Improving Care for People with Severe Persistent Mental Illness in the Palliative Phase

by

Erin E. Donald

BScN, Toronto Metropolitan University, 2006
MSN, Seattle University, 2012

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We acknowledge and respect the lək̓ʷəŋən peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

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Supervisory Committee

Dr. Kelli Stajduhar, Supervisor
School of Nursing

Dr. Susan Duncan, Departmental Member
School of Nursing

Dr. André Smith, External Member
Department of Sociology

Dr. Sally Thorne, Outside Member
School of Nursing, University of British Columbia

Abstract

Persons with severe persistent mental illness (SPMI) experience a greater burden and severity of chronic disease, late diagnosis, and premature death compared to the general population. These patients also receive fewer medical treatments, poorer quality of care, and are less likely to receive palliative care compared to the general population. Inequitable health outcomes are related to complex factors including social marginalization, stigma, lack of education and support from healthcare organizations, and siloed health services. The purpose of this study is to bring a critical theoretical perspective to understanding and improving care for the medically ill and dying with SPMI. This manuscript-based dissertation draws upon multiple lenses including a scoping review of the healthcare literature on palliative care for people with SPMI; a co-produced interpretive phenomenological analysis, in partnership with community members with lived experience of homelessness and chronic illness, investigating the appropriateness of patient-reported outcome and patient-reported experience measures for this population; and a critical analysis of historical influences on modern approaches to palliative care for people with SPMI, with an emphasis on inherited assumptions and attention to their role in present-day care. A critical synthesis of findings from these analyses informs key learnings and future recommendations for research, policy, practice, and education.

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Dedication

This dissertation is dedicated to my mother, Dr. Faith Donald, who has been an unfailing support and role model throughout my career. Though I faltered many times, I never once doubted that I had what I needed to achieve this goal because she has shown me from day one that I was capable of anything.

Chapter One: Introduction

Background

The goal of palliative care, succinctly defined by Reimer-Kirkham et al. (2016), is "…to prevent and alleviate the pain and suffering of one of society's most vulnerable groups, the dying, and their family members" (p. 294). Palliative care takes a whole person approach, recognizing both physical and mental suffering, and the complex interactions between them (Reimer-Kirkham et al., 2016; World Health Organization, 2022). A palliative approach to care can be provided by specialist palliative care services, non-specialist healthcare providers (HCPs), or combinations thereof according to need and setting (Sawatzky et al., 2016). In the context of this study, it is applied to the palliative phase where one or more advanced life-limiting conditions occur in combination with a need for acute or chronic symptom management. In Canada, access to palliative care varies by region and setting, and barriers exist even in well-resourced areas (Reimer-Kirkham et al., 2016; Stajduhar, 2011).

A growing public awareness of palliative care alongside shifting demographics has led to increased attention from researchers and policy makers. However, much of this interest is centred on what Stajduhar et al. (2019a) describe as "…a homogenously conceived normative population" — those who are housed, with caregivers close at hand, possessed of disposable income to pay for out-of-pocket costs, and of culturally dominant profiles" (p. 2). The result has been a surge of research and policy initiatives that have marginalized the needs and experiences of those whose social positioning and access to care is limited through structural inequity including economic, political, and cultural hierarchies (Stajduhar et al., 2019a). Among those excluded have been people with severe persistent mental illness (SPMI). In the most straightforward definition, severe persistent mental illnesses are those mental illnesses that are prolonged and recurrent, impair activities of daily living, and require long-term treatment (Woods et al., 2008). Common diagnoses include schizophrenia, bipolar disorder, and major depression (Woods et al., 2008). For people with SPMI, whose social capital is often limited by poverty, stigma, social isolation, trauma, inadequate health care throughout the disease trajectory, and other intersecting marginalized identities, palliative care can be difficult or impossible to access (Donald & Stajduhar, 2019; Edwards et al., 2021; Martens et al., 2013; Reimer-Kirkham et al., 2016; Shalev et al., 2020; Stajduhar et al., 2019a).

The prevalence of SPMI in the general population is estimated to be 4.2% in the United States (National Institute of Mental Health, 2017) and between 4.6% to 5.5% in Canada (Public Health Agency of Canada, 2012). A recent study of people with medical illness being cared for in a large university health system in the United States found that 11% had a pre-existing psychiatric condition on record (Lavin et al., 2017). Diagnosis or suspected diagnosis with any mental illness is associated with disparities in health care throughout the adult lifespan. People with mental illness experience excess mortality and die far more often from medical illness than by other causes. In a large national study of the United States conducted by Druss et al. (2011), participants with mental illness died an average of eight years younger compared to their counterparts without such a diagnosis. Poor baseline clinical characteristics accounted for 70% of excess mortality, suggesting a legacy of inadequate healthcare and contributing social determinants of poor health for years prior to the study’s start (Druss et al., 2011). In this same study, 25% of excess mortality was explained directly by health system factors including lack of coverage for physical and mental health care and fewer visits to HCPs (Druss et al., 2011). Gatov et al.’s (2017) multi-year population-level study of mortality in people with schizophrenia in

Ontario also found that those with this diagnosis died approximately eight years earlier than their counterparts without and experienced a mortality rate three times higher even after accounting for socioeconomic status. While Gatov et al.'s (2017) analysis demonstrated a decline in deaths by accident or suicide for people with schizophrenia between 1993 and 2012, the leading cause of death (circulatory disease) had not seen similar relief. These findings are echoed for patients with SPMI and cancer as demonstrated by both González-Rodríguez et al. (2020) and Fond et al. (2019, 2020) and are supported by Lawrence and Kisely (2010) who found that the majority of excess or early death in people with mental illness is due not to violent trauma or suicide as was once assumed (González-Rodríguez et al., 2020), but to medical illnesses including higher incidence and case fatality, suggesting discrepancies in treatment. People with mental illness are less likely to receive intensive treatment such as surgery or post-stroke intervention, less likely to receive care according to clinical standards, and less likely to be screened for diseases such as cancer (Fond et al., 2019, 2020; Lawrence & Kisely, 2010). Multiple studies and reviews identify individual, provider, and system factors contributing to these inequities (Donald & Stajduhar, 2019; Edwards et al., 2021; González-Rodríguez et al., 2020; Lawrence & Kisely, 2010; Shalev et al., 2020). Provider-level issues contributing to these discrepancies include stigma, time constraints, and knowledge gaps in differentiating between physical symptoms and mental distress. Systems-level issues include separation of physical and mental health care (also known as silo-ing), ambiguity in who is responsible for medical care, fragmentation between providers — particularly between medical providers and psychiatry — and under-resourcing in mental health settings, which limits time to focus on physical health concerns.

Studies such as these raise concerns about the quality of care available for people with SPMI while highlighting the many potential factors involved in meeting a complex set of care needs. Poorly managed physical co-morbidities often result in unmanaged symptoms including pain, limited mobility, and difficulty breathing. Lack of support from HCPs and services can compound symptoms of mental illness and cause distress for both patients and their families (Ehrlich & Dannapfel, 2017; Happell et al., 2016; Jerwood et al., 2021). For people with SPMI and advanced life-limiting conditions in the palliative phase, it is important to understand whether these complex needs are being met and how to best provide high quality care.

A recent scoping review of palliative care for people with SPMI established that very little research has been conducted on the subject, and there are many gaps in the literature (Donald & Stajduhar, 2019). More recent reviews have confirmed these findings (R. Brown et al., 2019; Edwards et al., 2021; Shalev et al., 2020; Wilson et al., 2020). The prevalence of people with SPMI in palliative care has received little attention; however, in a study of death records of people diagnosed with schizophrenia who died in Manitoba, Canadian researchers found that people with schizophrenia were less likely to receive palliative care (or see any other non-psychiatric specialist), less likely to receive opioids, and more likely to die in a nursing home compared to a matched cohort with no diagnosis of schizophrenia (Chochinov et al., 2012; Martens et al., 2013). A study of multi-year data in one United States health system concluded that people with SPMI in the last 30 days of life received fewer inpatient acute care services despite higher emergency department use and no significant difference in death at home or in hospice (Lavin et al., 2017). Conversely, Fond et al.'s (2019, 2020) nationwide cohort study in France found that people with mental illness were less likely than those without to receive high-intensity interventions at end-of-life, suggesting that people with mental illness are at risk for under- treatment compared to established practice norms for other members of society. While this research suggests that people with SPMI may not be receiving adequate care in the palliative phase, major research gaps have left researchers, policymakers, and HCPs with little understanding of the experiences of this population; their priorities and care needs; the kinds of structural and social factors that influence their care; data on where this population is being cared for and dying; and what kind of care they are receiving (Donald & Stajduhar, 2019; Goldenberg et al., 2000; Wilson et al., 2020).

Despite a recent rise in publications about palliative care for people with SPMI, output remains weighted towards reviews of existing literature with a few instances of small, experimental care models (Decorte et al., 2020; Etgen, 2020) and qualitative studies which are now starting to include people with mental illness as participants (Jerwood et al., 2021; Knippenberg et al., 2020). These reviews and early studies are beginning to address gaps in knowledge but have largely ignored complex issues related to care for people with SPMI such as stigma, poverty, and the structural conditions that operate within the context of care for people with SPMI at the end of life (or lack thereof). Furthermore, there has been no systematic analysis of the historical factors influencing care for people who experience mental illness and are in need of palliative care. This exclusion has greatly limited what can be understood about palliative care for people with SPMI. A thorough theoretical application and informed analytic approach are needed to support thoughtful and meaningful development in this body of literature.

Purpose of the Study

The purpose of this study is to bring a critical theoretical perspective to understanding and improving care for the medically ill and dying with SPMI. This study draws upon multiple lenses guided by an interpretive descriptive analytic approach and aims to:

a) Identify underlying assumptions, structural factors, and social factors influencing care for people with SPMI in the palliative phase and connect these to the provision of care in the present day;
b) Inform future research and theoretical analysis concerning the care of people with mental illness in the palliative phase; and
c) Inform improvements in research, policy, education, and practice for people with SPMI in the palliative phase.

Supplemented by a scoping review of the literature, I will draw on an interpretive descriptive approach (Thorne, 2016) to combine a historical inquiry on palliative care for people with mental illness as it was conceptualized during the development of the asylum movement in Ontario from 1850 to 1914 and beyond, alongside an engaged research process with people with lived experience of structural inequity and chronic illness including substance use. This study explores the research problem of poor palliative care for people with SPMI from these diverse perspectives, past and present. Such perspectives are needed to understand current complexities in care, inform future health care initiatives, develop promising practices, and to construct equitable and compassionate health policy. Health care literature has been lacking in addressing the structural and social issues that compound suffering and complexity for people with SPMI in the palliative phase (Allen et al., 2014; Donald & Stajduhar, 2019). The proposed study will begin to address these gaps with the ultimate aims of informing future inquiry and improving care.

The original plan for this dissertation was to conduct a secondary analysis and interview-based interpretive descriptive study to foreground the voices and lived experience of people with SPMI and life-limiting illness as well as their informal caregivers, healthcare providers, and key informants (see Appendix A). Before this study could be conducted, the COVID-19 pandemic resulted in the closure of planned recruitment sites and an increased burden on the original intended population for recruitment resulting from limited social services, high exposure to infection, and restricted access to healthcare. This dissertation was then re-conceptualized as a manuscript-based critical analysis of multiple viewpoints informing the research question. They are presented here as a scoping review of the healthcare literature on palliative care for people with SPMI (Donald & Stajduhar, 2019), a co-produced interpretive phenomenological analysis with community co-authors with lived experience of homelessness and chronic illness investigating the appropriateness of patient-reported outcome and patient-reported experience measures for this population (Donald et al., 2022), and a critical theoretical examination of historical influences on modern approaches to palliative care for people with SPMI with an emphasis on inherited assumptions and attention to their role in present-day care.

Definitions

Any researcher who draws from multiple perspectives will encounter varying and sometimes conflicting terminology. These variations can be as simple as the customs adopted by different academic disciplines. They can also be purposeful choices with deep and meaningful roots in identity, resistance, and healing from trauma. When including a historical perspective, the researcher also contends with how the meaning of language has changed over time and what is possible (or impossible) to express about the past using modern terminology. Herein follows a brief discussion of some of the most variable concepts and terms addressed in this research study alongside rationales for the terms chosen.

Defining Mental Illness and Mental Distress

Although Woods et al.’s (2008) definition of SPMI works well as an introduction due to its dynamic nature of duration, diagnosis, and need as categories which are familiar to clinicians and policymakers, mental illness remains poorly defined and conceptualized in this body of literature (Zumstein & Riese, 2020). Even within the health care system, clear-cut diagnostic definitions are lacking or inconsistently applied (Adam, 2014; Guloksuz & van Os, 2020; Jenkins, 2014). This warrants an exploration of the concepts of mental illness and mental distress, and clarification of their application in this study context.

Studying people with SPMI and life-limiting conditions requires acknowledgement of both the complexity of receiving care in the palliative phase as well as the complex nature of mental illness. Researchers, clinicians, and people with lived experience have theorized that mental illness is the result of multiple generative mechanisms; not only biology and inheritability, but trauma, the quality of relationships, and the social determinants of health, all of which may arise and influence a person’s experience of mental distress – an experience that may or may not result in a diagnosis of mental illness based on severity, duration, and access to diagnosing professionals (Allen et al., 2014; Morrow, 2013). These complex generative factors play roles in mental distress and mental illness that are not yet well-understood and require a philosophical perspective that acknowledges complexity and the often-unseen nature of contribution and causality (Collier, 1994).

In the modern Canadian context, mental illnesses are diagnosed and treated according to a combined biomedical approach and neoliberal ideology which situates understanding and descriptive power in professional practitioners and organizations (Beresford & Menzies, 2014; Jenkins, 2014). This manifests in the exclusive power of physicians and nurse practitioners to diagnose, and preferential government and health plan coverage for medication and hospitalization with far more limited resources allocated to housing, income support, talk therapy, and other interventions (Canadian Civil Liberties Association, 2017; Gaetz, 2010). A definition of mental illness that foregrounds mental distress is distinct from common psychiatric practice, which individualizes the experience of mental illness as a disease of the brain that renders those diagnosed (and functionally, those with suspected diagnoses) as dangerous, unfit citizens in need of substitute decision-making and the kind of forced treatment those with medical illnesses are exempt from (Adam, 2014; Beresford & Menzies, 2014). Psychiatric diagnoses rely on quasi-objective criteria, pathologizing experiences or behaviours that may not be troubling to an individual and those around them, or that in a society with adequate income, housing, and social supports might not require any pharmacological or professional intervention (DuBrul, 2014; Jenkins, 2014). Some scholars argue that significant system resource investment in biomedical treatment has shifted attention away from the social factors influencing mental health (Mooney, 2016; Morrow, 2013). For an increasing number of scholars with lived experience of mental distress and/or psychiatric diagnoses, the emphasis of knowledge development and advocacy is on mental distress and the ways in which personal experiences and structural barriers combine to shape the lives of those participating in (or branded by) the mental health system (Menzies et al., 2013).

Woods et al. (2008), in their original scoping review of palliative care for people with SPMI, included both experiential and diagnostic definitions to capture the complex ways people experience and are experienced within the healthcare system. Nevertheless, it is important to note that the sources Woods (2008) drew on for this definition were designed to provide standardization for the purposes of policymakers developing health services and social benefits programs (Zumstein & Riese, 2020). Zumstein and Riese (2020) caution scholars against problematizing the lack of a consensus definition of SPMI prior to fully exploring the concept and reflecting on what such a definition would be expected to accomplish.

The conceptual basis of diagnosis, duration, and disability adopted by Woods (2008) originated from the United States' National Institute for Mental Health which, in 1987, revised their language to replace 'chronically mentally ill' to SPMI "…because of the association chronicity has had with continuous and incurable illness" (Zumstein & Riese, 2020, p. 4). As will be demonstrated in the following work, this reflects only one of the recent historical shifts in thinking about the curability of mental illness. The timing of this decision coincided with widespread and destructive professional co-optation of patients' rights movements principles of recovery in mental illness throughout the late 1970s and 1980s (Anthony, 1993; Menzies et al., 2013), and is an example of government policymakers adopting the language of recovery in ways that would later be used to limit the adequate provision of social support. These are only two examples of the importance of considering historical context when reading and selecting terminology. In grappling with these historical influences, terminology becomes further complicated by the inclusion of a period prior to the modern concept of mental illness and diagnostic criteria, about treatment for people who are over 100 years dead in a society and system that differed significantly from that of the present day. Drawing on guidance from the discipline of history, this study eschews any attempt at posthumous diagnosis according to present-day criteria.

As these multiple perspectives are informed by health care, historical writing, and lived experience, the term 'severe persistent mental illness' will not always be appropriate. It cannot be said with accuracy that those thought to be 'insane' by contemporary understanding, or those committed to asylums in the 19th century were mentally ill according to modern definitions

(Porter, 2004), nor will the term ‘mental illness’ be ascribed to scholars and activists who have rejected it as an inauthentic and harmful representation of their experience. When discussing historical sources, contemporary terms will be used to reflect contemporary thinking with attention to critical analysis. When discussing the work of scholars or activists with lived experience, language reflective of both preferences and movement-building for alternative viewpoints to the dominant biomedical and neoliberal approach will be used in the spirit of respect for reclaiming.

Defining the Subjects of Study

Historical inquiry in nursing, while applied broadly to understand the impact of the past on the present day, often focuses on the history of nursing care and the nursing profession (Lundy, 2012). Nurses are not the focus of this study either historically or in the present day. This study aims, as much as possible given the limits of existing research, to focus on the experience of the person with a mental illness or thought to have a mental illness, those who are insane or thought to be insane, or those self-identifying as members of this group, who are also in the palliative phase.

Historically and in the present day, terminology describing those who need treatment or are in the position of being treated by medical and nursing professionals (particularly those professionals associated with asylums or psychiatry) has undergone frequent shifts according to changing customs and agendas, and debates continue (D. S. J. Costa et al., 2019; Goldstein & Bowers, 2015). What unites this group is that they are and were the population and individuals experiencing care or lack thereof in the palliative phase. On the topic of mental illness or insanity, they are the ones being investigated, theorized about, discussed by policymakers, managed by systems and by society, and frequently the ones with varying experiences of distress. While many modern sources encourage the use of person-first language (APA, 2020; Withers, 2012), terms such as ‘person with a mental illness’ do not capture the problematic nature of the term ‘mental illness’ addressed in the context of this study. Another alternative, ‘persons receiving care’, isn’t adequate to describe a group where many are not receiving care. ‘Persons in need of care’ also comes up against the limitations of assessing need in historical subjects.

The term ‘patient’ is broadly understood by modern readers as meaning not only those actively undergoing care in the health care system, but those awaiting care and those receiving or awaiting a broader range of services (“Definition of Patient,” 2021). First appearing in the 14th century, the term derives from Greek and Latin roots meaning ‘to suffer’ (“Definition of Patient,” 2021). While not all self-identified psychiatric survivor or Mad activists and researchers support the use of the term, a recent scoping review of all healthcare setting types including mental health concluded widespread support for the term ‘patient’ amongst patients themselves (D. S. J. Costa et al., 2019). With apologies to those who reject the term, where no other term is indicated, I have chosen to use it in this study to consistently anchor the inquiry in the lives of those past and present who experience some form of mental distress or labelling by the health care system and who are in the palliative phase of a life-limiting illness trajectory.

Organization of the Dissertation

Chapter One serves as a brief introduction to this manuscript-based dissertation guided by elements of interpretive description. Chapter Two presents a background literature review with a summary of both the history of palliative care and the history of mental health care, as well as an overview of current literature on care for people with SPMI in the palliative phase. In Chapter Three I have laid out the intended, and subsequently the actual, methodological approach to my inquiry including the philosophical and theoretical underpinnings of this dissertation. Chapter Four is the text of the comprehensive scoping review on care for people with SPMI in the palliative phase as published (Donald & Stajduhar, 2019). Chapter Five is the text of a published research study reporting a co-development process with fellow researchers and community co-authors with lived experience of homelessness, structural disadvantage, and chronic illness investigating the appropriateness of patient-reported outcome and patient-reported experience measures for this population (Donald et al., 2022). Chapter Six is a critical theoretical examination of historical influences on modern approaches to palliative care for people with SPMI in the palliative phase with implications for research and practice. Chapter Seven concludes the dissertation with a synthesis of the implications of previous chapters and resulting recommendations for this growing body of interdisciplinary research, policy, education, and practice.

Chapter Two: Review of the Literature

Introduction

This chapter will provide an in-depth review of the literature to inform and scaffold the development of an interpretive descriptive analytic approach bringing a critical theoretical perspective to understanding and improving care for the medically ill and dying with severe persistent mental illness (SPMI). Although originally planned as a two-phase study including a secondary analysis and interviews with people with SPMI and advanced life-limiting conditions and their formal and informal caregivers, it was not possible to proceed due to research restrictions resulting from the COVID-19 pandemic. Considering pandemic research restrictions, this dissertation was modified to incorporate three manuscripts, each critically examining the research topic through a different lens. This background literature review informed the choice of each of these lenses, including the current state of health literature on palliative care for with SPMI, the experience of people made marginal living with chronic illness including mental illness and mental distress, and a critical historical analysis of the history of mental health care in Canada and its inheritances in present-day care.

To provide context for the current state of knowledge, I will begin with a concentrated overview of the development of mental health care in Canada with an eventual focus on Ontario before moving on to a broad historical overview of palliative care. Here I will also touch briefly on some factors influencing the development of both palliative care and mental health care delivery systems. These factors, overlapping thematically and narratively, contribute depth and understanding to the current context of mental health care and palliative care. I will then explore the present-day experience of persons with mental illness in relationship to the health care system before reporting on the current state of cure for persons with SPMI in need of palliative care. This process will help to locate the study within the historical context of care and the present body of literature (Thorne, 2016).

Situating the Study in a Historical Context

The History of Mental Health Care in Canada

Early Historical Context.

The erosion of traditional pre-colonial practices through the physical and cultural genocide of Indigenous people, as well as the continued settler domination of academic knowledge has left limited sources that speak to the care of persons with mental distress on Turtle Island[1] prior to European contact (Brazzoni, 2013). Recent ethnographic work by Brazzoni (2013) and others to explore traditional pre-settler perspectives on the mental health of Indigenous people reveal that while traditional practices varied between groups and across regions, common perspectives emphasized connectedness between self, community, environment, and spirit (Duran & Firehammer, 2017). Mental health was not considered separate from physical health, and an ailment of the mind or spirit may simply require a different treatment the way a fever would be treated differently from a sprain (Duran & Firehammer, 2017).

Though early settler colonists to Canada cared for people showing signs of insanity or madness in home and community settings, they were emigrating from places such as Europe, the United Kingdom and its colonies, such as what is now the United States. These countries had developing or well-established systems of jails, workhouses, asylums, and hospitals for the destitute — religious or state institutions that acted as caretaker, jailor, or some combination of

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[1] Turtle Island is the name given to what settlers have called North America by the Algonquin and Iroquoian speaking people in the north-eastern part of the continent and is rooted in Indigenous wisdom about the creation of the world. The term has been chosen here because of its contemporary use by Indigenous rights activists while acknowledging that there is no single term used by Indigenous people to describe the continent.

the above for people whose insanity had been determined by local procedure — and these institutions would have seemed a natural function of government and order in colonial society (Allodi & Kedward, 1977; Finnane, 1985; Porter, 2004; Scull, 2015). Institutional settings for insane people throughout the 18th and early 19th centuries were more likely to be places of "segregation and dehumanization" than refuges of care (Frederick et al., 2017, p. 4). Beginning in the mid-nineteenth century, partly due to prominent advocates such as Dorothea Linde Dix in the United States (herself a survivor of asylum care); Phillipe Pinel in France; William Tuke in England; and Joseph Workhouse and Charles K. Clarke in Canada, the philosophy of asylum care shifted from a custodial approach to one of 'moral treatment', where a regimen of exercise, religious worship, genteel entertainment, and gendered work in purpose-built institutions with the philosophy of a middle-class household offered the possibility of a cure (T. E. Brown, 1981; D. W. Jones, 2002; Scull, 2015; D. Wright et al., 2003). And, according to asylum doctors, medical professionals working in asylums were the only ones capable of administering and delivering this revolutionary new care (Allodi & Kedward, 1977; Moran, 1998; Scull, 2015).

The process of medicalization, as well as the growing eugenics movement seeking control over the reproduction of persons with mental illness for the betterment of society through incarceration and deportation, expanded both state funding and oversight of asylums (Allodi & Kedward, 1977; Reaume, 2009; Scott, 2011; Scull, 2015). In Ontario, conflict and ill-will over funding and control between the provincial government and the developing profession of psychiatry played out in parliament and in the media, setting the foundation for ongoing criticism of both of government's role in maintaining psychiatric institutions and of the care provided there (Allodi & Kedward, 1977; Moran, 2000). When the first permanent Ontario asylum opened in 1850 it rapidly became overcrowded, a problem that only worsened over time and continued despite the construction of additional branches and regional asylums across the most populated areas of the province (Krasnick, 1982; D. Wright et al., 2003).

Alongside the slow cultural medicalization of insanity and the ongoing projects for the advancement of legitimacy for the psychiatric profession came the establishment of the professional psychiatric nurse in the style that K. Smith (2020) terms “Nightingale-type nursing” (p. 2). Arising in the late 19th century, the psychiatric nursing profession expanded rapidly through the first half of the 20th century with the establishment of professional associations, specialized training programs, and partnerships alongside physician organizations, such as the precursor to the American Psychological Association (Boschma, 2003; K. Smith, 2020).

World War I and II created new challenges for nineteenth-century asylums and care for the insane. For countries involved in the wars regionally and economically, the asylum systems and the people housed there were severely impacted both by regional destruction and by institutional deprivation as staff and funding were drained to contribute to the war effort (Scull, 2015; K. Smith, 2020). In Germany and Nazi-occupied regions prior to and during the second World War, institutionalized patients died en masse as psychiatrists and other officials implemented policies of mass murder and social cleansing, though patient casualties due to starvation and neglect were also high in England as critical levels of staff and funds were diverted to the war effort (Scull, 2015). After each war, soldiers returned home with symptoms of a disorder that would pass through many permutations of terminology and proposed etiology before becoming known as post-traumatic stress disorder, making mental health care for veterans a government priority and driving treatment in the community, offering psychiatrists alternatives to live-in institutional administration and practice (Scull, 2015). Despite increasing freedom and advancement for professionals, patients who ended up in institutions did not experience similar gains; as treatments changed, the practice of institutionalization continued.

The inter-war years saw the rise of the mental hygiene movement in the integration of mental health into public health (K. Smith, 2020). This movement was a vehicle by which the nursing profession expanded a broad definition of mental health practice beyond the institution. It also served to develop and strengthen discourses about the role of social issues in mental health and the importance of 'self-help' and healthy living as individual preventative measures against mental illness (K. Smith, 2020). Whereas determination of insanity in the 19th century was often initiated by family members, neighbours, or local administrators (as will be discussed further in Chapter Six), the mental hygiene movement represented the expanding role of health care providers (HCPs) as arbiters of normal and abnormal human behaviour. The growing nursing profession played a powerful role in developing and reinforcing these discourses through education, professional mandates, and investment in the role of the public health nurse (Boschma, 2013; K. Smith, 2020). This expansion was both ideological as health care services increased in availability, and geographical as formalized care for individuals and families entered homes and other community settings.

De-institutionalization as Policy.

De-institutionalization is defined in the technical sense as, "…a shift in practice of caring for individuals with mental illness from institutional environments to the community" (Shen & Snowden, 2014, p. 47) and as "…a massive depopulation of mental hospitals across the country" (Dyck, 2011, p. 181). In the post-war period, the continued expansion of then-called "mental hospitals" was a prominent and contentious issue in politics and public discourse (Scull, 2015). By the late 1950s most psychiatric patients in Canada were being cared for in dedicated provincial psychiatric institutions. In Ontario alone, in 1962, there were 545 psychiatric beds in general hospitals compared to 11,362 in provincial psychiatric hospitals (Hartford et al., 2003). In the eyes of the public, psychiatric hospitals were seen to provide a lower tier of care and were now almost synonymous with poor staffing, overcrowding, and underfunding. Public opinion was both shaped and reflected by media portrayals of terrible asylum conditions and sadistic staff in popular films and books such as Mary Jane Ward's *The Snake Pit* (1946) and Ken Kesey's *One Flew Over the Cuckoo's Nest* (1962) (Scull, 2015; K. Smith, 2020). Advocates, commissions, and advisory groups lobbied for change, often publishing the same findings and recommendations repeatedly over the following decades without a substantial shift on the part of government or institutions (Hartford et al., 2003). In what may have been a legacy of C. K. Clarke's antagonistic relationship with parliament, as a representative of the psychiatric profession in Ontario during his tenure at various institutions, it was not uncommon for public and professional advocacy to be met with government hostility (Allodi & Kedward, 1977; Hartford et al., 2003). Despite this, broad criticism and poor public opinion of psychiatric hospitals continued, and patients began organizing politically not only to speak out about the harmful effects they were experiencing at the hands of psychiatry and institutionalization, but to organize resistance in the form of radical alternatives including peer support and community living with collective decision-making (Beckman & Davies, 2013; Frederick et al., 2017; Starkman, 2013).

By 1983, provincially appointed reviewers in Ontario were advocating for a mental health system provided in "…the least restrictive and disruptive settings which are as close to the patient's or client's home as practical" (Heseltine, 1983, as cited in Hartford et al., 2003, p. 67). Partly supported (though perhaps not entirely instigated) by advancements in neuroleptic and antipsychotic medications (Scull, 2015), the number of beds in Ontario psychiatric hospitals fell by 43% between 1965 and 1975, then fell by another 10% by 1980 as people with mental illness were discharged into the community (Hartford et al., 2003). Yet no sufficient parallel policy or structural action had been taken to supply housing or income, and debate in government over responsibility for providing these supports continued to delay implementation of meaningful alternatives to institutionalization (Frederick et al., 2017; Hartford et al., 2003). The de-institutionalization movement internationally was initiated during the rise of the welfare state post-World War II, yet benefits were not enough to provide for patients in the community, did not increase with the rising cost of community living, and were more likely to be clawed back without reinstatement in response to changing economic policy in the latter decades of the 20th century (Dyck, 2011; Scull, 2015). As the number of psychiatric hospital beds across Canada declined sharply, spending on community-based mental health services received no comparable boost in the following decades and mental health care accounted for only 3% of provincial mental health budgets by 1990 (Goering et al., 2000). Though the de-institutionalization movement freed many people with mental illness from substandard conditions imposed by functional incarceration (Lawson, 1958), between loss of treatment and loss of shelter, discharge into the community meant a withdrawal of both personal and professional support.

Policy changes driven by cost efficiency and enabled by pharmaceutical advances occurred in the context of an international shift in thinking about the rights of disabled persons, including persons with mental illness (Hartford et al., 2003; Starkman, 2013). A series of changes to the Ontario Mental Health Act reduced vague criteria for involuntary commitment and treatment, including shifting the justification for commitment from welfare to safety, and requiring that risk of harm be both serious and imminent, further restricting the conditions under which a patient could be held against their will (Hartford et al., 2003). In the early 2000s, involuntary treatment was introduced to the community setting through the creation of community treatment orders and assertive community treatment (ACT) teams (Hartford et al., 2003; Trueman, 2003). These measures ensured that while coercive treatment may be more limited or may include some meagre (often conditional) offers of social services (Corring et al., 2017; Lawn et al., 2016), there is no health care location inside or outside the institution that is free of the threat of coercion (Trueman, 2003). Adverse experiences with the health care system including commitment and coercion can have a negative impact on the care experiences and help-seeking of patients with SPMI in the palliative phase (Donald & Stajduhar, 2019; Jerwood et al., 2018, 2021).

Despite advances, Canada continues to struggle with limited spending on mental health services, poor coordination, and inadequate social service support including housing and income (Frederick et al., 2017; Hartford et al., 2003; Wiktowicz, 2005). Many patients with SPMI in Canada live in material poverty and are unable to maintain adequate housing, the daily needs of living, and social integration even when connected with mental health services in the community (Frederick et al., 2017; Kirby, 2006). Currently, mental healthcare in Canada exists in a patchwork of public and private services fraught with barriers to access. Access to publicly funded psychiatrists depends on referrals from family physicians or nurse practitioners, and patients in need of care often experience long wait times for these primary care providers, psychiatrists, and inpatient psychiatric services should their needs become acute (Canadian Mental Health Association, 2018). The majority of mental health services in other countries with advanced healthcare systems is provided by counselors, psychologists, or addiction specialists; however, these services are not deemed medically necessary under the Canada Health Act and usually require payment out-of-pocket (Canadian Civil Liberties Association, 2017; Canadian Mental Health Association, 2018). Canada’s lack of a national medication payment plan has left medication coverage up to an array of provincial programs with barriers based on income, diagnosis, and ability to navigate complex administrative systems (Barua et al., 2018). For many patients with SPMI, leaving the institution behind has meant a struggle for survival in a disorderly and inadequate system of social supports spanning every part of life from healthcare to housing.

De-institutionalization as Ideology.

Public perception of poor-quality care in psychiatric hospitals provided a beneficent drive for de-institutionalization, but these policies arose within a growing philosophical, political, and economic context of neoliberalism (Gooding, 2016; Scull, 2015; Shen & Snowden, 2014). Rights-based approaches for providing the least restrictive form of care grew out of a liberal emphasis on the civil rights of the individual, a position inextricable from norms and values that conceptualize individuals as separate from their social contexts and allowed policies of de-institutionalization to focus on scaling back care without providing community-based replacements (Browne, 2001; Gooding, 2016). Patients with mental illness were relocated into a society increasingly adopting neoliberal political and economic policies, including reductions in income support and social programs with an emphasis on productivity and consumption as markers of citizenship and worth (Frederick et al., 2017; Morgen & Gonzales, 2008). Without adequate income support to escape poverty, an adaptable and accessible job market (or basic income and opportunities for meaningful community participation), and access to adequate care for management of mental and physical health needs, for many patients with mental illness the ideal of integrated community living has never materialized (Frederick et al., 2017).

The goal of de-institutionalization was the meaningful inclusion of patients with mental illness in the community setting but, as Frederick et al. (2017) report, the meaning of community remains undefined even in the advocacy and policy documents that are supposed to be guides for decision-making for Canada’s health care system. Intrinsic in the ideal of participation in society is the neoliberal value of self-improvement, with community conceptualized by the Mental Health Commission of Canada (2009) as a place where people with mental illness can “…[strive] to achieve their full potential”, suggesting that something more than being oneself or living well is required to meet an undefined criterion of success (p. 20). Recovery, an approach to activism and treatment that began as liberation from the extended authority of psychiatry and has since been co-opted by a self-management approach to care divorced from social context, has become widely integrated into the language of community services across Canada (Drake & Whitley, 2014; Morrow, 2013). In a mental health system dominated by discourses of recovery, community is the place where recovery is meant to materialize (Frederick et al., 2017). Yet participants with schizophrenia in Frederick et al.’s (2017) ethnographic study described community as a place where they continued to be marginalized by poverty and stigma, demonstrating little to no change a full decade after an in-depth Canadian Senate investigation (Kirby, 2006).

Rather than naturally occurring opportunities, patients with SPMI in the community have needs that require intentional and lasting interventions and support structures (Frederick et al., 2017; Kidd et al., 2016; Kirby, 2006). Failure to establish a parallel system of support in the community has had significant negative impacts on the lives of those with SPMI (Kirby, 2006; Mental Health Commission of Canada, 2012).

Across Canada, de-institutionalization has occurred alongside a dismantling of Canada's national housing strategy and other government cutbacks in services through the 1980s and 1990s, a process that has not been reversed (Gaetz, 2010). The off-loading of housing, social, and material support services to community-level initiatives (Gaetz, 2010) has meant that the mental and physical health needs reliant on those provisions have also been off-loaded to organizations that were never designed to support them. Instead, many patients with SPMI are caught in a cycle of poor discharge planning from hospitals or prisons, followed by falling through the cracks of incomplete and uncoordinated services provided by poorly prepared emergency programs (Gaetz, 2010). Estimates of the prevalence of mental illness amongst people who are homeless is as high as 74% (Kermode-Scott, 2012). Trans-institutionalization has become a major issue, with a Mental Health Commission of Canada (2012) report stating that a failure to provide sufficient community services "…has contributed significantly to the proportion of people living with mental illness among the homeless population and in jails and prisons, turning these into the 'asylums' of the 21st century" (p. 60). This is often the context in which patients with SPMI and advanced life-limiting conditions are falling ill and in need of palliative care in the present day.

