

**Improving Health Care for Individuals with Serious Mental Illness  
Across the Lifespan**

By:

Diana M. Hanan, RN, MSN, FNP-BC

A Dissertation

Presented to Boston College William F. Connell School of Nursing  
In partial fulfillment of the requirements for the degree of  
Doctor of Philosophy

## **Copyright Notice**

This document is copyrighted material. Under copyright law, no parts of this document may be reproduced without the expressed permission of the author.

© Copyright 2022 Diana M. Hanan

## **Abstract**

**OBJECTIVES:** Individuals with severe persistent mental illness (SPMI), also referred to as serious mental illness (SMI), experience significant inequities in health care access and outcomes. These inequities may span the lifetime of an individual living with SPMI, and include poorer cancer outcomes, shorter lifespans, barriers to having their needs met in long-term care, and a decreased likelihood of receiving hospice care when indicated. The purpose of this dissertation was to explore the causes of the disproportionately poor health outcomes for individuals living with SPMI and describe current facilitators and barriers to providing care to this vulnerable population.

**METHODS:** A qualitative descriptive study was carried out to explore health care professionals' perception of the needs of long-term care residents with SPMI and chronic medical conditions, and barriers and facilitators to meeting the needs of this population. A narrative review was performed to identify what is currently known about cancer symptom clusters in individuals with schizophrenia. Lastly, an integrated review was conducted to identify factors associated with hospice use by individuals with SPMI and potential barriers to use of hospice services.

**RESULTS:** Ten health care professionals were interviewed for the qualitative study. The themes that emerged were: coming to know the individual and their unique needs takes time; being flexible and adapting approaches facilitates trust; respecting the inherent worth of each person contributes to caring. Participants described the importance of a person-centered approach when caring for long-term care residents with SPMI and chronic medical conditions. The narrative review of current literature pertaining to cancer symptom clusters in individuals with

schizophrenia revealed that this phenomenon has been sparsely represented in research. No data directly pertaining to cancer symptom clusters in this population were identified. Data describing the related phenomena of health conditions that may influence cancer risk and outcomes, physical experiences of cancer, and emotional and behavioral symptoms which may impact ability to tolerate cancer treatments were identified. The integrated review of literature describing factors associated with hospice use among individuals with SPMI found that hospice and palliative care services may not be utilized by individuals with SPMI due to system-level barriers such as inadequate patient-provider communication, fragmented care, and absence of discussions around end-of-life care.

**CONCLUSIONS:** Systemic problems such as miscommunication, fragmentation of care, and stigma contribute to the health inequities experienced by individuals living with SPMI. Nurses and other health care providers can work to ameliorate these systemic problems by promoting and participating in collaborative care models and utilizing assessment techniques appropriate to individuals who may have difficulty communicating about their health-related symptoms. Individuals with SPMI should be offered opportunities to participate in research when appropriate so that they may benefit from newer treatments for disease, and health care providers may improve their understanding of how to address the medical needs of this population.

## Table of Contents

Copyright Notice	1
Abstract	2
Acknowledgments	5
Chapters	
I.    Introduction to the Dissertation	6
II.   Barriers and Facilitators to Caring for Individuals with Serious Mental Illness and Chronic Medical Conditions in Long Term Care	30
III.  Cancer Symptom Clusters in Individuals with Schizophrenia: A Narrative Review	49
IV.  Hospice Use Among Individuals with Severe Persistent Mental Illness	79
V.    Summary and Discussion	
Master References	123
Appendices	142

## **Acknowledgements**

First and foremost, I would like to acknowledge the courage and tenacity of the patients I have had the privilege of caring for over the past twelve years. My patients living with mental illness, and their families, inspire me to be a better nurse and human being. I will never stop trying to make health care more just for them.

I would like to acknowledge the Boston College William F. Connell School of Nursing for their support through the doctoral fellowship program.

I would like to acknowledge my dissertation committee, Dr. Karen Lyons, Dr. Jane Flanagan, and Dr. Ellen Mahoney, for their guidance, wisdom, patience, and understanding. Special thanks to Dr. Karen Lyons, my dissertation committee chair, for leading me on this most remarkable journey.

I would like to acknowledge Dr. Kelly Irwin at Massachusetts General Hospital, who has been an extraordinary mentor and source of support for me throughout the research process.

Thank you to Dr. Gillian Wies, who had faith in me and gave me faith in myself.

To my family, who came along for the ride: thank you for your encouragement, support, love, and for believing in me.

## **Chapter I: Introduction to the Dissertation**

## **Background and Significance**

It is currently estimated that 11.2 million adults in the United States population are living with a severe mental illness (SMI), also referred to as severe and persistent mental illness, or SPMI (National Institute of Mental Health [NIMH], 2019). Severe and persistent mental illnesses, or SPMI, refer to psychiatric illnesses that typically have their onset in early adulthood and have profound effects on relationships, capacity for educational attainment and employment, and social functioning (Carey & Carey, 1999). Disorders typically included under the rubric of SPMI are schizophrenia, schizoaffective disorder, bipolar disorder, severe major depression, and obsessive-compulsive disorder (Carey & Carey, 1999). Among individuals considered to have SPMI, ninety percent have schizophrenia, a psychiatric disorder characterized by significant alterations in thought process, cognition, and behavior (McCasland, 2007). An estimated 0.25-0.64% of adults in the United States currently have a diagnosis of schizophrenia (NIMH, 2018). Worldwide, an estimated 20 million individuals are affected (Ritchie & Roser, 2018).

Schizophrenia and the related disorders such as schizoaffective disorder are particularly recognized for their characteristic features, which can include the presence of delusions (fixed, false beliefs) or hallucinations, disorganized speech, disorganized or catatonic behavior, and withdrawal from daily life, which may include diminished emotional expression and lack of motivation to attend to activities of daily living (American Psychiatric Association, 2019). These characteristics can often call attention to affected individuals and result in feelings of fear and stigma toward individuals with SPMI. Unfortunately, fear and misunderstanding widen the distance between affected individuals and the services they need in order to manage their illness. The SPMI population has substantial needs for health-related services and social assistance,



without which living in the community would not be possible for many affected individuals (Kaldy, 2018; Scull, 2021). Individuals with SPMI struggle not only with chronic and potentially disabling psychiatric illnesses, but are also at a disadvantage when it comes to overall health and social status. For example, chronic health conditions, unemployment, homelessness, and incarceration disproportionately affect this population (Luciano & Meara, 2014; Hirschtritt & Binder, 2017; Council of Economic Advisors, 2018). As a result, many individuals with SPMI live on the edges of society, living lives that are less healthy, less stable, more isolated, and typically, shorter than individuals without severe mental illness.

Excess morbidity and mortality among individuals with SPMI have been well-documented in the health literature (Chochinov et al., 2012; Irwin et al., 2014). Individuals with SPMI have shorter lifespans than the general population, and this gap does not appear to have decreased over time (Irwin et al., 2014). Existing literature suggests that multiple factors have contributed to the systemic problems perpetuating the comparatively poorer health and lower life expectancy of individuals with SPMI. Among these are a higher prevalence of chronic diseases, inadequate access to services, and in some cases, impaired ability for self-care (Irwin et al., 2014; Colton & Manderscheid, 2006). Additionally, if individuals with SPMI develop cancer, they are more likely to die from it (Irwin et al., 2014).

Several studies to date have described potential strategies for remedying the problems of increased chronic health conditions and inadequate care for individuals with SPMI. Among them are more accessible primary care, optimal screening for and treatment of cancer, greater collaboration between psychiatric and primary healthcare providers, and improved coordination of care (Crompton et al., 2010; Irwin et al., 2014). These proposed solutions suggest that gaps in communication and care delivery are among the factors significantly contributing to the health

inequities experienced by individuals with SPMI. In order to bridge the chasm between individuals with SPMI and a healthy, quality life, the distinct vulnerabilities and experiences of this population must be acknowledged by those who care and advocate for them. That is, the individual person with SPMI must be known and understood by those who seek to deliver care that is person-centered.

### **Conceptual Framework**

To understand person-centered care, the meaning and significance of the person, that is, the notion of personhood, must first be explored. The concept of personhood, as examined from a psychosocial, ethical, and moral perspective, may be understood as a physical state and relational state--that is, a state of existence as relative to other human beings (White, 2013). Psychologist Thomas Kitwood defines personhood as follows: “A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust.” (Kitwood, 1997). Kitwood used the terms personhood and person-centered care in describing his approach to caring for individuals with dementia--an approach that rejected the standard medical approach, with its emphasis on the treatment of disease (Fazio et al., 2018). According to Kitwood, care should be provided with an emphasis on how it is delivered--in such a way as to honor the individual nature of the recipient, with the self at the center of care (Fazio et al., 2018).

The term “person-centered care” has been applied across nursing and medicine as a definition and means of promoting health services tailored to individual preferences and goals. In a 2015 strategy report, the World Health Organization described person-centered care as “an approach to care that consciously adopts the perspectives of individuals, families, and communities, and sees them as participants as well as beneficiaries of trusted health systems that

respond to their needs and preferences in humane and holistic ways” (World Health Organization [WHO], 2015b). More specifically, person-centered nursing care has been defined as “an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding” (McCormack & McCance, 2017). Thus, it might be said that person-centered care is an aesthetic, moral framework, and a practice model.

