Access To Palliative Care by Persons with Severe and Persistent Mental Illnesses in Ontario

By

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Author's declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

ABSTRACT

Objectives: This study's aims were to examine access to palliative care by persons with severe and persistent mental illnesses (SPMI), and determine the factors associated with access.

Methods: This study employed a retrospective study design using health administrative data based on the interRAI home care assessment. The prevalence of access to palliative care (PC) among home care clients with and without SPMI was determined. Univariate and multivariate logistic regression models were fitted to assess the association between access to palliative care and the social-demographic and clinical factors that may influence access to palliative care.

Results: Of the 616,296 home care clients, 155,642 (25.3%) had SPMI and 15,057 (2.5%) accessed PC. Of those who accessed PC, 23.5% (3,536) had SPMI. The association between SPMI and PC access was modified by sex (p-value=0.02) and age (p-value=0.04). Females less than 65 years who had SPMI had 15% lower odds (OR=0.85, CI=0.76, 0.95) of PC access compared to males who were more than 65 years and had no SPMI. Also, females aged 65-74 years with SPMI had 16% lower odds (OR=0.84, CI=0.76, 0.93) of PC access compared to males who were not aged 65-74 years and had no SPMI.

Conclusion: Overall persons with SPMI had lower access to PC compared to those without SPMI, a disparity that demands pragmatic healthcare system policy changes to improve access.

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To my lovely and amazing children Janelle, Mikayla, Ethan and Ivan I dedicate this work to you.

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CHAPTER 1: INTRODUCTION

The term "palliative care" emerged in Canada in the mid-1970s as a specialty in medicine largely focused on management of patients with cancer, but over the years the focus has evolved to incorporate other life-limiting illnesses (Health Canada, 2018). The World Health Organization (WHO) defines palliative care as:

> "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness by preventing and relieving suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual." (WHO, 2020, p1).

Globally, although an estimated 56.8 million people with life-limiting illnesses need palliative care, roughly 14% of this population receive palliative care (WHO, 2020). Low access to palliative care can be attributed to many factors including health system polices, lack of training for healthcare professionals, country-specific socio-cultural issues, misconceptions that associate palliative care solely with cancer, and poor access to opioids for pain relief (WHO, 2020). Globally, and in Canada the number of people with life-limiting illnesses who would benefit from palliative care is increasing, partly due to the burden of non-communicable diseases (Canadian Institute for Health Information (CIHI), 2023; Health Canada, 2018; WHO, 2020). Of the 153,524 deaths captured by the Canadian Institute of Health Information (CIHI) data from 2021 to 2022, 58% of the people who died received some form of palliative care (CIHI, 2023). These data included deaths in Ontario, Alberta, British Columbia and Yukon, and are therefore not representative of all the provinces and territories in Canada.

While palliative care access seems to have improved over the past few years among some patient groups, the same cannot be said for others. Patients with cancer tend to have early and better access to palliative care overall than those in underserved populations, for example, persons with mental illnesses and those experiencing homelessness (CIHI, 2023). Persons with severe and persistent mental illnesses (SPMI), which includes persons with schizophrenia, depression and bipolar disorder face unequal access to palliative care at the end of life, despite having higher rates of morbidity and mortality (Butler et al., 2018; Chochinov et al., 2012a). The inequitable access to palliative care by these persons poses the risk of poor management of pain and ailments at the end of life (Kashyap et al., 2021).

As part of the 2018 government of Canada's framework on palliative care, a key goal was to ensure that Canadians have equitable access to palliative care (Health Canada, 2018). A recent report by Health Canada acknowledges that there is more work to do to address the inequity in access to palliative care particularly for underserved populations (Health Canada, 2023). There is also very little research that focuses on access to palliative care by persons with SPMI globally and in Canada (CIHI, 2023; Butler et al., 2018) and the level of access to palliative care by persons with SPMI in Canada is currently unknown. In addition, factors that are associated with access to palliative care among persons with SPMI in Canada are under-investigated.

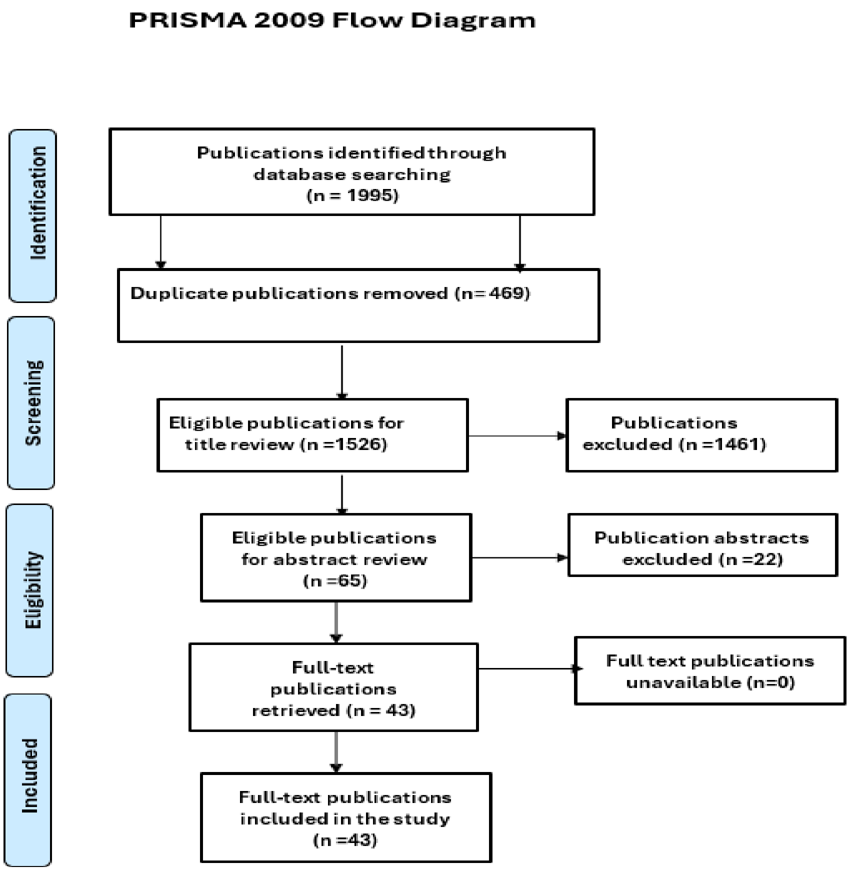
These gaps in research about palliative care utilization implies that there is no clear picture of the provision of palliative care for persons with SPMI. Addressing the issue of palliative care in persons with SPMI will help ensure that they have more equitable and timely access to palliative care to improve their quality of life at the end of life. Research about palliative care access among persons with SPMI will generate important information on palliative care in this underserved population, which could be useful for developing strategies and initiatives aimed at improving access.

The overall goal of this study is to explore access to palliative care by persons with SPMI and determine the factors associated with access to palliative care. The results may help to inform healthcare providers and leaders in the healthcare system on factors associated with reduced access, which should be addressed to improve access to palliative care among persons with SPMI.

CHAPTER 2: LITERATURE REVIEW

The literature review for this study focused on access to or utilization of palliative care by persons with severe and persistent mental illnesses (SPMI) and an overview of the current body of knowledge on palliative care access by persons with SPMI. PubMed, Web of science, CINAHL, PsycINFO and Medline were searched using the following syntax: ([mental illness OR mental disorders OR serious mental illness OR "severe and persistent mental illness") AND (palliative care OR terminal care OR "end of life care"]) AND (access OR utiliz*). A total of 1,995 articles (808 from PsycINFO, 800 from PubMed, 298 from Web of science, 77 from Medline, and 12 from CINAHL) were imported between December 6, 2023, and January 6, 2024, for screening and abstract review. After removing 469 duplicate articles, the remaining article titles were reviewed, after which 1461 articles were excluded. After reviewing 65 article abstracts, 22 were excluded. The remaining 43 articles were included for full-text review (Figure 1).

The following information was extracted from all the included articles: year and country of study, study aims and design, target population, population related definition or measures, study setting, recruitment/data source, sample size, study participant characteristics, terms used and their definition, findings in relation to study aims, author-identified study limitations and next steps.


PRISMA 2009 Flow Diagram

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta- Analyses:* The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Figure 1: PRISMA flow diagram illustrating articles identified and included in study

A number of themes emerged from the articles related to: definition of SPMI and palliative care; access to palliative care; paucity of research on palliative care; inclusion of persons with SPMI in end-of-life decision making/advance care planning; interdisciplinary education for healthcare professionals providing palliative care for persons with SPMI; collaboration between palliative care and mental health teams; referral of persons with SPMI for palliative care; stigmatization of persons with SPMI, and emergency department use among persons with SPMI at the end of life. Each of these themes is explored below.

2.1.1 Definition of severe and persistent mental illnesses (SPMI) and palliative care/end-of-life care

Severe and persistent mental illnesses

There is no consensus on the definition for severe and persistent mental illnesses (SPMI) in the literature, or which conditions qualify to be categorized as severe and persistent. Some literature use the term 'chronic persistent mental illness' (CPMI) in place of SPMI while others use severe mental illness (SMI). Jerwood and colleagues (2021) define SMI as "an umbrella term that describes illnesses such as schizophrenia, bipolar disorder, chronic depression, personality disorders and other mental illnesses or conditions where 'psychological problems 'are so debilitating that functional and occupational ability is impaired" (page 2). The underlying word 'debilitating' and the phrase 'impaired occupational ability' set the tone for the authors criteria to qualify a mental illness as severe. Park and colleagues (2022) define chronic persistent mental illnesses as "a smaller group of mental disorders, including schizophrenia, bipolar disorder, and chronic major depressive disorder that have persistent symptoms that impede health and well-being, requiring ongoing support (page 1)." In a study that looked at end-of-life care preferences, Elie and colleagues (2018) employed an adapted version of the National Institute of Mental Health (NIMH) definition of serious mental illnesses in their definition ("any DSM-5 mental illness diagnosed for at least 2 years resulting in serious functional impairment" ([page 2]). Elie and colleagues' definition adds a minimum timeline to the duration after which a diagnosis for a mental illness could be considered severe and persistent. Butler and colleagues (2018)'s definition of SPMI as a "prolonged or recurrent mental illness experienced by people 18 years and older" (page 2), introduces an age limit in the definition, which leaves one to wonder if a similar condition experienced in a person below that age wouldn't be considered as SPMI. The

National Institute of Mental Health (NIMH) defines serious mental illness as “a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities” (NIMH, 2023) (page 1).

The varied definitions of SPMI can be attributed not only to the different meanings that are given to the component attributes of the concept, but also to the circumstances in which the concept is being used. In a systematic review that sought to explore the level of ‘maturity’ of the concept of SPMI, Zumstein & Riese (2020) argue that SPMI is a partially mature concept due to the varied definitions and inconsistent components used in literature. In fact, the lack of a consensus on the definition and operationalization of SPMI has been noted (Elie et al., 2018). Regardless of the lack of consensus, the definitions provided by most authors have similar underlying focus: persistent and debilitating nature of the illness.

