The Pennsylvania State University

The Graduate School

HOSPICE AND PALLIATIVE CARE FOR PERSONS WITH SEVERE AND PERSISTENT MENTAL ILLNESSES

A Dissertation in
Nursing
by
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ABSTRACT

Severe and persistent mental illnesses affect approximately 5% of the United States population and refer to chronic and debilitating psychiatric disorders. This category of psychiatric illnesses is costly and has a significant impact on the quality of life of persons with these disorders. Severe and persistent mental illnesses are often life-long, cause significant impairment to activities of daily living, and in many cases, require long-term care. Palliative care is an appropriate approach to care for this population due to their significant and complex symptomatology. However, palliative care is rarely afforded to this population, particularly at the end of life. In order to explore this topic, a three-paper dissertation was completed detailing 1) a systematic review, 2) an integrative review, and 3) a grounded theory study which explored nurse experiences of caring for persons with severe and persistent mental illnesses.
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Chapter 1

Overview/Statement of Problem

Severe and persistent mental illnesses (SPMIs) affect approximately 5% of the United States (U.S.) population and refer to chronic and debilitating psychiatric disorders (Donald & Stajhudar, 2019). This category of psychiatric illnesses is costly and has a significant impact on the quality of life of persons with these disorders. Severe and persistent mental illnesses are often life-long, cause significant impairment to activities of daily living (ADLs), and in many cases, require long-term care (Donald & Stajduhar). Ruggeri et al. (2000) defined SPMI as any psychiatric illness of greater than two years duration with a severe level of dysfunction. Severe dysfunction can be measured as a score of fifty or less on the Global Assessment of Functioning Scale (Ruggeri et al.). Dysfunction is considered being unable to complete daily tasks in terms of occupational, social, or ADLs, such as basic hygiene. Schizophrenia, bipolar disorder, and major depression are common illnesses in persons with SPMI, but any psychiatric illness creating significant dysfunction can be included in this category. The annual cost of care for patients with SPMI is over $200 billion in the U.S., and rising (National Alliance on Mental Health, 2019).

Patients with an SPMI diagnosis have a higher risk of physical illness comorbidities, with at least 50% of this population having two or more physical comorbidities (Jones et al., 2009). Death from physical illness is also more common, with two to three times the mortality rate than that of the general population; translating to an approximately twenty-five-year shorter lifespan (De Hert et al., 2011). The combination of psychiatric symptomatology and psychiatric and physical comorbidities creates a high burden of illness for individuals with SPMI (Parabiaghi et al., 2006); resulting in a severely decreased quality of life, with few available services to address this burden.
Palliative care, a holistic approach to symptom management, is considered a fundamental human right (Brennan, 2007; Gwyther et al., 2009) and can ease disease burden and improve quality of life in the face of chronic and life-limiting illness (World Health Organization, 2018). As defined by the National Consensus Project (NCP) (2018), palliative care “… focuses on expert assessment and management of pain or other symptoms, assessment and support of caregiver needs, and coordination of care…” (p. i). Palliative care encompasses both specialty or primary palliative care over the course of chronic illness and end-of-life and hospice care during a terminal illness. End-of-life care refers to careful symptom management and holistic patient and family care focused on the last few days of life. End-of-life care is primarily pain management but also includes meeting other physical, psychosocial, or spiritual needs of the patient and family (NCP). According to the NCP guidelines for quality palliative care, caring for persons at the end of life is one of eight delineated palliative care domains. For this study, end-of-life care, also known as hospice, terminal, or comfort care, will be discussed under the broader context of palliative care.

End-of-life care is appropriate for persons with SPMIs and terminal illnesses. It can begin to address the increased burden of illness as a result of mental and physical comorbidities. However, despite its increase in utilization in non-psychiatric illnesses (Dumanovsky et al., 2016), it remains severely underutilized in general, but specifically within the SPMI population (Donald & Stajduhar, 2019). Particularly in cases of end-of-life care, persons with SPMIs are nearly half as likely to receive formal hospice care, and when hospice is provided, it is often to a lesser degree than their non-SPMI peers (Shalev et al., 2017).

In previous research exploring clinical healthcare staff views, the barriers, and facilitators to end-of-life care provision to persons with SPMIs have been delineated. These studies found
that palliative care and mental health staff and nurses are often uncomfortable providing end-of-life care to persons with SPMIs. They attributed the identified barriers to various aspects of psychiatric illness, lack of system support, and personal nursing abilities (Evenblij et al., 2016; Jerwood et al., 2018; McGrath & Forrester, 2006). In a phenomenological study, Morgan (2016) identified the theme of “no right place to die”, as staff felt they weren’t sure which setting would be prepared to handle patients with SPMIs at the end of life. This leaves the place of death too often in psychiatric hospitals, long-term psychiatric facilities, or nursing homes that accept patients with SPMIs (Lavin et al., 2017; Shalev et al., 2017). These settings have nurses who are typically skilled in psychiatric care but not necessarily end-of-life care.

**Home Health and Hospice**

Home health and hospice is one of many settings which can provide palliative and end-of-life care to persons with SPMIs throughout their chronic or terminal illnesses (Vossel, 2020). Home care services offer multiple benefits to patients, including improved quality of life, ability to remain in the home, and enhanced access to treatment (Molu et al., 2016). It also serves as an appropriate care pathway for palliative and end-of-life care, including for persons with SPMIs (Molu et al., 2016). However, home health and hospice nurses’ experiences caring for persons with SPMIs in a home setting have yet to be explored in the literature, despite its obvious benefits. Exploration of home health and hospice nurse experiences caring for persons with SPMIs can help describe barriers and facilitators to care in this setting, which can allow them to be addressed to enhance care to persons with SPMIs at the end of life.

**Purpose**

This three paper dissertation is separated into three distinct sections: a systematic review, an integrated review and a qualitative grounded theory study focused on home health and
hospice nurses’ processes and experiences of providing care to persons with SPMIs in the home setting.

**Paper One**

A systematic review was completed using the PRISMA guidelines. The systematic review synthesized and critiqued published research on palliative and end-of-life care for persons with SPMIs. The research question guiding this review was as follows:

1. What is currently known about palliative and end-of-life care for persons with SPMIs?

**Paper Two**

An integrated review was completed in order to explore person-level and environmental factors contributing to the end-of-life experiences of persons with SPMIs. This consisted of a review of literature from various scholarly databases. The guiding research questions for this paper were:

1. What are the comprehensive factors influencing the end-of-life period for persons with SPMIs?
2. What is the impact of person-level and environmental factors on the end-of-life period for persons with SPMIs?

**Paper Three**

The purpose of the grounded theory study was to explore home health and hospice nurses’ processes and experiences providing care to chronically and/or terminally ill patients with SPMIs in a home setting and to identify barriers and facilitators to care. The research questions guiding this study were:

1. What are the barriers to hospice care for persons with SPMI?
2. What are the facilitators to hospice care for persons with SPMI?

3. How does the home setting impact hospice care for persons with SPMIs?

**Significance**

Availability of palliative care and hospice care has greatly increased for persons living with chronic and life-limiting illnesses over the past two decades (Dumanovsky et al., 2019). Despite this increase, services remain highly underutilized and understudied in the SPMI population (Donald & Stajhudar, 2019; Woods et al., 2008). This three-paper dissertation will provide holistic insight into palliative care in this population by 1) providing a background and comprehensive understanding of the current knowledge about palliative care in SPMIs, 2) reviewing environmental and person-centered factors which can influence the end-of-life time period, and 3) evaluate home health and hospice nurses’ experiences and perceived barriers and facilitators to palliative care in this population. The overview provided by these papers will provide a holistic picture of the end-of-life period for persons with SPMIs. Understanding the process, barriers, and facilitators to care in the home health and hospice settings can help improve these services for this population and subsequently increase palliative and end-of-life care, which can be understood further by understanding influencing factors and the current literature base, exemplified in papers one and two.

**Conceptual Frameworks**

**Grounded Theory Approach**

The grounded theory approach to qualitative research was used to frame the methods and analysis for the grounded theory study. Grounded theory research is utilized when developing a new theory to describe a process or action to create a framework for future research. In this study, the process is nurses’ perceptions of palliative care, specifically end-of-life care, provision
to persons with SPMIs. Due to the emerging nature of this topic, grounded theory research is indicated. Tenets of grounded theory research, as initially defined by Glaser and Strauss (1967), are being used in the conceptualization of this study. These include Memoing, theoretical sampling, and analysis plans as delineated within grounded theory guidelines.

**Theory of Human Caring**

Jean Watson’s Theory of Human Caring focuses on the holistic care and the nurse-human interaction nurses can provide when caring for patients. Watson identified the wholeness of the person and the importance of the nurse in cultivating a meaningful nurse-patient interaction to perceive the wholeness of the patient appropriately (Watson, 2005). Health is identified as a unity of mind-body-and spirit, working in harmony (McEwen & Wills, 2016). This theory guided the exploration of holistic action nurses must take to provide end-of-life care and will be applied to both hospice and home health nurses.

**Key Terms**

Definitions of the key terms are below.

1. Severe and persistent mental illness
   a. Severe and persistent mental illness refers to psychiatric diagnoses which cause severe dysfunction and require two or more years of treatment (Ruggeri et al., 2000)

2. Palliative care
   a. Palliative care is a care approach that aims to address quality of life issues in patients and their families with a life-threatening illness, focusing on prevention and relief of suffering, physical, psychosocial, and spiritual (World Health
Organization, 2019). The term palliative care will encompass end-of-life care, further defined below.

b. Primary palliative care

i. Palliative care provided by non-specialized or certified general practitioners, including physicians, nurses, social workers, pharmacists, or any patient care providers (NCP, 2018)

c. Specialty palliative care

i. Palliative care delivered by a team of providers who have certifications or specialties in palliative care. This can include physicians, nurses, pharmacists, social workers, chaplains, etc., who have palliative care practice designations (NCP, 2018)

d. End-of-life care

i. Care to a person and their family in the final days of life, including the days leading up to death and the days after death. This includes comprehensive assessment and symptom management in social, spiritual, physical, psychological, and cultural aspects of care (NCP, 2020). End-of-life care is distinct from palliative care but falls under the umbrella of palliative care overall.

Conclusion

Persons with SPMI are experiencing disease burden from psychiatric and physical comorbidities, as well as enhanced care complexities. Despite the rise of palliative care usage in other non-psychiatric diagnoses, it is not utilized appropriately in the SPMI population. A systematic review related to the provision of palliative care with persons with SPMI was the first
step in determining the state of the science. An integrated review of factors influencing the end-of-life period for persons with SPMIs provided insight into the end-of-life needs in this population. The grounded theory will contribute to the development of a grounded theory to describe the nurses’ experiences and processes of providing end-of-life care to persons with SPMIs in the home setting.
Chapter 2

Severe and persistent mental illnesses (SPMIs) are a group of psychiatric disorders which cause significant impairment of daily functioning in an individual and often require long-term treatment (Donald & Stajduhar, 2019). Typically, SPMI refers to severe psychiatric disorders such as schizophrenia, bipolar disorder, and major depression. However, depending on the level of dysfunction within an individual, this can also include personality disorder, eating disorders, substance abuse disorders, or any psychiatric disorder meeting the criteria (Ruggeri et al., 2000). Individuals within the SPMI population are facing complex and significant health issues. Beyond dealing with the symptomatology of their psychiatric diagnosis, at least 50% of this population has two or more physical comorbidities (Jones et al., 2004). Death from these physical comorbidities is also more common, translating to an approximately 25-year shorter lifespan than their non-SPMI peers (De Hert et al., 2011). Some of the most common physical comorbidities experienced by persons with SPMI include cardiovascular diseases, respiratory diseases, and cancer. Even with physical medical comorbidities, persons with SPMI receive fewer referrals to palliative care than persons within the non-psychiatric population with the same comorbidities (Butler & O’Brien, 2018).

Palliative care is an approach to care which aims to address quality of life in persons with a life-limiting illness while utilizing a holistic and interdisciplinary practice (World Health Organization [WHO], 2019). While palliative care has grown considerably and supports persons with chronic and end-of-life diagnoses and their families, it has the potential to be expanded to include chronic illness diagnoses that individuals and families continue to suffer from, including psychiatric diagnoses such as SPMI (Dumanovsky et al., 2016). While the need and potential benefits of palliative care services within this population are well documented (Donald &
Stajduhar, 2019; Woods et al., 2008), these services are still highly underutilized (Butler & O’Brien, 2018). The SPMI diagnosis alone warrants palliative interventions. SPMI compounded with physical comorbidities heightens the need for palliative care.

The research questions guiding this literature review are: What is currently known about palliative care utilization within the SPMI population? How do nurses perceive palliative care implementation in this population? Understanding what is already known about current utilization can help determine what further research directions need to be explored. Throughout the literature synthesis, themes surrounding the aspects of palliative care utilization within the SPMI population emerged, including varying definitions of SPMI/severe mental illness (SMI), care complexities, palliative care needs within the SPMI population, including insight into the surrounding specific diagnoses. Furthermore, healthcare staff views of providing palliative care to persons with SPMI are synthesized and gaps identified.

**Theoretical Frameworks**

**Human Caring Theory**

Jean Watson’s Human Caring Theory is a grand theory of nursing that identifies the wholeness of the person and the purpose of the nurse in cultivating and curating this in their care, health, and wellness. This theory broadly identifies an integral part of the nurse in human caring and acknowledges the person as a complex being of mind-body-and-spiritual harmony (Watson, 2005). The theory places caring holistically for the person is the core of nursing, which is lost when a patient is reduced to a diagnosis or unidimensional object (Pajnkihar et al., 2017).

Jean Watson’s Human Caring Theory was developed in the 1970s during her time at the University of Colorado to integrate more holistic aspects of the human experience outside of curative factors. This theory was the first grand nursing theory to integrate spirituality as a
holistic nursing concept (McEwen & Wills, 2016). The theory has main conceptual elements of healing/caring arts (Caritas), the description of a transpersonal caring relationship between the patient and nurse, the introduction of the caring moment or caring occasion, and the identification of caring-healing modalities (Watson, 2005). It has been identified as a theory, framework, model, philosophy, and sometimes a middle-range theory (Pajnkihar et al., 2017). However, within nursing, is considered a grand theory (McEwen & Wills, 2016; Pajnkihar et al., 2017)

This theory and its model for health and wellness of the person is holistic and aims to define and describe health in the person’s life process and the role of the nurse in caring for the wholeness of the person. This theory can provide an integral framework for developing a grounded theory focused on describing and exploring a nursing concept, such as mental health nurses providing end-of-life (EOL) care to persons with SPMIs. The role of the nurse, their relationship to the patient, and the patient’s well-being are all critical theoretical aspects that can be translated to the bedside practice of nursing.

Relationship to Nursing Paradigm

The nursing metaparadigm consists of four overarching concepts connecting the nursing science: nursing, health, person, and environment. Within Human Caring Theory, three of these concepts are defined and integrated: nursing, health, and person (McEwen & Wills, 2016). The environment, however, has been addressed pragmatically through the application of this theory to practice (Norman et al., 2016).

Watson (2005) also delineated a nursing metaparadigm in which the Human Caring Theory exists. This metaparadigm illustrates the holistic nature and connectedness of mind-body-
spirit that Watson exemplifies in her Human Caring Theory (Pajnikar et al., 2017) and is shown in Figure 1.

**Figure 1.**

*Watson’s Metaparadigm*

![Watson’s Metaparadigm](image)

*Retrieved from Pajnikar et al. (2017).*

**Roots of Caring Theory**

Watson’s Human Caring Theory has its roots in phenomenology, which is part of the perceived, or interpretive, views movement. Phenomenology emphasizes how things appear, to the nurse and the person, as opposed to a “singular truth” about the phenomenon itself. No single truth is accepted as absolute truth, as it is dependent on the meaning of the phenomenon to an individual, and the existence is dependent on the perception of existence (McEwen & Wills, 2016). Perceived views rely on the perceptions of both the actor (nurse or researcher) and the subject (patient or person) being studied. Human Caring Theory is rooted in this interpretive nature as both the nurse’s ideals and qualities, and the patient’s needs and perceptions are identified of equal importance in a caring moment.
Human Caring Theory also represents an inductive and deductive model of health, as it pulls roots from nursing theorists (Nightingale and Rogers), as well as psychology underpinnings (Grigori, Johnson, and Koch) (McEwen & Wills, 2016). Pajnikihar et al. (2017) identify it as a retroductive theory due to its sourcing from other disciplines to develop abstract nursing-specific concepts.

**Major Concepts**

There are some major concepts within Human Caring Theory that are integral to understanding its view of nursing and health. These include the ten caritas processes, the transpersonal caring relationship, caring moments, and caring-healing modalities (Watson, 2005). These have evolved from the original publication of the theory and represent molded and emerging updated theoretical assumptions.

The ten caritas processes were developed originally initially as caritive factors in direct opposition to curative factors, which are medical terminology. Watson intended to separate nursing and define its distinct role in the holistic care of a person using the caritas processes (Pajnikihar et al., 2017). The caritas reflects those healing and those being healed and represents the core of nursing (Watson, 2005). Understanding these processes can be useful in developing a grounded theory of nursing practice, particularly using Corbin and Strauss’s (1997) axial coding framework, as these could guide the exploration of actions/strategies by the nurse to provide care. The ten caritas processes are listed in table 1.

**Table 1**

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1. Formation of a humanistic-altruistic system of values</td>
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<td>2. Instillation of faith-hope</td>
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<td>3. Cultivation of sensitivity to one’s self and to others</td>
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<td>4. Development of a helping-trusting, human caring relationship</td>
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<td>5. Promotion and acceptance of the expression of positive and negative feelings</td>
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<tr>
<td>6. Systematic use of a creative problem-solving caring process</td>
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</table>
7. Promotion of transpersonal teaching-learning
8. Provision for a supportive, protective mental, physical, societal, and spiritual environment
9. Assistance with gratification of human needs
10. Allowance for existential-phenomenological spiritual forces.

(Listed from Watson, 2005, pp. 297-298)

Transpersonal, as defined by Watson (2005), identifies a nurse’s understanding of a person’s subjective experience and inner world and transcends into connections with the person, spirit, and broader universe. Transpersonal caring, a key concept in this theory, describes moments when this transpersonal connection occurs through healing moments between a nurse and patient. Caring moments can be understood as human-to-human interactions with an exceptional understanding of nurse to patient (Watson). The focus of caring moments is not on disease or illness, as would be the science of medicine, but on healing and caring in a broader context (Watson, 2005). The final concept, caring-healing modalities, refers to the consciousness of the caring or transpersonal moments and is identified as transcending time, space, and physicality within the healing field (Watson).

**Defining Health and Mental Health**

Watson defines health and mental health as a unit within the theory and differentiates it from illness by describing harmony or disharmony within the mind-body-spirit. Explicitly, health is defined as “a subjective experience, unity and harmony with body-mind-spirit, health is associated with the degree of congruence between the self as perceived and the self as experienced” (McEwen & Wills, 2017, p. 180). The presence of disharmony between mind-body-spirit can cause a lapse in congruence, creating illness or perceived un-wellness, which is also a subjective state of the patient. Clinically, disharmony can occur when there is any disruption in physical health, mental health, or spiritual health, representing an integrative framework for understanding holistic health and wellness and illness, within patients.
The integration of mental and physical health into one health definition is appropriate when examining a person’s holistic wellness due to the interface between mental and physical health clinically. Mental and physical health are interrelated and significantly impact each other, despite siloed healthcare models. Philosophically understanding mental and physical needs as being parts of a greater whole can contribute to better integration of services clinically, which is currently not well accomplished (Doherty & Gaughran, 2014).

This definition of health also highlights the nurse’s role, who offers the “self as experienced” mirrored back to the patient and can contribute to harmony and holistic wellness. Watson identified caring moments, both actual and transpersonal, which can impact the patient and nurse’s well-being and caring experience. These moments serve as opportunities for the nurse to recognize and reflect the patient’s perceived self to enhance harmony (McEwen & Wills, 2016).

**Use in Developing Theory**

Watson’s Human Caring Theory has significant implications when used in the development of nursing theories, such as applying a grounded theory to nursing processes. Watson (2005) identified that this theory could be adopted as a model, framework, or ontological-epistemological foundation for furthering the nursing profession. This can be utilized in developing middle-range or practice theories, as it provides a base for a personal philosophy of nursing practice. In Corbin and Strauss’s grounded theory paradigm, which is intended for the proposed dissertation study, there are roots in both positivism and constructivism. In the constructivist aspects, there is an identified need for the researcher to establish their own worldview of the process of interest (Bernard, 2017). Adopting this theory as a philosophy of nursing can help the researcher build a solid ontological foundation. Furthermore, this can
provide a nursing-specific lens of data analysis which encourages 1) the viewpoint of caring as the core of nursing and 2) holistic health practices. This is particularly pertinent when examining the nursing process when caring (the core of nursing) for persons with SPMIs (centering integrative holistic health) at the EOL.

**Grounded Theory**

Grounded theory is a methodological and analytical approach to qualitative research with the goal of theory development following data collection and analysis. Unlike other qualitative methods, a grounded theory aims to delineate patterns in social processes, not solely lived experiences (Bernard, 2017). Social processes are identified as the focus within grounded theory, as the outcome is to develop a theory about a pattern or action (Glaser, 2005). Ground theory can be understood as both a methodology and a framework for research study development. It informs multiple aspects of study development, including sampling, data collection and organization, coding, and analyses (Chun Tie et al., 2019). Furthermore, paradigmatic underpinnings help to determine which philosophy of grounded theory a researcher adheres to, since variations of grounded theory have developed since its conceptualization in 1967.

**Historical Viewpoint**

Grounded theory was initially developed and disseminated by Barney Glaser and Anselm Strauss in their 1967 seminal publication “The Discovery of Grounded Theory”. The development occurred during a collaborative nursing study on dying patients within a hospital setting in response to the authors feeling limited by quantitative methodologies (Babchuk, 1996). Glaser and Strauss can be credited with highlighting the merits and necessity of qualitative data in science (Babchuk; Bernard, 2017). In the decades following their original publication, Glaser and Strauss divided ways and eventually published individual and contradictory works, sparking
some controversy within the qualitative methodological field (Babchuk). Since then, other perspectives of grounded theory inquiry have emerged (Chun Tie et al., 2019).

**Grounded Theory Perspectives**

Emerging grounded theory perspectives contain distinct differences that are necessary to understand when conducting grounded theory research. The three most popular perspectives of grounded theory are from Glaser, Charmaz, and Corbin and Strauss (Rieger, 2019). Understanding their similarities and differences can allow for a more in-depth application of grounded theory methodology to developing research.

Glaser and Strauss (1967) developed grounded theory from a positivist/postpositivist ontology, which acknowledges an objective truth and the independence of the data (knowledge) and the researcher (Rieger, 2019). Grounded theory rooted in post-positivism asserts that the researcher is purely objective and remains objective throughout data collection, analysis, and theory development (McEwen & Mills, 2016; Rieger). Glaser has since advocated for a purely inductivist approach and encourages grounded theorists to avoid predisposing literature and biases, including personal experiences (Bernard, 2017).

While Glaser has remained true to postpositivist and inductivist grounded theory, Strauss (later partnered with Julie Corbin) incorporated a more positivist/constructivist approach. He argued for enhanced use of deductive methods and analysis and close alignment to the literature base (Bernard, 2017). Constructivism asserts a more interactive, subjective role of the researcher and acknowledges a fluid, subjective truth (McEwen & Wills, 2016). This ontological view is in stark contrast to Glaser and Strauss’s (1967) original postpositivist seminal work. In their work, Strauss and Corbin have been identified as drifting in-between positivism and constructivism in order to uphold evolving qualitative research (Mills et al., 2006, pg. 4). Also differing from
Glaser’s grounded theory, Strauss and Corbin (1990) focus on “good science,” specifically the tenets of quantitative research, including generalizability, replicability, significance, and precision.