In mental health care settings, person-centered care may be described as an approach characterized by collaboration, shared decision-making, and personalized treatment (Royal College of Psychiatrists Person-Centered Training and Curriculum Scoping Group, 2019). For individuals with SPMI, the recognition of one’s status as a person and the delivery of care that is person-centered may foster greater rapport with healthcare providers (Mestagh & Hansen, 2014). However, historically, accounts of interactions between individuals with SPMI and providers of health and social services have reflected misunderstandings and mistreatment, due in part to stigma and assumptions about this population. Past efforts to meet the needs of individuals with SPMI reflect some of the underlying problems that have characterized approaches to providing care for these individuals.

The Community Mental Health Act (CMHA) of 1963, a federal government program, aimed to ameliorate mistreatment of individuals with SPMI by closing dysfunctional asylums (Powers, 2017). With the implementation of the CMHA, 560,000 individuals were moved out of overcrowded psychiatric facilities, and 1500 community health centers were created to meet the needs of the individuals newly released from hospitals and relocated to the community (Powers, 2017). However, some individuals did not have the capacity to make use of the available

community resources, and ultimately, funding for the community health centers declined, with the result that many individuals with chronic mental illness did not receive necessary treatment. Many ended up homeless or incarcerated (Powers, 2017). Ultimately, in many cases, a pattern of re-institutionalization emerged, with many older adults with SPMI ending up in nursing homes or prisons (Geller, 2000; Kim, 2016). This pattern continues today.

Ongoing limitations in funding for and availability of mental health services, particularly for individuals with SPMI, reflect unresolved disparities between individuals with SPMI and unaffected individuals (Wainberg et al., 2017). Stigma surrounding mental health conditions remains evident as well. Whereas medical conditions are generally discussed openly, a shroud of shame may keep mental illnesses from figuring into mainstream conversation. Author and law professor Elyn Saks, who has lived with schizophrenia for many years, articulates this in her poignant description of others' reactions to her diagnosis of breast cancer: "When you have cancer, people send flowers; when you lose your mind, they don't" (Saks, 2007).

Healthcare professionals, particularly nurses, are in a position to bring equity into care for individuals with SPMI. Relational approaches to nursing care, that is, care delivery with a focus on the nurse-patient relationship, have the potential to enhance the sense of personhood for patients, increase understanding between patients and nurses, and foster a trusting patient-provider relationship (Sofronas et al., 2018). Ultimately, the ability to understand the individual patient allows for the delivery of care that is more likely to be appropriate and efficacious. For individuals with SPMI, who face multiple barriers to receiving adequate care, this is especially pertinent. Health care throughout the lifespan, which includes primary care, management of acute and chronic conditions, and care at the end of life, requires a person-centered focus in order to truly meet the needs of this population and offer them the

opportunity to live better, healthier, and in accordance with their beliefs, preferences, and values.

## **Literature Review**

### **Adults with SPMI and Chronic Medical Conditions in Long-Term Care**

The place of residence for adults, particularly older adults, living with SPMI and chronic medical conditions, has changed over the past 60 years as shifts in ideologies about mental health treatment and funding for care have shaped the resources available to this population. With the deinstitutionalization movement, spearheaded by the Community Mental Health Act of 1963, individuals with serious persistent mental illness who lived in state-run psychiatric facilities were discharged into the community (Powers, 2017; Scull, 2021). While the intent of the Community Mental Health Act was to shift funding from inpatient mental health facilities to newly-established community mental health centers, the community resources ultimately failed to materialize, and many individuals found themselves going to long-term care facilities such as nursing homes (Scull, 2021).

It is currently estimated that approximately 19% of Medicare beneficiaries residing in nursing homes have a diagnosis of a SPMI (Hua et al., 2021). Data suggest that the percentage of individuals in long-term care with mental illness has increased over the past decade (Fullerton et al., 2009; Hua et al., 2021). While such facilities may provide for the basic safety and physical well-being of residents, concerns related to the placement of adults—primarily older adults—with SPMI in long-term care facilities have been raised regarding the capacity of facilities to meet the needs of this population. Individuals with SPMI, particularly older adults in long-term care have a more complex set of needs, including regular psychiatric care, which must be coordinated with any other necessary medical treatments (Birtley & Phillips, 2020), and acceptance and understanding from the staff who assist with daily care. Evidence suggests that

nursing homes may not be equipped to meet the needs of this population (Grabowski et al., 2010; Kaldy, 2018). Research to date has also suggested that long-term care residents with SPMI disproportionately reside in lower-quality facilities (Jester et al., 2020). These data raise concerns about the capacity of long-term care facilities to care for individuals with SPMI.

To date, minimal data on older adults with SPMI who reside in long-term care facilities has been examined. Given the large number of adults with SPMI who are aging in long-term care facilities, and the known disparities in health outcomes and lifespan for this population, an examination of care for adults with SPMI in long-term care may be instructive in facilitating and expanding care that matches the needs of this population. A specific focus on facilitators and barriers to care for these individuals may suggest both system and person-level strategies to improve care and ultimately, health outcomes for individuals living with SPMI.

A person-centered care model has been promoted as an ideal approach to caring for older adults living in long-term care (Yoon, 2018). Such an approach entails the establishment of respectful relationships and the honoring of the care recipient's unique preferences and needs (WHO, 2015b). The implementation of person-centered care in long-term care settings has been demonstrated to promote mental and physical well-being for individuals with complex needs, such as those with SPMI and dementia (Howard et al., 2021). Given the demonstrated benefits of person-centered care for these populations, this approach may be employed as one strategy used to facilitate better care for individuals with SPMI living in LTC.

### **Cancer and Adults with SPMI: Symptom Clusters**

Cancer among individuals with schizophrenia warrants special examination. Cancer is the second leading cause of death both in the United States (Centers for Disease Control and Prevention, 2020) and worldwide (WHO, 2015a), as well as among individuals with SPMI

(Hwong & Irwin, 2020). Individuals with SPMI, and schizophrenia in particular, tend to have poorer outcomes in terms of their cancer; it is known, for example, that they are more likely to die from cancer than individuals without schizophrenia (Irwin et al., 2014; Kisely et al., 2016). Some proposed factors contributing to poorer outcomes include both individual and system-level factors such as poorer overall physical health, decreased rates of cancer screening, later stage at cancer diagnosis, and inadequate quality of care (Bergamo et al., 2014; Irwin et al., 2019; Tran et al., 2009). A meta-analysis of cancer screening rates among adults with mental illness found that cancer screening in general occurred less in individuals with mental illness compared to the general population, and this was particularly true for women with schizophrenia (Solmi et al., 2020). Disruptions in cancer care may also contribute to poorer cancer outcomes for this population. A retrospective analysis of 95 individuals with breast cancer and schizophrenia treated at an academic medical center revealed that half of the individuals experienced disruptions in their care, including delays in surgery and not completing chemotherapy, endocrine therapy, or radiation (Irwin et al., 2017). The nature of the inequities in cancer detection, treatment, and outcomes suggest that the disadvantages experienced by individuals with SPMI are part of a greater problem—one that reaches beyond epidemiological origins. Indeed, studies examining cancer prevalence among individuals with SPMI have failed to determine consistent data; while some report increased rates of cancer, others have reported that individuals with schizophrenia are equally or even less likely than those in the general population to develop cancer (Hodgson et al., 2010; Lopes et al., 2014).

While disparities in cancer outcomes for individuals with schizophrenia have been widely recognized, the exact nature of these disparities in cancer-related morbidity and mortality and their causes remain unclear. Given the known presence of poorer cancer outcomes, yet

inconsistent data regarding contributing causes, a closer look at the experience of cancer in individuals with schizophrenia may yield valuable insights into the origins of these disparities. An examination of cancer specific to individuals living with schizophrenia may also help to facilitate a person-centered approach to cancer care—one that considers the needs and perspectives of this population. This information may also ultimately lead to the development of interventions to decrease cancer morbidity and mortality for this population.

When examining the experience of cancer, a study of symptom clusters may be highly informative. Symptom clusters, phenomena that have largely been examined in the context of cancer, refer to the presence of three or more concurrent related symptoms that may or may not have a common cause (Dodd et al., 2001). Knowledge and understanding of the presence and nature of symptom clusters in individuals with cancer may augment understanding of cancer morbidity and mortality (Kwekkeboom, 2016); specifically, symptom clusters in individuals with cancer may independently predict changes in functioning and treatment outcomes (Fan et al., 2007). Such insight could greatly enhance the current understanding of cancer in populations for which existing data are unclear. In the case of individuals with schizophrenia and cancer, knowledge of symptom clusters as they relate to cancer morbidity and mortality could enhance understanding of cancer burden in this population.

In the current literature, data pertaining to cancer symptom clusters in individuals with schizophrenia are sparse. The gap in knowledge about cancer symptom clusters in individuals with schizophrenia indicates a need for specific research into this phenomenon. Related data that have been examined to date include descriptions of potential risk factors for cancer, as well as factors related to mental illness which may impact cancer treatment and outcomes. This data



may serve to help build foundational knowledge of cancer symptom clusters in individuals with schizophrenia.