The History of Palliative Care in Canada

European Religious Roots.

A typical history of palliative care in health care literature will begin with a brief touch on the hospices of the early Middle Ages — religious houses that provided both hospitality and care to travelers, the poor, the sick, and the dying — before moving on to Dr. Cecily Saunders and the rise of the modern hospice movement in the 1960s and 1970s (Buck, 2007). However, the 1,500-year gap left untouched by these writings included shifts, developments, and changing trends in public consciousness, religion, healthcare, and professionalization that have profoundly influenced the development of how dying Canadians are now cared for.

Phipps (1988), drawing on various early and medieval records in the Christian church, traces the birth of the hospital as an institution of care for the ill in Europe to Constantine and other Christian leaders between 335 and 375 CE. Originally called *nosocomeia* in Greek, the Latin *hospitium* and variations (root word to hospice, hospital, and hostel) became the preferred term as the movement grew across Europe and the language of the Christian church shifted (Phipps, 1988)[2]. The letters of Saint Jerome (ca. 345-420) provide insight into the care provided in one of these early hospices, in a letter he wrote posthumously praising the work of Roman noblewoman Fabiola[3] who had dedicated her fortune and later life in part to establishing a hospice in Rome (St. Jerome, 2014). In his letter LXXVII, St. Jerome states:

> First of all she founded an infirmary and gathered into it sufferers from the streets, giving their poor bodies worn with sickness and hunger all a nurse's care. … How often did she carry on her own shoulders poor filthy wretches tortured by epilepsy! How often did she wash away the purulent matter from wounds which others could not even endure to look upon! She gave food with her own hand, and even when a man was but a breathing corpse, she would moisten his lips with drops of water (St. Jerome, 2014, p. 323).

Later, St. Jerome (2014) further describes the breadth and quality of care provided at Fabiola's hospice:

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[2] According to Roffey (2012), "The term 'hospital' is generally ascribed to religious institutions of the post-[Norman] Conquest period whose range of functions was the formal care of the ill and the infirm. In reality, this rather generic term covers a range of diverse institutions from those that focused on distinct groups, such as lepers and the terminally ill, through to 'hostels' offering respite to travellers and pilgrims" (p. 205). This has made it challenging to investigate care for the dying in medieval institutions and I have focused on institutions that are specific about care for the terminally ill where possible.

[3] Thank you to Dr. Kelli Stajduhar for making me aware of Fabiola and her contributions to early palliative care.

> Had I a hundred tongues, with a hundred mouths, with a voice of brass, I could not tell the names of all the maladies which Fabiola treated. She was, indeed, such a comforter that many poor people who were well fell to envying the sick (St. Jerome, 2014, p. 325).

Caring for travelers, the sick, and the poor was an integral part of the quickly-growing Christian Church after the adoption of the Rule of St. Augustine of Hippo (c. 400), and hospices spread across Europe alongside the new religion (Phipps, 1988). Beginning as early as the 6th century, religious orders such as the Benedictines had assumed responsibility for these institutions (Phipps, 1988). By the 9th century there existed well-developed, detailed liturgical traditions for spiritual care of the dying indicating monastic care at the deathbed and establishing a groundwork for complex and evolving involvement in dying by the clergy that would develop throughout the medieval period (Duclow, 1999; Roffey, 2012).

Plagues, famines, wars, and accidents made death an unpredictable event in the medieval European world, and in a context of religious doctrine which preached resisting temptation and seeking redemption in this lifetime for eternal reward in the next, proper preparation for death was a preoccupation for both clergy and laypeople (Duclow, 1999; Thornton & Phillips, 2009). The 15th century saw the emergence of the *Ars Moriendi* or in English ‘The Art of Dying Well’, an illustrated lay document produced in Latin, translated into multiple European languages, and distributed by traveling mendicant orders, which had been commissioned by the Catholic Church at the Council of Constance (1414-1418) (Thornton & Phillips, 2009). There are two surviving English versions of the original *Ars Moriendi*; one longer written treatise and the other a woodblock dramatization of a deathbed scene illustrating the principles of dying well through the death of a man named Moriens (Duclow, 1999; Thornton & Phillips, 2009). The *Ars Moriendi* remained popular through the 1700s when its principle messages were incorporated into the

Everyman morality play, "…in which Death informs Everyman he is about to die, starting the process where Everyman must overcome the five temptations if he is to die well" (Thornton & Phillips, 2009, p. 95).

Aside from religious practices, much can be drawn from the *Ars Moriendi* to understand the conceptualization of death and care for the dying and their families in medieval Europe. Duclow (1999) identifies several points of community involvement in the dying process including a deathbed surrounded by family, friends, and spiritual beings; responsibilities for the dying to make a will and dispose of their earthly belongings within the confines of the law[4]; and specific prayers said by friends and family to support the deathbed struggle against temptation in the face of pain and fear of dying. Duclow (1999) quotes the *Ars Moriendi*'s second last chapter, stating "…and it were possible, all a city should come together with all haste to a man that is nigh to death or dying" with the intent of supporting the dying person, and of thinking ahead in preparation for their own eventual demise (craft 36). Death was considered a public ritual, in which community members were expected to participate.

The *Ars Moriendi* also provides some clues to location of death at this time in Europe. The woodblock version illustrates the tale of the well-to-do Moriens dying in his bed at home complete with household servants (Duclow, 1999). In a study analyzing wills and bequests, as well as rules for conduct, Guidera (1999) demonstrates how religious Beguine women in the Low Countries (now Belgium and the Netherlands) also cared for the dying and the dead in their homes, suggesting that death at home was the norm for those with suitable abodes and caregivers. However, other documents indicate that Beguine women may also have provided

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[4] Though Thornton & Phillips (2009) point out that the dying Moriens is encouraged to consider the Church rather than his loved ones when disposing of his property.

care in institutions such as leprosaria[5] (Guidera, 1999). These orders would frequently receive requests and bequests in wills asking Beguine women to prepare bodies, accompany bodies to graveyards, receive burial in Beguine ceremonies, and to have prayers be said by Beguines on dates of significance after death or as intercessions to reduce time in purgatory, demonstrating that care for the dying did not end at the time of death or internment (Guidera, 1999).

Guidera (1999) also cites Ziegler's (1992) publication linking the devotional importance of the *Pieta*, or recurring image of a dying Christ across the Virgin Mary's lap, to the Beguines' work with the dying and dead, indicating that although care for the dying was not expressly included in Beguine statements of mission this work nevertheless played an important role for the women of these Orders. Though framed in a religious rather than a medical or nursing context in modern understanding, this evidence points towards supports and services for the dying and for bereaved families which were a stable part of medieval social structure.

The *Ars Moriendi* and other popular tales in the Middle Ages were already providing foundations for what it meant to have a 'good death'. In a time of limited physical recourse for cure or symptom management, the alleviation of spiritual distress was at the forefront, as was an acknowledgement that dying was not always an easy process and could require special care and attention (Duclow, 1999). Death was not always characterized as an ordeal though. While poor mortal Moriens might struggle with impatience and frustration "…lead[ing] the dying man to overturn his bedside table and kick his physicians," the myth of the Virgin Mary's peaceful 'dormition' stood in contrast (Duclow, 1999, p. 382). In this tale, Mary receives notice from an angel that she will die in three days, giving her time to set her affairs in order, put on her funeral

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[5] Drawing on research from England and northern France, Roffey (2012) traces the rise and decline of leprosaria in the medieval period including the transformation of some institutions into general hospitals and associated cemetery finds showing evidence of a range of illnesses. This suggests that care for dying patients without leprosy was also provided at these sites.

clothes, and summon the apostles she would like to attend her on her deathbed. When the time comes, she folds her hands and falls asleep. Like the patrons cared for by the Beguines, death is not the end of the story. The tale goes on to tell that during her funeral procession Mary's bier was attacked by a rival priest[6] but after being struck down the man converted to Christianity, and she eventually enters heaven by ascending in a manner similar to Christ (Duclow, 1999). The dormition became a popular tale in the Middle Ages, with St. Jerome (2014) also ascribing a dormition-like death to Fabiola:

> [Fabiola] had a presentiment of what was to happen, and had written to several monks, that they might come and relieve her from the heavy burden under which she groaned, and that she might make to herself friends of the mammon of unrighteousness, to receive her into everlasting habitations. They came, and were welcomed as friends; she fell asleep, as she had wished, and having at length rid herself of her burden, soared more lightly to heaven (p. 335).

Fabiola also experiences a type of posthumous attack and vindication, where the people of Rome had been said to have slandered her for her scandalous conduct in having taken a second husband, but after her death they praised her in the Christian manner with palm fronds and cries of alleluia (St. Jerome, 2014). In Western cultures influenced by Christianity, the connection between death and 'falling asleep', as well as persistent tales of premonitions and visions of approaching death (Kellehear, 2017) persist to this day.

Thus, in the Middle Ages it can be theorized that most care for the dying was provided at home where resources permitted, or in public institutions for the poor or others without caregivers. The spiritual well-being of both the dying person as well as their family and friends

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[6] In this case a Rabbi, in a typical example of early Christian anti-Semitic propaganda.

was of paramount importance, and the dying person was cautioned against losing hope or faith in the final days and hours. Preparing for death was a social and religious responsibility, and foreknowledge of death provided the opportunity for the dying person to express their wishes for care and companionship at the end of life. Care for the dying did not end with death but continued at the individual level with care for the body and soul, and at the community level through charity and reflection on mortality. Here we can see the foundations of the modern hospice and palliative care movement, in values and principles that continue to be extolled today.

Enter the Physician.

Medical historian Dr. Jacalyn Duffin (2014) situates the birth of medicine in palliative care, not the other way around. “For more than two thousand years,” Duffin (2014) writes, “therapy was aimed at relieving symptoms—hopefully curing, helping without harming, keeping people comfortable: palliation. Medicine writ large *was* palliative care” (p. 206). This aligns with existing evidence about medieval institutional care, such as the palliative diets catalogued in Silvester’s (2021) analysis of dental wear patterns in the remains of patients at a leprosarium. Lack of knowledge regarding etiology limited symptom management by the modern definition of the term, but treatment from experience or training and some prognostic guidance could provide comfort to dying patients and their families (Buck, 2007; Ferroul, 1999). Ferroul (1999) cites Hippocrates’ (ca. 460-370 BCE) *Prognostics*, demonstrating that the founding medical scholar valued open prognostication in the presence of sick patients in order to better predict their future situations and to inform care with the aim of avoiding crises – principles which will be familiar to any modern practitioner of palliative care. The skills of the physician in predicting death were to be valued as they allowed sick persons, friends, and family time to make preparations (Ferroul, 1999).

Disease in the Middle Ages was conceptualized as a cluster of symptoms, and physicians and surgeons trained separately, as surgical intervention dealt only with appendages, limbs, and teeth (Duffin, 2014). Midwives, healing women, and some members of religious orders rounded out the complement of health care providers (HCPs) during this era (Ferroul, 1999; Roffey, 2012). Though cures sometimes occurred, the physician's ability to deliver a cure was not guaranteed. Ferroul's (1999) research provides some evidence that physicians were in an ambiguous role in relation to care for the dying throughout the Middle Ages. Physicians wrote of struggles to be recognized as credible in relation to formalized training, whether or not to withdraw treatment if they expected someone to die, and whether it was wiser in some cases to flee the bedside to avoid blame for an imminent death (Ferroul, 1999). They also navigated what was arguably Church dominance of the dying process for Catholics during this era, given rules in some cases preventing clerics from becoming physicians lest they be responsible for deaths and endanger their mortal souls (and possibly the credibility of the Church), and strictures from both universities and the Church forbidding physicians from seeing dying patients unless a priest had first been called (Ferroul, 1999). Despite these strictures, Ferroul (1999) cites evidence of monks being called to provide medical treatments to the French King Charles VI in 1397, suggesting that some monastic orders were providing care outside of their institutions.

Political and economic shifts in Europe, including Protestant reformations in the 16th century (which saw the dissolution of religious orders in Britain and several other European countries) contributed to secular leaders and physician groups taking a greater role in the administration and delivery of medicine (Phipps, 1988). Simultaneously, advances in the natural sciences, the rise of capitalism and colonialism, and the development of secular nation-states were setting the stage for the Enlightenment (West, 2010). Through the mid-16th century and the

17th century, the scientific revolution swept through Europe and by the early 18th century scientific rationality had become the test of truth in Western science and philosophy (Dahnke & Dreher, 2016; West, 2010). Medicine advanced alongside other newly minted sciences and anatomy became a primary focus of interest (Dahnke & Dreher, 2016; Duffin, 2014). This altered the conceptualization of disease from the person's experience of symptoms to the physician's detection of anatomical abnormalities, shifting considerable authority for determining illness status into the hands of physicians (Duffin, 2014). This authority was further consolidated in two ways, 1) by the proliferation of academic medical training programs (in which physicians and surgeons now trained together in greater numbers, further excluding midwives, other healers, and marginalized members of society), and 2) by the development of anaesthetic and antiseptic techniques, which allowed for more successful surgical interventions (Duffin, 2014).

Throughout the 18th and 19th centuries medicine, and eventually professional nursing alongside it, expanded social and intellectual authority over both the body and mind (Allodi & Kedward, 1977; Duffin, 2014). By the early 20th century public expectations for technical, scientific, cure-based care in acute settings was growing (Duffin, 2014). Rapid scientific developments including hormones, antibiotics, diagnostic testing, and chemotherapy — all provided under the care of physicians and trained nurses — reinforced this trend (Duffin, 2014). The development of neuroleptic medication in the 1960s would similarly cement medicine's dominion over care for people with mental illness (Hartford et al., 2003).

Hospices and Care for the Dying under the Expanding State.

While those with caregivers and resources continued to die at home surrounded by family and friends, the secularization of European leadership and the scaling back of monastic orders left a gap in care for the sick and dying who did not have these resources. By the late 19th and early 20th century, some found a measure of care in almshouses or asylums but questionable practices, such as forced signature of autopsy release forms for experimentation or the training of new physicians, were sometimes required to receive treatment (Buck, 2007; S. L. Smith & Nickel, 1999). Unlike psychiatrists (then called alienists or medical superintendents of asylums), who had established a separate professional identity through the 18th and 19th centuries (Allodi & Kedward, 1977; Porter, 2004), for most in the medical profession care for the dying had been shifted outside the realm of medicine and now presented "…a threat to professional advancement" (Siebold, 1992, as quoted in S. L. Smith & Nickel, 1999, p. 51). As societies struggled to accommodate growing numbers of those aging without caregivers in the late 19th century due to labour displacement and immigration, religious orders from Catholic, Methodist, and Anglican denominations had opened dedicated hospices in Canada, the United States, and the United Kingdom to care for the dying (Buck, 2007; Cook, 1989). One of the earliest hospices of this type in this timeframe is Our Lady's Hospice opened by the Irish Sisters of Charity in Dublin in 1879 (Buck, 2007). Clearly responding to existing community need, Buck (2007) quotes the hospice's initial charter:

> Long and sadly has been felt the want of an institution into which those who have no relative or friend to watch beside them in their last hours may be received, tended by charitable hands, comforted and prepared for their passage to eternity (p. 115).

In an analysis of the hospice's expenses Buck (2007) reports that spending on medicine and chaplains was almost equal, and both far less than that for food and spirits. Buck (2007) attributes this to the limited power of medicine for symptom management for the dying at this time, alongside the emphasis on spiritual comfort and the prevalence of milk and whiskey as a common treatment. Providing a safe space and nourishing sustenance may have been foundations for comfort care as they were in medieval leprosaria (Silvester, 2021) and as they still are for many families and hospices today.

The Irish Sisters of Charity expanded at the turn of the century, opening a second hospice in London, which provided care alongside the existing Methodist St. Luke’s Home for the Dying Poor founded in 1893 (Buck, 2007). These two hospices provide some examples of diversity in this early re-birth of the hospice movement – St. Joseph’s was under the management of the Irish Sisters of Charity, while St. Luke’s was under the secular management of a physician and staffed by lay nurses (Buck, 2007). Other early variations can be seen here, including St. Luke’s dedication of service to the “respectable poor” versus the open-door policy at St. Rose’s Free Home for Incurable Cancer in New York City (founded in 1899) (Buck, 2007, p. 116). This mix of religious and secular leadership, as well as variation in populations served, continues to be seen in the modern hospice movement.

Social relationships and community support were a key factor in determining place of death and the role of the hospice. The Irish Sisters of Charity were explicit about the absence of a caregiver creating need for a hospice facility (Buck, 2007). Social changes impacting the availability of caregivers continued into the 20th century. S. L. Smith and Nickel (1999), in their article on shifts in birthing and dying trends in 20th century Canada, report similar observations only a few decades later during the post-war period when an increasing number of women entered the workforce and continued in employed work after marriage, resulting in fewer available caregivers in the home. Compounding this gap in caregiving was the economic impact of the Great Depression and the rising appeal of advanced training and professional identity associated with hospital nursing, which was rapidly eroding the private duty nursing and home care industry (S. L. Smith & Nickel, 1999). By the mid-20th century, the need created by these shifts in the availability of caregivers was being met by a rapidly expanding (and in Canada increasingly public) hospital-based health care sector (S. L. Smith & Nickel, 1999). Care for the dying was moving into the acute care setting.

Expert Care and the Modern Hospice Movement.

Just as a lack of caregiving resources at home was creating a need for alternatives, the profile of hospitals was changing (S. L. Smith & Nickel, 1999). The expansion of the hospital system in Canada, alongside a rise in professional status for both nursing and medicine, shifted the public perception of the hospital from a charitable endeavour that cared for those who were poor and diseased away from the public eye to a place of resources and expertise, with parallel movements occurring in the United States and the United Kingdom (Duffin, 2014; S. L. Smith & Nickel, 1999). By the 1950s, hospitals were the most common place of death in Canada, the United States, and the United Kingdom (Buck, 2011; S. L. Smith & Nickel, 1999).

This shift occurred alongside changing perceptions of the hospital, of medicine, and of dying. S. L. Smith and Nickel (1999) argue that this process of hospitalization de-naturalized death and disempowered lay caregivers by removing dying persons from society and maintaining an emphasis on curative care for as long as possible. Hospitals, as the place where the 'best' care was delivered, were now understood as the best places for the terminally ill to be cared for. Similar to ways in which the medicalization of mental illness occurred alongside the housing of persons in psychiatric institutions and the development of moral treatment, this shift in the location of dying laid the groundwork for medicine and nursing to later claim authority through the explicit professionalization of care for the dying in the development of the modern palliative care specialty (Allodi & Kedward, 1977; Duffin, 2014).

The rise of patients' rights movements impacted both psychiatric and palliative care. At the same time, public apprehension about psychiatric institutionalization was growing, increased medicalization and levels of intervention associated with curative medicine in the hospital were fueling concerns about quality of care for the dying (Allodi & Kedward, 1977; Buck, 2011; Duffin, 2014; Hartford et al., 2003; S. L. Smith & Nickel, 1999). While there were some notable early- and mid-twentieth century advocates, such as Alfred Worcester who advocated for improved care for the dying in a series of lectures published in 1929, it would be another few decades until a true movement began to take hold (Duffin, 2014).

Early voices in health care advocating for a different approach to care of the dying included social anthropologist and nursing ally Dr. Esther L. Brown, Dr. Florence Wald RN, and psychiatrist Dr. Elizabeth Kübler-Ross in the United States; Dr. Cecily Saunders and Dr. John Hinton in the United Kingdom; and Dr. Balfour Mount and Dr. David Skelton in Canada (Duffin, 2014; "Esther Lucile Brown, Nursing's Champion, Dies at 92," 1990; S. L. Smith & Nickel, 1999). The same rise in patients' rights movements that supported de-institutionalization in mental health was seen in public voicing of support for a de-institutionalized approach to death and dying (Buck, 2007; A. McKenzie, personal communication, October 28, 2019). Emerging movements in each country influenced one another (Duffin, 2014). While the modern hospice movement followed a similar course in each country, some key divergences early on resulted in different funding and care delivery structures in the modern day.

Most scholars trace the birth of the modern hospice movement to nurse and physician Dr. Cecily Saunders. Building on previous experience at St. Luke's Home for the Dying Poor, Dr. Saunders opened St. Christopher's Hospice in 1967 as a site where expert clinical care, education, and research could modernize care of the dying (Duffin, 2014). Saunders valued the hospice's independence from the National Health Service, claiming that because St. Christopher's was supported by the Catholic Church and charitable donations, no one would be turned away or discharged based on their inability to pay (Buck, 2007). Informed by her experiences as a healthcare professional, a caregiver, and by personal experience of loss, Saunders dedicated her professional career to the development of the hospice field as an advocate, clinician, and researcher (Buck, 2007; Duffin, 2014). She was an eloquent speaker and active correspondent, two factors that contributed to her powerful influence on the development of parallel hospice movements in Canada and the United States (Buck, 2009). In the early 1960s, Saunders had begun to correspond with Dr. Florence Wald, a former psychiatric nurse who was then Dean of the School of Nursing at Yale University (Buck, 2011). Saunders would eventually make several lecture tours in the United States and served in a visiting professorship at Wald's invitation (Buck, 2011).

Wald, an ardent supporter of the style of therapeutic relationship advocated by psychiatrist Dr. Sigmund Freud and psychiatric nurse theorist Dr. Hildegard Peplau (Abel, 2018), was already a reformer for the profession of nursing by the time she began corresponding with Saunders. By 1971, Wald had left Yale and had joined with Reverend Edward Dobihal to organize a modern hospice, which was launched as Hospice Inc. in Newhaven, Connecticut in 1974 (Buck, 2009). Buck's (2007, 2009, 2011) in-depth research into journals, meeting notes, correspondence, and government documents tells the story of a group of like-minded activists who began with a strong foundation in social justice and were guided by Wald's vision of a multidisciplinary team providing care at home and in a specialized facility. However, Hospice Inc. struggled to establish a foothold in a restrictive state medical system with no licensure avenue available for the type of care they wanted to provide; and against widespread misunderstandings of hospice care including concerns about segregating the dying, experimenting on the dying as research subjects, and false beliefs that they were performing euthanasia (Buck, 2011). A particular barrier was legislation against duplicating existing services, creating a need for Hospice Inc. to articulate and advocate for hospice and palliative care as a distinct service needed to address gaps in care that could not be met in existing settings (a process that would have lasting effects on the development of palliative care as a clinical and billing silo in the United States) (Buck, 2011). Despite these challenges, Hospice Inc. launched a home care service upon their inauguration and hired political consultant Dennis Rezendes to help navigate the legislative landscape (Buck, 2009, 2011). Rezendes was successful in securing a hospice designation as a unique healthcare provider category in Connecticut, and he went on to found the National Hospice Organization (NHO) in 1978 (Buck, 2011).

The NHO, far from being the kind of care-centred organization that Hospice Inc. had been, sought to standardize hospice services and "…both create and corner the market for hospice at the national level" (Buck, 2011, p. s38). The NHO and their push for a national hospice payment plan would eventually become reality in its first iteration in 1982 and see subsequent expansions over the next decade (Buck, 2011), but Wald would leave the NHO by 1978 (Buck, 2009). A 1974 article co-written by Wald introducing hospice care principles and the work of Hospice Inc. to American nurse readers is full of enthusiasm, but an article following shortly afterwards in 1979 (ostensibly about caring for the dying in nursing education) takes the full final third of the text to argue against the insufficiently-researched, standardized, regulation-heavy approach being pushed by the NHO (Craven & Wald, 1975; Wald, 1979). The present-day American Medicare hospice benefit, a national standardized payment program that requires patients to remove themselves from other reimbursement streams for care of their terminal condition (provided they meet administrative medical criteria projecting death within six months), persists in the United States. This has, in Buck's (2011) words, created a model of care where "…regulations [serve] to render hospice patients into living and dying components, thus creating and requiring them to straddle two divergent systems of care" (p. s42). In a population often dying of life-limiting conditions whose trajectories are uncertain, struggling with multiple co-morbidities, and experiencing mental illness in a privatized and employment-based insurance system making options for seeking care elsewhere limited or non-existent, this extreme example of siloed care is likely a major contributor to unmet palliative need for patients with SPMI in the United States.

The path taken by hospice and palliative care in Canada differed, perhaps because its original champions were clinicians located in hospitals, or because the Canadian healthcare system's priority for financing hospital care over other types of care was the most effective way of securing funding (S. L. Smith & Nickel, 1999). Dr. Balfour Mount was a urological surgeon at the Royal Victoria Hospital in Montreal who was inspired to conduct his own investigation of the care of dying patients in that hospital in 1973 after reading Dr. Elizabeth Kübler-Ross (Duffin, 2014). He is credited with coining the term 'palliative care' to avoid confusion with an alternate meaning of the word 'hospice' in France, and in 1974 he established a palliative care unit at Royal Victoria Hospital (Brooksbank, 2009; Duffin, 2014). In 1976 he launched the McGill International Congress in Care of the Dying, a biennial conference that has continued at the time of publication (Duffin, 2014). Another Canadian physician, Dr. David Skelton, became interested in the hospice movement after hearing Dr. Saunders speak in England when he was a medical trainee. After graduation, he specialized in geriatrics and took a position at St. Boniface Hospital in Winnipeg, where a new extension being built provided him with the opportunity to establish a palliative care unit and a short-term geriatric unit, also in 1974 (Duffin, 2014). He would establish a second palliative care unit in Edmonton not long afterwards. Both physicians integrated a spiritual component into care, Dr. Mount as part of embracing long-established principles of hospice care and Dr. Skelton as an ordained Anglican priest, a crossover that was considered controversial at the time for the secularized institution of medicine providing care paid for by a secularized state (Duffin, 2014).

In the following years, palliative care was adopted sporadically in Canada in different regions due to the country's provincial divisions in jurisdiction over health care. British Columbia initiated a pilot project in 1978 that grew into a provincial palliative benefits program, and a palliative care program began in Halifax, Nova Scotia in the early 1980s (Duffin, 2014). However, the hospice movement in Canada was not without debate as to whether care delivered in hospitals could break free of institutional biases (S. L. Smith & Nickel, 1999). Duffin (2014) points out that in the Canadian context it was often laypersons, clergy, and nurse activists who were pushing for palliative care services in alternative or community settings, citing the example of June Callwood who founded Casey House in 1988 (a stand-alone hospice for patients with HIV/AIDS) in memory of her son and continued to speak out for quality end-of-life care until her own death.

The creation, maintenance, and articulation of structures of care for the dying throughout Western history have had profound impact on the delivery of modern palliative care. Prior to cure becoming the focus of medicine and nursing, comfort – both physical and spiritual – was the goal of care. Principles adopted by the increasingly popular public health approach to dying including building on the "social potential" of communities and calling for an integrated understanding and responsibility for engaging with death and dying, hearken back to the *Ars*

Moriendi and the responsibility of one's friends and family to support the deathbed struggle against temptation, and beyond to the Christian value of charity that supported the work of religious orders (Becker et al., 2014, p. 403; Duclow, 1999; Kellehear, 1999).

Likewise, the Christian values of Dr. Saunders as well as her insistence on independence from government has arguably contributed to the current state of hospice funding in the United Kingdom, where 68% of hospices are run solely on charitable donations (Hospice UK, 2020). Rezendes' advocacy ensured a national hospice reimbursement program that has splintered care for patients in the United States but has resulted in widespread (if imperfect) access to standardized services, while Canada's provincial and regional health management structures without a national program have resulted in patchwork services that vary widely by location (Buck, 2011; Reimer-Kirkham et al., 2016; Stajduhar, 2011). While the letters of St. Jerome and other medieval documentation suggest that care for the dying was delivered at home or alongside care for non-terminal conditions, shifts in attitudes about medicine meant that by the time the champions of the modern hospice movement were ready to re-introduce palliative care principles to the modern healthcare system, they moved outside of existing care settings to do so — into the community or onto dedicated hospital units. And much like the field of psychiatry after the medicalization of mental illness, medicine did not relinquish authority over care for the dying when the location of that care was moved out of traditional institutions. The legacy of serving selective populations, from hospices like St. Luke's who made judgements about the 'respectable poor' to those like Casey House who were created to care for people who were highly stigmatized and left behind by the healthcare system have left both a legacy of the hospice as respectable refuge and as a site of radical healthcare activism (Duffin, 2014; Reimer-Kirkham et al., 2016). These inheritances and the choices that informed them have had lasting impacts on care for patients with advancing life-limiting conditions, many of whom are attempting to access services that are poorly integrated, or in need of care that is not available in the current Canadian healthcare system (Reimer-Kirkham et al., 2016; Stajduhar et al., 2019a).

Present-Day Context of Care

The Experience of Persons with Mental Illness in the Health Care System

The following review of the present-day context of care is extracted from the findings of the scoping review reported in Chapter 4 with updates from more recently published literature. In addition to facing unmet needs for living support and mental health care following de-institutionalization, patients with SPMI in the healthcare system frequently experience inadequate care related to physical conditions. Despite Canada's publicly funded healthcare system, not everyone receives the same level and quality of care. While pockets of good care exist, inequitable healthcare provision for physical illness plays a major role in the increased mortality and morbidity of patients with SPMI (Gerber et al., 2019; González-Rodríguez et al., 2020; Lawrence & Kisely, 2010; Shalev et al., 2020).

Unequal access to care and disparities in health outcomes are key indicators of inequity of healthcare for patients with SPMI (Donald & Stajduhar, 2019): Patients with SPMI suffer from more chronic diseases, greater severity of chronic disease, and late diagnosis compared to those without SPMI (Correll et al., 2017; Fond et al., 2019, 2020; Walker et al., 2015). Patients with concurrent mental and physical illnesses undertake "demanding health and illness workloads" each day to navigate both the healthcare system and daily life, compounding the burden and vulnerability imposed by these conditions (Ehrlich & Dannapfel, 2017, p. 22). Though there is some localized variability, in general they experience poor quality care, receive fewer medical and symptom management interventions, die prematurely from medical illness, and are less likely to receive palliative or other specialist care at end of life (Butler & O'Brien, 2018; Chochinov et al., 2012; Fond et al., 2019, 2020; Jester et al., 2020; Lavin et al., 2017; Lawrence & Kisely, 2010).

These inequities in care are related to multiple factors. One component is stigma against patients with mental illness. Stigma is related to both patient and system level barriers, reducing help-seeking, access, and participation in mental health services (Corrigan et al., 2014; González-Rodríguez et al., 2020). Provider and system-level barriers are also factors, and can include lack of insurance or coverage, lack of service availability or follow-up, coercive treatment approaches by providers, staff stigma and cultural incompetence, and/or workforce or model of care limitations (Corrigan et al., 2014; Gatov et al., 2017; Jerwood et al., 2018, 2021). Individual modifiable risk factors are also likely to play a role, including health beliefs, mental health literacy, and lack of a support network (Corrigan et al., 2014; Gatov et al., 2017; Knippenberg et al., 2020).

Patients with mental illness seeking healthcare report experiences of seeing multiple providers and specialists — a situation that prevents relationship-building and can contribute to re-traumatization when stories must be told over and over again to new providers (Ehrlich & Dannapfel, 2017). Even when seeking care for phsyical illness, patients with mental illness describe the entire visit and discussion being framed within the context of a mental health diagnosis; a situation participants in Happell et al.'s (2016) study reported they were unable to change regardless of how psychocologically well they felt or presented. Patients with mental illness reported being excluded from decision-making, and felt powerless when providers refused to order referrals or follow up tests, or attributed physical symptoms to psychological causes (Ehrlich & Dannapfel, 2017; Happell et al., 2016; Jerwood et al., 2021). Jones, Howard, and

Thornicroft (2008) proposed the term 'diagnostic and treatment overshadowing', building on work originally drawn from earlier research and theorizing about inequities in care for patients with learning disabilities. Diagnostic and treatment overshadowing can serve as an abbreviated term for the decreased attention to assessment, gaps in diagnosis, lack of treatment, biases in treatment decisions, and unwillingness to address barriers to care when care planning (S. Jones et al., 2008).

These experiences contribute to mistrust, fear of stigma, and hypervigilance, and may deter patients with mental illness from seeking care (Corrigan et al., 2014; Ehrlich & Dannapfel, 2017; Happell et al., 2016). A Vancouver, British Columbia study of homeless persons with mental illness (resulting in a sample with a high burden of physical illness, with over 80% reporting multiple chronic diseases) found that those with the greatest assessed health needs accessed health services at drastically lower rates (Currie et al., 2014). Proposed explanations were "stigma, mistrust in the medical system, negative past experiences, dissatisfaction with the prescription of medication without adequate psychological counseling and negative experiences with medication side effects" (Currie et al., 2014, p. 8). Research with HCPs confirms some of these concerns. Giandinoto and Edward (2015) interviewed HCPs caring for persons with co-morbid mental and physical illness about their experiences. Healthcare providers in their study reported feeling a lack of skills and knowledge, hypervigilance and anxiety in the face of perceived danger from patients with SPMI, and often responded with stories of their worst experiences providing care despite receiving more general prompts from interviewers (Giandinoto & Edward, 2015). Participants in Jerwood et al.'s (2018) focus group study of mental health HCPs and palliative care HCPs echoed latent assumptions and a lack of confidence in their own abilities, which occasionally led to avoidance of providing care including advance care planning. Lawrence and Kisely (2010) further explored the gap between the provision of psychiatric and primary care for patients with mental illness, identifying a number of barriers in place which prevent persons with mental illness from receiving primary care, or which render primary care access ineffective even when it is available and patients access it. Because primary care is an important point of identification and referral for palliative and specialist care in Canada, the United States, and the United Kingdom, this could be a major contributing factor to lack of access to palliative care and other delays in treatment.

Despite these negative experiences seeking care, some researchers heard from patients with SPMI that they want the opportunity to be more involved in their own care but were prevented by the assumption that they lacked the insight or capacity to do so (Ehrlich & Dannapfel, 2017; Happell et al., 2016; Jerwood et al., 2021). Regardless, patients with mental illness valued having a relationship with a provider who could come to know them and see them over time (Ehrlich & Dannapfel, 2017; Happell et al., 2016; Jerwood et al., 2021; Knippenberg et al., 2020). A recent report by the United Kingdom's Royal College of Psychiatrists (2019) is a step towards addressing the above-listed gaps and barriers to care. As part of a broader move towards taking responsibility for the integration of physical health care into psychiatric practice, this report recommends that psychiatrists take steps including conducting a full assessment and health history for medical co-morbidities, starting early conversations about advance care planning, and regularly screening for pain including doing so in consultation with family members who may be able to provide additional input about a patient's experience (Royal College of Psychiatrists, 2019). Though most of the recommendations are aimed at the individual provider, the report also urges collaboration between services, and the implementation of liaison geriatricians.

Disparities in the provision of mental health services, even those that are publicly funded, vary along lines of economic, social, and cultural privilege. One study in Toronto, Ontario found widespread disparities in use of mental health services from psychiatrists and family physicians (both publicly funded services), with residents of the highest socioeconomic neighbourhoods being 1.6 times as likely as those from the lowest socioeconomic neighbourhoods to access this care despite overwhelming levels of poverty amongst patients with the highest mental health care needs (Steele et al., 2006). A similar analysis of recommended versus met need for mental health services found the greatest discrepancies amongst those on social assistance, a common income source for patients with SPMI (Durbin et al., 2012). With recipients of social assistance in Canada living far below the poverty line (Ontario Social Assistance Review Advisory Council, 2014), it is unsurprising that the structurally vulnerable participants in need of a palliative approach in Stajduhar et al.'s (2019a) study prioritized daily survival over seeking out and managing their care. The division between social supports and health care also impacted the experience of living and dying with an advanced life limiting condition for participants in Stajduhar et al.'s (2019a) study. Echoing policymakers, HCPs had few resources at hand and a limited sense of scope and responsibility for the material limitations that impacted care (Stajduhar et al., 2019a). The overlap of social, physical, and mental health care needs is only one component of what makes the issue of palliative care for persons with SPMI so complex.

Similar to mental health care, palliative care in Canada exists in a patchwork state with funding and resources varying by province and region and relying on out-of-pocket payment and family support for many needs and services (Canadian Institute for Health Information, 2018). These supports translate into inequities in the delivery of palliative care, with those most affected by poverty, unstable housing or homelessness, social isolation, stigma, and other intersecting vulnerabilities being less likely to seek out and receive high quality care (Reimer Kirkham & Anderson, 2010; Stajduhar et al., 2019a). While the Canadian health care system shifts to increasingly embrace palliative approaches in healthcare (Canadian Institute for Health Information, 2018), recovery remains the dominant paradigm for the treatment of mental illness. This can leave patients with long-standing refractory experiences of mental distress and SPMI subject to mental health programs whose aims are at odds with an integrated palliative approach to mental and physical health needs (Trachsel et al., 2016). An analysis of how underlying theories and assumptions about mental health care and palliative care work through today's health care system, and how these theories and assumptions have been established, is needed to inform further development in practice, policy, education, and research and to contribute to an equitable health care system.

