of stasis/pressure ulcers[5]	Home care client experiences a pressure ulcer (E1= 1+) OR stasis ulcer (E3= 1)	All home care clients on re-assessment who are not imminently dying (death expected within days)	**interRAI-PC** **Section E. Skin Condition** 1. Most severe pressure ulcer (1+) 3. Presence of skin ulcer other than pressure ulcer (E.g., venous ulcer, arterial ulcer, mixed venous-arterial ulcer, diabetic foot ulcer) (1=Yes)	**Physical Aspects of Care**
Prevalence of a delirium-like syndrome[11]	Home care client experiences an acute change in mental status (F5=1) from their usual functioning and they experience one of: a fluctuating state of consciousness (F2=1), mental functioning that varies over the course of the day (F4c=1, 2), hallucinations or delusions (C6o=2, 3, 4)	All home care clients on re-assessment	**interRAI-PC** **Section F. Cognition** 5. Acute change in mental status from person's usual functioning—e.g., restlessness, lethargy, difficult to arouse, altered environmental perception (=1) AND 2. Fluctuating state of consciousness (=1) OR 4. Periodic disordered thinking or awareness c. Mental function varies over the course of the day (=1, 2) OR **Section C. Health Conditions** 6. Problem Frequency – Other o) Hallucinations (=2, 3, 4)	**Psychological and Psychiatric Aspects of Care**
Prevalence of nausea or vomiting[9]	Home care client experiences nausea (C6g= 2,3,4) or vomiting (C6h= 2,3,4)	All home care clients on re-assessment	**interRAI-PC** **Section C: Health Conditions** 6. Problem Frequency – GI Status g) Nausea (=2, 3, 4) h) Vomiting (=2, 3, 4)	**Physical Aspects of Care**

Prevalence of fatigue[10]	Home care client has the inability to complete normal daily activities (e.g., ADLs, IADLS) due to diminished energy (C3= 2, 3, 4)	All home care clients on re-assessment	**interRAI-PC** **Section C: Health Conditions** 3. Fatigue Moderate—Due to diminished energy, UNABLE TO FINISH normal day-to-day activities (=2) Severe – Due to diminished energy, UNABLE TO START SOME normal day-to-day activities (=3) Unable to commence any normal day-to-day activities (=4)	**Physical Aspects of Care**
Prevalence of sleep problems[13]	Home care client has difficulty falling asleep, staying asleep, waking up too early, experiences restlessness or experiences non-restful sleep (C6i= 2, 3, 4)	All home care clients on re-assessment	**interRAI-PC** **Section C: Health Conditions** 6. Problem Frequency – Sleep Problems i) Difficulty falling asleep or staying asleep; waking up too early; restlessness; non-restful sleep (=2, 3, 4)	**Physical Aspects of Care**

*Home care clients defined as >18 years with >1 interRAI-PC assessment

1. Barbera et al., 2015a; 2015b
2. De Schreye et al., 2017
3. Earle et al., 2003, 2005
4. Johnston & Burge, 2002
5. Grunfeld et al., 2006, 2008
6. Leemans et al., 2015
7. Peruselli et al., 1997
8. Harman et al., 2019
9. Schenck et al., 2010
10. Claessen et al., 2011
11. Miyashita et al., 2008
12. Raijmakers et al., 2012
13. Guthrie et al., 2022

Appendix H

Final Quality Indicator Definitions and Calculations

Title	**Numerator and Denominator Definitions** (*interRAI item number included following each descriptor in brackets)	**InterRAI PC Definition**
Prevalence of severe or excruciating daily pain	**N:** Client has daily pain that is severe or excruciating (pain_pc1 >= 3)* **D:** All clients who have had a re-assessment	**Section C: Health Conditions** 0. Pain Symptoms a) Frequency with which person complains or shows evidence of pain (=2, 3) 0 = No pain, 1 = Present, but not exhibited in last 3 days, 2 = Exhibited on 1-2 of last 3 days, 3 = Exhibited daily in last 3 days b) Intensity of highest level of pain present (=3, 4) 0 = No pain, 1 = Mild, 2 = Moderate, 3 = Severe 4 = Times when pain is horrible or excruciating **- Pain Scale –** *The interRAI Pain Scale uses two items (frequency and intensity of pain) to create a scale from 0 to 4. Scoring of the Pain Scale:* 0 = No pain, 1 = Less than daily pain, 2 = Daily pain, but not severe or excruciating, 3 = Daily pain that is severe, 4 = Daily pain that is excruciating
Prevalence of severe or excruciating pain that is not controlled by therapeutic regimen	**N:** Client has daily pain that is severe or excruciating and pain is not controlled by current therapeutic regimen (pain_pc1 >= 3 AND C1g = 4, 5) **D:** All clients who have had a	**Section C: Health Conditions** 1. Pain Symptoms a) Frequency with which person complains or shows evidence of pain (=2, 3) 0 = No pain, 1 = Present, but not exhibited in last 3 days, 2 = Exhibited on 1-2 of last 3 days, 3 = Exhibited daily in last 3 days b) Intensity of highest level of pain present (=3, 4)

	re-assessment	0 = No pain, 1 = Mild, 2 = Moderate, 3 = Severe 4 = Times when pain is horrible or excruciating g) Pain control – adequacy of current therapeutic regimen to control pain (from person's point of view) (=4, 5) 0 = No issue of pain 1 = Pain intensity acceptable to person; no treatment regimen or change in regimen required, 2 = Controlled adequately by therapeutic regimen, 3 = Controlled when therapeutic regimen followed, but not always followed as ordered, 4 = Therapeutic regimen followed, but pain control not adequate, 5 = No therapeutic regimen being followed for pain; pain not adequately controlled
Prevalence of emergency department visits	**N:** Client experiences an emergency department visit without an overnight stay (M3b >/= 1 AND A12a = 2, 3, 4) **D:** All clients who have a re-assessment and who are not imminently dying (A12a = 2, 3, 4)	**Section M: Treatments and Procedures** 3. Hospital and emergency room use b) Emergency room visit (not counting overnight stay), Code is for number of times during the last 90 days (or since last assessment if < 90 days) **Section A: Identification Information** 12. Prognosis a) Death imminent (within days) (=1), Less than 6 weeks (=2), 6 weeks or longer, but less than 6 months (=3), 6 months or longer (=4)
Prevalence of hospital admissions	**N:** Client experiences at least one hospital admission with an overnight stay (M3a >/= 1 AND A12a = 2, 3, 4) **D:** All clients who have a	**Section M: Treatments and Procedures** 3. Hospital and emergency room use 2. In-patient acute hospital with overnight stay, Code is for number of times during the last 90 days (or since last assessment if < 90 days) **Section A: Identification Information**

	re-assessment and who are not imminently dying (A12a = 2, 3, 4)	12. Prognosis a) Death imminent (within days) (=1), Less than 6 weeks (=2), 6 weeks or longer, but less than 6 months (=3), 6 months or longer (=4)
Prevalence of falls	**N:** Client experienced one or more falls within the last 90 days (C4 >/= 1 AND J2g = 0, 1, 2, 3, 4, 5) **D:** All clients who have a re-assessment and are not completely dependent in bed mobility (J2g == 0, 1, 2, 3, 4, 5)	**Section C: Health Conditions** 4. Falls: ≥1 (1=fall 31-90 days ago, 2=one fall in last 30 days, 3=two or more falls in last 30 days) **Section J: Functional Status** 2. g) Bed mobility: how moves to and from lying position, turns from side to side, and positions body while in bed (0=independent, 1- independent set up help only, 2=supervision, 3=limited assistance, 4=extensive assistance, 5=maximal assistance, 6=total dependence)
Prevalence of constipation	**N:** Client experiences constipation, no bowel movement in three days or difficult passage of hard stool (C6d = 2, 3, 4) **D:** All clients who have had a re-assessment	**Section C: Health Conditions** 6. Problem Frequency – GI Status d) Constipation: no bowel movement in 3 days or difficult passage of hard stool (2, 3, 4) 0 = Not present, 1 = Present, but not exhibited in last 3 days, 2 = Exhibited on 1 of last 3 days, 3 = Exhibited on 2 of last 3 days, 4 = Exhibited daily in last 3 days
Prevalence of shortness of breath at rest	**N:** Client experiences shortness of breath at rest (C2 = 3) **D:** All clients who have had a re-assessment	**Section C: Health Conditions** 2. Dyspnea (=1 Absent at rest, but present when performed moderate activities, =2 Absent at rest, but present when performed normal day-to-day activities, =3 Present at rest)
Prevalence of shortness of breath when	**N:** Client experiences shortness of breath when performing moderate or normal day-to-day activities	**Section C: Health Conditions**