### **Hospice Use Among Individuals with SPMI**

Health care for individuals at the end of life must be person-centered, taking into account individual beliefs and preferences, and include communication about understanding and expectations regarding the nature of any life-limiting illnesses. Advanced care planning, a process which promotes individuals communicating and sharing their preferences, values, and goals of care, has been shown to promote improved quality of life, care that is more consistent with the patients' wishes, and better outcomes for bereaved family members (Sokol-Hessner et al., 2015). Palliative care measures, and more specifically, hospice, a model of care whose focus is maintaining comfort and promoting quality of life, are one means of helping to achieve goals of care for individuals with limited life expectancy. Hospice is considered an optimal model of care for individuals nearing the end of life because it promotes care that is patient and family-centered, and helps to maximize quality of life for individuals (Vig et al., 2010). Specific benefits of hospice include improved symptom management and physical comfort, access to multiple support services, and fewer hospitalizations and invasive treatments unlikely to benefit the individual with terminal illness (National Hospice and Palliative Care Organization, 2017). Over the past two decades, hospice use in the United States has increased; in 2000, an estimated 23% of Medicare beneficiaries utilized hospice services prior to death; in 2010, the rate of hospice use was 44% (Zuckerman et al., 2016).

While use of end-of-life care services appears to have increased in the general population, existing literature suggests that for individuals with SPMI, significant barriers exist to planning for and obtaining optimal end-of-life care. Place of residence, in particular, residing in long-

term care facilities, lack of family connections, barriers to medical care, and care fragmentation appear to affect the ability of individuals with SPMI to access palliative care and hospice services (Chochinov et al., 2012). Underlying these concrete barriers are issues such as communication difficulties, stigma, and preconceived ideas about individuals with SPMI. Chochinov et al. (2012) report that some of the thought patterns that typify schizophrenia may lead to inadequate communication of symptoms by individuals with schizophrenia and cancer, potentially hindering palliative care referrals (Chochinov et al., 2012). Additionally, assumptions about the capacity of individuals with SPMI to make informed decisions about their care may hinder efforts to engage them in important conversations about their treatment and goals for care (Foti et al., 2005).

Given the higher incidence of chronic diseases and lower life expectancies for individuals with SPMI, providers should be prepared to consider issues surrounding the end of life for this population. When done thoughtfully with the guidance of healthcare providers and family members, choices and preferences can be honored, and individuals with SPMI may experience a sense of agency over their health and care (Foti, 2003). Trust and a therapeutic alliance with healthcare providers are integral to adequate management of SPMI, as symptoms of schizophrenia may impede development of such an alliance, particularly if providers are not willing to engage with these individuals during symptomatic periods. In the absence of a feeling of safety for both patient and provider, discussions about symptom management and advance care planning may not occur (Ganzini et al., 2010). Respect for the individual and recognition of autonomy may promote inclusive dialogue to facilitate appropriate optimal end-of-life care.

The observed trajectory of health status and healthcare for individuals with SPMI tells a story of disadvantages that persist over a lifetime and notably, frequently characterize older age

and the end of life--a time when personal agency, comfort, and appropriate care are most important. In order to improve the health and quality of life for this population, an exploration of the persistent, person-level factors contributing to the health inequities is needed.

The overall purpose of this dissertation is to cultivate a better understanding of the health-related experiences and challenges faced by individuals with SPMI. By examining three parts of health and healthcare—cancer care, concurrent medical and psychiatric care for long-term care residents, and care provided at the end of life—insights into how this population experiences health and disease, and how they are perceived and managed by the healthcare system will be gained. Visualizing the concept of personhood at the core of their care trajectories will help to illuminate the issues and challenges contributing to persistent inequities in health status and outcomes. Insights gained from the data may be used to generate improved care for individuals with SPMI, and in particular, care that is congruent with the individuals' needs and desires. Ultimately, appropriate, respectful, and person-centered care may lead to elimination of the disparities in health outcomes for this vulnerable population.

## Dissertation Purpose and Aims

**Table 1**

<b>Chapter Title</b>	<b>Aims</b>
Facilitators and Barriers to Care for Individuals with Serious Mental Illness and Chronic Medical Conditions in Long-Term Care	<ol style="list-style-type: none"><li>1. Describe health care workers' perceptions of the needs of individuals with serious mental illness and chronic medical conditions, who reside in long-term care facilities.</li><li>2. Describe barriers and facilitators to caring for individuals with serious mental illness and chronic medical conditions who reside in long-term care facilities.</li></ol>
Symptom Clusters in Individuals with Schizophrenia and Cancer: A Narrative Review	To summarize what is currently known about physical and psychological cancer-related symptoms in this under-researched population.
Hospice Use Among Individuals with Severe Persistent Mental Illness	Identify factors associated with use of hospice care and potential barriers to hospice use by individuals with SPMI.

The first aim is to describe barriers and facilitators to providing appropriate care for LTC residents living with SPMI and chronic medical conditions. Through a qualitative study consisting of interviews with nurses and other health care professionals, the needs of individuals with SMPI and chronic medical conditions in LTC, and factors shaping the care that they

receive, will be understood. The potential for enhanced person-centered care may be better understood, and ultimately guide improvements in care and overall health outcomes.

The second aim is to explore, via a narrative review, the current literature on cancer symptom clusters in individuals with schizophrenia. The identification and understanding of cancer symptoms experienced by individuals with schizophrenia may reveal important data that can be used to help bridge the knowledge gap in the current understanding of cancer morbidity and mortality in this population.

The third aim is to conduct an integrative review to identify factors associated with hospice use among individuals with severe persistent mental illnesses. The data obtained through this review may serve as the basis for improved knowledge of how to facilitate hospice care when desired, and how to overcome potential obstacles to obtaining desired services.

### **Summary**

Individuals living with SPMI face multiple challenges to maintaining good health, and lag behind the general population in terms of health status and life expectancy. Higher rates of chronic diseases and barriers to receiving appropriate care are manifestations of the inequities that exist for this disadvantaged population. Research to date suggests that deeper issues such as stigma, communication, and trust have contributed to these health inequities. Examining these problems within the framework of personhood may offer valuable insight into why individuals with SPMI have been left behind, even as healthcare for many has moved ahead. Healthcare providers, and in particular, nurses, with their holistic training, are in a position to model efficacious person-centered care for individuals with SPMI, and alter the health trajectory for this population.

## References

- American Psychiatric Association (2019). *Diagnostic and statistical manual of mental disorders* (5th ed).  
<https://dsm.psychiatryonline.org/doi/book/10.1176/appi.books.9780890425596>
- Bartels, S. J., Aschbrenner, K. A., Rolin, S. A., Hendrick, D. C., Naslund, J. A., & Faber, M. J. (2013). Activating older adults with serious mental illness for collaborative primary care visits. *Psychiatric Rehabilitation Journal*, *36*(4), 278–288.  
<https://doi.org/10.1037/prj0000024>
- Bergamo, Cara; Sigel, K., Mhango, G., Kale, M., & Wisnivesky, J. P. (2017). Inequalities in lung cancer. *Physiology & Behavior*, *176*(5), 139–148.  
<https://doi.org/10.1016/j.physbeh.2017.03.040>
- Centers for Disease Control and Prevention (2020, February). *Leading causes of death*. Retrieved from Centers for Disease Control and Prevention website:  
<https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>
- Chochinov, H. M., Martens, P. J., Prior, H. J., & Kredentser, M. S. (2012). Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada. *Schizophrenia Research*, *141*(2–3), 241–246.  
<https://doi.org/10.1016/j.schres.2012.07.028>
- Cole, M., & Padmanabhan, A. (2012). Breast cancer treatment of women with schizophrenia and bipolar disorder from Philadelphia, PA: Lessons learned and suggestions for

improvement. *Journal of Cancer Education*, 27(4), 774–779.

<https://doi.org/10.1007/s13187-012-0391-7>

Colton, C. W., & Manderscheid, R. W. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease*, 3(2), A42.

Cook, B., Wayne, G., Kafali, E., Liu, Z., Shu, C., & Flores, M. (2014). Trends in smoking among adults with mental illness and the association between mental health treatment and smoking cessation. *Journal of the American Medical Association*, 311, 172-182. <https://doi:10.1001/jama.2013.284985>

Council of Economic Advisors. (2019, September). *The state of homelessness in America*.