Charmaz, another prominent grounded theory researcher, draws heavily from Glaser’s traditional grounded theory approaches but applies a purely constructivist, as opposed to positivist lens (Rieger, 2019). Charmaz (2000) asserts that data are collected and produced interactively between the researcher and the participant (Bernard, 2017), which is also known as “co-construction” within inquiry (Chun Tie et al., 2019). This was developed in opposition the concept of purely objective researchers that occurred in positivist qualitative theory (Rieger). Charmaz asserts that data collection, analysis, and theory development are subjective and should be honored as such (Charmaz, 2000; Rieger). The use of frameworks in coding is not typical but not forbidden with Charmaz’s approach, with the author stating that the framework must “earn” its use in the analysis (Charmaz, 2014, p. 153).

Differences in the operationalization of each of these approaches exist, specifically in coding procedures, analytical process, and definitions of research quality. While strengths and weaknesses can be noted in each of these schools of grounded theory, they ultimately serve the purpose of providing nuanced yet similar ways to approach a variety of grounded theory research questions. These differences are necessary to understand and acknowledge when developing a grounded theory study.

**Grounded Theory Underpinnings**

Key similarities occur within the perspectives of Glaser, Strauss and Corbin, and Charmaz, which distinguish the approaches as grounded theory. For a grounded theory study to be of quality and rigorous, methodological congruence must be maintained throughout the study
(Chun Tie et al., 2019). This includes integrating theory-specific concepts such as theoretical sampling, coding stages (initial, intermediate, and advanced), Memoing, and constant comparative analysis. These concepts are essential within a grounded theory study, regardless of aligned perspective (Rieger, 2018). While different grounded theory perspectives exist, it is necessary to understand the underpinnings and similarities across these perspectives (Chun Tie et al.). This includes the use of staged coding and an iterative process from the beginning of data collection and analyses and should occur simultaneously. Babchuk (1996) further asserts that while there are pros and cons to each approach, it is necessary for researchers to cite seminal works appropriately throughout the process, no matter the approach being adopted and to carefully delineate steps in data collection, data analysis, and reporting to ensure a rigorous description of methods is provided.

**Grounded Theory Operationalization**

For this study, the guidelines set forth by Strauss and Corbin (1997) will be utilized. Being that Strauss and Corbin have roots in both positivist and constructivist ontologies (Rieger, 2019), their methodologies are well suited for dissertation research, in particular the aims of this study, which begin with a focused question prior to data collection and analysis and is heavily rooted in the relevant literature. Strauss and Corbin (1990) determine that this is appropriate to enhance theoretical sensitivity, and it is argued that grounded theory researchers should aim to use the literature base and their personal experiences as a basic understanding to theorize beyond. Despite this deductive approach, there is a predominantly inductive initial coding process before deductive axial coding. This allows for both inductive and deductive reasoning to be explored. Furthermore, the social process being examined in this study will fit nicely within the coding paradigm presented by Strauss and Corbin (1990). This coding paradigm includes
schemes in which to organize open coding and determine relations between codes and categories in the attempt to understand data relationships on a “meta-level” (Vollsteadt & Rezat, 2019). This includes a discussion of conditions, actions/interactions, and consequences. Even within this framework, the movement and action of the social process being studied can be understood and observed.

When choosing a grounded theory perspective to adhere to within a study, it is necessary to understand one’s own perspective of truth, knowledge, and the role of the researcher. This further leads to a clear choice of Strauss and Corbin’s approach to grounded theory research, as my personal beliefs lie midline on the positivist-constructivist continuum. I cannot surmise myself to be an entirely objective researcher, as I am a nurse who has worked with psychiatric patients. However, I cannot determine myself to be completely subjective and co-creating the data, as I have never practiced as a mental health nurse providing palliative care. It becomes necessary for me to understand the role of each of these in my research and theory creation. Strauss and Corbin’s approach best facilitates this and allows for both inductive and deductive analysis, capitalizing on my role in theory development of this study and providing a “crutch” where my understanding becomes limited.

**Definition of SPMI**

Within both the palliative care and general literature, there is an evident lack of congruence surrounding the terms “severe and persistent mental illness,” how it is defined, and what diagnoses “qualify” for this title. Sometimes this specific term is not used at all. For example, in a public health study determining death rates, Colton and Manderscheid (2006) used the terms “major mental health diagnosis” and “non-major mental health diagnosis.” Separately, Jerwood et al. (2018) refer to this same population as those with “severe mental illness” (SMI).
Differing terms, or similar definitions, with minor caveats exist throughout the literature. Without a well-understood definition and universal definition, prevalence rates are difficult to determine (Ruggeri et al., 2000). The incongruence in definitions creates a disjointed body of literature without a clear theoretical and conceptual basis for the population being discussed. Who would be included within this population makes the outcomes of research of persons with SPMI less clear on who it would impact and how to identify those in need.

The term “severe and persistent mental illness” was originally delineated by the National Institute of Mental Health in 1987, where it conceptualized SPMI as containing three dimensions (the 3 D’s): diagnosis, disability, and duration (Zumstein & Riese, 2020). Each of these dimensions had criteria necessary for a person to qualify as having an SPMI. Slade et al. (1997) argue that five dimensions should be included when attempting to determine the needs of health service allocation regarding definitions of mental health. While Slade et al. also include diagnosis, disability, and duration, they add safety and informal/formal support (SIDD). Safety refers to the safety of the individual with SPMI and those around them. This is related to the presence of symptoms such as self-directed violence or other-directed, abuse to or from others, or suicidality. The dimension of informal or formal support is identifying help from friends or family, or formal community services (Slade et al.). While these extra two dimensions may be necessary for holistic care, they may be challenging to evaluate for when identifying those who may benefit from mental health care and/or palliative care. Duration, diagnosis, and disability remain sufficient in determining objective severity and persistence. This is illustrated in Schinnar et al.’s (1990) study which evaluated the prevalence of SPMI varying by seventeen definitions applied to the same sample (n=222), resulting in differing percentages of sample inclusion of 4%-88%. The authors conclude that the NIMH (1987) definition identified middle-range
estimates. Despite the small sample size and outdated publication, few if any other publications exist that show this level of variance in applied definitions. Furthermore, Slade et al. developed the SIDD domains for community identification based on community surveys in the United Kingdom. As identified by Zumstein and Riese (2020), it is not realistic or necessary to identify an international definition of SPMIs due to the nuanced differences in mental health services and understanding across cultures, healthcare systems, and governing bodies.

Similarly, the definition of severe and persistent mental illnesses determined by Ruggeri et al. (2000) is often utilized to describe SPMI within the palliative care literature related to psychiatric illness. Ruggeri et al. state that an SPMI can be defined as a diagnosis of a prolonged or recurrent mental illness, impairment in activities of daily living, and a course of long-term treatment (>2 years). The impairment or dysfunction levels are operationalized as a score of 50 or below on the Global Assessment of Functioning Scale (Hall, 1995), indicating severe dysfunction (Ruggeri et al.). Like the NIMH definition, this definition does not indicate specific diagnoses but instead uses the 3 D’s and relies on the course of illness/treatment to demonstrate persistence and the impact of symptoms on functioning to denote severity.

When utilizing Ruggeri et al. (2000)’s SPMI definition, any mental illness at the level of severity and persistence defined can be included (Parabiaghi et al., 2006). This implies that in order to congregate SPMI by illness burden and not the presence of a specific diagnosis alone, the universally utilized SPMI definition should be the definition presented by Ruggeri et al. (Parabiaghi et al.). For an operationalized example, disorders such as generalized anxiety disorder (GAD), which is often considered long term and causes significant levels of dysfunction in patients (Castonguay & Oltmans, 2013), may be included on an individualized basis depending on its effect on functionality and length of the course of the disorder. Utilizing a
diagnosis-determined definition alone would miss persons suffering from GAD who are experiencing enhanced illness burden.

Parabiaghi et al. (2006) conducted a two-year longitudinal study to determine the external validity of the definition of SPMI delineated by Ruggeri et al. (2000). They found that when controlling for diagnosis of psychiatric illness, the Ruggeri et al. definition was equal in predicting psychopathology at the same rate of diagnosis alone. However, the Ruggeri et al.’s definition of SPMI was better able to capture disability and illness burden than diagnosis alone (Parabiaghi et al.); indicating, the Ruggeri et al. definition of SPMI is just as useful at catching psychopathology but better at catching illness burden. These findings are directly related to inclusion criteria in the context of palliative care, as one of the main goals is to reduce illness burden and increase quality of life.

Serious mental illness (SMI) is another commonly utilized term. This definition also was formed by the NIMH and is defined as “any mental, behavioral, or emotional disorder that results in serious functional impairment which substantially interferes with or limits one or more major life activities” (NIMH, 2019), but only focuses on diagnosis and disability. This definition also focuses on functional level and highlights disease burden as inclusion criteria and does not delineate by diagnosis alone. However, Ruggeri et al. (2000) operationalize functioning with a validated scale, creating a more complete clinical and conceptual picture.

Despite this delineated and validated definition by Ruggeri et al. (2000), much of the literature continues to define SPMIs by the type of disorder as opposed to the impact, leaving out many individuals with true SPMI’s as defined by Ruggeri et al. Further complicating this, varying types of disorders are used as defining SPMI and/or SMI. For example, Morgan (2016), in a study discussing nursing attitudes about patients with SPMI at the end-of-life, defines SPMI
by a diagnosis list, including schizophrenia, bipolar disorder, and depression, without describing further which subsets or types of the disorders are included. Butler and O’Brien (2018) cite the definition from Ruggeri et al. in their study determining palliative care access issues in New Zealand, but then further define the disorders by including schizophrenia, bipolar disorder, personality disorders, post-traumatic stress disorders (PTSD), and anorexia nervosa (AN). Unlike Morgan (2016), depression was not included but replaced with PTSD and AN.

In their pragmatic utility concept analysis, Zumstein and Riese (2020) identify a wide variety of theoretical and empirical definitions, with a special focus on SPMI in palliative care literature, which further fracture the literature basis. The authors determined that the concept of “severe and persistent mental illness” is only partially mature due to varying articulations and the need for further clarification and operationalization. They conclude that, particularly for palliative care, a definition created in conjunction with patients, caregivers, families, treatment teams, and government agencies should be utilized to fulfill the philosophy of palliative care. These conclusions were established after a rigorous systematic review conducted by two researchers, including an exhaustive search strategy and strict inclusion/exclusion criteria.

The lack of congruence between definitions creates a disjointed body of literature concerning persons with SPMI. In defining SPMI/SMI by diagnosis alone, there is the risk of including individuals who do not meet the specific criteria and excluding those who meet the criteria for a SPMI, but do not have a commonly included diagnosis. Future palliative care research needs to utilize a unified definition that is not based upon diagnosis alone, such as the one delineated by Ruggeri et al. (2000). Further complicating the definition of SPMI is the difficulties of SPMI diagnosis and classification. For this study, the definition of SPMI by
Ruggeri et al. will be used to facilitate a more comprehensive inclusion of persons as recipients of palliative care.

**Diagnosis and Classification of Mental Disorders**

What constitutes versus does not constitute a mental disorder arguably should require an objective answer. It can be argued that current psychiatric diagnosing symptoms are equivalent to medical practice circa the 19th century (Lilienfeld, 2014). However, diagnosis and classification of mental disorders differs from medical tactics. It is currently a clinically subjective process and largely relies on both professional and social contexts which may impact the recognition and classification of disorders (Frances & Widiger, 2012). Drawing the line between normal psychiatric occurrences and psychopathology has been debated and increasingly difficult to delineate (Stein et al., 2019). While there may not be one scientifically proven way to diagnose patients with mental health conditions correctly, it is necessary to understand the current widely accepted diagnostic tools and alternatives within psychiatry. It is necessary to understand our current classification systems’ pros, cons, and pragmatism as it frames our understanding of mental health issues.

**Diagnostic and Statistical Manual of Mental Disorders**

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) may be considered the most widely utilized and recognized text for psychiatric diagnosis. Despite its widespread use, benefits, and additions to the field of psychiatry, it also contains significant drawbacks, which continue in its most recent fifth edition (Frances & Widiger, 2012). The DSM was originally published in 1952 by the American Psychiatric Association (APA) in an attempt to develop a united diagnosis system in the United States, which at the time was relying on five different approaches to diagnosis from varying systems: the Army, the Navy, insane asylums,
veteran’s affairs, and prisons (Surís et al., 2016). More specifically, the DSM-I was conceptualized to address the growing need for mental health acknowledgment in veterans returning and reintegrating from World War II (Kinderman et al., 2017). The DSM was revised with the most recent edition published in 2013 and known as the DSM-5.

The DSM-5 has three major components: diagnosis classification, diagnostic criteria sets, and descriptive text (American Psychiatric Association [APA], 2020). The data classification within the DSM consists of codes congruent with the International Classification of Diseases (ICD) ninth edition, which can be used for data collection and billing. Diagnostic criteria sets are significant to each disorder and qualify symptoms, differential diagnoses, and rule-out criteria. Descriptive text accompanies each disorder and rigorously describes aspects of the disorder, including, but not limited to, diagnostic features, specifiers, or diagnostic measures (APA). The DSM traditionally does not contain treatment information or recommendations. Currently, the DSM-5 includes 20 chapters that are intended to encompass broad lists of mental health issues, for example, “neurodevelopmental disorders” or “schizophrenia spectrum and other psychotic disorders”. Chapters are further intra-organized by developmental lifespan considerations, with childhood disorders appearing first, if applicable (APA, 2013).

The first priority of the DSM is to guide practical clinical work. Frances and Widiger (2012) identify that the DSM provides a textbook language for clinical communication and translation of clinical practice for researchers, educators, students, insurance companies, and the legal system. This allows for dynamic communication and discussion across disciplines about the classification of mental disorders and provides a valuable clinical tool for disorder classification to understand better how to care for persons presenting with mental health distress
(APA, 2020). Despite its universal role in various systems and purposes, it is a master of none of these aspects and receives ongoing criticism in its usage.

**Criticisms of the DSM-5**

Kinderman et al. (2017) stated that the backlash to the 2013 publication of the DSM-5, nearly 20 years after its predecessor of the DSM-IV, was unprecedented in psychology. An outcry of prominent psychiatry figures and associations and the number of publications voicing conceptual concerns and petitions to boycott the manual emerged. Some of the major conceptual issues were identified by Frances and Widiger (2012). They described a lacking theoretical definition of mental disorder, limitations of descriptive psychology, its subjectivity to fads in diagnosing, and absence of a unifying theoretical underpinning. However, many of these issues branch from subjective psychiatric approaches in which the DSM is attempting to communicate across. Frances (2011) further describes the “grave dangers” of the developing DSM-5 in response to its published draft and focuses on the “reckless” new and expanded system of diagnosis. It was argued that while expanding the types of diagnoses, including new and not empirically tested diagnoses, and lowering the threshold for diagnoses, the number of people who would classify as “mentally ill” would drastically increase and potentially encompass those who did not need a diagnosis and/or treatment. The British Psychological Society (BPS) (2011) also expressed their concern over the increased “medicalization” of the DSM-5. They stated that the DSM-5 would continue to over-medicalize mental health while not being based on the same objectivity and empiricism required and expected in physical disorder diagnosis (BPS; Kinderman et al.).

As an alternative to this over-medicalization and classification, the BPS (2011) suggests an alternative treatment model. Illustrating with a clinical example, the BPS stated that according
to the DSM-5, two or three patients can present with schizophrenia yet have no overlapping symptoms or experiences (BPS). Because of this common occurrence, the BPS questioned the need for a classification system at all and instead recommended a treatment system based on a patient’s description or complaint of symptoms, with the example provided of “hearing voices” or “feelings of anxiety” (Kinderman et al., 2017). “Classifying” by what the person with a mental health issue is experiencing may be a more direct way to approach their treatment. Kindeman et al. expanded on the BPS statement further by identifying that the classification of all mental health issues as illnesses separates the persons’ subjective complaints from their social and political contexts, which are necessary for understanding the person holistically. Furthermore, classification has not been traditionally accurate in predicting treatment response (Insel et al., 2010). This method of treatment and identification would be especially effective in the context of palliative care for mental health, as it focuses less on the presence or absence of a diagnosis but more on the patient’s subjective experiences and their defined quality of life. However, a system such as this would lose the cross-communicative abilities the DSM-5 provides and may greatly depreciate the ability to communicate effectively about patients and their treatments on an interdisciplinary level or even between psychiatrists of different backgrounds.

Further criticisms were summarized by Lilienfeld (2014), who identified the categorical nature of the DSM-5 as problematic, most notably evidenced by “not otherwise specified” (NOS) diagnoses. The presence of NOS categories alone arguably illustrates the failures of the DSM-5. Furthermore, increasing the number of diagnostic categories is thought to occur organically on a spectrum or dimensional plane, as opposed to taxonomic (Lilienfeld). The issue of comorbidity and co-occurrence, in many diagnoses, including traumas, mood disorders, and personality disorders, is the rule rather than the exception (Lilienfeld & Treadway, 2016). While other
replacements have been suggested for the DSM, such as the International Classification of Diseases (ICD) and Research Domain Criteria (RDoC), Frances and Widiger (2012) argue that there is, unfortunately, no current better contender. The field has become flooded with too many options to choose from with similar arguments for prioritization, leading the majority to lean back on the DSM.

**International Classification of Diseases**

WHO developed the ICD system to serve as an international classification system of diseases, which included both medical and mental health disorders. The ICD system is a categorical classification system used to define, identify, and report disease data at an international level. Currently, over 100 countries utilize the ICD to monitor and report disease prevalence, morbidity, and mortality. Available in 43 languages, the ICD allows for cross-cultural communication about disease classification (WHO, 2020). The ICD is currently in its 11th edition and is referred to as the ICD-11. The ICD-11 offers categorical definitions and descriptions of both physical and mental diagnoses and specifies a coding system in which to identify the diagnosis. The ICD codes for disorders are embedded within the DSM to provide further tracking and standardized identification of diagnoses, particularly for billing purposes. Due to the similar categorical classification systems, the ICD often is lumped into DSM criticisms (Lilienfeld & Treadway, 2016).

**Research Domain Criteria**

Research Domain Criteria (RDoC) is a framework for psychopathology launched by the National Institute on Mental Health (NIMH) following continued frustrations with the ICD and DSM classification systems, echoing many of the reservations as described above (Insel et al, 2010). RDoC relies heavily on biological assumptions about mental illness and stems from an
understanding of dysfunctional neurocircuitry (Lilienfeld, 2014). Insel et al. describe the three assumptions of RDoC: mental illnesses are brain disorders, dysfunctions in neural circuits can be measured with tools within neuroscience (such as brain imaging), and biosignatures, conglomerated from genetics and neuroscientific clinical data, will be valuable in clinical treatment when used alongside a presentation.

RDoC, as it stands currently as a NIMH proposal, can begin to address many of the voiced concerns over the DSM-5 classifications system. For example, RDoC, as identified by Lilienfeld (2014), is more in line with dimensional psychopathology, which the DSM-5 is lacking. It furthermore will allow more integration of neuroscience into diagnostics within psychopathology and further address the issues of “medicalization” without the science to back it up, as discussed within the DSM-5 (Lilienfeld). Conceptual barriers also exist within the RDoC proposal. Lilienfeld identified that RDoC over-rely on biological units and measures, which furthermore are subject to measurement error. Moreover, it may be difficult to define behavioral phenotypes to pathological neurocircuitry (Lilienfeld).

**Relationship to Palliative Care Provision**

Current practices in defining, diagnosing, and classifying mental health conditions are notably less than ideal (Frances & Widiger, 2012; Hyman, 2010; Lilienfeld, 2014; Stein et al., 2010; Suris et al., 2016). Psychiatric illness is challenging to define and even more difficult to diagnose accurately, which is why the importance of looking at the population as a whole is so intensified. This understanding lends itself further to utilizing more holistic, person-centered approach to mental health issues, their impact on quality of life, and their role in palliative care. This section also delineates the issues with qualifying persons for palliative care, or illness
severity, when using diagnosis alone. Diagnosis of mental health issues is still largely misunderstood and hotly debated.

When looking at one specific diagnosis for the inclusion of palliative care, it is noted that persons within this diagnosis are being lumped together in the same bucket. In actuality, this may not be the case. For example, it has been argued that persons with schizophrenia should be evaluated on a spectrum, much in the same way as autism, instead of “fitting the bill” for schizophrenia. This would more accurately describe the severity, symptoms, and impairment that may be occurring within this population. Furthermore, it would more likely encompass persons who may not be meeting certain severity clauses but meeting other aspects of schizophrenia. This concept can be applied to other psychiatric issues and can be especially useful in the application of palliative care. For example, a diagnosis of anxiety or generalized anxiety disorder may not fall under the assumptions of “severe” or “SPMI” and oftentimes may not be. However, there are persons with severe cases of GAD that produce distressing functional impairment and remain refractory to treatment. In some cases, GAD may be more disruptive than mild cases of schizophrenia. However, public opinion will typically see schizophrenia as the more disruptive disorder; the patient who has schizophrenia may receive prioritized access to treatment, even if (looking on a spectrum) it is not causing the same severe symptoms or disruption. SPMIs do not need to be competitive or pitted against each other. Still, it is essential to understand that severity wavers and no one diagnosis is entirely undeserving of palliative intervention.

Therefore, for this study, it is necessary to understand SPMI and those who may fall under this category using a more holistic, patient-based, quality of life focused subject. Therefore, the definition proposed by Ruggeri (2000) will be utilized, and specific diagnoses within this population will not be addressed. Current needs and quality of life, as well as care
setting, will be used to identify patient populations of interests, as opposed to specific psychiatric diagnoses.

**Psychiatric Care Model: Recovery in Care**

**Recovery Model**

In the history of mental health treatment, recovery was not always considered a viable end-goal in care. Maintenance, with an expectation of gradual deterioration, was expected. This represented a relatively pessimistic view of care goals for persons experiencing mental illnesses (Morgan & Townsend, 2017). More recently, The Substance Abuse and Mental Health Services Administration (SAMHSA) has moved toward a model of recovery for persons with mental illnesses (Morgan & Townsend; SAMHSA, 2020). Beyond a “model” of recovery, the conceptual integration of recovery into mental health care can be recognized as a social movement (Warner, 2010) or an individual journey of care autonomy (Jacob, 2015). Regardless of defined processes or dimensions, the underlying mantra of recovery is that the Recovery Model is meant to serve as an ongoing treatment guide, vision, and perspective of care, as opposed to an endpoint in care (Hummelvoll et al., 2015; Jacob; SAMHSA).

The Recovery Model has defined dimensions and processes which facilitate its integration into care. SAMHSA has identified four dimensions critical to facilitating recovery in mental illness: health, home, purpose, and community. Health refers to holistic health, including effective management of mental and/or physical diseases. Home refers to the person experiencing mental illness having a safe, stable, and supportive place to live. Purpose refers to a persons’ autonomy, independence, and perceived meaning in society, and community is defined as family, friends, and support systems. Hope is a critical foundation within each of these dimensions and determines a belief that illnesses and mental health struggles can be overcome.
Hummelvoll et al. (2015) further identify three interacting processes in recovery: personal, social, and spiritual. Personal processes necessitate the redefining of self and self-attributes, such as self-esteem or self-control. Social processes refer to the relationship between person and environment. Spiritual processes define an individual’s ideological world (Hummelvoll et al.).

While the concept of recovery may have been brought to light in antipsychiatry movements of the 20th century (Hummelvoll et al., 2015), the Recovery Model now may be seen as a complementary perspective to normal psychiatric practice (Jacob, 2015). Jacob clarified that the goal of the recovery model is not for persons to attain their premorbid level of function. It instead focuses on providing autonomy to the patients and views “recovery” as a journey in which the patient is in charge. The goals of the recovery model include independence and autonomy in holistic care, which is sharply contrasted from previous paternalism within psychiatry and medicine (Jacob). The ultimate purpose is to facilitate persons with mental health struggles to take control of their lives, regardless of symptoms, and find meaning in it. Recovery is possible, and in some cases, probable. Hummelvoll et al. further identified that the setting for recovery is that of everyday life, situating it as a personalized and highly individualistic journey.