performing moderate/normal day-to-day activities	(C2 = 1, 2) **D:** All clients who have had a re-assessment	2. Dyspnea (=1 Absent at rest, but present when performed moderate activities, =2 Absent at rest, but present when performed normal day-to-day activities, =3 Present at rest)
Prevalence of caregiver distress	**N:** Client's primary caregiver expresses feelings of distress, anger, or depression (O4c = 1 AND O2aA = 0, 1, 2, 3, 4, 5, 6, 7, 8) **D:** All clients on re-assessment with a primary caregiver (O2aA = 0, 1, 2, 3, 4, 5, 6, 7, 8)	**Section O: Social Supports** 4. Informal Helper Status c) Primary informal helper expresses feelings of distress, anger, or depression (0=No, 1=Yes) **Section O: Social Supports** 2. Two Key Informal Helpers a. Relationship to person 1 = Child or child-in-law, 2 = Spouse, 3 = Partner/significant other, 4 = Parent/guardian, 5 = Sibling, 6 = Other relative, 7 = Friend, 8 = Neighbour, 9 = No informal helper
Prevalence of negative mood	**N:** Client has a DRS score of ≥4 (drs_pc1 >= 4) **D:** All clients who have had a re-assessment	**Section H. Mood** 1. Indicators of Possible Depressed, Anxious, or Sad Mood a) Made negative statements, b) Persistent anger with self or others c) Expressions, including nonverbal, of what appear to be unrealistic fears, d) Repetitive health complaints, e) Repetitive anxious complaints / concerns (non-health related), f) Sad, pained, or worried facial expressions, g) Crying, tearfulness Depression Rating Scale [DRS] score 4+, DRS scores range from 0 to 14 Each of 7 items are scored as follows: 0 = Not present/present, but not exhibited in last 3 days, 1 = Exhibited on 1-2 of last 3 days, 2 = Exhibited daily in last 3 days
Prevalence of no advance directives	**N:** Client does not have an advance directive in place for any of the following: not resuscitating, not intubating, not hospitalizing, sending	**Section N: Responsibility / Directives** 2. Advance Directives 0 = Not in place 1 = In place a. Advance directives for not resuscitating b. Advance directives for not intubating

	to emergency department, not tube feedback, and medication restriction (N2a = 0 AND N2b = 0 AND N2c = 0 AND N2d = 0, AND N2e = 0 AND N2f = 0) **D:** All clients who have had a re-assessment	c. Advance directives for not hospitalizing d. Advance directives for not sending to emergency department e. Advance directives for not tube feeding f. Advance directives for medication restriction
Prevalence of ulcers	**N:** Client has a pressure ulcer or another type of ulcer (E1 >/= 1 OR E3 = 1 AND A12a = 2, 3, 4) **D:** All clients who have a re-assessment who are not imminently dying (A12a = 2, 3, 4)	**Section E. Skin Condition** 3. Most severe pressure ulcer (1+) 0 = No pressure ulcer, 1 = Any area of persistent skin redness, 2 = Partial loss of skin layers, 3 = Deep craters in the skin, 4 = Breaks in skin exposing muscle or bone, 5 = Not codeable – e.g., necrotic eschar predominant 3. Presence of skin ulcer other than pressure ulcer (E.g., venous ulcer, arterial ulcer, mixed venous-arterial ulcer, diabetic foot ulcer) (1=Yes) **Section A: Identification Information** 12. Prognosis a) Death imminent (within days) (=1), Less than 6 weeks (=2), 6 weeks or longer, but less than 6 months (=3), 6 months or longer (=4)
Prevalence of a delirium-like syndrome	**N:** Client experiences an acute change in mental status and also experiences at least one of the following: Fluctuating state of consciousness, Mental functioning varies over the course of the day or Hallucinations (F5 = 1 AND (F2 = 1 OR F4c = 1, 2 OR C6o = 2, 3, 4) AND A12a = 2, 3, 4)	**Section F. Cognition** 5. Acute change in mental status from person's usual functioning—e.g., restlessness, lethargy, difficult to arouse, altered environmental perception (0=No, 1=Yes) AND 2. Fluctuating state of consciousness (0=No, 1=Yes) OR 4. Periodic disordered thinking or awareness c. Mental function varies over the course of the day (=1, 2)

	D: All clients who have a re-assessment who are not imminently dying (A12a = 2, 3, 4)	0 = Behaviour not present, 1 = Behaviour present, consistent with usual functioning, 2 = Behaviour present, appears different from usual functioning, (e.g., new onset or worsening; different from a few weeks ago) OR **Section C. Health Conditions** 6. Problem Frequency – Other o) Hallucinations (=2, 3, 4) 0 = Not present, 1 = Present, but not exhibited in last 3 days, 2 = Exhibited on 1 of last 3 days, 3 = Exhibited on 2 of last 3 days, 4 = Exhibited daily in last 3 days **Section A: Identification Information** 12. Prognosis a) Death imminent (within days) (=1), Less than 6 weeks (=2), 6 weeks or longer, but less than 6 months (=3), 6 months or longer (=4)
Prevalence of nausea or vomiting	**N:** Client experiences vomiting or nausea (C6g = 2, 3, 4 OR C6h = 2, 3, 4) **D:** All clients who have had a re-assessment	**Section C: Health Conditions** 6. Problem Frequency – GI Status g) Nausea (=2, 3, 4) h) Vomiting (=2, 3, 4) 0 = Not present, 1 = Present, but not exhibited in last 3 days, 2 = Exhibited on 1 of last 3 days, 3 = Exhibited on 2 of last 3 days, 4 = Exhibited daily in last 3 days
Prevalence of fatigue	**N:** Client experiences an inability to complete normal day-to-day activities due to fatigue (C3 = 2, 3, 4) **D:** All clients who have had a	**Section C: Health Conditions** 3. Fatigue Moderate—Due to diminished energy, UNABLE TO FINISH normal day-to-day activities (=2) Severe – Due to diminished energy, UNABLE TO START SOME normal day-to-day activities (=3)

	re-assessment	Unable to commence any normal day-to-day activities (=4)
Prevalence of sleep problems	**N:** Client has difficulty falling asleep, staying asleep, waking up too early, experiences restlessness or experiences non-restful sleep (C6i = 2, 3, 4) **D:** All clients who have had a re-assessment	**Section C: Health Conditions** 6. Problem Frequency – Sleep Problems i) Difficulty falling asleep or staying asleep; waking up too early; restlessness; non-restful sleep (=2, 3, 4) 0 = Not present, 1 = Present, but not exhibited in last 3 days, 2 = Exhibited on 1 of last 3 days, 3 = Exhibited on 2 of last 3 days, 4 = Exhibited daily in last 3 days

Appendix I

List of Covariates for Propensity Score Analysis

Covariates	**Coding**
Sex	1=Male 2=Female
Age	Year-Month
Marital status	1=Never married 2=Married 3=Partner/significant other 4=Widowed 5=Separated 6=Divorced
Home Care Jurisdiction Identifier	Coded as an acronym (e.g., CHA, NA)
Living arrangement	1=Alone 2=With spouse/partner only 3=With spouse/partner and other(s) 4=With child (not spouse/partner) 5=With parent(s) or guardian(s) 6=With sibling(s) 7=With other relative(s) 8=With nonrelative(s)
Time since last hospital stay	0=No hospitalization within 90 days 1=31 to 90 days ago 2=15 to 30 days ago 3=8 to 14 days ago 4=In the last 7 days 5=Now in hospital
Instrumental Activities of Daily Living Self-Performance: Meal preparation, ordinary housework, managing medications	0=Independent 1=Set-up help only 2=Supervision 3=Limited assistance 4=Extensive assistance 5=Maximal assistance 6=Total dependence 8=Activity did not occur
Activities of Daily Living Self-Performance: bathing, personal hygiene, walking, locomotion, transfer toilet, toilet use, eating	0=Independent 1=Set-up help only 2=Supervision 3=Limited assistance 4=Extensive assistance 5=Maximal assistance 6=Total dependence 8=Activity did not occur

Formal care: Home health aides: number of days	Continuous variable (number of days)
Formal care: Home health aides: total minutes in last week	Continuous variable (total minutes in last week)
Formal care: Home nurse: number of days	Continuous variable (number of days)
Formal care: Home nurse: total minutes in last week	Continuous variable (total minutes in last week)
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) score	0=No symptoms 1=Minimal health instability 2=Low health instability 3=Moderate health instability 4=High health instability

Appendix J

Ethics Approval Certificate from Hamilton Integrated Research Ethics Board

HiREB
Hamilton Integrated Research Ethics Board

Sep-29-2021

Project Number:13960-C

Project Title: Comparing Quality Indicators for Home Care Clients Receiving Palliative Care Before and During the COVID-19 Pandemic

Local Principal Investigator: Dr. Sharon Kaasalainen

This will acknowledge receipt of your Retrospective Review of Medical Charts/Health Records Application for the above named study. We wish to confirm that the study has been reviewed by the HiREB Executive and has been given final approval. The submission has been approved on ethical, scientific and privacy grounds.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
interRAI Canada Data Server access policy	Aug-17-2021	Aug-17-2021
Thesis Research Proposal - Kruizinga, J. vAugust 26	Aug-26-2021	26Aug2021
interRAI-PC_with_watermark	Sep-20-2021	September 20 2021

We are pleased to issue ***final approval*** for the above-named study for a period of 12 months from the date of this approval letter. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or study documents must be approved by the Hamilton Integrated Research Ethics Board.

Retrospective chart review applications may proceed remotely. If this chart review application is part of a larger quality improvement project (involving residents/staff/patients), the chart review portion may proceed, but please check with your Department Head/Chair about the implementation of the overall project.

It is important to point out that you are permitted to retrieve only the data that you have included in your approved Data Collection Form.

If you require a listing of chart identifiers for this project, please contact the Decision Support Services department who will be able to assist you with this data extraction. There will be a charge for data extraction so please discuss your requirements to enable the assigned analyst to generate an estimate of workload. Decision Support Services will require your written consent to pay prior to commencing with the data extraction. Please allow 4-6 weeks for the completion of the request after your consent to pay is received. If you have any questions regarding the billing and consent process, you should discuss this as well.

Once you have the chart identifiers and you require access to the patient's health records through the Health Records Department at Hamilton Health Sciences, please submit the listing as follows:

MUMC, Juravinski Hospital, Juravinski Cancer Centre, Hamilton General, Chedoke and St. Peters, contact:
Mike Taylor, Manager, Health Records, ext 76767.