Retrieved from <https://www.whitehouse.gov/wp-content/uploads/2019/09/The-State-of-Homelessness-in-America.pdf>

Crompton, D., Groves, A., & McGrath, J. (2010). What can we do to reduce the burden of avoidable deaths in those with serious mental illness? *Epidemiologica e Psichiatria Sociale*, 19, 4-7. <https://doi.org/10.1017/S1121189X00001524>

Domino, M. E., Wells, R., & Morrissey, J. P. (2015). Serving persons with severe mental illness in primary care-based medical homes. *Psychiatric Services*, 66(5), 477–483. <https://doi.org/10.1176/appi.ps.201300546>

Farasatpour, M., Janadhan, R., Williams, C.D., Margenthaler, J.A., Virgo, K.S., & Johnson, F.E. (2012). Breast cancer in patients with schizophrenia. *The American Journal of Surgery*, 206(5), 798-804. <https://dx.doi.org/10.1016/j.amjsurg.2012.06.013>

- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *Gerontologist*, *58*, S10–S19.  
<https://doi.org/10.1093/geront/gnx122>
- Foti, M.E. (2003). Do it your way: A demonstration project on end-of-life care for persons with serious mental illness. *Journal of Palliative Medicine*, *6*(4), 661-668. <https://doi.org/10.1089/109662103768253830>
- Foti, M.E., Bartels, S.J., Merriman, M.P., Fletcher, K.E., & Van Citters, A.D. (2005). Medical advance care planning for persons with serious mental illness. *Psychiatric Services*, *56*(5), 576-590. <https://doi.org/10.1176/appi.ps.56.5.576>
- Fullerton, C.A., McGuire, T.G., Feng, Z., Mor, V., & Grabowski, D.C. (2009). Trends in mental health admissions to nursing homes, 1999-2005. *Psychiatric Services*, *60*(7), 965-971.
- Ganzini, L., Socherman, R., Duckart, J., & Shores, M. (2010). End-of-life care for veterans with schizophrenia and cancer. *Psychiatric Services*, *61*(7), 725-728.  
<https://doi.org/10.1176/ps.2010.61.7.725>
- Geller, J.L. (2000). The last half-century of psychiatric services as reflected in psychiatric services. *Psychiatric Services*, *51*, 41-67.
- Hennekens, C.H., Hennekens, A.R., Hollar, D., & Casey, D.E. (2005). Schizophrenia and increased risks of cardiovascular disease. *American Heart Journal*, *150*(6), 1115-1121.  
<https://doi.org/10.1016/j.ahj.2005.02.007>



Hirschtritt, M.E. & Binder, R.L. (2017). Interrupting the mental illness-incarceration recidivism cycle. *Journal of the American Medical Association*, 317(7), 695-696. <https://doi.org/doi:10.1001/jama.2016.20992>

Hodgson, R., Wildgust, H.J., & Bushe, C.J. (2010). Review: Cancer and schizophrenia: Is there a paradox? *Journal of Psychopharmacology*, 24(4S), 51-60. <https://doi.org/10.1177/1359786810385489>

Howard, E. P., Martin, L., Heckman, G. A., & Morris, J. N. (2021). Does the person-centered care model support the needs of long-term care residents with serious mental illness and intellectual and developmental disabilities? *Frontiers in Psychiatry*, 12, 1–9. <https://doi.org/10.3389/fpsy.2021.704764>

Hua, C. L., Cornell, P. Y., Zimmerman, S., Winfree, J., & Thomas, K. S. (2021). Trends in serious mental illness in us assisted living compared to nursing homes and the community: 2007-2017. *American Journal of Geriatric Psychiatry*, 29(5), 434–444. <https://doi.org/10.1016/j.jagp.2020.09.011>

Hwong, A.R. & Irwin, K.E. (2020). Reducing global disparities in cancer screening for people with mental illness. *Lancet Psychiatry*, 7(1), 4-6. [https://doi.org/10.1016/S2215-0366\(19\)30470-5](https://doi.org/10.1016/S2215-0366(19)30470-5)

Irwin, K. E., Henderson, D. C., Knight, H. P., & Pirl, W. F. (2014). Cancer care for individuals with schizophrenia. *Cancer*, 120(3), 323–334. <https://doi.org/10.1002/cncr.28431>

Irwin, K. E., Park, E. R., Shin, J. A., Fields, L. E., Jacobs, J. M., Greer, J. A., Taylor, J. B., Taghian, A. G., Freudenreich, O., Ryan, D. P., & Pirl, W. F. (2017). Predictors of

- disruptions in breast cancer care for individuals with schizophrenia. *The Oncologist*, 22(11), 1374–1382. <https://doi.org/10.1634/theoncologist.2016-0489>
- Irwin, K. E., Park, E. R., Fields, L. E., Corveleyn, A. E., Greer, J. A., Perez, G. K., Callaway, C. A., Jacobs, J. M., Nierenberg, A. A., Temel, J. S., Ryan, D. P., & Pirl, W. F. (2019). Bridge: Person-centered collaborative care for patients with serious mental illness and cancer. *The Oncologist*, 24(7), 901–910. <https://doi.org/10.1634/theoncologist.2018-0488>
- Kilbourne, A., Almirall, D., Goodrich, D., Lai, Z., Abraham, K.M., Nord, K.M., & Bowersox, N.W. (2014). Enhancing outreach for persons with serious mental illness: 12-month results from a cluster randomized trial of an adaptive implementation strategy. *Implementation Science*, 9(163). <https://doi.org/10.1186/s13012-014-0163-3>
- Kim, D.-Y. (2016). Psychiatric deinstitutionalization and prison population growth: A critical literature review and its implications. *Criminal Justice Policy Review*, 27, 3-21. <https://doi.org/10.1177/0887403414547043>
- Kisely, S., Forsyth, S., & Lawrence, D. (2016). Why do psychiatric patients have higher cancer mortality rates when cancer incidence is the same or lower? *Australian & New Zealand Journal of Psychiatry*, 50(3), 254-263. <https://doi.org/10.1177/0004867415577979>
- Kitwood, T. (1997). *Dementia reconsidered*. Open University Press.
- Knapik, G.P. & Graor, C.H. (2013). Engaging persons with severe persistent mental illness into primary care. *The Journal for Nurse Practitioners*, 9(5), 283-287.

<https://doi.org/10.1016/j.nurpra.2013.02.019>

- Lichstein, J.C., Domino, M.E., Beadles, C.A., Ellis, A.R., Farley, J.F., Morrissey, J.P., Gauchat, G.W., DuBard, A., & Jackson, C.T. (2014). Use of medical homes by patients with comorbid physical and severe mental illness. *Medical Care*, *52*, S85-S91.
- Lin, H-Y., Hsieh, J-G., Hsieh, C-J., & Wang, Y-W. (2020). Differences in the opioid consumption of terminally ill schizophrenic and nonschizophrenic cancer patients: Analysis of secondary national population data. *Journal of Pain and Symptom Management*, *59*(6), 1232-1238. <https://doi.org/10.1016/j.jpainsymman.2019.12.360>
- Lopes, R., Soares, R., Figueiredo-Braga, M., & Coelho, R. (2014). Schizophrenia and cancer: Is angiogenesis a missed link? *Life Sciences*, *97*(2), 91–95.  
<https://doi.org/10.1016/j.lfs.2013.12.023>
- Luciano, A. & Meara, E. (2014). The employment status of people with mental illness: National survey data from 2009 and 2010. *Psychiatric Services*, *65*(10), 1201-1209. <https://doi.org/10.1176/appi.ps.201300335>
- Mazereel, V., Detraux, J., Vancampfort, D., van Winkel, R., & De Hert, M. (2020). Impact of psychotropic medication effects on obesity and the metabolic syndrome in people with serious mental illness. *Frontiers in Endocrinology*, *11*, Article 573479.
- McCasland, L.A. (2007). Providing hospice and palliative care to the seriously and persistently mentally ill. *Journal of Hospice and Palliative Nursing*, *9*(6), 305-313.

<https://doi.org/10.1097/01.NJH.0000299313.99514.0c>

McCormack, B. & McCance, T. (2017). *Person-centred practice in nursing and health care*. Wiley Blackwell.

Mesdagh, A. & Hansen, B. (2014). Stigma in patients with schizophrenia receiving community mental health care: a review of qualitative studies. *Social Psychiatry and Psychiatric Epidemiology*, 49, 79-87. <https://doi.org/10.1007/s00127-013-0729-4>

Mitchell, A.J., Vancampfort, D., Sweers, K., van Winkel, R., Yu, W., & De Hert, M. (2013). Prevalence of metabolic syndrome and metabolic abnormalities in schizophrenia and related disorders—a systematic review and meta-analysis. *Schizophrenia Bulletin*, 39, 306-318. <https://doi.org/10.1093/schbul/sbr148>

National Institute of Mental Health (2018, May). Schizophrenia. Retrieved from <https://www.nimh.nih.gov/health/statistics/schizophrenia.shtml>

Olfson, M., Gerhard, T., Huang, C., Crystal, S., & Stroup, T. S. (2015). Premature mortality among adults with schizophrenia in the United States. *JAMA Psychiatry*, 72(12), 1172–1181. <https://doi.org/10.1001/jamapsychiatry.2015.1737>

Powers, R. 2017. *No one cares about crazy people: The chaos and heartbreak of mental health in America*. Hachette Books.

Reddy, F., Reavis, E., Polon, N., Morales, J., & Green, M. (2017). The cognitive costs of social exclusion in schizophrenia. *Schizophrenia Bulletin*, 43(S1), S54. <https://doi.org/10.1093/schbul/sbx021.140>

Ritchie, H. & Roser, M. (2018). Mental Health. Retrieved from

<https://ourworldindata.org/mental-health>

Saha, S., Chant, D., & McGrath, J. (2007). A systematic review of mortality in schizophrenia.

*Archives of General Psychiatry*, 64(10), 1123-1131.

Saks, E. (2007). *The center cannot hold: My journey through madness*. Hyperion.