Palliative care

The terms “palliative care” and “end-of-life care” are used interchangeably mostly, but the later term is used oftentimes to conceptually imply care provided immediately before death. Definitions of terms are essential because they provide the basis for a common understanding of those terms and contextualizing research findings.

The World Health Organization (WHO) defines palliative care as:

> “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness by preventing and relieving suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (WHO, 2020, p1).

The WHO's (2020) definition clearly includes the main players in palliative care - the patients facing life-limiting illness, their caregivers/families and the healthcare providers.

The Ontario Palliative Care Network (OPCN) defines palliative care as "an approach to, and philosophy of care, appropriate for any individual and/or family living with, or at risk of developing a life-threatening illness (page 1)." (Ontario Health, n.d.). The OPCN's definition also equally includes patients and their families as key players.

Only three articles (Butler et al., 2018; Park, Hegadoren, et al., 2022; Trachsel et al., 2019) provided a definition for the terminology they used. Trachsel and colleagues (2019) adopted the WHO definition while Park and colleagues (2022) defined Palliative End-of-Life Care (PEOLC) as a "support to improve quality of life, pain and symptom management, peaceful and dignified death and support for family" (page 2). Butler and colleagues (2018) also define palliative care as "a holistic approach to providing care to people of any age diagnosed with a life-threatening, incurable illness" (page 1). The definition by Butler and colleagues (2018) reflects the evolved nature of palliative care from the initial primary focus on persons with cancer to persons living with a serious and life-threatening illness. Importantly, embedded in all these definitions is the focus of palliative care – that is, to relieve pain and suffering, and improve quality of life for persons living with a serious and life-limiting illness.

2.1.2 Access to palliative care

If the global picture of access to palliative care (WHO, 2020) is anything to go by, then a lot needs to be done to ensure equitable and early access to palliative care worldwide. Annually, 56.8 million people are estimated to require palliative care, the majority of whom are in low- and middle-income countries (WHO, 2020). It is estimated only 14% of this population have access to palliative care (WHO, 2020), leaving one to wonder what happens to the remaining who do not have access and more so, what are the main barriers that result in the unmet need for palliative care in these populations?

There is limited information about the annual estimated number of people in Canada who require palliative care, and what percentage of that population have access to palliative care. This is due to lack of data standardization and insufficient measurement of access to palliative care across the provinces and territories in Canada (CIHI, 2023; Health Canada, 2023). Even though palliative care focus has shifted from just patients with cancer to any individual facing life-threatening illness, persons with cancer still have higher access to palliative care than those with other illnesses (Health Canada, 2023). Not many studies have reported the rate of access to palliative care by persons with SPMI. In fact, the rate of access to palliative care among persons with SPMI is unknown.

Palliative care delivery in Canada follows the pattern of healthcare delivery in Canada, where various provinces and territories are responsible for the management, organization and delivery of healthcare for their residents (Health Canada, 2023). Data from the provinces of Ontario, Alberta, British Columbia and Yukon territories indicate 58% (89,000) of those who died in 2021-2022 received palliative care, of which 61% received it in hospitals, 15% in home care, 2% in long term care, 21% in both hospital and home care, and the remaining 1% in other settings (CIHI, 2023). In Ontario, of the 95,000 people who died in 2014-2015, 57% (54,000) received at least one form of PC in their last year of life. Among the 54,000 who received PC, 47.7% began receiving PC in their last month of life while 12.7% started in their second-to-last month of life (Health Quality Ontario, 2016). The decision to initiate palliative care across the various provinces and territories in Canada is usually based on comparing a patient's condition against checklists or assessment tools (CIHI, 2023). Palliative care is most beneficial, effective and meets the patient's needs and care goals when commenced early in the course of a life-limiting illness, preferably soon after diagnosis (CIHI, 2023; Haun et al., 2017; Qureshi et al., 2019; Salins et al., 2016; WHO, 2020), but in most cases in Canada, palliative care is provided very late in the course of a person's life-limiting illness, especially among underserved populations (Health Canada, 2023). When palliative care is provided early on for persons with life-limiting illness, it reduces the number of unnecessary hospitalizations and emergency department visits and lessens the burden on health institutions and the entire healthcare system (WHO, 2020). When persons with schizophrenia are referred early for palliative care services, it helps to develop trust and good understanding between the person with schizophrenia and the palliative care team and results in better health outcomes (McNamara et al., 2018). Most patients with SPMI prefer early referral for palliative care services to enable them to establish meaningful relationships with their care providers while they are mentally well and able to do so (Morgan, 2016). They worry that if those relationships are not made early on, that they might never happen (Morgan, 2016).

Of the studies that reported on the rate of access to palliative care, only one was from Canada (Chochinov et al., 2012), with most originating in Europe (Fond et al., 2019, 2021), the United States (Ganzini et al., 2010; Kashyap et al., 2021), and Oceania-Australia & New Zealand (Butler et al., 2018; McNamara et al., 2018; Spilsbury et al., 2018).

In a study that compared the health care use patterns of persons with schizophrenia near the end-of-life in the province of Manitoba, Canada, persons with schizophrenia were two to three times less likely to have access to palliative care than their counterparts without schizophrenia (Chochinov et al., 2012). Factors that accounted for the low access to palliative care included: age (the very young and the very old had less access), location (less palliative care in non-urban settings), cause of death, healthcare provider bias, difficulty of the healthcare providers building rapport with the patients, homelessness, and incarceration (Chochinov et al., 2012).

While five of the articles reviewed indicated a comparatively low access to palliative care among persons with SPMI compared with the general population (Butler et al., 2018; Chochinov et al., 2012; Kashyap et al., 2021; McNamara et al., 2018; Spilsbury et al., 2018), two articles (Fond et al., 2021; Ganzini et al., 2010) indicated otherwise. These contradictory findings should be looked at in the context of the country-specific health policies and systems as well as guidelines for palliative care in these countries or jurisdictions, and the populations used in these studies. For example, the study by Ganzini and colleagues (2010) suggested that veterans in the United States with schizophrenia who died of cancer had comparatively similar end-of-life care and in some instances, better end-of-life care than counterparts without mental illness. The US Veterans Health Administration (VA) is the largest integrated healthcare system in the United States and provides one of the highest quality care and services in the nation (US Veterans Health, n.d.) which could be the reason why persons with schizophrenia had similar or better end-of-life care than those without mental illness.

When it comes to emergency department use at the end-of-life, Kashyap and colleagues (2021) indicated that persons with mental illness visit the emergency department (ED) relatively more than patients without mental illness, with anxiety and bipolar disorders accounting the most for these ED visits in the last 30 days of life.

2.1.2.1 Factors related to access

A better understanding of the factors that are associated with access to palliative care among persons with SPMI will inform research and policies to address inequities in access. These factors can be categorized into four main domains: healthcare system, healthcare providers, social, and individual.

2.1.2.1.1 Healthcare system

While many healthcare agencies exist purposely to advance healthcare services for the public, a key problem when it comes to offering palliative care for persons with SPMI is the lack of coordination between these agencies which usually results in fragmented and siloed care for this population (Morgan, 2016; Park, Hegadoren, et al., 2022). The lack of coordinated care between palliative care and mental health teams results in delayed access to palliative care in this population. Delay in offering palliative care due to late medical diagnosis of life-limiting illness for persons with SPMI (Fond et al., 2019; McNamara et al., 2018), unsuitable social environment (Toor, 2019), limited staff capacity and scarcity of critical resources (Chochinov et al., 2012; McNamara et al., 2018), and organizational policy changes and cuts in healthcare budget (Evenblij et al., 2016), are the additional healthcare system factors that affects access to palliative care among persons with SPMI.

2.1.2.1.2 Healthcare Providers

Healthcare providers play a major role in determining who has access to palliative care and at what time after the diagnosis of a life-limiting illness they are deemed eligible to receive palliative care. With regards to persons with SPMI, some healthcare professionals feel uncomfortable providing palliative care to this population, especially persons with schizophrenia, due to lack of adequate training in mental health and palliative care (Chochinov et al., 2012; Matthew et al., 2022; McNamara et al., 2018). Additionally, lack of proactiveness by healthcare providers that ensures continuity of care for persons with SPMI during transition from one health provider to another (e.g., transfer from home care to hospital and vice versa) contributes to sub-optimal palliative care access (Park, Hegadoren, et al., 2022). Also, due to lack of collaboration between palliative care and psychiatric teams, each team feels inadequate to manage the symptoms of a patient that requires treatment pertaining to the other team (Chochinov et al., 2012; Morgan, 2016; Toor, 2019). Stigmatization, prejudice and discrimination against persons with SPMI by healthcare providers has devastating effects that leads to persons with SPMI receiving substandard palliative care services, or avoidance of care by persons with SPMI because of the effect of stigma and discrimination (Evenblij et al., 2016; Kashyap et al., 2021; Morgan, 2016).

Prejudice against persons with mental illness is commonly reported in literature (Evenblij et al., 2016; Knaak et al., 2017; Park, Hegadoren, et al., 2022). For persons with SPMI diagnosed with a life-limiting illness, their ‘dying’ or palliative status oftentimes brings an added layer of stigma from healthcare providers they encounter (Jerwood et al., 2021). Stigmatization and discrimination against persons with SPMI result in substandard and inadequate treatment from healthcare providers (Park, Mutoni, et al., 2022). A study participant in the qualitative study by Jerwood et and colleagues (2021) described the experience of stigma when he told the general practitioner that he had a problem with his prostate, only to get the response “don’t be silly you’re not old enough, I’m not even going to examine you”. Ten weeks after his encounter with the general practitioner, it was discovered that he had late-stage prostate cancer. Persons with SPMI’s previous experiences of stigma from healthcare providers negatively impacts their willingness to seek palliative care when faced with life-limiting illness. Some persons with SPMI perceive that mental illnesses such as schizophrenia and personality disorders are more stigmatized than anxiety and depression, and these perceptions are corroborated in literature (Chochinov et al., 2012; Jerwood et al., 2021). Even though connection with care providers, be it informal or therapeutic relationship is essential to the palliative care experience for persons with SPMI, stigmatization at the hands of healthcare providers in part, prevents this important connection, which leads to poor outcomes for these persons (Park, Hegadoren, et al., 2022). For many healthcare providers, it is difficult to work in a healthcare system that stigmatizes patients (Park, Mutoni, et al., 2022).