**Criticisms of the Recovery Model**

Bayetti et al. (2016) apply a critical lens to the implementation of the recovery model in mental health care. In their literature review, the authors identify “elephants in the room” regarding recovery, largely in the Recovery Model's failure to address distinctly lacking political economies. While the authors are specifically referencing the disparities noted among race, gender, and class in India, the same disparities can be seen among persons with mental illness in the United States (Centers for Disease Control [CDC], 2013). It is not reasonable to assume that every person in need of mental health services has a home, for example, or a system of social
support. Oftentimes, particularly in racial and ethnic minority groups, persons with mental illnesses aren’t even given equal access to care (Cook et al., 2016), let alone service options in line with the autonomy of the Recovery Model.

Further criticisms exist due to the questionability of the empiricism of the Recovery Model and the ability to support it with rigorous evidence (Peysar, 2001; Warner, 2010). Peysar goes so far as to suggest the recovery model can actually impede recovery due to its lack of scientific evidence. However, Warner offers a rapid review of empirical evidence to support recovery and recovery-based care in persons with schizophrenia. The author also describes clear evidence to support a central tenet of recovery, empowerment, and the building blocks of empowerment, which can include a persons’ insight, level of internalized sigma, or presence of peer support.

It is important to recognize the limitations of the Recovery Model and acknowledge that it may not be applicable to all persons with mental health issues at this time. However, the United States healthcare system should continue to adopt the Recovery Model as a social movement and recognize the impact that allow all persons with mental illnesses a stake in their recovery process. While the Recovery Model may not yet be seen as possible for all persons, it can be viewed as an ultimate goal in health care to achieve.

Recovery as a Concept

The concept of recovery has its roots in person-centeredness. It focuses on persons taking control of their lives and situations and serving as the “person in charge” of their recovery (Hummelvoll et al., 2015). Three types of recovery can be understood: spontaneous recovery, clinical recovery, recovery alongside active symptoms. Spontaneous recovery occurs when a diagnosis has previously been provided, but the person recovers without formal treatment.
Spontaneous recovery is often attributed to individual characteristics, such as resilience. Clinical recovery is a recovery in response to formal clinical intervention, such as medications. Recovery alongside active symptoms occurs when the person with a mental illness identifies themselves practicing autonomy and control in their lives over their illness and symptoms, regardless of its continued presence (Hummelvoll et al.).

**Palliative Care Connection**

The integration of palliative care is well suited to serve as an adjunct perspective to the Recovery Model. There is a distinct overlap in many of the conceptual underpinnings of both the recovery model and palliative care philosophies, most notably in the emphasis on patient involvement and holistic care. Furthermore, palliative care integration is not always contingent on the presence of a prognosis or potential for recovery (except for in cases of hospice care, specifically). Therefore, palliative care integration will not hinder or halt recovery model goals but could instead serve as another tool for patients to choose to integrate. Jacob (2015) stated that patients with mental illnesses should have full care autonomy and, when feasible, choose services to include in their care or not include. At this time, patients with mental illnesses, specifically SPMIs, are not being given palliative care services as an option (Butler & O’Brien, 2016).

**Palliative Care**

**Definition**

Palliative care is most often defined utilizing the World Health Organization (WHO) (2019) definition: an approach to care that focuses on improving patients and family members’ quality of life of during life-threatening illnesses. Goals of palliative care include prevention and relief of suffering (WHO). An interdisciplinary team most often delivers palliative care to
provide holistic and comprehensive care to the individual and family (Dumanovsky et al., 2016). Palliative care is considered most effective when introduced early in a chronic illness (Rowland & Shumann, 2010). Palliative care can be provided as a specialty service with an interdisciplinary care team or as primary palliative care. Dimensions of palliative care further delineate the role and scope of palliative care services.

**Domains**

The National Consensus Project (NCP) (2018) described eight specific domains of palliative care:

- Structure and process of care
- Physical aspects of care
- Psychological and psychiatric aspects of care
- Social aspects of care
- Spiritual and existential aspects of care
- Cultural aspects of care
- Ethical and legal aspects of care

These domains of palliative care aim to provide insight into the holistic needs of a person receiving palliative care services.

**Specialty Palliative Care**

The NCP defines specialty palliative care as being delivered to patients by specifically trained care providers, including board-certified physicians or palliative-certified nurses, social workers, pharmacists, chaplains, or other potential care team members. The specialist or certified palliative care providers should be providing effective palliative care in the domains mentioned.
above and aim to improve the quality of life of patients and families experiencing complex health issues or symptomatology.

**Interdisciplinary Team**

Interdisciplinary team (IDT) members can include physicians, nurses, social workers, pharmacists, chaplains, family members, or any person identified as benefiting the patient and family’s care (NCP, 2018; WHO, 2019). The NCP presents guidelines for IDT working in the context of palliative care. They identify that IDTs should aim to provide holistic, patient-focused care to those in need. Furthermore, the IDT should be continuously available and have the skills to provide developmentally and culturally appropriate care.

The use of IDTs in palliative can be considered more effective than solo specialists alone. In an exploration of the process of IDT care provision, Ciemins et al. (2016) developed a grounded theory detailing this process. The authors reported clinically relevant professional attributes identified by IDT members during semi-structured interviews, which provided rich insight into the impact of IDTs on IDT members, patients, and families. Professional characteristics identified by participants included increased self-awareness and humility. As a team, IDT members discussed the benefits of having a shared purpose as professionals and enhanced holistic thinking while collaborating with other IDT members. These professional qualities were identified as positively impacting the patient’s palliative care and palliative care outcomes.

The patient-focused outcomes discussed by Ciemins et al. (2016) are augmented by the findings of O’Mahoney et al. (2010), specifically in an intensive care unit (ICU) setting. O’Mahoney et al. reported the outcomes of 157 patients who received care from a newly integrated ICU palliative care team utilizing a case-control design. The findings reported on a
variety of palliative care outcomes. For example, in relation to advanced directives, the authors found a significant increase in the presence of advance directives pre-IDT (33%) to post-IDT intervention (83.4%). The use of opioids was also significantly higher in the intervention group (p=0.01). At the same time, the utilization of laboratory and radiological testing was significantly lower (p=0.004, p=0.027), showing patients were subject to increase comfort measures and shielded from unnecessary tests. The study, however, was not blinded, which could indicate significant bias in results. These results are important despite limitations since they can be triangulated with other literature. In their review of the literature, Ehikpehae and Kiernan (2018) found similar findings in a multitude of studies: interdisciplinary teams are beneficial to patients receiving palliative care, including end-of-life care, and have impact on comfort measures and service utilization.

**Primary Palliative Care**

Primary palliative care is non-specialty, non-team frontline palliative care and refers to palliative skills that all providers are trained in, such as skilled assessment and communication (Ahia & Blais, 2014). All frontline staff, including nurses, can provide palliative care. Sreedhar et al. (2020) defined the key component, or skills, of primary palliative care: efficient communication, symptom management, psychosocial, emotional, and spiritual support to patients and families, and facilitation of shared decision-making among care teams, patients, and their caregivers. Some primary palliative care goals acknowledgment/management of distressing events and their holistic impact on the patient and family (Sreedhar et al.). One can argue that all nurses have been trained in the basic skills needed to provide primary palliative care and should use these skills to tailor all care provision to a palliative perspective when possible. This can enhance patients’ care and quality of life (Erencoff et al., 2020).
Paice et al. (2018), in their summary of the 2017 Palliative Nursing Summit, identified the integral role of nursing in promoting primary palliative care and moving it forward in practice. The authors determined that nurses are well suited to extract evidence-based resources and practices to holistically apply symptom management practices to diverse groups of patients. Nurses should prioritize primary palliative care as being effective, efficient, and safe.

**Primary and Specialty Palliative Care Comparison**

Primary and specialty palliative care are meant to be complementary, not competitive. Both care interventions provide distinct, yet overlapping, services intended to provide more holistic care to patients and families in the face of chronic illness. In a rigorous systematic review, Erencoff et al. (2020) aimed to compare interventions and outcomes of randomized control trials focused on specialty and primary palliative care services. They noted no trials exist directly comparing the two services. One criterion assessed in both specialty palliative care and primary palliative care trials was the amount of NCP domains addressed in the study, out of the eight total which have the potential to be addressed by palliative care providers. The authors used this criterion to ascertain the comprehensiveness of palliative care interventions, as a higher number of domains met (out of eight) is an indicator of more comprehensive care. They found that specialty palliative care was more comprehensive, with trials averaging incorporation of 4.2 NCP domains, as opposed to primary palliative care trials, which incorporated 3.1 (p=0.02). Furthermore, they found that while specialty palliative care interventions had an even split of providers, physicians (44%) and nurses (44%), primary palliative care interventions were delivered overwhelmingly by nurses (75%). Overall, the authors determined that specialty palliative care was more strongly associated with decreased symptoms than primary palliative care.
Despite its potential of being less effective than specialty services, primary palliative care can help facilitate closing the accessibility gap that specialty palliative care services cannot fill at this time. Primary palliative care can enhance the spread of basic palliative care skill application to more patients when the availability of specialty palliative care services falls short. This can, in-turn, free-up specialty palliative care services to allow focus on more complex or comprehensive cases that require specialty intervention (Quill & Abernathy, 2014). A model of primary and specialty palliative care should be utilized to address all patient needs and increase accessibility.

**History of Palliative Care**

In the 1960s, Cicely Saunders introduced palliative care. As a new nurse working with Dr. Mike Richards, they described the needs of terminal cancer patients and developed a palliative program of research in the context of breast oncology (Clark, 2007). Palliative care was conceptualized as an alternative option for persons with terminally ill cancer to die comfortably, as all previous treatment options were strictly curative (Clark). While its roots are in oncology and end of life, the scope of palliative care has dramatically expanded since the 1960s (Clark) and is now used in non-oncological diagnoses, including heart failure, chronic obstructive pulmonary disease, dementia, and other life-limiting illnesses (National Institute on Aging [NIA], 2019). Palliative care has also moved beyond end-of-life care. Although it still encompasses hospice as a subset of palliative care specific to end of life, it is appropriate early in a chronic and life-limiting illness (NIA; WHO, 2019).

While psychiatric symptomatology secondary to primary medical illness such as anxiety or depression following a diagnosis of a chronic illness is addressed within the scope of palliative care, persons diagnosed with SPMIs are often left out of the conversation. In their book
addressing the entire spectrum of palliative care nursing, Stevens et al. (2009) discussed all potential populations and healthcare settings a palliative care nurse might. Persons with SPMI, or any psychiatric population, were not discussed, even within chapters devoted explicitly to marginalized groups within society and how to access them from a palliative nurse perspective (Stevens et al., p. 35-53).

In the same year that Stevens et al. (2009) were published, Woods et al. (2008) disseminated a systematic review which was the first publication to synthesize the state of literature related to palliative care within the SPMI population. They concluded that although the topic was beginning to gain traction within research, gaps in the literature were numerous and very little was known about the palliative care needs of persons with SPMI. This review, updated in 2019 by Donald and Stajhudar, drew similar conclusions. Although there has been ongoing research in this area since the Wood et al. review, very little was known about the specific palliative care needs, and the voices of patients and caregivers were largely missing from the data available.

**Palliative Care Needs of the SPMI Population**

Specific palliative care needs of the SPMI population are currently not well addressed within the literature in the context of palliative care. In their systematic review of the literature concerning palliative care and SPMI, Woods et al. (2008) concluded that persons with SPMI should be “assumed to have the same palliative care needs as the general population.” While this is an appropriate starting point to address palliative care needs and service utilization, it can be expected, due to the nature of the care complexities, that palliative care needs may be highly complex, adaptive, or different from the general population. However, there is not currently literature to support this or provide insight into specific palliative care needs of the SPMI
population as a whole, leaving a significant gap in literature and care. Within the current literature, primary research is limited in determining what is specifically needed by this population within the domains of palliative care. While care complexities are described, symptomatology is not well addressed and the specific needs of this population, who are experiencing debilitating psychiatric symptoms, are not yet appropriately delineated. However, insights can be drawn from understanding the needs of persons with SPMI in the domains of palliative, respectively. For example, to determine holistic starting points for palliative care interventions, needs within physical, psychosocial, spiritual, and end-of-life domains can be explored.

**Projected Needs in Palliative Care Domains**

Care complexities are common themes throughout the literature potentially serving as both reasoning for and barriers to palliative care utilization within the SPMI population. Care complexities identified as specific to this population fall into palliative care domains as described by the NCP. Exploring the care needs through the lens of NCP’s domains allows a more holistic view of persons with SPMI diagnoses during palliative care encounters.

**Psychiatric Domain**

Psychiatric symptoms alone provide a more complex aspect to care than those with general medical illness. Within SPMI, there is a range of psychiatric symptoms including (but not limited to) anxiety, depression, paranoia, delusions, mania, dysthymia, and overall, seemingly “unusual” behavior (Castonguay & Oltmanns, 2012; Donald & Stajhudar, 2019). These are typical of multiple types of psychiatric disorders and create barriers to care for the person. In a qualitative study by Jerwood et al. (2018), clinicians who had contact with persons with SPMI identified that psychiatric symptoms (referred to as the “presentation of the patient”)

were an aspect of this population that makes caring for them more challenging. Patients may be distrusting, paranoid, or even combative during care. Anxiety or delusions can interrupt the care process by facilitating patient mistrust of the healthcare system (Jerwood et al.; Donald & Stajhudar). Evenblij et al. (2016) further identified that the presence of psychiatric symptoms also could potentially mask ongoing physical symptoms, particularly the presence of pain. Psychiatric symptoms (for example, word salad in schizophrenia) may make it more difficult for persons with SPMI to communicate effectively and comfortably. The presence of psychiatric symptoms may also increase the use of psychiatric medications, which can further exacerbate psychiatric symptoms or interfere with medications used with physical illnesses (Donald & Stajhudar).

Furthermore, denial of illness becomes a problem due to psychiatric illness. Often, persons with SPMI will deny any physical or psychiatric illness leading to a lack of care-seeking and increased risk behaviors (Donald & Stajhudar, 2019). Engagement in health risk behaviors, such as smoking, poor diets, binge drinking, and lack of exercise, may be considered symptoms of psychiatric illness as opposed to conscious behaviors (CDC, 2003; Jerwood et al., 2019). Butler and O’Brien (2018) concur that these lifestyle factors cannot be considered choices but instead refers to them as physical and environmental consequences of having an SPMI diagnosis.

Physical Domain

Physical illnesses are common comorbidities in persons with SPMI and contribute to care complexity and illness burden. Some of the most common physical comorbidities in persons with SPMI include respiratory diseases, cardiovascular disease, diabetes, cancers, gastrointestinal diseases (such as Crohn’s disease or irritable bowel syndrome (IBS)) and human immunodeficiency virus (HIV) (Butler & O’Brien, 2018). In their comparative study, Jones et al.
(2009) determined that approximately 50% or more persons with SPMI have two or more chronic, comorbid medical conditions. While their sample size only contained an n=147, they compared their findings with a Medicaid data set of 11,185. They found that their determined prevalence rankings were nearly identical and therefore considered more generalizable. This increased risk of diseases is considered to be due to the presence of an SPMI diagnosis, which may entail decreased immune function, reduced or delayed access to care, and engagement in high-risk behaviors (Jerwood et al., 2018; Mahoney et al., 2018; Morgan, 2016)

Higher rates of physical comorbidities in persons with SPMI lead to an average shorter lifespan of approximately 15 – 25 years compared to non-SPMI peers (Colton & Manderscheid, 2006; De Hert et al., 2011). Colton and Manderscheid compared years of potential life lost (YPLL) in persons with mental health versus non-mental health issues. Looking across 8 U.S. states, they found the mean YPLL was approximately 27.6 years. This rate averaged two years higher for major mental health diagnoses (schizophrenia, bipolar disorder, major depression, delusion, and psychotic disorders) compared to non-major mental health diagnoses (other mental health diagnoses). Furthermore, Lawrence et al. (2013) determined that the life expectancy gap for psychiatric patients has increased since 1985 for both males and females (2.4-year increase for males, 1.6-year increase for females). Seventy-seven percent of deaths contributing to this excess mortality are associated with medical illness, with the majority categories being cancer (13.5%) and cardiovascular disease (29.9%). Suicide also was a main contributor to excess mortality (13.9%) (Lawrence et al.). Death from physical illness is also occurring faster than in the non-psychiatric population with the same physical illness. For example, Kisely et al. (2015) found that persons with psychiatric illness and cancer experience increased mortality despite having a similar cancer incidence as the general medical population (hazard ratio = 2.27).
Mahoney et al. (2018) address a specific need of the SPMI and comorbid physically ill population by assessing how appropriate pain management impacts acute care utilization within this population. In a study of 74 participants, 59% of whom had current psychiatric disorders, pain management related to physical illness utilizing an opioid treatment plan was correlated to a decrease in acute care utilization. The results were both statistically ($t=-2.49, P=0.15$) and clinically significant, as participants showed a 31% reduction in acute care use in the 12-month period as opposed to the 12-months prior to the study. However, this study poorly defined SPMI and did not include patient-specific outcomes of symptom management (e.g., objective pain measures) to determine if the symptom of pain was well controlled. They also did not consider the distorted relationship with pain that persons with SPMI may have, which includes reduced recognition or understanding of pain or distinct presentations of pain from that of the general medical population (Evenblij et al., 2016). This suggests that typical pain scales (i.e., numerical pain scales given during standard treatment) may not be sufficient in measuring actual pain levels in persons with SPMI. Yet, they are used in studies measuring pain in persons with psychiatric illness (Mahoney et al.).

**Social Domain**

Persons with SPMI face social issues that can further complicate the care trajectory of psychiatric and physical illness comorbidities. Persons with SPMI may not have a strong support system from family or friends. Psychiatric symptomatology and associated stigma may be isolating and difficult for loved ones to cope with. Often, potential support systems have “cut ties” with persons with SPMI (Evenblij et al., 2016; Morgan, 2016). In a mixed-methods study by Evenblij et al., nurses identified a disjointed social support system as one of the biggest challenges in caring for persons with SPMI. They described the lack of social contacts for
external support and difficulty bonding with care staff. Nurses felt quality of care was lost without this trust between patient and provider.

Stigma may also play a major role in the care and treatment of persons with SPMI within the healthcare system as well as socially with loved ones. In their review of the current literature, Donald and Stajhuder (2019) identified that stigmatization of persons with SPMI might often delay appropriate treatment for psychiatric or physical illness. Brown et al. (2019) further described this stigma as persons with SPMI may be seen as “troublesome, disruptive, or even dangerous” (p. 11). For example, Mittal et al. (2014) identified primary care providers (nurses and physicians) as significantly more likely than mental health providers to have stereotype and have negative attitudes. Thus, outside of the mental health realm, persons with SPMI may face stigmatization from those who should be providing them care. Logically, an illness creating such tumultuous symptoms that feed into that stigma should be placed as a priority of healthcare providers due to the inherent marginalization, but it instead serves as a barrier to all care.

End of Life

In a survey of mental health nurses, Evenblij et al. (2016) found the most common physical or emotional needs at the end of life, specifically for a psychiatric inpatient SPMI population, was lack of energy, lack of appetite, pain, and sadness. While this study provides valuable insight into potential physical needs at the end of life, it is from a provider point of view (as opposed to patient) and was from a pre-formed survey of palliative care needs. It, therefore, may not catch complex or unique psychiatric needs and needs beyond physical illness. As further identified by Elie et al. (2018), persons with SPMI may have a completely redefined relationship with suffering and personal values due to the nature of their disease, the care complexities accompanying it including stigmatization and societal marginalization, and the quality of life
associated with lifelong psychiatric illness. Current measures to determine burden or suffering which are not tailored to persons with SPMI and consider these intricate care complexities (Elie et al.) may not be sufficient.

**Access to Care**

Persons with SPMI have decreased access and later than their non-SPMI peers (Butler & O’Brien, 2018; Donald & Stajhudar, 2019; Woods et al., 2008). Happell et al.’s (2012) systematic review determined that persons with serious mental illness have reduced access to preventative medical services for cancer or infectious diseases when looking at a specific diagnosis individually or as a group. This may potentially increase mortality within specific disease cohorts, such as cancer within a person with SPMI (Kisley et al., 2015).

Specific to palliative care access, Butler and O’Brian (2018) performed a retrospective cohort study to determine if persons with SPMI were receiving palliative care referrals in hospitals with specialty palliative care as often as their non-SPMI peers. They found that the SPMI population was 3.5 times less likely to receive palliative care referrals than the hospital’s general population included in the study. Persons with SPMI were less likely to receive palliative care referrals at the end of life. Despite this study being done in rural New Zealand without highly generalizable results, it gives important insight into how persons with SPMI may not be receiving the care they deserve. Furthermore, their outcome measure was “referral” to palliative care services. The actual rate of service utilization was not determined; therefore, the exact number of persons with SPMI receiving palliative care may be less than they initially determined. This is the only study found that compared palliative care access rates between the SPMI and non-SPMI populations.
Palliative Care Integration

While palliative care needs are not yet appropriately explored from the perspective of the individual or caregiver of the SPMI population and within all potential domains, palliative care is still understood as an appropriate approach to care that should be integrated into psychiatric disease trajectory. In their cross-sectional study, Trachsel et al. (2019) surveyed 457 German psychiatrists to determine the perceived level of appropriateness for palliative care within the SPMI population. Seventy-five percent of the responding psychiatrists agreed that palliative care would be appropriate in persons with SPMI, specifically in anorexia, schizophrenia, depression, bipolar disorders, and substance abuse disorders. While this study is not necessarily generalizable to the U.S., it provides insight into the acceptability of a palliative care approach by psychology providers. Furthermore, a diagnoses approach definition was used, so the results are only useful for specific diagnosis and not generalizable to all persons with SPMI defined by function.

Gaps exist in the literature related to palliative care needs in persons with SPMI. Most glaringly, there are no studies that were done within the context of palliative care and psychiatric illness (SPMI or non-SPMI), which contain the voices of persons with SPMI. The mention of family members or caregivers’ needs is also distinctly lacking, despite a focus on palliative care outcomes (WHO, 2019). Furthermore, palliative care needs mentioned within this population are about common physical comorbidities (Elie et al., 2018; Morgan, 2016), when the burden and symptoms of psychiatric illness alone may warrant palliative care intervention.

Palliative Care in Specific Diagnoses

Insight into palliative care provision and utilization can be understood when examining literature about palliative care integration into specific SPMI diagnoses. Often, conclusions about
the SPMI population are made from studies conducted purely on persons with one diagnosis, most often schizophrenia. While all inferences about the entire SPMI population should not be made based on research about solely persons with schizophrenia, this literature base can provide preliminary insight into palliative care integration in the SPMI population.

**Schizophrenia**

**Palliative care provision**

Relyea et al.’s (2019) scoping review of the literature aimed to determine what was known about end-of-life care for people with schizophrenia. Following the inclusion of 32 articles found within peer-reviewed literature and gray literature, the authors provided a narrative synthesis and found four overarching themes: stigma affecting quality and access of care, issues related to consent and capacity of patients, best practices, and barriers to care. Stigmatization of healthcare workers towards persons with schizophrenia was identified in 13% of articles and was identified as negatively impacting care, particularly in the attribution of physical illness to psychiatric symptomatology. This was identified by authors as contributing to lower quality of life in patients.