Patients with Severe Persistent Mental Illness in Need of Palliative Care

After years of being at risk for inequitable treatment in society and within the healthcare system, patients with SPMI often reach the palliative phase with highly complex needs as individuals and as a population (Donald & Stajduhar, 2019; Druss et al., 2011; Edwards et al., 2021; González-Rodríguez et al., 2020; Shalev et al., 2020). These are the major themes of a systematic scoping review conducted from 2017 to 2019, as published by Donald and Stajduhar (2019) with recent updates and synthesis to provide a narrative background on the current state of care.

Complexity of Care.

Studies of early mortality reveal that patients with SPMI approach end-of-life earlier than those without, and late presentation to the healthcare system often results in high needs and a short timeline for care before death (Baker, 2005; Fond et al., 2019, 2020; González-Rodríguez et al., 2020; Moini & Levenson, 2009; Stajduhar et al., 2019a). Literature reviews and case studies (which collectively make up the majority of published research on the topic of palliative care for persons with SPMI) ascribe late presentation to a combination of disease and system issues, including provider and health service barriers to care, as well as challenges with care seeking and follow-up on the part of patients with SPMI (Baker, 2005; Davie, 2006; González-Rodríguez et al., 2020; Peryer et al., 2020; Shalev et al., 2020; Terpstra et al., 2014; Woods et al., 2008). The co-existence of physical and psychological illness can create confusion about symptoms and etiology, e.g., when unusual behaviours convey or obscure symptoms including pain, or in cases of diagnostic overshadowing (Baker, 2005; Griffith, 2007b; S. Jones et al., 2008; Kelly & Shanley, 2000; Morgan, 2016). Additional complexities result from social disadvantages experienced by persons with SPMI including stigma, discrimination, isolation, and poverty (Baker, 2005; Bloomer & O'Brien, 2013; Candilis et al., 2004; Craun et al., 1997; Morgan, 2016). Morgan's (2016) qualitative phenomenological study of 20 nurses drawn from psychiatric and palliative professional associations reports how stigma manifests in both specialties, with fears related to SPMI, "chaotic" family systems, lack of information, and lack of structural supports heard from both groups (p. 36). Participants in Jerwood et al.'s (2018) published report of focus groups with 23 HCPs from various clinical backgrounds identified challenging behaviours and beliefs on the part of the person with SPMI and their family as well as unsuitable clinical care settings as barriers to providing adequate care. Participants in Jerwood et al.'s (2018) study also saw examples of stigma throughout the healthcare system, from bold block lettering of a psychiatric diagnosis on a referral form for physical care, to a person's physical care needs not being taken as seriously by HCP colleagues. Complexity of health needs persists through the terminal phase, as demonstrated in Picot et al.'s (2015) collaborative nurse practitioner initiative and case study, a joint approach which allowed providers to meet both palliative and mental health needs through end of life but which deviated from usual care. In response to conflicting treatment philosophies and risks for over- and under-treatment in other parts of the healthcare system, researchers and clinicians seeking for a way to provide better palliative care for persons with SPMI also chose to create an independent treatment model (Decorte et al., 2020).

Accessing Care.

Patients with SPMI in the palliative phase of care experience issues in accessing care resulting from both system and HCP sources. The same issues that prevent patients with SPMI from receiving timely testing, treatment, and referral to disease specialists in primary care and other non-specialist settings (Corrigan et al., 2014) can block avenues to palliative care. Late diagnosis is emblematic of difficulties accessing providers and being properly assessed, both in general and specialist care settings (Baker, 2005; Davie, 2006; Peryer et al., 2020; Webber, 2012). Contributing to late diagnosis is system silo-ing, or the geographic and administrative barriers between healthcare specialties (Baker, 2005; Davie, 2006; Etgen, 2020; González-Rodríguez et al., 2020; Jerwood et al., 2018; Lawrence & Kisely, 2010; Stajduhar et al., 2019a). Silo-ing concentrates resources, limiting access to settings with capacity to care for persons with both psychiatric and palliative care needs where such settings do exist. Silo-ing contributes to disruptions in transfers, loss of care continuity, and care in settings that are unable to meet the needs of patients with SPMI in the palliative phase (Chochinov et al., 2012; Gammonley et al., 2021; Jerwood et al., 2018; Jester et al., 2020; Martens et al., 2013; Morgan, 2016; Terpstra et al., 2014).

Lack of training in palliative care and in mental health care are recurrent issues that inhibit access to quality palliative care for patients with SPMI (Cai et al., 2011; Evenblij et al., 2016; Gerber et al., 2019; Jerwood et al., 2018; Morgan, 2016; Webber, 2012). As an example of these sometimes-overlapping factors, in Evenblij et al.'s (2016) mixed methods study, nurses in mental health facilities in the Netherlands reported both their own struggles providing palliative care for patients with SPMI in a recovery-oriented mental health system and without support, as well as the struggles patients with SPMI faced in receiving adequate care outside of psychiatric settings once they had been labelled as a psychiatric patient.

Decision-making and End-of-life Conversations.

Patients with SPMI may also experience presumed incompetence and may be assumed to be incapable of informed decision-making based solely on psychiatric diagnosis, regardless of legally determined competence (Candilis et al., 2004; Ehrlich & Dannapfel, 2017; Happell et al., 2016; Jerwood et al., 2018, 2021; McGrath & Forrester, 2006; Szasz, 2005). Consequently, they are often excluded from medical decision-making, and medical advance directive completion rates for patients with SPMI are low (Baker, 2005; Cai et al., 2011; Candilis et al., 2004; Happell et al., 2016; Terpstra et al., 2014). Patients with SPMI may be estranged from friends or family, and their strongest relationships may be with HCPs who are restricted from acting as proxy decision-makers, making it difficult to find someone to fill this role (Candilis et al., 2004; Foti, 2003; Knippenberg et al., 2020).

End-of-life conversations with patients with SPMI can be daunting for HCPs, who may lack training or fear that the patient will cope poorly with discussions of illness and death (Baker, 2005; Bloomer & O'Brien, 2013; Foti, 2003; Irwin et al., 2014; Jerwood et al., 2018; Terpstra et al., 2014). Despite this, Webber (2012), a clinical nurse specialist in palliative care, shares her clinical experience on the importance of control over symptom management, levels of intervention, and meaningful relationships for patients with SPMI approaching end of life. Webber (2012) cautions against assuming that a patient with SPMI will lack insight to understand health information, or fearing that patients with SPMI are emotionally unprepared to handle difficult conversations about death and dying. Likewise, Foti et al. (2005) (N=142 in a survey-based design as part of a demonstration project), Sweers et al. (2013) (N=20 in qualitative interviews), and Elie et al. (2018) (n=106 in a cross-sectional questionnaire design) explored advance care planning for patients with SPMI. These researchers found that such conversations were not unduly distressing, and that patients with SPMI shared many of the same concerns as patients without SPMI in regards to palliative care, namely; burdens on family, suffering and symptom management, interpersonal issues, spiritual issues, and funeral arrangements. Despite these findings there are some key differences and conflicting data that should be explored further, including one study demonstrating hesitance to discuss medical and end-of-life issues without prompting (Knippenberg et al., 2020). As well, too narrow a focus on preferences for care at end of life can obscure the context in which these decisions occur, particularly when palliative care needs are not being adequately met for quality living until death, as this review suggests is the case for patients with SPMI (Donald & Stajduhar, 2019; Pesut & Thorne, 2019).

In light of these challenges, it is clear that improved approaches to practice, policy, and research are needed to improve health care for patients with SPMI (Donald & Stajduhar, 2019). Despite there being very few limitations in search strategy or inclusion for this scoping review, this body of literature contains only a small number of descriptive or exploratory studies of quality and even fewer intervention studies. High-quality exploratory studies are desperately needed to fill gaps in existing knowledge, and to inform improvements in practice and policy.

These studies must be conducted with awareness for the complex sociopolitical and historical factors influencing present day care.

Conclusion

Though both modern palliative care and de-institutionalization were informed by the patients' rights movements (Buck, 2007; Menzies et al., 2013), neither group ultimately benefitted as originally envisioned. De-institutionalization has not led to supported community integration, and patients with SPMI in need of palliative care are not in the same position to access it as their housed, financially secure fellow community members who do not have a mental health diagnosis (Frederick et al., 2017; Reimer-Kirkham et al., 2016). Gaps, inequity, and prejudices in mental health care, palliative care, and the social support structures needed for palliative care and de-institutionalization to be effective have left this population 'doubly vulnerable.' A critical theoretical perspective is best suited to approach this topic to be mindful of structures and power relationships while investigating care needs and experiences for the purpose of addressing inequities and improving care (Browne, 2000). Previous research on the topic of patients with SPMI in the palliative phase has trended towards superficial descriptions, and it is clear from this literature review that this is a complex issue in need of much deeper attention and analysis using a methodology that allows for the exploration of multiple facets, including both the historical foundations of care and the experiences of some of the most vulnerable members of society with SPMI in need of palliative care. By providing an in-depth review of the literature including a broad overview of the historical context and the modern state of palliative and mental health care in Canada, this chapter informed my own positioning as a researcher and created a scaffold for an interpretive descriptive study exploring palliative care for persons with SPMI. In Chapter Three I will detail the general methodology I applied to achieve the study aims, including both the originally intended study design and the adaptations that ultimately occurred because of COVID-19 pandemic conditions and the resulting restrictions on research approaches.

Chapter Three: Methodology

Introduction

People with severe persistent mental illness (SPMI) in the palliative phase of care have been a sorely under-researched group, and in this chapter I demonstrate how interpretive description (ID) and a critical theoretical perspective were combined to try to make a meaningful contribution to research and practice for this population (Donald & Stajduhar, 2019). I begin by laying out my theoretical positioning then demonstrating how I strived to apply them to inform nursing research for people with SPMI in the palliative phase of care. This chapter briefly describes both the initial planned two-phase study followed by a full description of the altered dissertation re-designed in response to limitations resulting from the COVID-19 pandemic. Subsequently, I will outline steps taken to maintain scientific integrity with attention to personal reflexivity.

Theoretical Positioning

A Critical Theoretical Perspective in Nursing

A critical theoretical perspective is informed by critical social theory, which originated in Germany in the 1920s and 1930s with a group of philosophers known as the Frankfurt School (Browne, 2000; Mill et al., 2001). The Frankfurt School began as a way to incorporate the critical economic work of Marx while broadening its application beyond that of class struggle in order to further theorize about oppression in other forms (Browne, 2000). Critical social theory has now expanded to include other philosophers with radical (Latin; from the root) approaches and an analysis of domination and control in society including Habermas, Giddens, Bourdieu, and Foucault (Browne, 2000; Mill et al., 2001).

An interpretive descriptive approach to research emphasizes the researcher-practitioner as instrument (Thorne, 2016). Rather than an explicit linkage to an existing theoretical tradition, this dissertation is informed by a critical theoretical perspective. A critical theoretical perspective draws from multiple critical theoretical traditions with attention to power dynamics, sociopolitical contexts, and discourses that shape healthcare practices (Blanchet Garneau et al., 2019). From within an applied discipline, a critical theoretical perspective allows nurse scientists to look through and beyond the lens of the individual to the larger political, social, and historical perspectives informing palliative care for people with SPMI.

The purpose of inquiry from a critical perspective in nursing is to critique what is happening in our applied practice perspective with the aim of informing and improving practice. One use of a critical theoretical perspective is to develop normative theories; theories that are concerned with what *should* be (Mill et al., 2001). For theorizing from a critical perspective to be emancipatory, theories must reveal power imbalances in social structures and knowledge (Browne, 2000). Attention to power imbalance and other elements of a critical perspective play an important role for nurses seeking to critique and improve care.

Browne (2000) defines nursing science as "…a practice science, the ultimate purpose of which is to (a) generate knowledge to meet its social and moral mandates, (b) inform nursing practice, and (c) develop possibilities for improving practice" (p. 36). While theoretical development is important to the advancement of nursing science, for nursing scholars this should take the form of work designed to improve health for populations, communities, families, and individuals (Browne, 2000). Mill et al. (2001), while acknowledging debate concerning the type of knowledge needed to inform the nursing discipline, attest that nursing "…is a scientific discipline where [this type of knowledge] encompasses the biological, human, and practical sciences” (p. 118). A critical theoretical perspective is well-suited to investigation and theorizing for each of these dimensions, making it a useful approach for nursing. Nurse scholars have adopted a critical theoretical perspective as a way to bring attention to sociopolitical influences and other manifestations of power in health and nursing practice, serving as a way to better align nursing disciplinary knowledge and the realities of practice in complex environments (Blanchet Garneau et al., 2019; Browne, 2000; Horrill et al., 2022; Lavoie et al., 2018). By this reasoning, nursing knowledge must be able to account both for group and population level patterns as well as individual variance (Mill et al., 2001; Thorne, 2016). Nurses are able to broaden their gaze using a critical social theoretical perspective, applying critique to the environmental context of clinical phenomena and identifying what does and does not facilitate well-being (Mill et al., 2001). The use of a critical theoretical perspective facilitates focusing on the development of knowledge for the purposes of action, supporting nursing as a practice discipline, and as a discipline engaged in public policy and advocacy (Mill et al., 2001). Critical social theory has been combined successfully with other emancipatory theories such as socialist-feminist and black-feminist perspectives, providing a framework for the use of emancipatory theories geared towards specific populations or health states (Blanchet Garneau et al., 2019; Browne, 2000; Horrill et al., 2022; Lavoie et al., 2018; Reimer Kirkham & Browne, 2006).

Research From a Critical Theoretical Perspective.

Research from a critical theoretical perspective starts from a critical position on how knowledge is developed and how it is applied (Mill et al., 2001). A critical theoretical perspective provides a way of conducting research for emancipatory aims, but its value also lies in “…considering the normative implications of nursing in relation to public policy, health-care ethics, and the interpretation of human need” (Mill et al., 2001, p. 111). Researchers approach a wide variety of methodologies and methods from a critical theoretical perspective (Browne, 2000; Horrill et al., 2022; Mill et al., 2001; Reimer-Kirkham et al., 2016). Both methods which collect objective data and those which collect subjective data are valued (Browne, 2000). As long as the researcher maintains a critical stance regarding ideology and power imbalances, and produces, aims, and disseminates knowledge for the purpose of emancipation, a variety of methodologies and methods can be applied (Mill et al., 2001).

Analysis from a critical theoretical perspective makes use of “dialogue and relational reasoning, such strategies explore relationships within and between phenomena by juxtaposing ideas with their antitheses” (Mill et al., 2001, p. 115). Analysis is always guided by thoughtful critique of values, ideologies, and social structures (Mill et al., 2001), however Browne (2000) cautions that critical social theory has been developed with an emphasis on groups and societies, thus privileging generalizable information. This is something for the nurse researcher to keep in mind, as nursing’s disciplinary concern is with both groups and individuals whose unique experiences nurses encounter in practice (Browne, 2000; Thorne & Sawatzky, 2014).

Knowledge produced by research from a critical theoretical perspective is intended to be emancipatory, but the dissemination and application of findings is a delicate process. Findings should facilitate understanding or action by individuals or groups, but researchers should be careful not to impose their views and come into an existing complex context with the expectation of being experts or saviors (Browne, 2000). A critical theoretical perspective may facilitate change, but the purpose in most cases is for researchers to increase the possibility for change led by groups and individuals themselves if they so choose (Browne, 2000). To produce the kind of generalizable-yet-particular knowledge nurses need, a methodology that is compatible with a nursing epistemology is needed.

A Critical Theoretical Perspective and Persons with SPMI in the Palliative Phase of Care.

Critical analysis guides researchers to be sensitive to power structures and hidden expressions of value in social structures and truth claims (Browne, 2000). Browne (2000) asserted that one of the most important applications of a critical theoretical perspective in nursing is in the critique of liberalism as well-suited to research in nursing, healthcare, and mental illness (Browne, 2001; Morrow, 2013). Liberal philosophy promotes a radical individualization that removes people from their social contexts (Browne, 2001). At a policy level, liberalism has resulted in drastic cuts to social services, which have had negative impacts on people with mental illness and those with other disabilities and chronic diseases (Morrow, 2013). This focus on individualism has also framed mental illness (and other medical conditions) as personal problems, ensuring that the amelioration of social ills have not been included in treatment plans and other types of intervention (Morrow, 2013). As Morrow (2013) so poignantly states, “[f]or people experiencing mental distress, who in the course of ‘treatment’ may lose certain citizenship rights and who may rely on and off on the social service system for most of their lives, the emphasis on private solutions to social problems is particularly reprehensible” (p. 328). While research is sparse, there is reason to be concerned that people with SPMI in the palliative phase of care continue to be subject to oppressive social structures and complexity in expressions of agency in healthcare (Donald & Stajduhar, 2019; Horrill et al., 2022). Using a critical theoretical framework makes it clear that the researcher must focus on issues of power, agency, and harm; and pay attention to the social structures as well as the current power dynamics influencing the nursing profession and the health care system (Browne, 2000).

However, Browne (2000) cautions against the use of a critical theoretical perspective "…without adequate attention to the ideological context in which emancipatory ideas arise" (p. 36). This context is the liberal ideological underpinnings of the nursing profession, an orientation shared by the modern Western approach to mental health and mental illness discussed in further length in Chapter 2 (Browne, 2001; Morrow, 2013). Successful adoption of a critical theoretical perspective must be accompanied by critical self-reflection, both on nursing's disciplinary context, and on the researcher's individual approach to research and analysis (Browne, 2000). Thus, reflexivity is central to a critical theoretical perspective in order to give proper attention to the contextual nature of knowledge and knowledge development (Mill et al., 2001). The knower is always contextually positioned, and has largely obtained knowledge through the subjectivity of other knowers (textbooks, lectures, discussion, etc.) (Mill et al., 2001).

In order to engage with critical theoretical perspectives, Browne (2000) asserts that nursing must engage in ideological critical self-reflection, both as individual scholars, and in regards to the nursing profession.

Methodology

Interpretive Description

Interpretive description (ID) is a qualitative methodological approach developed to tackle the complexity inherent in the applied sciences, including nursing (Thorne, 2016). Thorne (2016) describes ID as "…a strategy for excavating, illuminating, articulating and disseminating the kind of knowledge that disciplines with an application mandate tend to need in order to enact their mandate…" (p. 11). For nurses this means the deep work of caring for individuals, families, communities, and populations, in health and illness, from the antenatal period until after death. Thorne and other early thinkers in ID problematized the drawing of methodologies from more theoretical, non-applied disciplines including the social sciences as often missing the end goal of creating and disseminating knowledge valuable to practice professions (Thorne et al., 1997, 2016). Interpretive description was developed as a way to bring an openness to the changes in methodology that nurse scholars were already making in their use of other qualitative research, and to develop a framework for ensuring that research is credible and coherent while also being meaningful and applicable to practice (Thorne, 2016; Thorne et al., 2004). Thorne (2016) identifies the qualities of a nursing study, which include a normative moral imperative to improve upon a situation; a focus on the specific (and avoidance of over-generalization) through recognition of both patterns and variance; and the assumption that knowledge will be put to use.

Research questions suited to ID are contextually immersed and practically oriented (Thorne et al., 2016). For this reason, nursing studies using ID are seldom limited to explanation, and aim to produce useful knowledge in order to advance the health of individuals, families, communities, and populations (Thorne et al., 2016). The design process in ID is known as ‘scaffolding’, and roots the study contextually in existing literature, disciplinary orientation, and theoretical background (Thorne, 2016; Thorne et al., 2016). This process includes an examination of where the researcher themselves is positioned personally, theoretically, and as a practicing member of the discipline (Thorne, 2016). This initial work lays the foundation for the ongoing reflective practice asked of researchers who take up a critical theoretical perspective, and continues throughout the course of the study (Browne, 2000).

Data Collection and Analysis in Interpretive Description.

In order to inform and explore findings at all stages of analysis, and to allow flexibility for the researcher to reach out and explore further depth and/or variation over the course of a study, data collection and analysis are connected an iterative process (Thorne et al., 2004). With the purpose of nursing disciplinary action ever in mind, choice in sampling is guided by balancing the explanatory depth and appreciation of variation (Thorne et al., 2016). Nursing practice requires understanding how to transfer knowledge between groups and individuals and back again, both in their own experience as nurses caring for individuals, communities, and families; and as nurses trying to make generalizable knowledge work in specific practice (Thorne et al., 2004; Thorne & Sawatzky, 2014). Methodological choices in ID reflect this balance (Thorne et al., 2016). Interpretive description includes multiple data sources also as a way to avoid the epistemological challenges inherent in any individual data collection method (which may be amplified by over-reliance on a single method), and to capture to the complexity of health-related phenomena (Thorne, 2016).

Thorne and her colleagues provide many practical suggestions for handling data during analysis (Thorne, 2016; Thorne et al., 2004). These suggestions encourage the researcher to slow down, to reflect, to think about complexity, to look beyond first impressions, and to allow new ideas and connections to emerge (Thorne, 2016; Thorne et al., 2004). Data analysis in ID follows a path that aligns with the assumptions of hidden structures and the priority of producing knowledge for emancipation central to a critical theoretical perspective: finding patterns, looking past the obvious for hidden elements, and "…rigorously deconstructing what we think we see, testing hunches as to how it might fit together in new ways, and taking some ownership over the potential meanings and impact of the outcomes that we will eventually render as findings" (Thorne, 2016, p. 156). Pattern recognition is used to identify knowledge that could be returned to the clinical setting (Thorne et al., 2016). The result is the production of a "tentative truth claim" about health-related phenomena, recognizing that all of the variations present in the real world are unlikely to be captured in the limits of a research study, but that commonalities and variance can still be uncovered and be of use in practice (Thorne et al., 2004, p. 4).

Interpretive Description and Persons with SPMI in the Palliative Phase of Care.

Interpretive Description, as a practice-oriented research approach designed to tackle complexity, is an ideal methodology to use for a nursing study of persons with SPMI in the palliative phase of care. In her methodological guidebook, Thorne (2016) briefly describes the context of evidence-informed practice and its emphasis on quantitative research, through the ranking of evidence sources that place qualitative studies towards the bottom of the list. In this environment, what can qualitative and other types of non-quantitative studies contribute to clinicians and policy makers looking for the 'best' evidence? Thorne (2016) proposes four 'strategic' aims for qualitative research, targeting the areas where qualitative data can make important contributions, and where findings are most likely to result in meaningful practice changes. These aims are *filling gaps*, *challenging assumptions*, *illuminating subjectivities*, and *interpreting variance* (Thorne, 2016). These aims illustrate four major access points for the challenge and revision of clinical information to reach practice.

Both the original proposed study and the final submitted dissertation with post-COVID-19 adaptations meet all four of ID's epistemological aims: filling gaps, challenging assumptions, illuminating subjectivities, and interpreting variance (Thorne, 2016). As has been demonstrated above, there are overwhelming gaps in the literature on this topic and the unique contributions made by this dissertation help to advance this field (Donald & Stajduhar, 2019). Broad assumptions apply both to persons with SPMI whose experiences and behaviours are subject to almost limitless pathologizing, and persons in a palliative phase who are so often characterized as limited to having cancer and receiving care from only specialized care providers in specialized care settings (Littlejohn, 2003; Stajduhar, 2011). These assumptions, which are addressed in Chapter Five as unexamined historical inheritances continuing to inform research and practice in the present day, are challenged through open discussion. Researchers can open space for the inclusion of lived experience of persons with SPMI in the palliative phase of care in research and policy, thus illuminating subjectivities. Interpreting variance has been a key task in producing a dissertation and disseminating findings that encourage clinicians to respond with flexibility and sensitivity to each new person they encounter in the variety of settings persons with SPMI in the palliative phase access (or attempt to access) services (Donald & Stajduhar, 2019; Schrader et al., 2013). Care in emphasizing variance will be especially important, as there is so little research on this topic that any one study, publication, or report carries the risk of being given more weight than it should.

Purpose of the Study

The purpose of this study is to bring a critical theoretical perspective to understanding and improving care for the medically ill and dying with SPMI. This interpretive analysis aims to:

a) Identify underlying assumptions, structural factors, and social factors influencing care for people with SPMI in the palliative phase and connect these to the provision of care in the present day;

b) Inform future research and theoretical analysis concerning the care of people with mental illness in the palliative phase; and

c) Inform improvements in research, policy, education, and practice for people with SPMI in the palliative phase.

To achieve these aims, I have explored this complex clinical phenomenon from multiple perspectives, using a variety of data sources and methodological approaches to produce findings for informing practice and policy-making (Thorne et al., 2016). Methodological choices have been made with attention to coherence and congruence in study design guided by ID (Hunt, 2009).

Due to unforeseen circumstances, this dissertation went through two major iterations in design. The first study plan, combining a secondary analysis to inform subsequent in-person interviews with people with SPMI and life-limiting illness in the palliative phase and their caregivers, was approved by the thesis committee by proposal late in 2019. In early 2020, ethics approval had been obtained for the initial secondary analysis portion of this planned study. Then in March of 2020, the COVID-19 pandemic fundamentally changed the research landscape. In response to the rapidly spreading virus, organizations and established research relationships in the community that were previously planned as sites of recruitment were shutting down all research activities to respond to the crisis. Many of these organizations in downtown Victoria, including those providing meals, shelter, and other necessities for survival, closed their doors. The broader Equity in Palliative Approaches to Care (EPAC) team led by Dr. Stajduhar pivoted focus to provide support for long-standing community partners and the dissertation process was delayed. It became clear that not only would it be impossible to recruit and conduct interviews in-person in the foreseeable future, but that the intended community for recruitment was now so over-burdened by both COVID-19 and its detrimental effects on services and survival that it would be unreasonable and unethical to request participation at this time. In discussion with my supervisor, we decided to shift to an alternate dissertation plan out of respect for potential participant and organizational limitations and priorities related to COVID-19. Here I will briefly review the study as originally planned, followed by the methodology for the revised dissertation.

Original Study Plan

This study was to be conducted in two phases: phase one was to have been comprised of secondary data analysis from a recent ethnographic study of people who are structurally vulnerable living with advanced life-limiting disease in Victoria, BC [Equitable Access to Care (EAC), led by Dr. Kelli Stajduhar]. Phase two would have involved original data collection and analysis from administrators, healthcare and services providers, persons with SPMI with advanced life-limiting conditions, and their informal caregivers. Data collection in phase two would have been undertaken at multiple sites to sample from a variety of settings where persons with SPMI may be receiving care. Ethical approval was obtained for phase one just prior to COVID-19 and would have been sought for phase two before proceeding. An in-depth description of the original study plan can be found in Appendix A.

Revised Dissertation Plan in Response to COVID-19

By March of 2020 when the COVID-19 pandemic response began, I had done extensive background research to inform the proposal. A systematic scoping review that I had completed was accepted for publication (Donald & Stajduhar, 2019). I immersed myself in historical research and supplemented my learning with a graduate-level historiography class to better understand methods, methodology, and epistemology in the field of history. During this process, I noticed significant similarities between palliative care and mental health care in the past and present that I wanted to explore further. Shortly afterwards, I also had the opportunity to partner in a co-produced study with a small team of researchers and people with lived experience to inform recommendations on the use of patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) for people who are homeless and underhoused (Donald et al., 2020). A different sort of study began to take shape out of these components: a manuscript-based dissertation that explored both the current state of care as represented in the literature, but allowed for deeper engagement with the unspoken ideas and assumptions that appeared to be shaping this growing field of inquiry.

A Scoping Review of Palliative Care for People with Severe Persistent Mental Illness

Under the supervision of Dr. Stajduhar, I conducted and published a scoping review to inform my understanding of the field of care and of the scope of the literature on palliative care for people with SPMI (Donald & Stajduhar, 2019). The aims of the scoping review were to map the literature, determine the extent and range of what had been published, and to report the findings. I used the five-stage framework put forth by Arksey & O'Malley (2005), which includes 1) identifying the research aim(s), 2) identifying relevant studies, 3) study selection, 4) charting the data, and 5) collating, summarizing, and reporting the results.

The database searches were conducted in two stages: the first search was run in September of 2017 with no time restrictions. A second search was run to update the findings prior to preparation for publication in May of 2018 and was limited to articles published from August 2018 onwards. Databases searched included Web of Science, PubMed, Medline (EBSCO), CINAHL, Healthsource, Academic Search Complete, PsycInfo, PsycArticles, and Cochrane Database of Systematic Reviews and Central Register of Controlled Trials. Following guidance from a previous review on palliative care for people with SPMI conducted by Woods (2008), search terms were split into two major concept groups: 'mental health', 'mental illness', 'schizophrenia', 'major depression', 'bipolar disorder'; and 'palliative', 'end of life', 'end-of-life', 'hospice', 'end stage', and 'end-stage'. The search also included reference lists of included articles. The initial September 2017 search produced 1,401 articles, which were narrowed down to 32 articles following an initial title and abstract review followed by a full text review. Reference list searches for these studies produced an additional 5 articles for a total of 37 included articles. An additional 9 articles were identified in the updated search conducted in May of 2018. Figure 1 details the search process. The findings of the scoping review are reported in detail in Chapter Four.

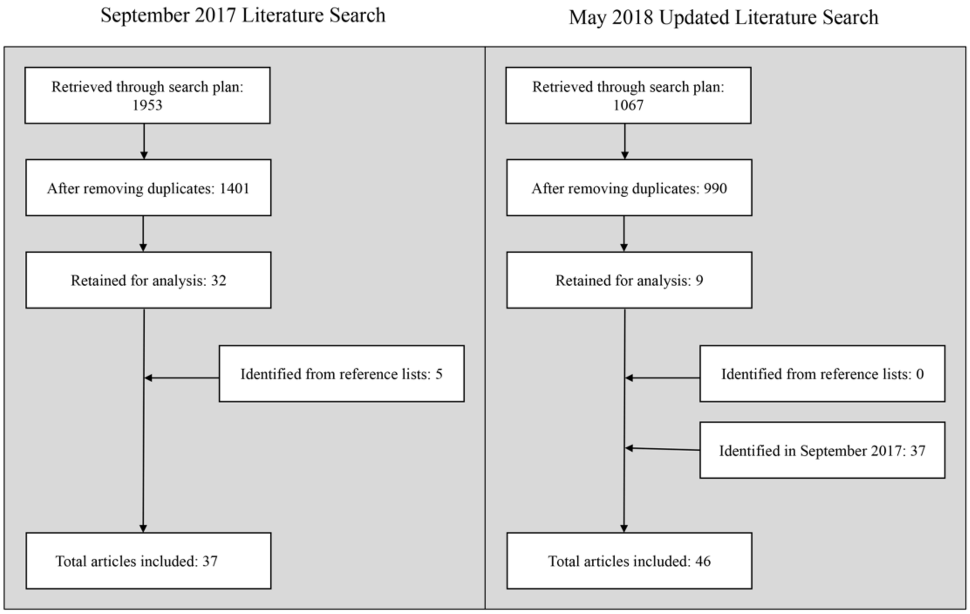

Figure 1: Article Selection Process

In the Arksey & O'Malley (2005) framework, stages four (charting the data) and five (collating, summarizing, and reporting the results) contribute to the scaffolding process for an interpretive descriptive study. Charting the data allowed for data extraction and the identification of relevant themes and context. Collating, summarizing, and preparing the findings for reporting provides a comprehensive overview of the field of literature. While overarching themes were used in this scoping review for the purposes of organizing the results (Donald & Stajduhar, 2019), the findings of all studies were reported with the aim of telling the story and providing a broad overview of available literature (Arksey & O'Malley, 2005). Though obvious gaps and areas of attention were identified, no attempt was made to report on the 'weight' of evidence (Arksey & O'Malley, 2005, p. 27).

The first step to scaffolding an interpretive descriptive study is conducting a literature review, which was accomplished through by this scoping review (Donald & Stajduhar, 2019; Thorne, 2016). The purpose of scaffolding in interpretive description is to "…[set] up the initial position from which you will build out your study design" (Thorne, 2016, p. 59). This scoping review revealed both gaps in knowledge, methodological approaches, and theoretical grappling. Originally, this review informed a study plan that was designed to address gaps in knowledge and methodological approaches, but it had also revealed a lack of depth of analysis that I wasn't quite ready to report on at that time. The second component of scaffolding in an interpretive descriptive study is working out what the researcher themselves will be bringing to the study. While I felt passionately about using my privilege as a researcher to increase the representation of voices with direct knowledge of care, particularly patient and informal caregiver voices, the longer I sat with the findings of the scoping review, the more I was troubled by the ahistorical and atheoretical approach to a field of care that includes deep theoretical and historical complexity. The process of revising my study in light of COVID-19 restrictions, as informed by this scoping review, guided me fully into the second component of scaffolding: understanding what it was that I as a researcher most wanted to bring to this evolving body of knowledge from within my own disciplinary and theoretical orientation (Donald & Stajduhar, 2019; Thorne, 2016). It brought up other research problems, problems that pulled my attention the longer I sat with them. In the relative quiet and isolation of my own COVID-19 lockdown, I had the space to turn my attention to these issues. This scoping review had served as effective scaffolding for both study plans.

A Co-development Process to Advance Methods for the Use of Patient-Reported Outcome Measures and Patient-Reported Experience Measures with People who are Homeless and Experience Chronic Illness

Prior to the onset of the COVID-19 pandemic, Dr. Stajduhar, in partnership with Dr. Richard Sawatzky and other members of the Equity in Palliative Approaches to Care (EPAC) research team, received funding for a multi-phase investigation into advancing methods for the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) for people who are homeless and experience chronic illness, including life-limiting illness and those in need of palliative care. This study took place as part of an ongoing program of research in partnership with a local inner-city community and service organizations serving people who are socially disadvantaged (Stajduhar et al., 2019a; Stajduhar, Giesbrecht, Mollison, Dosani, et al., 2020; Stajduhar, Giesbrecht, Mollison, & d'Archangelo, 2020; Watts, 2019). As the project co-ordinator for the early phase of this study, one of my roles included co-ordinating an initial advisory process with people with lived experience of homeless and chronic illness to inform later phases of the study. The initial proposed plan had been to reach out to existing patient advisory groups and partner sites and issue open invitations to join an advisory committee, who we could then engage through in-person meetings in easily accessible locations, providing food and honoraria in appreciation of advisory committee members' time and expertise. Just as we were preparing to implement this plan, the COVID-19 pandemic was declared. In response, our partner organizations were no longer able to continue with patient advisory groups, accommodate face-to-face meetings, or support research activities.

I worked closely with fellow researchers Dr. Stajduhar and Kara Whitlock — at the time a Master of Social Work Student and person with lived experience of homelessness and chronic illness, identified here with consent — to identify alternative options for stakeholder input on the study. With advice from EPAC partners in the community, we decided to pursue a smaller advisory team with people with previous experience of homelessness and chronic illness who were now in stable enough life circumstances to attend regularly via videoconferencing. Potential advisory committee members were identified through Kara Whitlock's existing networks as well as relationships established through the EPAC partner organizations. Invitations were extended to join the advisory committee if a potential member self-identified as a person with experiences of poverty and homelessness, and/or healthcare discrimination, were >18 years of age, and spoke English. The recruitment period lasted 10 weeks, during which Kara Whitlock called and screened each potential member for inclusion. Six potential members were identified, with three members discontinuing over the first two meetings. Further information about this process and the advisory committee members themselves can be found in Chapter Five. While we did not collect information from these members on why they chose to leave the committee, it was a time of significant increased health burden across the community related to COVID-19 and it is possible that the additional burden of participation in a research study was not possible to maintain, particularly given the requirement of attending regular meeting times with stable access to technology.

The aim of this phase of the study was, "What is most important to measure about our healthcare, and how can it best be measured using PROMs and PREMs?" The advisory committee met eight times, with five meetings devoted to building rapport and an open discussion about what was most important to measure, followed by three meetings in which we collectively discussed examples of common PROMs and PREMs (please see Chapter Five for more details). In line with the principles of meaningful engagement, all advisory committee members were paid $25 an hour for their expertise (Boilevin et al., 2019). In the end, the full series of meetings were attended by three advisory committee members with lived expertise, Kara Whitlock, Dr. Stajduhar, and me. Although we did not collect demographic information on advisory committee members and chronic illness, through the discussion process several advisory committee members divulged their own experiences with symptoms or diagnoses of mental illness and trauma indicating representation of both chronic illness and mental illness (and/or mental distress) in the dataset resulting from this study.