Sofronas, M., Wright, D.K., & Carnevale, F. A. (2018). Personhood: An evolutionary concept

analysis for nursing ethics, theory, practice, and research. *Nursing Forum*, 53, 406-415.

<https://doi.org/10.1111/nuf.12267>

Sokol-Hessner, L., Zambeaux, A., Little, K., Macy, L., Lally, K., & Adams, K.M. (2015).

“Conversation Ready”: A framework for improving end-of-life care (2<sup>nd</sup> ed.). Boston,

MA: Institute for Healthcare Improvement

Solmi, M., Firth, J., Miola, A., Fornaro, M., Frison, E., Fusar-Poli, P., Dagnioti, E., Shin, J.,

Carvalho, A.F., Stubbs, B., Koyanagi, A., Kisely, S., & Correll, C.U. (2020). Disparities

in cancer screening in people with mental illness across the world versus the general

population: Prevalence and comparative meta-analysis including 4717839

people. *Lancet Psychiatry*, 7, 52-63. [https://doi.org/10./S2215-0366\(19\)30414-6](https://doi.org/10./S2215-0366(19)30414-6)

Tran, E., Rouillon, F., Loze, J. Y., Casadebaig, F., Philippe, A., Vitry, F., & Limosin, F. (2009).

Cancer mortality in patients with schizophrenia: An 11-year prospective cohort study.

*Cancer*, 115(15), 3555–3562. <https://doi.org/10.1002/cncr.24383>

- Vig, E.K., Starks, H., Taylor, J.S., Hopley, E.K., & Fryer-Edwards, K. (2010). Why don't patients enroll in hospice? Can we do anything about it? *Journal of General Internal Medicine*, 25(10), 1009-1019. <https://doi.org/10.1007/s11606-010-1423-9>
- Wainberg, M.L., Scorza, P., Shultz, J. M., Helpman, L., Mootz, J.J., Johnson, K.A., Neria, Y., Bradford, J.E., Oquendo, M.A., Arbuckle, M.R. (2017). Challenges and opportunities in global mental health: A research-to-practice perspective. *Current Psychiatry Reports*, 19(5), 1-10. <https://doi.org/10.1007/s11920-017-0780-z>
- White, F.J. (2013). Personhood: An essential characteristic of the human species. *Linacre Quarterly*, 80(1), 74-97. <https://doi.org/10.1179/0024363912Z.00000000010>
- World Health Organization (2015a). Cancer. Retrieved from [https://www.who.int/health-topics/cancer#tab=tab\\_1](https://www.who.int/health-topics/cancer#tab=tab_1)
- World Health Organization (2015b). WHO global strategy on people-centred and integrated health services: Interim report. Retrieved from [https://apps.who.int/iris/bitstream/handle/10665/155002/WHO\\_HIS\\_SDS\\_2015.6\\_eng.pdf?jsessionid=7C9EFD2192529AF8C9CA118CE4F95F48?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/155002/WHO_HIS_SDS_2015.6_eng.pdf?jsessionid=7C9EFD2192529AF8C9CA118CE4F95F48?sequence=1)
- Yoon, J. Y. (2018). Relationships among person-centered care, nursing home adjustment, and life satisfaction: A cross-sectional survey study. *International Psychogeriatrics*, 30(10), 1519–1530. <https://doi.org/10.1017/S1041610218000194>
- Zuckerman, R. B., Stearns, S.C., & Sheingold, S.H. (2016). Hospice use, hospitalization, and medicare spending at the end of life. *The Journals of Gerontology: Series B*, 71(3), 569-580. <https://doi.org/10.1093/geronb/gbv109>

**Chapter II: Barriers and Facilitators to Caring for Individuals with Serious Mental Illness  
and Chronic Medical Conditions in Long-Term Care**

**Authors:**

Diana M. Hanan, MSN, FNP-BC

Karen S. Lyons, PhD, FGSA

Ellen K. Mahoney, PhD, RN, FGSA

Jane M. Flanagan, PhD, RN, AHN-BC, ANP-BC, FAAN

**Target Journal: *Annals of Long-Term Care*, Impact Factor 0.08**

## Abstract

**OBJECTIVE:** Many older adults in the United States with serious persistent mental illness (SPMI) reside in long-term care facilities and evidence suggests that the number of long-term care residents with SPMI is increasing. Health care professionals who work in these settings may face challenges in providing appropriate care for residents with SPMI and concurrent chronic medical conditions. The purpose of this study was to describe health care professionals' perceptions of the needs of individuals with SPMI and chronic medical conditions and describe barriers and facilitators to caring for these residents.

**METHODS:** 10 health care professionals were recruited and interviewed for this study. A qualitative descriptive design was employed.

**RESULTS:** The themes that emerged from the interviews were: coming to know the individual and their unique needs takes time; being flexible and adapting approaches facilitates trust; respecting the inherent worth of each person promotes caring. Underlying these themes were references to the importance of person-centered care.

**CONCLUSIONS:** Caring for individuals with SPMI and chronic medical conditions in long-term care requires an individualized approach and a commitment to person-centered interventions.



## **Background**

An estimated 11.2 million individuals in the United States are living with serious mental illness (National Institute of Mental Health, 2019), also referred to as (SMI) or serious persistent mental illness (SPMI). Conditions that fall under the rubric of SPMI include schizophrenia, schizoaffective disorder, bipolar disorder, and severe depression (McCasland, 2007). As a whole, individuals living with SPMI experience poorer health outcomes and have shorter life expectancies compared to the general population (Mazereel et al., 2020). These disparities have been attributed to inadequate access to primary care (Domino et al., 2015), health system factors such as poor integration of care (Rodgers et al., 2018), low socioeconomic status, and effects of social stigma (Lee, et al., 2018).

Among the social challenges faced by individuals living with SPMI are difficulties in procuring and maintaining stable housing due to limited family connections (Scull, 2021) and higher rates of incarceration compared to the general population (Hirschtritt & Binder, 2017). For these reasons, many middle-aged and older individuals with SPMI will eventually reside in long-term care facilities (Kaldy, 2018). The social context of this phenomenon and its health implications can be best understood by examining the history of housing for individuals with SPMI.

Deinstitutionalization, a movement towards release of individuals in mental health hospitals and into the community, began in the 1960's (Scull, 2021). The movement was sparked by criticisms of hospital conditions, changes in ideology about the treatment of individuals with mental illness, and changes in public funding for state-run facilities (Scull, 2021). The 1963 Community Mental Health Construction Act offered grants to states for the establishment of community mental health centers—planned alternatives to institutionalization

(Slovenko, 2002). While this movement was welcomed by advocates who criticized conditions in residential mental health facilities, long-term outcomes of deinstitutionalization were not as positive as intended. A substantial number of individuals discharged from state-run institutions found themselves homeless or without permanent housing (Scull, 2021; Sisti et al., 2015). Others, particularly older individuals with SPMI were admitted to nursing homes (Scull, 2021). Admission of older and middle-aged adults with SMI to long-term care (LTC) facilities is a trend that has continued to the present day. A 2008 study estimated that 500,000 individuals with SPMI resided in nursing homes/long-term care (Fullerton, 2008). Recent data suggests that the prevalence of SPMI in long-term care (LTC) facilities has increased in the United States as a whole (Hua et al., 2021). Analysis of a 2018 minimum data set for Missouri LTC residents revealed that the prevalence of schizophrenia was 7.71%, and of an unspecified psychotic disorder 4.48% (Petroski et al., 2019).

While LTC facilities can provide safety and monitoring of medical conditions, individuals with SPMI in these settings have a more complex set of needs, including psychiatric care, which must be coordinated with other medical treatments and teams (Birtley & Phillips, 2020). Additionally, it requires acceptance and understanding from the staff who assist with daily care. Evidence suggests that LTC facilities may not be equipped to meet the needs of this population (Grabowski et al., 2010). The care teams serving LTC residents typically include nurses, nurse practitioners, CNA's, physicians, physical and occupational therapists, and social workers. While mental health care providers are much needed in LTC facilities, many facilities lack access to providers with psychiatric training such as psychiatrists and advanced practice psychiatric nurses (Birtley & Philips, 2020). Research to date has also suggested that residents with SMI disproportionately reside in lower-quality LTC facilities (Jester et al., 2020).

To date, there is a paucity of research on older adults with SPMI who reside in LTC facilities. Older adults with SPMI who live in LTC facilities tend to be a less visible population by virtue of the environment and the fact that they differ from more typical LTC residents, many of whom require long-term care placement due to neurocognitive disorders such as dementia (Van der Wolf et al., 2019). Given the large number of adults with SPMI who are aging in LTC facilities, and the known disparities in health outcomes and lifespan for this population, an examination of the care for adults with SPMI in LTC may be instructive in facilitating and expanding care that matches the needs of this population. A specific focus on barriers and facilitators to care for these individuals may suggest both systemic and person-level strategies to improve care and ultimately, health outcomes for individuals living with SPMI.

### **Purpose**

The purpose of this study was to understand health care professionals' perceptions of the needs of individuals with SPMI and chronic medical conditions living in LTC, including the factors that serve as facilitators and barriers to the fulfillment of these individuals' needs.