Concerns of consent were identified in 41% of articles and further classified into subthemes, capacity for end-of-life decision-making, difficulties in understanding terminal diagnoses, and significant lack in substitute decision-makers (Reylea et al., 2019). While the capacity for end-of-life decision making has been echoed in other studies regarding the entire SPMI population (Elie et al., 2018; Foti, 2003), they were not identified as concerns but rather areas of improvement on the end of the healthcare professional. Persons with SPMIs were identified as having the ability to take part in decision-making (Elie et al.; Foti).
Another systematic review on end-of-life care in schizophrenia concluded with major themes focusing on health care disparities, ethics, and palliative care (Baruth et al., 2020). These themes are similar to themes developed by Reylea et al. (2019). Both studies focused on stigmatization and disparities faced by persons with schizophrenia and ethical concerns and problems with palliative care provision. Neither systematic review included the method of systematic critique or quality evaluation of their included literature, despite an equally rigorous search and inclusion/exclusion methods. Many of Baruth et al.’s and Reylea et al.’s conclusions were based on a significant number of case studies, which had no apparent methodologies or rigor. Therefore, while these studies provide valuable insight and an overview of current literature, it should be noted that the current literature base detailing palliative/end-of-life care in persons with schizophrenia has room for significant improvement in rigorous methodologies and is not currently all encompassing.

Some of the studies included in the above literature reviews provide valuable insight based on rigorous methodologies. For example, McNamara et al. (2018) conducted interviews with various health care professionals who have either provided direct care to persons with schizophrenia at the end of life or supervised end-of-life care provision in Australia. After 16 semi-structured interviews and independent thematic analysis by two authors, they determined two overarching domains of themes: unmet needs of the person with schizophrenia at the end of life and barriers and facilitators to palliative care provision to persons with schizophrenia at the end of life.

The unmet needs of persons with schizophrenia identified by the participants were insightful. Participants identified a “colorful” personal and social history, which can often lead to alienation and a lack of caregivers or social support at the end of life. Participants also identified
significant delays in physical healthcare, from both the system and individual side, leading to advanced and often untreated physical illness at the end of life. Further exacerbating end-of-life difficulties is the lack of a designated or “safe,” service to utilize for end-of-life care. Hospices are often not equipped or comfortable providing end-of-life care to persons with schizophrenia, and hospitals or psychiatric facilities may be equipped for the psychiatric portion, but not the end-of-life portion (McNamara et al., 2018).

McNamara et al. (2018) also identified barriers and facilitators to end-of-life care in persons with schizophrenia, which focused mainly on system-wide issues. Participants in this study identified difficulties in prognosis and understanding disease progression due to decreased health care interaction by those with schizophrenia and misunderstanding of symptoms, most often cancer. Furthermore, poor collaboration between healthcare sectors, such as palliative care and mental health care, created siloed healthcare provision and a decreased holistic focus.

**Palliative care access**

Beyond palliative care provision to persons with schizophrenia, some studies have been conducted which address access to palliative care by persons with schizophrenia. Within three prominent retrospective matched cohort studies, differing and contradictory results have emerged. Fond et al. (2019) and Viprey et al. (2020) both conducted retrospective cohort studies using nationally representative French data exploring palliative care utilization of persons with schizophrenia and cancer at the end of life. Fond et al. looked at all cancers, while Viprey et al. looked specifically at lung cancers. Using case-matching and multivariable generalized linear models, both studies concluded that when controlling for age, sex, and diagnoses, persons with schizophrenia were more likely to receive palliative care services at the end of life (odds ratio
Findings by Fond et al. (2019) and Viprey et al. (2020) differ from findings by Chochinov et al., 2012 who determined in their similarly designed retrospective cohort study that persons with schizophrenia were less likely to receive palliative care in the last six months of life (odds ratio 0.48, 95% CI 0.41-0.57, p = <0.001), and less likely to receive opioid analgesia at the end of life (relative risk 0.7157, p = 0.0006). Spilsbury et al. (2018) also found in their retrospective matched cohort study that persons with schizophrenia were less likely to receive specialist palliative care services at the end of life (case 6.5%, control 15.8%, p<0.0001).

While these results are based in Canada and Australia, respectively, which are different health systems from the Fond et al. (2019) and Viprey et al. (2020) studies set in France, they still provide differing conclusions, which should both be taken into consideration. Furthermore, while Fond et al. and Viprey et al. concluded about the increased palliative care use in persons with schizophrenia, they also both concluded that persons with schizophrenia were less likely to receive “high-intensity” end-of-life care, which consists of interventions such as chemotherapy and surgery. While this can be considered a “lost opportunity” for persons with schizophrenia (Fond et al.; Viprey et al.), interventions such as chemotherapy can hinder a person’s placement in hospice care and can be considered a barrier to a “good death” (Harrington & Smith, 2011).

While insights gathered from literature detailing the experience, needs, access to, and barriers to palliative care provision in persons with schizophrenia, they denote only a portion of the necessary understanding of the experience of providing palliative care to persons with SPMIs. Therefore, it is necessary to understand what is being researched and take it as a piece of
the puzzle instead of a complete picture. Understanding these results helps us gain further insight to continue to triangulate the SPMI population’s needs.

**Other Specific Diagnoses**

Literature about palliative care implementation in other specific SPMI diagnoses exists but is limited in terms of quality and quantity. However, it is important to continue to evaluate and incorporate this literature because it builds a groundwork for conglomerating and triangulating further needs and insights of palliative care provision to the SPMI population.

**Bipolar Disorder**

Fond et al. (2019) repeated their retrospective study on schizophrenia but focused on bipolar disorder as the diagnosis of interest in the replication (Fond et al., 2020). The authors found similar results, which they determined were not significantly different from their study on schizophrenia (Fond et al., 2019; Fond et al., 2020). Persons with bipolar disorder received specialty palliative care more often than their case-matched controls, who did not have an SPMI diagnosis (odds ratio 1.49, CI 1.32-1.69, p = <0.001). No other studies were identified that examined palliative care in bipolar disorder, specifically.

**Severe and enduring eating disorders (SEEDS)**

Severe and enduring eating disorders, particularly anorexia nervosa (AN), have only been mentioned in one relevant article, which reflects a literature review on the use of harm reduction, palliative care, and the concept of futility in persons with AN (Westmoreland & Mehler, 2016). The authors discuss these concepts in relation to AN as they are not previously discussed effectively. The authors identify that palliative care, including hospice care, may be helpful for persons with intractable AN who do not wish to pursue treatment. Since the article is published within the contexts of “law and psychiatry,” the authors also present both sides of the argument.
of futility of treatment in SEEDS, including AN. They state that futility, and thus terminal positionality of the diagnosis, are difficult or near impossible to determine due to the psychiatric nature of the disease. However, ignoring the potential terminality of SEED diagnoses can potentially continue the stigma that the mind and the body are separate, which complicates social views and patient preferences in end-of-life care (Westmoreland & Mayer). While offering useful insight on the ethics of palliative care administration, particularly at the end of life, in persons with AN, this study does not provide valuable clinical insight, and lacks a rigorous literature review methodology.

**Substance abuse disorders**

Two articles discussed the topic of terminality in persons with substance abuse disorder by identifying the potential need for advance care planning (ACP) in persons with substance abuse and discussing the ethics around hospice referrals. In a perspective piece, Brown (2020) identified difficult clinical situations involving persons with substance abuse disorders and noted that the healthcare system is not equipped currently to provide them with appropriate care. Persons with addiction may be forced to treat it as terminal; for example, choosing hospice care versus recovery as inpatient hospice care is more conducive to some lifestyles of persons with substance abuse (Brown). While mainly a perspective piece, the article provides insights into providers’ ethical dilemmas of trying to coordinate care but is not empirical. Fleshner et al. (2019) further explored the use of the question, “would you be surprised in this patient died in the next year?” which is a validated question for physicians prognosticating in patients for hospice. Applying this question to persons with substance abuse may warrant earlier intervention for end-of-life actions such as advance care planning, an opportunity few persons with severe substance abuse are given (Fleshner et al.).
Relating to other provider dilemmas at the end of life, Sager et al. (2020) discussed a case study of opioid misuse and illicit fentanyl use in the contexts of terminal cancer. The authors identified that in their experience, the most important factors for “success” in the management of substance abuse disorder in terminal illness were increased visits with patients (once weekly) frequent contact with the psychiatry team. However, these are not always feasible due to limited resources and increased burden on the patient for travel time and cost-coverage of increased visits. Furthermore, the authors elaborated on urine drug screening in end-of-life care. They identified that urine drug screening is necessary for clinical decision-making but did not cause a reflexive action in prescribing. By not being punitive, the authors identified they were better able to build rapport with the patient and counsel him on reducing misuse of illicit substances while maintaining pain control (Sager et al.).

In terms of incorporating typical interventions for persons with substance abuse, Groninger and Knapik (2019) identified the potential to incorporate the Alcoholics Anonymous (AA) 12-step program to illustrate the integration via two case studies. The 12-step program in AA assists persons recovering from addiction through a series of stepwise goals done both individually and collectively within an AA local support group. The authors identified the potential spiritual benefit to patients in recovery or actively using substances at the end of life due to the spiritual roots of the AA 12-steps. The authors identify that hospice staff should perform a substance abuse screening (even for past abuse) in their comprehensive assessment. Hospice staff should also be familiar with the 12-steps to provide insight into incorporation into end-of-life care, have 12-steps materials on hand to disperse if needed (Groninger & Knapik). Due AA programs’ popularity and success, it is reasonable to discuss the role of AA in a patient’s recovery to potentially facilitate spiritual care.
While the studies mentioned above begin to provide valuable insight into palliative care and substance abuse, there are significant limitations. In their rapid evidence review, including a quality critique, Witham et al. (2019) identified 60 studies related to end-of-life care for persons with alcohol and drug problems. They found that only half (n=32) of the studies were empirically based, and of the empirical articles, only 28.1% (n=9) were of high quality. Many of the limitations were methodological as well as content. There is a need for more studies outside the context of White persons with cancer when exploring end-of-life care needs (Witham et al.), particularly due to high rates of other illnesses within the population of substance abuse, including cardiovascular and respiratory disease. The authors further identified a lack of studies about alcoholism and liver cirrhosis at the end of life, which can have significant unique implications on a person’s dying process. The authors determine the literature is new, underdeveloped, and in need of in-depth qualitative exploration.

**Borderline personality disorder**

Borderline personality disorder (BPD) is a psychiatric illness that can occur on a spectrum that consists of labile moods and disturbances in self-image and behavior (NIMH, 2017). Persons with BPD can experience sudden outbursts of anger or anxiety and depression for varying lengths of time. Persons with BPD may have self-harm or suicidal tendencies, difficulty trusting others, and an erratic social history. A borderline personality disorder affects between 1-6% of the population (Chapman et al., 2019; ten Have et al., 2016), and up to 20% of the psychiatric population (Chapman et al.).

When examining palliative care considerations for persons with BPD, Hill (2005) identified factors for provision success from a single case study analysis. Predictors for successful hospice care implementation included agency-related factors and nurse-related
factors. Nurse-related factors consisted of nurse’s ability not to take things personally and having a solid relationship with family members and a mental health nurse, if available. Because persons with BPD often use outward deflection as a coping mechanism, insults to care providers are common and expected. The nurse should be able not to internalize any statements made by the person with BPD. Hill suggests nurses working with BPD patients should seek private therapy. Relationships and collaborations with family and mental health nurses (if either are available) are encouraged to facilitate effective care provision and reduce nurse burnout and assist the nurse in setting care boundaries. For example, Hill identified limiting the number of calls by the patient to the agency. Collaboration with the family helped keep the number to less than five calls from the patient to the agency per day. Agency-related factors included providing nurse consistency to the patient, with one nurse as the ideal number, and strong support by hospice nurse supervisors to continually back the nurse in the field as professional and personal support (Hill).

Feely et al. (2013) presented another case study regarding a person with BPD at the end of life. They focused on applying “unifying principles” of caring for persons with BPD as presented by Hay and Passik (2000). Feely et al. describe a case of a hospice patient with BPD and substance abuse who was receiving less than optimal symptom control due to staff limitations of understanding how to manage and work clinically with BPD. After psychiatric-focused education provided by interdisciplinary team members, effective care and symptom management were able to be achieved by hospice staff. Unifying principles of care for BPD included both staff and patient-focused processes. Staff-focused processes included educating staff and using regular debriefings to remain focused on symptom management to preserve the health of the care team. Another principle focused on provider and staff demeanor, which consisted of maintaining emotional neutrality and consistent reassurance to the patient of
nonabandonment. Patient-focused principles included maintaining consistent providers to ensure patient comfort and boundary setting with calm, consistent enforcement (Feely et al.; Hay & Passik).

Terpstra and Williamson (2019) explored similar facilitators to palliative care for persons with BPD in their case study vignette series and revealed similar results. Facilitators to care identified in case studies included the usefulness of building rapport, using negotiation tactics and flexibility in care, and setting patient boundaries. A large aspect of building rapport was recognizing personal and social stigmas against persons with BPD and setting them aside in care. BPD is one of the most stigmatized mental health disorders, and the name of the disorder is often used as a derogatory term (Terpstra & Williamson). Understanding personal biases can help nurses build rapport with persons with BPD. In terms of flexibility, the authors described a patient demanding opioid medications and would become violent when refused, despite increasing somnolence and a nearly comatose state. The providers worked with the patient, who agreed to do physical therapy and massage therapy, while slowly reducing opioid medications to a safe level. Within two months, the patient had a 40% opioid reduction and reported a decrease in pain. Boundaries were also identified as a necessary aspect of working with persons with BPD, which was also discussed by Hall (2005). A boundary example was provided when the authors described staff offering the patient actions and consequences, including, if the patient’s room remained soiled, the staff enter twice daily to clean. The patient, desiring increased privacy, worked independently to keep the room clean within her preferences.

The case study series by Terpstra and Williamson (2019) allows further insight into palliative care for persons with BPD, but like Hall (2005) and Feely et al. (2013), offers a limited glimpse due to the nature of case studies. Crowe et al. (2011) identified the importance of case
studies in providing in-depth analysis of specific occurrences and the strengths in using them to learn more about a phenomenon. However, each of these case studies lacks transparency in data collection and analysis (Crowe et al.), confirming this research area needs further exploration with more rigorous methods. Despite that, from what has been done, the most commonly identified tactic was boundary setting for the patient to maintain control (Feely et al.; Hall et al.; Terpstra & Williamson). This is important to note as it is not a typical part of hospice care for non-SPMI peers. It is important to understand the needs of patients with BPD as they constitute a large portion of SPMI comorbidity, and persons providing end of life care for SPMI patients are likely to encounter BPD spectrum tendencies.

Factors Complicating the End of Life for Persons with SPMIs

Various factors related to both the person and the environment can effect EOL care for persons with life-limiting illnesses and SPMIs. It is necessary to understand these factors in order for them to properly be addressed. While literature is scarce on the influence of these factors on the SPMI and terminally ill population, preliminary inferences can be made from periphery literature, examining both effects on EOL populations and, if available, on SPMI populations.

Person-Level Factors

It is important to note that the person-level factors discussed are intersectional in EOL care, as they are in life (Gott et al., 2020). While discussed as separate pieces, they actually represent a complex web of the influences of a person on their EOL experience and care.

Gender and Sexuality Considerations

Gender has been examined as an influencer to EOL care in terminally ill populations, including the impact of identification as a gender minority or member of the Lesbian-Gay-Bisexual-Transgender (LGBT+) community. Gott et al. (2020) identified a significant lack of
research on gender-informed palliative care, despite complex and intersecting gender considerations for men, women, and transgender persons.

Gender has been shown to influence EOL care, including how persons may accept or receive support and experience their disease. Ullrich et al. (2019) identified that females at the EOL might be more expressive in their emotions and seek more provider involvement in their care, while males may rely heavily on a partner for care and support and seek to maintain autonomy longer. However, symptoms may be expressed or internalized differently. Gott et al. (2020) identified that women might internalize pain or fatigue due to a long social history of these symptoms, often being dismissed or ignored in women or labeled hysteria. Furthermore, women who need to accept the care provided have expressed feeling like a “failure” in their caregiver role. This is true for the other side; when men must take on the role of a caregiver, it has been identified they may feel like failures in this aspect if they are inexperienced (Gott et al.).

Gender also has significance in mental health care and the experience of mental illness. Gender impacts a persons’ relationships to self, others, and society and impacts their daily experiences, which in turn influences mental health and illness (Judd et al., 2009). Gender can also influence the types and severity of an illness (for example, higher rates of depression/anxiety in women and higher rates of substance abuse/suicide in men) (WHO, 2020). There are high rates of abuse within severe mental illnesses that also vary by gender. Men with SPMIs are at a higher risk for physical victimization, while women with SPMIs are at a higher risk for sexual and/or domestic violence (Khaliefeh et al., 2015). These risks can be elevated at the EOL and should be considered when providing EOL care.
Within the LGBT community, significant barriers have been identified for palliative care recipients and persons with mental health needs. Considerations that can complicate EOL care include discrimination by the healthcare system, social isolation, fear and mistrust of healthcare professionals, and poor clinical preparation of providers, all of which have been identified as contributing to suboptimal palliation in the LGBT population (Haviland et al., 2020).

**Racial and Ethnic Considerations**

Systemic racism permeates all aspects of the healthcare system and impacts minority populations seeking health care in any fashion, which should be considered by all healthcare professionals when providing care (Feagin & Bennefield, 2014). Mental health and palliative/EOL care are no exception. Inferences for the impact of race on EOL care for persons with SPMIs can be made when examining the impact of race on EOL services in general. There are significant considerations for both EOL attitudes and access to EOL care. Rosenfeld et al. (2007) identified racial attitudinal differences, as White patients may accept of hospice services, particularly in the home setting, while African American patients may prefer aggressive treatment choices. Race has also been shown to influence EOL care preferences, EOL spirituality needs, and cultural considerations, which are largely ignored within the literature (Kraukauer, 2002; Gardner et al., 2018). Furthermore, minority populations may have different attitudes due to poor communication styles of majority White providers with minority populations (Rosenfeld et al.). In a study of differences between White, Hispanic, and African American hospice patients, 20% of African American patients believed their care would be better if they were of a different race (Rosenfeld et al.). Furthermore, it has been shown that the treatment of minority patients in EOL care differs. For example, less analgesia is used in minority populations, despite similar levels of EOL pain (Krakauer et al.).
Disparities impacting access and quality of care are the norm in mental health care (McGuire & Miranda, 2008). While SPMIs have a higher lifetime prevalence in White Americans than minority populations, there are still significant implications to care access. Racial minorities more often have inadequate access to care, and when care is accessed, it is often of poorer quality (McGuire & Miranda). This is noted particularly among racial minority patients with comorbid substance abuse issues, who have identified significant discrimination, hostility, and poorer treatment overall, leading to distrust of the mental health system or even stopped treatment (Mays et al., 2017). These differences in care illustrate significant access issues in mental healthcare for racial minorities that extends into EOL care. For example, Orstein et al. (2020) found that despite an increase in hospice service availability, persons of minority populations, particularly African Americans, are less likely than White persons to receive hospice care for more than three days, regardless of life-limiting diagnosis. Furthermore, racial minorities are more likely to die in hospitals without EOL planning engagement, which is often associated with a poorer death experience (Orlovic et al.).

**Socioeconomic Status**

The impact of socioeconomic status (SES) is not well understood in EOL care utilization but is known to be associated with worse health outcomes in patients (Lewis et al., 2011). Socioeconomic status typically consists of an interplay between income, education, and occupation (American Psychiatric Association, 2020), all of which can impact access to, quality of, and preferences within healthcare. Davies et al. (2019) found that lower SES is indicative of a higher likelihood to experience a hospital death, a measure that typically indicates poor EOL care. However, Wales et al. (2018) identified that the desire for a home death was more likely to occur in patients with a higher SES who had a more stable home environment to facilitate a good
death. Therefore, persons with SPMIs, who frequently experience poverty (Topor et al., 2016) may have different preferences for their place of death. However, these EOL preferences may not be met due to the decreased access to healthcare services among lower SES groups (Lawrence & Kisley, 2010), which unfortunately encompasses many persons with SPMIs (Sylvestre et al., 2018).

Beyond preferences, the presence of monetary poverty can have implications for disease burden in patients with SPMIs. When comparing combinations of chronic illnesses, mental illness, and substance abuse, Walker et al. (2016) found that an added layer of poverty to any combination above increased the risk for poor health and poorer quality of life. This concept of increased illness burden in patients with monetary poverty can be applied to EOL situations in SPMIs, as lower SES has been associated with earlier mortality in persons with SPMIs (Martin et al., 2014).

**Cognitive/Functional Impairment**

Cognitive impairment is typically discussed in the context of dementia and its impact on patients. While there is a correlation between SPMIs and dementia development (Ahern et al., 2020; Reppermund et al., 2020) and high incidence of comorbid dementia and SPMIs (Forando et al., 2020), cognitive impairment can be present in persons with SPMIs solely as a result of the mental illness (Trivedi, 2006). Functional impairment is also noted significantly in persons with SPMIs and has been demonstrated in a variety of SPMI diagnoses, including anxiety, obsessive-compulsive disorders, and schizophrenias (Tanner et al., 2019). Both cognitive and functional impairment can complicate EOL care by necessitating increased formal or informal caregiver involvement. However, this may not be available to persons with SPMIs due to decreased healthcare access options (Lawrence & Kisley, 2010) and frequently strained family
relationships (Zabeen et al., 2020). Cognitive decline was also found to be a predictor of enhanced symptom burden at the EOL, which was distressing for both patients and caregivers (Klinkenberg et al., 2004). Furthermore, the presence of cognitive impairment can make the process of consenting for hospice more difficult (Fields & Calvert, 2015), and impact persons with SPMIs who may not have caregivers to help with decision-making.

**Symptom Burden**

Type of physical illness can clinically define symptoms that may contribute to extraneous symptom burden at the EOL. Persons with chronic respiratory diseases, for example, may experiences aggravated shortness of breath at the EOL, which can be difficult to manage, particularly in the last week of life (Kinkenberg et al., 2004). Additionally, polypharmacy, often associated with the treatment of SPMIs, can aggravate symptoms at the EOL and should be considered when evaluating symptom presentation (Schenker et al., 2019). However, mental health symptoms, such as anxiety and depression, are prevalent at the EOL, regardless of a mental health history (Kozlov et al., 2019). It is known that the quality of life of persons with SPMIs is decreased over the course of a lifetime (Sagayadevin et al., 2018), which can complicate exacerbated EOL mental health symptoms. Symptom burden and symptom severity of both mental and physical symptoms is a clinically complicating factor at the EOL. Fox et al. (2018) identified that the severity of mental health symptoms often reduces treatment-seeking by persons with SPMIs, due to internalized stigma (or self-stigma) and fear of repercussions from health care workers. Furthermore, typical palliation does not account for persons with mental health histories, such as substance abuse or psychiatric medications, who may react differently to palliative medicines and receive sub-optimal symptom control (de Veer et al., 2018).

**Previous Life History and Course of Treatment**
A person’s previous life history can impact their EOL experiences. Within the SPMI population, there are high rates of trauma and victimization which be a risk factor for or a result of their illness (de Mooij et al., 2015). Therefore, trauma-informed palliative and EOL care are indicated for this population. Trauma-informed EOL care aims to recognize how the synergistic properties of a person’s life history and traumas can impact the EOL experience and symptoms, including pain and anxiety (Ganzel, 2018).

The integration of palliative care services in the course of treatment can also impact quality of life at the EOL. Persons who receive earlier palliative care integration may experience a higher quality of life at the EOL, evidenced by fewer aggressive treatment decisions and more care preferences being honored. The decision to enter hospice care can also be complicated by the type of diagnosis, as persons with cancers versus non-cancer diagnoses can be more likely to enroll and receive formal hospice and early palliative care (Waldrop & Meeker, 2012).

Preferences for Care

End-of-life preferences for persons with SPMIs have been explored briefly in the literature. Traschel (2018) identified the ethical need of exploring EOL preferences of persons with SPMIs. As persons with SPMIs are shown to have intact decision-making, not including preferences for care at the EOL is a ethical issue, not a clinical one. In studies examining decision-making abilities of persons with SPMIs, it has been shown that persons with SPMIs have strong care preferences and have the ability to state these, identifying they should be included in care planning (Elie et al., 2018; Foti, 2003; Foti et al., 2005; O'Neal et al., 2008). This can include preferences for daily living, location of care, or services provided.