Interpretive Phenomenological Analysis with a Co-Development Framework.

The methodological approach chosen to guide the engagement and analytical approach was interpretive phenomenological analysis (IPA) using a co-development framework (J. A. Smith, 1996; Tuffour, 2017). Interpretive phenomenological analysis arose as part of an effort by J. A. Smith (1996) to evoke the power of qualitative research in medical sociology from his own disciplinary positioning in psychology. J. A. Smith (1996) wrote that in this approach, "…having a commitment to document, as closely as possible, the participants' own experience…" could help overcome some of the critiques and problematization associated with assuming a connection between health state, cognition, and vocalization that was the standard in the quantitatively dominated psychological tradition at the time (p. 268). By the time of Tuffour's (2017) publication, IPA had become much more widely adopted across academic disciplines.

There are many reasons IPA was adopted as an ideal approach for this study. Interpretive phenomenological analysis has a flexible design, thus making it ideal for incorporating alongside a co-development framework (Tuffour, 2017). It is intended to examine "…detailed and nuanced analysis of the lived experience…" of a small number of participants, suiting the limited number of members that comprised our advisory committee (Tuffour, 2017, p. 1). Both principles of co-development and the aim of the research study centred advisory committee members' experiences, aligning with IPA's aims of "…listening to people narrating their stories in their own natural settings to identify how their experiences and behaviours are shaped by their social, cultural, economic and historical worlds" (Tuffour, 2017, p. 2).

The co-development framework adopted alongside IPA was guided as closely as possible by the existing relationships established through the EPAC program of research Action Team of community partners and informed by co-development literature (Moll et al., 2020; Ocloo & Matthews, 2016; Woolf et al., 2016). Our approach was also informed by careful reading of *Research 101: A manifesto for ethical research on the downtown eastside*, the product of a collective workshop project responding to harm and unethical practice perpetrated by some health research approaches in an over-researched Vancouver neighbourhood with high levels of homelessness and chronic illness (Boilevin et al., 2019; Neufeld et al., 2019). The process was far from perfect: COVID-19 limitations meant that our advisory committee members were limited to those who were more stably housed and had regular access to technology and internet for video conferencing, biasing data gathered away from those who remained homeless or in less stable housing; the closure of patient advisory groups meant that we reached out to extend direct invitations or to gather names through networking, an approach critiqued by Moll (2020) as limiting diversity and opportunity to participate; the limitations on participation, likely from both technology and COVID-19, meant that the advisory committee was smaller than we had originally intended and this limitation also resulted in a lack of diversity in representation; and we do not know how the videoconferencing format may have altered what advisory committee members shared or how they shared their experiences. Nevertheless, it was a valuable learning experience that produced important input for the overarching study to advance methods on

PROMs and PREMs for people who are homeless with chronic illness and contributed to the literature both on the use of PROMs and PREMs for people experiencing homelessness and chronic illness, and to future co-development studies.

Analyzing and Reporting the Findings.

Meetings were recorded and transcribed before being individually read and jointly analyzed by Kara Whitlock and myself. As an interpretive approach informed by hermeneutics, IPA acknowledges the role played by researchers in the interpretation of results and formed a baseline for this joint analytical approach (Donald et al., 2022; Tuffour, 2017). As a researcher with experience in qualitative analysis paired with a researcher with lived experience in the phenomenon under study, we were able to supplement each other's insights and identify nuance in the data that one researcher or a group of researchers from a more homogenous positionality may not have. Once we had a set of themes and a list of recommendations related to PROMs and PREMs, we returned to the advisory committee and met with them to share and receive feedback. This process acted as a form of member-checking and became the basis for a report back to the larger research team for the multi-phase study, and, later, for a conference poster co-presented by Kara Whitlock and Daniel J. Sands (identified here and in the primary publication as a member of the advisory committee with lived expertise) (Donald et al., 2020). Based on this research report, I drafted an article for publication (Donald et al., 2022). All members of the advisory committee chose to remain involved throughout the research report process. To make participation in the publication process as accessible as possible, the draft was read aloud to allow for questions to be asked and feedback to be provided over the course of an additional eight meetings. Please see Chapter Five for the full published manuscript (Donald et al., 2022).

Dying While Mad: Critical Reflections Invoking an Historical Lens

The historical background research I conducted for Chapter Two engaged my interest and revealed some important themes in the history of palliative care and mental health care. While researching, I began to suspect that these historical inheritances were playing a far greater role in present-day care than I had recognized in the literature identified by the scoping review (Donald & Stajduhar, 2019). While I had not previously sought to make a theoretical or historical contribution to this body of literature, I became increasingly convinced that these findings should be part of the conversation on palliative care for people with SPMI. Motivated by these thoughts, I contacted Dr. Sara Beam, an Associate Professor of History at the University of Victoria and was granted permission to participate in her upcoming graduate-level Historiography course in the Fall term of 2019. At the time I was taking the course primarily for interest and with an eye towards further exploring the role of history in palliative care for people with SPMI in a post-doctoral capacity. With the onset of COVID-19 in the Winter term of 2020 and the shifting focus of my dissertation, my experience in the course became a starting point for selecting a historiographical approach and reckoning with the disciplinary positioning of the tertiary literature that would make up most of my data sources for a series of critical reflections on the role of historical inheritances in palliative care for people with SPMI in the present-day.

While many potential topics of discussion arose as I investigated the historical literature and compared it to what I had learned about care in the present-day, it was beyond the scope of this dissertation to explore all of these. I selected three of what I deemed the most important topics for discussion as can been seen in more detail in Chapter Six. Here I will discuss historiography more broadly as well as the specific historiographical approach for this section of the dissertation.

Historiography.

Quoting Streubert and Carpenter (1999), Lundy (2012) essentializes historical research in nursing as a "…an effort to establish *bodies of evidence* from the past, which help with the understanding of current and future issues in health care" (p. 382, emphasis added). However, the study of history is not simply an amassing of available data. Lundy (2012) goes on to add "[i]n addition to creating a body of evidence, historical research can *illuminate* previous historical accounts" (p. 382, emphasis added). This is the work of the field of history and the practice of historiography — not merely investigating *what happened*, but doing so by carefully and deliberately selecting sources, synthesizing information, and writing a narrative in a way that is critically sound and defensible (Lefkowitz, 2008). Historiography can describe any part of this process from the choices made in an individual study, to the school of historical practice a study draws from, to the time and place of a study's focus, or it can refer to a written (or other) product (Lefkowitz, 2008). Historiography is a broad and context-specific term that, if phrased in equivalent terms for the discipline of nursing, can include a background literature review, methodology, methods, analysis, and/or the process of preparing and presenting findings as results. Although historians may be making varied choices in subject focus, methodological approach, data selection, and narrative synthesis depending on the needs of the study in question, each choice must be critically defensible in order to produce an epistemologically sound study (Megill, 2007). In this sense, the practice of historiography aligns with that of an interpretive descriptive study (Thorne, 2016).

Primary and secondary sources are defined differently by different academic fields (Lombard, 2010). In the discipline of nursing a primary source is a published, peer-reviewed research study and a secondary source is a synthesis of existing studies compiled by someone other than the original researcher (Sender, 2022). In the discipline of history, primary sources are accounts related directly to a subject or event created contemporaneously (Bebbington, 2021). They are the equivalent of raw data in a nursing study. While some instructional guides consider oral histories to be primary sources, Megill (2007) asserts that the malleable nature of memory, influenced as it is by culture, identity, and the search for meaning, does not provide the same type of evidence as that generated at the same time as an event. Length of time or degree of involvement from either an event or subject distorts the quality of data and diminishes what can be learned (Megill, 2007). This does not mean that nothing about the patient care experience, for example, can be learned from oral histories (or interviews with caregivers and HCPs), but epistemological caution must be maintained. Data sources pertaining to an original event or subject of study that have been removed by distance, degree of involvement, or time, are considered secondary data sources in the field of history (Megill, 2007). In this dissertation I have used to term *tertiary sources* to refer to publications produced by historians reporting on original historical studies.

Primary sources in history can be uncovered, identified, or collected, but unlike most nursing studies they cannot be generated. A historian or archivist may find more documents if they spend more time searching, but if the documents were not preserved or never existed then they cannot produce more. They are limited to the sources that were generated at the time under study and preserved into the present day. Lombard (2010) quotes Anderson on this topic, stating that: “Both [archivists and historians] need to understand the context of creation, to know who created a record and why, and its custodial history” (p. 251). This is because historians have no way of exerting control over the conditions of primary source data production, collection, and preservation (including choices made about what to preserve or destroy). This is high on the list of factors to account for when historians consider objectivity and rigour.

Like nursing, the discipline of history treads a difficult path between the limitations of research in a complex world and a bias towards Newtonian scientific philosophy (Megill, 2007). Megill (2007) identifies four overlapping types of objectivity, a technique he uses to explore the complexity of objectivity in historical research. The four types are: absolute or aperspectival, intended to observe the subject without any input from the viewer and generally considered more theoretical than realistically possible to attain; disciplinary objectivity, or that which is based on the authority of disciplinary consensus; dialectical objectivity, or that in which the subject is acknowledged to play an active role in knowing (and will be familiar to qualitative nurse researchers who have studied the hermeneutic process); and procedural objectivity, or the removal of human involvement through standardized processes (Megill, 2007). The role played by these approaches to objectivity are best understood in concert with the goals of history-writing[7]. The four tasks of history-writing are description (what was), explanation (how did it come to be), arguing or justifying, and interpretation (Megill, 2007). According to Megill (2007), and with a view long-supported by the post-positivist paradigm movement in nursing research (Clark, 1998), there is no history-writing without some degree of interpretation.

Under COVID-19 closures it was impossible for me to access primary data held in archives, even assuming I could have obtained the specialized training required to do so. The historical component of this dissertation was limited to reading tertiary sources. For the beginning of the timeframe, I selected 1850 to capture a major turning point in social, political, medical, and professional approaches to care for people considered to be insane. This was the rise of institutionalization and the implementation of moral treatment in Canada. For the end of

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[7] For Megill (2007), history-writing seems to represent the most important part of the historiographical process, as it comprises presenting sources, synthesizing evidence, composing and articulating arguments, and demonstrating defensibility.

the timeframe, I selected 1914, as the experience of institutionalization would go on to change drastically in response to World War I and subsequent social conditions. For the location I selected Upper Canada/Ontario as the site of a widespread, establishing network of institutions for Canada's largest English-speaking population within the timeframe. The limited but valuable background in historiography I acquired helped me to gauge quality and perspective as I encountered different types of studies and movements within the discipline of history including social history, quantitative analysis, history from the bottom up, and critical feminist history. Perhaps the most interesting changes have been watching shifts from meliorist or 'Whig' history defending institutionalization to the more critical approaches adopted after the translation of Foucault's History of Madness in 1972 (T. E. Brown, 1985), followed by the infusion of social history approaches that sought to explain the asylum as a negotiation between stakeholders both within and without, though Wright et al. (2003) maintains that divisions in provincial jurisdiction of mental health care in Canada "…prevented an overarching revisionist monograph from appearing in Canada in psychiatric historiography" (p. 101).

Armed with this knowledge and my own disciplinary sensitivity to identifying the subject under study (i.e. the patient, the social impact of the institution, or the profession as much of the history of mental health and mental illness is focused on the development of treatment and of the psychiatric professions themselves) I read extensively in tertiary historical literature to select findings, consider their origins (concerning both the subject and the positionality from which they were written), and reflect critically on how these findings may be continuing to influence care today based on my own clinical experience and on the outcomes of the scoping review (Donald & Stajduhar, 2019). Because the discipline of history is a retrospective practice taking place over time, while learning about positionality it proved impossible to solely consider findings from the originally selected time period, particularly as I encountered the perspectives of scholars and activists with lived experience who had begun to openly enter the scholarly literature following the patients' rights movements of the 1970s. In consultation with my supervisor and with the aim of selecting the three most relevant critical reflections for researchers and practitioners to consider in a growing field of practice and literature, I have written Chapter Six with the intention of manuscript preparation and publication to further inform and add depth to the dialogue on palliative care for people with SPMI.

Scientific Integrity

Quality in Interpretive Description

Nursing research findings have ethical implications. When they are eventually disseminated, the researcher must assume there is chance they will be acted upon (Thorne, 2016; Thorne et al., 2016). For this reason quality, coherence, and integrity are highly valued in the ID process, and the thinking that goes into developing findings will be articulated in the research reports (Thorne et al., 2004). Interpretive description includes four primary criteria for evaluation:

1. *Epistemological Integrity* has been demonstrated throughout the research design phase, proposal, research conduct, analysis, and reporting to ensure I am following a defensible line of reasoning and that my assumptions do not vary without transparency and reporting on what has caused a shift;
2. *Representative Credibility* has been ensured both through incorporating a range of perspectives as demonstrated by each of the three manuscripts included, but also that I am not making claims about findings or applicability beyond what these manuscripts could reasonably represent;

3. *Analytic Logic* has been established through thorough, clear, concise, and transparent reporting of my assumptions and reasoning at each stage of the research process; and,
4. *Interpretive Authority* has been sought by conducting ongoing constant-comparative analysis resulting in the production of reflections and recommendations supported across manuscripts.

Reflexivity was maintained throughout the research process through journaling and debriefing with peers. In ID, reflexivity is both an approach for building a credible study, and a thought process to consider the reasons for decision-making and create room to explore different conceptualizations (Thorne, 2016). Reflexivity includes both reflection on previous experiences and reflection in experience, in a way that opens up new possibilities and direction in the research process (Reis, 2011, p. 4); it has been long been considered a component of ensuring quality and reducing researcher bias in qualitative studies (May, 2014). In the research and writing of these manuscripts, reflexivity was a useful tool for exploring and identifying my own positionality and what I was bringing to each study as a researcher, a collaborator, a nurse, and a person steeped in North American cultural ideas about the history of mental illness, madness, and institutionalization.

Conclusion

Facing significant disruption due to COVID-19, this dissertation shifted to combine two research studies and one discussion paper including a scoping review (Donald & Stajduhar, 2019), a co-development study with partners with lived expertise on the topic of PROMs and PREMs for people with chronic illness and experience of homelessness (Donald et al., 2022), and a critical reflection on the importance of history in the study and practice of palliative care for people with SPMI. Together these works address and explore gaps in the current body of research concerning palliative care for people with SPMI by contributing the first scoping review in a decade since the Woods et al. (2008) review, initiating a conversation about a deeper level of thought and analysis in publication on care for people with SPMI in the palliative phase, and exploring co-development and the meaningful involvement of people with chronic illness experiencing poverty and unstable housing in research on patient-centred healthcare evaluation further promoting the involvement of people with a high likelihood of mental distress and trauma in need of a palliative approach in their own care. Combined, the contributions made by this dissertation address challenges in the literature and practice of care for people with SPMI in the palliative phase from different angles and have the potential to encourage greater uptake of critical theoretical approaches and the involvement of people with lived expertise in future research endeavours.

Chapter Four: A Scoping Review of Palliative Care for Persons with Severe Persistent Mental Illness

To inform this dissertation, a systematic scoping review guided by Arksey & O'Malley (2005) and overseen by Dr. Stajduhar was conducted to gain a comprehensive view of the body of published peer-reviewed literature. Updated and published in 2019, this scoping review provided me with limited insight into the state of care for people with SPMI in the palliative phase as well as the presence and absence of information available in this literature (Donald & Stajduhar, 2019). There has continued to be a rise of interest in care for people with SPMI in the palliative phase; however, the literature continues to be dominated with reviews. Examples include Gonzàlez-Rodríguez et al. (2020), Wilson et al. (2020), Shalev et al. (2020), Peryer et al. (2020), and the MENLOC review (Coffey et al., 2022; Edwards et al., 2021; Hannigan et al., 2022).

The full text of the published article is included below, as it appeared in *Palliative and Supportive Care* under the authorship of myself and Dr. Stajduhar (Donald & Stajduhar, 2019).

A Scoping Review of Palliative Care for Persons with Severe Persistent Mental Illness

Abstract

Objectives: Persons with severe persistent mental illness (SPMI) experience a greater burden and severity of chronic disease, late diagnosis, and premature death compared to the general population. Persons with SPMI also receive fewer medical treatments, poor quality of care, and are less likely to receive palliative care. A systematic scoping review was undertaken to determine the extent, range, and nature of research activity about persons with SPMI requiring palliative care, and to identify gaps and opportunities for future research.

Methods: A systematic scoping review using the framework provided by Arksey and O'Malley (2005) was undertaken in September 2017 and updated in May 2018 in order to map literature on this topic, determine the extent and range of what has been published, and report the findings. This five-stage framework was conducted by, 1) identifying the research question, 2) identifying relevant studies 3) study selection, 4) charting the data, and 5) collating, summarizing and reporting the results. A narrative approach to analysis was used in order to synthesize and interpret findings. A search of multidisciplinary healthcare databases resulted in 46 included articles.

Results: Four major themes were identified from the included studies: complexity of care; limited access to care (both through systems and healthcare providers); competence and autonomy; and the potential for relationships between mental health and palliative care.

Significance of Results: This review reveals a highly vulnerable population with complex needs that are not reliably being met by the healthcare system and providers. Research in this area must continue to develop using rigorous qualitative and quantitative study designs, and interventions should be developed and tested based on existing knowledge in order to inform care. The voices of persons with SPMI in need of palliative care must be represented in future studies to address gaps. In order to expand a body of literature addressing mainly individuals, system perspectives and sociocultural analysis can bring much to contextualizing the experience of living with SPMI in the palliative phase of care. Adoption of a palliative approach, which promotes the principles of palliative care across non-specialized care settings provided by non-specialist palliative providers, has the potential to increase access to high-quality palliative treatment for persons with SPMI.

Keywords: Palliative care, end-of-life, mental health, severe mental illness, healthcare delivery

Introduction

Severe persistent mental illnesses (SPMIs) are those that are prolonged and recurrent, impair activities of daily living, and require long term treatment (Woods et al., 2008). Common diagnoses include schizophrenia, bipolar disorder, and major depression (Woods et al., 2008). The prevalence of SPMI is estimated to be 4.2% in the United States (National Institute of Mental Health, 2017). While a recent count of persons with SPMI in Canada has not been conducted, rates were between 4.6% to 5.5% when last broken down by diagnosis in national survey (Public Health Agency of Canada, 2012). Persons with SPMI suffer from more chronic diseases, greater severity of chronic disease, and late diagnosis (Correll et al., 2017; Walker et al., 2015). They receive fewer medical treatments, experience poor quality care, die prematurely from medical illness, and may be less likely to receive palliative care (Chochinov et al., 2012; Lavin et al., 2017). Palliative care is defined by the World Health Organization (2022) as "…an approach that improves the quality of life of patients and their families facing the problem 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". Palliative care can be provided by specialist palliative care services, by non-specialist healthcare providers, or by any combination thereof according to need and setting (Sawatzky et al., 2016).

Unequal access to care and disparities in health outcomes are key indicators of inequity of healthcare for persons with SPMI. While there is evidence that these inequities persist for those approaching end-of-life (Chochinov et al., 2012), very little is known about palliative care for persons with SPMI (Woods et al., 2008). Scoping reviews allow the researcher to "…'map' relevant literature in the field of interest" (Arksey & O'Malley, 2005, p. 20). In 2008, Woods et al. conducted a scoping review identifying four themes related to palliative care for persons with SPMI: decision-making capacity and advance care planning, access to care, provision of care (both illness- and healthcare provider-related issues), and vulnerability. In order to update this review and capture new knowledge, a systematic scoping review was undertaken to determine the extent, range, and nature of research activity about persons with SPMI requiring palliative care, and to identify gaps and opportunities for future research.

Methods

The purpose of this scoping review was to map literature on this topic, to determine the extent and range of what has been published, and to report the findings (Arksey & O'Malley, 2005). This approach is particularly appropriate when addressing a broad topic encompassing a variety of study designs, and is used to summarize and interpret existing findings rather than conduct a quality appraisal (Arksey & O'Malley, 2005). The framework provided by Arksey and O'Malley (2005) was used. This five-stage framework includes: 1) identifying the research question/aim, 2) identifying relevant studies, 3) study selection, 4) charting the data, and 5) collating, summarizing, and reporting the results.

Studies were included if the primary topic was palliative care for persons with SPMI, included adults over 18, was published in English, and was published in a peer-reviewed journal. The conceptual definition of SPMI was based on that used by Woods et al. (2008) provided above. Publications were included if the term severe mental illness or SPMI was used; or included schizophrenia, bipolar disorder, or major depression. Studies were excluded if they did not meet inclusion criteria, or if the SPMI had not been present prior to terminal medical diagnosis. Where studies included information about both SPMI and dementia, only information related to SPMI was extracted. No time restrictions were applied to the searches.

In order to identify relevant studies, the following databases were searched during September 2017 and again in May 2018: Web of Science, PubMed, Medline (EBSCO), CINAHL, Healthsource, Academic Search Complete, PsycInfo, PsycArticles, and Cochrane Database of Systematic Reviews and Central Register of Controlled Trials. Search terms were drawn from two concept groups: Mental Illness and End-of-life. Specific terms included were: 'mental health', 'mental illness', 'schizophrenia', 'major depression', 'bipolar disorder'; and 'palliative', 'end of life', 'end-of-life', 'hospice', 'end stage', and 'end-stage'. The reference lists of included articles were also searched. Original searches produced 1401 articles after duplicates were removed. Title and abstract reviews followed by full text reading produced 32 articles. The reference lists of these articles were searched for relevant articles, resulting in the inclusion of a further 5 articles for a total of 37 articles. An updated search in May 2018 identified an additional 9 articles for a total of 46 (Figure 1).

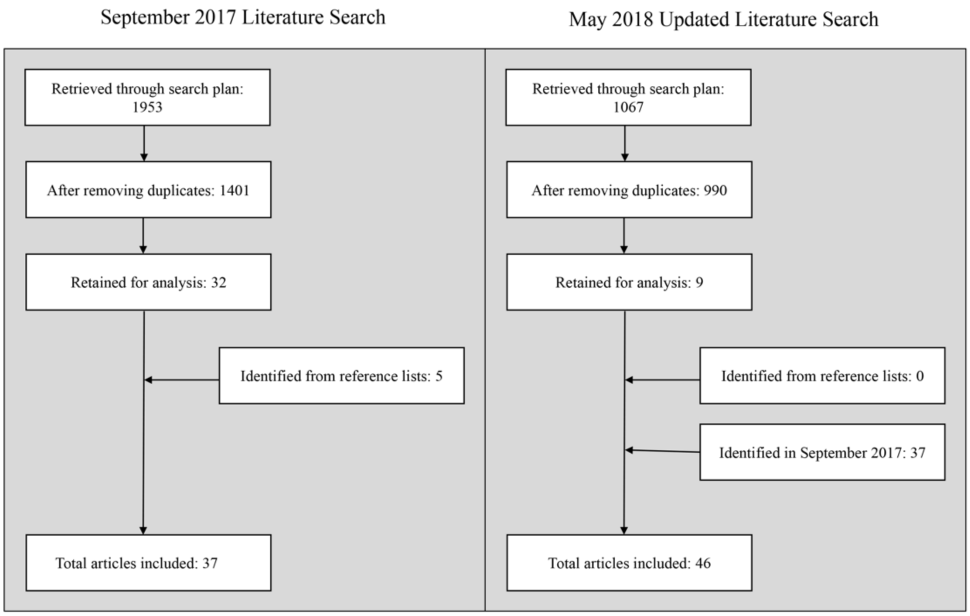

Figure 4.1: Article Selection Process

Articles were coded using NVivo 10 in order to chart the data and identify key issues and themes (Arksey & O'Malley, 2005). An iterative codebook was developed to act as an analytical framework and inform a narrative review of the data (Arksey & O'Malley, 2005). Codes were then grouped to identify and articulate themes, and to reveal gaps. Greenhalgh et al. (2018) describe narrative review as "a scholarly summary along with interpretation and critique" (p. 2). Using a scoping review methodology, a narrative approach to analysis draws on published literature not only to provide a synopsis, but also to examine critically how information has been presented, built upon, and how it may be useful to advancing health systems and clinical practice (Greenhalgh et al., 2018). Suggestions for practice resulting from narrative review are evidence-informed rather than evidence-based, and this approach to analysis is especially relevant for bodies of research containing very few if any clinical trials (Arksey & O'Malley, 2005; Greenhalgh et al., 2018).

Results

Description of Identified Studies

Forty-six eligible articles were identified after excluding duplicates and determining the relevance of the articles (Figure 1). Descriptive studies made up the majority of included articles (18 total: 9 quantitative, 8 qualitative, and 1 mixed methods) followed by qualitative case studies (9), literature reviews (8), intervention studies (5 articles representing 3 studies; 2 of which used mixed-methods evaluation, and one of which used quantitative methods alone), and other (6, including discussion and theoretical analysis). Articles originated in the Unites States (20), Australia (7), Europe (5), Canada (6), the United Kingdom (5), New Zealand (1), Taiwan (1), and South Africa (1). The majority of articles featured all SPMI (31), with 14 focused on schizophrenia. With the exception of one article on post-traumatic stress disorder (PTSD), no other specific SPMIs were addressed. Profession of the first author included MD (21), Nursing (11), Social Work (5), and other or unknown (9). The majority of articles were published in mental health journals (26), with 14 appearing in palliative care journals. General or other journal types comprised the remaining 6 articles. Forty-four articles have been published since 2000, and over half of all included articles (27) published since 2010.

Findings from our review resulted in four themes being drawn from the collected articles: complexity of care; limited access to care; competence and autonomy; and relationships between mental health and palliative care.

Complexity of Care.

Persons with SPMI at the end of the life are part of a highly complex population. Studies showing early mortality reveal that persons with SPMI are approaching end-of-life early, and late presentation often results in high needs and a short timeline for care (Baker, 2005; Moini & Levenson, 2009). Reviews and case studies found that late presentation can be due to both disease and system issues, resulting in overlapping and interacting health effects with high symptom burden and treatment interactions (Baker, 2005; Davie, 2006; Terpstra et al., 2014; Woods et al., 2008). The co-existence of physical and psychological illness can create confusion about symptoms and etiology, for example when unusual behaviours convey or obscure the presence of symptoms including pain (Baker, 2005; Griffith, 2007b; Kelly & Shanley, 2000; Morgan, 2016). Nurses in qualitative studies report that co-occurring disorders such as substance abuse can make pain management challenging due to both physiological factors and provider stigma (Evenblij et al., 2016; Morgan, 2016). Persons with schizophrenia are thought to have a decreased response to pain, which can mask illness (Evenblij et al., 2016; Terpstra et al., 2014; Webber, 2012). Treatment for one illness may influence the other, including medication interactions as identified in an intervention study by Picot et al. (2015) and a case study analysis by Terpstra et al. (2014). Changes during decline in health may influence the physical as well as the psychological state, and cause complications including changes in drug metabolism (Craun et al., 1997; Picot et al., 2015; Terpstra et al., 2014). In their discussion of end-of-life care for persons with PTSD, Feldman (2017) reminds readers that "[t]he treatment of psychosocial issues at the end-of-life is not a straightforward extension of evidence-based approaches for physically healthy individuals" (p. 117), and emphasizes attention to the complex nature of the illness experience for persons with SPMI and the importance of making decisions for care with an understanding of this context.

Psychiatric symptoms lend their own complexity to palliative care, such as delusions, psychosis, denial of illness (both psychiatric and physical), and social withdrawal or apathy, all of which can hinder or obstruct participation in care (Craun et al., 1997; Griffith, 2007b, 2007a; Kelly & Shanley, 2000; Moini & Levenson, 2009; Rice et al., 2012). While severity of psychiatric symptoms varies widely, active psychiatric illness can prevent persons with SPMI from identifying changes in physical health, seeking out diagnosis, and participating in treatment (Moini & Levenson, 2009; Rice et al., 2012; Terpstra et al., 2014; Webber, 2012). Psychiatric symptoms often result in special care needs such as requiring quiet space or increased time for explanations and assessments, which may not be possible in some facilities (Baker, 2005; Craun et al., 1997; Geppert et al., 2011; McNamara et al., 2018; Woods et al., 2008). Psychiatric symptoms may influence healthcare behaviours and help-seeking patterns for persons with SPMI, making it difficult to assess, collaborate on, and provide care (Jerwood et al., 2018; Moini & Levenson, 2009; Terpstra et al., 2014; Woods et al., 2008). A recent qualitative study by Jerwood et al. (2018) found that challenges experienced by staff may differ by specialty or setting: where mental health clinicians report increased difficulty with the content of challenging conversations including despair and suicidality, palliative care clinicians were more likely to report discomfort with care-seeking, care-rejecting, or aggressive behaviours. Lifestyle factors such as smoking may provide challenges for staff and facilities which are increasingly adopting smoke-free policies or require staff accompaniment for persons leaving the unit (Griffith, 2007b; Terpstra et al., 2014).

Complexity in care needs affects not only the person with an SPMI, but also those around them. Persons with SPMI may have close existing relationships with mental health staff in other settings, and the needs of end-of-life may result in separation from those staff members and relationships, limiting potential for collaboration and continuity of care (Bloomer & O'Brien, 2013; Geppert et al., 2011). Family caregivers of persons with SPMI may also have special needs that can differ from those of other palliative patients, as many may have been lifelong caregivers for people with SPMI, or may be suffering from damaged relationships (Bloomer & O'Brien, 2013; Davie, 2006; Evenblij et al., 2016; Geppert et al., 2011; Morgan, 2016). A case study analysis by Geppert et al. (2011) provides the example of family members who have been advocates for access to care over many years, and may perceive a lack of aggressive care associated with a palliative approach as "…a failure to appreciate their loved ones value and humanity" (p. 183). The importance of an advocate is echoed by multidisciplinary healthcare provider participants interviewed by McNamara et al. (2018), who shared that without an assertive advocate, professional or lay, persons with schizophrenia are unlikely to receive high-quality end-of-life care.

Additional complexities reported in the literature seem to result from social disadvantages experienced by persons with SPMI including stigma, discrimination, isolation, and poverty (Baker, 2005; Bloomer & O'Brien, 2013; Candilis et al., 2004; Craun et al., 1997; Morgan, 2016). Alienation from friends and family members places persons with SPMI at a disadvantage in palliative care settings that rely on lay caregivers, such as community-based hospice care (Baker, 2005; Craun et al., 1997). Special populations, such as those who are homeless or incarcerated are reported to experience additional complexities from systems that are not prepared to care for them (Baker, 2005; D. K. Wright et al., 2017). According to Baker's (2005) literature review, follow up and continuity of care are particularly challenging for persons with SPMI who are homeless, and those suffering from SPMI and terminal illness who are incarcerated are increasingly vulnerable to the harsh environment found in prisons where adequate pain and symptom management is often not provided.

Davie (2006) identifies persons who are dying and persons with SPMI as individuals facing many challenges unique to these conditions. Both a terminal diagnosis and a diagnosis of SPMI can evoke grief, hopelessness, and fear as well as being subject to the impact of stigma and social disadvantages that may come with each condition. When these diagnoses co-exist, a person experiences the impacts and complexities of both. In an ethical analysis by Levin and Feldman (1983), the authors contend that the complexity innate in caring for patients with SPMI and terminal illness should alter the way disease is considered, recognizing how these overlapping complexities cannot be considered separately when treating patients and designing treatment and support programs.

Limited Access to Care.

The articles reviewed suggest limited access to care is a serious issue for persons with SPMI at end-of-life. Two primary access issues emerged in the studies reviewed: system challenges and challenges with healthcare providers.

System Challenges.

Late diagnosis contributes to complexity in care and is a system-wide issue that spans providers, settings, and is influenced by access to the healthcare system itself. Late diagnosis is emblematic of difficulties accessing and being properly assessed by the healthcare system, both in general and specialist care settings (Baker, 2005; Davie, 2006; Webber, 2012). Persons with SPMI may not seek medical attention in a timely manner, or may not report early symptoms, and disconnection between systems of care (such as limited communication between psychiatrists and primary care providers) may result in fewer or less frequent physical examinations (Baker, 2005). Contributing to late diagnosis is system silo-ing, or the barriers that exist in place between healthcare specialties (Baker, 2005; Davie, 2006). Studies by Jerwood et al. (2018), Lloyd-Williams et al. (2014), and Bloomer and O'Brien (2013) showed that silo-ing concentrates resources and expertise in narrowly defined populations, such as the availability for specialist care for mental health on a mental health unit in a way that is not available on a palliative care unit. This concentration of resources results in limited access to settings with capacity to care for complexity, such as for a person with SPMI who is experiencing active psychiatric symptoms and cannot be cared for on a general medical unit despite their potentially high need for medical care (Terpstra et al., 2014). Such variations in setting capacity can strongly influence the care received by a person with SPMI, and can limit the system resources available to them (Baker, 2005; Terpstra & Terpstra, 2012). Institutional and legal guidelines in psychiatric facilities may not be in line with what would normally be considered in palliative care and may not meet the needs of people with SPMI who are at end-of-life (Jerwood et al., 2018; McGrath & Forrester, 2006). Guidelines such as those investigated by McGrath and Forrester (2006), requiring a coroner’s inquest into all deaths in an inpatient mental health facility, are system factors that can facilitate or hinder care. In this case, staff were hindered in their discussions of death, and reported feeling concern that routine actions such as giving morphine might be perceived under inquiry as hastening death resulting in criminal charges (McGrath & Forrester, 2006). These types of guidelines are examples of system contributions that limit access to appropriate care for persons with SPMI at end-of-life.

Persons with SPMI at end-of-life are often transferred between settings and may be underserved (such as having psychiatric medications discontinued) when they are admitted to acute care (Jerwood et al., 2018; Morgan, 2016; Terpstra et al., 2014). Settings unable to meet the needs of persons with SPMI may result in transfer or discharge to equally inappropriate settings, such as nursing homes ill-equipped to provide palliative care for patients with schizophrenia and other SPMI (Cai et al., 2011; Chochinov et al., 2012; Jerwood et al., 2018; Lavin et al., 2017; Martens et al., 2013). Relatedly, persons with SPMI may not have access to the care they need because of the potential loss of information between service providers and settings (Davie, 2006; Terpstra et al., 2014).

Analyses of palliative care use and related indicators show that persons with SPMI are not receiving the same palliative care services as their counterparts without SPMI. A quantitative descriptive study by Chochinov et al. (2012) comparing a Canadian provincial cohort of persons with schizophrenia against those without found that persons with schizophrenia had lower rates of seeing non-psychiatric specialists, were less likely to receive opioid analgesia, and were less likely to receive palliative care. Similar results were reflected in New Zealand, where Butler and O'Brien (2018) found that persons with schizophrenia in a region well-populated with healthcare resources were 3.5 times less likely to access specialist palliative care. A study in Taiwan identified that persons with schizophrenia and cancer were less likely than people without schizophrenia in a matched cohort to receive chemotherapy, but more likely to receive invasive treatments and be admitted to the ICU in the final month of life (Huang et al., 2017). Patients in an institutionalized setting may not be entitled to the same services as someone dying at home, such as specialist palliative nursing care management provided by hospice organizations in the United States (McGrath & Forrester, 2006). It is not yet known why these disparities in treatment exists, but some articles addressing general system issues in access to care provide further information. A person with SPMI who has experienced barriers to healthcare access in the past, such as discrimination, may be hesitant to attempt to seek care again (Bloomer & O'Brien, 2013; Jerwood et al., 2018; McNamara et al., 2018). In addition, ethical issues arise when a patient with SPMI who lacks competence and does not have a substitute decision-maker refuses treatment, and providers must decide whether to impose guardianship and force treatment (Harman, 2017; Levin & Feldman, 1983).

The exception to articles identifying limited access to care was that of Ganzini et al. (2010)'s cross-sectional study of persons with schizophrenia and cancer in the Veteran's Administration (VA) system in the United States. Ganzini et al. (2010) found that patients experienced the same or better palliative care than counterparts without schizophrenia, and the authors assert that common symptoms of SPMI including denial of illness and impaired decision-making capacity do not undermine care in the presence of institutional support. Ganzini et al. (2010) proposes several system possibilities for these findings, including fewer financial and insurance barriers within the single-payer VA system, and liberal regulations for surrogate decision-makers within the VA.

Challenges with Healthcare Providers.