If you require any type of computer assistance, including passwords, please contact the Hamilton Health Sciences ICT department at ext 43000.

Sincerely,

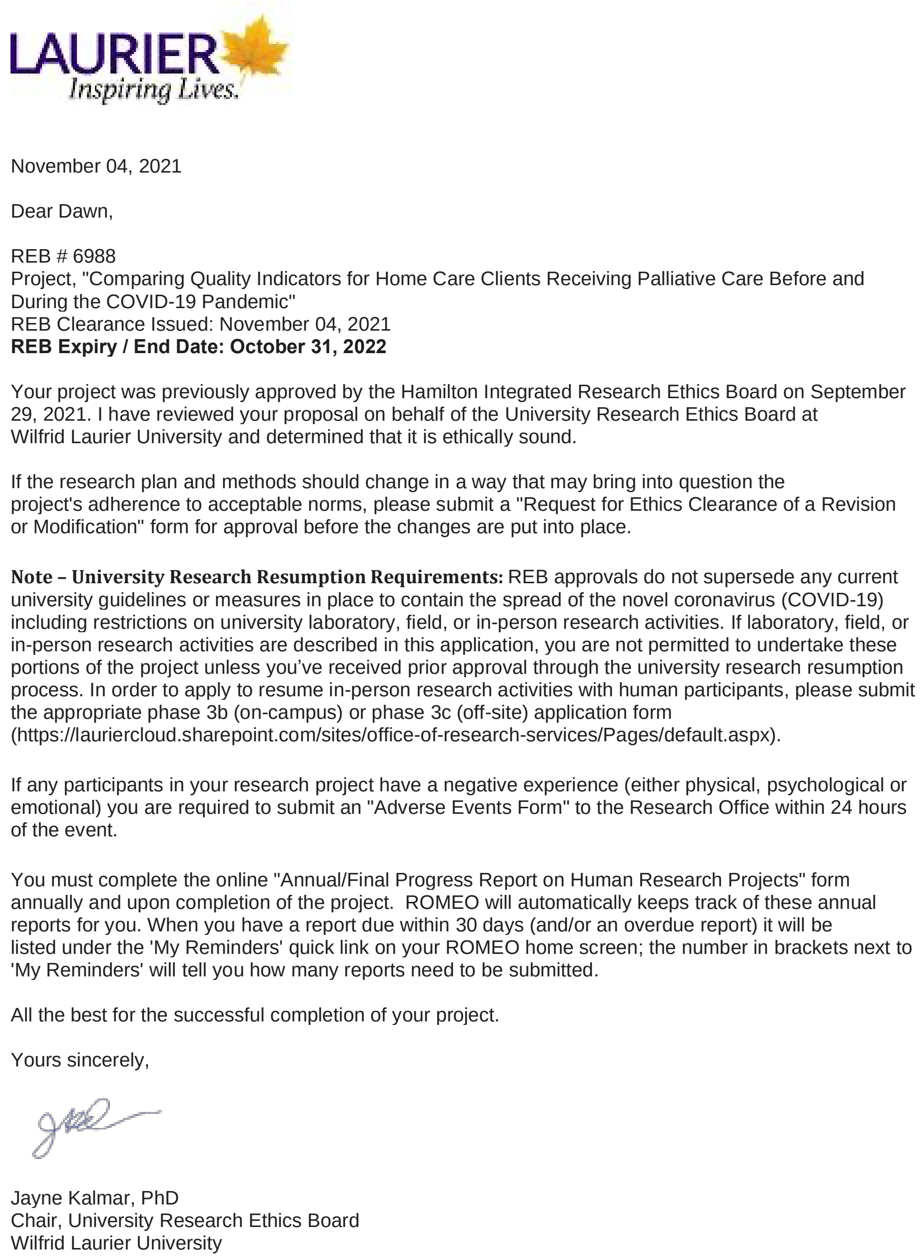
Dr. Mark Inman, MD, PhD
Chair, Hamilton Integrated Research Ethics Board

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

The Hamilton Integrated Research Ethics Board (HiREB) represents the institutions of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, Research St. Joseph's-Hamilton, and the Faculty of Health Sciences at McMaster University and operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; For studies conducted at St. Joseph's Healthcare Hamilton, HiREB complies with the Health Ethics Guide of the Catholic Alliance of Canada

Appendix K

Ethics Approval Certificate from Wilfrid Laurier University's Research Ethics Board



LAURIER
Inspiring Lives.

November 04, 2021

Dear Dawn,

REB # 6988
Project, "Comparing Quality Indicators for Home Care Clients Receiving Palliative Care Before and During the COVID-19 Pandemic"
REB Clearance Issued: November 04, 2021
REB Expiry / End Date: October 31, 2022

Your project was previously approved by the Hamilton Integrated Research Ethics Board on September 29, 2021. I have reviewed your proposal on behalf of the University Research Ethics Board at Wilfrid Laurier University and determined that it is ethically sound.

If the research plan and methods should change in a way that may bring into question the project's adherence to acceptable norms, please submit a "Request for Ethics Clearance of a Revision or Modification" form for approval before the changes are put into place.

Note – University Research Resumption Requirements: REB approvals do not supersede any current university guidelines or measures in place to contain the spread of the novel coronavirus (COVID-19) including restrictions on university laboratory, field, or in-person research activities. If laboratory, field, or in-person research activities are described in this application, you are not permitted to undertake these portions of the project unless you've received prior approval through the university research resumption process. In order to apply to resume in-person research activities with human participants, please submit the appropriate phase 3b (on-campus) or phase 3c (off-site) application form (https://lauriercloud.sharepoint.com/sites/office-of-research-services/Pages/default.aspx).

If any participants in your research project have a negative experience (either physical, psychological or emotional) you are required to submit an "Adverse Events Form" to the Research Office within 24 hours of the event.

You must complete the online "Annual/Final Progress Report on Human Research Projects" form annually and upon completion of the project. ROMEO will automatically keeps track of these annual reports for you. When you have a report due within 30 days (and/or an overdue report) it will be listed under the 'My Reminders' quick link on your ROMEO home screen; the number in brackets next to 'My Reminders' will tell you how many reports need to be submitted.

All the best for the successful completion of your project.

Yours sincerely,

Jayne Kalmar, PhD
Chair, University Research Ethics Board
Wilfrid Laurier University

Appendix L

Pre-COVID and COVID Cohort Assessment Breakdown

Type of assessment	**Pre-COVID (n=**27,625)	**COVID (n=**13,320)
	n (%)	
First assessment	16,154 (58.5%)	9,094 (68.3%)
Routine reassessment	9,965 (36.1%)	3,634 (27.3%)
Return assessment	770 (2.8%)	234 (1.8%)
Significant change in status reassessment	733 (2.7%)	355 (2.7%)
Other – e.g., research	1 (0.0 %)	1 (0.0 %)
Total number of assessments	**n (%)**	
1 assessment	14,736 (73.2%)	9,379 (84.1%)
2 assessments	3,823 (19.0%)	1,481 (13.3%)
3 assessments	1,122 (5.6%)	245 (2.2%)
4 assessments	370 (1.8%)	42 (0.4%)
5 assessments	70 (0.3%)	10 (0.0%)
6 assessments	5 (0.0%)	4 (0.0%)
7 assessments	1 (0.0%)	0 (0.0%)
8 assessments	1 (0.0%)	0 (0.0%)
Total	20,128 (n=2 NA Client Identifiers)	11,158 (n=2 NA Client Identifiers)

Appendix M

Pre-COVID Cohort: Steps to Arrive at Final Cohort

Steps Taken to Remove Assessments	**Number of Assessments**
# Records falling within start and end date	27,625
# Records with duplicate IDs (all assessments including multiple assessments)	3,480
Non-Duplicate IDs (i.e., IDs unique to pre-COVID cohort)	24,145
Less: # with initial assessments (A8=1)	14,578
Subtotal – # records with non-initial assessments	9,567
# records with 1 non-initial assessment (pre-COVID_final_1)	4,160
# records with multiple non-initial assessments	5,407
# records with most recent non-initial assessment for multiple assessments (pre-COVID_final_2)	2,187
Total – pre-COVID_final_1 + pre-COVID_final_2 – A7 assessments	6,346

Appendix N

COVID Cohort: Steps to Arrive at Final Cohort

Steps Taken to Remove Assessments	**Number of Assessments**
# Records falling within start & end date	13,320
Duplicate IDs (i.e., IDs in both pre-COVID and COVID cohorts)	3,074
Less: # with initial assessments (A8=1)	259
Subtotal - # records with non-initial assessments	2,815
# records with 1 non-initial assessment (COVID_final_1)	1,348
# records with multiple non-initial assessments	1,467
# records with most recent non-initial assessment for multiple assessments (COVID_final_2)	645
Non-Duplicate IDs (i.e., IDs unique to COVID cohort) = 13,320-3074	10,246
Less: # with initial assessments (A8=1)	8,835
Subtotal - # records with non-initial assessments	1,411
# records with 1 non-initial assessment (COVID_final_3)	1,098
# records with multiple non-initial assessments	313
# records with most recent assessment for multiple assessments (COVID_final_4)	141
Total: COVID_final_1 + COVID_final_2 + COVID_final_3 + COVID_final_4 – A7 assessments	3,231