Veteran Status
A person’s veteran status is an integral part of their EOL experience (Shamas & Gillepse-Heyman, 2018). It has implications for the SPMI population due to the prevalence of SPMIs among military veterans (Trivedi et al., 2015). Persons with a veteran status may cope with life-limiting illness differently due to ingrained military culture (Shamas & Gillepse-Heyman). Furthermore, the effects of military-related post-traumatic stress disorder (PTSD) can have implications for EOL care experiences and is often under-appreciated outside the Veteran’s Affairs (VA) community, where less than half of all veterans are enrolled (Shamas & Gillepse-Heyman). Veterans have also been shown to have complicated spiritual distress at the EOL, which needs special intervention by EOL interdisciplinary teams and specialized chaplains (Chang et al., 2014).

**Environment Related Factors**

Factors of the environment surround the person with SPMI can influence their EOL care and experience. These can include the setting in which care is occurring, insurance and reimbursement issues, social support and stigmatization, and the impact of COVID-19.

**Setting of Care**

The setting of care at the EOL, or place of death, can impact the EOL experience for persons with SPMIs. Persons with SPMIs have been shown to die most often in nursing homes (NH) (Lavin et al., 2017; Martens et al., 2013; Wilson et al., 2020). This setting has implications for the EOL care of persons with SPMIs.

**Nursing Home.** The quality of life in nursing homes (NH) at the EOL can potentially be considered less than optimal due to a of appropriate facilities and training of NH staff in EOL care (Pivodic et al., 2018). The EOL period in nursing homes can be viewed from both the EOL patient and the staff perspective. Patients at the EOL in NHs have identified that they wish to
remain autonomous until the EOL, which is not always an option in NHs (Carlson, 2007). However, persons who reside in NH, even those with SPMIs, often wish to die within the NH as it is their identified home environment. Patient factors facilitating this can include having a preference to die at home, a primary terminal diagnosis of cancer, and having multidisciplinary palliative care integrated early on in illness and carried through to the EOL (Costa et al., 2016). Cordner et al. (2010) found that, in NHs, those with higher cognitive function subsequently received more pain medication resulting in an overall higher quality of life, while those with behavioral issues had a lower quality of life. While this study was done in NH residents with dementia at the EOL, preliminary inferences can be made about the SPMI population in NHs at the EOL.

Furthermore, from the nursing perspective in NHs, there is a lack of training, support, and staffing in NHs to provide exemplary EOL care, often leading to the use of hospitals and emergency services for NH residents at the EOL (Carlson, 2007). While EOL education and training are needed in NHs to provide adequate symptom management at the EOL, high clinical staff turnover rates may further impede educational programs and enhanced care (Carlson).

**Homelessness.** Approximately one-third of homeless individuals suffer from an SPMI (Harvard Health, 2014), or about one-sixth of the SPMI population are homeless. This makes it necessary to discuss homelessness in EOL care provision when discussing the SPMI population. Persons experiencing homelessness (PEH) have significant barriers to effective palliative and EOL care impacting care delivery and their EOL experiences.

De Veer et al. (2018) identified significant implications in EOL care for PEH, including complex care trajectories and access issues. Late, if any, access to palliative care is common among the homeless SPMI population due to both patient and provider factors. Palliative care
clinicians are often uneducated about providing EOL care to PEH, and PEH are often distrustful of the healthcare system or experience a need for enhanced autonomy. The combination of these creates a vicious cycle of lapsed care provision (de Veer et al.). Furthermore, PEH may put off care or avoid healthcare professionals due to a fear of not being treated with dignity or respect at the EOL because of their housing status (Klop et al., 2018). Other complicating factors included: proper identification for care, unwillingness to accept growing health issues, lack of transportation, active psychosis or addictions, risks to personal safety, and social support groups not recognized by healthcare providers (Klop et al.; van Dongen et al., 2020).

**Social Support**

Social support at the EOL is integral in a persons’ meaningfulness of life and has roots in impacting the psychosocial, spiritual, and existential needs a person may have (Dobrikova et al., 2016). More broadly, familial relations can be a mediator to various of EOL concerns, such as the place of death or time of palliative care provision. Unfortunately, family ties of persons with SPMI are often turbulent or strained due to past painful events related to psychiatric symptomology (de Veer et al., 2018). Impacts of SPMIs on the family can span generations and induce adverse physical, mental, and social outcomes (Fekadu et al., 2019). Beyond familial relationships, persons with SPMIs are known to have diminished social networks, with subsequent reduced social support and capital (Sweet et al., 2018). Support to persons with SPMIs is often from other persons with SPMIs (de Veer et al.), who are not able to care for sick or terminally ill persons and are often unreliable in support provision.

**Reimbursement for Care**

While hospice care and effective symptom management at the EOL can be considered a human right (Adams, 2008; Praill, 2005), it is necessary to discuss care costs and
reimbursements since can impact care provided to persons with SPMIs at the EOL. Medicare and Medicaid services provide coverage for persons with mental health conditions over age 65 and under age 65, respectively. Medicaid provides health care coverage to persons with low-incomes or disabilities, which encompasses much of the SPMI population. Medicaid covers nearly one-third of the SPMI adult population (Zur et al., 2017).

Under both Medicare and Medicaid, hospice benefits entail reimbursement of nearly 100% of hospice costs across a variety of settings, including inpatient, outpatient, and home hospice (Hospice Foundation of America, 2020). However, prior to hospice intervention, treatment for comorbid physical and mental health conditions can be expensive. In 2010, the average cost for a Medicare beneficiary was approximately $9,000. The average cost for a beneficiary with an SPMI and substance abuse disorder was over $40,000 (The SCAN Foundation, 2013). Fortunately, if preferred by persons with SPMIs and determined eligible, effective hospice intervention (as covered by Medicare/Medicaid) is cost-effective and reduces unnecessary and unwanted medical interventions and can save up to $383 million in national yearly healthcare costs (Pham & Krahn, 2014).

While Medicare and Medicaid largely cover formal hospice services across settings, some states have not accepted these national expansions and leave upwards of 30% of their population under age 65 incapable of dying with dignity through hospice services (Betancourt, 2016). This includes Texas and Wisconsin, which have the highest numbers of uninsured citizens. While the Hospice Foundation of America (2020) identifies “charity care”, or hospice care provided for free from agencies or by donations, this occurs in less than 1% of hospice encounters (Betancourt). When persons cannot afford hospice or are uninsured without assistance, their options for dying with dignity becomes limited.
**Stigma**

Differing types of stigma can impact the EOL process for persons with SPMIs, including self-stigma, societal stigma, and healthcare stigma. The effects of stigmatization have been identified as reducing help-seeking in healthcare as well as increasing the disease burden of a mental disorder (Gierk et al., 2018).

Self-stigma, also known as internalized stigma, frequently occurs in the SPMI population and contributes to low self-esteem and self-worth (Abiri et al., 2016). This occurs when societal stigma is internalized, and the person believes negative beliefs about themselves (Corrigan & Rao, 2012). Self-stigma is well established in young persons with SPMIs and has recently been shown to expand into geriatric persons, including persons with SPMIs residing in NHs (Tzouvara et al., 2018). The presence of self-stigma could impact psychosocial or existential aspects of end-of-life care, as well as negatively impact social functioning (Yanos et al., 2012).

Societal stigma is the most common type of stigmatization against persons with SPMIs and contributes to enhanced prejudices, stereotypes, and discrimination of this population (Corrigan & Rao, 2012). Societal stigma is known to contribute to self-stigma and healthcare stigma and works similarly in deterring persons from seeking healthcare and receiving adequate healthcare (Tzouvara et al., 2018). This can be influenced largely by news and media representation of persons with SPMIs, which is often poorly (Ross et al., 2018).

Clement et al. (2015) found that healthcare stigmatization was one of the biggest deterents in seeking healthcare, with men, ethnic minorities, and veterans being the most deterred. Furthermore, when physical or mental health care is provided, it is often to a lesser degree or poorer quality. Operationalized types of stigmatization that occur in healthcare include negative attitudes, unconscious biases, pessimism about ongoing therapies, and poor mental
health skills among providers (Knaak et al., 2017). Within the mental health field, persons with substance abuse or active psychosis are often recipients of the highest levels of stigma (Rao et al., 2009). This has implications for EOL care, where substance abuse and schizophrenia will occur, potentially without healthcare provider self-awareness of stigmatizations impacting care.

**COVID-19**

Implications of COVID-19 should be considered when providing EOL care to persons with SPMIs during the period of the pandemic. Muruganadam et al. (2020) noted that isolation associated with COVID-19 has increased the incidence of non-adherence to medications in persons with SPMIs, which has subsequently exacerbated symptoms. Disruption of services and previous routines associated with COVID-19 can be more stressful for the person with SPMI than otherwise (Barber et al., 2020). These enhanced stresses can permeate to EOL care when provided to persons with SPMIs during the COVID-19 pandemic.

**Current Understanding of Staff Views of Palliative Care Provision in SPMI Population**

Clinical staff’s point of view is an integral part of the literature pertaining to palliative care for persons with severe and persistent mental illnesses. Exploring staff views was a focus of three articles pertaining specifically to end-of-life care, and one pertaining to palliative care. Jerwood et al. (2018) explored clinical staff’s views of caring for persons with severe mental illness at the end of life. Clinical staff were identified as those from a mental health trust and a hospice who had “some experience” working with persons with severe mental illness and end-of-life care. While the specific clinical staff was not defined, it was identified that they were a multidisciplinary group. Focus groups were utilized as a data collection method, with the inclusion of 23 clinical staff within the groups. As opposed to focus groups, McGrath and Forrester (2006) and Morgan (2016) used individual interviews to identify clinical staff’s views.
McGrath and Forrester identified clinical staff (nurses, educators, and coordinators) from an institutionalized mental health facility who had been involved in the care of dying clients. Like McGrath and Forrester, Evenblij et al. (2016) performed a mixed-methods study to explore inpatient mental health nurses’ experiences providing inpatient palliative care. Morgan interviewed nurses from both a hospice/palliative care background and a mental health background. Results from each of these qualitative studies provide similar and complementary insights.

Each of the studies identified themes from the clinical staff related to preparedness of clinical staff in caring for a person with severe and persistent mental illnesses at the end of life. Jerwood et al. (2018) identified this concept in two overarching themes, “the structure of the system” and “the confidence of the clinician” (p.7). The topics that emerged from their focus groups pertained to the “siloing” of healthcare professionals into specializations, such as mental health or palliative care, leaving no one prepared to provide care from both specialties, and allowing patients to “fall through the cracks”. This concept is echoed within Morgan (2016), who identified the theme of the need for continued support and education for nurses working in palliative care and/or mental health in order to prepare both sides to act adequately. Evenblij et al. (2016) identified this topic as “little attention” to palliative care within psychiatry. However, McGrath and Forrester (2006) identified, from the perspective of institutional mental health staff, that there is a distinct theoretical overlap between mental health care and palliative care, due to the holistic, person-centered nature of both specialties.

Issues of legality was another cross-cutting theme within the staff views literature, particularly related to risk and resuscitation in end-of-life scenarios for those with mental illness. McGrath and Forrester (2006) and Jerwood et al. (2018) discussed the legality and lack of
guidance or clear policy surrounding cardiopulmonary resuscitation, specifically within an institutional mental health setting. McGrath and Forrester further illustrated this staff concern by highlighting the follow-up of a death within the mental health institution, palliative or not, requires coronial inquest. Coronial inquests can cause distress to clinical staff who are uncomfortable with a litigious inquiry. Some staff even reported police questioning following the death of a patient who was considered palliative due to the setting of institutionalized mental health (McGrath & Forrester).

The theme of “characteristics of the client impacting care” emerged in interviews by Morgan (2016) and Evanblij et al. (2016), as well as focus groups by Jerwood et al. (2018). Morgan described the stigma of mental illness from the nurse impacting care, specifically in an end-of-life setting when palliative care nurses may not be experienced in mental health diagnoses and presentations. Patient symptoms also create potential barriers: hostility or paranoia can make establishing trust difficult (Morgan), and refusal of care and aggression can create symptom management issues (Jerwood et al.). Furthermore, the concept of family appeared in the results of each study. Jerwood et al. and Morgan identified a lack of familial or social support, creating a barrier to care. Morgan referred to this specifically as “chaotic family systems”, which could also potentially impact the nurse’s safety. McGrath and Forrester (2006) elaborated, stating that while many institutionalized patients do not have family contact, the clinical staff within the institution becomes a replacement family. This can create complicated grief scenarios for staff following the death of a patient.

Jerwood et al. (2018) discussed the theme of “the problem of partnership,” which describes communication issues between team-members about persons with severe mental illnesses, particularly about a person’s mental health history, diagnoses, symptoms, advice on a
specific patient, and end-of-life issues. This lack of communication was identified on a larger scale, such as between primary care and mental health care facilities, creating gaps in patient care transitions. This theme did not occur within the other studies, which may be attributable to the fact that Jerwood et al. utilized focused groups, allowing for interdisciplinary communication of clinical staff within interviews.

Morgan (2016) discussed other themes related to advocacy and place of death. Within interviews, the theme of advocacy, and specifically regrets of nurses’ lack of advocacy emerged. Nurses expressed regret over patient scenarios where they should have expressed stronger patient advocacy. “No Right Place to Die” was a theme Morgan described as frequently appearing in interviews. Nurses described that there is no one place to go to receive appropriate care at the end of life for someone with a severe mental illness. Examples provided included mental health units, geriatric-psychiatric units, medical units, and nursing homes, none of which were identified as adequately prepared to handle persons at the end of life with severe mental illnesses.

Using a quantitative approach to capturing staff views, Trachsel et al. (2019) aimed to explore the palliative care services’ acceptability for persons with severe and persistent mental illnesses by surveying psychiatrists. In their survey of 457 psychiatrists in Switzerland, over 75% of psychiatrists agreed that palliative care was appropriate for persons with SPMIs. However, 45.4% of the respondents indicated the term “palliative” was related solely to end of life. This can potentially be coinciding with the fact that almost all respondents indicated that an SPMI could be considered a terminal illness. Respondents also indicated that the goal of care to persons with SPMIs is not curative but more focused on reduction in suffering and increase in functioning. This idea overlaps with McGrath and Forrester’s (2006) discussion of the
similarities theoretically between palliative care and mental health care, in general, and not solely at the end of life.

**Nurse’s Role in Holistic Care Provision**

Hardy and Thomas (2012) identify the intimate relationship between physical and mental illness and highlight the role nurses have in merging these concepts in practice. Simple monitoring of physical health can potentially reduce physical and mental morbidities. Physical assessments include weight, body mass index, waist circumference, blood pressure screening, routine lab work, lipid panels, and urinalysis. In many cases, these measures are effective in identifying underlying health issues and are relatively cheap and quick to implement regularly. Due to the high rates of physical comorbidity in persons with SPMIs, it is necessary to implement these ongoing measures.

Beyond just physical measurements and monitoring, nurses can also impact patients’ healthcare experience in care delivery. Ross and Goldner (2009) found that nurses, more so than other health care team members, were more instrumental in a care experience due to ongoing compassion and provision of dignified care, or unfortunately, practice from stigmatization and misunderstanding. Nurses’ attitudes have the ability to impact care and care attitudes, which is especially important in psychiatric nursing due to levels of stigmatization and mistrust of healthcare professionals.

While mental health patients are often blamed for not taking care into their own hands, with non-compliance or simply “not caring,” there are other factors at play that contribute to decreased services, particularly in terms of their physical health. This include the lack of skills of healthcare providers, who are able to serve as both mental and physical health experts, stigmatization within the healthcare field, which does not go unnoticed by patients, and an
inability to effectively communicate physical issues, combined with not always being believed (Hardy & Tomas, 2012). Hardy and Thomas discussed the implications of the outcomes of the Chief Nursing Officer’s Review of Mental Health Nursing England in 2006. One of the outcomes identified highlighted mental health nurses as being perfectly situated to facilitate physical health care of SPMI patients through assessment, treatment, and referrals. This was accompanied by detailed recommendations for competency building for mental health nurses.

**Conclusions**

Significant gaps exist regarding palliative and end-of-life care provision to persons with SPMIs. While staff and nursing views have preliminary exploration, home health nurses’ views have not been delineated. Furthermore, no theories or frameworks exist to define the process of mental health nurses providing palliative, specifically end-of-life, care to persons with SPMIs. The proposed study aims to fill this gap by developing a grounded theory to explain this process, along with a systematic and integrative review in order to understand palliative care in SPMI more broadly.
Chapter 3

The purpose of this three-paper dissertation was to synthesize and then expand upon the body of knowledge surrounding palliative and end-of-life care for persons with SPMIs. A systematic review aided in the synthesis of current published research, an integrated review of described the unique factors that influence the end-of-life period, and a grounded theory study explored home health and hospice nurses’ experiences and processes when caring for persons with SPMIs at the end of life at home.

Paper #1: Systematic Review

Systematic Review Overview

The purpose of a systematic review was to identify and synthesize the available literature on a subject to develop insights, inferences, and a summarized overview of the currently state of the science about a topic. This can be used in guiding further research and decision-making about a topic (Gopalakrishnan & Ganeshkumar, 2013). The purpose of the systematic review was to identify and synthesize current research to identify gaps and opportunities for continued research related to palliative care for persons with SPMIs.

Paper #1 Description

A systematic review was completed in 2020 detailing the current state of the science on palliative and end-of-life care for persons with SPMIs. The research question guiding this review was:

1. What is currently known about palliative and end-of-life care for persons with SPMIs?

In order to determine the most up-to-date and relevant research, five scholarly databases were accessed, including Cumulative Index for Nursing and Allied Health Literature (CINAHL),
ProQuest, PubMed, Cochrane, and PsycINFO. The following keywords were used in the searches: severe and persistent mental illness, severe mental illness, serious mental illness, palliative care, hospice care, terminal care, end-of-life care, and comfort care. No time limiters were applied in the searches, but articles were limited to the English language.

Following the searches, titles were reviewed independently by two authors for inclusion. Inclusion criteria consisted of the article’s discussion of primary or specialty palliative care, hospice or end-of-life care, and persons with a severe and persistent mental illness, which could be referred to as a severe mental illness, serious mental illness, or SPMI. Exclusion criteria were literature reviews, commentaries, or opinion pieces. Research investigating a specific SPMI only, such as schizophrenia or bipolar disorder, were excluded from the review. The aim was to include only studies looking at the population of SPMIs as a whole. Any discrepancies for inclusion were resolved by a meeting between the two independent reviewers. A critical appraisal of the included articles was conducted independently by two reviewers using the Mixed Methods Appraisal Tool (MMAT) developed by McGill University (McGill, 2011). Nine articles met the inclusion criteria and were synthesized and used in thematic development.

Paper #2: Integrated Review

Integrated Review Overview

Integrated reviews aim to synthesize previous research on a topic in order to garner a more comprehensive understanding of a particular issue (Temple, 2021). The purpose of an integrated review can be numerous, and can include goals such as evaluating literature strength, identifying gaps in the literature, understanding central issues in a topic, or helping serve as a basis for developing a research question (Russell, 2005). This particular integrative review had
the purpose of bridging two parts of the literature, that on end-of-life care and that on SPMIs. This is within the scope of integrated reviews (Russell, 2005).

**Paper #2 Description**

This paper details the intersection of person-level and environmental-level factors which may impact the end-of-life period for persons with SPMIs. The research questions were:

1. What are the comprehensive factors influencing the end-of-life period for persons with SPMIs?
2. What is the impact of person-level and environmental factors on the end-of-life period for persons with SPMIs?

Using literature of psychiatric and end-of-life backgrounds, the review bridges the gap in a not-well understood area to develop a more comprehensive overview of the literature. Person-level factors include aspects of the persons such as gender and race, while environmental factors included external aspects such as healthcare setting and the presence of COVID-19.

**Paper #3: Grounded Theory**

**Qualitative Methodology Overview: Grounded Theory**

Grounded theory methodology is appropriate in areas of research where little is known about emerging phenomena. It aims to identify, explore, and describe a process inherent to the identified phenomena in order to better understand its existence (Chun Tie et al., 2018). This methodology is appropriate to explore end-of-life care for persons with SPMIs due to the emergent nature of the knowledge base. Grounded theory research is indicated in this body of research. It will serve as a foundational flexible methodology to explore the process of providing end-of-life care to persons with SPMIs.
**Theoretical definitions:** There are different grounded theory approaches and schools of thought; however, consistent tenets are “required” of a study to meet grounded theory criteria. These include theoretical sensitivity, theoretical sampling, Memoing, and constant comparative analysis. Each is described in Table 1. Staged coding, the final critical aspect in grounded theory studies, is described below, and the specific approach to be used is delineated in Table 2.

**Table 1.**

**Tenets of grounded theory**

<table>
<thead>
<tr>
<th>Critical Aspect</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theoretical sensitivity</td>
<td>• Ability of the researcher to identify important data</td>
</tr>
<tr>
<td></td>
<td>• Permeates entire research process</td>
</tr>
<tr>
<td></td>
<td>• Enhanced by data immersion</td>
</tr>
<tr>
<td>Theoretical sampling</td>
<td>• Purposive selection of participants who can answer the research question</td>
</tr>
<tr>
<td></td>
<td>• Following initial data collection, theoretical sampling aims to follow</td>
</tr>
<tr>
<td></td>
<td>analyses</td>
</tr>
<tr>
<td></td>
<td>• Answers more questions that come up</td>
</tr>
<tr>
<td>Memoing</td>
<td>• Reflective notes developed by the researcher throughout the entire</td>
</tr>
<tr>
<td></td>
<td>process of grounded theory</td>
</tr>
<tr>
<td></td>
<td>• Details researcher’s thoughts, feelings, interpretations</td>
</tr>
<tr>
<td></td>
<td>• Serves as another form of data and audit trail</td>
</tr>
<tr>
<td>Constant comparative analysis</td>
<td>• Method of data analysis</td>
</tr>
<tr>
<td></td>
<td>• Begins immediately with first data collected and works iteratively to</td>
</tr>
<tr>
<td></td>
<td>become more abstract</td>
</tr>
<tr>
<td></td>
<td>• Comprises of ongoing comparison between previously collected data,</td>
</tr>
<tr>
<td></td>
<td>ongoing data collection, and potential data</td>
</tr>
</tbody>
</table>

(Definitions adapted from Chun Tie et al. 2019)
Coding and Analysis

A staged coding and analysis strategy delineated by Corbin and Strauss will be used. This consists of a first stage of opening coding, a secondary stage of axial coding, and a final stage of selective coding. Coding procedures include using the definitions and tactics delineated by Corbin and Strauss (1997) and presented in Table 2. The phenomenon of interest is nurses providing home health care to persons with SPMIs.

Table 2.

Coding definitions

<table>
<thead>
<tr>
<th>Coding Stage</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open coding</td>
<td>This is the first step in the coding process. Open coding involves fragmenting, conceptualizing, and organizing the data, using line-by-line analysis. The results of this process are preliminary “open” codes and resulting categories of codes.</td>
</tr>
<tr>
<td>Axial coding</td>
<td>The process of placing the codes and categories developed in the open coding stage into the axial coding framework, which emphasizes the key process and the factors influencing or being influenced by the process.</td>
</tr>
<tr>
<td>Causal conditions</td>
<td>“events or happenings which lead to the occurrence or development of the phenomenon” (p.197)</td>
</tr>
<tr>
<td>Contexts</td>
<td>“a set of properties that pertain to the phenomenon in a dimensional range, conditions in which the strategies occur” (p.197)</td>
</tr>
<tr>
<td>Actions/Interactions</td>
<td>“Strategies devised to handle, carry out, respond to the phenomenon” (p.197)</td>
</tr>
<tr>
<td>Intervening Conditions</td>
<td>“Structural conditions bearing on the inter/actional strategies that pertain to the phenomenon” (p.197)</td>
</tr>
<tr>
<td>Consequences</td>
<td>“Outcomes or results of process with actions/interactions” (p.197)</td>
</tr>
<tr>
<td>Selective Coding</td>
<td>This is the third and final step in the staged coding process and refers to the explication of a story line from the data, following the axial coding structure.</td>
</tr>
</tbody>
</table>
Coding is done on a line-by-line basis, with ongoing iterative discussion and independent Memoing. All codes, categorization, and placement into axial coding categories was done following extensive analysis, Memoing, and data comparison.