Access to care is dependent on healthcare providers and some access to care issues for persons with SPMI are specific to the people they encounter within the healthcare system. Lack of training in palliative care or mental health care, particularly for those outside of mental health or palliative specialties, is a recurrent issue in the literature that inhibits access to palliative care for persons with SPMI (Cai et al., 2011; Evenblij et al., 2016; Morgan, 2016; Webber, 2012). Lack of awareness of mental or physical health issues, particularly as one condition may obscure or compound the other, also limits access to palliative care (Webber, 2012). In some cases the symptoms of psychiatric illness such as active hallucinations, disordered self-care, or negative symptoms such as not being forthcoming with information or exhibiting a flat affect may result in healthcare provider avoidance of caring for patients with SPMI (Craun et al., 1997; Davie, 2006; Moini & Levenson, 2009; Terpstra et al., 2014; Woods et al., 2008). Healthcare providers may be subject to internalized stigma that can result in access to care issues for patients with SPMI (Cai et al., 2011; Chochinov et al., 2012; McGrath & Jarrett, 2007).

Competence and Autonomy.

Competence and autonomy was a common theme across articles. One literature review (Candilis et al., 2004) and one qualitative study of staff members in psychiatric hospital (McGrath & Forrester, 2006) found that persons with SPMI suffer from presumed incompetence and might be assumed to be incapable of informed decision-making solely based on psychiatric diagnosis. As a result, persons with SPMI are often excluded from medical decision-making and forming advance directives (Candilis et al., 2004; Terpstra & Terpstra, 2012). Advance directive completion is very low for persons with SPMI (Baker, 2005; Cai et al., 2011; Terpstra & Terpstra, 2012). Often the chronic episodic nature of SPMI results in fluctuating capacity, where a person may be capable of autonomous decision making at some times but not others depending on disease status or the complexity of the decision (Candilis et al., 2004; Irwin et al., 2014; Terpstra et al., 2014; Webber, 2012). Decision-making conversations happening on the timeline of healthcare providers may miss out on opportunities to involve a person with SPMI during times of capacity (Foti, Bartels, Merriman, et al., 2005). Standardized tools may not be designed for persons with SPMI and may be inadequate for eliciting or documenting preferences, whereas interviews or customized tools with tailored education may be better suited (Elie et al., 2018; Foti, Bartels, Merriman, et al., 2005; Woods et al., 2008). Foti et al. (2005) used a semi-structured interview format that was successful in allowing persons with SPMI to talk about their wishes for care, and in 2003, Foti developed a workbook called "Do It Your Way" to assist persons with SPMI select a healthcare proxy and make decisions to guide future care (Foti, 2003). This approach was revisited and expanded upon by Elie et al. (2018), whose results suggest that persons with SPMI are comfortable discussing end-of-life issues (including medical assistance in dying) regardless of previous suicidality and were able to make treatment choices even in cases of mild cognitive impairment.

In cases where persons with SPMI are unable to make their own healthcare decisions (either temporarily or long-term), a proxy decision-maker is often sought. Persons with SPMI may be estranged from friends or family, or may have their strongest relationships with healthcare providers who are restricted from acting as proxy decision-makers, making it difficult to find someone to fill this role (Candilis et al., 2004; Foti, 2003). Persons with SPMI who do not have a close friend or family member lack not only a substitute decision-maker, but an advocate for end-of-life care wishes (Jerwood et al., 2018; McNamara et al., 2018). Third party decision-makers such as public trustees or guardians may have strict limits to their decision-making capacities, such as the need to seek (and await) a court order for the withdrawal of life-sustaining treatments or permission to forgo resuscitation (Harman, 2017).

Having end-of-life conversations with persons with SPMI can be daunting for healthcare providers, who may lack education or training or who may assume the person with a SPMI will cope poorly with discussions of illness and death (Baker, 2005; Bloomer & O'Brien, 2013; Foti, 2003; Irwin et al., 2014; Terpstra & Terpstra, 2012). Despite this, Foti et al. (2005), Foti et al. (2005), and Elie et al. (2018) found that such conversations were not unduly distressing, and that persons with SPMI share many of the same concerns as persons without SPMI in regards to palliative care – namely: burdens on family, suffering and symptom management, interpersonal issues, spiritual issues, and funeral arrangements. Sweers et al. (2013) similarly found in discussions of end-of-life preferences for persons with schizophrenia that death was considered to be a natural process, was not frightening, and that concerns were greatest for loss of quality of life and loss of skilled companionship. Participants reported feeling positive and reassured after discussing death (Sweers et al., 2013).

Relationships Between Mental Health and Palliative Care.

Mental health and palliative care are divided by silo-ing, yet share many similarities in treatment philosophy and approaches to caring (McGrath & Holewa, 2004; Terpstra & Terpstra, 2012; D. K. Wright et al., 2017). Both mental health and palliative care are person-centered (McGrath & Holewa, 2004; D. K. Wright et al., 2017), focused on the therapeutic relationship (Baker, 2005; McGrath & Holewa, 2004; Picot et al., 2015; Sweers et al., 2013), share hope for a good outcome regardless of prognosis (D. K. Wright et al., 2017), and are centered on compassionate and holistic care (McGrath & Holewa, 2004; Picot et al., 2015). Respect for autonomy is important in both mental health and a palliative care (McGrath & Holewa, 2004;

Webber, 2012) as is concern for quality of life as defined by the person receiving care (Griffith, 2007a; McGrath & Holewa, 2004). Both specialties aim to provide continuity of care (Baker, 2005) and to anticipate future needs to prevent crises (Bloomer & O'Brien, 2013). Lack of familiarity with mental health or palliative care breeds stigma, fear, and emotional distress in providers (Jerwood et al., 2018; McGrath & Jarrett, 2007).

Many authors recommended joint endeavours between palliative care and mental health, whether that was collaborating in treatment teams, or providing cross-training and sharing resources (Bloomer & O'Brien, 2013; Davie, 2006; Kelly & Shanley, 2000; Lloyd-Williams et al., 2014; McCormack, 2006; McGrath & Jarrett, 2007; Picot et al., 2015; Terpstra et al., 2014; Terpstra & Terpstra, 2012; Woods et al., 2008). Galappathie & Khan (2016) emphasize the importance of psychiatrists staying up to date on palliative care practices.

Two intervention studies identified by the review are examples of such collaboration (Byock et al., 2006; Foti, 2003; Picot et al., 2015; Taylor et al., 2012). The Integrated Mental Health and Palliative Care Task (IMhPaCT) study combined a cross-training initiative alongside a joint collaboration between palliative care and mental health nurse practitioners (NPs) (Picot et al., 2015; Taylor et al., 2012). The cross-training initiative involved two workshops – one on palliative care provided to mental health practitioners and vice versa provided by a team including a mental healthcare recipient (Taylor et al., 2012). The workshops were supplemented with skills modeling and self-directed learning modules, including staff members who were identified as liaisons between mental health and palliative care (Taylor et al., 2012). In the NP collaboration component patients were seen by both a palliative care NP and a mental health NP in case conference (Byock et al., 2006; Foti, 2003), as well as independent and joint follow up (Picot et al., 2015). Although a systematic assessment of patient outcomes was not reported for the IMhPaCT project, qualitative feedback from staff on the cross-training was positive (Picot et al., 2015; Taylor et al., 2012). “Do It Your Way” was a demonstration project whose primary objective was to develop advance care planning tools for persons with SPMI, and also included stakeholder collaboration and cross training components (Byock et al., 2006; Foti, 2003). Stakeholders including those from palliative care and mental health came together and “…helped to design, support, and participate in the project’s initiatives” (Foti, 2003, p. 664). Cross-training initiatives involved workshops about palliative care for mental health providers and vice versa along with meetings that brought palliative care and mental health practitioners together (Foti, 2003). Both Taylor et al. (2012)’s and Foti (2003)’s cross training initiatives contained similar material covering common topics including the characteristics and trajectories of both life-limiting and psychiatric diseases, symptom control and medications, presentation of case studies, and system context including legal guidelines and referral information. These types of collaborations have promise for increasing access to care for persons with SPMI: Mental health and palliative care staff in Jerwood et al. (2018)’s qualitative study reported that when palliative care was successfully provided to persons with SPMI it was usually driven by an individual staff person who understood both contexts of care.

Discussion

Twenty-nine new articles have been published since Woods et al. (2008)’s scoping review in 2008. Woods et al. (2008) came to similar conclusions: They identified four themes including decision-making capacity and advance care planning, access to care, provision of care (both illness- and healthcare provider-related issues), and vulnerability. While this speaks to the validity of the findings of this review, it also reveals that the scope and lay of the literature, as well as the clinical settings being investigated, have not made significant progress since the original review was done. This body of evidence does not develop in sophistication until very recently, as studies cite each other but rarely build on previous findings. Particularly lacking were more rigorous and advanced investigative study designs as well as a lack of intervention studies informed by previous findings. While some progress has been made in the past year towards more rigorous investigation of the current state of palliative care for persons with SPMI, studies continue to draw on large administrative data and healthcare provider perspectives, excluding persons with SPMI and their caregivers as expert data sources in their own experience. It is likely that a combination of stigma against mental illness in funding bodies, challenges in accessing this population due to disparities in location and access to care, gatekeeping on the part of organizations, and conservative requirements for capacity to consent from ethics review boards have all contributed to the limited progress in this field (Bloomer & O'Brien, 2013; Carlsson et al., 2017; Keogh & Daly, 2009; McNamara et al., 2018). While research with persons with SPMI and with persons in the palliative phase can be challenging due to capacity for communication and other barriers, existing bodies of research in both mental illness and palliative care attest to the possibility of including such persons in research and their perspectives are invaluable for informing care (Carlsson et al., 2017).

What the authors drew from this review was the picture of a highly vulnerable population. Moore and Miller (1999) identify vulnerability as diagnosis with an illness, and subsequent lack of ability to maintain autonomy, independence, and self-determination as a result of that illness. However, this definition fails to capture the many social factors, such as limited access to care (including timely diagnosis), that persons with SPMI may experience. Reimer-Kirkham et al. (2016) identify structural and social inequities as a key component of vulnerability for persons in need of palliative care, paying special attention to the frequent presence of mental illness in those who suffer from structural vulnerability such as extreme poverty and poor housing. For persons with SPMI medical and psychiatric complexity, late presentation, presumed incompetence, barriers to system access, and stigma and discrimination result in high susceptibility to harm.

It is vital that research continue to inform treatment, educate providers, and empower individuals with SPMI. When conducting research with vulnerable populations it is always important to ask: Whose voice is being represented? As Moore and Miller (1999) attest, some research questions will always require input from a vulnerable group in order to uncover answers, and this is the case for persons with SPMI who hold unique perspectives on their own experiences and goals of care. While two studies in this review included persons with SPMI directly (Elie et al., 2018; Foti, 2003), it is overwhelmingly the voices of researchers and healthcare providers who are represented here. Keogh and Daly (2009), in their article on the ethics of conducting research with persons with mental illness, recommend: special attention to the capacity to consent, using a process approach to informed consent, and seeking ongoing participant understanding of the research and the participant's voluntary role. Approaches such as these can provide an avenue for researchers to seek input from persons with SPMI while protecting research participants, promoting better care, and avoiding harm.

Gaps in the literature are numerous and include the above-mentioned scarcity of persons with SPMI represented in research; underrepresentation of caregivers, family, and friends; the effects and effectiveness of psychiatric treatment during the palliative phase and vice versa; research on the physical and psycho-social experience of dying for persons with SPMI (including needs, reactions, values, and experiences of persons with SPMI); and evidence-based strategies for healthcare providers working with persons with SPMI at end-of-life.

Perhaps the most glaring gap in the literature is that it has failed to address organization and system level factors in providing palliative care for persons with SPMI. In this capacity we advise researchers not to neglect a public health perspective on palliative care, which integrates social justice and health equity and pays attention to the sociopolitical, economic, cultural, and historical factors that influence populations, such as those with SPMI, in need of palliative care (Reimer-Kirkham et al., 2016).

Recommendations

Two sets of recommendations are presented here: recommendations from the including articles, and recommendations from the researchers conducting this review. As mentioned above, a partnership approach between mental health and palliative care is promoted by the authors of many included articles (Bloomer & O’Brien, 2013; Butler & O’Brien, 2018; Candilis et al., 2004; Davie, 2006; Elie et al., 2018; Griffith, 2007b; Harman, 2017; Jerwood et al., 2018; McGrath & Jarrett, 2007; McNamara et al., 2018; Terpstra & Terpstra, 2012; Woods et al., 2008). Providers are urged to be aware of the medical and psychiatric complexity, to know symptoms of both psychiatric and chronic life-limiting illnesses and to know how to react, and to be alert to changes (Baker, 2005; Candilis et al., 2004; Feldman, 2017; Griffith, 2007a; Moini & Levenson, 2009; Woods et al., 2008). Providers are also encouraged to respect the patient, to build therapeutic relationships, and to make full use of the multidisciplinary healthcare team as well as any existing relationships with healthcare providers the person with SPMI may have (Baker, 2005; Bloomer & O’Brien, 2013; Butler & O’Brien, 2018; Craun et al., 1997; Griffith, 2007b, 2007a; McNamara et al., 2018; Terpstra & Terpstra, 2012; Woods et al., 2008). Existing relationships with health care providers are opportunities for collaboration to maintain continuity of care, minimize adverse events, and capitalize on connections to established support systems

(Bloomer & O'Brien, 2013; Craun et al., 1997). Also recommended in the included articles was a reduction in silo-ing in all specialties and primary care to ensure access to care wherever it is needed, and to collaborate with existing services (such as street nurses or community outreach workers who may already be in contact with persons with SPMI) (Baker, 2005; Bloomer & O'Brien, 2013; Candilis et al., 2004; Jerwood et al., 2018; Moini & Levenson, 2009). Some authors recommended NPs as an ideal role to provide coordination and care for persons with SPMI at end-of-life (Baker, 2005; McGrath & Jarrett, 2007). Providers are encouraged to engage in end-of-life care conversations with persons with SPMI (Baker, 2005; Butler & O'Brien, 2018; Elie et al., 2018; Foti, 2003; Foti, Bartels, Van Citters, et al., 2005; Terpstra & Terpstra, 2012). More research is encouraged to develop the field, to overcome barriers, to identify strategies, and to learn more about the current state of care for persons with SPMI (Baker, 2005; Bloomer & O'Brien, 2013, 2013; Elie et al., 2018; Foti, Bartels, Van Citters, et al., 2005; Griffith, 2007b; Jerwood et al., 2018; Lavin et al., 2017; Lloyd-Williams et al., 2014; Terpstra & Terpstra, 2012; Woods et al., 2008). It is important to recognize the heterogeneity in this population and to seek diversity when investigating the experiences of persons with SPMI (Woods et al., 2008). More research into advance care planning was also called for (Bloomer & O'Brien, 2013; Candilis et al., 2004; Elie et al., 2018; Foti, Bartels, Merriman, et al., 2005; Lavin et al., 2017). Two studies by Nahm (2009), and Nahm et al. (2012) examined potential shifts in psychiatric symptoms at end-of-life and suggested studying the experiences of persons with SPMI at end-of-life as a way to better understand SPMI and develop new options for treatment. Some authors called for a greater commitment to providing care and redressing injustice for persons with SPMI at end-of-life (Baker, 2005; Davie, 2006; Webber, 2012).

Recommendations from the researchers conducting this review include a call for more research targeting system issues and leadership. While this review did not assess for quality, it is clear that more rigorous quantitative and qualitative study designs are needed to move this field forward. Follow-up is needed for successful intervention studies with rigorous patient, family, provider, and system outcome measurements. New interventions including treatment plans, collaborative team approaches, and system shifts should be developed and tested based on what is already known. Further research needs to involve persons with SPMI and their caregivers to capture their perspective and input in the study design, implementation, and analysis process.

Knowing that persons with SPMI in need of palliative care do not always have access to palliative care specialists, this field of study would benefit from engaging (in research and practice) with a palliative approach. A palliative approach makes use of the skills and principles of palliative care embedded in non-specialist care settings and adapted for persons with life-limiting conditions upstream in the disease trajectory (Sawatzky et al., 2017). A palliative approach has the potential to bring high-quality palliative care to persons with SPMI wherever they are cared for and supports collaboration and cross-training between palliative care, mental health, and primary care specialties.

Conclusion

The aim of this scoping review was to determine the extent, range, and nature of research activity about persons with SPMI approaching end-of-life, and to identify gaps and opportunities for future research. Research in this population is limited and includes few intervention studies. Narrative themes in the research include complexity of care, limited access to care (both through systems and healthcare providers), competence and autonomy, and the relationship between mental health and palliative care. Emerging from this research is the picture of a highly vulnerable population. The voices of people with SPMI and their caregivers are largely missing from this research. Key recommendations from the literature include collaboration between mental health and palliative care, as well as specific recommendations for clinicians working with this population. Key recommendations from the researchers of this scoping review include conducting more rigorous quantitative and qualitative studies, and the adoption of a palliative approach in the care of persons with SPMI in order to ensure high-quality palliative care across settings. Persons with SPMI suffer from a high burden of chronic disease and high medical acuity, yet they are receiving very little attention from researchers when it comes to determining needs and providing care in the palliative phase. While initial research suggests people with SPMI are receiving substandard care compared to the general population, leaders and providers in healthcare cannot hope to improve care without high quality investigation and input from persons with SPMI themselves.

Chapter Five: A Co-Development Process to Advance Methods for the Use of Patient-Reported Outcome Measures with People who are Homeless and Experience Chronic Illness

As part of a larger study, I acted as project co-ordinator for an advisory committee of people with lived experience of homelessness and chronic illness working in partnership with researchers to inform methods for advancing the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in this population. The following is a peer-reviewed publication I led to report on the outcomes of this research (Donald et al., 2022). This publication was developed in partnership with committee members, and a statement of authorship contribution follows along with the full text of the article as published.

Participation in this process led to valuable learning about meaningful engagement of people with lived experience in the research process. Preparation involved deep reading in the literature and consultation with colleagues with lived experience of unstable housing, chronic illness, and substance use. I also drew on the experience of my colleagues in the Equity in Palliative Approaches to Care (EPAC) research team who have previous experience in conducting ethnographic studies in this community and have established relationships with community partner organizations and people with lived experience through the EPAC action team. Receiving ongoing feedback from advisory committee members during the study and maintaining a flexible approach that changed in response to committee member needs throughout the process taught me about adaptation and thinking critically about integrating the participation of people with lived experience alongside the need for scientific rigour and the demands of funders. Most importantly, this study was a process in adjusting my outlook. This approach to research challenged what I had previously learned, consciously and unconsciously, about my need for control as a researcher, a healthcare provider, and a professional. I had to learn to see my own contribution as valuable only to the extent that it supported a path to a meaningful experience and engagement process to further both the research aim and a lasting relationship with advisory committee members and the community to whom we had reached out.

Preface

Authors

Erin E. Donald, PhD(c), RN[1,2], Kara Whitlock, MSW[1], Tracy Dansereau, Daniel J. Sands, David Small, Kelli I. Stajduhar[1,2], PhD, RN, FCAHS, FCAN

[1] Institute on Aging and Lifelong Health, University of Victoria

[2] School of Nursing, University of Victoria

Author Contributions

Erin Donald, Kara Whitlock, and Dr. Kelli Stajduhar contributed to study conception and design in partnership with an existing community advisory team of inner-city workers and peers who are not involved in the authorship of this article. All authors participated in data collection and analysis. Erin Donald wrote the initial draft of the article and led subsequent revisions. Kara Whitlock worked with Erin Donald to develop concepts and contribute to the discussion and methodology sections. Dr. Kelli Stajduhar provided written feedback on the article. Erin Donald, Kara Whitlock, Tracy Dansereau, Daniel J Sands, and David Small met to verbally read through the article, provide feedback, and make changes. In total, these meetings accumulated to 8 hours of conceptual and technical contribution to the manuscript. The final version including order of authorship was read and approved by all authors prior to submission.

Abstract

Introduction: People who experience social disadvantage including homelessness suffer from numerous ill health effects when compared to the general public. Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) collect information from the point of view of the person receiving care. Involvement in research and health care decision-making, a process which can be facilitated by the use of PROMs and PREMs, is one way to promote equity in care.

Methods: This article reports on a co-development and consultation study investigating the use of PROMs and PREMs with people who experience homelessness and chronic illness. Data were analyzed according to interpretative phenomenological analysis.

Results: Committee members with lived experience identified three themes for the role of PROMs and PREMs in health care measurement: trust and relationship-building; health and quality of life; and equity, alongside specific recommendations for the design and administration of PROMs and PREMs. The co-development process is reported to demonstrate the meaningful investment in time, infrastructure, and relationship-building required for successful partnership between researchers and people with lived experience of homelessness.

Conclusion: PROMs and PREMs can be meaningful measurement tools for people who experience social disadvantage, but can be alienating or reproduce inequity if they fail to capture complexity or rely on hidden assumptions of key concepts.

Patient or Public Contribution: The study was conducted in active partnership between researchers and people with experience of homelessness and chronic illness; including priority setting for study design, data construction, analysis, and co-authorship on this article.

Keywords: Homeless, homelessness, health equity, patient-reported outcomes, patient-oriented research, substance use

Introduction

Homelessness is defined as “living in a shelter, public space, abandoned vehicle, or someone else’s home” (Argintaru et al., 2013, p. 578). There is considerable overlap and movement between homelessness and unstable housing, a situation in which a person or family is housed but has experienced multiple moves over the past year (Argintaru et al., 2013). Internationally, 1.6 million people experience inadequate housing, with an estimated 400,000 of those located in Canada (Argintaru et al., 2013; Ayano et al., 2019). People experiencing homelessness suffer from death rates 2 to 5 times higher than the general public for the same causes, have worse physical and mental health, have more chronic conditions, experience higher rates of traumatic brain injury and substance misuse, and experience earlier declines in health typically associated with aging (Ayano et al., 2019; Fazel et al., 2014).

Worse physical and mental health is coupled with an unmet need for care (Argintaru et al., 2013; Fazel et al., 2014). One study of unmet health need found no significant differences between people who were homeless and vulnerably housed, suggesting these groups share similar health states and challenges accessing care (Argintaru et al., 2013). There are many barriers to care including lack of transportation, lack of child care, long waitlists, competing priorities for survival, inaccessible care settings (such as those with abstinence-only drug policies), and discrimination in the health care system (Argintaru et al., 2013; Milaney et al., 2018; Stajduhar et al., 2019a). Even in countries with policy mandates for universal access to care, divisions of responsibility between care sectors, and between health and social services, can lead to people ‘falling between the cracks’ (Milaney et al., 2018; Stajduhar et al., 2019a).

People experiencing homelessness and vulnerable housing are impacted by both individual and structural circumstances resulting in social disadvantage (Bonevski et al., 2014).

Socially disadvantaged groups experience poverty, discrimination, stigmatization, and marginalization that impact access to health care and inclusion in health care research (Dugas et al., 2017). These factors limit choices and opportunities, increasing the risk of harm from other individuals and social structures (Stajduhar et al., 2019a). Social disadvantage shifts over time in response to changes in external social forces and their impact on intersecting identities such as disability status, Indigeneity, and sexual or gender orientation (Abramovich, 2012; Boyd et al., 2020; Martin et al., 2019; Stajduhar et al., 2019a). In Canada, where Indigenous people are up to 8 times more likely to be homeless or precariously housed compared to non-Indigenous Canadians, historical and ongoing colonization has been particularly destructive to the health of Indigenous people. This has resulted in and ongoing inequalities in health and social positioning to this day (Baskin, 2019; Patrick & Patrick, 2014; Thistle & Smylie, 2020).

Despite these impacts, it is important to recognize the vibrant strength and resilience inherent in people who are experiencing housing issues and in the communities and relationships formed in these contexts (Neufeld et al., 2019; Stajduhar et al., 2019a). Though often overlooked, this community strength and resilience is a powerful source of expertise and insight for researchers and organizations working in these contexts.

Inclusion in health research and decision-making is vital to reducing inequities in the health care system (Bonevski et al., 2014). When researchers, policymakers, and health care providers (providers) base their decision-making on research that has excluded people who are socially disadvantaged, the results are likely to reproduce inequity (Bonevski et al., 2014; Stajduhar et al., 2019a). One way of including what matters to people who are socially disadvantaged in both research and health care is through the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs). PROMs and PREMs are measurements of health status, quality of life, experience, and satisfaction from the point of view of the person receiving care and their family (Bryan et al., 2014; Schick-Makaroff et al., 2020). This paper reports on the co-development and initial consultation study investigating the use of PROMs and PREMs with people who experience social disadvantage, as reported jointly by members of a committee of people with lived experience of homelessness and researchers. To inform this study and in the context of lived experience of homelessness, we joined together to ask, “What is most important to measure about our health care, and how can it best be measured using PROMs and PREMs?”

Methods

This study used interpretative phenomenological analysis (IPA) with a co-development framework (J. A. Smith, 1996; Tuffour, 2017). Co-development is both a method and a philosophy which involves research activities done *with* or *by* members of a group instead of *about* or *for* them (Moll et al., 2020; Ocloo & Matthews, 2016). The aim is to authentically involve stakeholders in all phases of research, including the ongoing commitment to work together for change (Moll et al., 2020; Woolf et al., 2016). Joint efforts between stakeholders can strengthen the influence of research through collective impact (Woolf et al., 2016). When members of the public are involved in research testing and designing the use of tools like PROMs and PREMs, these tools can become clearer, more acceptable, and better meet the needs of the people who will use them (Dugas et al., 2017; Neale & Strang, 2015).

The co-development process is part of a larger study funded by the British Columbia SUPPORT Unit Patient-Centred Measurement Methods Cluster, part of Canada’s Strategy for Patient-Oriented Research (SPOR) with the overall aim of advancing methods in the use of PROMs and PREMs with people who are socially disadvantaged and who experience chronic illness. The study is part of a larger multi-year program of research that relies on and invests in relationships with a local inner-city community and service organizations serving people who are socially disadvantaged (Stajduhar et al., 2019a; Stajduhar, Giesbrecht, Mollison, Dosani, et al., 2020; Stajduhar, Giesbrecht, Mollison, & d'Archangelo, 2020; Watts, 2019). Ethical approval was obtained from the University of Victoria. Alongside other relevant stakeholders including clinicians and a community health centre, the authors make up the People With Lived Experience Advisory Committee (the committee) engaged as expert consultants and co-knowledge producers throughout the study. KW and KS were co-chairs of the committee. KW is a research assistant with lived experience. TD, DJS, and DS are expert contributors, sharing their own lived experience and expertise. All committee members with lived experience have a history of homelessness and chronic illness, including but not limited to substance use. ED is a doctoral candidate and coordinator for this phase of the project, and KS is the principal investigator. The grant was crafted with input from an action team involved in KS's program of research and included roles for the committee at each stage (Bonevski et al., 2014; Brett et al., 2014; Dugas et al., 2017; Woolf et al., 2016).

Engagement Process

The committee co-chairs originally planned to reach out to patient advisory groups from inner-city organizations and extend open invitations to join the committee (Boilevin et al., 2019) but just as they were starting, the COVID-19 pandemic hit North America. For a community already facing rampant social inequity, COVID-19 compounded existing crisis conditions. Community partners no longer had capacity to support research, patient advisory groups shut down, and new restrictions prohibited face-to-face meetings. KW reached out to existing organizational partners working in the inner city to ask how we might best shift our engagement process considering these emerging restrictions and additional burdens facing potential members. With the awareness that this would limit who we could successfully engage, and recognizing that community-based research with people who face social disadvantage requires flexibility and re-prioritization based on community need (Moll et al., 2020; Neufeld et al., 2019; Woolf et al., 2016), the committee co-chairs chose to pursue the suggestion of smaller virtual video meetings with an advisory committee consisting of people who had lived experience of homelessness but were now housed in stable living situations and had access to equipment and internet services that would allow for full video participation. Although the research team recognized that this meant our research may not capture the perspectives that we had originally hoped, flexibility in community research requires the research agenda to adapt to community capacity(Brett et al., 2014). This flexibility is demonstrated by shifting our gaze from what we had hoped to do (i.e., engage in face-to-face focus groups in community alongside building an ongoing advisory committee of 8-10 people living with social disadvantage) to what was possible (i.e., a smaller virtual advisory committee with experience of homelessness but who were now housed).

KW reached out through existing relationships and networks (Dugas et al., 2017) to invite a diverse group to participate. Initially, recruitment posters were distributed to, and posted on bulletin boards of, inner city organizations describing the study and inviting potential participants to contact the research team. When services were disrupted due to COVID-19, the team adapted their recruitment approach and relied on previous research relationships with inner city service providers to distribute the posters to clients they had relationships with. Potential participants were recruited for participation on the advisory committee if they self-identified as a person with experiences of poverty and homelessness, and/or health care discrimination, were >18 years of age, and spoke English.

Over the 10-week recruitment period, six potential participants with lived experience responded to the recruitment advertisement. KW called and screened each of the six potential participants for inclusion and participation in the advisory committee. While all six potential participants met the inclusion criteria and expressed interest in participating, three people left or did not attend the initial two meetings despite multiple attempts to follow up by phone and email. While we are unclear why this occurred, it is likely that the increased burden in the context of multiple health emergencies facing the inner-city community may have limited some people's capacity to participate. By the third meeting, participation had stabilized to six members, three with lived experience of homelessness and chronic illness, one member with lived experience and a researcher role, and two members of the research team without lived experience. The committee met eight times by video conference between May 2020 and August 2020. Committee members with lived experience were compensated $25 per hour for their time and expertise (Boilevin et al., 2019).

Taking direction from Boilevin and colleagues (Boilevin et al., 2019) on conducting ethical research with vulnerable populations, the research team intentionally built in time to develop the trust necessary for this experiential exploration. One way we built this relationship was to encourage authentic sharing by all group members, especially from the research team to disrupt traditional power dynamics embedded in research relationships (Boilevin et al., 2019; Hankivsky, 2014). This practice aligns with recommendations that researchers approach community members with the willingness to share about themselves and their own positionality with the same openness being asked of community partners (Boilevin et al., 2019; Moll et al., 2020).

Another important process was beginning with reflexivity; defining our own identities and experiences (Moll et al., 2020). For example, DJS introduced themselves by presenting their own positioning, explaining where they came from, how they saw themselves, and who they were in the context of the world around them. Although DJS is providing their own perspective of the needs and experiences of people with lived experience of homelessness and chronic illness, this location is not static (Moll et al., 2020).

The first five meetings included collaborating on the committee objectives, drafting our guidelines for group process (see Appendix A), and defining terms relevant to PROMs and PREMs (e.g., measurement, health care) in the context of homelessness and chronic illness. The committee spent these meetings exploring our experiences in relation to health and health care services, as well as describing how these were impacted (or not) by shifting circumstances. For each meeting, KW and ED prepared discussion prompts guided by the research question and designed to elicit an insider's perspective on meaning making in relation to PROMs and PREMs (Peat et al., 2019; J. A. Smith, 1996) (see Appendix B). These prompts were seldom required after the meeting began, as participants with lived experience played an active role in guiding the conversation.

For the final three meetings, the committee focused on identifying and refining these PROMs and PREMs concepts through discussions of how they might be demonstrated in practice for people experiencing homelessness and chronic health issues. For example, the concept of trust with a health care provider was described as the provider actions that have inspired greater or lesser trust for committee members. Moving vague experiential concepts into a tangible realm was often the impetus for deeper conversation as people articulated the meaning(s) and interpretations of lived experiences.

Finally, as concepts were explored and refined, the group transitioned to discussing examples of commonly used PROMs and PREMs, including the Veterans Rand 36-Item health Survey (VR-36), the Veterans Rand 12-Item Health Survey (VR-12), and the World Health Organization Quality of Life - Abbreviated (WHOQoL-BREF) (Kazis et al., 2006; The WHOQoL Group, 1998). Committee members provided feedback on the suitability of these tools and used them as a launching point for discussion about facilitators and barriers to tool administration. Collectively, these meetings generated a series of themes, as well as specific recommendations for the design and delivery of PROMs and PREMs (see Table 1).

Analysis

Analysis was guided by interpretative phenomenological analysis (IPA), an approach that combines multiple philosophies to produce a nuanced exploration of lived experience and the meaning people make of their lives (Peat et al., 2019; Spiers & Smith, 2019; Tuffour, 2017). Originally proposed by Jonathan Smith for the psychology of health care (J. A. Smith, 1996), IPA has since been adopted by researchers across disciplines, including nurse researchers in partnership with service users (Mjøsund et al., 2017). By promoting "…an interpretive process between the researcher and the researched…" (Peat et al., 2019, p. 7), IPA is particularly well-suited to the investigation of under-researched phenomena and to research in partnership (Mjøsund et al., 2017).

Meetings were recorded and transcribed. ED and KW jointly conducted the initial data analysis by reading and re-reading transcripts, recording their reflections in the margins, and meeting frequently to discuss their interpretations in an active hermeneutic process (Peat et al., 2019; Spiers & Smith, 2019). By including one team member with lived experience of homelessness and chronic illness (KW) and one researcher (ED) in this initial stage of analysis, KW and ED benefitted from each other's insight while reinforcing reflexivity that investigated and challenged both researcher privilege and the potential projection of personal experience on findings (Boilevin et al., 2019; Spiers & Smith, 2019). This inclusion of a perspective of lived experience in the initial stages of our analysis allowed for more meaningful comparisons and a more complete understanding of findings. As we explored the differences in our interpretations of the advisory committee process, we came to recognize how our personal frames of reference exposed the tensions that emerged from the measurement of multiple perspectives and priorities across different levels of health care. For example, ED's broad population measurement lens contrasted with and complemented KW's focus on the individual point of measurement. Bridging micro-level perspectives of care to broader macro-level performance measures of health systems became critical to the creation of our shared understanding. As Kwon et al. (Kwon et al., 2019) state, we can benefit from acknowledging the role of these tensions in our analytic process. When ED and KW produced a set of proposed themes, they returned these to the committee as a whole for discussion and feedback (Peat et al., 2019). This acted as a form of member checking and prompted the creation of a plain language summary and report back to the full research team jointly produced by all committee members.

Results

Three themes emerged from conversations about PROMs and PREMs. These are trust and relationship-building; health and quality of life; and equity. The committee proposed specific recommendations for design and administration of PROMs and PREMs with people who experience social disadvantage, comprising a fourth category of findings. See Table 1 for these recommendations.

Trust and Relationship-Building

Trust and relationship-building was the first and most important concept identified for inclusion in health care measurement. A trusting relationship with both individuals and organizations was deemed crucial to all good health care and to the implementation of PROMs and PREMs. Trust was understood to be multi-dimensional, with organizations, providers, and persons receiving care all having a role in relationship-building. However, these relationships are built in a system with severe power imbalances, where persons receiving care have little recourse against mistreatment or stigma. When organizations and providers incorporate feedback to change or improve systems of care, trusting relationships are possible. PROMs and PREMs can facilitate this process.

Factors that contribute to developing a trusting relationship include taking the time to listen, treating people with respect, and acknowledging shared humanity. Additional important factors include access to shared decision-making, resolving conflict, and understanding the vulnerability inherent in seeking care. When committee members felt cared for, it opened the door to feeling heard and believed. This was described as a necessary ingredient for good care over all eight meetings and was a rare experience across health settings. When persons receiving care did not feel heard and believed, or when they felt shamed, dismissed, or stigmatized, this resulted in unaddressed care needs and eventual care avoidance:

> *You know, you're not getting tested for this as often as you should because you're afraid to go to the doctor because the doctor will look down his nose at you and make you feel bad about yourself, make you feel uncom— you know, you're going to feel all these things from the doctor, so you won't go. So you don't get your blood works or your whatever or your medications renewed as often as you should. And that affects your overall health.*

Being believed, heard, and accepted was not just imperative for relationship-building, committee members suggested it was a crucial component to consider in the design and implementation of PROMs and PREMs. Members shared that when providers did not believe them or did not have an understanding of their circumstances, they were more likely to receive poor care and experience a cascade of harm. These experiences of poor care were explicitly linked to their consideration of outcome measures. For example, throughout our co-development process, committee members repeatedly expressed a desire for PROMs and PREMs that included separate dimensions for measuring the establishment of trust and relationship-building in their interactions with providers. Committee members suggested that these core competencies would be a precursor to them even contemplating whether they would engage in the completion of PROMs and PREMs in clinical settings.

Committee members stressed the importance of ensuring that care would not be negatively impacted by a person's response to a PROM or PREM, and of explicitly communicating this to persons receiving care (see Table 1). Prompt and respectful responses to feedback provided via PROMs and PREMs can reinforce relationships and build trust.

Health and Quality of Life

Health was described by advisory committee members as a multi-dimensional concept including physical, mental, spiritual, cultural, social, and ecological components. While physical and mental health were understood to be addressed primarily addressed by the health care system, committee members were explicit about the importance of accessing social connections, community involvement, and safe and pleasant housing as factors that significantly influenced their health.