Appendix O

Propensity Score Analysis Before Matching

Variable (n)	**Stratified by Cohort**		
	0	**1**	**SMD**
n	**6132**	**3072**	
Home Care Jurisdiction (%)	n (%)	n (%)	1.403
Central East	636 (10.4)	460 (15.0)	
Central	667 (10.9)	624 (20.3)	
Champlain	655 (10.7)	914 (29.8)	
Central West	0 (0.0)	3 (0.1)	
Erie St. Clair	570 (9.3)	32 (1.0)	
Hamilton Niagara Haldimand Brant	871 (14.2)	47 (1.5)	
Mississauga Halton	70 (1.1)	1 (0.0)	
North East	365 (6.0)	540 (17.6)	
North Simcoe Muskoka	198 (3.2)	224 (7.3)	
North West	57 (0.9)	92 (3.0)	
South East	71 (1.2)	72 (2.3)	
South West	1968 (32.1)	63 (2.1)	
Toronto Central	2 (0.0)	0 (0.0)	
Waterloo Wellington	2 (0.0)	0 (0.0)	
Age (mean (SD))	72.70 (13.33)	73.10 (13.34)	0.030
Sex = 2 (%)	3255 (53.1)	1685 (54.9)	0.035
Marital status (%)			0.070
1=Never married	419 (6.8)	197 (6.4)	
2=Married	3400 (55.4)	1647 (53.6)	
3=Partner/significant other	218 (3.6)	106 (3.5)	
4=Widowed	1414 (23.1)	772 (25.1)	
5=Separated	170 (2.8)	109 (3.5)	
6=Divorced	511 (8.3)	241 (7.8)	
Living arrangement (%)			0.101
1=Alone	1334 (21.8)	646 (21.0)	
2=With spouse/partner only	2628 (42.9)	1216 (39.6)	
3=With spouse/partner and other(s)	864 (14.1)	483 (15.7)	
4=With child (not spouse/partner)	733 (12.0)	433 (14.1)	
5=With parent(s) or guardian(s)	91 (1.5)	54 (1.8)	
6=With sibling(s)	96 (1.6)	43 (1.4)	
7=With other relative(s)	99 (1.6)	64 (2.1)	
8=With nonrelative(s)	287 (4.7)	133 (4.3)	
Time since last hospital stay (%)			0.132
0= No hospitalization within 90 days	4471 (72.9)	2358 (76.8)	
1=31 to 90 days ago	616 (10.0)	242 (7.9)	
2=15 to 30 days ago	361 (5.9)	159 (5.2)	
3=8 to 14 days ago	260 (4.2)	98 (3.2)	

4=In the last 7 days	347 (5.7)	148 (4.8)	
5= Now in hospital	77 (1.3)	67 (2.2)	
Formal care: Home health aides: number of days (mean (SD))	1.91 (2.77)	1.90 (2.76)	0.004
Formal care: Home health aides: total minutes in last week (mean (SD))	216.07 (673.93)	212.25 (577.39)	0.006
Formal care: Home nurse: number of days (mean (SD))	1.92 (2.00)	1.78 (1.87)	0.073
Formal care: Home nurse: total minutes in last week (mean (SD))	101.61 (189.50)	104.88 (243.06)	0.015
Instrumental Activities of Daily Living Self-Performance – Meal preparation (%)			0.123
0=Independent	1115 (18.2)	427 (13.9)	
1=Set-up help only	130 (2.1)	59 (1.9)	
2=Supervision	79 (1.3)	46 (1.5)	
3=Limited assistance	825 (13.5)	422 (13.7)	
4=Extensive assistance	548 (8.9)	304 (9.9)	
5=Maximal assistance	535 (8.7)	285 (9.3)	
6=Total dependence	2817 (45.9)	1493 (48.6)	
8=Activity did not occur	83 (1.3)	36 (1.2)	
Instrumental Activities of Daily Living Self-Performance – Ordinary housework (%)			0.110
0=Independent	677 (11.0)	266 (8.7)	
1=Set-up help only	43 (0.7)	20 (0.7)	
2=Supervision	41 (0.6)	28 (0.9)	
3=Limited assistance	600 (9.8)	293 (9.5)	
4=Extensive assistance	435 (7.1)	260 (8.5)	
5=Maximal assistance	503 (8.2)	303 (9.9)	
6=Total dependence	3727 (60.8)	1850 (60.2)	
8=Activity did not occur	106 (1.7)	52 (1.7)	
Instrumental Activities of Daily Living Self-Performance – Managing medications (%)			0.107
0=Independent	2559 (41.7)	1182 (38.5)	
1=Set-up help only	486 (7.9)	276 (9.0)	
2=Supervision	513 (8.4)	256 (8.3)	
3=Limited assistance	614 (10.0)	343 (11.2)	
4=Extensive assistance	405 (6.6)	185 (6.0)	
5=Maximal assistance	345 (5.6)	141 (4.6)	
6=Total dependence	1169 (19.1)	665 (21.6)	
8=Activity did not occur	41 (0.7)	24 (0.8)	
Activities of Daily Living Self-Performance – Bathing (%)			0.130
0=Independent	1948 (31.8)	812 (26.4)	

1=Set-up help only	227 (3.7)	136 (4.4)	
2=Supervision	463 (7.6)	220 (7.2)	
3=Limited assistance	938 (15.3)	481 (15.7)	
4=Extensive assistance	1022 (16.7)	577 (18.8)	
5=Maximal assistance	565 (9.2)	307 (10.0)	
6=Total dependence	734 (12.0)	422 (13.7)	
8=Activity did not occur	235 (3.8)	117 (3.8)	
Activities of Daily Living Self-Performance – Personal hygiene (%)			0.151
0=Independent	3121 (50.9)	1371 (44.6)	
1=Set-up help only	497 (8.1)	231 (7.5)	
2=Supervision	434 (7.1)	238 (7.7)	
3=Limited assistance	693 (11.3)	422 (13.7)	
4=Extensive assistance	480 (7.8)	309 (10.1)	
5=Maximal assistance	310 (5.1)	152 (4.9)	
6=Total dependence	581 (9.5)	343 (11.2)	
8=Activity did not occur	16 (0.3)	6 (0.2)	
Activities of Daily Living Self-Performance – Walking (%)			0.149
0=Independent	3545 (57.8)	1589 (51.7)	
1=Set-up help only	433 (7.1)	220 (7.2)	
2=Supervision	728 (11.9)	420 (13.7)	
3=Limited assistance	348 (5.7)	221 (7.2)	
4=Extensive assistance	229 (3.7)	118 (3.8)	
5=Maximal assistance	160 (2.6)	62 (2.0)	
6=Total dependence	107 (1.7)	70 (2.3)	
8=Activity did not occur	582 (9.5)	372 (12.1)	
Activities of Daily Living Self-Performance – Locomotion (%)			0.151
0=Independent	3696 (60.3)	1661 (54.1)	
1=Set-up help only	416 (6.8)	201 (6.5)	
2=Supervision	669 (10.9)	373 (12.1)	
3=Limited assistance	325 (5.3)	232 (7.6)	
4=Extensive assistance	232 (3.8)	133 (4.3)	
5=Maximal assistance	155 (2.5)	77 (2.5)	
6=Total dependence	347 (5.7)	232 (7.6)	
8=Activity did not occur	292 (4.8)	163 (5.3)	
Activities of Daily Living Self-Performance – Transfer toilet (%)			0.161
0=Independent	4155 (67.8)	867 (60.8)	
1=Set-up help only	348 (5.7)	194 (6.3)	
2=Supervision	336 (5.5)	208 (6.8)	
3=Limited assistance	278 (4.5)	201 (6.5)	
4=Extensive assistance	268 (4.4)	162 (5.3)	
5=Maximal assistance	186 (3.0)	105 (3.4)	

6=Total dependence	248 (4.0)	173 (5.6)	
8=Activity did not occur	313 (5.1)	162 (5.3)	
Activities of Daily Living Self-Performance – Toilet use (%)			0.163
0=Independent	4279 (69.8)	1926 (62.7)	
1=Set-up help only	279 (4.5)	187 (6.1)	
2=Supervision	261 (4.3)	153 (5.0)	
3=Limited assistance	290 (4.7)	206 (6.7)	
4=Extensive assistance	243 (4.0)	145 (4.7)	
5=Maximal assistance	201 (3.3)	106 (3.5)	
6=Total dependence	458 (7.5)	292 (9.5)	
8=Activity did not occur	121 (2.0)	57 (1.9)	
Activities of Daily Living Self-Performance – Eating (%)			0.107
0=Independent	4169 (68.0)	1943 (63.2)	
1=Set-up help only	935 (15.2)	534 (17.4)	
2=Supervision	338 (5.5)	209 (6.8)	
3=Limited assistance	188 (3.1)	109 (3.5)	
4=Extensive assistance	108 (1.8)	66 (2.1)	
5=Maximal assistance	89 (1.5)	50 (1.6)	
6=Total dependence	286 (4.7)	155 (5.0)	
8=Activity did not occur	19 (0.3)	6 (0.2)	
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) score (%)			0.058
0=No symptoms	876 (14.3)	383 (12.5)	
1=Minimal health instability	1637 (26.7)	838 (27.3)	
2=Low health instability	1709 (27.9)	888 (28.9)	
3=Moderate health instability	1495 (24.4)	739 (24.1)	
4=High health instability	415 (6.8)	224 (7.3)	