Memoing is the process of extensive notetaking of the researcher’s thought processes throughout data collection and analyses (Rieger, 2019). This process allows for tracking and collection of the understanding of the researcher and serves as an illustrative tool for the researcher to use when thinking about the data and what the participants are saying. Memoing is done throughout the data analysis process in order to reflectively work through ideas in the data and determine the meaning while tracking personal thought processes. Researchers use Memoing tactics during the analysis process by taking set breaks to memo or when they needed time away from the data to think through what was occurring. Memos are then used later to inform the researchers of their previous thought processes and allowed for more in-depth insight into the explicating story line of the data.

Paper #3: Home Health and Hospice Nurses’ Experiences Providing End-of-Life Care to Persons with SPMIs

A study exploring home health and hospice nurses was completed using a grounded theory design. The aims of the study were to explore barriers and facilitators to home health and hospice care provision to persons with SPMIs. Guiding research questions included:

1. How do nurses experience the process of caring for persons with SPMIs at home?
2. What are barriers and facilitators to home health and hospice care for persons with SPMIs?
3. How does the home environment impact care to persons with SPMIs?
This study was designed to be part of a larger grounded theory study aiming to examine end-of-life care to persons with SPMIs, described below.

**Design**

A qualitative grounded theory design was employed in order to explore home health and hospice nurses’ perceptions of caring for persons with SPMIs in a home setting. Nurses who identified as RN or LPN were purposively and conveniently sampled using online methodologies. Interviews were guided by a semi-structured interview guide.

**Sample/Setting**

Purposive and snowball sampling strategies were used to recruit currently practicing home health and hospice nurses. Previously identified sites were used for initial participant recruitment, and recommendations from participants were used for subsequent recruitment. IRB approved social media flyers were used to recruit participants via Facebook and Twitter. In order to be included in study, participants had to have self-identified experience as a home health, hospice, or palliative care nurse (RN or LPN), been actively working (full- or part-time) in the home health setting and be primarily English speaking. Non-nursing-certified personnel, retired nurses, or nurses who do not provide hands-on patient care were excluded. Participation was considered voluntary and not tied to their specific worksite.

**Data Collection**

The primary form of data collection was one-on-one semi-structured interviews between the primary investigator and participants. Prior to the beginning of the interview, verbal consent was obtained from participants. Interviews were audio-recorded. The researcher followed a pre-developed interview guide which detailed 8-10 open-ended questions related to the topic of interest, with the number of questions varying depending on the individual participant’s previous
experiences. Interviews occurred on an individual basis via Zoom or telephone. Interviews lasted between 20-40 minutes. The semi-structured interview guide was reviewed and updated as necessary throughout the data collection period. Interviews continued until saturation of data occurred or no new ideas or themes emerged. interviews (Creswell & Poth, 2018).

Participants were asked not to provide any identifying information, however, if identifying information was provided, it was not transcribed into final transcript. Any identifying information to nurse, a patient, or worksite was removed. Immediately following the interview, the investigator recorded field notes. Recorded interviews were transcribed verbatim, and following data integrity checks, audio recordings were destroyed.

Data Sets

The final data set consisted of 24 one-on-one interviews. The average length of interviews was approximately 25 minutes, which translated to approximately 7 pages of written data per interview. All interviews, both audio and transcribed versions, were stored securely on the researcher’s password-protected laptop. For the purposes of this in-depth preliminary study, the first four transcripts were utilized for coding and analysis to develop a preliminary look at the developing grounded theory from the data.

Data Analysis

Upon transcription, data were entered into NVivo software for analysis. A sequence of open, axial, and selective coding as described by Corbin and Strauss (2009) was utilized in order to identify preliminary insights into the developing grounded theory. Axial coding categories included the causal factors, contexts, actions/interactions, intervening conditions, and consequences as delineated within this sector of grounded theory. Coding is an iterative process throughout these stages. Open, axial, and selective coding are currently ongoing.
**Ethics**

Nurses’ confidentiality will be maintained throughout the course of the study. The nurse’s identity only will be known to the primary researcher, who will be conducting the interviews. Transcriptions will be completed by a trained transcriptionist who will not be aware of the identity of the participants, maintaining further confidentiality. Sensitive topics will be discussed, including end-of-life care provision to patients. Nurses will be referred to nationally represented crisis counseling (Crisis Line) if they disclose to the researcher distress during or following the interviews.

**Quality Assurances**

Aspects of validity and reliability are discussed below. In order to ensure validity and reliability, as well as overall rigor of the study, guidelines proposed by Morse et al. (2002) will be followed in the development, implementation, and evaluation of the proposed grounded theory study.

**Validity.** Threats to study quality can occur upon conception. Study reliability and validity must be discussed prior to study execution to ensure high study quality and rigor. Validity has broader epistemological concepts and delineated categories that should be considered. Internal validity is present when the researchers study what they intend to study, which is noted in data collection and analysis (Hupcey & Kitko, 2017). This will be ensured as the research questions detail the inquiry of a process, which is appropriate for grounded theory. Adherence to Corbin and Strauss’s grounded theory methodologies will enhance internal validity. External validity is present when the results of the study are generalizable outside the contexts of the completed study (Hupcey & Kitko). This will be ensured through an adequate sample size (preliminary sampling of n=25) utilizing purposive and theoretical sampling.
Other types of validity include descriptive, interpretive, theoretical, and evaluative. Descriptive validity refers to the accuracy or credibility of the data, while interpretive validity refers to the meaning of the analysis and analysis accuracy (Hupcey & Kitko, 2017). Member checking will occur during on-going data collection and iterative analysis to ensure data and analytical accuracy. Theoretical validity, particularly important in grounded theory studies, questions the validity of the developed model. The model should fit the data it was derived from but be abstract enough to be extended beyond just the data (Hupcey & Kitko). This will be determined through intensive data immersion and member checking.

Reliability. Reliability is present in a qualitative study when there is consistency over time throughout the data, settings, and purpose of the research. There is both internal and external reliability (Hupcey & Kitko, 2017). Internal reliability is also referred to as dependability and concerns the clarity of the research method and purpose, and internal data quality checks and peer reviews occurring. External reliability refers to freedom of researcher-specific bias and is present when, theoretically, other researchers would come to similar conclusions in a different setting. This also speaks to the replicability of the data (Hupcey & Kitko). The researcher’s biases should be addressed prior to the study in order to uphold reliability (Creswell & Poth, 2016).

Transferability. Transferability, also known as generalizability, refers to the applicability of the data to larger groups or settings. While often ignored in qualitative methodologies, it is particularly important when developing a qualitatively driven theory (Hupcey & Kitko, 2017), such as in the studies proposed above.
Chapter Summary

This chapter presents a three-paper dissertation including a systematic review, an integrated review and a study using the tenets of grounded theory which aimed to explore end-of-life care for persons with SPMIs in the home setting. The systematic review paper will offer insight into the current state of the science, the integrated review will explore factors influencing end-of-life care for persons with SPMIs, and the grounded theory to fill a gap discovered in the systematic review by examining the process of end-of-life care provision from the point of view of home health and hospice nurses.
Severe and persistent mental illnesses (SPMIs) can be defined as psychiatric disorders requiring two or more years of treatment and causing a score of 50% or less on the Global Assessment of Functioning (GAF) scale, which is indicative of severe disruption in occupational or school activities (Ruggeri et al., 2000). Schizophrenia, bipolar disorder, and depression are often included as SPMIs, but, by definition, SPMIs can include any psychiatric diagnosis that causes severe dysfunction and requires two or more years of treatment. Severe and persistent mental illness is estimated to affect approximately 4% of the population in the United States (U.S.) (National Alliance on Mental Health, 2019); however, this number may change based on the definition utilized and inclusion criteria for SPMI (Parabiaghi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006). Regardless, persons with SPMIs face a severely elevated disease burden due to multifaceted factors impacting their care and quality of life. Furthermore, they may often have debilitating mental, physical, and social care complexities and difficulties obtaining appropriate access to care (Donald & Stajhudar, 2019).

The psychiatric symptomatology accompanying an SPMI diagnosis is often debilitating physically and psychosocially. While symptoms can range based upon varying diagnoses and psychiatric comorbidities, common symptoms such as anxiety, depression, hallucinations, paranoia, and disassociations, are difficult and complex to deal with and require intensive, ongoing treatment to manage (Castonguay & Oltmanns, 2012). Pharmacological solutions for psychiatric disorders are similarly disruptive to a person’s quality of life, with frequently unmanageable or debilitating side effects. The presence of psychiatric symptoms may impede care or displace trust within the healthcare system (Jerwood et al., 2018).
Along with psychiatric illness and potential psychiatric comorbidities, there is often other physical comorbidities. Approximately 50% or more of persons with an SPMI diagnosis have two or more chronic comorbid conditions (Jones et al., 2009). The high rates of comorbid physical conditions may be due to the presence of an SPMI diagnosis, the lack of access to care, a potentially decreased immune function, and engagement in high-risk behaviors (Mahoney et al., 2018). Engagement in high-risk behaviors such as smoking, unprotected sex, binge drinking, or lack of exercise can be considered a symptom of psychiatric illness (Mahoney et al., 2018). Symptoms of SPMIs and stigma associated with a psychiatric illness often create an “othering” effect within persons with SPMIs, where they no longer feel welcome within the bounds of society which may lead to increased suffering in persons with SPMI (Morgan, 2016). Many times, support systems (family, friends) no longer engage with persons with SPMIs, greatly reducing necessary support and subsequently reducing their quality of life (Morgan, 2016).

**Palliative care**

Palliative care should be introduced early in a chronic illness to positively impact one’s quality of life throughout a disease trajectory. However, palliative care also can serve as an umbrella term for palliative services, including hospice and end-of-life care. Due to the care complexities associated with an SPMI diagnosis throughout the illness trajectory and at the end of life, and the burden on an individual with an SPMI diagnosis and their family members, palliative care interventions are considered appropriate for this population (World Health Organization [WHO], 2020). Despite this, palliative care is rarely utilized appropriately within the SPMI population.
Purpose

The purpose of this systematic review was to identify and critique the relevant literature surrounding palliative care and persons with SPMIs as a population to determine what is currently known about the integration of palliative care and end-of-life care into the care of persons with SPMI.

Methods

In order to identify the most relevant literature, scholarly databases were accessed, including the Cumulative Index for Nursing and Allied Health Literature (CINAHL), ProQuest, PubMed, Cochrane, and PsycINFO. Keywords utilized within the searches were severe and persistent mental illness, severe mental illness, serious mental illness, palliative care, hospice care, terminal care, end-of-life care, and comfort care. No time limiters were used within the database searches. Each database’s titles were pooled for review independently by two reviewers to identify relevant articles based on the pre-determined inclusion or exclusion criteria. Any inclusion discrepancies were resolved in a meeting of reviewers.

Inclusion criteria

Inclusion criteria were a primary research study, using any methodology, written in English, any year of publication, and including both palliative care (specialty or primary) or hospice or end-of-life care. The population of focus was persons with a serious mental illness (described as serious mental illness, severe mental illness, severe and persistent mental illness).

Exclusion criteria

Articles excluded from final inclusion were literature reviews, commentaries, editorials, project descriptions, singular case studies, or opinion pieces. Articles that discussed palliative or
end-of-life care regarding a specific mental illness (such as schizophrenia or bipolar only) were not included. Articles focusing on caregivers only were not included.

**Critical Appraisal**

A critical appraisal of the literature was conducted independently by two reviewers using the Mixed-Methods Appraisal Tool (MMAT). Articles were screened initially with two questions: “Are there clear research questions or objectives?” and “Does the collected data address the research question or objective?”. A “yes” response to both of these questions moved the article to its corresponding methodological category delineated within the tool. Methodological categories in the MMAT include qualitative, quantitative randomized control trials, quantitative non-randomized, quantitative descriptive, and mixed methods. Each subsection of methodologies contains four answer points to consider when determining the study’s quality. Any score discrepancies of individual articles were resolved in a meeting between the article reviewers.

**Results**

**Critical Appraisal**

The final critique scores are included in Table 1 and represented by “*” as recommended with scores ranging from one criterion met (*) to all criteria met (***)**. Scores ranged from two criteria to five criteria being met, with the majority (n=6) meeting four or five criteria, indicating high-quality studies within their respective methodologies. Overall, the current literature’s quality is good, with studies of both qualitative and quantitative methodologies. However, there is room for improvement in both the quantity and variability of the studies. As it stands, the literature covers three main content areas, described below.
Content Areas

The articles’ focuses were variable and related to three content areas around palliative care of persons with severe and persistent mental illnesses. The authors broke down content areas into staff views, utilization of palliative care services, and end-of-life care preferences. Table 2 presents the themes within the content areas.

Staff Views

The clinical staff’s point of view is an integral part of the literature on palliative care for persons with SPMIs as preliminary insights into this process can be explored to identify areas of needs or improvements. Exploration of staff views was a focus of three articles pertaining to end-of-life care and one pertaining to palliative care. Results from each of these qualitative studies provide similar and complementary insights.

Each of these studies identified themes from clinical staff related to their preparedness in caring for a person with SPMIs at the end of life. Jerwood et al. (2019) identified this concept in two overarching themes, “the structure of the system” and “the confidence of the clinician.” They elaborated that topics which emerged within their focus groups pertained to the “siloing” of healthcare professionals into specializations, such as mental health or palliative care, leaving no one prepared to address when a person needs care from both specialties; allowing patients to “fall through the cracks.” This concept is echoed by Morgan (2016) who identified the theme of need for continued support and education for nurses working in palliative care and/or mental health in order to prepare both to adequately provide care. Evenblij et al. (2018) identified this topic as “little attention” to palliative care within psychiatry. However, McGrath and Forrester (2006) identified, from the perspective of institutional mental health staff, that there is a distinct
theoretical overlap between mental health care and palliative care due to the holistic, person-centered nature of both specialties.

Issues of legality was another cross-cutting theme within the staff views literature, particularly related to risk and resuscitation in end-of-life scenarios for those with mental illness. McGrath and Forrester (2006) and Jerwood et al. (2019) discussed the legality and lack of guidance or clear policy surrounding cardiopulmonary resuscitation, specifically within an institutional mental health setting. McGrath and Forrester (2006) further illustrated this staff concern by highlighting the follow-up of a death within the mental health institution, palliative or not, requires coronial inquest. Coronial inquests can cause distress to clinical staff who are uncomfortable with a litigious inquiry. Some staff even reported police questioning following the death of a patient who was considered palliative due to the setting of institutionalized mental health (McGrath and Forrester).

The theme of “characteristics of the client impacting care” emerged in interviews as well as focus groups. Morgan (2016) described the stigma of mental illness from the nurse impacting care; specifically, in an end-of-life setting when palliative care nurses may not be as experienced in mental health diagnoses and presentations. Patient symptoms also create potential barriers, for example, hostility or paranoia can make establishing trust difficult, and refusal of care and aggression can create symptom management issues. Furthermore, the concept of family appeared in the results of each study. Jerwood et al. (2019) and Morgan (2016) identified a lack of familial or social support, creating a barrier to care. Morgan (2016) referred to this specifically as “chaotic family systems,” which could potentially impact the nurse’s safety. McGrath and Forrester (2006) elaborated that many institutionalized patients do not have family contact, so the
institution’s clinical staff becomes a replacement family. This role can create complicated grief scenarios for staff following the death of a patient.

Jerwood et al. (2018) discussed the theme of “the problem of partnership,” which describes communication issues between team members about persons with severe mental illnesses, particularly about a person’s mental health history, diagnoses, symptoms, advice on a specific patient, and end-of-life issues. This lack of communication was identified on a larger scale, such as between primary care and mental health care facilities, creating gaps in patient care transitions. This theme did not occur within the other studies, which may be attributable to the fact that Jerwood et al. (2018) utilized focused groups, allowing for interdisciplinary communication of clinical staff within interviews.

Morgan (2016) discussed other themes related to advocacy and place of death. Within interviews, the theme of advocacy and specifically regrets of nurses’ lack of advocacy emerged. Nurses expressed regret over patient scenarios where they should have displayed greater patient advocacy. “No Right Place to Die” was a theme Morgan (2016) described as frequently appearing in interviews. Nurses stated that there is no one place to go to receive appropriate care at the end of life for someone with a severe mental illness. Examples provided included mental health units, geriatric-psychiatric units, medical units, and nursing homes, none of which were identified as adequately prepared to handle persons at the end of life with severe mental illnesses.

Utilizing a quantitative approach to capturing staff views, Trachsel et al. (2019) aimed to explore palliative care services’ acceptability for persons with severe and persistent mental illnesses by surveying psychiatrists. In their survey of 457 psychiatrists in Switzerland, over 75% of psychiatrists agreed that palliative care was appropriate for persons with SPMIs. However, 45.4% of the respondents indicated the term “palliative” was related solely to end of life. This
view of the term palliative care can potentially be attributed to the fact that almost all respondents indicated that an SPMI could be considered a terminal illness. Respondents also stated that the goal of care for persons with SPMIs is not curative but more focused on reducing suffering and increasing functioning. This idea overlaps with McGrath and Forrester’s (2006) discussion of the similarities theoretically between palliative care and mental health care, in general, and not solely at the end of life.

Utilization

The content area of “utilization” includes themes such as access and utilization factors at the end of life. While these studies touch on similar foci, they highlight the current literature’s disparate nature and what is being studied.

Lavin et al. performed a retrospective cohort study on those who died within a specific healthcare system within a four-year period to determine rates and types of healthcare utilization at the end of life in persons with psychiatric illnesses. Their cohort consisted of 16,214 deceased persons, 10% of whom had a psychiatric illness or a psychiatric medication prescribed. They found that having a psychiatric illness was associated with nursing home death, as well as decreased acute care services (except for emergency department) at the end of life, which was contrary to their original hypothesis that having a psychiatric illness would increase acute care services at the end of life. Nonetheless, this study’s findings were valuable as the authors included a broad spectrum of psychiatric illness and captured psychiatric symptoms without formal diagnoses by including those who had psychiatric medications prescribed. Previous research had focused solely on those with schizophrenia.

Butler and O’Brien also completed a retrospective cohort study, which reviewed rates of access to specialty palliative care services by persons with SPMI as compared to non-SPMI
peers. Their study, taking place in New Zealand, also captured the Maori tribe culture. The authors concluded that persons with an SPMI diagnosis are 3.5 times less likely to receive a referral to specialty palliative care services at the end of life than non-SPMI peers. These findings are complementary to the findings of Lavin et al. Despite hypothesizing that persons with SPMI have increased services usage near the end of life, the reality may be that persons with SPMI may not even have access to services, despite a shown increased need.

**End-of-Life Preferences**

Both and Foti et al. (2009) and Elie et al. (2015) aimed to assess persons with SPMI’s ability to dictate end-of-life care preferences, but with very different approaches. Foti et al. assessed persons with SPMI’s ability to participate in end-of-life care decisions. They used hypothetical patient scenarios and asked persons with SPMI to identify their preferences for the patient in the scenario (other) and themselves as if they were in the hypothetical scenario (self). Scenarios and answers were modeled after and collected using the Health Care Preferences Questionnaire (HCPQ). Answers related to self or other were compared. Elie et al. using a cross-sectional comparative design, also utilized the HCPQ but compared responses between persons with SPMI to their non-SPMI peers. Both studies reached the same conclusion: persons with SPMI can, without significant distress, take part in end-of-life care conversations and dictate personal end-of-life care preferences. Elie et al. found that the preferences identified by their SPMI group were not significantly different from the non-SPMI group, including the distinction of medical assistance in dying (MAID). In fact, persons with SPMI were less likely to indicate a preference for MAID, despite their apprehension that the opposite would occur were persons with SPMI given the option.
Discussion

The current literature on palliative and end-of-life care for persons with SPMIs, while providing valuable insight, is still very limited. Preliminary work detailing the barriers according to staff, rates of access, and ability of persons with SPMIs to partake in end-of-life care discussions have been started, yet there are large gaps outside and within these topical areas.

The inclusion of research detailing the entire severely mentally ill population in this systematic review was a deliberate one. Previous systematic reviews effectively highlighted the dire need and gaps within the palliative care for persons with SPMI literature but their conclusions relied heavily or partially on literature describing only persons with schizophrenia. While schizophrenia is a hallmark disease of the SPMI group, it tends to overshadow other illnesses and leaves a large gap in the understanding of the needs of the overall SPMI population.

Using a broader, standardized SPMI definition can identify more persons suffering from SPMI including those with anxiety and depression. This identification is imperative for enhancing this literature base, mainly due to the relevance of identifying persons in need of palliative care.

Within the literature included in this review, different definitions of SPMI were utilized in nearly every article, with some of these definitions being problematic. These differing definitions lead to a fragmented literature base, where the persons it may be intending to evaluate are misrepresented or findings that are overgeneralized. For example, Morgan (2016) utilized the term severe mental illness and defined it by the diagnosis of schizophrenia, bipolar, and depression. Other articles did not define their population at all. Some used more inclusive definitions, such as Lavin et al., who stated the inclusion of anyone with a mood or psychiatric disorder or identified use of prescription psychiatric medications. Moving forward, it is necessary to fill the gaps of this literature by utilizing unified and inclusive definitions.
severe and persistent mental illness or severe mental illness by definition alone, which is often confined to schizophrenia, bipolar disorder, or major depression, erases other psychiatric disorders’ visibility, leaving these individuals without the needed care which subsequently can impact their quality of life. The lack of clarity and inclusivity of whom are actually being discussed in a literature base or leaves out those who are suffering and could benefit from palliative care. It is suggested that the definition delineated by Ruggeri et al. (2000), defining SPMI as psychiatric disorders requiring two or more years of treatment and causing a score of 50% or less on the GAF scale, which is indicative of severe disruption in occupational or school activities, is reliable and valid in categorizing those with debilitating psychiatric issues and should be utilized in unifying the literature moving forward.

It is also notable within this literature that the location of articles published is disparate, including studies and insights from the U.S., New Zealand, Australia, United Kingdom, Netherlands, and Switzerland. While the insights provided by research from various international locations is useful, the results are not entirely generalizable, particularly within the U.S. healthcare system. The U.S. has notably a higher rate of suicide (an indicator of population-level mental health) than other countries in this literature, yet has lower mental health services utilization in the country as a whole. Furthermore, the U.S. healthcare system notoriously turns a blind eye to mental health issues. Therefore, literature based within the U.S. is necessary in order to understand the complexities of how the U.S. culture and healthcare system are impacting persons with SPMIs.

While preliminary insights have been provided within the areas of staff views, current utilization patterns, and persons with SPMIs’ ability to participate in personal end-of-life care conversations, there are significant gaps that need to be addressed. As noted previously by
Donald and Stajhudar (2019), the voices of persons with severe mental illness and their perceived palliative care and end-of-life care needs are glaringly missing from the literature. Including persons with SPMIs as participants is necessary to round out the literature base and make clinically competent strides in enhancing palliative care and end-of-life care for persons with severe mental illness. If we do not know what is actually needed from the afflicted persons’ perspective, how can we implement it effectively?

Furthermore, rounding out of the current literature is necessary. In exploring the views of staff, all settings for palliative and end-of-life care have not been explored. The types of staff included need to be delineated further, as barriers and facilitators may differ depending on the healthcare provider’s role. Understanding the differing and overlapping providers, nursing staff, direct unlicensed staff, social workers, spiritual support staff, and other members of interdisciplinary teams’ needs is vital in identifying actionable barriers and facilitators. Barriers have remained a large focus of staff interviews, and while helpful, shifting focus to highlight actionable facilitators also is necessary. These barriers and facilitators effectively explored in conjunction with patient needs can provide a clearer clinical picture of what is needed for the advancement of effective palliative care for persons with SPMIs. Different settings of palliative or end-of-life care provision need to be explored further.