2.1.2.1.3 Social factors

The social environment of persons with SPMI also plays a role in their access to palliative care. Being homeless or incarcerated (Chochinov et al., 2012b; McNamara et al., 2018), having no family or social supports (Evenblij et al., 2016; Kashyap et al., 2021; McNamara et al., 2018), struggling with addictions (Evenblij et al., 2016), living alone or in self-isolation (Evenblij et al., 2016; McNamara et al., 2018) can prevent a person with SPMI from receiving access to palliative care. For the most part, these persons lack strong advocates or the social support necessary to facilitate their access to palliative care (McNamara et al., 2018; Park, Hegadoren, et al., 2022). They usually become ‘lost in the system’ and have no regular follow-ups, a situation that complicates their referral to and access to palliative care services.

2.1.2.1.4 Individual factors

Personal attitudes, behaviours and circumstances of persons with SPMI are also critical issues that tend to limit their access to palliative care. Particularly for persons with schizophrenia, any form of aggression or hostility towards healthcare professionals can result in limited access to palliative care teams (Fond et al., 2019). Hostile behavior towards healthcare providers in the palliative care team usually results in patients being transferred to psychiatric units for appropriate treatment and as a result, they do not receive the appropriate palliative care they require (Fond et al., 2019). The severe mental illness experienced by patients can also result in psychological distress, and inability to participate in advance care planning when they are diagnosed with life-limiting illness which affects their utilization of palliative care services (Kashyap et al., 2021). The experience of an unstable mental state and inability to appropriately communicate or process information also results in delayed or lack of access to palliative care (Chochinov et al., 2012b; Evenblij et al., 2016; McNamara et al., 2018; Morgan, 2016). Persons with schizophrenia, may not always verbalize their pain or disease symptoms, as they tend to have a higher pain tolerance compared to the general population (Stubbs et al., 2015). As a result, they often have late diagnosis of life-limiting illnesses such as cancer, even if they have regular primary care provider examinations (Terpstra et al., 2014). A plausible reason why they do not verbalize their pain could be a result of the negative symptoms of schizophrenia, or perhaps their delusional thoughts and perceptions alter their understanding and recognition of pain and disease symptoms, affecting how these are communicated to a healthcare provider (Terpstra et al., 2014).

2.1.3 Inclusion of persons with SPMI in end-of-life decision-making/advance care planning

Persons with SPMI are oftentimes assessed and treated differently from those who do not have mental illnesses. Persons with SPMI desire to engage with and be treated as any ordinary individual in society by healthcare providers and the entire healthcare system when they seek care, and not merely defined by their diagnosis (Jerwood et al., 2021). They also want their healthcare providers to be curious about their medical needs as they would for any other patient and be comfortable to ask them questions about their wellbeing, trusting that they have the capacity to express their needs irrespective of their medical conditions (Jerwood et al., 2021; Kotze & Roos, 2020). Inclusion of persons with SPMI in decision-making about palliative care and advance care planning ensures that they are treated with dignity and respect. In some instances, persons with SPMI may prioritize quality of life over longevity and prefer that nothing be done to prolong their life in situations when they become very ill, and this can only be realized when they are involved in decision-making (Elie et al., 2018; Kotze & Roos, 2020). Some healthcare providers often try to avoid conversations with persons with SPMI, because they are not comfortable initiating such conversations or it is their assumption that persons with SPMI lack mental capacity for these conversations (Jerwood et al., 2021). These actions of healthcare providers are then viewed by persons with SPMI as discrimination, negatively impacting the care they receive (Park, Mutoni, et al., 2022). A better approach for healthcare providers would be to focus less on their assumptions and prejudices and work more on how to effectively communicate with persons with SPMI (Jerwood et al., 2021; McNamara et al., 2018). To ensure shared decision-making with regards to palliative care for persons with SPMI, healthcare providers must make efforts to build good relationships with their patients and have clear and open communication with them. This will lead to well-designed care plans and suitable advance care planning (Jerwood et al., 2021; McNamara et al., 2018).

2.1.4 Collaboration between palliative care and mental health teams and interdisciplinary education for healthcare professionals providing palliative care for persons with SPMI

Lack of coordination between palliative care teams and mental health teams is seen as a major factor that influences persons with SPMI's access to palliative care. The issue stems from lack of formal planning to integrate these two areas in the healthcare system at various healthcare institutions and settings (Butler et al., 2018). Persons with SPMI desire to be treated holistically by healthcare providers instead of receiving fragmented care based on various healthcare providers' specialization (Jerwood et al., 2021). Fragmented care across varying medical specializations without proper collaboration between the various medical fields leads to suboptimal care and to important symptoms and health concerns of patients being overlooked or neglected. When mental healthcare providers and providers in other fields do not effectively collaborate when they are both providing care to persons with SPMI who need palliative care, it adversely affects the quality of care provided (Park, Mutoni, et al., 2022).

Hughes and colleagues (2023) illustrated what the lack of collaboration between health teams might look like using the fictional case of a man with a depressive disorder at the end-of-life; the man was having thoughts of suicide but had not acted on those thoughts because of the impact it might have on his spouse. A psychiatric trainee advised that the patient should be reviewed by his general practitioner (GP) and referred to the mental health team as appropriate. A palliative care consultant who examined the patient was reluctant to prescribe antidepressants, while the patient's GP thought the antidepressants would interact with the patient's other medications. The palliative clinical nurse specialist was frustrated at the turn of events for her patient and thought she might be left to support this patient without help. This case highlights the complex issues persons with SPMI must deal with, and the reason why palliative care and psychiatric teams need to collaborate.

A key challenge for most clinicians involved in providing care for persons with SPMI either in homecare settings, hospitals or emergency departments is the lack of requisite training to provide better care for this population. The lack of coordination between mental health and palliative care teams is evident in the lack of specialized interdisciplinary training in these areas. A proposition for interdisciplinary education and hybrid ‘palliative care-mental health’ specialization for healthcare providers is seen as the most suitable model of care for persons with SPMI to enhance the quality and access to palliative care (Park, Hegadoren, et al., 2022). The interdisciplinary education would provide the necessary knowledge and skills for clinicians in both the areas of mental health and palliative care to provide practical solutions to bridge the “mental health-palliative care’ gap (WHO, 2020).

2.1.5 Summary/critique of the body of literature on SPMI and palliative care

The 43 articles reviewed consisted of 21 reviews, 13 quantitative and 9 qualitative studies, with most of the articles originating from Europe (32.6%), the United States (27.9%) and Canada (6%). Most of the studies reviewed focused on SPMI, a term that encompasses schizophrenia, major depressive disorders, bipolar disorder, anxiety and personality disorders. Nine out of the 43 studies reviewed however, focused just on schizophrenia while only one focused on major depressive disorder. Interestingly, none of the articles reviewed indicated which medical conditions constitute SPMI, nor did the articles that employed a quantitative study design indicate which mental illnesses they included as SPMI in their analysis, even though some of these studies provided definitions for SPMI.

Eight quantitative studies reviewed used a retrospective cohort study design, used administrative datasets. and had large sample sizes (except for the study by Ganzini et al., (2010)). The study by Kashyap and colleagues (2021) which used secondary data, identified patients with mental illness using diagnostic codes from insurance claims which has the potential of patient (exposure) misclassification because the diagnostic coding used by insurance claims might not be as accurate as the International Classification of Diseases-10 (ICD-10) or the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) classification of diseases. The use of the unvalidated “mentalism” concept/approach in the cross-sectional study that examined hospital-based doctors' viewpoints about end-of-life care and medical decision-making in people living with mental illness limits the findings of the study (Dunn et al., n.d.). For the most part, most of the qualitative studies reviewed sought to explore the experiences, perspectives and perceptions of palliative care providers about providing palliative care for persons with SPMI. Only one study explored the views of persons with SPMI and those of their carers on their experiences, challenges, goals and expectations of accessing palliative care.

Overall, there is lack of research on palliative care among persons with SPMI and particularly sparse research on access among this population. Only one study measured access to specialist palliative care among SPMI (Butler et al., 2018). In addition to other indicators, Fond and colleagues (2021) had “access to palliative care in the last 31 days” as one of the palliative care indicators for the study’s outcome measures, but the study did not measure access to palliative care or include it in the analysis.

2.2 Research question

Although there seems to be some progress to improve access to palliative care overall in Canada (CIHI, 2023), it is unknown whether these improvements are seen among underserved groups in general, or among persons with SPMI specifically. Without knowing about access, it becomes difficult to not only address the factors that relate to access, but also to monitor improvement in access for this population. This study seeks to address these issues.

The *aims of this study* are to examine:

1) access to palliative care by home care clients with SPMI in Ontario, Canada, and

2) factors that are associated with access to palliative care by home care clients with SPMI.

CHAPTER 3: METHODOLOGY AND CONCEPTUAL FRAMEWORK

Except for the study by Butler and colleagues (2018), there are no other published studies that looked at access to palliative care services by people with SPMI. As in their study, the current study will compare the use of palliative care services by persons with SPMI with that of those without SPMI.

This study explores how having SPMI influences a person's access to palliative care compared to those without SPMI, and how various social determinants of health relate to this access. Analysis of existing health administrative data is necessary to determine access to palliative care and examine how social, medical and personal behavioral factors are associated with access to palliative care for persons with SPMI (Government of Canada, 2014).

This study also explores how age and sex interact/intersect when comparing access to palliative care for persons with SPMI and those without. Exploring intersectionality of these factors is necessary because these factors are typically interconnected and interact in a complex manner to produce a cumulative effect (Gkiouleka et al., 2018) and therefore must be examined through an intersectional lens.

The conceptual framework of this study is informed by the Queensland Health's (2001) framework for addressing the social determinants of health and wellbeing (CCSDH, 2015). To better understand and address health inequities, the complex relationships between various determinants of health must be appreciated. Determinants of health are the many factors that influence our health, and these determinants are grouped into medical, social and ecological (Raphael et al., 2020).

The relationship between the main exposure variable (SPMI diagnosis), social and personal factors and the outcome variable (access to palliative care) is demonstrated in Figure 1 below.