	False	**True**	**Sum**
	8	13	21

Appendix P

Propensity Score Analysis using Nearest Neighbour Matching Method

Variable (n)	**Stratified by Cohort**		
	0	**1**	**SMD**
n	**2479**	**2479**	
Home Care Jurisdiction (%)	n (%)	n (%)	0.062
Central East	462 (18.6)	438 (17.7)	
Central	579 (23.4)	593 (24.0)	
Champlain	636 (25.7)	673 (27.1)	
Erie St. Clair	24 (1.0)	32 (1.3)	
Hamilton Niagara Haldimand Brant	49 (2.0)	47 (1.9)	
Mississauga Halton	1 (0.0)	1 (0.0)	
North East	357 (14.4)	354 (14.4)	
North Simcoe Muskoka	184 (7.4)	177 (7.1)	
North West	55 (2.2)	47 (1.9)	
South East	63 (2.5)	54 (2.2)	
South West	69 (2.8)	63 (2.5)	
Age (mean (SD))	73.52 (13.43)	73.21 (13.31)	0.023
Sex = 2 (%)	1328 (53.6)	1356 (54.7)	0.023
Marital status (%)			0.023
1=Never married	160 (6.5)	171 (6.9)	
2=Married	1359 (54.8)	1338 (54.0)	
3=Partner/significant other	95 (3.8)	94 (3.8)	
4=Widowed	603 (24.3)	609 (24.6)	
5=Separated	74 (3.0)	74 (3.0)	
6=Divorced	188 (7.6)	193 (7.8)	
Living arrangement (%)			0.038
1=Alone	533 (21.5)	526 (21.2)	
2=With spouse/partner only	1008 (40.7)	998 (40.3)	
3=With spouse/partner and other(s)	385 (15.5)	376 (15.2)	
4=With child (not spouse/partner)	322 (13.0)	332 (13.4)	
5=With parent(s) or guardian(s)	39 (1.6)	48 (1.9)	
6=With sibling(s)	35 (1.4)	40 (1.6)	
7=With other relative(s)	40 (1.6)	44 (1.8)	
8=With nonrelative(s)	117 (4.7)	115 (4.6)	
Time since last hospital stay (%)			0.040
0= No hospitalization within 90 days	1826 (73.7)	1867 (75.3)	
1=31 to 90 days ago	219 (8.8)	211 (8.5)	
2=15 to 30 days ago	136 (5.5)	127 (5.1)	
3=8 to 14 days ago	103 (4.2)	92 (3.7)	
4=In the last 7 days	141 (5.7)	131 (5.3)	
5= Now in hospital	54 (2.2)	51 (2.1)	

Formal care: Home health aides: number of days (mean (SD))	2.17 (2.83)	2.08 (2.83)	0.033
Formal care: Home health aides: total minutes in last week (mean (SD))	226.79 (542.38)	219.37 (528.87)	0.014
Formal care: Home nurse: number of days (mean (SD))	1.88 (1.92)	1.79 (1.89)	0.048
Formal care: Home nurse: total minutes in last week (mean (SD))	104.17 (189.48)	103.81 (237.63)	0.002
Instrumental Activities of Daily Living Self-Performance – Meal preparation (%)			0.044
0=Independent	315 (12.7)	331 (13.4)	
1=Set-up help only	50 (2.0)	50 (2.0)	
2=Supervision	34 (1.4)	35 (1.4)	
3=Limited assistance	307 (12.4)	313 (12.6)	
4=Extensive assistance	234 (9.4)	252 (10.2)	
5=Maximal assistance	232 (9.4)	240 (9.7)	
6=Total dependence	1278 (51.6)	1233 (49.7)	
8=Activity did not occur	29 (1.2)	25 (1.0)	
Instrumental Activities of Daily Living Self-Performance – Ordinary housework (%)			0.061
0=Independent	181 (7.3)	197 (7.9)	
1=Set-up help only	18 (0.7)	19 (0.8)	
2=Supervision	23 (0.9)	21 (0.8)	
3=Limited assistance	225 (9.1)	210 (8.5)	
4=Extensive assistance	171 (6.9)	187 (7.5)	
5=Maximal assistance	215 (8.7)	244 (9.8)	
6=Total dependence	1611 (65.0)	1565 (63.1)	
8=Activity did not occur	35 (1.4)	36 (1.5)	
Instrumental Activities of Daily Living Self-Performance – Managing medications (%)			0.043
0=Independent	893 (36.0)	929 (37.5)	
1=Set-up help only	228 (9.2)	230 (9.3)	
2=Supervision	227 (9.2)	219 (8.8)	
3=Limited assistance	262 (10.6)	265 (10.7)	
4=Extensive assistance	174 (7.0)	169 (6.8)	
5=Maximal assistance	113 (4.6)	119 (4.8)	
6=Total dependence	560 (22.6)	530 (21.4)	
8=Activity did not occur	22 (0.9)	18 (0.7)	
Activities of Daily Living Self-Performance – Bathing (%)			0.044
0=Independent	601 (24.2)	619 (25.0)	
1=Set-up help only	94 (3.8)	99 (4.0)	
2=Supervision	173 (7.0)	190 (7.7)	
3=Limited assistance	389 (15.7)	385 (15.5)	
4=Extensive assistance	485 (19.6)	489 (19.7)	

5=Maximal assistance	275 (11.1)	263 (10.6)	
6=Total dependence	361 (14.6)	340 (13.7)	
8=Activity did not occur	101 (4.1)	94 (3.8)	
Activities of Daily Living Self-Performance – Personal hygiene (%)			0.038
0=Independent	1054 (42.5)	1091 (44.0)	
1=Set-up help only	196 (7.9)	192 (7.7)	
2=Supervision	216 (8.7)	217 (8.8)	
3=Limited assistance	331 (13.4)	331 (13.4)	
4=Extensive assistance	254 (10.2)	242 (9.8)	
5=Maximal assistance	142 (5.7)	129 (5.2)	
6=Total dependence	280 (11.3)	271 (10.9)	
8=Activity did not occur	6 (0.2)	6 (0.2)	
Activities of Daily Living Self-Performance – Walking (%)			0.035
0=Independent	1242 (50.1)	1270 (51.2)	
1=Set-up help only	180 (7.3)	172 (6.9)	
2=Supervision	352 (14.2)	357 (14.4)	
3=Limited assistance	181 (7.3)	176 (7.1)	
4=Extensive assistance	116 (4.7)	106 (4.3)	
5=Maximal assistance	55 (2.2)	56 (2.3)	
6=Total dependence	63 (2.5)	56 (2.3)	
8=Activity did not occur	290 (11.7)	286 (11.5)	
Activities of Daily Living Self-Performance – Locomotion (%)			0.045
0=Independent	1293 (52.2)	1327 (53.5)	
1=Set-up help only	174 (7.0)	156 (6.3)	
2=Supervision	325 (13.1)	333 (13.4)	
3=Limited assistance	186 (7.5)	177 (7.1)	
4=Extensive assistance	124 (5.0)	113 (4.6)	
5=Maximal assistance	63 (2.5)	67 (2.7)	
6=Total dependence	178 (7.2)	174 (7.0)	
8=Activity did not occur	136 (5.5)	132 (5.3)	
Activities of Daily Living Self-Performance – Transfer toilet (%)			0.030
0=Independent	1509 (60.9)	1522 (61.4)	
1=Set-up help only	141 (5.7)	152 (6.1)	
2=Supervision	190 (7.7)	184 (7.4)	
3=Limited assistance	154 (6.2)	146 (5.9)	
4=Extensive assistance	135 (5.4)	128 (5.2)	
5=Maximal assistance	80 (3.2)	78 (3.1)	
6=Total dependence	128 (5.2)	132 (5.3)	
8=Activity did not occur	142 (5.7)	137 (5.5)	
Activities of Daily Living Self-Performance – Toilet use (%)			0.029

0=Independent	1545 (62.3)	1571 (63.4)	
1=Set-up help only	140 (5.6)	141 (5.7)	
2=Supervision	143 (5.8)	141 (5.7)	
3=Limited assistance	168 (6.8)	155 (6.3)	
4=Extensive assistance	116 (4.7)	115 (4.6)	
5=Maximal assistance	88 (3.5)	82 (3.3)	
6=Total dependence	229 (9.2)	226 (9.1)	
8=Activity did not occur	50 (2.0)	48 (1.9)	
Activities of Daily Living Self-Performance – Eating (%)			0.024
0=Independent	1529 (61.7)	1543 (62.2)	
1=Set-up help only	447 (18.0)	441 (17.8)	
2=Supervision	181 (7.3)	174 (7.0)	
3=Limited assistance	96 (3.9)	90 (3.6)	
4=Extensive assistance	50 (2.0)	51 (2.1)	
5=Maximal assistance	39 (1.6)	43 (1.7)	
6=Total dependence	132 (5.3)	131 (5.3)	
8=Activity did not occur	5 (0.2)	6 (0.2)	
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) score (%)			0.055
0=No symptoms	296 (11.9)	311 (12.5)	
1=Minimal health instability	594 (24.0)	644 (26.0)	
2=Low health instability	731 (29.5)	697 (28.1)	
3=Moderate health instability	662 (26.7)	641 (25.9)	
4=High health instability	196 (7.9)	186 (7.5)	