### **Study Design**

Because little is currently known about the experiences of providing care to meet the specific needs of individuals with SPMI residing in LTC, a qualitative design was used to explore this phenomenon, including barriers and facilitators to care. Specifically, this study had a qualitative descriptive design, a methodology which supports a comprehensive summary of the event to be described (Sandelowski, 2000).

### **Protection of Human Subjects**

The Institutional Review Board of Boston College approved the study. All participants were assured of their confidentiality/privacy throughout the interview process as described under study procedures. To assure anonymity, participants were provided with pseudonyms for any reporting of the qualitative data.

### **Recruitment Procedures**

The data were obtained from health care professionals who work closely with LTC residents. Health care professionals who care for individuals with SPMI and chronic medical conditions in LTC bear witness to the daily needs and challenges experienced by these residents. As caregivers to these individuals, often for extended periods of time, they are able to develop significant insight into residents' thought processes, emotional responses, and behaviors.

Recruitment consisted of advertisements distributed to local contacts in the health care industry and posted on organizations' websites (American Psychiatric Nurses Association and the Gerontological Society of America). Additionally, participants were recruited through snowball sampling. Once a person agreed to be contacted, the inclusion and exclusion criteria were reviewed to determine eligibility. Inclusion criteria included employment in a LTC facility in the role of a registered nurse, nursing assistant, social worker, physician, physical therapist, or occupational therapist, and experience caring for LTC residents with concurrent SPMI and one or more medical conditions. Additionally, participants needed to be able to speak and understand English, provide written consent, and be willing to be interviewed via Zoom or telephone. If eligible, an appointment for a Zoom interview was set up at a mutually convenient date and time. At the day and time of the interview, a verbal or written consent as required by IRB was obtained, and the interview commenced. It should be noted that this study occurred during the COVID -19 pandemic, so in-person interviews were not possible.

## **Study Procedures**

Interviews were conducted with participants via the Zoom platform, with the exception of one interview, which was conducted over the phone due to technological constraints. Most participants opted to be interviewed from their homes. Interviews were recorded with the permission of participants. The interviews conducted via Zoom were saved as audio files, with the video portion deleted to protect privacy. Participants were not referred to by name during the interviews, and were not asked to provide the names or specific locations of the LTC facilities where they worked.

The interview guide was developed and reviewed in consultation with the research team who collectively have expertise in LTC, geriatrics, chronic illness and mental health. Open-ended questions were created to facilitate objective/unrestricted responses.

## **Data Analysis**

Descriptive content analysis was performed using a process described by Erlingsson and Brysiewicz, (2017). All of the interviews, which were conducted by the PI, were transcribed verbatim. Once transcribed, the transcripts were carefully reviewed for accuracy. The transcripts were then re-read to identify initial codes. All transcripts were read and re-read by both the interviewer and an additional researcher, J.F. who has expertise in qualitative methods. Initial codes were identified separately by the interviewer and J.F.; the researchers then came together to discuss codes. Each transcript was read multiple times to assure understanding of interviewees' responses to the questions and to verify that all codes had been identified. Once all codes were identified, the process of analysis involved collapsing codes into categories. This was followed by developing the categories into themes that captured the overall essence of the experience.

Reflexivity was exercised prior to and throughout the data collection process. The PI took notes prior to and after the interviews to clarify personal thoughts and feelings related to expectations for and reactions to the data collection. These reflections were discussed with J.F., which facilitated a thorough and objective analysis of the interview data.

## **Findings**

Ten individuals participated in the study. This consisted of one registered nurse (RN), two physical therapists, four nurse practitioners, one occupational therapy assistant, one physician, and one social worker. The interview questions were well-received by participants. However, the order in which questions were asked was modified at times to allow for flexibility and to facilitate a more natural conversational flow. Participants seemed comfortable with the Zoom format. Interviews lasted between twenty and forty-five minutes. Three themes were identified. They were: 1) Coming to know the individual and their unique needs takes time; 2) Being flexible and adapting approaches facilitates trust; 3) Respecting the inherent worth of each person promotes caring.

### **Theme 1: Coming to Know the Individual and Their Unique Needs Takes Time**

Time was frequently mentioned by participants as a necessary component of caring for LTC residents with medical conditions and SPMI. Participants described needing to take the time to adequately meet the needs of residents with both SPMI and chronic medical conditions. They verbalized needing more time to provide care for these residents compared to residents without SPMI, and described how and why taking more time is both necessary and beneficial. Jennifer, a nurse practitioner working in suburban Boston, describes how taking the time to be with residents and demonstrating patience and willingness to take the time facilitates trust and building a relationship: “I’ve seen some people get kind of...paranoid due to that [mental

illness]. They get suspicious of people and they just need more time and patience um, and understanding...”

While participants expressed that time was necessary to get to know and understand the needs of their residents with SPMI, time was also described as a limited entity. Finding the time necessary to adequately meet the needs of these residents was described as a challenge by multiple participants. Debra, a nurse practitioner working in Boston, reported, “One of the cons is there is not enough time for staff to really sit down and ask questions individually...”.

Participants described that although it takes time to get to know these individuals, this need was not always recognized by administration and that often the approach was assumed to be a one size fits all. This was a source of frustration for participants in being able to provide person centered care. However, the lack of time also served as motivator for some who viewed making time as something they were committed to doing to assure that care they provided met these individuals’ needs.

## **Theme 2: Being Flexible and Adapting Approaches Facilitates Trust**

Offering choices and being flexible were frequently mentioned by participants as necessary components to providing care for residents living with SPMI and chronic medical conditions. Participants described the importance of giving residents choices in their daily activities, being flexible when providing care, and when appropriate, allowing residents to choose to refuse care. Flexibility and adaptability on the part of health care providers were described as facilitators to meeting the medical needs of residents, avoiding emotional distress and conflict, and demonstrating respect for residents’ boundaries.

When describing the importance of offering choices to residents, Jane, a physical therapist working in the Chicago area, stated, “And then I think also, sometimes giving

people a little bit more choice to feel that they have some freedom.” Sharon, a physician in the Boston area who sees residents in multiple long-term care facilities, described her approach to facilitating medical care for residents with SPMI when the residents may not want to receive care or undergo medical procedures: “I think the first thing to ask yourself, is...’how badly do I need this?’...In the moment, how badly do I need that, and do I need it right now?...So I feel like, if the answer is, can we postpone this...’til they’re in a better frame of mind, can we do that?”

Across participants, the importance of flexibility was mentioned. Often providers were able to articulate that the facility was home for these individuals, and as such, they should have this freedom. Others who did not articulate this specifically, did describe that an appealing aspect of working in this setting was this ability to provide flexibility in meeting the patients’ needs.

### **Theme 3: Respecting the Inherent Worth of Each Person Promotes Caring**

Respecting residents and upholding their dignity was frequently mentioned. Participants described making efforts to help residents feel dignified despite being dependent on others for care. Allison, a nurse in South Carolina, states, “I respect my patients and I’ve always thought that because of having a mental illness they deserve our respect, because they have more to deal with to get through a day successfully than we do, because their minds are consistently working against them.” Preserving the dignity of residents was also described by participants as an act demonstrated through providing personal care in a respectful manner. Joann, an occupational therapy assistant and rehab supervisor, describes this: “Um, we don’t use words like, uh, ‘bib’ for their—we use ‘clothing protector’--we provide them with a clothing protector when they eat, um, so that they, you know, remain clean and dignified.”

Within the theme of respecting the worth of each individual, participants described the notion of being able to understand and empathize with LTC residents with SPMI and medical



conditions. For participants, these strategies were specific means of showing respect and promoted the ability to build connections with these residents. “Getting into their world” was a common phrase used by participants when describing how they attempted to understand the psychological experiences of their residents affected by SPMI. Sharon, a Boston-area physician, described this as, “...if you can really, kind of wrap your head around...moments that—where you can *imagine, try* to imagine, what it must be like...to be in that moment where you’re paranoid—you, you can’t tell if someone’s trying to hurt you or not hurt you.” Joann, occupational therapy assistant and rehab supervisor, stated “...the worst thing is to say, or deny what they’re feeling or seeing...So you can find a lot of enjoyment in getting into their world and seeing them relax when you don’t make them feel like they’re crazy.”

Respect for the individual resident entailed upholding dignity, recognizing the inherent worth of the individual, and empathizing with the individual. The notion of “getting into their world” was seen as one means of respecting the experiences of individuals with SMI and understanding the origins of residents’ responses to interactions with long-term care staff.

### **Trustworthiness and Validation of the Data**

Miles and Huberman’s criteria for ensuring trustworthiness of qualitative research were applied in evaluating the data obtained. Those standards are objectivity, auditability, authenticity, transferability and utilization (Miles & Huberman, 1994). Objectivity or neutrality was assured by the use of journaling reflections prior to and during the interviews as well as during the analysis process. This was employed to protect against interviewer bias. Auditability is the ability for another to easily follow the steps of the research protocol. This was ensured by providing the steps of study procedures and by minimizing variation in interview techniques,

except when indicated by study participants' need for clarification of questions or desire to elaborate on questions discussed. To assure authenticity the interviewer asked participants for clarification when responses to questions were unclear. Participants were also invited to contact the interviewer after the interviews if they wished to provide any additional information or comments. Transferability refers to the possibility that the findings will be relatable to others who provide care to residents in LTC with SPMI and chronic illness. The common themes identified within the data across several health-related disciplines suggests there may be transferability to LTC professionals as a group; additional research would promote increased transferability. The utilization of the findings from this qualitative study may lay the ground work for quantitative studies analyzing specific phenomena related to the care of LTC residents with SMI and chronic medical conditions.