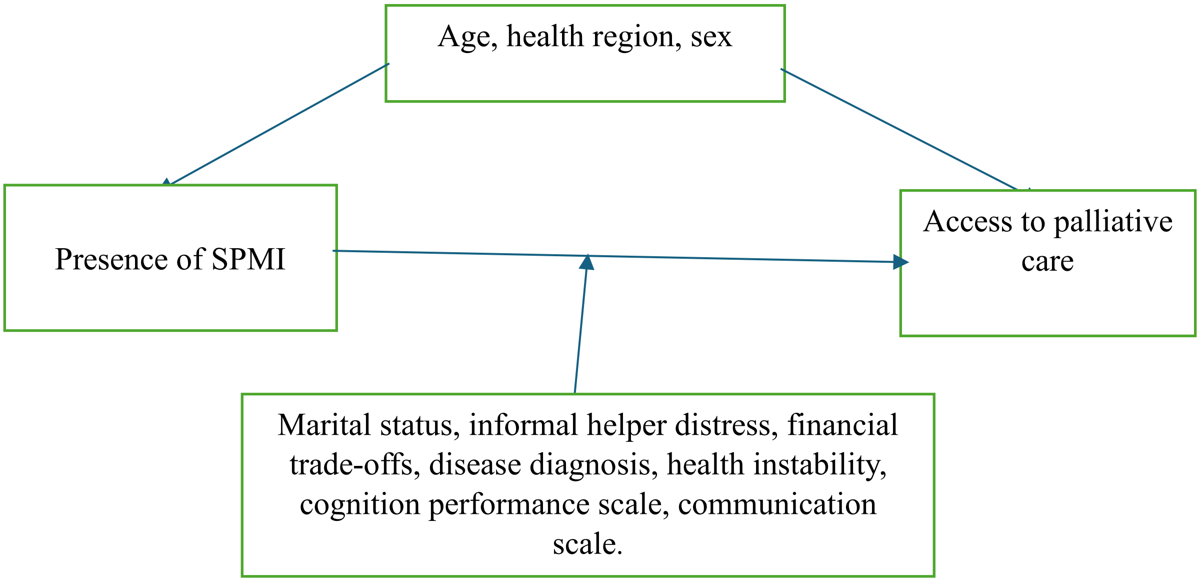


Figure 1: Conceptual framework of the relationship between disease diagnosis (SPMI vs non-SPMI), social, medical and personal factors and access to palliative care.

CHAPTER 4: METHODS

4.1 Hypothesis

This study hypothesizes that there is a difference in access to palliative care among persons with serious illness with and without SPMI.

4.2 Study design

This study uses existing, health administrative data, to explore access to palliative care among home care clients with and without SPMI.

4.3 Study population

This study is based on adults (i.e., ≥ 18 years) receiving home care services in Ontario. Comparisons will be made between those with and without SPMI.

4.4 Data source

Data for this study are population-level anonymized home care data from 2019 to 2023. The data are based on the interRAI Home Care assessment (Morris et al., n.d.) which includes information on demographic, social, and clinical information, as well as service utilization. The anonymized data for the study are stored on a secure server at the University of Waterloo. Access to the data was granted after provision of a TCPS2 certificate and signing the interRAI Confidentiality Agreement.

4.5 Variables

Access to palliative care

The dependent variable (primary outcome of interest) is access to palliative care, measured as whether a person received/was offered palliative care services.

SPMI

Diagnoses are recorded in the interRAI Home Care assessment. The following diagnoses were used to identify those with SPMI: bipolar disorder, depression, and schizophrenia.

Other variables:

The independent variables for this study include age, sex, marital status, financial trade-offs, health region, health instability, cognition performance scale, communication scale, disease diagnosis, informal helper distress. These variables are measured as follows:

AGE: Age is based on birthdate and categorized as <65 yrs, 65-74 yrs, 75-84 yrs and 85+ yrs.

SEX: male (M), female (F) and not assigned male or female (UN).

MARITAL STATUS: originally measured as never married (1), married (2), partner/significant other (3), widowed (4), separated (5) divorced (6). The original categories “married” and “partner/significant other” were re-categorized as “partnered” (1) and all others were re-categorized as “no partner” (0).

FINANCIAL TRADE-OFFS: The assessment asks whether persons had made trade-offs in purchasing necessities (e.g., food, rent, heating) in the last 30 days due to limited funds, and is scored as No (0), Yes (1).

HEALTH REGION (LHIN): Local Health Integrative Networks (LHINs) were used as the regional divisions for the purpose of administration of public healthcare services in Ontario: Erie St Claire (1), South West (2), Waterloo Wellington (3), Hamilton Niagara Haldimand Brant (4), Central West (5), Mississauga Halton (6), Toronto central (7), Central (8), Central East (9), South East (10), Champlain (11), North Simcoe Muskoka (12), North East (13), North West (14).

HEALTH INSTABILITY: This was measured using the Changes in Health, End-stage disease and Symptoms and Signs (CHESS) score, which is a measure of health instability and is associated with mortality in patients (Hirdes et al., 2003; Williams et al., 2022). CHESS scores range from 0 to 5, where: no health instability (0), minimal health instability (1), low health instability (2), moderate health instability (3), high health instability (4), very high health instability (5).

COGNITIVE PERFORMANCE SCALE (CPS): This scale provides a description of a person's cognitive status (Morris et al., 1994). The CPS is measured as: intact (0), borderline intact (1), mild impairment (2), moderate impairment (3), moderate/severe impairment (4), severe impairment (5) and very severe impairment (6). These scores were recoded as: 0=*intact (CPS=0)*; 1=*mild impairment (CPS=1,2)*; 2=*moderate or worse impairment (CPS=3,4,5,6*).

COMMUNICATION SCALE: The communication scale sums up a person's capacity to communicate with others and their ability to understand information they receive (CIHI, 2025). The communication scale consists of a score from 0 to 8, where: 0=intact, 1=borderline intact, 2=mild impairment, 3=mild/moderate impairment, 4=moderate impairment, 5=moderate/severe impairment, 6=severe impairment, 7=severe/very severe impairment, and 8=very severe impairment. These scores were recoded as: 0=*intact (score=0),* 1=*mild impairment (score=1,2), and* 3=*moderate or worse impairment (score=3 or more).*

DISEASE DIAGNOSES: Diagnoses are recorded on the assessment and coded as 0=Not present, 1=primary reason for current services, 2=present and receiving active treatment, or 3=present but no active treatment (e.g., monitoring). In this study, diagnoses were coded as 0=Not present and 1=Present (score 1, 2, or 3). Diagnoses considered included: Alzheimer disease, dementia, any paralysis (i.e., hemiplegia, paraplegia, quadriplegia), multiple sclerosis, Parkinson's disease, stroke/CVA*,* coronary heart disease, chronic obstructive pulmonary disease (COPD), congestive heart failure, cancer and diabetes.

INFORMAL HELPER DISTRESS: The assessment includes measures of informal caregiver distress such as the inability to continue caregiving activities, reports of distress by the primary informal helper, and family/close friends feeling overwhelmed by the person's support needs. Each is coded as 0=No, 1=Yes.

4.6 Data analysis

All analyses were conducted using SAS version 9.4. Missing values in the dataset were identified. Given that this study used secondary data, it was not possible to identify the reasons for the missing data (even though knowing the reasons is necessary to determine the approach to handling missing data (Harrell, 2001). However, frequencies of all variables were generated to know the overall percentage of missing values in the dataset. If ≤ 5% of values in the data are missing, those missing values would be excluded from the statistical analysis (Harrell, 2001; Langkamp et al., 2010; Montelpare et al., 2020). Categorical baseline characteristics of study participants were presented using frequencies. The mean and standard deviation of age were generated. Chi-square tests were done to measure the differences between persons with SPMI and those without with respect to participant characteristics.

The association between access to palliative care and the independent variables were identified by performing univariate and multivariate logistic regressions. For all statistical analyses, the level of significance was set at 0.05.

How age and sex modify the relationship between SPMI and PC access was assessed by introducing interaction terms for these variables and SPMI in the multiple logistic regression model. All considered variables were entered into the multivariate logistic regression model at once and the overall model fit was assessed by Hosmer-Lemeshow goodness of fit test.

CHAPTER 5: RESULTS

5.1 Missingness

No variables in the analysis had more than 5% missing values, and so none were excluded from the analysis.

5.2 Participant characteristics

After removing duplicates and sorting the dataset to the most recent interRAI home care assessment, 616,296 assessments of unique individuals were used for the study.

Table 1 shows that, overall, home care clients were on average 80 years old, female (59.1%), had no partner/significant other (61.9%), and few had made financial trade-offs in the last month (3.2%). The majority of home care clients lived in Central East (14.7%), Hamilton-Niagara-Haldimand-Brant (12.1%), Central (12%), Champlain (9.2%) and South West (8.1%) health regions. Coronary heart disease (30.9%), diabetes (29.7%), dementia (26.2%) and cancer were the most common disease diagnoses among home care clients. Approximately 13.6% of home care clients experienced no health instability, while 73.6% experienced minimal-to-moderate health instability, and 12.9% had high/very high health instability. Just over half (52.7%) of home care clients had mild cognitive impairment, 29.3% had moderate or worse cognitive impairment, and 18% had intact cognitive function. Similar proportions of clients had no (41.1%) and mild (38.8%) communication impairment, with 20.1% experiencing moderate or worse communication impairment. Child/child-in-law (48.6%) and spouse (28.7%) were the most reported primary informal helper. Child/child-in-law was the most common secondary informal helper (49%), with 33.9% reporting no secondary helper. Thirty-two percent of informal helpers indicated that they were unable to continue with caring activities, 39.4% experienced distress, and 49% had family or close friends who felt overwhelmed.

A total of 155,642 home care clients had SPMI, representing approximately 25.3% of all clients. As seen in Table 1, compared to persons without SPMI, those with SPMI were statistically significantly younger (75.9 years vs 80.9 years), more often female (64.8% vs 57.1%), more often did not have a partner (66.8% vs 60.2%), and had a higher proportion of people who had made financial trade offs (5.4% vs 2.4%). The proportion of home care clients with SPMI varied across the Local Health Integration Network (LHIN) regions examined. Persons with SPMI also, overall, had more medical diagnoses and more health instability. In particular, except for congestive heart failure and cancer, they had higher prevalence of all other considered medical conditions. There were statistically significant differences in cognitive performance and communication scores, with fewer persons with SPMI having no cognitive impairment (13.4% vs 19.5%) and no communication impairment (37% vs. 42.4%). There was higher prevalence of caregiver distress among those supporting persons with SPMI compared to those without SPMI on all measures considered.