Health was understood to be a fluctuating state that could easily be impacted by the ability (or inability) to respond with agency to life events. Intersecting marginalization, minority identities, and history of trauma(s) had a compounding effect on health, but committee members emphasized that paternalistic assumptions about identity and trauma could erase their individual circumstances and autonomy when wielded in care settings.

Quality of life encompassed all of these dimensions of health and the ability to live well according to one's own values. Quality of life included having one's needs met; having choices; and having a purpose, a hope, or something to live for:

> *So, for me personally, it's being able to look after myself, as much freedom to do as much as I can with my person, whether it's physical limitations, mental limitations, addiction limitations.*

Advisory committee members agreed that PROMs and PREMs measuring multiple dimensions of health, quality of life, and experience in the care setting could be effective ways to capture this complexity.

Equity

PROMs and PREMs were seen by committee members as a powerful tool for data collection at both the individual and system level and as a way to capture individualized data in a standardized framework that could help ensure equitable care. As one member stated:

> *You go to a doctor with pain, you get nothing because you were a drug addict. Not ARE a drug addict, WERE a drug addict. They might relapse, they might start using [again] … It's ludicrous. The whole thing is insane. If a questionnaire, generic questionnaire to patients to get some sort of grip on what's happening … that would be friggin' amazing.*

Committee members described having unique care needs due to their experiences of homelessness, substance use, or chronic illness, but reported having little choice or control over their care. Committee members were informed about their own health and had clearly identified preferences and values for their care, which they reported were not always valued by providers. If a committee member wanted to change a course of treatment, refuse treatment, or switch providers, they were often restricted in doing so based on the limited services available, restrictive policies, limited financial resources, or due to stigma and lack of providers with relevant expertise.

Committee members reported that providing feedback on a questionnaire such as a PROM or PREM could mean risking their care. Members described many instances of having to choose between accepting poor treatment or forgoing care entirely. While some of this is rooted in a relationship with an individual provider or site, systemic factors play a powerful role. Committee members described how forms that demonstrate inclusivity had influenced their impression of an organization or set the tone for a health care encounter:

> *I think, you know, if I can see myself in, that I'm reflected or represented in this form, I'm going to be much more involved and engaged with it and more honest, right?*

According to committee members, PROMs and PREMs have the ability to convey risk or safety in their design. Clarity and accessibility were key to committee members' recommendations (see Table 1).

Discussion

These findings offer insight into the complex health experiences of committee members in the context of PROMs and PREMs. In discussions of trust and relationship-building, committee members were clear that while individual relationships with health care providers were important, a broader trust in organizations and systems impacted the delivery of care. These findings echo those presented by Treloar et al.(Treloar et al., 2014) whose interviews with staff and clients at syringe programs describe a multi-dimensional trust-building process that relies not only on personal relationships but on organizational actions and reputation built over an extended period of time. Committee members had countless experiences of poor care before, during, and after their time on the street, and had little trust in the health care system. For committee members, accessing the health care system was a completely different experience than that of the general public who were involved in studies designing commonly used PROMs and PREMs (Gadermann et al., 2013). Any assumptions of trust and relationship with the health care system that are inherent in the design of existing PROMs and PREMs should be in the minds of researchers and organizations who are interested in using these tools with people who are socially disadvantaged.

In relation to the design and implementation of PROMs and PREMs it is not enough to elicit feedback. A trusting relationship requires feedback to be acted upon, an idea that continues to be met with some debate and resistance (Anhang Price et al., 2015; Coulter et al., 2014). For committee members, both providers and organizations need to be listening to PROMs and PREMs for these tools to have meaning. Consideration should be given not only to how PROMs and PREMs are traditionally used as overall group measures, but how they might also be used to reflect individual outcomes and experiences that could guide clinical encounters between providers and people who experience social disadvantage.

Committee members experience health and quality of life in holistic, multi-dimensional ways. Despite Canada’s fragmented health and social services systems, committee members understood health to incorporate a range of social and systemic health determinants including housing, income, community connection, and spirituality. In this way, committee members pushed back against Canada's colonial isolation of health services which divide the disease-focused emphasis of the health care system from the social spaces and areas of policy impact where health is shaped (Brassolotto et al., 2014; T. Horrill et al., 2018). Hubley et al., in their recent review of literature on subjective quality of life in homelessness, found few studies that had conducted analyses of individual domains or how changes in social circumstances or health status were related to change in subjective quality of life over time (Hubley et al., 2014). While Hubley et al. (2009) recommend further research using standardized tools, tools developed for the general public may not identify differences relevant to the lives of people who are socially disadvantaged and we are encouraged by this same research team's development of population-specific measures involving input from people with lived experience.

Committee members believed that well-designed PROMs and PREMs, when used for health service accountability, development, and evaluation, have the ability to improve care. This might mean making the needs of people who are socially disadvantaged visible to providers and policymakers, or allowing for a person's health status to be compared objectively to other population members. However, PROMs and PREMs can be alienating and perpetuate inequity if they fail to capture complexity, assume a shared understanding of concepts (Neale & Strang, 2015), or locate health inequities within the individual rather than within the individual's access to care and determinants of health.

Committee members believed that PROMs and PREMs must be co-developed alongside people with lived experience and should move beyond being sensitive to being representative, a position supported by Neale and Strang (Neale & Strang, 2015). Meaningful co-development and participatory-based research allows for increased access, richer data, and deeper analysis while providing opportunities to strengthen communities and community partners (Damon et al., 2017; Woolf et al., 2016). As Wiering et al. (2017) point out, if we are to truly capture the patient's perspective, it is essential that they are involved in the development of measures that are most meaningful to them. Engaging people with social disadvantage in the development of PROMs and PREMs, and in the design of how they are implemented, is therefore necessary to ensure that outcomes and experience measures are representative of their perspective, and that measures are relevant, meaningful and valid. However, involving people experiencing social disadvantage in research does not guarantee meaningful participation. If research engagement is mere tokenism, it can lead to frustration, disillusionment with research, and harm relationships with the community (Brett et al., 2014; Damon et al., 2017). Research can be helpful, but it has also caused harm by perpetuating stigma, increasing inequality, exploiting pain, and exhausting community resources (Boilevin et al., 2019; Brett et al., 2014; Moll et al., 2020). Key facilitators to respectful and reciprocal research include openness, authentic listening, investing time for trust and capacity-building, sharing power, including diverse voices, valuing people's time, and sharing the benefits (Boilevin et al., 2019; Bonevski et al., 2014; Dugas et al., 2017; Moll et al., 2020).

Meaningful co-development requires time, funding, and infrastructure (Bonevski et al., 2014; Woolf et al., 2016). We have tried to do justice to this process by reporting our methods in detail. This was particularly true in the context of COVID-19 where we experienced delays in forming the committee and getting comfortable working together in virtual space. Co-development relies on relationship-building, developing trust, and being with communities and partners in shared space (Dugas et al., 2017; Moll et al., 2020; van Zyl & Sabiescu, 2020). It was more difficult to engage in the emerging context of fieldwork over videoconferencing, where committee members did not have an opportunity to gather together, share food, and get to know one another in person. Despite this, relationships were built by a shared commitment to improving care, overcoming tensions, and an openness to vulnerability. Often the interactions that supported these relationships happened in the margins — over emails, through encouragement or socialization before and after meetings, and in sharing humour. Participating openly in reflective exercises and sharing personal experiences helped create a trusting environment (Boilevin et al., 2019). Researcher reflexivity is vital to co-development (Moll et al., 2020; van Zyl & Sabiescu, 2020), and KW played a key role in identifying power imbalances and promoting researcher self-reflection.

One component of co-development is maintaining ongoing relationships (Boilevin et al., 2019; Woolf et al., 2016). This article reports findings from the first phase of the committee's involvement in this research study. Since the meetings have finished, the committee has continued to meet to produce an infographic and joint conference presentation (Donald et al., 2020), co-write a report of findings, participate in four workshops with researchers and clinical stakeholders, advise policymakers preparing for an upcoming survey, and collaborate on this article (Richards et al., 2020). While this study aims to advance methods in the use of PROMs and PREMs with people who are socially disadvantaged and experience chronic illness, the preliminary nature of this research is unlikely to result in immediate change before further research and policy advocacy. It was important for researchers in this study to be clear about the expected outcomes in order not to raise hopes or make false promises (Moll et al., 2020; Neufeld et al., 2019). Despite this, committee members with lived experience identified the value of participating in the co-development process as well as the possibility that it could make a positive difference in the lives of people down the line. This echoes research on co-development which has found that peer engagement is often driven by a desire to help others (Brett et al., 2014; Dugas et al., 2017).

This study's main strength is the people who came together to be involved in it. During an extraordinarily difficult time, committee members with and without experience of co-development, research, or technology joined and from the first meeting had thoughtful questions, insightful feedback, and a willingness to challenge assumptions. Other strengths include a co-development process that engages people with lived experience through each step of the study (Bonevski et al., 2014; Moll et al., 2020; Woolf et al., 2016), the contribution this study makes as part of an ongoing relationship between researchers and community members in this locale (Brett et al., 2014; Woolf et al., 2016), and attention to ethical principles articulated by a similar community of people with lived experience of homelessness and substance use (Boilevin et al., 2019).

There are many barriers to video meetings for people who are socially disadvantaged including needing a secure, private location; an electronic device with a functioning video camera and microphone; time to participate; and internet access. Due to COVID-19 restrictions we bypassed some formal community channels and extended direct invitations, a process which is not always recommended (Boilevin et al., 2019; Dugas et al., 2017). Moll et al. criticize invited spaces, raising concerns about tokenism and perpetuating marginalization which may have been reproduced by our small group number (Moll et al., 2020). Committee members were in more stable life circumstances than those who may have joined the committee prior to COVID-19, and no committee member became homeless during this phase of the study. A different committee composition, or a different format involving a larger group and more targeted discussion topics as originally planned, may have led to different findings.

Both researchers and policymakers stand to benefit from creating meaningful roles for engagement with people with lived experience when designing or selecting PROMs and PREMs. When transferring general population PROMs and PREMs to socially disadvantaged groups, it is important to thoughtfully address any underlying assumptions and seek feedback through co-development or methods such as cognitive interviewing in addition to traditional validation measures (Neale & Strang, 2015; Woolf et al., 2016). When selecting and designing PROMs and PREMs for people who are socially disadvantaged, it will also be important to measure experience in the health care system in ways that are sensitive to exposure to stigma and include measures of choice.

Conclusion

This article reports on the findings of the People with Lived Experience Advisory Committee in the first phase of the study "Towards Equity-Informed Care". Committee discussions aimed to identify and explain what is most important to measure about health care in the context of lived experience of homelessness and chronic illness, and how can it best be measured using PROMs and PREMs. Themes were trust and relationship building; health and quality of life; and equity. Specific recommendations produced by the committee have been presented in Table 1 with the aim of informing PROM and PREM adaptation and implementation for use with people with experience of homelessness and chronic illness.

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Table 5.1. Recommendations for the Design and Implementation of PROMs and PREMs

Recommendation	Rationale	Examples
Questionnaires should be designed with accessibility in mind.	This includes traditional measures of accessibility for people who experience a range of disabilities and chronic illnesses, but also for those who are using substances, live with memory loss, experience symptoms of mental or physical distress, or who experience challenges reading.	Accessibility may include large font, translations, verbal administration, additional time for completion, and many other strategies. For implementation by: Researchers, policymakers, or decision-makers at local clinical sites who are designing PROMs and PREMs for use in practice.
Demographic data should be as inclusive as possible. with "tick all boxes that apply" format and a wide range of options.	People who are homeless or vulnerably housed with chronic illnesses often experience intersecting marginalized identities (racial identity, sexuality, etc.). Tool designers and administrators can be more inclusive by being as flexible as possible when asking people to self-identify.	Include "tick all boxes that apply" options rather than forced choice. Include a wide range of demographic options. Where possible, allow respondents to provide their own language for categories such as gender, sexuality, religion/spirituality, etc. For implementation by: Researchers, policymakers, or decision-makers at local clinical sites who are designing PROMs and PREMs for use in practice.
Use multiple options for scales, or simple scales where possible.	Committee members were divided on preference for visual, numeric, or written response scales. This demonstrated a variety of preferences and that different scales are more accessible to different respondents.	For example, when rating satisfaction, use of a visual analogue scale alongside a written or numeric scale. For implementation by: Researchers, policymakers, or decision-makers at local clinical sites who are designing PROMs and PREMs for use in practice.

Have a “not applicable” option for all questions.	Being forced to provide an answer to a question that does not apply can be frustrating and alienating. Like providing as many demographic options as possible, “not applicable” options for answers allow respondents to ensure their participation is more reflective of their experience.	Include a not applicable option for all answers. For implementation by: Researchers, policymakers, or decision-makers at local clinical sites who are designing PROMs and PREMs for use in practice.
Clarify a limited time range.	To qualify for social services, treatment coverage, and access to specialized clinics (such as those which accept people who are homeless or vulnerably housed), people are frequently expected to recount their life stories including reliving multiple instances of trauma.	Ask about a limited time range to avoid misunderstanding. For implementation by: Anyone designing or administering a PROM or PREM.
Ask about time ranges in ways that are relevant to a person’s experience.	Memory issues, either permanent or temporary, are a common access barrier. For example, a person may not be able to remember six months ago, or may not be able to align their experience with months of the year.	Use prompts such as “for this visit”, “since you started seeing me”, or “compared to your best/worst day?” to be more accessible for those with memory issues. For implementation by: Anyone designing or administering a PROM or PREM.
Ask about perceived ability and barriers to accessing care.	Many PROMs and PREMs are designed for populations who do not experience significant barriers to accessing care. For people who are homeless or vulnerably housed with chronic illness, it is an indispensable component of both health care experience and outcome. These responses will also be important for any provider, organization, or researcher who is interested in making care more accessible and collecting information about	Include questions about perceived ability to access care and perceived barriers to care on PROMs and PREMs. For implementation by: Researchers, policymakers, or decision-makers at local clinical sites who are designing PROMs and PREMs for use in practice.

	who may not be able to access care.	
Tools should be generic enough to use across sites and between professional roles.	People who are homeless or vulnerably housed with chronic illness form care relationships in a variety of settings with people in different roles. A person's primary provider may not be immediately visible or expected.	Avoid provider- or role-specific language in the design of PROMs and PREMs. For implementation by: Researchers, policymakers, or decision-makers at local clinical sites who are designing PROMs and PREMs for use in practice.
Experience measures are equal to or more important than outcome measures. An ideal approach would measure both.	PROMs and PREMs depend on a trusting relationship between person and provider/organization for engagement and authenticity. People who are homeless or unstably housed, and those with stigmatized chronic illnesses, are more likely to have negative experiences in the health care system. Experience measures can build trust by demonstrating the importance of respecting clients' dignity.	Include a combination of evaluation and outcome measures when designing and selecting evaluation tools for this population. For implementation by: Researchers, policymakers, or decision-makers at local clinical sites who are designing or selecting PROMs and PREMs for use in practice.
Emphasize that there are no wrong answers and no penalty for answering honestly.	With few options to switch providers and little power in the health care system, people may be wary of the risk of losing access to care or receiving substandard care if they provide negative feedback.	Include standardized language in the design of PROMs and PREMs. However, standardized language is not a substitute for a trusting relationship. Some techniques may include administration of PROMs and PREMs by third parties (not providers), periodic re-evaluation using PROMs and PREMs as relationships develop, and establishing a relationship prior to introducing a PROM or PREM.

		To be implemented by: Researchers, decision-makers, and practitioners who are using PROMs and PREMs in research or practice.

Appendix A

How We Work Together – Guidelines for Ethical Engagement

(Document can be updated as our learning grows)

- Respect is key
- No war stories, keep things specific, don't go off on long rants
- Patience
- Don't yuck my yum
- Acknowledge 'ouch' with 'oops'. Just go ahead and say 'ouch' if someone has said something that's hurtful.
- There are no dumb questions
- It's always okay for anyone to say we need to have a break or to step away from the meeting to have a smoke or go to the bathroom
- Please tell us if anyone is using language that doesn't sit right
- Use person-first language

Chapter Six: Dying While Mad: Critical Reflections Invoking a Historical Lens

The following is a manuscript intended for submission for publication in 2023. This manuscript is the result of extensive reading and reflection on the history of mental health care, the history of palliative care, Mad studies and other survivor research, and the application of my own professional lens.

Introduction and Background

People with persistent mental illness experience increased morbidity and mortality from medical illness, and are at risk of over- and/or under-treatment throughout the disease trajectory including at end-of-life (Chochinov et al., 2012; Decorte et al., 2020; Donald & Stajduhar, 2019; Druss et al., 2011; Fond et al., 2019, 2020; Gatov et al., 2017; González-Rodríguez et al., 2020; Lawrence & Kisely, 2010; Martens et al., 2013; Shalev et al., 2020). Systemic inequity and social disadvantage play a role in both the inequitable health outcomes of people with mental illness (Corrigan et al., 2014; Currie et al., 2014; González-Rodríguez et al., 2020; Lawrence & Kisely, 2010) and in limited palliative care access for people who are made marginal (Reimer-Kirkham et al., 2016; Stajduhar, 2013; Stajduhar et al., 2019a). Research suggests that systemic and social injustice contribute significantly to the poor state of palliative care for many people with mental illness. Despite these disparities, it has now been well-established that people with mental illness themselves are barely represented in the healthcare literature that investigates their own care needs and experiences in the palliative phase, either as research participants or as patient partners (Donald & Stajduhar, 2019; Ehrlich & Dannapfel, 2017; Jerwood et al., 2021; Knippenberg et al., 2020).

A rise in attention concerning palliative care for people with persistent mental illness has been demonstrated by a sharp increase in publications over the past 15 years. This growing body of literature has largely taken an ahistorical and atheoretical stance to the investigation of a complex and multi-faceted issue. Through a series of critically oriented reflections on common threads between mental health and palliative care in both past and present, this paper will argue that care for people with persistent mental illness who are dying is a process saturated with historical inheritance and theoretical complexity that persists in the modern day. By bringing these reflections forward and drawing out some of the challenging questions they present for modern-day researchers, policymakers, and clinicians, I hope to further conversations involving the integration of a critical theoretical perspective as well as considerations of historical contributions to both present and future research and care design.

For the purposes of this paper, the term 'palliative care' is guided by the World Health Organization (2022) and is defined as a person-centred approach to relieve serious physical, psychological, social, or spiritual disease-related suffering including, but not limited to, end-of-life. Palliative care can be delivered by a specialist palliative care team or in a generalist care setting by dedicated professionals, or as part of a palliative approach (Sawatzky et al., 2016). Mental illness in the context of this discussion is more challenging to define given the use of varied terminology according to context, intended audience, and the positionality of scholars and contributors whose work is included here. The term 'mental illness' represents a particular biomedical stance that is reflected in health literature and policy and has thus far dominated scholarly literature on this topic. However, it carries assumptions about pathology and diagnostic criteria developed more recently that do not reflect the way terms such as 'insanity' or 'lunacy' have been applied in the past. In addition, just as medically oriented scholars seek to understand mental illness, a praxis of activism and scholarship has developed that challenges the dominance of this biomedical framework and expresses alternatives grounded in lived experience. Part of this praxis involves use of terms including ‘Mad’ and ‘crazy’, both as acts of reclaiming discriminatory labels and to uncouple experiences of madness from the biomedical language and gatekeeping processes of diagnosis and access to diagnosing professionals. There is no single best term to represent all these perspectives, contexts, and experiences. For this reason, varying terminology related to mental illness, insanity, and/or madness will be used for the purposes of this paper according to context.

At the intersection of dying while mad there exist numerous disciplinary perspectives, both scholarly and clinical. Much like the present-day silo-ing of mental health care and palliative care (Donald & Stajduhar, 2019; Edwards et al., 2021; Gerber et al., 2019; González-Rodríguez et al., 2020; Peryer et al., 2020), these scholarly divisions have resulted in gaps in knowledge at these intersections. Historians have contributed extensive scholarship on the development of treatments; the birth and growth of the psychiatric, medical, and nursing professions; the rise and fall of institutionalization; and the role these institutions have played in the societies in which they were built (Finnane, 1985; Jackson, 2016; Moran, 2000; Porter, 2004; K. Smith, 2020; D. Wright et al., 2008). Medical and nursing scholars tell stories about their own professional and clinical development, or describe influential figures such as Dr. Cecily Saunders, Dr. Lillian Wald, Dr. Balfour Mount, Dr. David Skelton, Dr. Joseph Workman, or Dr. Charles K. Clark (Boschma, 2003, 2013; Brooksbank, 2009; Buck, 2009; Duffin, 2014; Kendler et al., 2022). By and large, the work of these scholars remains focused on their own disciplines and fields of professional interest. Meanwhile, mad patients have lived and died of life-limiting illness in the past and in the present, their voices absent in the literature, and their care experiences still largely a mystery to all but those care providers and family members or friends who have been in close contact with them (Donald & Stajduhar, 2019; Peryer et al., 2020;

Wilson et al., 2020). Even for these, the few studies that do report on the experiences of patients with mental illness and the staff who care for them during the palliative phase describe uncertainty, lack of connection, and ambiguity (Ehrlich & Dannapfel, 2017; Giandinoto & Edward, 2015; Happell et al., 2016; Jerwood et al., 2018, 2021; Knippenberg et al., 2020).

In this paper, I draw on historical considerations and a critical theoretical lens to explore what seem to be taken-for-granted assumptions that inform current directions in palliative care, in mental health care, and the subsequent challenges in imagining appropriate care for people with mental illness who have life-limiting conditions. Three lines of reflective inquiry have been chosen as the most pressing and emerged from a deep and thoughtful reading of the literature: Defining mental illness and the palliative patient; moral treatment, recovery, and a good death; and patient voices, mad people's perspectives, and history from the bottom up.

Theoretical Orientation

Atheoretical research and the production of new knowledge without delving deeply into explanatory factors risks perpetuating existing systems (Billieux et al., 2015; van der Linden, 2015; Windschitl, 2004). When existing systems are inequitable, as they are in the case of palliative care for people with mental illness (Donald & Stajduhar, 2019; Edmunds, 2018), atheoretical production of new knowledge can perpetuate this inequity in systems and health outcomes. A critical theoretical perspective can be applied to develop deeper understandings of explanatory factors and existing inequities through a process of identifying and explaining patterns, generalizing, explaining objective phenomena, and understanding individual variance and subjective experience (Mill et al., 2001). A critical theoretical approach is leveraged to challenge unquestioned assumptions and the power structures they reproduce, and to create opportunities for imagining meaningful alternatives (Box, 2005).

Historiographer Alan Megill (2007) argues that the true value of the study of history is to explore the differences between the past and the present. Here I compare the past to the present to identify inherited assumptions as those ideas and structures that have not changed over the development of the treatment of mental illness despite ongoing narratives of transformation and reform (Kirby, 2006). Inspiration for this discussion began with research into mental health care in Canada with an historical focus on care for insane patients in the province of Ontario during the second half of the 19th century, from 1850 at the opening of the first permanent asylum in Ontario, to 1914 at the start of World War I, and was eventually supplemented by information drawn from other provinces and other former British colonies both during and post-institutionalization. A similar process of comparison is used between past and present in palliative care, and between the fields and processes of palliative care and mental health care, to identify how these persistent assumptions and similarities overlap and support each other in the present day. This time period, coinciding with the rise of the major public asylums across England, Europe, and their colonies[8] (Porter, 2004; Scull, 2015), was chosen because it represented a major turning point in social, political, medical, and professional approaches to care for people considered to be insane. The development of asylums in Ontario influenced care for the insane in other settings (e.g., hospital, community healthcare, residential support, etc.) and prompted debate about social services in English-speaking Canada in the context of a colonial government facing expansion and struggling for growing independence[9].

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[8] The asylum movement took hold much earlier in England and Europe, developing later in colonial settings.

[9] Although the Asylum Act passed in Canada in 1839, a split of territory into the provinces of Upper and Lower Canada shortly afterwards left the government in turmoil as to how to enact the legislation. In addition, these provinces did not yet have authority over major financial decisions and permission to borrow money to build the first asylum in Upper Canada was delayed by the need for trans-Atlantic travel to England to secure permission from the British Crown (Jackson, 2016). The Toronto Asylum would not open in a permanent location until 1850.

As I engaged with this historical material, I began to envision numerous possible lines of reasoning through which to interpret it. Toward this end, I have selected reflections, each representing an examination of a particular line of reasoning in the body of material through a critical theoretical lens. Together they demonstrate some of the intriguing possibilities that arise within this body of focused study and create a basis upon which suggestions for future fruitful inquiry and analysis can be launched. By exploring our understanding of what has happened historically and how these ideas and practices continue to influence approaches to care, I hope to introduce new avenues of inquiry for research that engage with some of the root causes of inequitable treatment of people with mental illness in need of palliative care and encourage researchers and practitioners to consider historical influences when engaging in research and program development.

Reflection 1: Defining Mental Illness and the Palliative Patient

It is difficult to draw assumptions about the patients cared for by hospices and asylums prior to modern medical and administrative designations that drive program placement by diagnostic category and reimbursement[10]. Despite this, the history of the psychiatric profession and the development of mental health treatment has catalogued in detail seemingly infinite (and frequently competing) variations in the quest to define and diagnose mental illness. These variations continue with ongoing revisions to the Diagnostic and Statistical Manual of Mental Disorders (DSM), currently in its 5th edition and most recently revised in March of 2022. Each new update to the DSM shifts the inclusion criteria for diagnosable mental illnesses, sometimes

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[10] See, for example, Roffey (2012)'s assertion that the term 'hospice' was used for a wide variety of caring institutions in the medieval era and the lack of distinction in caring for the dying as evidenced by the remains of patients with terminal illnesses discovered on the grounds of leprosaria, or Wright (2013)'s citation of Rothman (1994) concluding that patients with tuberculosis were cared for en masse in asylums prior to the establishment of separate sanitoriums in late nineteenth-century North America suggesting that admission was not always associated with a classification of insanity.

eliminating existing diagnoses or creating new ones to accommodate ongoing shifts in social norms or professional consensus (*APA - Diagnostic and Statistical Manual of Mental Disorders Fifth Edition Text Revision DSM-5-TR*, n.d.; Drescher, 2015; Saldana et al., 2021).

Identifying and Classifying Mental Illness

Asylum charts and registers, and other historical documents such as civil or court records, reveal fluctuating identifications and classifications of insanity through unclear terminology or conflicting diagnoses, even for the same patient (Sturdy & Parry-Jones, 1999). This problem of ‘misdiagnosis’ persists in the modern day, spanning diagnostic categories and causing suffering, stigma, and potentially delayed or inappropriate treatment responses (Gama Marques & Bento, 2020; Stahnke, 2021). Debate continues over whether psychiatric diagnoses as they are currently presented in the DSM and operationalized in varying contexts by various parties serve a helpful purpose for patients who are ultimately living with what Szmukler (2014) has termed ‘functional’ conditions rather than an illness ‘status’ that better serves administrative classification (Pickersgill, 2014).

Nowhere is the issue of diagnosis more muddled than in the health care system’s interface with racialized and marginalized populations. Saldana (2021) reports on inequity in the diagnosis of Black Americans, tracing the history of psychiatric disorders used to characterize slaves who refused to work or attempted to escape slavery, including intellectual inferiority and an aversion to work being accepted psychiatric consensus as demonstrated through publication up until the 1970s. In more recent years Black and Latin American patients have been diagnosed with schizophrenia at rates three to four times higher than their White counterparts, while comparative underdiagnosis of Black patients with affective disorders continues (Saldana et al., 2021; Schwartz & Blankenship, 2014). Similar challenges face patients from visible ethnic minority groups in Canada and internationally who, when encountering the psychiatric system, are diagnosed and treated according to standards set for White patients despite the role culture, racism, and oppression play in determining mental health[11] (Corneau & Stergiopoulos, 2012; Jarvis, 2007).

Although a high percentage of diagnostic symptoms are behavioural or subjective and can only be gleaned by self-report, the quest to find a biological basis for mental illness is as old as medicine and continues in the present day with massive amounts of attention, effort, and funding. Despite over two centuries of dedicated investigation (Porter, 2004), objective medical evidence of a biological basis for the human expressions classified as mental illness remains elusive (Horwitz & Grob, 2016; Woolfson, 2019). As Toronto Asylum Medical Superintendent Daniel Clark wrote in his 1884 asylum report, “We take refuge from our ignorance by applying medical terms”. While early psychiatrists[12] debated the nature of the mind and soul in relation to madness[13], and sometimes rejected the push in psychiatry towards the increasingly scientific and biologically focused model of disease being adopted by medicine (Horwitz & Grob, 2016), modern psychiatry and associated professions as well as governments, particularly in Canada and the United States (Jarvis, 2007), now couch related discussions almost entirely in a biological basis. Behavioural ‘symptoms’ are ‘manifestations of’ illnesses such as schizophrenia, implying by phrasing that they emerge from a deeper, innate, and individual biological pathology. Public

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[11] To apply an example from the late 18th century, it was common for Chinese men in British Columbia who had worked on the railroad to be committed to insane asylums when there was no longer any work available (Scott, 2011). Chinese patients were segregated, diagnosed and treated without interpreters, and subject to mass deportation (Scott, 2011).

[12] At various time periods referenced in this study, early psychiatrists went by other professional descriptors such as Alienist or Asylum Superintendent. For clarity I will use the term psychiatrist unless referring to an individual’s title.

[13] James Crichton-Browne (1880), a 19th century Scottish psychiatrist and the Lord Chancellor’s Visitor in Lunacy, described early psychiatry as “…a department of medical science that is in intimate relation with philosophy…” (p. 262).

awareness and pharmaceutical marketing campaigns equate mental illness to biological illnesses with empirical biological criteria (e.g., diabetes) or promote the framing of mental illness (especially depression) as a chemical imbalance in the brain despite a lack of clinical evidence for this explanation and well-established critique for its use in the promotion of pharmaceuticals (Acker & Warner, 2020; Ang et al., 2022; France et al., 2007). Despite well-established evidence of the impact of antenatal (Kim et al., 2015), neonatal (Ramphal et al., 2020), childhood (Johnson et al., 2019), and present-day psycho-social-economic (Hudson, 2005) factors on mental health and well-being, these biological narratives persist.

The idea of precipitating life factors for mental illness is not a new one, with some early registers in Australia listing cause of insanity as "disappointment" when referring to tragic or traumatic life events (Finnane, 1985, p. 141). Recent biomedical research reflects a similar approach with the theory that sudden trauma, viral infection, or adverse childhood events alter bodily processes including DNA, metabolic function, and inflammatory response and may contribute to the development of mental illness (Daniels et al., 2020; Hagberg et al., 2012; Ridout et al., 2018). Comparatively few resources are dedicated to understanding these types of psychosocial or holistic adversities as root causes (and consequently as pathways for potential treatment and alleviation of suffering) independent of a biomedical framework (Jarvis, 2007).

Contesting the Definition, Source, and Care Systems for Mental Illness

The source of mental illness, philosophically and biologically, remains contested. Anti-psychiatry, a diverse movement for whom this consolidating and contentious label was coined in 1971 (Cooper, 1971), arose alongside a renewed wave of criticism of the mental health system by scholars and patients/ex-patients/consumers/psychiatric survivors themselves. International shifts in thinking about the rights of disabled people supported advocacy and activism by Mad patients who explored new ways to care for themselves and for each other in the wake of de-institutionalization and the corresponding scarcity of resources in a fractured and siloed community care model (Hartford et al., 2003; Starkman, 2013). Regardless of the professional project to establish well-defined criteria with empirical biological evidence for diagnosis and standardization (Hyman, 2018), Mad people are exploring their own varied lived experiences and histories to understand their own lives and to navigate a society, economy, and healthcare system that is too often hostile and exclusionary.

Despite attempts to define and standardize mental illness historically and in the present day, this process remains fraught by politics and contingent on the needs of politicians, clinicians, and families. While published studies on the care of dying patients in the asylum in the latter half of the 19th century are extremely limited, attention paid by historians to the process of committal allows for comparison between present-day diagnosis and historic declarations of lunacy. Although posthumous diagnosis of any one individual based on historical records is not supported epistemologically, for the sake of analysis studying the conditions related to asylum admission can serve as an informative substitute for the functional processes of defining insanity for the purpose of this reflection.

Political and policy interests were historical contributors to the definition of an insane patient in Ontario, in relation both to individual political interests and to funding concerns associated with the rapid growth of the asylum system and an increasing public demand for services. A patronage system of provincially-appointed positions ensured that asylum oversight was conducted by men who sometimes found it expedient to value their patrons' political agendas over therapeutic concerns (Bartlett, 2000; Moran, 2000). Politicians at the local level also exerted pressure on the asylum to the extent that they were able when it came to managing the budget (Moran, 2000). One example of this is the local push to transfer insane inmates held due to risk to themselves and others from gaols (which were funded at the county level) to asylums (which were funded by the province) (Moran, 2000).

Political interests, budgets, and jurisdictional issues continue as concerns in the present day. Starting in approximately 1965, in response to rising public pressure and ballooning institutional costs, a de-institutionalization approach was adopted across Ontario and patients were discharged from psychiatric hospitals to the community with poorly-organized or non-existent structures of support (Frederick et al., 2017; Hartford et al., 2003). Despite the existence of social service benefits such as welfare and very limited supportive housing, these were not enough to provide for patients in the community and were subject to clawbacks during subsequent periods of recession and neoliberal conservative economics in the late 20th century (Dyck, 2011). Patients with mental illness in Ontario encountered huge gaps in mental health care related to income, location, functional level, and severely limited provincial coverage for any treatment other than an acute care admission. These gaps can be traced back in some capacity (though not exclusively) to scattered funding initiatives and unsuccessful attempts to address this issue through government policy (Canadian Civil Liberties Association, 2017; Canadian Mental Health Association, 2018). Though supposedly the ideal site of care, mental health services currently in the community frequently lack the capacity or mandate to provide healthcare including prevention, disease screening, and early or late management of life-limiting illness. This places an immense burden on patients with mental illness and life-limiting illness who must navigate two healthcare systems to access what will likely be, at best, an uncoordinated response to holistic health needs (Donald & Stajduhar, 2019; Sinding et al., 2013). Through health system design by policy and funding allocation, government – federal, provincial, and local – continues to play a role in the identification and diagnosis of a patient with a life-limiting illness and mental health needs who may or may not receive a mental health diagnosis.

Defining and Identifying the Palliative Patient

The definition, or identification, of a palliative patient is also an inexact and inconsistent process. Recent publications reflect researchers' ongoing efforts to develop and test standardized screening tools (Kabelka & Dušek, 2022; Meffert et al., 2016; Mittmann et al., 2020; Thoonsen et al., 2012) and to tailor identification to specific disease groups and settings (Dillen et al., 2019; Dogbey et al., 2022; Esteban-Burgos et al., 2021; Schoenherr et al., 2020). Research related to the identification of a palliative patient is frequently associated with system outcomes including use of other health care services such as emergency room visits and acute care admissions (Goldwasser et al., 2018; Leniz et al., 2021) as well as service costs across palliative care delivery models (Salamanca-Balen et al., 2018; Yadav et al., 2020). Sometimes this research is presented as an argument for advancing the professional project of specialist palliative care (Zhang & Mattsson, 2022). Such research also reflects concerns about resource strain on nations with aging populations and the looming late-stage capitalist narrative of desperate resource scarcity in society at large and in public services specifically (Mehta et al., 2019). While it may not be immediately visible at the bedside, government and public interest play a role in the identification of the palliative patient.

The needs and interests of clinicians have also played, and continue to play, a role in identification and diagnosis both in palliative care and in the case of mental illness. The asylum was the site of a significant professional project for the development of both psychiatry and nursing. As both administrator and medical manager of an asylum, an early psychiatrist exercised jurisdiction over nearly all aspects of life for both patients and staff, including the allocation of unclaimed cadavers for research autopsy, teaching, or for exchange with nearby medical schools for associated positions and privileges (Connell, 1907; Reaume, 2009; D. Wright et al., 2013). Early psychiatrists struggled for, and largely maintained, professional autonomy in the context of shifting public opinion about issues such as the use of alcohol for treatment (Krasnick, 1982) and, most notably, for control over admissions and discharges in the crowded and understaffed institutions they managed (Finnane, 1985). In the inaugural issue of *The Bulletin for Ontario Hospitals for the Insane*, the first periodical for psychiatry in Canada, then-administrator of the Toronto Asylum C.K. Clarke (1907) writes that insane persons were to be 'rescued' as soon as possible from well-meaning but misguided family members and their community physicians who would do irreparable harm by delaying professional treatment. Through specialist publication, early psychiatrists and the occasional psychiatric nurse had a disseminated voice with which to promote ideas related to moral treatment, eugenics, professional education, and the importance of erecting a treatment and research centre in Ontario to rival international institutions (Clarke et al., 1907; Davis, 1914).