	False	**True**	**Sum**
	21		21

Appendix Q

Propensity Score Analysis using Near Weights Method

Variable (n)	**Stratified by Cohort**		
	0	**1**	**SMD**
n	**2389.9**	**2383.2**	
Home Care Jurisdiction (%)	n (%)	n (%)	0.006
Central East	435.3 (18.2)	434.6 (18.2)	
Central	548.0 (22.9)	546.2 (22.9)	
Champlain	622.3 (26.0)	615.7 (25.8)	
Erie St. Clair	32.0 (1.3)	32.0 (1.3)	
Hamilton Niagara Haldimand Brant	47.0 (2.0)	47.0 (2.0)	
Mississauga Halton	1.0 (0.0)	1.0 (0.0)	
North East	351.4 (14.7)	352.2 (14.8)	
North Simcoe Muskoka	176.2 (7.4)	176.9 (7.4)	
North West	54.8 (2.3)	55.0 (2.3)	
South East	58.8 (2.5)	59.6 (2.5)	
South West	63.2 (2.6)	63.0 (2.6)	
Age (mean (SD))	73.43 (13.40)	73.44 (13.25)	<0.001
Sex = 2 (%)	1295.3 (54.2)	1297.7 (54.5)	0.005
Marital status (%)			0.008
1=Never married	158.5 (6.6)	158.9 (6.7)	
2=Married	1301.1 (54.4)	1289.8 (54.1)	
3=Partner/significant other	86.7 (3.6)	85.4 (3.6)	
4=Widowed	593.9 (24.8)	595.6 (25.0)	
5=Separated	70.7 (3.0)	71.8 (3.0)	
6=Divorced	179.1 (7.5)	181.7 (7.6)	
Living arrangement (%)			0.014
1=Alone	508.6 (21.3)	505.6 (21.2)	
2=With spouse/partner only	963.8 (40.3)	958.3 (40.2)	
3=With spouse/partner and other(s)	373.6 (15.6)	367.7 (15.4)	
4=With child (not spouse/partner)	319.1 (13.4)	325.7 (13.7)	
5=With parent(s) or guardian(s)	35.7 (1.5)	37.3 (1.6)	
6=With sibling(s)	34.4 (1.4)	36.0 (1.5)	
7=With other relative(s)	40.7 (1.7)	41.7 (1.7)	
8=With nonrelative(s)	114.0 (4.8)	111.1 (4.7)	
Time since last hospital stay (%)			0.009
0= No hospitalization within 90 days	1767.0 (73.9)	1765.1 (74.1)	
1=31 to 90 days ago	213.2 (8.9)	214.0 (9.0)	
2=15 to 30 days ago	131.2 (5.5)	129.9 (5.4)	
3=8 to 14 days ago	93.7 (3.9)	89.9 (3.8)	
4=In the last 7 days	131.2 (5.5)	130.6 (5.5)	
5= Now in hospital	53.1 (2.2)	53.7 (2.3)	

Formal care: Home health aides: number of days (mean (SD))	2.09 (2.79)	2.07 (2.83)	0.006
Formal care: Home health aides: total minutes in last week (mean (SD))	223.41 (556.41)	221.63 (551.03)	0.003
Formal care: Home nurse: number of days (mean (SD))	1.85 (1.90)	1.85 (1.93)	0.003
Formal care: Home nurse: total minutes in last week (mean (SD))	103.86 (197.79)	103.78 (193.57)	<0.001
Instrumental Activities of Daily Living Self-Performance – Meal preparation (%)			0.014
0=Independent	306.7 (12.8)	315.2 (13.2)	
1=Set-up help only	50.1 (2.1)	48.5 (2.0)	
2=Supervision	35.6 (1.5)	33.7 (1.4)	
3=Limited assistance	300.7 (12.6)	300.7 (12.6)	
4=Extensive assistance	226.8 (9.5)	227.9 (9.6)	
5=Maximal assistance	225.5 (9.4)	223.5 (9.4)	
6=Total dependence	1216.7 (50.9)	1206.3 (50.6)	
8=Activity did not occur	27.8 (1.2)	27.4 (1.2)	
Instrumental Activities of Daily Living Self-Performance – Ordinary housework (%)			0.018
0=Independent	181.3 (7.3)	186.6 (7.8)	
1=Set-up help only	17.7 (0.7)	17.2 (0.7)	
2=Supervision	22.1 (0.9)	19.4 (0.8)	
3=Limited assistance	208.9 (9.1)	209.1 (8.8)	
4=Extensive assistance	166.5 (6.9)	170.7 (7.2)	
5=Maximal assistance	212.8 (8.7)	213.8 (9.0)	
6=Total dependence	1543.8 (65.0)	1528.7 (64.1)	
8=Activity did not occur	36.9 (1.4)	37.7 (1.6)	
Instrumental Activities of Daily Living Self-Performance – Managing medications (%)			0.013
0=Independent	868.5 (36.3)	876.8 (36.8)	
1=Set-up help only	217.2 (9.1)	217.6 (9.1)	
2=Supervision	211.5 (8.8)	207.4 (8.7)	
3=Limited assistance	255.7 (10.7)	254.0 (10.7)	
4=Extensive assistance	165.3 (6.9)	165.1 (6.9)	
5=Maximal assistance	119.0 (5.0)	116.1 (4.9)	
6=Total dependence	530.4 (22.2)	525.1 (22.0)	
8=Activity did not occur	22.4 (0.9)	20.9 (0.0)	
Activities of Daily Living Self-Performance – Bathing (%)			0.010
0=Independent	594.3 (24.9)	598.6 (25.1)	
1=Set-up help only	87.8 (3.7)	86.7 (3.6)	
2=Supervision	175.4 (7.3)	173.4 (7.3)	
3=Limited assistance	370.1 (15.5)	366.9 (15.4)	
4=Extensive assistance	460.7 (19.3)	465.4 (19.5)	

5=Maximal assistance	266.3 (11.1)	262.8 (11.0)	
6=Total dependence	338.2 (14.1)	333.1 (14.0)	
8=Activity did not occur	97.3 (4.1)	96.3 (4.0)	
Activities of Daily Living Self-Performance – Personal hygiene (%)			0.014
0=Independent	1031.1 (43.1)	1033.9 (43.4)	
1=Set-up help only	186.9 (7.8)	189.2 (7.9)	
2=Supervision	207.9 (8.7)	202.5 (8.5)	
3=Limited assistance	318.2 (13.3)	315.4 (13.2)	
4=Extensive assistance	239.9 (10.0)	244.5 (10.3)	
5=Maximal assistance	130.4 (5.5)	128.9 (5.4)	
6=Total dependence	270.0 (11.3)	263.6 (11.1)	
8=Activity did not occur	5.5 (0.2)	5.3 (0.2)	
Activities of Daily Living Self-Performance – Walking (%)			0.009
0=Independent	1212.1 (50.7)	1215.7 (51.0)	
1=Set-up help only	165.8 (6.9)	164.5 (6.9)	
2=Supervision	341.3 (14.3)	336.9 (14.1)	
3=Limited assistance	172.2 (7.2)	171.7 (7.2)	
4=Extensive assistance	106.4 (4.5)	106.1 (4.5)	
5=Maximal assistance	57.1 (2.4)	55.4 (2.3)	
6=Total dependence	56.2 (2.4)	54.3 (2.3)	
8=Activity did not occur	278.7 (11.7)	278.6 (11.7)	
Activities of Daily Living Self-Performance – Locomotion (%)			0.010
0=Independent	1261.3 (52.8)	1266.2 (53.1)	
1=Set-up help only	153.9 (6.4)	150.2 (6.3)	
2=Supervision	321.1 (13.4)	317.1 (13.3)	
3=Limited assistance	174.7 (7.3)	171.8 (7.2)	
4=Extensive assistance	113.5 (4.8)	114.8 (4.8)	
5=Maximal assistance	63.0 (2.6)	61.9 (2.6)	
6=Total dependence	167.6 (7.0)	167.9 (7.0)	
8=Activity did not occur	134.9 (5.6)	133.4 (5.6)	
Activities of Daily Living Self-Performance – Transfer toilet (%)			0.013
0=Independent	1452.1 (60.8)	1453.5 (61.0)	
1=Set-up help only	141.9 (5.9)	141.5 (5.9)	
2=Supervision	178.3 (7.5)	170.8 (7.2)	
3=Limited assistance	146.3 (6.1)	145.4 (6.1)	
4=Extensive assistance	129.5 (5.4)	131.2 (5.5)	
5=Maximal assistance	81.3 (3.4)	82.6 (3.5)	
6=Total dependence	121.6 (5.1)	120.0 (5.0)	
8=Activity did not occur	139.0 (5.8)	138.2 (5.8)	
Activities of Daily Living Self-Performance – Toilet use (%)			0.017

0=Independent	1496.5 (62.3)	1502.8 (63.1)	
1=Set-up help only	133.6 (5.6)	130.7 (5.5)	
2=Supervision	136.8 (5.8)	134.9 (5.7)	
3=Limited assistance	156.2 (6.8)	148.6 (6.2)	
4=Extensive assistance	110.5 (4.7)	113.6 (4.8)	
5=Maximal assistance	87.7 (3.5)	87.0 (3.6)	
6=Total dependence	220.0 (9.2)	216.2 (9.1)	
8=Activity did not occur	48.7 (2.0)	49.5 (2.1)	
Activities of Daily Living Self-Performance – Eating (%)			0.005
0=Independent	1488.7 (62.3)	1487.0 (62.4)	
1=Set-up help only	419.7 (17.6)	417.4 (17.5)	
2=Supervision	169.1 (7.1)	167.2 (7.0)	
3=Limited assistance	90.6 (3.8)	89.4 (3.7)	
4=Extensive assistance	52.4 (2.2)	52.4 (2.2)	
5=Maximal assistance	40.8 (1.7)	41.7 (1.7)	
6=Total dependence	123.6 (5.2)	122.9 (5.2)	
8=Activity did not occur	5.2 (0.2)	5.3 (0.2)	
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) score (%)			0.012
0=No symptoms	283.5 (11.9)	288.9 (12.1)	
1=Minimal health instability	590.2 (24.7)	591.3 (24.8)	
2=Low health instability	690.6 (28.9)	679.0 (28.5)	
3=Moderate health instability	634.5 (26.5)	631.0 (26.5)	
4=High health instability	191.1 (8.0)	193.1 (8.1)	