Table 1: Population characteristics by presence of SPMI

Characteristics	Overall (N=616296) N (%)	SPMI(N=155642) N (%)	No SPMI (N=460654) N (%)	Test statistic and p-value
Mean age (SD)	79.6 (13.5)	75.9 (13.9)	80.9 (13.1)	t=127.45; p<0.0001
Age categories (years)				χ^2(df=3) =18124.0; p<0.0001
< 65	80553 (13%)	30715 (19.7%)	49838 (10.8%)	
65-74	98560 (16%)	33313 (21.4%)	65247 (14.2%)	
75-84	183476 (29.8%)	46157 (29.7%)	137319 (29.8%)	
85+	253707 (41.2%)	45457 (29.2%)	208250 (45.2%)	
Sex				χ^2(df=2) =2851.2; p<0.0001
Female	363957 (59.1%)	100848 (64.8%)	263109 (57.1%)	
Male	252185 (40.9%)	54740 (35.2%)	197445 (42.9%)	
Other	154	54 (0.03%)	100 (0.02%)	
Marital status				χ^2(df=1) =2130.2; p<0.0001
No partner	381433 (61.9%)	103974 (66.8%)	277459 (60.2%)	
Partner	234863 (38.1%)	51668 (33.2%)	183195 (39.8%)	
Made financial trade offs	19606 (3.2%)	8408 (5.4%)	11198 (2.4%)	χ^2(df=1) =3334.5; p<0.0001
Health region (LHIN)				χ^2(df=13) =3825.6; p<0.0001
Erie St Claire	30382 (4.9%)	7747 (5.0%)	22635 (4.9%)	
South West	49681 (8.1%)	14441 (9.3%)	35240 (7.7%)	
Waterloo-Wellington	29455 (4.8%)	8034 (5.2%)	21421 (4.7%)	
Hamilton-Niagara-Haldimand-Brant	74303 (12.1%)	20593 (13.2%)	53710 (11.7%)	
Central West	29291 (4.8%)	5901 (3.8%)	23390 (5.1%)	
Mississauga-Halton	36496 (5.9%)	7445 (4.8%)	29051 (6.3%)	
Toronto central	43782 (7.1%)	10599 (6.8%)	33183 (7.2%)	
Central	73955 (12%)	16256 (10.4%)	57699 (12.5%)	
Central East	90850 (14.7%)	19459 (12.5%)	71391 (15.5%)	
South East	31740 (5.2%)	8801(5.7%)	22939 (5.0%)	
Champlain	56562 (9.2%)	16471 (10.6%)	40091 (8.7%)	
North Simcoe Muskoka	25508 (4.1%)	7192 (4.6%)	18316 (4.0%)	
North East	31690 (5.1%)	9647 (6.2%)	22043 (4.8%)	
North West)	12601 (2%)	3056 (2.0%)	9545 (2.1%)	

Table 1: Population characteristics by presence of SPMI (CONTINUED)

Characteristics	Overall (N=616296) N (%)	SPMI (N=155642) N (%)	No SPMI (N=460654) N (%)	Test statistic and p-value
Disease diagnoses				
Alzheimer's disease	44010 (7.1%)	11345 (7.3%)	32665 (7.1%)	χ^2(df=1) =6.9; p=0.009
Dementia	161338 (26.2%)	44903 (28.9%)	116435 (25.3%)	χ^2(df=1) =769.0; p<0.0001
Paralysis	24353 (4%)	7209 (4.6%)	17144 (3.7%)	χ^2(df=1) =253.9; p<0.0001
Multiple sclerosis	6638 (1.1%)	2361 (1.5%)	4277 (0.9%)	χ^2(df=1) =378.1; p<0.0001
Parkinson's disease	27907 (4.5%)	8710 (5.6%)	19197 (4.2%)	χ^2(df=1) =549.4; p<0.0001
Stroke/CVA	99491 (16.1%)	27118 (17.4%)	72373 (15.7%)	χ^2(df=1) =252.0; p<0.0001
Coronary heart disease	190186 (30.9%)	50108 (32.2%)	140078 (30.4%)	χ^2(df=1) =173.9; p<0.0001
COPD	88505 (14.4%)	29684 (19.7%)	58821 (12.8%)	χ^2(df=1) =3757.9; p<0.0001
Congestive heart failure	90650 (14.7%)	21687 (13.9%)	68963 (15.0%)	χ^2(df=1) =99.7; p<0.0001
Cancer	115233 (18.7%)	24628 (15.8%)	90605 (19.7%)	χ^2(df=1) =1131.6; p<0.0001
Diabetes	183177 (29.7%)	49571 (31.9%)	133606 (29.0%)	χ^2(df=1) =451.1; p<0.0001
Health instability (CHESS)				χ^2(df=5) =381.4; p<0.0001
0=None	83610 (13.6%)	19677 (12.6%)	63933 (13.9%)	
1= Minimal	140872 (22.9%)	34645 (22.3%)	106227 (23.1%)	
2= Low	177132 (28.7%)	44793 (28.8%)	132339 (28.7%)	
3= Moderate	135319 (22%)	34916 (22.4%)	100403 (21.8%)	
4=High	72117 (11.7%)	19837 (12.8%)	52280 (11.4%)	
5=Very high	7246 (1.2%)	1774 (1.1%)	5472 (1.2%)	
Cognition Performance Scale (CPS)				χ^2(df=2) =2927.3; p<0.0001
Intact	110732 (18%)	20919 (13.4%)	89813 (19.5%)	
Mild impairment	324947 (52.7%)	87432 (56.2%)	237515 (51.6%)	
Moderate/severe impairment	180617 (29.3%)	47291 (30.4%)	133326 (28.9%)	
Communication Scale[1]				χ^2(df=3) =1674.8; p<0.0001
Intact	253001 (41.1%)	57576 (37%)	195425 (42.4%)	
Mild impairment	238979 (38.8%)	66414 (42.7%)	172562 (37.5%)	
Moderate or worse impairment	124131 (20.1%)	31629 (20.3%)	92502 (20.1%)	

Table 1: Population characteristics by presence of SPMI (CONTINUED)

Characteristics	Overall (N=616296) N (%)	SPMI (N=155642) N (%)	No SPMI (N=460654) N (%)	Test statistic and p-value
Primary informal helper relationship to person				χ^2(df=8) =8514.3; p<0.0001
Child/child-in-law	299186 (48.6%)	70251 (45.1%)	228935 (49.7%)	
Spouse	176823 (28.7%)	38986 (25.1%)	137837 (29.9%)	
Partner/significant other	9965 (1.6%)	3109 (2%)	6856 (1.5%)	
Parent/guardian	15073 (2.5%)	4813 (3.1%)	10260 (2.2%)	
Sibling	30250 (4.9%)	10934 (7%)	19316 (4.2%)	
Other relative	26766 (4.3%)	6642 (4.3%)	20124 (4.4%)	
Friend	28341 (4.6%)	8887 (5.7%)	19454 (4.2%)	
Neighbour	4723 (0.8%)	1284 (0.8%)	3439 (0.8%)	
No informal helper	25168 (4.1%)	10736 (6.9%)	14432 (3.1%)	
Second informal helper relationship to person				χ^2(df=8) =4498.0; p<0.0001
Child/child-in-law	302135 (49%)	66399 (42.7%)	235736 (51.2%)	
Spouse	9892 (1.6%)	2103 (1.4%)	7789 (1.7%)	
Partner/significant other	1518 (0.3%)	492 (0.3%)	1026 (0.2%)	
Parent/guardian	8224 (1.3%)	2341 (1.5%)	5883 (1.3%)	
Sibling	20152 (3.3%)	6650 (4.3%)	13502 (2.9%)	
Other relative	37583 (6.1%)	8873 (5.7%)	28710 (6.2%)	
Friend	21308 (3.5%)	6096 (3.9%)	15212 (3.3%)	
Neighbour	6446 (1%)	1521 (1%)	4925 (1.1%)	
No informal helper	209037 (33.9%)	61167 (39.3%)	147870 (32.1%)	
Informal helper distress				
Unable to continue caring activities	197068 (32%)	53319 (34.3%)	143749 (31.2%)	χ^2(df=1) =498.2; p<0.0001
Primary informal helper distressed	242656 (39.4%)	66432 (42.7%)	176224 (38.3%)	χ^2(df=1) =955.3; p<0.0001
Family or close friends overwhelmed	301932 (49%)	81671 (52.5%)	220261 (47.8%)	χ^2(df=1) =1010.4; p<0.0001

[1] Missing n=20 among those with SPMI and n=165 for those without SPMI

5.3 PC access

A total of 15,057 home care clients had access to PC, representing 2.5% of the home care population. Of those clients who had access to PC, 23.5% (n=3,536) had SPMI.

Table 2 shows that the mean age for persons who accessed PC was 81 years, that they were more often female (54.9%), had no partner (56.3%), and had not made financial trade-offs (2.9%). The most common diagnoses included cancer (54.3%), coronary heart disease (33.8%), diabetes (26.7%) and dementia (24.7%). The majority of persons who accessed PC had moderate to very high health instability (71.8%), and some level of cognitive (82.1%) or communication (61.7%) impairment. Child/child-in-law was the most reported informal helper by persons who accessed PC for both informal helper 1 and 2 (respectively 48.6% and 54.9%). In terms of informal helper distress, 36.4% of informal helpers were unable to continue with caring activities, 49% were distressed, and 61.3% felt overwhelmed.

Statistically significant differences existed between those with and without SPMI who accessed PC (Table 2). Persons with SPMI were younger (78.5 years vs 81.4 years), more often female (60.4% vs 53.2%), less often partnered (39.6% vs 45%), and had a higher proportion who had made financial trade-offs (4.2% vs 2.4%). The proportions of persons with SPMI who accessed PC varied across the health regions. Persons with SPMI had higher prevalence of all considered medical conditions except for congestive heart failure, and had more health instability, cognitive and communication impairment than those without SPMI. Persons with SPMI had the same proportion of informal helper 1 being child/child-in-law and lower proportion being spouse (30% vs 34.7%), and a lower proportion of child/child-in-law and spouse for informal helper 2. There was higher prevalence of caregiver distress among informal helpers assisting persons with SPMI compared to those without SPMI on all measures considered.

Table 2: Population characteristics of persons who accessed PC by presence of SPMI

Characteristics	Overall (N=15057) N (%)	SPMI (N=3536) N (%)	No SPMI (N=11521) N (%)	Test statistic and p-value
Mean age (SD)	80.7 (12.5)	78.5 (12.7)	81.4 (12.4)	t=12.06; p<0.0001
Age categories (years)				χ^2(df=3) =140.9; p<0.0001
< 65	1760 (11.7%)	532 (15.1%)	1228 (10.7%)	
65-74	2554 (17%)	716 (20.3%)	1838 (16%)	
75-84	4263 (28.3%)	1041 (29.4%)	3222 (28%)	
85+	6480 (43%)	1247 (35.3%)	5233 (45.4%)	
Sex				χ^2(df=1) =56.6; p<0.0001
Female	8267 (54.9%)	2136 (60.4%)	6131 (53.2%)	
Male	6786 (45.1%)	1399 (39.6%)	5387 (46.8%)	
Marital status				χ^2(df=1) =32.4; p<0.0001
No partner	8474 (56.3%)	2137 (60.4%)	6337 (55%)	
Partner	6786 (43.7%)	1399 (39.6%)	5184 (45%)	
Made financial trade offs	430 (2.9%)	150 (4.2%)	280 (2.4%)	χ^2(df=1) =32.0; p<0.0001
Health region (LHIN)				χ^2(df=13) =58.7; p<0.0001
Erie St Claire	1030 (6.8%)	226 (6.4%)	804 (7%)	
South West	1101 (7.3%)	299 (8.5%)	802 (7%)	
Waterloo-Wellington	875 (5.8%)	228 (6.4%)	647 (5.6%)	
Hamilton-Niagara-Haldimand-Brant	1649 (11%)	391 (11.1%)	1258 (10.9%)	
Central West	949 (6.3%)	184 (5.2%)	765 (6.6%)	
Mississauga-Halton	700 (4.7%)	166 (4.7%)	534 (4.6%)	
Toronto central	602 (4%)	129 (3.7%)	473 (4.1%)	
Central	1553 (10.3%)	333 (9.4%)	1220 (10.6%)	
Central East	1764 (11.7%)	364 (10.3%)	1400 (12.2%)	
South East	1385 (9.2%)	314 (8.9%)	1071 (9.3%)	
Champlain	1346 (8.9%)	376 (10.6%)	970 (8.4%)	
North Simcoe Muskoka	1180 (7.8%)	277 (7.8%)	903 (7.8%)	
North East	569 (3.8%)	163 (4.6%)	406 (3.5%)	
North West)	354 (2.4%)	86 (2.4%)	268 (2.3%)	