Facing cure rates far below those initially promised, early psychiatrists expressed frustration regarding admission of those patients who they felt were not legitimately insane or who could not benefit from asylum treatment (Montigny, 1995; Porter, 2004; Scull, 2015). This included many admissions which came through the gaol system, as psychiatrists protested that these patients had been rendered incurable due to a lack of early intervention or were not likely to have been insane in the first place and were merely being sent to the asylum to reduce overcrowding in the gaols (Moran, 2000). As there were only two avenues to asylum admission — the civil and the criminal — and as the civil process was fraught with barriers and private expenses compared to the criminal process, by 1860 almost one-third of asylum patients were admitted from gaols (Bartlett, 2000; Montigny, 1995).

The asylum project played an important role in the development of professional nursing. Early asylums were staffed predominantly with attendants who were male, came from lower social classes, and did not receive specialist education in their duties (Boschma, 2003). By the late 19th-century with the rise of what K. Smith (2020) calls 'Nightingale-style nursing', high-quality care for patients was becoming synonymous with middle-class women delivering or overseeing care in settings that modelled the ideal Victorian home. Side-by-side, nursing and psychiatry gained respect by mutually reinforcing each other's professional development and esteem. A psychiatrist, responsible for a high number of patients he could not oversee directly, relied on nurses to implement his orders and use their best judgement at a remove, just as nurses, as respectable and virtuous middle class women who had been professionally educated, raised the professional profile of the institution itself (Boschma, 2003; K. Smith, 2020). Davis (1914), Head Nurse in the Toronto Hospital for the Insane, described the skills and values necessary for psychiatric nursing in a publication in the *Bulletin of the Ontario Hospitals for the Insane* in the early 20th century. While pointing out her concerns about undertreatment of the lunatic in the general population and lack of generalist physicians' and nurses' awareness of insanity, Davis (1914) paints a gentle picture of persistence, self-sacrifice, non-judgement, and deep investment in patients' experiences of insanity in the asylum while emphasizing what would presently be called relational practice, continuity of care, and patient-centred care. Arguments for nursing education at the time advocated for a 2 to 3 year program in basic medical competency even for psychiatric nurses, suggesting the medical role nurses likely played in caring for patients with life-limiting illness in the asylum (K. Smith, 2020).

While information about medical care for patients with life-limiting conditions in asylums is extremely limited, asylum clinicians were arbiters of all care provided by virtue of their presence and of their clinical decision-making for a suffering patient. As Wright (2008) and Montigny (1995) both point out, the asylum was the only public option for full-time supervision and medical care available in Ontario in the latter half of the 19th century, meaning that some patients without caregivers may have ended up in asylums regardless of their mental state (Buck, 2007). While some studies focusing on adjacent topics provide limited insight into medical symptoms (Moran, 2000), one study by Reaume (2009) reports what is most likely a case of diagnostic overshadowing – still a problem in the modern day (S. Jones et al., 2008; Morgan, 2016). Despite this particular case where the patient is described as having died in agony due to a strangulated hernia that was not diagnosed until after death, Reaume (2009) did find case notes describing staff's efforts to make patients' dying weeks and days more comfortable.

Silo-ing of treatment modalities within the mental health system (notably still quite gendered between professions such as psychiatry, social work, and counseling) create challenges for clinicians defining and identifying patients with mental illness — particularly those with life-limiting conditions — in modern systems. This can be a site of particular challenge for clinicians who are identifying varied needs expressed by patients encountering physical, psychological, spiritual, and social or resource-based challenges in a system designed to designate services based on diagnoses as administrative categories rather than articulated as functional needs (Pickersgill, 2014). This site of ambiguity where clinical judgement and experience meets standardized diagnostic and service criteria allows for clinician influence on whether a patient is diagnosed with a mental illness or identified as needing a palliative approach. While some clinicians will act to bypass system barriers or independently collaborate between services, others may avoid caring for patients with mental illness and life-limiting illness due to stigma, discomfort, or lack of knowledge (Donald & Stajduhar, 2019; Etgen, 2020; Jerwood et al., 2018).

The Importance of Family and Social Supports

Social historians have argued that families played an important role in both admission and discharge from early Ontario asylums (Montigny, 1995; Moran, 2000; D. Wright et al., 2008). Studies of correspondence from asylum logs have many examples of families writing to push for the admission or release of family members displaying distressing or intolerable behaviours (Montigny, 1995; Moran, 2000; Reaume, 2009), despite little evidence that the public shared contemporary medical opinions about etiologies and treatments for madness (D. Wright, 1997). While some patients were most certainly abandoned, many families seem to have used the asylum as a form of respite care, requesting that a family member be discharged even if their symptoms had not improved (D. W. Jones, 2002; Montigny, 1995). A study of the Hamilton Asylum registers from 1876 to 1902 found that approximately 50% of patients admitted during the study period were discharged (C. A. Smith et al., 2007). The presence of a social support system outside the institution played a role in this; being married nearly doubled the odds of being discharged in C. A. Smith et al.'s (2007) study, while Montigny (1995)'s study of Kingston's Rockwood Asylum found an increased percentage of widowed and childless older adult patients when compared to the general population. It also was not unusual for the family of an asylum patient, even one who had lived in the asylum for a long time, to provide care at home during the final days and weeks of life. Providing care for ill and dying patients could be taxing — Warsh (1989), in her study of the private Homewood Retreat in Guelph describes the maladies and substance use challenges of female patients admitted after long periods of caring for sick relatives. In each case, lack of sleep is listed as one of the primary causes of these maladies (Warsh, 1989).

It is well-established that caregiving for both patients with a severe mental illness and patients dying of a life-limiting illness can be just as taxing in the present day, despite caregivers' dedication and satisfaction in caring for their friends and relatives (M. J. Brown & Cohen, 2020; Carretero et al., 2008; Roth et al., 2015). However, a disintegration of extended family and social networks in the present day, as well as highly limited opportunities for system support and respite, have resulted in a situation where patients with a severe and/or persistent mental illness are much less likely than their counterparts without these conditions to have a close friend or family member to act as a caregiver when they reach an advanced stage of life-limiting illness (Donald & Stajduhar, 2019; Knippenberg et al., 2020). Jerwood (2021), in one of the few studies to speak directly with patients and their family members, reports that carers expressed feeling overlooked or ignored by staff despite their long-time familiarity with the person they have cared for.

The identification of patients with a mental illness as well as the identification of patients in need of palliative care has been complicated historically and in the present day by competing professional, political, social, and individual factors. These historical inheritances, combined with siloed health, mental health, and social care systems, result in highly individualized experiences and access to care that are influenced by social standing, marginalization, and the presence or absence of informal caregivers and advocates. This level of complexity in the identification of people with mental illness and a life-limiting condition highlights the need for a cautious, critical approach to existing research. Likewise, researchers designing and conducting future studies should be mindful of these factors and how they may influence access to partners, participants, and data at each stage of the research and decision-making process.

Reflection 2: Moral Treatment, Recovery, and a Good Death

In the present-day, mental health treatment and palliative care are informed by two powerful ideologies; recovery and the ideal of a good death. Like identification and designation, these philosophies of care also have solid foundations in the past that can obscure their impact in thinking about research, policy, and care in the present day.

Moral Treatment and Recovery

The curability of mental illness has been a long-standing concern to all affected. While treatments such as bleeding, exorcism, pilgrimage, balancing of the humours, and countless others were all practiced in Europe for centuries, a new era in therapy arose with the introduction of moral treatment and associated claims of high cure rates (Porter, 2004; Scull, 2015). Moral treatment was a reform movement developed towards the end of the 18th century and was informed by Enlightenment philosophy and the high value placed on rationality and reason. However, Scull (2015) cautions the reader not to consider moral treatment as a manifestation of kindness and cites Scottish psychiatrist W.A.F. Browne's words from Royal Crichton Asylum report in 1849 describing moral treatment as a "…'great moral machine' whose goal was to ensure that 'the impress of authority is never withdrawn, but is stamped on every transaction'" (p. 207-208). Porter (2004), while condemning Foucault's characterization of moral treatment as a replacement of physical with mental restraints, allows that the resulting "…concern with self-mastery…open[ed] up a new psychiatric space" (p. 309). Structured along the lines of the middle-class family, with the staff as parents disciplining through approval, disapproval, and “reluctant coercion” when necessary, asylum administrators who had adopted moral treatment sought to instill in their patients a desire to be good (Porter, 2004, p. 309).

By the mid-19th century and the establishment of asylums in Ontario, moral treatment was considered best practice amongst early psychiatrists, writers, and politicians who paid attention to the field (Moran, 2000). Moran (2000) summarizes moral treatment as “…closely supervised work, religion, and recreation” (p. 5). A highly structured environment was an important component of moral treatment, and segregation of patients according to severity of symptoms was believed to maximize chances for improvement (Krasnick, 1982; Moran, 2000). It also provided a powerful incentive for patients to behave and conduct themselves appropriately, as transfer in or out of a less pleasant unit was applied as a method of discipline (Krasnick, 1982; Moran, 2000). Leisure activities created settings in which patients could practice improving themselves and their social graces (Moran, 2000; Porter, 2004). Labour was strictly gendered and neither patients nor their families were compensated, with all proceeds and benefits from patient labour going to maintain the asylum itself (Moran, 2000).

Despite promises of high cure rates, no more than 30% to 50% of admissions were ever claimed to be cured, even in the most optimistic of reports (T. E. Brown, 1981; Reaume, 2009; Scull, 2015; C. Smith, 2011). By the late 19th century, low cure rates were seen as evidence of the failure of the asylum project as a whole (T. E. Brown, 1981; C. Smith, 2011).

Recovery, as it is currently manifested in healthcare and policy, shares many similarities with moral treatment. Emerging separately from both psychiatric survivor and professional realms, psychiatric survivor approaches to recovery — which challenge medical and professional dominion over the lives of Mad people themselves — lost out in the policy and funding arena (Harper & Speed, 2012; Morrow, 2013; Wallcraft & Hopper, 2015). As a result, the psychiatric survivor vision of recovery as "…not only about overcoming or 'managing' illness, symptoms, or presumed deficiencies; rather, it is about reclaiming the possibility of a real life, the kind of life that people (with choices) want to live" (Wallcraft & Hopper, 2015, p. 91), has not materialized in a social context where supports for full community integration are lacking or non-existent (Beresford, 2015; Frederick et al., 2017; Harper & Speed, 2012).

Instead, the dominant government policy and healthcare system's emphasis on recovery as independence, work, self-improvement, and social conformity align with the values of moral treatment that ruled the asylum (Morrow, 2013). While promoting similar expectations of productive labour and socially acceptable behaviour alongside threats of coercion in the form of involuntary treatment stays and community treatment orders, the individual patient with a mental illness lives in a society with few options for housing, economic security, and community integration (Corring et al., 2017; Harper & Speed, 2012). For those with mental distress, most of whom also live with social inequities that act as barriers to recovery under any model, it doesn't matter how 'good' a patient wants to be – the likelihood of 'recovery' is low (Harper & Speed, 2012). Despite this, policymakers, healthcare organizations, and mainstream mental health advocacy groups alike espouse a doctrine of recovery in the form of limited, medically-oriented treatment programs aimed at personal empowerment and full citizenship in society, but have disregarded the inequitable barriers to citizenship and empowerment as well as the social causes and effects of mental distress (Drake & Whitley, 2014; Harper & Speed, 2012; Mental Health Commission of Canada, 2012). For many patients, recovery-oriented care models have failed to deliver meaningful opportunities for recovery.

A Good Death

The idea of a ‘good death’ is older, but no less enshrined in the delivery of palliative care. Recorded in the detailed liturgical guides for clergy ministering to the dying, the principles of a good death became available for lay study in Europe in the early 15th century with the publication of the *Ars Moriendi*. The *Ars Moriendi*, or ‘Art of Dying Well’, was translated into multiple languages and distributed by travelling mendicant orders of the Catholic Church (Duclow, 1999; Thornton & Phillips, 2009). Juxtaposing two deathbed scenarios, protagonist, family, and community members are alternately shown displaying appropriate or inappropriate deathbed behaviour (Duclow, 1999; Thornton & Phillips, 2009). By the 16th century, the *Ars Moriendi* had been adapted into the Everyman play, a morality play where Death comes to collect Everyman, who is astonished and must go through a process to come to grips with his own mortality (Paulson, 2007; Thornton & Phillips, 2009). This play would have been performed first in churches and cathedrals, then later in the inner courtyards of inns or on festival days in the tradition of morality plays of the time, and ideas about what it meant to recognize one’s own mortality and prepare for it individually and as a community would have received widespread cultural saturation in England and parts of Europe (Paulson, 2007).

Ideas about the peaceful deathbed scene where the dying patient is surrounded by friends and family and had undergone psycho-spiritual preparation for death were firmly in place by the opening of the first dedicated, charitable hospices in the late 19th century (Buck, 2007; Cook, 1989). Like the expanding asylums and other social welfare institutions and programs of the time, hospices (most of which were religious institutions) were responding to a lack of caregiving resources in the home (Buck, 2007) and thus were drawing on the image of nuns, nurses, and attendants standing in for caring family members and friends. Religious principles in the form of compassion, comfort, and charity were the foundation of care and would continue to guide many advocates of hospice care in the modern palliative care movement even as advances in medical science improved symptom management (Buck, 2007). A peaceful deathbed scene, free from psycho-spiritual anguish, attended by compassionate caregivers (informal or formal), has remained a powerful measure of success in palliative care (Cottrell & Duggleby, 2016).

While these are not the only elements of a good death, they are key to the core concept and bear considering in light of the experiences of people, providers, and systems who are working within recovery-oriented paradigms. Recovery, focused on productive contribution to society, independence, and ‘getting better’, is antithetical to the palliative principles of comfort care, planning for expected decline, and resting peacefully amongst family and friends. Many literature reviews on the topic of palliative care for people with mental illness have pointed out that mental health and palliative care are siloed (Donald & Stajduhar, 2019; Edwards et al., 2021; González-Rodríguez et al., 2020; Woods et al., 2008), but it is more than the organization of care delivery that has created such a wide gulf. There are philosophical and ideological incommensurabilities between these two foundational ideals. These inherited assumptions about the aims and measures of success in mental health care and palliative care are likely contributors to the disrupted care experiences of people with mental illness and life-limiting conditions. The positionalities of professionals, decision-makers, and funders in care settings, research, and policy may have led to narrowed interpretations of research and clinical findings depending on which professional framework is being applied. Attempts to advance practice and inquiry in this field without addressing and unpacking these tensions will limit progress and reproduce inequities at the expense of patients.

Reflection 3: Patient Voices, Mad Peoples’ Perspectives, and History from the Bottom Up

In recent years, there has been widespread encouragement from governments and funding bodies to involve patients, families, and communities in health research (CIHR, 2011; MacFarlane & LeMaster, 2022; Ocloo & Matthews, 2016). According to the Canadian Institute for Health Research (2013), patients in patient-oriented research are "…active, informed, and motivated participants in their own care and have opportunities to define research priorities" (p. 2). The ultimate goal of patient engagement in research is to improve health care research and, subsequently, care delivery (Canadian Institutes of Health Research, 2013). However, patient-oriented research has been limited by existing social inequity that favours involvement by members of socially normative groups (Lightbody, 2017; Ocloo & Matthews, 2016), by a neoliberal theoretical framework that emphasizes individuals rather than communities (Pauly et al., 2019), and by language that defines these participants as those already in contact with the health system rather than those who (for reasons of exclusion or choice) are not already patients in the traditional sense (MacFarlane & LeMaster, 2022; Pauly et al., 2019). As Pauly et al. (2019) point out, patient-oriented research initiatives use the term 'stakeholder' to describe distinct groups including patients, health researchers, and health care providers despite the fact that each person arrives to a collaborative endeavour bringing multiple lived perspectives. This framing also ignores the likelihood that everyone involved in such a collaboration already has or will, voluntarily or otherwise, spend time in the role of the patient. For these reasons and others, patient-oriented research often falls short in incorporating meaningful engagement and knowledge translation, particularly for groups who have been marginalized (Beresford, 2010; Boilevin et al., 2019; MacFarlane & LeMaster, 2022).

Health researchers in both palliative care and mental health are increasingly adopting engagement processes to involve patients and families in research studies, though terminology differs with ‘peer’ being used in lieu of ‘patient’ in many mental health publications (Baker, 2005; Barbic et al., 2019; Beresford, 2010; Blackwell et al., 2017; DeCamp et al., 2022; Dell et al., 2022; Donald et al., 2022; Fortuna et al., 2019; Rahimzadeh et al., 2015). Despite this, true engagement remains elusive (Beresford, 2010; MacFarlane & LeMaster, 2022). Meaningful engagement in research requires significant investment in time and infrastructure (Bonevski et al., 2013; Donald et al., 2022; Woolf et al., 2016). Engaging in reciprocal, respectful research processes that are informed by patient and peer experiences and share power equally with patient and peer participants is a challenging process with barriers to overcome and potential harms to mitigate or avoid. Some of these barriers are related to the structures of health research itself; for example, inequitable control of funds, inflexible grant timelines limiting participation, or the pressure to publish driving researcher priorities when given limited time and funding for reciprocal knowledge translation activities (Boaz et al., 2021; Boilevin et al., 2019; Williams et al., 2020). Other barriers such as lack of attention to differences in social and economic capital, misconceptions about competence for decision-making, stigma against people with mental illness, inequity and exclusion from health services where participants and peers are typically recruited, as well as perceived vulnerability and the need for ‘gatekeeping’ have been particular challenges for patient and peer involvement in palliative care and mental health research in both participant and partner roles (Beeker et al., 2021; Bloomer & O’Brien, 2013; Carlsson et al., 2017; DeCamp et al., 2022; Donald & Stajduhar, 2019; Keogh & Daly, 2009; McNamara et al., 2018; Reimer-Kirkham et al., 2016). Subsequently, research that includes people with pre-existing mental illness in the palliative phase of care as participants or partners is limited at this time (Ehrlich & Dannapfel, 2017; Elie et al., 2018; Foti, 2003; Jerwood et al., 2021; Knippenberg et al., 2020).

Recent turns in the study of the history of mental health care have also generated inquiries into what has been conceptualized as history from the bottom up, or the search for the ‘patient voice’ (Swartz, 2018; D. Wright & Saucier, 2012). However, facing the reality of sifting through institutional records for the lived experience of people who seldom, if ever, created records which were subsequently archived presents an epistemological challenge (Swartz, 2018). How rigorously can any scholar piece together a lived experience of insanity and confinement from the medical casebooks, admissions records, government reports, and selected correspondence that are most frequently available to institutional historians (Craig, 1990)? If a rigorous inquiry in the discipline of history is, as historiographer Megill (2007) describes, a purposefully-selected sum of available evidence combined with the researcher’s imagination to formulate and draw from a series of coherent explanations, then Swartz (2018) identifies an additional level of challenge when writing the ‘voice’ of the asylum inmate:

> One of the paradoxes of this branch of historical work is that much of what is written about the insane is saturated in rationality, and so we become complicit in erasing the very phenomenon with which we are preoccupied. But in archival reading, particularly its dreamwork, there is a way of conjuring up our subaltern: there are traces everywhere of the underworld of the asylum, its shadowy or forgotten pieces, its madnesses (p. 298).

Existing research into the lived experience of being mad while dying has, thus far[14], reflected the rationality of the biomedical paradigm that pervades patient-oriented research in both palliative and mental health care. With an awareness that patient partnership and collaboration in research remain subject to epistemic hierarchies from within the scholarly institution, who is best

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[14] With some notable exceptions. See, for example, Roman et al.’s (2009) use of a variety of sources including Indigenous art; Indigenous oral history; and film, testimony, and documentary evidence from the Mad self-advocacy movement to investigate the life of asylum patients in British Columbia.

positioned to conduct, consult, and participate in inquiries to understand the lived experience of dying while mad? How can this imagination enter research and praxis for informing and improving care?

During the literature search for this critical reflection, I observed that peer research partners in health studies were frequently drawn from peer workers who were already participating in the work of healthcare or healthcare-adjacent organizations. Studies such as Fortuna et al.’s (2019), where requirements for peers included being in active treatment and being willing to tell one’s own recovery story, may serve to ensure that peer partners are equally embedded in a biomedical approach (Woods et al., 2022). This practice privileges the individual, bio-medical, and ‘psy’ (psychiatry, psychology, and psychotherapy) models that have dominated research on mental illness and maintain an epistemic injustice between these approaches and the lived experience of being Mad (LeBlanc & Kinsella, 2016). Mad scholars and psychiatric survivor researchers who have grown the Mad Studies and survivor research movements in scholarship have challenged this epistemic injustice. Sweeney (2016) described survivor research with similar terms including “survivor-controlled research, survivor-led research, service-user-controlled research, and service-user-led research”, terms that distinguish these endeavours from traditional patient-oriented research approaches where academic researchers control the level of survivor involvement (p. 36). Mad Studies, a constantly-emerging and democratic term used to describe the exploration of the lived experience of people who identify as Mad in holistic, social, economic, philosophical, and historical contexts both inside and outside of the academy, contributes a rich environment for cultivating the imagination Swartz (2018) identified as crucial to understanding both mad history and the experience of madness in the present day (L. Costa, 2014; LeFrançois et al., 2016; Menzies et al., 2013). “The invocation of ‘madness’”, writes

McWade (2016), “is both a way of self-identifying and a mode of rejecting ‘mental illness’ or ‘disorders’ that pathologise emotions, spirituality, and neurodiversity” (para. 2). Given the acknowledged psycho-spiritual complexity of dying, opening research and practice to such epistemic and experiential alternatives offers a meaningful avenue for inquiry into exploring and improving the palliative care experience of dying while mad.

There is hesitance within the field of Mad Studies and survivor research concerning its integration with academia, particularly with disciplines such as psychiatry, social work, and nursing (Ingram, 2016), and for good reason. Professional co-option and distortion of survivor praxes such as recovery and peer support have perpetuated both epistemic and material injustice against people with lived experience in treatment and research (Beresford & Russo, 2016; LeBlanc & Kinsella, 2016; Morrow, 2013; Voronka, 2017). Researchers seeking meaningful partnerships with people with madness, mental distress, and/or mental illness should consider a wider range of perspectives than those typically presented in literature about patient engagement. Researchers can reinforce sanism through epistemic privileging when they choose partners solely through organizations that operate according to biomedical and recovery perspectives (LeBlanc & Kinsella, 2016). When health researchers work alongside Mad scholars, Mad activists, and survivor researchers, they create possibilities for expanding their understanding beyond biomedical and recovery perspectives, and of accessing the dreamwork of un-reason referenced by Swartz (2018) to inform deeper analysis and subsequent recommendations and implementation for improved supports[15].

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[15] For some examples of the contribution of a Mad studies perspective, please see Aho’s (2017) introduction to the special journal edition of American Quarterly *Mad Futures*, summarizing contributions following the roundtable “Affect Theory Meets Mad Studies”, as well as Schrader’s (2013) brief series of reflections on topics such as Mad Pride, voice-hearing, neurodiversity, and normalizing versus non-pathologizing approaches.

Mad scholars and survivor researchers themselves continue to publish in ongoing dialogue about the conditions for meaningful alliance and partnership with health and social science researchers in the context of epistemic dominance and ongoing injustice perpetuated by governments and healthcare systems. While it is beyond the scope of this paper to summarize this dialogue, it is important for health researchers to know that the conversation is not a straightforward one. Nor does the epistemic authority on meaningful engagement with people with Madness, mental distress, or mental illness lie in the healthcare literature (Beresford, 2010). The psychiatric survivor and Mad activist movements hold valuable knowledge which is positioned outside the health and social care systems (Beresford & Russo, 2016; Menzies et al., 2013). Researchers seeking meaningful collaboration must be willing to reflect on what they themselves bring to a partnership in the form of supporting movement-building and working alongside Mad-identified partners towards liberation.

Conclusion

Through a series of critically-oriented reflections, this paper has argued that care for people with persistent mental illness who are dying is a process saturated with historical inheritance and a theoretical complexity that persists in the modern day. These selected reflections into the identification of people with mental illness and those in need of palliative care; moral treatment, recovery, and a good death; and patients' voices, Mad people's perspectives, and history from the bottom up cast light on the complexities faced by researchers, policymakers, and clinicians who seek to improve palliative care for people with mental illness. Inequitable care influenced by social standing; fluctuating identities influenced by multiple stakeholders and agendas in a fractured care system; and biomedical dominance to the exclusion of other policy, research, and treatment modalities means a cautious and critical approach must be taken to research, education, policy, and practice. A cautious and critical approach also benefits researchers, policymakers, and clinicians who are operating between philosophically and ideologically incommensurate approaches inherent in the present-day manifestations of recovery and the quest for a good death. Meaningful engagement with people with lived experience of mental illness, Madness, and mental distress goes beyond the significant time and infrastructure already necessary for building trusting partnerships; researchers, policymakers, and clinicians must understand what it means to be an ally to this highly stigmatized and marginalized group, and to honour the value brought by those who are thinking outside the biomedical perspective. By bringing these reflections forward and drawing out some of the challenging questions, I have sought to highlight the critical need for thought-provoking inquiries, professional introspection, and further conversations involving the integration of a critical theoretical perspective as well as considerations of historical contributions to both present and future research, policy, and care design for present-day researchers, policymakers, and clinicians.

Chapter Seven: Discussion and Conclusion

Introduction

It has been well-established in the literature that people with severe persistent mental illness (SPMI) do not receive the same quality of care and access to palliative care as those without (Donald & Stajduhar, 2019; Edwards et al., 2021; Shalev et al., 2020; Wilson et al., 2020; Woods et al., 2008). The purpose of this interpretive descriptive analysis has been to bring a critical theoretical perspective to understanding and improving care for the medically ill and dying with SPMI. A critical theoretical perspective allows nurse scientists to analyze data through the lens of the individual and beyond to the wider political, social, and historical contexts that inform research, education, policy, and care (Blanchet Garneau et al., 2019). The purpose of theorizing in the interpretive descriptive tradition is to support critical reflection with the aim of enacting nursing's moral, ethical, and disciplinary mandate for improving health and well-being (Browne, 2000; Mill et al., 2001). This has been accomplished through a thorough review of the healthcare literature on the topic of palliative care for people with SPMI followed by critical reflection on the dominant themes and gaps therein, an in-depth consultation study with individuals with chronic illness and social marginalization to gather first-person perspectives on health priorities and experiences in the healthcare system, and a critical analysis of the historical inheritances and assumptions informing care in the present day. Through the application of a critical theoretical perspective, I have drawn attention to the role of social, political, economic, and medical and nursing disciplinary power in the lives of people with SPMI and palliative need in the past and present. This discussion and conclusion emphasize key learnings as well as implications and recommendations resulting from the synthesis of these three manuscripts.

Critical Theoretical Perspectives in Palliative Care for People with SPMI

Although the original study plan was not possible due to the COVID-19 pandemic, an alternate approach allowed for a manuscript-based dissertation exploring alternate facets of this complex issue. These included an updated literature review following Woods et al. (2008), a co-developed consultation on patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) alongside community partners with experiences of homelessness and chronic illness and/or substance use, and a series of critical reflections on the historical inheritances and theoretical complexities that influence modern palliative care for people with SPMI. The strength of this dissertation is in its critical theoretical reflection on multiple data sources. Immersion in healthcare literature for the scoping review presented here as Chapter 4 provided a close examination of the current state of healthcare research on palliative care for people with SPMI. The production of this manuscript also prompted reflection on what was present and what was missing from that literature, most prominently a more fulsome inclusion of the voices of people most affected by palliative need and SPMI as well as a theoretical and historical analysis of this complex area of care. That review set the stage for a more in-depth and critical consideration of this complex area of care, including an understanding of its historical context.

The study on PROMs and PREMs as presented in Chapter 5 was an opportunity to hear directly from people living in circumstances made vulnerable by social inequity and chronic disease, including mental illness and mental distress, as partners. The research question “What is most important to measure about our health care, and how can it best be measured using PROMs and PREMs?” prompted discussion not only concerning measurement, but also about what was important to these partners about their healthcare and about the role health (or poor health) played in their lives. As our collective concern for quality assurance in health care develops, the challenge of how we determine our progress in this regard will require ongoing critical reflection on measurement tools, including what they can capture and what they may miss (Sawatzky et al., in press). The final manuscript, presented here as Chapter 6, is a somewhat experimental and creative chapter, and is the product of deep reading and reflection spanning the historiography of mental health care in Canada from 1850 to the present. Though originally intended as a focused historical analysis study, it became evident in the process of working through the material that there were many threads of inquiry and competing narratives in the past and present that were continuing to impact scholarly and public conversations about mental health and palliative care. The rise of Mad people's history and survivor research is challenging the boundaries of academic space, and disciplines such as sociology and social work are becoming enriched by the emerging presence of Mad-identified scholars in knowledge development about issues surrounding mental illness. Nursing and the wider palliative care field would do well to partner more fully with Mad-identified perspectives from within and without the academy, and to open ourselves up more fully to the patient in our midst. Considered together, these studies can help readers in nursing and palliative care break free from traditional and siloed disciplinary thinking which, while attentive to providing good palliative care for people with SPMI, can also limit our collective imagination of what good care can be.

This multi-faceted approach to exploring palliative care for people with SPMI, including partnering directly with people who are impacted by structural vulnerability, chronic illness, and discrimination and stigma in the healthcare system, has resulted in key learnings, as well as implications and recommendations for researchers, policymakers, clinicians, and educators.

Key Learnings

Who is the Patient? Who is the Participant? Who is the Partner?

As researchers and clinicians, we make assumptions about what makes someone a patient, participant, or partner. A researcher may be designing inclusion and exclusion criteria and make decisions about inclusion based on diagnosis or rely on recruitment through a local mental health service or hospice where there is existing gatekeeping in place for service inclusion. A clinician may be developing a new program or pilot to address an unmet need and target that program to patients whose cost of care will be reimbursed. A grant-funding body or government commission may want to include a person with lived experience to provide a 'patient voice' and reach out to an organization that is already steeped in a biomedical approach to provide a representative. An educator may select disciplinary peer-reviewed materials for course resources rather than drawing on grey literature or other media produced by patients or survivor researchers. In each of these scenarios, those with control over inclusion have failed to account for the fluid nature of a designation of madness, mental illness, and palliative need, as well as the variety of stakeholders who play a role in determining these designations. When a growing, advancing body of literature, policy, education, and clinical care proceeds without thoughtful reflection on who has been included, who has been excluded, and why, we are unintentionally fortifying an inequitable approach and limiting what can be learned about the experience of being a person with persistent mental distress now in need of palliative care.

Breaking Down Internal and External Silos

The siloed nature of general health care, mental health care, palliative care, and the social care system is perpetuated by system structures on multiple levels. From distinct administration on provincial levels to separate physical locations for care to specific specialties and education programs, patients and caregivers are expected to act as the bridges between services. While some service coordination programs exist for specific disease groups, such as oncology navigator roles to co-ordinate cancer care (Hartzell, 2015; Loiselle et al., 2020), or assertive community treatment teams that liaise between mental health services and social services (Kortrijk et al., 2019; Lalonde, 2013; Stergiopoulos et al., 2018), these programs are not yet available as standard care and have not been adapted to the context of patients with both mental illness and life-limiting illness in need of a palliative approach or palliative care.

This structural silo-ing legitimizes and therefore reinforces barriers to care in the minds and actions of practitioners, administrators, and other decision-makers. With limited funding and segregated care systems, it is all too easy for a practitioner or service to label a particular patient need as someone else's responsibility to address. Differences in care philosophies contribute to this, as do reduced informal contact and interaction between providers in different systems. On the basis of the analytic lens of this series of inquiries, we can begin to envision that team-based services, wraparound services, and open lines of communication with specialists for timely consultation could help us begin to take advantage of in-the-moment education opportunities that might start to break down silos in both perception and practice. Explorations in this direction in the future may hold promise for feasible modifications within our current systems and services as well as for the possibility of entirely new models of care. With that optimistic vision in mind, we can begin to explore possible implications and recommendations that may arise from the foundation laid in this dissertation project.

Implications and Recommendations

This dissertation's critical theoretical orientation allowed for consideration of distinct angles of examination on the research question which, taken together, have informed a series of possible recommendations for research, policy, practice, and education. This direction for pushing thinking to new levels aligns Mill et al.'s (2001) guidance that research from a critical theoretical perspective should focus on informing action for the purpose of emancipation. Emancipatory theorizing is focused on imagining possibilities for more a more equitable distribution of power and resources, and to facilitate understanding and the possibility for emancipatory action by individuals and groups. The critical theoretical approach taken in this dissertation, combined with reflexive analysis of practice throughout the process and the subsequent synthesis of the findings from all three parts of the inquiry, has brought to light worrisome power imbalances in both social structures and epistemology (Browne, 2000). These include power imbalances resulting from the historic and present-day disciplinary power nursing holds in mental health and palliative care. These recommendations, therefore, are intended to begin to address those historic understandings and imbalances with the ultimate aim of improving well-being for people with SPMI in need of palliative care.

Research

Research analysis that doesn't account for the existence of underlying factors (historical and present-day) influencing findings will fail to identify important gaps and opportunities for improving care (Clark et al., 2008; Cruickshank, 2002). Strategically selected and critically applied interpretive approaches are needed to investigate beyond the surface and foster a deeper understanding of both the current state of palliative care for people with mental illness, and what can be done to improve it. As researchers begin to move forward with pilot programs (e.g. Decorte et al., 2020) and recommendations, these must be informed by the kind of thoughtful study designs and approaches to analysis that are capable of evaluating causes, as well as trends in what constitutes current and evolving healthcare.

Over the past few years, the number of literature reviews of palliative care for people with mental illness has skyrocketed (Bates et al., 2022; Coffey et al., 2022; Edwards et al., 2021; Peryer et al., 2020; Shalev et al., 2020; Wilson et al., 2020). This volume of reviews is unlikely to uncover undiscovered literature or produce new findings and is more likely the result of a 'publish or perish' culture that is diverting resources away from primary studies that could have a greater impact on patient care (Rauch & Ansari, 2022). The publication of a review is also the easiest type of research to conduct in the topic area of a population group who require significant efforts by researchers to reach out to and support through the research process (as demonstrated by this study's eventual inability to overcome COVID-19-related challenges to speak with participants and their families). However, further reviews on the state of care are not productive at this time, nor are they a responsible use of research funding and other resources. It is now time to advance the field of literature with quantitative and qualitative descriptive studies that explore the current state of care (or lack thereof) with sufficient depth, detail, richness and critical analysis to inform interventions, the implementation and evaluation of which will also further develop knowledge to improve patient care, programs, and policy.

The ideological foundation of the patient-oriented research movement can be found in the slogan 'nothing about us without us' (Charlton, 1998). These words embody a moral stance that values inclusion and sharing power over paternalism and stigmatization. Arguably, it is a manifestation of beneficence and non-maleficence in the conduct of research, freed from a narrow focus on the individual research participant as a body acted upon by researchers. Research in partnership also carries benefits through the inclusion of knowledge, insight, perspectives, and access not held by researchers, and strengthens both the investigative practices and knowledge produced by research studies. Meaningful partnerships with people with mental illness, Mad people, Mad activists, peers, and survivor researchers are moral imperatives for strengthening this growing body of research and, if ethically implemented with attention to mitigating the risk of further oppression and epistemic injustice, would continue to enrich the knowledge that can be developed through future research projects. Therefore, I would argue that researchers should approach projects in this field with a sincere collaborative intent, with a sophisticated understanding of how to meaningfully develop and enact these partnerships, and with full awareness that there will be specific complexities associated with the Mad palliative care context.

Policy

Meaningful partnerships are not just for research. Consideration of how to include people with mental illness, Mad people, Mad activists, peers, and psychiatric survivors should be a priority for policymakers. Although the most convenient approach for policy work is to reach out to well-established and well-funded organizations for their insights and input, it is important to consider expanding upon these avenues for representation given what is known about the context of diversity of experience in madness and mental distress. In particular, policymakers should not limit themselves to organizations and patient representatives who may be steeped in a single perspective, particularly when that perspective (the biomedical perspective) is also shared by other, more powerful stakeholders in the policy process creating an epistemic consensus that fails to challenge or disrupt existing factors contributing to inequity. Meaningful representation in policy would require finding mechanisms to create space for a diversity of voices and perspectives, both within and between stakeholder groups.