Studies of utilization and access need replication internationally to explore differing access rates to palliative care between the general medical population and those with SPMI. Furthermore, differentiating specialty and primary palliative care will be necessary moving forward. While specialty palliative care has grown in the U.S. in recent years, exploration of primary palliative care’s reach remains unexplored within this population. Furthermore, all of the included studies described persons with some form of SPMI and additional chronic, comorbid
physical conditions which warranted palliative or hospice intervention. However, it begs the question, is palliative care only warranted in the case of comorbid physical conditions, or should the presence of an SPMI alone warrant palliative care intervention? Can an SPMI diagnosis be considered life-limiting, and in some cases, warrant hospice intervention alone? Traschel et al. (2019) highlighted this concept in their psychiatrist survey, where 58% of the participants indicated an SPMI alone could be a terminal illness. This concept, however, has not been bridged into other literature, and only persons with chronic or terminal physical comorbidities are the focus.

In addition to expanding current content areas, other areas need further exploration. These include, but are not limited to, availability of different palliative care services (primary versus specialty), and contexts in which they can occur, needs of patients with SPMIs alone or with chronic conditions, needs of caregivers of persons of SPMI in the palliative care context, and staff support.

**Conclusions**

Persons with SPMI deserve equal access to palliative care and hospice care; however, that is not currently afforded on an international level. While preliminary insights have begun to address aspects of this larger issue, more work is needed to effectively begin to implement palliative care and hospice care services to persons with SPMIs. Some of the first steps in doing this are defining SPMI in the context of palliative care, uniting the literature on this definition, rounding out current literature content areas (staff views, utilization, and end-of-life preferences), and exploring new content areas.
Paper 2

Person-Centered Care Considerations when Providing End of Life Care to Persons with Severe and Persistent Mental Illnesses

Severe and persistent mental illnesses (SPMIs) affect approximately 4% of the United States (U.S.) population and refer to chronic and debilitating psychiatric disorders (Donald & Stajhudas, 2019). This category of psychiatric illnesses is costly and has a significant impact on the quality of life of persons with these disorders. Severe and persistent mental illnesses are often life-long, cause significant impairment to activities of daily living (ADLs) and, in many cases, require long term care (Donald & Stajduhar). These illnesses permeate all aspects of healthcare, including geriatrics and hospice, and can greatly impede the quality of care provided and the quality of life of the person. Various factors related to both the person and the environment can influence end of life (EOL) care for older adults with life-limiting illnesses and SPMIs. It is necessary to understand how these factors influence the EOL time-period in order to provide person-centered care (PCC) to persons with SPMIs at the EOL. While literature is scarce on the influences in the SPMI and terminally ill population, preliminary inferences can be made from periphery literature, examining both influences on EOL population and, if available, influences on SPMI populations. PCC utilizes the dimensionality of the person in the process of care in order to provide care which is more effectively tailored to the person. Understanding the integration of the person-level and environmental factors below is necessary in the development and provision of PCC in persons with SPMIs at the EOL.
**Person-Level Factors**

It is important to note that the person-level factors discussed are intersectional in EOL care, as they are in life (Gott et al., 2020), and while discussed as separate pieces, actually represent a complex web of the influences of a person on their EOL experience and care.

**Gender and Sexuality Considerations**

Gender has been examined as an influencer to EOL care in terminally ill populations, including the impact of identification as a gender minority or member of the Lesbian-Gay-Bisexual-Transgender (LGBT+) community. Gott et al. (2020) identified a significant lack of research related to gender-informed palliative care, despite complex and intersecting gender considerations for men, women, and transgendered persons.

Gender has been shown to influence EOL care, including how persons may accept or receive support and experience their disease. Ullrich et al. (2019) identified that females at the EOL may be more expressive in their emotions and seek more provider involvement in their care, while males may rely heavily on a partner for care and support and seek to maintain autonomy longer. However, symptoms may be expressed or internalized differently. Gott et al. (2020) identified that women may internalize pain or fatigue due to a long social history of these symptoms often being dismissed or ignored in women or labeled as “hysteria”. Furthermore, women who need to accept care provided have expressed feeling like a “failure” in their caregiver role. This is true for the other side, when men must take on the role of a caregiver, it has been identified they may feel like failures in this aspect (Gott et al., 2020).

Gender also plays a significance in mental health care and the experience of mental illness. Gender has an impact on a persons’ relationships to self, others, and society, and impact their daily experiences, which in turn influence mental health and illness. Gender can also
influence the types and severity of illness (for example, higher rates of depression/anxiety in women, and higher rates of substance abuse/suicide in men) (WHO, 2020). Within severe mental illnesses, there are high rates of abuse that also vary by gender. Men with SMIs are at a higher risk for physical victimization, while women with SMIs are at a higher risk for sexual and/or domestic violence (Khaliefeh et al., 2015). These risks can be elevated at the EOL and should be taken into consideration when providing EOL care.

Within the LGBT community, significant barriers have been identified for palliative care recipients and persons with mental health needs. Considerations which can complicate EOL care include discrimination by the healthcare system, social isolation, fear and mistrust of healthcare professionals, and poor clinical preparation of providers, all of which have been identified as contributing to suboptimal palliation in the LGBT population (Haviland et al., 2020).

Racial and Ethnic Considerations

Systemic racism permeates all aspects of the healthcare system and impacts minority populations seeking health care in any fashion, which should be considered by all health care professionals when providing care (Feagin & Bennefield, 2014). Mental health and palliative/EOL care are no exception. Inferences for the impact of race on EOL care for persons with SPMIs can be made when examining the impact of race on EOL services in general. There are significant considerations for both EOL attitudes as well as access to EOL care. Rosenfeld et al. (2007) identified racial attitudinal differences, as White patients may be more accepting of hospice services, particularly in the home setting, while African American patients may prefer aggressive treatment choices. Race has been shown to influence EOL care preferences, EOL spirituality needs, and cultural considerations, which are larger ignored within the literature (Krakauer et al., 2002). Furthermore, minority populations may have differing attitudes due to
poor communication styles of majority White providers with minority populations (Rosenfeld et al.). In a study of differences between White, Hispanic, and African American hospice patients, 20% of African American patients believed their care would be better if they were of a different race (Rosenfeld et al., 2007). Furthermore, it has been shown that treatment of minority patients in EOL care differs. For example, less analgesia is utilized in minority populations, despite similar levels of EOL pain (Krakauer et al., 2002).

Mental health disparities, as in differences in access and quality of care, are the norm in mental health care (McGuire & Miranda, 2008). While SPMIs have a higher lifetime prevalence in White Americans as opposed to minority populations, there are still significant implications to care access. Racial minorities more often have poorer access to care, and when care is accessed, it is of poorer quality (McGuire & Miranda, 2008). This is noted particularly among racial minority patients with comorbid substance abuse issues, who have identified significant discrimination, hostility, and poorer treatment overall, leading to distrust of the mental health system, or even stopped treatment (Mays et al., 2017). These differences in care illustrate significant access issues in mental health care for racial minorities and extends into EOL care. Access to care also remains an issue. Orstein et al. (2020) found that despite an increase in hospice service availability, persons of minority populations, particularly African Americans, are less likely than White persons to receive hospice care for more than three days, regardless of life-limiting diagnosis. Furthermore, racial minorities are more likely to die in hospitals without EOL planning engagement (Orlovic et al., 2019).

**Socioeconomic Status**

The impact of socioeconomic status (SES) is not well understood in EOL care utilization but is known to be correlated with worse health outcomes in patients (Lewis et al., 2011). SES
typically consists of income, education, and occupation (APA, 2020), all of which can have impacts on access to, quality of, and preferences within healthcare. Davies et al. (2019) found that lower SES is indicative of a higher likelihood to experience a hospital death, a measure which typically indicates poor EOL care. However, Wales et al. (2018) identified that the desire for a home death was more likely to occur in patients with a higher SES, who had a more stable home environment to facilitate a good death. Therefore, persons with SPMIs, who frequently experience poverty (Topor et al., 2016) may have different preferences for their place of death. However, these EOL preferences may not be able to be met, due to the decreased access to healthcare services among lower SES groups (Lawrence & Kisley, 2010), which unfortunately encompasses many persons with SPMIs (Sylvestre et al., 2018).

Beyond preferences, the presence of monetary poverty can have implications for disease burden in patients with SPMIs. When comparing combinations of chronic illnesses, mental illness, and substance abuse, Walker et al. (2016) found that an added layer of poverty to any combination above increased the risk for fair or poor health and poorer quality of life. This concept of increased illness burden in patients with monetary poverty can be applied to EOL situations in SPMIs, as lower SES has been associated with earlier mortality in persons with SPMIs (Martin et al., 2014).

**Symptom Burden**

Type of physical illness can clinically define symptoms that may contribute to extraneous symptom burden at the EOL. Persons with chronic respiratory diseases, for example, may experiences aggravated shortness of breath at the EOL, which can be difficult to manage, particularly in the last week of life (Kinkenberg et al., 2004). Additionally, polypharmacy, often associated with treatment of SPMIs can aggravate symptoms at the EOL and should be considered when evaluation symptom presentation (Schenker et al., 2019). However, mental
health symptoms, such as anxiety and depression, are particularly common at the EOL, regardless of a mental health history (Kozlov et al., 2019). It is known that quality of life of persons with SPMIs is decreased over the course of a lifetime (Sagayadevin et al. 2018), which can complicate exacerbated EOL mental health symptoms. Symptom burden and symptom severity of both mental and physical symptoms is a clinically complicating factor at the EOL. Fox et al. (2018) identified that the severity of mental health symptoms often reduces treatment seeking by persons with SPMIs, due to internalized stigma (or self-stigma) and fear of repercussions from health care workers. Furthermore, typical palliation does not account for persons with mental health histories, such as substance abuse or psychiatric medications, who may react differently to palliative medicines and receive sub-optimal symptom control (de Veer et al., 2018).

Preferences for Care

End-of-life preferences for persons with SPMIs has been explored briefly in the literature. Traschel (2018) identified the ethical need of exploring EOL preferences of persons with SPMIs. As persons with SPMIs are shown to have intact decision making, not including preferences for care at the EOL is a morality issue, not a clinical one. In studies examining decision-making abilities of persons with SPMIs, it has been shown that persons with SPMIs have strong care preferences, and have the ability to state these, identifying they should be included in care planning (Elie et al., 2018; O'Neal et al., 2008). This can include preferences for daily living, location of care, or services provided.

Veteran Status

A person’s veteran status is an integral part of their EOL experience (Shamas & Gillepse-Heyman, 2018) and has implications for the SPMI population due to the prevalence of SPMIs
among military veterans. Persons with a veteran status may cope with life-limiting illness differently due to ingrained military culture (Shamas & Gillepse-Heyman, 2018). Furthermore, the effects of military-related post-traumatic stress disorder (PTSD) can have implications for EOL care experiences and is often under-appreciated outside the Veteran’s Affairs (VA) community, which less than half of all veterans are enrolled in (Shamas & Gillepse-Heyman, 2018).

**Environmental Factors**

**Setting of Care**

**Nursing Home.** The quality of life in nursing homes (NH) at the EOL can potentially be considered less than optimal due to lack of appropriate facilities and training of NH staff in EOL care for older adults (Pivodic et al., 2018). The EOL period in nursing homes can be viewed from both the older adult at the EOL and the staff perspective. Patients at the EOL in NHs have identified that they wish to remain autonomous until the EOL, which is not always an option in NHs (Carlson, 2007). However, persons who reside in NH, even those with SPMIs, often wish to die within the NH as it is their identified home environment. Patient factors facilitating this can include having a preference to die at “home”, a primary terminal diagnosis of cancer, and having multidisciplinary palliative care that was integrated early on in illness and carried through to the EOL (Costa et al., 2016). Cordner et al. (2010) found that, in NHs, those with higher cognitive function subsequently received more pain medication which resulted in an overall higher quality of life, while those with behavioral issues had a lower quality of life. While this study was done in NH residents with dementia at the EOL, preliminary inferences can be made about the SPMI population in NHs at the EOL.
Homelessness. Approximately one-third of homeless individuals suffer from an SPMI (Harvard Health, 2014), or about one-sixth of the SPMI population, making it necessary to discuss homelessness in EOL care provision when discussing the SPMI population. De Veer et al. (2018) identified significant implications in EOL care for persons experiencing homelessness, including complex care trajectories and issues of access. Late, if any, access to palliative care is common among, due to both patient and provider factors. Palliative care clinicians are often uneducated in how to provide EOL care to PEH, and PEH are often distrustful of the healthcare system or experience a need for enhanced autonomy. The combination of these creates a viscous cycle of lapsed care provision (de Veer et al., 2018). Furthermore, PEH may put off care or avoid healthcare professionals due to a fear of not being treated with dignity or respect at the EOL because of their housing status (Klop et al., 2018). Other complicating factors included: proper identification for care, unwillingness to accept growing health issues, lack of transportation, active psychosis or addictions, risks to personal safety, and social support groups not recognized by healthcare providers (Klop et al., 2018; van Dongen et al., 2020).

Social Support

Social support at the EOL is integral in a persons’ meaningfulness of life, and has roots in impacting the psychosocial, spiritual, and existential needs a person may have (Dobrikova et al., 2016). More broadly, familial relations can be a mediator to a variety of EOL concerns, such as place of death or time of palliative care provision. Unfortunately, family ties of persons with SPMI are often turbulent or strained due to past painful events related to the psychiatric symptomology (de Veer et al. 2018). Beyond familial relationships, persons with SPMIs are known to have diminished social networks, with subsequent reduced social support and capital (Sweet et al., 2018). Support to persons with SPMIs is often from other persons with SPMIs (de
Veer et al., 2018), who are not able to care for sick or terminally ill persons and are often unreliable in support provision.

**Stigma**

Differing types of stigma can impact the EOL process for persons with SPMIs, including self-stigma, societal stigma, and healthcare stigma. The effects of stigmatization have been identified as reducing help-seeking in healthcare as well as increasing the disease burden of a mental disorder (Gierk et al., 2018).

Self-stigma, also known as internalized stigma, occurs frequently in the SPMI population and contributes to low self-esteem and self-worth. This occurs when societal stigma is internalized, and negative beliefs about the self are believed by the person with an SPMI. Self-stigma is well established in young persons with SPMIs and has recently been shown to expand into geriatric persons, including persons with SPMIs residing in NHs. The presence of self-stigma could impact psychosocial or existential aspects of end of life care, as well as negatively impact social functioning (Tzouvara et al., 2018).

Societal stigma is the most common type of stigmatization against persons with SPMIs and contributes to enhanced prejudices, stereotype, and discrimination of this population. Societal stigma is known to contribute to self-stigma and healthcare stigma and works similarly in deterring persons from seeking healthcare and receiving adequate healthcare (Tzouvara et al., 2018). This can be influenced largely by news and media representation of persons with SPMIs, which is often poorly (Ross et al. 2018).

Clement et al. (2015) found that healthcare stigmatization was one of the biggest deterrents in seeking healthcare, with men, ethnic minorities, and veterans being the most deterred. Furthermore, when physical or mental health care is provided, it is often to a lesser
degree or poorer quality. Operationalized types of stigmatization that occur in healthcare include negative attitudes, unconscious biases, pessimism about ongoing therapies, and poor mental health skills among providers (Knaak et al., 2017). Within the mental health field, persons with substance abuse or active psychosis are often recipients of the highest levels of stigma (Rao et al., 2009). This has implications for EOL care, where substance abuse and schizophrenia will occur, potentially without healthcare provider self-awareness of stigmatizations impacting care.

**COVID-19**

Implications of COVID-19 should be considered when providing EOL care to persons with SPMIs during the period of the pandemic. Muruganadam et al. (2020) noted that the isolation of the COVID-19 has increased incidence of non-adherence to medications in persons with SPMIs, which has subsequently exacerbated symptoms. Disruption of services and previous routines associated with COVID-19 can be more stressful for the person with SPMI than otherwise (Barber et al., 2020). These enhanced stresses can permeate to EOL care when provided to persons with SPMIs during the COVID-19 pandemic.

**Conclusions**

Both person level and environmental level factors contribute to a person’s care and care experience. It is necessary to examine the potential influence these aspects of a person may have on their care experience, preferences, and decisions. Particularly in cases of SPMI, care may be experienced differently. Godfrey et al. (2018) explains PCC as seeing the person and their entire purpose, as opposed to their diagnosis or condition. The factors discussed in this article represent a small portion of potential influences on a person but encompass ones that are often overlooked as having an influence, particularly in the SPMI population. Literature is scarce pertaining to EOL care for persons with SPMIs, particularly how to incorporate PCC into this process. This
article provides a synthesized view of relevant literature in order to begin to build a lens in which patients can be viewed holistically. Further research on PCC in this population, as well as within this specific care period, is necessary.
Paper 3

Home Health and Hospice Nurses’ Perceptions of Caring for Persons with Severe and Persistent Mental Illnesses

Severe and persistent mental illnesses (SPMIs) refer to severe psychiatric disorders characterized by the presence of a DSM-5 diagnosis, a significant level of patient dysfunction, and a diagnosis lasting > 2 years (Citation). Persons with SPMIs, reflecting over 5% of the United States adult population (National Institute of Mental Health, 2021), are often not afforded effective medical care throughout the course of their illness or at the end of life (Donald & Stajhuder, 2019), despite experiencing enhanced medical disease burden (Baughman et al., 2016). Home health and home hospice services are a cost-effective option to care delivery for persons with SPMIs in the home or community setting and can provide an optimal approach to care for persons who have difficulty exiting their home for medical care (Landers et al., 2013). However, home health and hospice care provision and the perceptions of home health nurses providing care to persons with SPMIs has not been explored in the literature. It is necessary to explore nursing views to establish insights into current care practices. Therefore, this study aims to fill this gap and explore home health and hospice nurse perceptions of caring for persons with SPMIs in a home setting.

To better understand the home health and hospice nurses’ perception of caring for persons living with SPMI(s) in a home setting, a grounded theory approach was utilized to collect, analyze, and report findings. The following research questions were used to guide the study:

1. How do nurses experience the process of caring for persons with SPMIs at home?
2. What are barriers and facilitators to home health and hospice care for persons with SPMIs?

3. How does the home environment impact care to persons with SPMIs?

Methods

To explore the experiences of home health and hospice nurses providing care to the SPMI population, a grounded theory approach was used. This methodology is appropriate to explore end-of-life care for persons with SPMIs due to the emergent nature of the knowledge base (Donald & Stajhuda, 2019). It will serve as a foundational, flexible methodology to explore the process of providing care to persons with SPMIs. Individual, semi-structured interviews were conducted between the researcher and home health and hospice nurse participants for data collection.

Following Institutional Review Board approval, snowball and purposive sampling methods were utilized to recruit nurses. Social media flyers were posted in targeted social media groups specific to home health and hospice nurses practicing in the United States. Following a nurse’s response to the flyer, if the inclusion criteria were met, the nurse was verbally consented and a Zoom interview scheduled. Inclusion criteria were English-speaking nurses (licensed practical nurse (LPN) or registered nurse (RN)) currently practicing in home health/hospice or having practiced in home health/hospice within the previous year.

Interviews were conducted using the Zoom link provided, so no identifiers were collected. Interviews were audio recorded only and transcribed verbatim by the team (KR). Any potentially identifying information was removed from the final transcript. The semi-structured interviews were facilitated with an investigator developed interview guide, a sample of which is shown in Figure 1. Following the interview, participants were offered a $10 Amazon gift card,
at which time they could provide their email address. All interviews, both audio and cleaned transcribed versions, were stored securely on the researcher’s password-protected laptop, under the university password-protected storage system.

Data from transcripts were coded by the research team using the grounded theory approach detailed by Corbin and Strauss (2008). This consists of a first stage of opening coding, a secondary stage of axial coding, and a final stage of selective coding. Coding procedures include using the definitions and tactics delineated by Corbin and Strauss (1997) and presented in Table 2. Coding is done on a line-by-line basis, with ongoing iterative discussion between the researchers (KR, JH, ME, KK). The phenomenon of interest is nurses providing home health care to persons with SPMIs. The research team consisted of two doctoral-prepared qualitative researchers and two PhD students with qualitative research experience.

Table 2.

Coding definitions

<table>
<thead>
<tr>
<th>Coding Stage</th>
<th>Definition</th>
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<tr>
<td>Open coding</td>
<td>This is the first step in the coding process. Open coding involves fragmenting, conceptualizing, and organizing the data, using line-by-line analysis. The results of this process are preliminary “open” codes and resulting categories of codes.</td>
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<tr>
<td>Axial coding</td>
<td>The process of placing the codes and categories developed in the open coding stage into the axial coding framework, which emphasizes the key process and the factors influencing or being influenced by the process.</td>
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<tr>
<td>Causal conditions</td>
<td>“Events or happenings which lead to the occurrence or development of the phenomenon” (p.197)</td>
</tr>
<tr>
<td>Contexts</td>
<td>“A set of properties that pertain to the phenomenon in a dimensional range,</td>
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Following transcription, data were entered into NVivo software for analysis. A sequence of open, axial, and selective coding as described by Corbin and Strauss (2009) was utilized in order to identify preliminary insights into the developing grounded theory. Axial coding categories included the causal factors, contexts, actions/interactions, intervening conditions, and consequences as delineated within this sector of grounded theory. Coding was an iterative process throughout these stages. Ongoing collaborative research team meeting were used throughout data coding and analysis to enhance credibility.

**Results**

The final data set consisted of 24 one-on-one interviews. The average length of interviews was approximately 25 minutes, which translated to approximately 7 pages of written text per interview. An exhaustive list of codes, categories, and axial coding is included in Table X. All codes are directly from transcribed interviews, which were then collapsed into categories, and categories were then axial coded into the developed axial coding model. The model was organized according to axial definitions provided by Corbin and Strauss (2009). The model is presented in Figure X. Each corresponding axial coding category will be discussed. In provided quotes, the corresponding T number refers to the participant identification number.
Causal Events

Causal events led to a person with an SPMI needing care from the home health/hospice nurse. These included the category of “Reason on Home Health/Hospice”. Participants discussed the three reasons persons with SPMIs are receiving home health/hospice services. These include primary diagnoses of both psychiatric and physical origin, both of which were identified as appropriate for home health. One participant said:

So, you'd have whatever the medical issue diagnosis was that we were seeing them for, and then you'd also see whether they have a mental health history or have history of depression, or they're on some psych meds too or they're very anxious (T23).

Contexts

Contexts of caring for persons with SPMIs were explored. Two broad categories emerged. First, “home”, which included physical aspects of the home, patient, and family. Within this category, physical characteristics of houses were discussed as both barriers and facilitators, as well as familial and patient considerations which may impact care. The second category, “nursing scope of practice” also emerged as a context of care, which described the broad scope of nursing practice with various populations, as well as the limitations of their skill sets.

Home

In terms of the physical aspects of the home, participants discussed how the home can impact stability of the patient either positively or negatively. Participants agreed overall the home is an appropriate place for care to be provided, given a supportive home environment.
I think if you have a supportive home environment, whether or not the person has a severe and persistent mental illness, you’re more likely to reach the goals that are indicated for that patient (T001).

Barriers to care were explicitly discussed by participants. These spanned the physical home, family, and patients. Participants discussed barriers in each of these segments, including poor familial support, families suffering from mental illness, patient symptoms as barriers, stigmatization, and depleted home environments.