Table 2: Population characteristics of persons who accessed PC by presence of SPMI (CONTINUED)

Characteristics	Overall (N=15057) N (%)	SPMI (N=3536) N (%)	No SPMI (N=11521) N (%)	Test statistic and p-value
Disease diagnoses				
Alzheimer's disease	793 (5.3%)	204 (5.8%)	589 (5.1%)	χ^2(df=1) =2.3; p=0.12
Dementia	3721 (24.7%)	1102 (31.2%)	2619 (22.7%)	χ^2(df=1) =103.4; p<0.0001
Paralysis	527 (3.5%)	151 (4.3%)	376 (3.3%)	χ^2(df=1) =8.1; p=0.004
Multiple sclerosis	105 (0.7%)	46 (1.3%)	59 (0.5%)	χ^2(df=1) =24.3; p<0.0001
Parkinson's disease	553 (3.7%)	195 (5.5%)	358 (3.1%)	χ^2(df=1) =44.3; p<0.0001
Stroke/CVA	2124 (14.1%)	594 (16.8%)	1530 (13.3%)	χ^2(df=1) =27.6; p<0.0001
Coronary heart disease	5088 (33.8%)	1312 (37.1%)	3776 (32.8%)	χ^2(df=1) =22.7; p<0.0001
COPD	3212 (21.3%)	1010 (28.6%)	2202 (19.1%)	χ^2(df=1) =144; p<0.0001
Congestive heart failure	3211 (21.3%)	787 (22.3%)	2424 (21%)	χ^2(df=1) =2.4; p=.0.12
Cancer	8177 (54.3%)	1731 (49%)	6446 (56%)	χ^2(df=1) =53.4; p<0.0001
Diabetes	4012 (26.7%)	1006 (28.5%)	3006 (26.1%)	χ^2(df=1) =7.7; p=0.006
Health instability (CHESS score)				χ^2(df=5) =16.1; p<0.0001
0=None	472 (3.1%)	91 (2.6%)	381 (3.3%)	
1= Minimal	1320 (8.8%)	278 (7.9%)	1042 (9%)	
2= Low	2447 (16.3%)	584 (16.5%)	1863 (16.2%)	
3= Moderate	3715 (24.7%)	891 (25.2%)	2824 (24.5%)	
4=High	4372 (29%)	999 (28.3%)	3373 (29.3%)	
5=Very high	2731 (18.1%)	693 (19.6%)	2038 (17.7%)	
Cognitive Performance Scale (CPS)				χ^2(df=2) =122.3; p<0.0001
Intact	2694 (17.9%)	428 (12.1%)	2266 (19.7%)	
Mild impairment	7084 (47%)	1685 (47.7%)	5399 (46.9%)	
Moderate/severe impairment	5279 (35.1%)	1423 (40.2%)	3856 (33.5%)	
Communication Scale[1]				χ^2(df=3) =99.8; p<0.0001
Intact	5745 (38.3%)	1112 (31.5%)	4633 (40.2%)	
Mild impairment	5311 (35.4%)	1369 (38.7%)	3942 (34.2%)	
Moderate or worse impairment	3929 (26.2%)	1048 (29.6%)	2881 (25%)	

Table 2: Population characteristics of persons who accessed PC by presence of SPMI (CONTINUED)

Characteristics	Overall (N=15057) N (%)	SPMI (N=3536) N (%)	No SPMI (N=11521) N (%)	Test statistic and p-value
Primary informal helper relationship to person				χ^2(df=8) =75.5; p<0.0001
Child/child-in-law	7319 (48.6%)	1718 (48.6%)	5601 (48.6%)	
Spouse	5059 (33.6%)	1060 (30%)	3999 (34.7%)	
Partner/significant other	314 (2.1%)	79 (2.2%)	235 (2%)	
Parent/guardian	163 (1.1%)	54 (1.5%)	109 (1%)	
Sibling	627 (4.2%)	201 (5.7%)	426 (3.7%)	
Other relative	599 (4%)	140 (4%)	459 (4%)	
Friend	564 (3.8%)	161 (4.6%)	403 (3.5%)	
Neighbour	65 (0.4%)	12 (0.3%)	53 (0.5%)	
No informal helper	347 (2.3%)	111 (3.1%)	236 (2%)	
Secondary informal helper relationship to person				χ^2(df=8) =73.2; p<0.0001
Child/child-in-law	8262 (54.9%)	1755 (49.6%)	6507 (56.5%)	
Spouse	272 (1.8%)	59 (1.7%)	213 (1.9%)	
Partner/significant other	28 (0.2%)	9 (0.3%)	19 (0.2%)	
Parent/guardian	132 (0.9%)	44 (1.2%)	88 (0.8%)	
Sibling	491 (3.3%)	152 (4.3%)	339 (2.9%)	
Other relative	925 (6.1%)	216 (6.1%)	709 (6.2%)	
Friend	491 (3.3%)	112 (3.2%)	379 (3.3%)	
Neighbour	113 (0.8%)	27 (0.8%)	86 (0.8%)	
No informal helper	4343 (28.8%)	1162 (32.9%)	3181 (27.6%)	
Informal helper distress				
Unable to continue caring activities	5483 (36.4%)	1435 (40.6%)	4048 (35.1%)	χ^2(df=1) =34.7; p<0.0001
Primary informal helper distressed	7372 (49%)	1954 (55.3%)	5418 (47%)	χ^2(df=1) =73.4; p<0.0001
Family or close friends overwhelmed	9227 (61.3%)	2347 (66.4%)	6880 (59.7%)	χ^2(df=1) =50.5; p<0.0001

[1] Missing n=7 among those with SPMI and n=65 for those without SPMI

5.4 Factors associated with PC access

Table 3 presents crude and adjusted associations between explanatory variables and PC access. In the unadjusted logistic regression model, several variables were associated with lower odds of PC access, including: SPMI (OR=0.91, CI=0.87, 0.94); female (OR=0.84, CI=0.81, 0.87); financial trade-offs (OR=0.90, CI=0.81, 0.99); residing in Mississauga Halton (OR=0.91, CI=0.83, 0.99), Toronto central (OR=0.65, CI=0.59, 0.72), Central East (OR=0.92, CI=0.86, 0.99), and North East (OR=0.85, CI=0.77, 0.94) health regions; Alzheimer's disease (OR=0.72, CI=0.67, 0.77); dementia (OR=0.93, CI=0.89, 0.93); paralysis (OR=0.88, CI=0.81, 0.96) multiple sclerosis (OR=0.64, CI=0.53, 0.78); Parkinson's disease (OR=0.8, CI=0.73, 0.87); stroke/CVA (OR=0.85, CI=0.81, 0.89); and diabetes (OR=0.86, CI=0.83, 0.89).

Several variables were associated with higher odds of PC access, including increasing age (65-74 yrs OR=1.19, CI=1.12, 1.27; 75-84 yrs OR=1.06, CI= 1.01, 1.13; 85+ yrs OR=1.17, CI=1.11, 1.24); having a partner (OR=1.27, CI=1.23, 1.31); and residing in Erie St Claire (OR=1.63, CI=1.51, 1.77), Waterloo Wellington (OR=1.43, CI=1.31, 1.56), Central West (OR=1.56, CI=1.44, 1.69), South East (OR=2.13, CI=1.98, 2.29), Champlain (OR=1.14, CI=1.06, 1.22), North Simcoe Muskoka (OR=2.26, CI=2.1, 2.44), and North West (OR=1.35, CI=1.2, 1.52) health regions. The following diagnoses were associated with higher odds of PC access: coronary heart disease (OR=1.15, CI=1.11, 1.19); COPD (OR=1.64, CI=1.58, 1.71), congestive heart failure (OR=1.59, CI=1.53, 1.66), and cancer (OR=5.49, CI=5.31, 5.67). Having any form of health instability, any cognitive impairment, and moderate/severe cognitive or communication impairment were also associated with higher odds, as well as presence of any form of caregiver distress.

In the adjusted model, many variables remained significantly associated with PC access. Having a partner/significant other was associated with 7% greater odds of accessing PC (OR=1.07, CI=1.03,1.12) when compared to persons who had no partner/never married. Making financial trade-offs due to limited funds was associated with 16% lower odds of accessing PC (OR=0.84, CI=0.76,0.94). Compared to residing in Central LHIN region, those in Hamilton-Niagara-Haldimand-Brant (OR=0.7, CI=0.65,0.75); Mississauga Halton (OR=0.89, 0.81,0.98); Toronto central (OR=0.79, CI=0.71,0.87); Central East (OR=0.67, CI=0.63,0.72) and North East (OR=0.68, 0.61,0.75) LHIN regions had lower odds of having accessed PC. However, residing in Erie St Claire (OR=1.33, CI=1.22,1.44); Waterloo-Wellington (OR=1.22, CI=1.12,1.34); South East (OR=1.27, CI=1.17,1.38) and North Simcoe (OR=1.46, CI=1.35,1.59) LHIN regions were associated with higher odds of PC access. In the multivariate model, residence in Central West, Champlain, and North West were no longer statistically significant.

Health instability was significantly associated with higher odds of PC access with each level of the CHESS scale, where those with the highest level of health instability had 71.88 times greater odds of having accessed PC (CI=64.48, 80.3). Both cognitive performance (measured as cognitive performance scale) and communicative abilities (measured as communication scale) were associated with PC access in the adjusted logistic regression model. Persons with mild and moderate/severe cognitive impairments had 27% (OR=0.73, CI=0.69, 0.78) and 16% (OR=0.84, CI=0.78, 0.91) lower odds of PC access respectively when compared to those with intact cognition. Persons with mild communication impairment had 9% (OR=0.91, CI=0.86, 0.95) lower odds of PC access while persons with moderate/severe communication impairment had 31% (OR=1.31, CI=1.22, 1.40) higher odds of PC access when compared to those with intact communication ability.