The policies created in social and health care systems play a powerful role in maintaining silos and barriers between mental health care, palliative care, general healthcare, and social care.

While individual providers on the frontlines may diligently work to establish relationships between services and sites of care, they will always be swimming against the current unless supported by the kinds of policy changes that can break down barriers and create meaningful networks of support for providers and patients who are struggling to navigate these disparate systems.

Practice

De-silo-ing is not just a policy imperative; achieving success will clearly require buy-in at the practice level from both practitioners and administrators. It is apparent the experience, education, and the mental barriers of self-perception and perception of one's role all create expectations about the type of care that can and should be offered to an individual patient or family. This type of mental silo-ing contributes to poor care in the form of diagnostic overshadowing (S. Jones et al., 2008; Morgan, 2016), stigma related to either mental illness or the dying process (Corrigan et al., 2014; González-Rodríguez et al., 2020), and inequitable treatment within the healthcare system (Donald & Stajduhar, 2019; Edwards et al., 2021; González-Rodríguez et al., 2020; Lawrence & Kisely, 2010; Shalev et al., 2020). Practitioners and administrators in frontline services can support patients with mental illness in need of palliative care by working to break down the internal silos inherent in existing practice patterns, to build relationships with colleagues across services, and to provide and engage in education that builds competency to care for this group of patients and their families.

A history of trauma can be both a triggering factor in the development of mental illness and have a significant impact on patients' experience of mental distress. Traumatic experiences in the healthcare system may arise secondary to stigma, powerlessness, inability to access care, or care in inappropriate settings (Donald et al., 2022; Stajduhar et al., 2019b). Traumatic experiences can also arise in the course of routine care for life-limiting conditions including cancer treatment and critical care admissions (Ganzel, 2016). A universal trauma-informed approach to care, which Ganzel (2016) recommends for everyone in palliative care, is especially important for those with mental illness and mental distress. Raja et al. (2015) recommend a universal approach that involves providers understanding their own trauma history (both personal, if applicable, and vicarious) and reactions as they work with patients. Raja et al.'s (2015) recommendations include using patient-centred communication and care to offer choice, control, and ways to signal distress; to approach evaluations and discussions of health-behaviour through the lens of maladaptive coping mechanisms; and to maintain education and resources for referral and continuity of care in the case of a patient disclosing trauma or having a negative experience during care. By incorporating a universal trauma-informed approach to care, both palliative care and mental health care practitioners can work toward providing the best possible circumstances for collaboration, relationship-building, improved symptom control, and quality of life for these patients.

Education

Recommendations for educators include finding ways to break down silos of knowledge within curriculum and including principles of equity and vulnerable populations as standard and integrated themes across all aspects of professional practice education. When mental health care and palliative care are separated out into special topic classes or programs, this promotes the mental segregation of these types of care and deprives students of the opportunity to understand the ways that mental health care, palliative care, and a palliative approach to care are vital forms of knowing to incorporate into all healthcare contexts. Graduates of nursing, medicine, social work, and other programs will inevitably encounter people with mental illness in any medical care setting, just as those who work in specialized mental health or palliative care settings will inevitably encounter patients with both life-limiting conditions and mental illness or mental distress. Therefore, integrated education is needed to prepare learners for the complexity they will encounter in real world care settings, and to prepare them to care for the realities of patients with both medical and mental health needs.

Likewise, educators in palliative care should do what they can to incorporate learning on how to care for those who typically do not have access to palliative care services including those with mental illness, those who are homeless, those who use substances, and other groups who often experience higher rates of mental distress due to stigmatization, racialization, and marginalization in mainstream society (Stajduhar et al., 2019a). Partnering with people with lived experience offers an important opportunity to enhance curriculum design, inform pedagogical practices, and contribute to preparing learners in healthcare for the diversity they will encounter in practice (Whitelaw et al., 2022).

Conclusion

This manuscript-based interpretive descriptive analysis has brought a critical theoretical perspective to understanding and improving care for the medically ill and dying with SPMI. Implications have been considered related to the siloed nature of care and to the fluid designation of patients, partners, and participants in research and practice. Recommendations have been offered for research, policy, practice, and education. It has been well-established that palliative care for people with mental illness remains inadequate and inequitable, and further research is needed in the form of primary studies to investigate the current state of care and to identify generative mechanisms to inform future interventions. Meaningful partnership with people with lived experience of mental illness, madness, and mental distress as patient partners and scholars will be essential for understanding the diversity of experience in this population and ensuring that future interventions and evidence-based practice changes address historical power imbalances and present-day stigma.

This study has opened the door for justifying new forms of inquiry, new patterns of engaging with the work of providing high-quality palliative care and a palliative approach to people with SPMI, and new angles from which to consider the complex challenge of providing end of life care for those who are living with SPMI in the palliative phase. It has shed light on a population at the margins, and whose complexity has rarely attracted the kind of scholarly attention that might help with actual improvements to care. This work has not provided final answers, but instead invites scholars, practitioners, and policymakers to engage with the fascinating complexity of this challenge. By understanding the past and opening ourselves to sincere and meaningful collaboration with the people most affected by our research, policy, education, and practice, we begin to gain the kinds of wisdom that might take us into a more promising future.

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Appendix A: Original Study Plan

Original Study Plan Phase One: A Secondary Analysis

In secondary analysis, a researcher approaches an existing body of data collected in an original study with a new, related research question (Heaton, 2004c). While secondary analysis has the benefit of making maximum of use of resources (including that of participants) produced by original research, there are additional reasons secondary analysis can be beneficial for research on the topic of SPMI and the palliative phase of care. Long-Sutehall et al. (2012) identify the benefits of using secondary analysis when the research involves both sensitive topics (in this case, declining health and dying within the life context of SPMI and associated social and health care inequities), and eliciting information from a population which may be difficult for researchers to access. Additionally, in the case of this research question very little original research has been produced that could inform the development of a study approach or interview guide for persons with SPMI and their informal caregivers (Donald & Stajduhar, 2019). In this case, secondary analysis can be an avenue for the development of an approach to research for persons with SPMI in the palliative phase and will be employed in this study to inform recruitment protocol, procedural consent processes, and initial interview guides. Secondary data would have been sifted from a recently completed three-year ethnographic study led by Dr. Kelli Stajduhar titled Equitable Access to Care (EAC) (Stajduhar & Mollison, 2018).

Thorne (1994), in her chapter *Secondary analysis: Issues and implications*, identifies five types of secondary analysis. This study would have undertaken two of those types: Retrospective interpretation and amplified sampling. In retrospective interpretation, a researcher accesses an existing database with new research questions that were not the focus of exploration in the original study. Amplified sampling, though perhaps traditionally intended by Thorne (1994) to indicate the use of multiple secondary databases, would have been applied in principle here as secondary analysis would have been used to compliment a larger study including primary data. In the ID approach, secondary data is seen as a valuable source of "collateral data sources" for a primary study (Thorne, 1994, 2016). Secondary data can provide an additional angle of vision, in this case that of 1) a study led by an expert researcher, 2) the richness of ethnography, and 3) the context of the structural vulnerability experienced by many people with mental illness and advanced life-limiting conditions. While it was not my aim to limit this study to people with mental illness and advanced life-limiting conditions who are structurally vulnerable, the EAC study data would have allowed for more insight into the experience of these conditions than I would be likely to gather in my own research.

Research Design for Original Study Plan Phase One

The plan for phase one was to conduct a secondary analysis of data from the Equitable Access to Care Study (EAC) led by Dr. Kelli Stajduhar. The EAC study took place from 2014 to 2017 in Victoria, British Columbia, Canada. The main objectives of the EAC study were to:

1. Provide a detailed contextual description of the experiences of homeless and barely housed individuals in accessing healthcare services at end-of-life in Victoria, BC;
2. Identify barriers and facilitators to promoting quality care for this population;
3. Review promising programs and practices; and
4. Develop recommendations for improving access to end-of-life care for structurally vulnerable people (Stajduhar & Mollison, 2018, p. iii).

In the EAC study, homeless and barely housed individuals are described as *structurally vulnerable*, meaning they are impacted by structural inequities that result from policies and social conditions that disadvantage some while benefitting others (Stajduhar, 2013; Stajduhar &

Mollison, 2018). Through attention to structural vulnerability and how context produces health inequities that could be remedied, Dr. Stajduhar and her research team developed, conducted, analyzed, and disseminated findings from this study using a critical theoretical perspective of social justice and equity (Stajduhar, 2013). These researchers used ethnographic methods to collect data using field observations, longitudinal interviewing, focus groups, and researcher reflections. Participants included 25 structurally vulnerable people, 25 support people (family members, informal caregivers, or informal care providers), and 69 service providers (Stajduhar & Mollison, 2018). Additional data were collected through a review of existing programs that provide palliative care for homeless and barely housed individuals, interviews with the administrators of those programs, and three knowledge exchange meetings. Secondary analysis of selected EAC data from phase one of the proposed study would have been used to inform development of interview guides and approaches for data collection during phase two.

Original Study Plan Phase One Data Selection

The planned secondary analysis would have included a purposive sample of fourteen people with SPMI who were part of the EAC study (N=14). Seven of these participants self-identified as having a mental illness and seven were identified by HCPs as having a diagnosed or suspected mental illness. Repeated longitudinal interviews are available for these fourteen participants and are supplemented by detailed field observations for a total of 20 interviews and 39 field observations. Both transcripts and original audio-recordings (Heaton, 2008) from interviews and field observations for these fourteen participants would have been used in data analysis.

Original Study Plan Phase One Data Analysis

Thorne (1994) maintains that interactive intimacy with text remains possible through imagination and mutual questioning between text and researcher. To employ this intimacy and begin from a fresh perspective, I had planned to use un-coded texts and employ a process of listening to the original recordings while reading the text for accuracy and speech variations that convey emotions and meanings, followed by reading over the transcripts and memo-ing before undertaking original coding using NVivo v.12. Strategies proposed by Thorne (1994) will be followed, including the constant comparative method (using periods of subjectivity alternated with periods of objectivity); and focus on criteria that emphasize the research aims – conceptual development, linkages, and density – rather than the methodological process. Quality criteria would include an audit trail and the production of a research report that "convincingly portrays an analysis that has not fallen prey to known errors of interpretation" (Thorne, 1994). Appropriate distance would have been maintained from the original study team to maximize opportunities to understand the original study context while maintaining independence of integrity and findings for the proposed study (Heaton, 2004b, 2008; Long-Sutehall et al., 2012).

Issues of Epistemology in Secondary Analysis

Issues of epistemology in secondary analysis are best described as problems of suitability, and of the limits of knowledge claims (Thorne, 1994). Suitability was established in part through interview and ongoing discussion with the lead researcher and project coordinator, as well as review of the proposal and final report. The EAC study interviewed a population of people who are in the palliative phase of care, some of whom identified or were identified as having mental illness (Stajduhar & Mollison, 2018). This study also approached the research problem from a critical theoretical perspective, thus the assumptions about power and knowledge hierarchies and the importance of using research knowledge to promote equitable care align with my own study (Stajduhar, 2013). Although the EAC study employed a distinct methodology (ethnography), ID makes use of similar techniques including interviews and field observations used commonly in ethnography, as long as they are positioned in congruence with the study aims (Stajduhar, 2013; Thorne, 2016). In this case, I would not have expected dissonance resulting from an ethnographic approach or ethnographic methods that could not be accounted for by caution in knowledge claims from the resulting analysis (Thorne, 2016). However, it is important to note that the focus of the EAC study was not to analyze the experience of people with SPMI in the palliative phase, and while findings identify some experiences of mental illness and acknowledge the impact of these experiences on care, an in-depth analysis of this topic has not yet been conducted (Stajduhar & Mollison, 2018). Likewise, the EAC study did not employ peer researchers or analysts with experiences of mental illness during this process (A. Mollison, personal communication, November 21, 2018). In this case, where our research purposes diverge, there is an opportunity for new insights and knowledge to be produced through this process of secondary analysis.

I would not have been able to make a knowledge claim of findings extending beyond that of the population of the original study – the best I would have been able to do is to identify care needs and experiences of persons with SPMI in the palliative phase of care who are structurally vulnerable, which may not reflect the experiences of the participants I would have encountered in phase 2 of the originally planned study. However, the participant data selected from the EAC study are best thought of not as diverging from my own intended study population, but as a subset. Although not all persons with SPMI are structurally vulnerable in the sense employed by the EAC study, persons with SPMI experience structural vulnerability at a significantly higher rate than the general population and even those who are not structurally vulnerable are at an increased risk of becoming so (Canadian Population Health Initiative of the Canadian Institute for Health Information, 2009). Thus, I could reasonably expect to encounter structural vulnerability in some of the participants and accounts sought out in phase 2 (particularly given planned recruitment sites shared by the EAC study), and would benefit from both a deeper contextual understanding of the experience as well as the ability to discern both structural vulnerability and its impact.

I do not maintain that this analysis would have provided a fixed interview guide, but would have (coupled with a recent systematic scoping review by Donald & Stajduhar) informed development of a starting interview guide for persons with SPMI, their informal caregivers, and health care providers. This interview guide would then be adapted in response to participant and methodological guidance once use began with participants. I make no assumption that this data would have resulted in an interview guide that would be appropriate or well-suited to originally planned phase two study participants, but I assumed it would have provided a better starting point than basing interview guide development solely on an existing body of literature I know is scant, seldom addresses care providers directly, and did not include interviews with persons with SPMI or their informal caregivers at the time of planned study development (Donald & Stajduhar, 2019).

While experts on secondary analysis are concerned that there be an appropriate level of fit between research questions and study populations, Heaton (2004a) also presents the issue of too close a fit; a risk in both research question and population where there is a high level of overlap. High rates of structural vulnerability amongst persons with SPMI indicate that such an overlap may have been the case (Canadian Population Health Initiative of the Canadian Institute for Health Information, 2009). There would have been risk of attributing experiences of structural vulnerability which are worsened or more prominent in persons with mental illness as experiences of having a mental illness and being in the palliative phase. Ongoing reflexivity as well as ongoing consultation with the primary researchers (both of whom have had extensive experience working with persons who are structurally vulnerable, with and without mental illness, with and without advanced life-limiting disease) would have been my primary tactics to reduce this chance of error; especially in the final stages of study analysis when I would have been integrating what I have learned in phase 2. Early interviewing would have needed to be particularly sensitive to whether I was on the "wrong track" and malleability in my interview guides early on would hopefully have helped me to avoid any mistaken assumptions.

Access and Distance

Access to data, and distance — both from the research setting and from original researchers — have an impact on the outcome of secondary analytical studies (Heaton, 2008). Prior to COVID-19, I was fortunate to share a physical location with the lead researcher and project coordinator, as well as the ability to have shared electronic access to transcripts and recordings once ethics approval has been obtained.

Much of the quality in qualitative analysis comes from researcher time spent in close proximity to participants and their environments (Heaton, 2004a). This is especially true in ethnography and in the EAC study where researchers and research assistants spent extensive time in the field with participants – in the streets, in makeshift housing, in doctor's offices, and in the hospital (Stajduhar et al., 2019; Stajduhar & Mollison, 2018). As the original researchers and research assistants were the instruments in this study, no amount of consultation (final or iterative) would have been able to replace that; they will always have insight and tacit knowledge about the research and participants that I will never have, a concern for the epistemological integrity of findings in secondary analyses (Heaton, 2008; Thorne, 1998). However, as Long-Sutehall et al. (2012) respond, it is not uncommon for members of the research team who have not been involved in data collection to participate in analysis and reporting. Nor does it diminish the very real benefits of iterative communication with the original research team in order to glean insight into process and context (Thorne, 1998).

In the EAC study, research team members and the project coordinator, who collected the majority of the data, played an ongoing role in analysis – sometimes through coding, and always through iterative communication and bi-monthly meetings to discuss findings (A. Mollison, personal communication, November 21, 2018). Through access to both the lead researcher and project coordinator, as well as the possibility of conferring with other EAC research team members as needed, I would have had the opportunity to consult with persons who were at varying degrees of closeness to the field. Long-Sutehall et al. (2012) also contend that distance can be reduced by accessing original recordings in addition to transcriptions, as I intended to do.

Distance can be a disadvantage if the secondary analyst misses important information about the context of the study, however distance also provides an opportunity to bring a new perspective and avoid the inherent biases of the original researchers and is an established tradition in many academic disciplines (Thorne, 1994, p. 266). In the context of my own perspective, distance may have helped me to separate out the experiences of persons with SPMI (for whom structural vulnerability has a symbiotic relationship with mental health status and may worsen it) and those who do not (but may suffer from poor mental health as a result of structural vulnerability) (Early-Onset Illness and Mortality Group, 2011). To some extent the biases and effects of choices from previous researchers are unavoidable in secondary analysis as each step in theoretical approach, data selection and collection, and experience has been guided by the perspectives of the original researchers (Thorne, 1994). Likewise, my own biases and assumptions (both known and unknown) would have guided not only my analysis, but also the questions I would have asked and the information I would have requested from the original research team (Thorne, 1994). Maintaining a detailed audit trail including rationale behind decisions made and questions asked would have helped me not only to perceive my own bias, but to identify artefacts of bias from the original study in the data I would have been analyzing (Thorne, 1994). In maintaining an audit trail, my aim would have been to account for how I would have accessed the original researchers, and used this access to understand "…apparent strategy shifts, implicit preconceptions and biases, sources and timing of inductive inspiration, and eventual coding and interpretation may yield sufficient insight to account for the influence of artifacts of the original researcher's process" (Thorne, 1994, p. 272).

Because of the close physical proximity and ease of consulting both the lead researcher and project coordinator, one last concern would have been caution in allowing my own analysis to be unduly (though unintentionally) influenced by the original research team. To maintain my own insight and keep from being unnecessarily influenced as a novice researcher, I would have engaged in ongoing reflective analysis, self-awareness, reflexivity, and memo-ing in addition to maintaining an audit trail. I would also have approached consultation with the EAC research team with flexibility, for example by consulting in a more iterative fashion at the beginning of my analysis, and then, as I would have progressed, returning only when I would have been ready to discuss more fully-formed ideas.

Ethical Issues in Secondary Analysis

Thorne (1998) identifies four central components of ethical conduct in secondary research: confidentiality, informed consent, non-maleficence, and fidelity. Attention to confidentiality in research data requires not only the cleaning and de-identification of data by removing names and dates of birth, but also attention to potential identification by context (Thorne, 1998). Transcripts I would have accessed had been de-identified, but would have included demographic information such as age, gender, medical condition, and income status; and would have been likely to include stories, details, or other information that could have been used to identify participants to those known to them (for example health care providers or members in a shared community). Primary researchers are more likely to be sensitive to these identifying contexts through their tacit knowledge and immersion in the field, thus I would have consulted with the lead EAC researcher (who is also my doctoral supervisor) at each stage of reporting to ensure I would not have accidentally provided identifying details (Thorne, 1998). Despite transcripts being de-identified, I am aware of the risk that other information in transcripts or recordings could result in unintentional participant identification (Heaton, 2004b). In this case, I would have maintained confidentiality as is my professional and ethical obligation as a researcher and as a registered nurse (Peter & Storch, 2008).

While participants in the EAC study signed an informed consent providing permission for secondary analysis and for data to be shared with students, this is not enough on which to assume informed consent for a secondary study (Long-Sutehall et al., 2012). Long-Sutehall et al. (2012) emphasize the importance of congruence in research aims between the primary and secondary study, drawing attention to "…whether the new questions in any way shift the focus of the initial intention of research" (p. 339). Both the EAC study and my own would have aimed to improve the provision of palliative care, and both would have approached the research problem from a critical theoretical perspective.

The need for fidelity, as an "…obligation for truth-telling" recognizes the risk that the further the researcher is positioned in time and space from the participant, the greater the risk of misinterpretation (Thorne, 1998, p. 551). In putting into place thoughtful strategies related to access and distance with the original researchers, I had hoped to remain as faithful as possible to the perspectives shared by the EAC research participants and to reflect their experience truthfully in what would have been my own analysis.

In the applied health sciences, a researcher must always assume their research findings may be taken up (appropriately or inappropriately) and to be mindful of any potential harm that might result from this (Thorne, 1998, 2016). At each stage of research reporting and dissemination I would have been mindful of this risk and would always have sought to communicate any findings within the limitations of the study and my own limited experience with research and health policy.

Quality and Analytic Process in Secondary Analysis

Borrowing from traditions such as philosophy and history, in which it is often impossible to interact directly with the original sources (environments or persons) in ways favoured by health researchers, Thorne (1994) maintains that interactive intimacy with text remains possible through imagination and mutual questioning between text and researcher. From an analytical perspective, ID broadly groups textual data from secondary analysis alongside original textual sources such as policy documents, meeting minutes, or media reports (Thorne, 2016). All of these sources can be approached inductively, and Thorne (1994) encourages the researcher to pass over content analysis for a more inductive approach. At the time that chapter was published, health sciences had made few moves to embrace the inductive approaches to text used in other traditions (Thorne, 1994). Since that time, nursing has taken further steps to embrace inductive textual analysis and techniques for doing so while keeping the ultimate goal of application and improvement of health in mind (Thorne, 2016).

Strategies proposed by Thorne (1994) at that time include the constant comparative method (periods of subjectivity alternated with periods of objectivity, distance/immersion); focus on criteria that emphasize the ends — conceptual development, linkages, and density — rather than the methodological process. Quality criteria include an audit trail and the production of a research report that "convincingly portrays an analysis that has not fallen prey to known errors of interpretation" (Thorne, 1994, p. 275). To employ this technique and begin from a fresh perspective, I would have used un-coded texts and employed a process of reading over and memo-ing before undertaking original coding using NVivo v.12.

Audit trails contribute to transparency, but do not ensure it and may contribute to internal quality assurance even if an external audit is never undertaken (Heaton, 2004a). Explicitly recording my decisions and rationale for making them would have helped me keep track of my assumptions and reduce errors resulting from impulsivity or thoughtlessness. They would have been a form of reflexivity for taking an additional reflexive step to examine decisions and actions above and beyond the reflexivity I would have used to examine thoughts, feelings, and assumptions.

Research Design for Original Study Plan Phase Two

Phase two of this study would have consisted of original research with persons with SPMI, their informal caregivers, health care providers, key informants, and text sources including policies and clinical guidelines from participating organizations. While the first phase of the study would have informed an initial interview guide, subsequent interview questions and avenues of exploration for new data would have been responsive to iterative analysis and opportunities presented through data collection.

Original Study Plan Phase Two Sampling and Recruitment

In ID studies, the benefits of using multiple data sources on a topic to provide varying perspectives are foundational (Thorne, 2016). While people with SPMI and their informal caregivers have a perspective on their care that cannot be captured by HCPs, so do HCPs have a perspective from their role inside the system and their ability to view persons with SPMI and their informal caregivers in the context of care. Often aware of political, social, and economic factors that are not immediately visible in practice settings, key informants —including administrators, policymakers, and decision-makers — will be sought for their ability to speak to the care of persons with SPMI in the palliative phase within a broader organizational and social context.

This study would have included participants over 18 years of age, able to speak and read English, and who would have been able to provide informed and ongoing consent. **For persons receiving care**: Status of SPMI would have been determined by self-report, or by diagnosis or suspicion of diagnosis by a HCP to ensure that those who have been unable to access formalized psychiatric diagnoses, or whose records have not been transferred to the recruitment site, have the opportunity to participate in this study. In accordance with the concept of a palliative approach, any person determined by the referring HCP to be in an advanced stage of life-limiting illness will be considered to be in the palliative phase of care (N=15-20) (Sawatzky et al., 2016). **For informal caregivers**: Informal caregivers (including but not limited to family members, chosen family, advocates, or friends) would have been included as identified by persons with SPMI or by HCPs. To ensure a broad perspective from informal caregivers, recruitment of informal caregivers would have been open to those who are linked study participants as well as those providing care for individuals who would have been unable to participate in this study. Ethical and analytical caution would have been taken with informal caregivers and no data about the person cared for would have been shared with these participants (N=15-20). **For HCPs**: Any HCP working directly with persons with SPMI in the palliative phase of care for two or more years would have been invited to participate. Special attention would have been paid to the recruitment of nurses for the development of new nursing knowledge and contribution to nursing practice (N=15-20). **For key informants**: Key informants would have included administrators, policy-makers, and decision-makers in clinical sites, health authorities, community (e.g. advocacy organizations), and government (N=10). Invitations would also have been sent via email to public guardians and trustees who are the legal decision-makers in British Columbia for persons with SPMI who are deemed incapable of informed decision-making for healthcare and who do not have a substitute decision-maker.

Scant research exists to show where people with SPMI in the palliative phase are being cared for, and few settings are designed to care for this population (Donald & Stajduhar, 2019). Consequently, sites and networks that provide care for this population and with whom Dr. Stajduhar and myself have established research and professional collaborations would have been drawn from to recruit participants. A combination of purposive sampling and snowball sampling would have been used, originating through the following sites and networks:

- Victoria Cool Aid Society and Community Health Centre, a primary care and multi-service site for people who are homeless, mentally ill, low-income, or experience problematic substance use (Victoria Cool Aid Society, n.d.);

- May’s Place Hospice, a free-standing hospice facility specializing in providing care to persons with mental health challenges and problematic substance use (The Bloom Group, 2018);
- Through professional connections with the Victoria, BC and Vancouver, BC Assertive Community Treatment (West et al., 2015) teams;
- Through a co-existing network of service providers established by Dr. Kelli Stajduhar’s EAC research team.

While these would have been initial points of contact for recruiting key informants and engaging in access to participants with SPMI in the palliative phase of care, initial expression of interest had already resulted in connections with relevant service providers and sites listed above prior to COVID-19. Study design would have remained flexible and open to the possibility of new (and unexpected) sources of key informants and participants.

Rationale for Original Study Plan Phase Two Sampling.

Currently there is very little published research representing the voices of people with SPMI in the palliative phase or their informal caregivers (Donald & Stajduhar, 2019; Ehrlich & Dannapfel, 2017; Jerwood et al., 2021; Knippenberg et al., 2020). When the voices of people affected by care are not represented in research or policy-making, health care providers risk an inefficient use of resources at best and harm at worst. Therefore, the ethical recruitment and participation of people with SPMI and their informal caregivers would have been a priority for this study. The purpose of ethical recruitment would have been to take into account the needs and perspectives of people in this group; to recognize existing principles and standards for the research involvement of people with SPMI as well as people in the palliative phase; and to help establish a standard for the involvement of people with SPMI in the palliative phase in studies that inform their care. Thorne (2016) writes about not privileging the patient perspective over the practitioner's, as both have valuable insights to a particular phenomenon. While this may be true, the lack of representation of patient/person perspectives in research about people with SPMI in the palliative phase emphasizes the importance of including them without any further delay or excuse. The historic slogan adopted by the disability activism movement, "Nothing about us without us" is as important an approach today as ever (Charlton, 1998). It is unacceptable that any movement towards the improvement of care of people with SPMI and advanced life-limiting conditions would go forward without their input, and yet evidence points towards a serious need for such reform (Donald & Stajduhar, 2019). Researchers and clinicians are left with the only alternative: to involve people with SPMI in the palliative phase of care and their informal caregivers in the dialogue as soon as possible to move towards improvements in care that are meaningful for the most important people in the process.

This is not the say there is no role in this body of research for health care providers, or even that health care provider perspectives have been well-represented (they have not)(Donald & Stajduhar, 2019). In ID studies, the benefits of using multiple data sources on a topic to provide varying perspectives are clear (Thorne, 2016). While people with SPMI and their informal caregivers have a perspective on their care that cannot be captured by health care providers, so do health care providers have a perspective from their role inside the system and their ability to view multiple people with SPMI and their informal caregivers in the broader context of care. The "thoughtful practitioner" can be a powerful data source for this perspective (Thorne, 2016, p. 92). Thoughtful practitioners, with their sometimes-extended experience in a field or setting, may be able to identify potential variations or diversities that may not have appeared in my own data set (Thorne, 2016). For this reason, health care providers would have been sought and selected "….in a highly purposive manner specifically for that capacity to consider practice phenomena over time and context" (Thorne, 2016, p. 93).

Administrators and policymakers bring yet another kind of understanding to studies of health care phenomena. Often aware of political, social, and economic factors that are not immediately visible in practice settings, these key informants would have been sought for their ability to speak to the care of persons with SPMI in the palliative phase in a broader context. Key informant perspectives would have been particularly important given the role of non-health government organizations and policies in the lives of persons with SPMI living with advanced life-limiting conditions, such as housing, income, and food security (Allen et al., 2014). One or more public guardians would also have been sought to provide perspective on the experiences of those making decisions on behalf of persons with SPMI deemed legally incompetent and lacking another substitute decision-maker.

While there seem to be few sites designed from a system perspective to provide care for people with SPMI in the palliative phase, specialty hospices such as May's Place, sites such as the Cool Aid Society, or health authorities including Island Health and Vancouver Coastal Health may have organizational policies and clinical guidelines pertaining to this population. These types of documents can provide insight into standards for clinical practice and preparedness to care for people with SPMI in the palliative phase of care and their informal caregivers. As a final source of data, I would have worked with key informants and health care providers to identify these documents and, with organizational permission, would have performed an interpretive textual analysis for inclusion in my study.

Methods for Data Collection

The primary method of data collection for this study would have been individual interviews for people with SPMI in the palliative phase of care, or joint interviews if they wish to be accompanied. Interview data would have been supplemented by texts of policy documents and practice guidelines in order to provide a formal organizational perspective. I selected interviews as the primary data collection method in order to deeply explore the personal experience of people with SPMI in the palliative phase, their informal caregivers, health care providers, and key informants. While using primarily interviews as a format risks over-emphasizing the individual subjective experience, by using multiple data sources from multiple positions within the experience of care I was hoping to mitigate this risk (Thorne, 2016). By including a robust sample size, I had also hoped to capture a variety of perspectives and experiences to inform findings and recommendations relevant to practice.

Initial interview guides would have been formed based on secondary analytical data from the EAC study analyzed in phase one but would have remained flexible and responsive through iterative analysis as the study proceeded. Interviews would have been held at the location most convenient for the participant, as long as privacy could have been reasonably assured. With consent, interviews would have been audio-recorded and transcribed by myself, with transcribed texts providing the bulk of material for analysis. After each interview I would have recorded my thoughts and observations, appending these to the interview text as an additional unit of analysis.

Alongside organization texts and interview transcripts, my own memo-ing and note-taking throughout the research process would have served as the third source of data for this study.

Analysis for the Original Study Plan Phase Two

Similar to phase one, data analysis would have occured primarily through iterative reading and coding of text sources including memo-ing, interview transcripts, and texts from organizational documents. I would have listened to interview recordings, and would have transcribed them as is recommended for new researchers using ID (Thorne, 2016). Analysis would have been guided by the ID process of finding familiarity with the data, looking for patterns, expanding on associations, and testing relationships (Thorne, 2016). Informed by a critical theoretical perspective, I would have sought to maintain vigilance in identifying power relationships, oppression, and opportunities for emancipation (Browne, 2000).

While the findings of phase one may have helped inform the analysis of phase two and/or the interpretation of data, insight would have unfolded iteratively over the course of the study and during the data analysis process. It was possible that findings from the secondary analysis would have had relevance and brought depth alongside the experience shared by participants in phase one. It would also have been possible that data from a population experiencing structural vulnerability in their entirety would have drawn attention from the variety of life experiences of people with SPMI in the palliative phase of care. In the ID approach, secondary data can act as a "collateral data source", providing another angle of vision for the primary study, as would have been the case here (Thorne, 2016). While it would not have been my aim to limit my study to people who are structurally vulnerable, many people with mental illness experience structural vulnerability and incorporating the EAC data may have provided more information on that experience than phase two research could have explored. To guide the data analysis process, I would have proposed ideas and sought guidance from both my supervisor and my committee. If there had been a role for phase one data comparison with phase two data during the final analysis and/or interpretation, I would have needed to be thoughtful about the implications of methodological variations between ID and ethnography, and to be clear about limitations resulting from any divergence (Thorne, 1994).

Ethics and Consent for Phase Two of the Original Study Plan

All participants would have had the right to participation, to informed consent including the opportunity to ask questions and receive answers, and to leave the study. Participants who chose to leave the study at any time would have been able to keep any honoraria provided and would have been given the option to have their data withdrawn. During the course of an interview, a participant may have become distressed. My clinical experience conducting conversations on sensitive topics of death and dying would have allowed me to re-focus the discussion on therapeutic communication and support, or to assess need and offer further support, including referral if needed. If a participant had become distressed during an interview, this would have prompted an offer to stop the interview.

While ethically conducting research with people with SPMI, particularly those in the palliative phase of care who may be termed “doubly vulnerable” can be challenging, it is unethical to exclude these participants from the body of research informing their care, as has traditionally been the case (Donald & Stajduhar, 2019; Keogh & Daly, 2009; Moore & Miller, 1999). To minimize potential harm of research participation while maximizing opportunities for people with SPMI to be involved, consent would have needed to be informed and ongoing, with specific attention to the challenges faced by people with SPMI (Bagaric et al., 2014). Maximizing opportunities would have included maintaining an assumption of competence unless shown otherwise in order to avoid stigmatization, and providing adequate time for information processing and conversation about risks (Bagaric et al., 2014). Informed, written consent would have been obtained from all participants, and ongoing consent procedures would have been applied including confirming consent prior to interviews and being sensitive to any hesitation or potential shifts in mental state during the interview process prompting offers to stop the interview (Bagaric et al., 2014; Keogh & Daly, 2009). My clinical experience caring for people in the palliative phase experiencing compounding vulnerabilities (including SPMI, poverty, illicit drug use, and racialization) would have informed a sensitive and caring approach to interviewing. This approach would have been supported through ongoing mentoring from my supervisor, Dr. Stajduhar, and my doctoral committee, who have experience conducting sensitive, ethical research with populations experiencing multiple vulnerabilities.

For phase two of the originally planned study, a full ethics application would have been submitted to the Research Ethics Boards of the University of Victoria, Island Health Authority, and Vancouver Coastal Health Authority, and any relevant organizational review boards.

Reflexivity and the Researcher

In ID, reflexivity is both an approach for building a credible study, and a thought process to consider the reasons for decision-making and create room to explore different conceptualizations (Thorne, 2016). Pillow (2003) cites Altheide and Johnson (1998) in defining reflexivity as "…an acceptance and acknowledgement that '*how* knowledge is acquired, organized, and interpreted is relevant to *what* the claims are" (p. 176). Reflexivity includes both reflection on previous experiences and reflection in experience, in a way that opens up new possibilities and direction in the research process (Reis, 2011, p. 4). It has been long been considered a component of ensuring quality and reducing researcher bias in qualitative studies (May, 2014).

Reflexivity is often presented as methodological tool by which the researcher is able to overcome or minimize the problematic impact of their own positioning and privilege (Pillow, 2003). Like Pillow (2003), I have my doubts that this is ever truly possible and I remain skeptical of reflexivity alone as a stand-alone indicator of quality in research. Pillow (2003) challenges this notion of reflexivity from the post-modern perspective that neither the self nor the other are ever truly knowable. In adapting this to my own research, I return to critical realism – particularly the ontological and epistemological stratification of reality that acknowledges some generative mechanisms can never be directly observed and only inferred from their effects on the world (Clark et al., 2008). As a result of my own positionality (disciplinary and personal) I hold pre-existing observations of the effects of generative mechanisms that, in some cases, have been reflected in the findings of each component of this dissertation. It would be short-sighted and irresponsible not to seek out and acknowledge the ways in which these experiences have impacted my research, analysis, and reporting. Like Reis (2011) I could never be "impartial" or "detached" from my research (p. 5).

However, I am wary of the many pitfalls catalogued by Pillow (2003) and other researchers including reflexivity as the narcissistic confessional tale, as the solution for the problems of academic misrepresentation, or as a way of inscribing my own experience onto that of perspectives encountered in my research. Instead I would like to embrace reflexivity with the purpose of disrupting hegemonic patterns of knowledge production about mental illness and palliative care (LeBlanc & Kinsella, 2016). In order to engage with this kind of critical reflexivity, I will avoid what Pillow (2003) describes as the use of reflexivity to move knowledge towards a more familiar alignment with established 'truth', and open myself to the possibility of reflexivity as a practice disruptive to truth-telling. Situating personal reflexivity within a critical reflexivity that looks broadly at knowledge production will not only align with the critical theoretical perspective informing this research study, but it will also keep reflection embedded in each stage of the research process.

Appendix A References

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