Poor familial support was identified repeatedly as a major barrier to caring for persons with SPMIs at home. Participants identified the role of family in typical home health/hospice care, but acknowledged many persons with SPMIs have strained or lacking relationships with family members, impeding their care potential at home. An example quote to support this belief is:

*I would say really just lack of support. So it's hard for the patients to continue doing well when they don't have a support system in place (T025).*

Participants also identified that when patients do have family members around, they are often suffering from similar mental illnesses. This creates a further barrier due to lack of suitable caregivers and caregivers who often interfere with care. One participant stated:

*Another thing that is difficult, and we don’t know this, is sometimes the family has some type of mental illness that impacts the care of the patient (T001).*

*I don’t know if the patient had psych issues, but the family had a lot of psych issues for sure. They had a lot of angst amongst the primary caregiver. That was definitely a dynamic that made me want to quit (T006).*
Patients’ actions because of their SPMI also were discussed as barriers. These actions included nonadherence to care or medications, visit cancellations, distrust of healthcare providers, and poor coping. Each of these barriers were attributed to psychiatric illness as “symptoms” by participants. Nonadherence to medication regimens was discussed as an extremely impactful barrier to effective care, and often not due to the fault of the patient, but of their psychiatric illness. A participant stated:

*The biggest problem that I see is them just not being compliant with their medications (T025).*

*...in a home health scenario after they’ve been home, sometimes they fall into old habits where they’re not taking their medications on time, or even at all, or they can’t get to them, so we try to assist them... (T002).*

Other patient considerations impacting care which were discussed included patient distrust of healthcare providers, patient not “fitting into” societal constraints, need for routine, and stigmatization. Participants described that persons with SPMIs often do not trust the healthcare system, leading to difficulties with rapport building. Furthermore, participants stated persons with SPMIs as often “living outside the norm” and trying to reconcile care for these patients while meeting their preferences for living. For example, one participant stated:

*What we consider normal routine, is really not normal for someone who’s lived a life on the outskirts of the norm. I’m trying to tell them they should be asleep at a certain time and they shouldn't be watching TV at a certain time and eating at a certain time. All of that is not necessarily their norm (T011).*
However, although persons with SPMIs were identified as living outside the “norm”, the need for an established routine for the patient was discussed as a critical necessity. Deviation from routine was seen as a barrier to care. One participant stated:

> It would be different in the sense that if you have someone with heart failure at the end of life, their mental status is a little different, but if you have someone with psychiatric issues, you still need to maintain a certain routine. I have found that if you get out of their ordinary routine, versus someone who’s just medial like heart failure, it can really alter their comfort, their anxiety, their pain, everything about that (T003).

Participants also identified the impact of stigmatization on the SPMI population. Stigma was described as coming from society and those around persons with SPMIs, as well as from inside the healthcare system, all of which having detrimental outcomes to persons with SPMIs. One participant stated:

> I know that I’ve had nurses that are very reluctant to go just because of the stigma of the psychiatric diagnosis. So, I know that has a negative connotation to some of the nurses, just because I guess of the unknown (T20).

**Nursing Scope of Practice**

Nursing scope of practice emerged as a category which helps describe the context of care provision to the SPMI population in the home. Participants described both barriers and facilitators of the nursing scope of practice. For instance, participants stated that all nurses are trained in mental health, and therefore should be capable of handling the SPMI population effectively in any context. One participant said:
I'm thinking to myself; MOST NURSES should be able to competently handle
depressed, even very depressed patients and then patients with anxiety. They
should be able to intervene, even if that meant making a mental health referral
(T013).

Despite the identified universality of nursing practice, nursing scope limitations were also
discussed. Nurses identified that they often felt they were practicing outside of their scope,
particularly trying to fill the shoes of licensed counselors or social workers, which resulted in
significant frustration and feelings of futility for nurses. One participant stated:

So, nursing plays, we wear many hats, to the best of our ability. I mean I’m not
even going to brag and say that I’m good at all these things, I try but I wasn’t
formally trained, of course (T017).

Actions/Interactions

Actions/interactions are the processes nurses take when caring for persons with SPMIs and how
they go about providing care. Two major categories emerged: nurse tactics and role of the nurse.
Nurse tactics refers to how the nurse provides care and decisions the nurse makes when
providing care to persons with SPMIs at home, while role of nurse refers to tasks described as
necessary when providing care.

Nurse Tactics

Nurse tactics included actions taken by the nurse, such as increasing visit frequency when
needed, maintaining a strict schedule, keeping a consistent staff assignment, and remaining firm
with the patient. Each of these tactics were identified as having a heightened priority within the
SPMI population as each helps build and maintain nurse-patient rapport. Rapport was identified
as absolutely crucial in care of the SPMI population, particularly in their home setting. Rapport
was necessary not only for patients, but for nurses as well. Participants described needing to become comfortable and trusting of the patient before being able to “relax” in the home setting. Participants identified that by building and maintaining trust, they were able to accomplish more with the patient. One participant stated:

*I think going in and being able to build that rapport with the patient is the most important thing. It's for them seeing that they can trust you* (T025).

The importance of communication and listening also was stressed. Communication skills with patients and interdisciplinary team members was identified as a necessary component of care. Listening, particularly, to the patient and their needs was highlighted, even if not a medical intervention.

*...ultimately the difference they’re going to remember, is if you listened. Sometimes you’re just their company, because they have no family, or don’t speak to them, nobody who visits them just calls them on the phone. You’re making a really big difference in their life just by coming in and listening to them...*(T006).

**Role of Nurse**

Within the role of the nurse, codes included differentiating psychiatric symptoms and managing long-term psychiatric medication usage. Participants also discussed the difficulty in caring for persons with SPMIs due to poor medical history/documentation and at times, there was no noted psychiatric history, despite severe psychiatric illness. “Hidden” or undiagnosed psychiatric symptoms impeded care leaving the nurse unprepared. Often times, nurses felt as if they were “guessing” that there was psychiatric illness, as opposed to walking in prepared with a diagnosis. Furthermore, participants highlighted that the only indication of a psychiatric problem is a medication list.
But we do go into many homes that are very unsavory, if that’s the right word, and I think in the back of my mind it always registers. “there is something going on mentally with these people, why would you live like this?” To me, there has to be some sort of risk behaviors, all these risk behaviors. In some way, shape, or form, psychiatric issues. Something there (T005).

Intervening conditions

Intervening conditions consisted of structural aspects of healthcare systems which impact the strategies (actions/interactions) by the nurse when caring for the SPMI population in a home setting. Three main categories emerged including agency resources, other resources, and nurse preparation.

Agency Resources

Agency resources and other resources referred to facilitative resources both within the home health/hospice agency and within the community. Agency resources included knowledgeable and available supervisors, case conferences, interdisciplinary teams, and set agency guidelines for care. The most useful agency resources were the presence of a designated psychiatric nurse within the company. Participants described the collaborations with agency psychiatric nurses as necessary and fruitful. One participant stated:

…we do have access to behavioral health, I do believe that some companies, companies are built different, and I do believe, currently I am in a better place than I was before because we have access to behavioral health nurse (T017).

Within agency resources, social workers were identified as one of the most influential and necessary team members. The impact of social workers could not be understated and was mentioned by nearly all participants. Some examples include:
We do also have an excellent backup of our MSWs, our social worker, where if you feel anything is not quite right, you have to contact our social worker and she gets involved in the case immediately (T005).

So, if nursing kind of get stuck or like we feel like we're just not making progress or not making through they can go out and they [social work] go kind of above and beyond and working and kind of as a therapist or whatever we need (T022).

Other Resources

Other resources included community resources such as Area Agencies on Aging, Adult Protective Services, transportation services, local crisis numbers, free healthcare clinics, and local psychiatric hospitals or institutions. These were identified as crucial in coordinating effective care for the SPMI population. However, many participants stated the resources, albeit essential, are difficult to access. One participant stated

There's so much more to it and the resources while there are lots of - I have a whole binder filled with resources. It's not that easy to access. Everybody says, 'oh, use the resources while they're there.' But again, you're jumping through a ton of hoops (T017).

Nurse Preparation

Nurse preparation was a significant category providing insight into how the educational, professional, and personal experiences of nurses impacted their care to persons with SPMIs. Furthermore, participants identified limitations to their own preparation and knowledge when caring for persons with SPMIs.

Previous professional experiences were described as the most important factor in preparation for caring for the SPMI population, along with self-education. Nurses stated their
previous experiences as nurses or unlicensed personnel were significant in feeling more comfortable as a nurse and impacted their choices when caring for persons with SPMIs at home. One participant stated,

_I also worked at a teaching service for a hospital, and we had a lot of patients who had a lot of hallucinations. Maybe that’s why I feel that I’m ok (T008)._ 

Educational experiences were identified as important, but undergraduate education was noted to be significantly lacking in preparing nurses to care for psychiatric patients. Furthermore, participants identified that if you did not specialize in psychiatric nursing, you missed valuable skills. One participant indicated stigmatization may impact the decision to specialize.

_I think partly because we don’t specialize in it and partly because it’s so stigmatized, a lot of nurses, myself included, just don’t have that exposure, and don’t have the training for it (T004)._ 

The preparation of the nurse, as well as the availability of agency and other community resources were seen as impacting the actions/interactions of the nurse when entering the process of caring for persons with SPMIs in the home setting.

**Consequences**

The axial coding category of consequences was interpreted as the outcomes identified by the participants. Within this, a category of nurse perceptions emerged, which consisted of nursing outcomes of caring for persons with SPMIs at home.

Within nurse perceptions, participants discussed nursing outcomes such as patients’ scaring nurses and threats to nurse safety, which often resulted in nursing danger anticipation.
Participants identified an enhanced sense of alertness when caring for persons with SPMIs at home. This was due to both the patient population and the home setting. A participant stated:

*You have to remain alert. A different kind of alert in the back of your mind that just because it's going swimmingly in two seconds, they can lash out. They may not recognize you, and they think their world has changed in the blink of an eye. So, you remain on guard. A little more than usual* (T011).

Participants also discussed the frequent presence of weapons in homes, which enhanced feelings of danger. Guns, axes, and knives were each mentioned as inhibiting safety in homes and therefore impacted care of persons with SPMIs. Nurses identified when they sensed danger, care was often curtailed.

*Oh yes, in that when patient when nurses are afraid for their safety, if they think they're in an unsafe environment - they are in and out of there in a flash* (T013).

Apprehension was noted as being present not just when caring for persons with SPMIs at home, but as present for any home health cases due to the unknowns associated with home health.

*Even though I’ve done this for years, and I’ve got a lot of experience nursing behind me, and I’ve been in the field, there still is that little level of apprehension as the nurse going to that door for the first time, there really is* (T05).

Consequences for approaching care were also discussed. Participants described how they had to approach care differently with the SPMI population as a result of their past experiences. Three codes emerged describing these considerations, including: “Doing the best we can”, “Meet them where they’re at”, and “Hands are tied”. Nurses described that they were doing the best they can with this population given the difficulties. Example quotes include:
I think in a lot of ways we're going about it the same way in trying to do the best you can with not going into it with a bias or with a prejudice and trying to do what's right for them (T024).

I mean, as far as my agency goes and the doctors, I mean, I feel like we're all doing the best that we can with this population in a home setting (T025).

This included meeting patients “where they’re at” in order to provide the best care. One nurse stated:

I think there's a huge comfort in nurses being able to meet patients where they're at and in their home and in the comfort of their home and then the as clinician going in being able to see them (T016).

Other consequences included a prioritization of non-psychiatric symptoms and patients. Nurses described patients with SPMIs as being on the “backburner” or “pushed to the wayside”.

One participant described psychiatric symptoms as: “It's more like this is something else that you're dealing with rather than our primary focus” (T024). Even more pointedly, one participant described psychiatric symptoms as being a roadblock in care for persons with SPMIs.

When I get there to try to provide the medical care, the mental health becomes an automatic roadblock. Because they just simply cannot get on board with the plan of care the same way that they would if they didn't have that issue (T017).

Discussion

The home setting can be an appropriate place to receive care for persons with SPMIs, if the nurses providing care are given the proper training, preparation, and resources. Furthermore, the home environment must be conducive to effective care and support, including family and/or
caregivers and a clean, peaceful environment. However, this is not always the case for persons with SPMIs.

Throughout the interviews, nurses described their experiences of caring for persons with SPMIs as generally limited, and when they did care for persons in this population, it was often with apprehension due to poor preparation. Nurses who felt comfortable with SPMI assignments often stated it was due to previous professional experiences caring for persons with SPMIs in a different venue in the past. Facilitators to enhancing the nurse experience included agency support.

Throughout the axial coding model, barriers and facilitators were noted by nurse participants. Barriers were identified within nurses themselves, healthcare systems, patients, patient lifestyles, and family systems. Nurses identified their own lack of training or comfort with psychiatric patients. In a quantitative study by Joubert and Bhagwan (2018), it was found that psychiatric nurses reported frustration with illness denial in the mental health population. Furthermore, enhanced feelings of frustration and anger, as well as enhanced exposure to violence and abuse, were noted among psychiatric nurses. Similar sentiments emerged in this study for home health nurses working with mental health patients.

**Implications**

Results from this study provide insight into the needs of nurses caring for persons with SPMIs at home. It is clear from interviews that expanded community and agency resources are necessary in order to best assist nurses in providing appropriate care to the SPMI population. Furthermore, enhanced training or education may be necessary for nurses who have not previously had experience with this population.

**Conclusions**
This qualitative grounded theory study explored the experiences of home health and hospice nurses caring for persons with SPMIs at home. Nurses identified that while the home is an appropriate place to receive care, there are necessary resources and preparation which should not be ignored. There is a need for growing research with this population and in this care venue.

Dissertation Summary

The purpose of this dissertation was to explore hospice and palliative care for persons with SPMIs. To do this, three separate papers were completed. Paper one consisted of a systematic review of the literature exploring hospice and palliative care provision to persons with SPMIs. Paper two was an integrative review detailing the end-of-life considerations for persons with SPMIs. Paper three reflected a grounded theory study exploring home health and hospice nurse perceptions of caring for persons with an SPMI at home.

Next Steps

This research has set the foundation for a significant research trajectory. The findings of each paper have pointed to new and necessary research areas needing exploration. Most notably, there is more work to be done to continue developing the grounded theory from paper 3. While extensive interviews have been completed with home health/hospice nurses, more insight is needed to develop a comprehensive grounded theory. Interviews with other nurses providing end of life care (such as mental health nurses), as well as persons with SPMI and their families, are necessary to continue to understand the phenomenon of the end-of-life period for persons with SPMIs.
Conclusion

Persons with SPMIs experience complex symptoms from their mental illness, and often, comorbid physical illnesses. Despite this, they are often not provided effective care for ailments or symptoms, particularly at the end-of-life. This dissertation attempted to provide insight and progress in improving palliative and end-of-life care for persons with SPMIs. In order to do this, three papers were developed. The first, a systematic review, detailed the current state of knowledge about persons with SPMIs throughout illness and at the end of life. Paper two focused on the end-of-life period for persons with SPMIs and evaluated person-level and environmental factors which may contribute to the end-of-life period. Finally, paper 3 consisted of a grounded theory study which explored home health and hospice nurse perceptions of caring for persons with SPMIs at home. This dissertation provided insight into various aspects of the topic of palliative care for persons with SPMIs and has identified gaps for future research.

Future research can be informed by the conclusions of this dissertation and papers. Next steps include more studies pertaining to staff views, specifically examining mental health nurse perceptions of caring for the SPMI population at the end-of-life. More importantly, there is a need for research including persons with SPMIs and their experiences/preferences. This is a necessary step in determining how to best care for persons with SPMIs. Results from this paper can also be applied to similar populations for insights. For example, these papers did not examine services/care for persons living with dementia and dementia disorders, however, experiences and care for the SPMI population may be comparable to care for persons with dementia. Understanding the overlap of care, as well as the implications for nursing, is necessary.
References


https://doi.org/10.1177/2050312118822927


https://doi.org/10.1177/070674371205700804


https://doi.org/10.1186/s12904-016-0077-8


https://doi.org/10.1186/1471-2288-11-100
https://doi.org/10.1371/journal.pmed.1002782


https://doi.org/10.15761/NPC.1000113


https://doi.org/10.1017/S1478951519000087

experiences of patients and proxies. *BMC Palliative Care, 18*(1), 56.

https://doi.org/10.1186/s12904-019-0443-4


https://doi.org/10.1016/j.jagp.2017.09.018


https://doi.org/10.1016/j.jpainsymman.2012.04.004


https://doi.org/10.1136/bmjopen-2019-032391


https://doi.org/10.1177/1049909119832809

Harvard Medical. (2014). The homeless mentally ill. 
https://www.health.harvard.edu/newsletter_article/The_homeless_mentally_ill


https://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/Paying-for-Care

https://doi.org/10.19043/ipdj.5SP.009

[https://doi.org/10.1176/appi.ajp.2010.09091379](https://doi.org/10.1176/appi.ajp.2010.09091379)

[https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4418239/?report=printable](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4418239/?report=printable)


[https://doi.org/10.1080/10398560802596108](https://doi.org/10.1080/10398560802596108)

[https://doi.org/10.1017/S0033291714001962](https://doi.org/10.1017/S0033291714001962)

[https://doi.org/10.1177/002216781771698262](https://doi.org/10.1177/002216781771698262)

[https://doi.org/10.1016/j.jpainsymman.2003.05.008](https://doi.org/10.1016/j.jpainsymman.2003.05.008)

review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC Palliative Care, 17*(1), 67.

https://doi.org/10.1186/s12904-018-0320-6


https://doi.org/10.1177/1359786810382058


https://doi.org/10.1016/j.jpainsymman.2017.04.003


https://doi.org/10.1016/j.jpainsymman.2010.10.265


https://doi.org/10.1016/j.brat.2014.07.019


The SCAN Foundation. (2014). Medicare spending for beneficiaries with severe mental illness and substance use disorder.

https://www.thescanfoundation.org/sites/default/files/1pgdatabrief_no38_medicare_spending_for_beneficiaries_with_severe_mental_illness_and_substance_use_disorder.pdf


https://doi.org/10.1080/2156857X.2015.1134629


https://doi.org/10.1016/j.jagp.2017.09.026


https://doi.org/10.1186/s12888-019-2091-x


Appendix A – Paper 1 Acceptance Email

Your Submission to The Journal of Hospice and Palliative Nursing
em.jhpn.3f1.74c52d.3cc58c61@editorialmanager.com <em.jhpn.3f1.74c52d.3cc58c61@editorialmanager.com>
on behalf of
Betty Rolling Ferrell <em@editorialmanager.com>
Tue 7/20/2021 5:42 PM
To:
  - Riley, Kiernan E <kir5292@psu.edu>

Jul 20 2021 05:42:37:316PM

RE: JHPN-D-21-00066R1, entitled "Palliative Care in Severe and Persistent Mental Illness: A Systematic Review"

Dear Ms. Riley,

The reviews of your manuscript are complete. The reviewers thought the article would be of interest to JHPN readers but had some suggestions for changes, which are listed below.

Please revise the article to address these comments and resubmit. An editorial review will be conducted to evaluate whether the peer review comments have been addressed, and at that time a publication decision will be made.

Include with your revised submission an itemized, point-by-point response to the review comments, which will facilitate the editorial review. To keep the process moving, please submit the revisions by Oct 18 2021 11:59:59:000PM. If this date is not feasible, contact the editorial office to request an extension. Make sure your submission is no more than 20 pages, including references, tables and figures.

To submit a revision, go to https://www.editorialmanager.com/jhpn/ and log in as an Author. You will see a menu item called "Submission Needing Revision." Please click on this item to obtain your submission record and begin the revision process.

With Kind Regards,

Betty Rolling Ferrell, PhD, CHPN, FAAN, FPCN
Editor-in-Chief
The Journal of Hospice and Palliative Nursing
Appendix B – Paper 2 Acceptance Email

Your Submission to Journal of Gerontological Nursing: JGN-2021-132

Journal of Gerontological Nursing <em@editorialmanager.com>
Reply-To: Journal of Gerontological Nursing <prs_staff@slackinc.com>
To: Kiernan E Riley <kiernanriley4@gmail.com>

Dear Kiernan Riley,

We are delighted to inform you that your manuscript titled "Person-Centered Care Considerations for End-of-Life Care to Persons with Severe and Persistent Mental Illnesses," (JGN-2021-132) has been accepted for publication as a(n) Feature Article in the Journal of Gerontological Nursing, pending certain revisions. The attached comments, made by the Editorial Board, should assist you.

Your revision is due by Oct 04, 2021. To submit your revision, please go to https://www.editorialmanager.com/jgn/ and login as an Author. You will find your manuscript in the "Submissions Needing Revision" folder.

In accordance with the International Committee of Medical Journal Editors' (ICMJE) guidelines, all authors are required to complete and submit the Author Statement-ICMJE Form for Disclosure of Potential Conflicts of Interest. This form is found at https://www.healio.com/nursing/journals/jgn/submit-an-article, and must be uploaded for each author at the time of manuscript resubmission, if not previously submitted. Completion of this form for each author is required prior to acceptance of any manuscript.

Per journal policy, final manuscript acceptance is contingent upon successfully passing a plagiarism software check.

When you submit the revised manuscript online, the changes you made to the manuscript must be outlined in your Response to Reviewers. Be sure you add continuous line numbers to your revision. Please indicate exactly where in the manuscript each reviewer recommendation was addressed (e.g., page number, line number, as well as highlighting the revised text) (see example below). In addition, please also be sure that your references conform to APA style (7th edition). Upon receipt of your revised manuscript, our reviewers will examine it again.

REVIEWER 1 COMMENT #2: Background: Consider adding a sentence in the first paragraph of the introduction that describes the increasing number of older people undergoing elective surgery, which may better highlight the importance of screening for delirium in this population.

RESPONSE: We thank the reviewer for their comment and have added this to the Background/Introduction, Lines 72-74: "Increasing numbers of older adults are undergoing surgery;4 and those who develop delirium experience negative consequences including longer lengths of stay, higher likelihood of institutional discharge, and increased morbidity and mortality.5,6"

If you have any questions about the revision, please email me at awiegand@slackinc.com.

If you choose not to submit a revision, please e-mail prs_staff@slackinc.com as soon as possible to notify us. Until a manuscript is formally withdrawn, it is considered under review at the journal that issued the revision decision.

Thank you for your interest in the Journal of Gerontological Nursing.
Appendix C – Paper 3 IRB Approval

EXEMPTION DETERMINATION

Date: March 30, 2020
From: Joanie Tan,  
To: Kiernan Riley

<table>
<thead>
<tr>
<th>Type of Submission:</th>
<th>Initial Study</th>
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<tbody>
<tr>
<td>Title of Study:</td>
<td>Home health hospice and palliative care nurses’ perceptions of caring for persons with severe and persistent mental illness</td>
</tr>
<tr>
<td>Principal Investigator:</td>
<td>Kiernan Riley</td>
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<tr>
<td>Study ID:</td>
<td>STUDY00014624</td>
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<td>STUDY00014624</td>
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<tr>
<td>Funding:</td>
<td>Nursing (UNIVERSITY PARK)</td>
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</table>
| Documents Approved: | • Funding Request (1), Category: Sponsor Attachment  
| | • HRP 591 (3), Category: IRB Protocol  
| | • Interview Guide (1), Category: Data Collection Instrument |

The Office for Research Protections determined that the proposed activity, as described in the above-referenced submission, does not require formal IRB review because the research met the criteria for exempt research according to the policies of this institution and the provisions of applicable federal regulations.

Continuing Progress Reports are not required for exempt research. Record of this research determined to be exempt will be maintained for five years from the date of this notification. If your research will continue beyond five years, please contact the Office for Research Protections closer to the determination end date.

Changes to exempt research only need to be submitted to the Office for Research Protections in limited circumstances described in the below-referenced Investigator Manual. If changes are being considered and there are questions about whether IRB review is needed, please contact the Office for Research Protections.

Penn State researchers are required to follow the requirements listed in the Investigator Manual (HRP-102), which can be found by navigating to the IRB Library within CATS IRB (http://irb.psu.edu).

We would like to know how the IRB Program can better serve you. Please fill out our survey; it should take about a minute: https://www.research.psu.edu/irb/feedback.
Vita
Kiernan Riley

EDUCATION

Pennsylvania State University – State College, PA - PhD December 2021
Pennsylvania State University – Scranton, PA – BSN May 2018

SELECTED PUBLICATIONS


SELECTED ACHIEVEMENTS

- Recipient Janet Williamson Graduate Award in Nursing May 2021
- Recipient of PhD School-Selected Poster Award for Eastern Nursing Research Symposium from Penn State CON October 2020
- Recipient of Eastern Nursing Research Society Travel Scholarship March 2020