Several disease diagnoses were associated with PC access after adjusting for other factors. Alzheimer's disease (OR=0.72, CI=0.66,0.78), dementia (OR=0.81, CI=0.77,0.85), Parkinson’s disease (OR=0.91, CI=0.83,0.99), stroke/CVA (OR=0.82, CI=0.77,0.86), coronary heart disease (OR=0.96, CI=0.92,0.99), and diabetes (OR=0.85, CI=0.83, 0.89) were associated with lower odds of accessing PC, whereas paralysis (OR=1.29, CI=1.17,1.42), COPD (OR=1.26, CI=1.21,1.32), congestive heart failure (OR=1.31, CI=1.26,1.38), and cancer (OR=4.19, CI=4.04,4.34) were associated with higher odds.

Having an informal helper who reported being unable to continue in caring activities was associated with lower odds of PC access (OR=0.88, CI=0.85,0.92), whereas having family or friends who felt overwhelmed was associated with 12% higher odds of PC access (OR=1.12, CI=1.07, 1.18). Primary caregiver report of feeling distressed was not statistically significantly associated with PC access.

Age and sex showed statistically significant interaction with SPMI in relation to PC access. More specifically, the results of the adjusted model showed that the association between SPMI and PC access was modified by sex (p-value=0.02) and age (p-value=0.04). The effect modification showed that females who were less than 65 years and had SPMI had 15% lower odds (OR=0.85, CI=0.76, 0.95) of PC access compared to males of same age without SPMI. Similarly, females who were aged 65-74 years with SPMI had 16% lower odds (OR=0.84, CI=0.76, 0.93) of PC access compared to males of same age and had no SPMI. Together, these results indicate that women with SPMI aged less than 75 had lower odds of PC access than women without SPMI, but that no such association was evidenced for men. Result of the Hosmer-Lemeshow goodness of fit test (χ^2(df=8) =61.7; $p<0.0001$) showed that the multivariate regression model did not fit the data well, possibly because the population-level dataset used for this study had other variables that were not included in the analysis.

Table 3: Crude and Adjusted Odds ratios for access to PC by persons with SPMI compared to those without SPMI

Characteristics	**Unadjusted OR (95% CI)**	**p-value**	**Adjusted OR (95% CI)**	**p-value**
SPMI	0.91 (0.87, 0.94)	<0.0001	0.94 (0.82, 1.06)	0.28
Age categories (REF < 65 years)				
65-74 years	1.19 (1.12, 1.27)	<0.0001	0.95 (0.87, 1.03)	0.23
75-84 years	1.06 (1.01, 1.13)	0.03	0.80 (0.72, 0.87)	<0.0001
85+ years	1.17 (1.11, 1.24)	<0.0001	0.87 (0.80, 0.94)	0.0002
Female sex (REF=Male)	0.84 (0.81, 0.87)	<0.0001	1.04 (0.99, 1.08)	0.09
Has a partner (REF=No partner)	1.27 (1.23, 1.31)	<0.0001	1.07 (1.03, 1.12)	0.0002
Made financial trade offs	0.90 (0.81, 0.99)	<0.0001	0.84 (0.76, 0.94)	0.001
Health region (REF=Central)				
Erie St Claire	1.63 (1.51, 1.77)	<0.0001	1.33 (1.22, 1.44)	<0.0001
South West	1.06 (0.98, 1.14)	0.16	1.01 (0.93, 1.1)	0.74
Waterloo Wellington	1.43 (1.31, 1.56)	<0.0001	1.22 (1.12, 1.34)	<0.0001
Hamilton Niagara Haldimand Brant	1.06 (0.99, 1.14)	0.11	0.70 (0.65, 0.75)	<0.0001
Central West	1.56 (1.44, 1.69)	<0.0001	1.08 (0.99, 1.18)	0.08
Mississauga Halton	0.91 (0.83, 0.99)	0.04	0.89 (0.81, 0.98)	0.02
Toronto central	0.65 (0.59, 0.72)	<0.0001	0.79 (0.71, 0.87)	<0.0001
Central East	0.92 (0.86, 0.99)	0.02	0.67 (0.63, 0.72)	<0.0001
South East	2.13 (1.98, 2.29)	<0.0001	1.27 (1.17, 1.38)	<0.0001
Champlain	1.14 (1.06, 1.22)	0.0007	0.99 (0.92, 1.07)	0.80
North Simcoe Muskoka	2.26 (2.10, 2.44)	<0.0001	1.46 (1.35, 1.59)	<0.0001
North East	0.85 (0.77, 0.94)	0.001	0.68 (0.61, 0.75)	<0.0001
North West	1.35 (1.20, 1.52)	<0.0001	1.08 (0.95, 1.23)	0.22
Health Instability (CHESS) (REF=0. None)				
1= Minimal	1.67 (1.50, 1.85)	<0.0001	1.66 (1.49, 1.84)	<0.0001
2= Low	2.47 (2.23, 2.72)	<0.0001	2.41 (2.18, 2.66)	<0.0001
3= Moderate	4.97 (4.51, 5.47)	<0.0001	4.51 (4.09, 4.98)	<0.0001
4=High	11.35(10.32,12.49)	<0.0001	10.09 (9.13,11.15)	<0.0001
5=Very high	106.34 (96.01,117.78)	<0.0001	71.88 (64.48,80.13)	<0.0001
Cognition Performance Scale (REF=intact)				
Mild impairment	0.89 (0.86, 0.94)	<0.0001	0.73 (0.69, 0.78)	<0.0001
Moderate or worse impairment	1.21 (1.15, 1.27)	<0.0001	0.84 (0.78, 0.91)	<0.0001
Communication scale				
(REF=intact)	0.98 (0.94, 1.02)	0.26	0.91 (0.86, 0.95)	<0.0001
Mild impairment	1.41 (1.35, 1.47)	<0.0001	1.31 (1.22, 1.40)	<0.0001
Moderate/severe impairment				

Table 3: Crude and Adjusted Odds ratios for access to PC by persons with SPMI compared to those without SPMI (CONTINUED)

Characteristics	Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Disease diagnoses				
Alzheimer’s disease	0.72 (0.67, 0.77)	<0.0001	0.72 (0.66, 0.78)	<0.0001
Dementia	0.93 (0.89, 0.93)	<0.0001	0.81 (0.77, 0.85)	<0.0001
Paralysis	0.88 (0.81, 0.96)	0.004	1.29 (1.17, 1.42)	<0.0001
Multiple sclerosis	0.64 (0.53, 0.78)	<0.0001	0.95 (0.77, 1.16)	0.59
Parkinson’s disease	0.80 (0.73, 0,87)	<0.0001	0.91 (0.83, 0.99)	0.03
Stroke/CVA	0.85 (0.81, 0.89)	<0.0001	0.85 (0.81, 0.89)	<0.0001
Coronary heart disease	1.15 (1.11, 1.19)	<0.0001	0.96 (0.92, 0.99)	0.03
Chronic obstructive pulmonary disease	1.64 (1.58, 1.71)	<0.0001	1.26 (1.21, 1.32)	<0.0001
Congestive heart failure	1.59 (1.53, 1.66)	<0.0001	1.31 (1.26, 1.38)	<0.0001
Cancer	5.49 (5.31, 5.67)	<0.0001	4.19 (4.04, 4.34)	<0.0001
Diabetes	0.86 (0.83, 0.89)	<0.0001	0.85 (0.82, 0.89)	<0.0001
Informal helper distress				
Unable to continue in caring activities	1.23 (1.19, 2.27)	<0.0001	0.90 (0.86, 0.94)	<0.0001
Primary informal helper distressed	1.49 (1.45, 1.54)	<0.0001	1.02 (0.98, 1.07)	0.37
Family or close friends overwhelmed	1.67 (1.62, 1.73)	<0.0001	1.12 (1.07, 1.18)	<0.0001
Interaction (sub-levels)				
SPMI*sex (REF=male)			0.91 (0.82, 0.99)	0.02
SPMI*ageCAT (65-74)			0.99 (0.84, 1.13)	0.85
SPMI*ageCAT (75-84)			1.09 (0.95, 1.22)	0.22
SPMI*ageCAT (85+)			1.14 (1.01, 1.27)	0.04
Interaction terms (SPMI*age categories and SPMI*sex)				
SPMI at age<65 yrs and female			0.85 (0.76, 0.95)	0.0042
SPMI at age<65 yrs and male			0.94 (0.83, 1.06)	0.32
SPMI at age 65-74 and female			0.84 (0.76, 0.93)	0.0006
SPMI at age 65-74 and male			0.92 (0.83, 1.03)	0.13
SPMI at age 75-84 and female			0.92 (0.85, 1.0)	0.06
SPMI at age 75-84 and male			1.02 (0.93, 1.11)	0.71
SPMI at age 85+ and female			0.97 (0.90, 1.05)	0.44
SPMI at age 85+ and male			1.07 (0.98, 1.17)	0.12

CHAPTER 6: DISCUSSION

6.1 Summary of study findings

This study is one of few to examine access to palliative care by persons with SPMI in Canada. Of the 616,296 home care clients in this study, 155,642 (25.3%) had SPMI and 15,057 (2.5%) had access to PC. Of those who accessed PC, 23.5% (n=3,536) had SPMI. Persons with SPMI were younger, more often females and single, often made financial trade offs, had more medical comorbidities and more health instability, and had higher prevalence of caregiver distress compared to persons without SPMI. The association between having SPMI diagnosis and access to PC was modified by sex and age. Women with SPMI aged less than 75 had lower odds of PC access than women without SPMI.

6.2 Access to palliative care

While there are relatively few studies that examines access to PC by persons with SPMI, some studies have shown that persons with SPMI are less likely to have access to PC (Butler et al., 2018; Chochinov et al., 2012; McNamara et al., 2018). This is the first known study that explored access to PC among persons with SPMI in the province of Ontario, Canada. Results of this study shows that 23.5% of home care clients who accessed PC had SPMI. Home care clients with SPMI also have 9% lower odds of PC access compared to those without SPMI, similar to findings of Butler and colleagues (2018) which showed that persons with SPMI were 3.5 times less likely to access specialist PC services (Butler et al., 2018). While this study population was home care clients in Ontario, Canada, Butler and colleagues examined access to specialist PC among the general population in New Zealand's capital and coast health district, the geographically different locations of these studies could be a probable reason for the relatively larger access. The 2023 CIHI report also indicates that underserved populations (which include persons with SPMI) often have late referrals for palliative care (CIHI, 2023), which explains the low PC access for persons with SPMI in this current study. Similar to this current study, some studies have shown that persons with schizophrenia were less likely to have access to palliative care compared to those without schizophrenia (Chochinov et al., 2012; McNamara et al., 2018; Spilsbury et al., 2018). A population-based study in Taiwan by Huang and colleagues (2018) reported that cancer patients with schizophrenia received more PC consultation services than those without schizophrenia. Another study in France by Fond and colleagues (2019) reported that cancer patients with schizophrenia had higher chance of receiving PC than those without schizophrenia, but less likely to have chemotherapy. Conflicting reports about access to PC across the globe could be due to differing healthcare systems and policies (Diminic et al., 2015), healthcare workforce and resources (Poudel et al., n.d.), societal norms and social supports (McNamara et al., 2018) and how these interplay in different countries. Possible reasons for higher access to PC for persons with SPMI in some countries could be due to integrated healthcare systems in these countries that effectively integrates mental health into their overall healthcare systems, whereas countries with more fragmented and siloed healthcare systems would have the opposite. The implications of the inequity in access to PC for persons with SPMI is far reaching, as siloed/fragmented care for persons with SPMI leads to poor pain and symptom management, and other poor health outcomes (Donald & Stajduhar, 2019; Morgan, 2016; Moureau et al., 2023; Shalev et al., 2020).