	False	**True**	**Sum**
	21		21

Appendix R

Propensity Score Analysis using Overlap Weights Method

Variable (n)	**Stratified by Cohort**		
	0	**1**	**SMD**
n	**1451.3**	**1451.3**	
Home Care Jurisdiction (%)	n (%)	n (%)	<0.001
Central East	257.3 (17.7)	257.3 (17.7)	
Central	311.2 (21.4)	311.2 (21.4)	
Champlain	366.2 (25.2)	366.2 (25.2)	
Erie St. Clair	30.1 (2.1)	30.1 (2.1)	
Hamilton Niagara Haldimand Brant	44.3 (3.1)	44.3 (3.1)	
Mississauga Halton	1.0 (0.1)	1.0 (0.1)	
North East	211.5 (14.6)	211.5 (14.6)	
North Simcoe Muskoka	101.2 (7.0)	101.2 (7.0)	
North West	33.6 (2.3)	33.6 (2.3)	
South East	34.0 (2.3)	34.0 (2.3)	
South West	61.0 (4.2)	61.0 (4.2)	
Age (mean (SD))	73.36 (13.43)	73.36 (13.34)	<0.001
Sex = 2 (%)	790.1 (54.4)	790.1 (54.4)	<0.001
Marital status (%)			<0.001
1=Never married	96.6 (6.7)	96.6 (6.7)	
2=Married	785.2 (54.1)	785.2 (54.1)	
3=Partner/significant other	52.6 (3.6)	52.6 (3.6)	
4=Widowed	362.4 (25.0)	362.4 (25.0)	
5=Separated	44.0 (3.0)	44.0 (3.0)	
6=Divorced	110.5 (7.6)	110.5 (7.6)	
Living arrangement (%)			<0.001
1=Alone	309.1 (21.3)	309.1 (21.3)	
2=With spouse/partner only	583.2 (40.2)	583.2 (40.2)	
3=With spouse/partner and other(s)	225.1 (15.5)	225.1 (15.5)	
4=With child (not spouse/partner)	196.1 (13.5)	196.1 (13.5)	
5=With parent(s) or guardian(s)	22.4 (1.5)	22.4 (1.5)	
6=With sibling(s)	21.3 (1.5)	21.3 (1.5)	
7=With other relative(s)	25.9 (1.8)	25.9 (1.8)	
8=With nonrelative(s)	68.1 (4.7)	68.1 (4.7)	
Time since last hospital stay (%)			<0.001
0= No hospitalization within 90 days	1077.8 (74.3)	1077.8 (74.3)	
1=31 to 90 days ago	127.9 (8.8)	127.9 (8.8)	
2=15 to 30 days ago	79.7 (5.5)	79.7 (5.5)	
3=8 to 14 days ago	56.0 (3.9)	56.0 (3.9)	
4=In the last 7 days	78.4 (5.4)	78.4 (5.4)	
5= Now in hospital	31.6 (2.2)	31.6 (2.2)	

Formal care: Home health aides: number of days (mean (SD))	2.07 (2.79)	2.07 (2.83)	<0.001
Formal care: Home health aides: total minutes in last week (mean (SD))	223.35 (573.61)	223.35 (556.09)	<0.001
Formal care: Home nurse: number of days (mean (SD))	1.85 (1.90)	1.85 (1.93)	<0.001
Formal care: Home nurse: total minutes in last week (mean (SD))	104.56 (205.00)	104.56 (202.26)	<0.001
Instrumental Activities of Daily Living Self-Performance – Meal preparation (%)			<0.001
0=Independent	193.8 (13.4)	193.8 (13.4)	
1=Set-up help only	30.1 (2.1)	30.1 (2.1)	
2=Supervision	22.0 (1.5)	22.0 (1.5)	
3=Limited assistance	183.7 (12.7)	183.7 (12.7)	
4=Extensive assistance	138.1 (9.5)	138.1 (9.5)	
5=Maximal assistance	134.7 (9.3)	134.7 (9.3)	
6=Total dependence	731.9 (50.4)	731.9 (50.4)	
8=Activity did not occur	17.0 (1.2)	17.0 (1.2)	
Instrumental Activities of Daily Living Self-Performance – Ordinary housework (%)			<0.001
0=Independent	116.5 (8.0)	116.5 (8.0)	
1=Set-up help only	10.5 (0.7)	10.5 (0.7)	
2=Supervision	13.3 (0.9)	13.3 (0.9)	
3=Limited assistance	128.3 (8.8)	128.3 (8.8)	
4=Extensive assistance	104.5 (7.2)	104.5 (7.2)	
5=Maximal assistance	130.5 (9.0)	130.5 (9.0)	
6=Total dependence	924.7 (63.7)	924.7 (63.7)	
8=Activity did not occur	23.1 (1.6)	23.1 (1.6)	
Instrumental Activities of Daily Living Self-Performance – Managing medications (%)			0.013
0=Independent	534.5 (36.8)	534.5 (36.8)	
1=Set-up help only	130.7 (9.0)	130.7 (9.0)	
2=Supervision	125.8 (8.7)	125.8 (8.7)	
3=Limited assistance	154.6 (10.7)	154.6 (10.7)	
4=Extensive assistance	98.7 (6.8)	98.7 (6.8)	
5=Maximal assistance	72.6 (5.0)	72.6 (5.0)	
6=Total dependence	321.4 (22.1)	321.4 (22.1)	
8=Activity did not occur	13.0 (0.9)	13.0 (0.9)	
Activities of Daily Living Self-Performance – Bathing (%)			0.010
0=Independent	366.8 (25.3)	366.8 (25.3)	
1=Set-up help only	56.1 (3.9)	56.1 (3.9)	
2=Supervision	106.5 (7.3)	106.5 (7.3)	
3=Limited assistance	223.0 (15.4)	223.0 (15.4)	
4=Extensive assistance	275.3 (19.0)	275.3 (19.0)	

5=Maximal assistance	158.8 (10.9)	158.8 (10.9)	
6=Total dependence	205.6 (14.2)	205.6 (14.2)	
8=Activity did not occur	59.3 (4.1)	59.3 (4.1)	
Activities of Daily Living Self-Performance – Personal hygiene (%)			0.014
0=Independent	630.6 (43.4)	630.6 (43.4)	
1=Set-up help only	114.8 (7.9)	114.8 (7.9)	
2=Supervision	123.4 (8.5)	123.4 (8.5)	
3=Limited assistance	191.5 (13.2)	191.5 (13.2)	
4=Extensive assistance	143.8 (9.9)	143.8 (9.9)	
5=Maximal assistance	78.9 (5.4)	78.9 (5.4)	
6=Total dependence	165.2 (11.4)	165.2 (11.4)	
8=Activity did not occur	3.2 (0.2)	3.2 (0.2)	
Activities of Daily Living Self-Performance – Walking (%)			0.009
0=Independent	739.9 (51.0)	739.9 (51.0)	
1=Set-up help only	100.2 (6.9)	100.2 (6.9)	
2=Supervision	203.0 (14.0)	203.0 (14.0)	
3=Limited assistance	103.6 (7.1)	103.6 (7.1)	
4=Extensive assistance	64.2 (4.4)	64.2 (4.4)	
5=Maximal assistance	35.5 (2.4)	35.5 (2.4)	
6=Total dependence	34.4 (2.4)	34.4 (2.4)	
8=Activity did not occur	170.7 (11.8)	170.7 (11.8)	
Activities of Daily Living Self-Performance – Locomotion (%)			0.010
0=Independent	770.2 (53.1)	770.2 (53.1)	
1=Set-up help only	92.7 (6.4)	92.7 (6.4)	
2=Supervision	191.0 (13.2)	191.0 (13.2)	
3=Limited assistance	105.2 (7.3)	105.2 (7.3)	
4=Extensive assistance	68.4 (4.7)	68.4 (4.7)	
5=Maximal assistance	38.5 (2.7)	38.5 (2.7)	
6=Total dependence	103.8 (7.2)	103.8 (7.2)	
8=Activity did not occur	81.6 (5.6)	81.6 (5.6)	
Activities of Daily Living Self-Performance – Transfer toilet (%)			0.013
0=Independent	883.3 (60.9)	883.3 (60.9)	
1=Set-up help only	86.5 (6.0)	86.5 (6.0)	
2=Supervision	104.0 (7.2)	104.0 (7.2)	
3=Limited assistance	88.7 (6.1)	88.7 (6.1)	
4=Extensive assistance	78.6 (5.4)	78.6 (5.4)	
5=Maximal assistance	50.0 (3.4)	50.0 (3.4)	
6=Total dependence	75.7 (5.2)	75.7 (5.2)	
8=Activity did not occur	84.5 (5.8)	84.5 (5.8)	
Activities of Daily Living Self-Performance – Toilet use (%)			0.017

0=Independent	910.5 (62.7)	910.5 (62.7)	
1=Set-up help only	80.6 (5.6)	80.6 (5.6)	
2=Supervision	80.6 (5.6)	80.6 (5.6)	
3=Limited assistance	93.5 (6.4)	93.5 (6.4)	
4=Extensive assistance	67.6 (4.7)	67.6 (4.7)	
5=Maximal assistance	53.0 (3.7)	53.0 (3.7)	
6=Total dependence	135.7 (9.3)	135.7 (9.3)	
8=Activity did not occur	29.9 (2.1)	29.9 (2.1)	
Activities of Daily Living Self-Performance – Eating (%)			0.005
0=Independent	908.0 (62.6)	908.0 (62.6)	
1=Set-up help only	252.0 (17.4)	252.0 (17.4)	
2=Supervision	100.9 (6.9)	100.9 (6.9)	
3=Limited assistance	54.6 (3.8)	54.6 (3.8)	
4=Extensive assistance	32.3 (2.2)	32.3 (2.2)	
5=Maximal assistance	25.3 (1.7)	25.3 (1.7)	
6=Total dependence	75.2 (5.2)	75.2 (5.2)	
8=Activity did not occur	3.1 (0.2)	3.1 (0.2)	
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) score (%)			0.013
0=No symptoms	174.3 (12.0)	174.3 (12.0)	
1=Minimal health instability	366.4 (25.2)	366.4 (25.2)	
2=Low health instability	415.9 (28.7)	415.9 (28.7)	
3=Moderate health instability	379.9 (26.2)	379.9 (26.2)	
4=High health instability	115.0 (7.9)	115.0 (7.9)	