### **Discussion**

The data obtained from this original qualitative study provide a rich description of the needs of LTC residents living with both SPMI and concurrent medical conditions as perceived by their care providers. Within this data, facilitators and barriers to meeting the needs of this population were illuminated. Facilitators to providing for the needs of this population were identified as taking the time to get to know the individual, willingness to be flexible and adapt care to residents' unique needs, and respecting the inherent worth of the individual. These actions were described by health care professionals across disciplines as a means of reaching the individual, building rapport, facilitating collaboration, and ultimately, being able to effectively provide care. Participants described applying these facilitators when faced with challenges to being able to provide appropriate, person-centered care within long-term care facilities.

While limited time could make it difficult to communicate with and complete care for residents with SPMI, participants made efforts to take the time to listen and respond to their residents' needs. When witnessing symptoms of SPMI that contributed to residents declining or being unable to tolerate medical treatments, health care professionals employed flexibility in their approaches, adapting standard plans and timelines to accommodate residents' emotional capacity to participate in their care. "Getting into the world" of the resident facilitated understanding and appreciation of the resident's experience, and fostered rapport between residents and providers.

In the face of organizational challenges in caring for long-term care residents with SPMI and medical conditions, health care professionals can work to promote respect, dignity, and the provision of person and needs-centered care for these individuals. The participants in this study described dedication to caring for this population using approaches that are personal, empathic, and adaptable. Recognition that the needs of individuals with SPMI in long-term care are not the same as the needs of more typical long-term care residents (Howard et al., 2021) is a step toward promoting an environment that is congruent with the needs and preferences of these individuals. While the deinstitutionalization movement offered hope for better care in better places for individuals with SPMI (Sisti et al., 2015; Scull, 2021), eventual placement in LTC facilities was an outcome for many older adults with SPMI (Scull, 2021). Acknowledging this phenomenon and the current population residing in LTC will be instructive in shaping a culture that promotes dignity, respect, and quality care. A culture which promotes the dignity of each individual and a willingness to get into the world of residents living with SPMI may ultimately help to generate improved care and health outcomes for older adults with SPMI and chronic medical conditions.

Education and training for healthcare professionals who work in LTC settings may provide a starting point for culture change and procedures. As study participants reflected on how they strive to meet the needs of their residents with SPMI and medical conditions, it was apparent that education and guidance on working with this unique population were perceived as needs. In a commentary on addressing the unmet needs of adults with SPMI residing in LTC, Birtley and Philips (2020) suggest that nurses and nurse practitioners can play a major role in providing mental health education, training, and support to LTC health professionals and administrative staff (Birtley & Philips, 2020). The inclusion of all members of the health care team in LTC is a necessary element of a shift in care culture. The participants in this qualitative study, who represented six health care professions who serve LTC residents, spoke to the power of all who work in these settings to demonstrate respect and empathy for those who may not be able to speak for themselves.

### **Limitations**

While this study was strengthened by the perspectives of health care professionals representing multiple disciplines and geographical areas within the United States, diversity in gender and ethnicity were lacking among the participants, as all participants were female and Caucasian. The higher proportion of females working in LTC facilities contributed to this limitation. For future studies, concerted efforts to recruit male providers as well as health care professionals representing a diverse set of ethnic and cultural backgrounds should be employed in order to give a more comprehensive presentation of the experiences of LTC staff. Additionally, the inclusion of nursing assistants, or CNA's, who often spend a lot of time with residents and provide much of their personal care, may offer valuable perspectives on the daily experiences of LTC residents living with SPMI and chronic medical conditions.

Due to health concerns posed by the Covid pandemic, interviews with LTC residents themselves were not possible. While data from health care professionals who bear witness to the daily experiences of their residents provided rich insights into the needs of this population, first-hand accounts from LTC residents living with SMI and chronic medical conditions may provide unprecedented and invaluable knowledge of their experiences and needs.

### **Conclusion**

Individuals living with SPMI and chronic medical conditions are vulnerable to poorer health outcomes, shorter lifespans, and inadequate care. In LTC settings, the final homes for many of these individuals, having their emotional and physical needs met can be accomplished through the provision of respect, flexible approaches to care, and time to build trust and caring relationships with healthcare providers. The culture of LTC, which must continue to adapt to accommodate adults living with SPMI and chronic medical conditions, can be shaped by these foundational elements of person-centered care to best serve the persons themselves and promote better health and health outcomes.

## References

- Birtley, N.M. & Phillips, L. (2020). The business and practice of psychiatric advanced practice nursing in long term care. *Archives of Psychiatric Nursing*, 34(5), 288-296.  
<https://doi.org/10.1016/j.apnu.2020.07.007>
- Domino, M. E., Wells, R., & Morrissey, J. P. (2015). Serving persons with severe mental illness in primary care-based medical homes. *Psychiatric Services*, 66(5), 477–483.  
<https://doi.org/10.1176/appi.ps.201300546>
- Erlingsson, C. & Brysiewicz (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, 7, 93-99. <http://dx.doi.org/10.1016/j.afjem.2017.08.001>
- Grabowski, D.C., Aschbrenner, K.A., Rome, V.F., & Bartels, S.J. (2010). Review: Quality of mental health care for nursing home residents: A literature review. *Medical Care Research and Review*, 67(6), 627-656. <https://doi.org/10.1177/1077558710362538>
- Hirschtritt, M.E. & Binder, R.L. (2017). Interrupting the mental illness-incarceration-recidivism cycle. *Journal of the American Medical Association*, 317(7), 695-696.  
<https://doi.org/10.1001/jama.2016.20992>
- Howard, E.P., Martin, L., Heckman, G.A., & Morris, J.N. (2021). Does the person-centered care model support the needs of long-term care residents with serious mental illness and intellectual and developmental disabilities? *Frontiers in Psychiatry*, 12, Article 704764.  
<https://doi.org/10.3389/fpsy.2021.704764>

- Hua, C.L., Cornell, P.Y., Zimmerman, S., Winfree, J., & Thomas, K.T. (2021). Trends in serious mental illness in us assisted living compared to nursing homes and the community: 2007-2017. *American Journal of Geriatric Psychiatry*, 29(5), 434-444. <https://doi.org/10.1016/j.jagp.2020.09.011>
- Jester, D.J., Hyer, K., & Bowblis, J.R. (2020). Quality concerns in nursing homes that serve large proportions of residents with serious mental illness. *The Gerontologist*, 60(7), 1312-1321. <https://doi.org/10.1093/geront/gnaa044>
- Kaldy, J. (2018). When mental illness and aging make nursing homes necessary: What's next? *Caring for the Ages*, 19(5).
- Lee, E. E., Liu, J., Tu, X., Palmer, B. W., Eyler, L. T., & Jeste, D. V. (2018). A widening longevity gap between people with schizophrenia and general population: A literature review and call for action. *Schizophrenia Research*, 196, 9–13. <https://doi.org/10.1016/j.schres.2017.09.005>
- Mazereel, V., Detraux, J., Vancampfort, D., van Winkel, R., & De Hert, M. (2020). Impact of psychotropic medication effects on obesity and the metabolic syndrome in people with serious mental illness. *Frontiers in Endocrinology*, 11, Article 573479. <https://doi.org/10.3389/fendo.2020.573479>
- McCasland, L. (2007). Providing hospice and palliative care to the seriously and persistently mentally ill. *Journal of Hospice and Palliative Nursing*, 9(6), 305-313. <https://doi.org/10.1097/01.NJH.0000299313.99514.0c>

Miles, M.B. & Huberman, A.M. (1994). *Qualitative Data Analysis* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.

National Institute of Mental Health (2018, May). Schizophrenia. Retrieved from <https://www.nimh.nih.gov/health/statistics/schizophrenia.shtml>

Petroski, G.F., Birtley, N.B., & Phillips, L.J. (2019). Prevalence of mental disorders in 2018 for Missouri nursing home residents. *Unpublished raw data*.

Reddy, F., Reavis, E., Polon, N., Morales, J., & Green, M. (2017). The cognitive costs of social exclusion in schizophrenia. *Schizophrenia Bulletin*, 43(S1), S54. <https://doi.org/10.1093/schbul/sbx021.140>

Rodgers, M., Dalton, J., Harden, M., Street, A., Parker, G., & Eastwood, A. (2018). Integrated care to address the physical health needs of people with severe mental illness: A mapping review of the recent evidence on barriers, facilitators and evaluations. *International Journal of Integrated Care*, 18(1), 9. <https://doi.org/10.5334/ijic.2605>

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 33, 334-340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)

Scull, A. (2021). “Community care”: Historical perspectives on deinstitutionalization. *Perspectives in Biology and Medicine*, 64(1), 70-81. <https://doi.org/10.1353/pbm.2021.0006>



Sisti, D.A., Segal, A.G., & Emanuel, E.J. (2015). Improving long-term psychiatric care: Bring back the asylum. *Journal of the American Medical Association*, 313(3), 243-244.

doi:10.1001/jama.2014.16088

Slovenko, R. (2002). The transinstitutionalization of the mentally ill. *Ohio Northern University Law Review*, 29: 641-660.