6.3 Factors associated with access to palliative care

6.3.1 Socio-demographic factors

This study's results show that independently, older age groups (compared to persons below 65 years) were associated with higher odds of access to PC, even though the results did not indicate a pattern of increasing odds of access with increasing age. Current literature on access to palliative care among different age groups are conflicting. While a study by Evers and colleagues (2002) have shown that older adults, especially those above 80 years are relatively more likely to access PC than younger age groups, some other studies indicate otherwise (CIHI, 2023; Kurkowski et al., 2022; Rostoft et al., 2022). The disparities in PC access in older vs younger population could be due to clinical judgment of healthcare professionals when making decisions about prioritizing access to palliative care (Kurkowski et al., 2022). When healthcare professionals evaluate the care they provide, solely with the lens of the potential for patient's to recover, which differs from palliative care goals, the treatments they provide could be related to whether they perceive older adults as persons with less potential for recovery or vice versa (Kurkowski et al., 2022), which could negatively influence PC access. According to the CIHI, 2023 report on access to PC, older adults aged 85+ were less likely to receive PC compared to younger age groups, even though they are more frail and experience higher medical comorbidities (CIHI, 2023).

Independently, females in home care had 16% lower odds of PC access compared to their male counterparts, but in the adjusted logistic regression model, sex and age modified the association between SPMI and PC access, pointing to the complex association between sex, age and PC access. Similar to this study, findings from Blum and colleagues (2024) indicates that women with heart failure had greater symptom burden and were much older at the time of their initial PC consultation, implying that females are likely to have late referral for PC compared to their male counterparts. On the contrary, in a population-based study by Gitau and colleagues (2023), that looked at the association between sex and PC utilization, females had 9% higher chance (adjusted RR=1.09, CI=1.08,1.10) of receiving PC compared to males. After controlling for other covariates in this present study, females less than 65 years who had SPMI had 15% lower odds of PC access, a clear indication of the intersectionality between age, sex and having SPMI in relation to access to PC. Similarly, females aged 65-74 years with SPMI also had 16% lower odds of PC access. Having SPMI for males, however, was not associated with lower odds of PC access. This is the first known study that examined how age, sex and SPMI intersects in relation to the association between having SPMI and PC access. The present study's results highlight the need to consider age and sex of a person with SPMI when examining access to PC.

Having a partner/significant other was associated with 7% higher odds of PC access after adjusting for all other covariates in this present study. This finding confirms what has been reported in literature (Adsersen et al., 2019; Cai et al., 2017; Lackan et al., 2005). Possible reasons for higher PC access for persons with partners/significant other is mainly due to the partners (spouses) advocating for their referral for PC services and informal support (CIHI, 2023; McNamara et al., 2018). Those without partners or any informal support were more likely to experience unequal access to care. As such, healthcare providers and various actors in the healthcare system should be proactive in developing care plans that are tailored towards the needs of persons who do not have such informal support or advocates.

Having controlled for all covariates, when informal helpers were unable to continue with caring activities it resulted in 10% lower odds of PC access, while persons who's family or close friends felt overwhelmed was associated with 12% higher odds of PC access. Current literature points to caregiver distress and it's impact on PC utilization (Adejoh et al., 2021; Ahmad Zubaidi et al., 2020; Gardiner et al., 2020; Mercadante et al., 2022). The burden of caregiving alongside the physical, emotional and financial strains that comes with it (Ahmad Zubaidi et al., 2020; Gardiner et al., 2020) often leads some caregivers no choice than to stop providing the informal support. Since these caregivers mostly push for persons with SPMI to have access to palliative care within the healthcare system (CIHI, 2023), their inability to continue the caregiving would result in reduced access to PC. The likely reasons for higher access to PC for persons whose family or friends felt overwhelmed by caregiving duties could be attributed to the fact that these informal helpers do not quit the caregiving duties but instead advocate more for PC for the people they are caring for, which in turn can improve pain control and better care for other comorbidities. Healthcare providers must be trained to screen for and recognize signs of caregiver distress among informal helpers who accompany patients for routine care and provide necessary support and mental health resources/referral to address those needs. Likewise, appropriate government and non-governmental agencies should provide financial assistance to alleviate the economic burden of caregivers.

Persons who reported to have made financial trade-offs in purchasing necessities such as food, rent, heating due to limited funds had 16% lower odds of PC access after adjusting for other covariates. This study's finding is in agreement with other studies (French et al., 2021; Rowley et al., 2021; Santos Salas et al., 2024) that show that low socioeconomic status leads to disparities in PC access. Persons with lower socio-economic status, an underserved group, commonly experience less access to palliative care than the general population (Barbera et al., 2006; CIHI, 2023).

This study’s findings show that living in Erie St Claire, Waterloo Wellington, Sout East and North Simcoe Muskoka LHIN regions were associated with higher odds of PC access after adjusting for all other covariates, while living in the other regions were associated with reduced access (except 4 health regions that showed statistically non-significant association). While this finding does not necessarily provide a picture about rural-urban trend for PC access, it provides useful information about PC access in the various LHIN regions and points to which regions require improvement. Particularly, this study shows that persons living in North East LHIN (a part of northern Ontario) had a 32% lower odds of PC access after adjusting for other covariates, similar to findings of a study by Conlon and colleagues (2019) which showed that decedent rural cancer residents in northern Ontario (North East and North West LHIN regions) had 10% lower odds of receiving PC compared to those in the southern regions. These geographic disparities in PC access emphasizes the need for pragmatic and targeted interventions and policies such as expanding telehealth services to include more PC consultations, particularly in northern and sparse communities, providing good incentives to attract more healthcare professionals to these underserved communities and provision of necessary resources to improve PC.

6.3.2 Health related factors

This current study demonstrates that having any form of health instability was associated with increased odds of PC access. While there are limited studies that directly link the CHESS score to PC access, this study’s findings show that increasing health instability (measured by CHESS score) is associated with increasing odds of PC access.

The ability of a person to communicate with others as well as their cognitive status, both measured as outcome scales with InterRAI assessment tools are part of other assessment tools that provides a comprehensive outlook of home care resident's clinical status (Büla & Wietlisbach, 2009; CIHI, 2025). This study showed that having cognitive impairment and mild communication impairment were all associated with lower odds of PC access, while moderate/severe communication impairment was associated with increased odds of access. This finding of low PC access for persons with cognitive impairment is consistent with current literature that shows that persons with cognitive impairment face disparities in PC access (Donath et al., 2024; Hanson et al., 2019; Xie et al., 2025). Some have reported that this can be attributed to difficulty expressing pain, distress and discomfort which hinders healthcare professionals and/or caregivers' recognition of the need for palliative care for such patients (McNamara et al., 2018; Xie et al., 2025). Healthcare providers and caregivers need to facilitate early discussions with persons with SPMI soon after they are diagnosed with life-limiting illness regarding their palliative care needs before they experience cognitive and communication decline. Healthcare providers should also be trained to screen for cognitive and communication decline in patients to better understand and recognize their PC needs in advance. Alternatively, for those with existing (or lifelong) cognitive or communication impairments, efforts must be made by health care providers to ensure that they understand their situation and care options.

Among the disease conditions considered, having Alzheimer's, dementia, Parkinson's, stroke, coronary heart disease, and diabetes were all associated with lower odds of PC access after adjusting for other covariates. This finding indicates that having these comorbid conditions are related to reduced probability of PC access, similar to findings in other studies (Guion et al., 2022; Sadowska et al., 2023). On the other hand, persons with paralysis, COPD, congestive heart failure and cancer had higher odds of PC access, findings that are also consistent with what is reported in literature (Health Canada, 2018; Kao et al., 2023; Rush et al., 2017; Wice et al., 2023).

6.4 Strengths and limitations

6.4.1 Strengths

The population-level InterRAI home care data for Ontario provided large sample size (enhanced statistical power) for the study. This allowed for robust statistical analyses that were able to detect significant differences between groups in the study population. Also, given the population-level nature of the data, the findings are representative of the current situation in Ontario's home care sector. This study also provided the level of access to PC for persons with SPMI in Ontario, the first known study that gives an overview of access to PC for this population.

6.4.2 Limitations

This study has some limitations that need to be considered. First, the use of administrative dataset for this study limits the ability of the researcher to adjust for other confounders (such as a person's household income quintile, ethnicity, severity or stage of life-limiting illness, number of emergency department visits) that are not captured in the dataset. Secondly, since Ontario transitioned the 14 LHINs to Ontario Health that has different regional divisions, the regional differences observed in this study, although relevant, might not be applicable for the current regional divisions. Data for this study overlap with the COVID pandemic which could introduce non-differential misclassification bias in the study, as the pandemic could have influenced home care assessments and access to palliative care services. Future studies could compare data collected prior and post COVID pandemic to see if there could be variations in the outcome.

CHAPTER 7: CONCLUSION

This study examined access to palliative care by persons with SPMI and factors associated with access. In Ontario's home care population, 2.5% (15,057) had access to PC, of whom 23.5% (3,536) had SPMI. Overall, among those who accessed PC, persons with SPMI were mostly younger, were mostly females, had no partner, made more financial trade-offs, had higher prevalence of medical conditions, had greater health instability and more caregiver distress compared to those without SPMI.

After controlling for personal, social, functional and clinical characteristics of study participants, having SPMI was associated with lower access to palliative care. Sex and age modified the association between SPMI and PC access. Females less than 65 years who had SPMI had 15% lower odds of PC access compared to males of same age without SPMI. Also, females aged 65-74 years with SPMI had 16% lower odds of PC access compared to males of same age who had no SPMI. Other variables considered in this study were also associated with PC access. Healthcare policies and programs aimed at increasing access to PC for persons with SPMI must incorporate targeted projects that promote equitable access to PC.

Further research that examines PC in persons with SPMI should explore the timing of onset of receipt of palliative care relative to when they are diagnosed with life-limiting illnesses. Furthermore, future research should explore the impact of PC access on overall quality of life of persons with SPMI overall, and over time.

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