	False	**True**	**Sum**
	21		21

Appendix S

QI Statistical Results – Weights Method

QI#	**QI Description**	**Pre-COVID Cohort (%) n=2389.9**	**COVID Cohort (%) n=2383.2**	**Statistical Analysis of Difference**				
				X^2 (z)[a]	**QI Diff (QI CI)[b]**	**X^2 (z) p-value[b]**	**OR (p-value) (95% CI)[c]**	**Effect Size[d]**
QI1	Prevalence – Severe & Excruciating Pain	15.74	16.21	0.20 (0.45)	0.005 (-0.03, 0.05)	0.65	1.04 (0.66) (0.89, 1.21)	0.02
QI2	Prevalence of severe or excruciating pain that is not controlled by therapeutic regimen	6.24	6.76	0.53 (0.73)	0.005 (-0.04, 0.08)	0.47	1.09 (0.49) (0.87, 1.37)	0.05
QI3	Prevalence of emergency department visits	19.07	20.13	0.85 (0.92)	0.01 (-0.02, 0.05)	0.36	1.07 (0.35) (0.93, 1.23)	0.04
QI4	Prevalence of hospital admissions	24.02	24.21	0.03 (0.17)	0.002 (-0.03, 0.04)	0.87	1.01 (0.87) (0.89, 1.15)	0.01
QI5	Prevalence of falls	24.10	22.69	1.24 (1.11)	-0.01 (-0.06, 0.02)	0.27	0.92 (0.26) (0.80, 1.06)	-0.05
QI6	Prevalence of constipation	18.30	16.42	2.94 (1.71)	-0.019 (-0.07, 0.005)	0.086	0.88 (0.087) (0.75, 1.02)	-0.07
QI7	Prevalence of shortness of breath at rest	15.21	15.52	0.089 (0.30)	0.003 (-0.03, 0.05)	0.77	1.02 (0.75) (0.88, 1.20)	0.01
QI8	Prevalence of shortness of breath when performing moderate/normal day-to-day activities	49.79	51.32	1.12 (1.06)	0.015 (-0.01, 0.04)	0.29	1.06 (0.29) (0.95, 1.19)	0.03
QI9	Prevalence of caregiver distress	22.98	22.77	0.03 (0.17)	-0.002 (-0.04, 0.03)	0.86	0.99 (0.85) (0.86, 1.13)	-0.01

QI#	QI Description	Pre-COVID Cohort (%) n=2389.9	COVID Cohort (%) n=2383.2	Statistical Analysis of Difference				
				X^2 (z)[a]	QI Diff (QI CI)[b]	X^2 (z) p-value[b]	OR (p-value) (95% CI)[c]	Effect Size[d]
QI10	Prevalence of negative mood	8.18	6.32	6.13 (2.48)	-0.019 (-0.01, -0.12)	0.01	0.76 (0.01) (0.61, 0.94)	-0.15
QI11	Prevalence of no advance directives	44.90	45.93	0.52 (0.72)	0.01 (-0.02, 0.04)	0.47	1.04 (0.47) (0.93, 1.17)	0.02
QI12	Prevalence of ulcers	12.25	12.67	0.19 (0.44)	0.004 (-0.03, 0.05)	0.66	1.04 (0.66) (0.87, 1.23)	0.02
QI13	Prevalence of a delirium-like syndrome	4.56	4.33	0.14 (0.37)	-0.002 (-0.08, 0.06)	0.70	0.95 (0.71) (0.72, 1.25)	-0.03
QI14	Prevalence of nausea or vomiting	19.77	17.22	5.16 (2.27)	-0.026 (-0.005, -0.08)	0.02	0.84 (0.02) (0.73, 0.98)	-0.10
QI15	Prevalence of fatigue	40.80	41.54	0.27 (0.52)	-0.007 (-0.02, 0.04)	0.60	1.03 (0.60) (0.92, 1.16)	0.02
QI16	Prevalence of sleep problems	35.65	35.06	0.18 (0.42)	-0.006 (-0.04, 0.02)	0.67	0.97 (0.66) (0.87, 1.10)	-0.02

[a] $z^2 = \chi^2$, used frequencies from 2x2 table obtained using proportions, χ^2 obtained from R (see note [b])

[b] QI Diff= COVID-pre-COVID, 95% obtained from R [res<-prop.test(x=c(385, 1993), n=c(375, 2009))

[c] OR stats from online calc: https://www.medcalc.org/calc/relative_risk.php

[d] *d* = LogOddsRatio x ($\sqrt{3}/\pi$) = Ln(OR) x 0.551328

Appendix T

QI Statistical Results – Overlap Weights Method

QI#	QI Description	Pre-COVID Cohort (%) n=1451.3	COVID Cohort (%) n=1451.3	Statistical Analysis of Difference				
				X^2 (z)[a]	95% CI (QI Diff)	X^2 (z) p-value	OR (p-value) (95% CI)	Effect Size[b]
QI1	Prevalence of severe or excruciating daily	15.57	16.29	0.28 (0.53)	0.007 (-0.04, 0.06)	0.60	1.05 (0.60) (0.86, 1.29)	0.03
QI2	Prevalence of severe or excruciating pain that is not controlled by therapeutic regimen	6.24	6.81	0.38 (0.62)	0.006 (-0.05, 0.10)	0.54	1.10 (0.53) (0.82, 1.47)	0.05
QI3	Prevalence of emergency department visits	19.35	20.00	0.19 (0.44)	0.007 (-0.04, 0.06)	0.66	1.10 (0.53) (0.82, 1.47)	0.05
QI4	Prevalence of hospital admissions	23.88	23.87	5.17e-6 (7.19e-4)	0.0001 (-0.04, 0.04)	0.998	0.99 (0.98) (0.84, 1.19)	-0.01
QI5	Prevalence of falls	24.10	22.56	0.89 (0.94)	-0.015 (-0.07, 0.02)	0.34	0.92 (0.33) (0.77, 1.10)	-0.05
QI6	Prevalence of constipation	18.09	16.29	1.66 (1.29)	-0.018 (-0.08, 0.02)	0.198	0.88 (0.19) (0.73, 1.07)	-0.07
QI7	Prevalence of shortness of breath at rest	15.37	15.62	0.04 (0.2)	0.0025 (-0.05, 0.06)	0.85	1.02 (0.84) (0.83, 1.25)	0.01
QI8	Prevalence of shortness of breath when performing moderate/normal day-to-day activities	49.62	51.15	0.68 (0.82)	0.015 (-0.02, 0.05)	0.41	1.06 (0.41) (0.92, 1.23)	0.03
QI9	Prevalence of caregiver distress	22.55	22.32	0.02 (0.14)	-0.002 (-0.05, 0.04)	0.88	0.99 (0.87) (0.83, 1.18)	-0.01

QI#	QI Description	Pre-COVID Cohort (%) n=1451.3	COVID Cohort (%) n=1451.3	Statistical Analysis of Difference				
				X^2 (z)[a]	95% CI (QI Diff)	X^2 (z) p-value	OR (p-value) (95% CI)	Effect Size[b]
QI10	Prevalence of negative mood	8.04	6.18	3.82 (1.95)	-0.019 (-0.10, 0.05)	0.05	0.75 (0.05) (0.57, 1.00)	-0.16
QI11	Prevalence of no advance directives	44.85	45.42	0.09 (0.3)	0.006 (-0.03, 0.04)	0.76	1.02 (0.77) (0.88, 1.18)	0.01
QI12	Prevalence of ulcers	12.33	12.65	0.07 (0.26)	0.003 (-0.05, 0.06)	0.79	1.03 (0.79) (0.83, 1.28)	0.02
QI13	Prevalence of a delirium-like syndrome	4.54	4.32	0.08 (0.28)	-0.002 (-0.11, 0.08)	0.78	0.95 (0.82) (0.67, 1.35)	-0.03
QI14	Prevalence of nausea or vomiting	19.72	17.03	3.51 (1.87)	-0.027 (-0.09, 0.003)	0.06	0.84 (0.06) (0.69, 1.01)	-0.10
QI15	Prevalence of fatigue	40.74	41.60	0.22 (0.47)	0.009 (-0.03, 0.05)	0.64	1.04 (0.64) (0.89, 1.20)	0.02
QI16	Prevalence of sleep problems	35.25	34.91	0.04 (0.2)	-0.003 (-0.04, 0.04)	0.85	0.99 (0.85) (0.85, 1.15)	-0.01

[a] $z^2 = \chi^2$, used frequencies from 2x2 table obtained using proportions, χ^2 obtained from R (see note [b]):

[b] QI Diff= COVID-pre-COVID, 95% obtained from R [res<-prop.test(x=c(236, 1214), n=c(462, 2438))

[c] OR stats from online calc: https://www.medcalc.org/calc/relative_risk.php

[d] *d* = LogOddsRatio x ($\sqrt{3}/\pi$) = Ln(OR) x 0.551328