Van der Wolf, E., van Hooren, S.A.H., Waterink, W., & Lechner, L. (2017). Well-being in elderly long-term care residents with chronic mental disorder: A systematic review.

*Aging & Mental Health*, 23(3), 287-296. <https://doi.10.1080/13607863.2017.1408773>

## **Chapter III**

### **Symptom Clusters in Individuals with Schizophrenia and Cancer: A Narrative Review**

#### **Authors:**

Diana M. Hanan, MSN, FNP-BC

Ellen K. Mahoney, PhD, RN, FGSA

Jane M. Flanagan, PhD, RN, AHN-BC, ANP-BC, FAAN

Karen S. Lyons, PhD, FGSA

**Target Journal: *Psycho-Oncology*, Impact Factor 3.894**

## Abstract

**OBJECTIVE:** Individuals with schizophrenia are known to have poorer cancer outcomes compared to the general population, though the etiology of this disparity remains unclear. The study of cancer symptom clusters in the general population, which has provided insight into cancer morbidity, may improve understanding of the disease process in individuals with schizophrenia. The aim of this narrative review was to summarize what is currently known about cancer symptom clusters in individuals with schizophrenia.

**METHODS:** A literature search was conducted using the databases CINAHL, MedLine, and PubMed. Additionally, an ancestry search was performed. No date filters were applied.

**RESULTS:** No articles specifically examining cancer symptom clusters in individuals with schizophrenia were identified. 18 articles relevant to cancer symptom clusters in individuals with schizophrenia were reviewed. Related topics present in the current literature were: physical health conditions affecting individuals with schizophrenia and connection to cancer risk and outcomes; physical symptoms and experiences of cancer; emotional and behavioral symptoms of schizophrenia that may influence ability to tolerate or complete cancer treatments.

**CONCLUSIONS:** Presentations of cancer symptoms and responses to cancer treatment may differ significantly in individuals with schizophrenia as compared to the general population. Further research is needed to better understand how cancer risk, symptoms, and reactions to treatment might differ in this population. This information may ultimately contribute to interventions used to improve cancer treatment and outcomes for individuals with schizophrenia.

Keywords: cancer, oncology, schizophrenia, symptoms, symptom clusters

## Introduction

It is currently estimated that 11.2 million adults in the United States population are living with a severe mental illness (SMI), also referred to as severe and persistent mental illness, or SPMI (National Institute of Mental Health [NIMH], 2019). Among individuals considered to have SPMI, ninety percent have schizophrenia (McCasland, 2007), a psychiatric disorder characterized by significant alterations in thought process, cognition, and behavior (McCasland, 2007). An estimated 0.25-0.64% of adults in the United States currently have a diagnosis of schizophrenia (NIMH, 2018). Worldwide, an estimated 21 million individuals are estimated to be affected by schizophrenia (Charlson et al., 2018).

Schizophrenia stands out among chronic mental illnesses for its particularly devastating impact on individuals' capacity to function and live safely and independently, and without high risk for illness, injury, and even homelessness and incarceration (Hirschritt & Binder, 2017). Individuals with schizophrenia are disproportionately affected by certain medical conditions such as cancer and heart disease (Irwin et al., 2019a; Mazereel et al., 2020), and on average, have lower life expectancies as compared to the general population (Irwin et al., 2014; Mazereel et al., 2020). Reasons for these disparities are thought to include lifestyle factors such as high rates of smoking, substance abuse, and obesity (Irwin et al., 2014) as well as effects of neuroleptic medications, which may include weight gain, diabetes, and cardiovascular disease (Mazereel et al., 2020). Additionally, individuals with schizophrenia may have lower rates of encounters with medical providers and are less likely to receive regular preventative care (Domino et al., 2015).

Efforts to reduce disparities in disease incidence and outcomes have included the implementation of collaborative care models and the promotion of medical homes for individuals with chronic medical conditions and serious mental illness (Irwin et al., 2019a). Additionally,

recent research has explored the need to increase the uptake of indicated screening such as lung cancer screening for individuals with schizophrenia, many of whom are smokers (Irwin et al., 2019a). These initiatives reflect recognition of the significant morbidity and mortality experienced by individuals living with schizophrenia, as well as early progress in establishing improved care for this previously overlooked population. However, universal acknowledgement of the needs of these individuals and the health inequities faced by them is needed. Ultimately, widespread implementation of interventions to address inequities and excess mortality among individuals with schizophrenia must occur to effect change.

Among the medical conditions that disproportionately impact individuals with schizophrenia, cancer merits specific recognition. Although it is known that individuals with SPMI such as schizophrenia have poorer cancer outcomes, many questions about cancer in this population remain. Cancer incidence in this population has been estimated to be lower, higher, or the same as that for individuals not affected by SPMI (Chou, et al., 2016). Reasons for the discrepancies in estimated cancer incidence rates have been thought to include results from studies examining incidences of different types of cancers—some of which may be more, and others less prevalent in individuals with schizophrenia as compared to the general population—and geographic variation among published studies (Chou et al., 2016). Additionally, a wide range of medical and social factors, such as higher rates of smoking (Irwin et al., 2019b) and socioeconomic status (Irwin et al., 2017) have been implicated in the cancer morbidity and mortality experienced by individuals with schizophrenia. Both data inconsistencies and the breadth of potential factors contributing to cancer suggest the need for closer examination of the experience of cancer in individuals with schizophrenia. Such data could help to answer the

question of how individuals with schizophrenia might experience cancer, both from a physical and psychological standpoint.

When examining the experience of cancer, with the goal of understanding morbidity and ultimately improving outcomes, observing symptom clusters may offer valuable information for health care providers. Within the broader context of cancer, the identification of symptom clusters, which can be described as the presence of three or more concurrent related symptoms that may or may not have a common cause (Dodd et al., 2001), has emerged as a means of improved understanding about cancer morbidity and mortality (Kwekkeboom, 2016). In chronic diseases and conditions such as cancer, individuals commonly experience multiple concurrent symptoms which are interrelated (Miaskowski et al., 2017), which underscores the importance of acknowledging the presence and potential effects of symptom clusters. Symptom clusters most commonly recognized by oncologists and other healthcare providers include gastrointestinal, which may include anorexia, nausea, and vomiting, neuropsychological, which may include sleep disturbances, fatigue, and depression, and respiratory, which are characterized by shortness of breath and cough (Donovan & Jacobsen, 2007; Esper, 2010).

Symptom clusters in individuals with cancer may independently predict changes in functioning and treatment outcomes (Fan et al., 2007). For healthcare providers, knowledge of symptom clusters may allow for better assessment and anticipation of symptoms, and may permit more efficient symptom management, by facilitating a single-treatment approach to symptom control and palliation (Kwekkeboom, 2016). For example, understanding that some symptoms co-occur and that certain specific symptoms may trigger the onset of additional symptoms has encouraged clinicians to tailor symptom screening and management to target existing and potential sources of cancer-related morbidity (Al Qadire et al., 2020).

Symptom clusters have the potential to tell part of the illness story for individuals with cancer. However, as of yet, there is a lack of research describing symptom clusters in individuals with cancer who are also living with schizophrenia. For individuals with schizophrenia, insight into cancer symptomatology and symptom clusters may prove to be especially valuable, for the experience of physical illness has not been well-described in this population—a population known to be more vulnerable to poor health outcomes, though less represented in health research (Humphreys et al., 2015). Thus, understanding the physical and psychological experience of cancer through an understanding of symptom clusters could contribute to a better understanding of the cancer trajectory and poorer cancer outcomes for individuals with schizophrenia and cancer.

Given the lack of focus on symptom clusters and experiences of cancer in individuals who are also living with schizophrenia, the current narrative review sought to summarize what is currently known about physical and psychological cancer-related symptoms in this under-researched population. In doing so, research into this needed area can move forward, and ultimately facilitate the development of more effective interventions and management of cancer symptoms for this population.

## **Methods**

Data for this narrative review were obtained by means of a literature search to obtain currently available information on symptom clusters identified in individuals with schizophrenia who are living with cancer. Consistent with accepted guidelines for a narrative review, the aim of this literature search was to identify and comprehensively summarize the available literature pertaining to the research question, while not utilizing a strictly systematic approach (Baethge et al., 2019). Given the current paucity of data specifically related to symptom clusters in

individuals with schizophrenia and cancer, this approach allowed for the inclusion of all relevant data on this and closely related topics—an asset in analyzing an understudied and poorly understood phenomenon. The literature search was conducted using the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, and PubMed databases.

Additionally, an ancestry search was performed. The search terms used were as follows: “schizophrenia and cancer symptoms” “cancer AND symptom clusters”; “schizophrenia and multimorbidity”; “schizophrenia and physical symptoms”; “cancer symptoms in schizophrenia”; “symptom clusters AND cancer.” Date filters were not applied. Additionally, an ancestry search was performed.

Records containing descriptions of symptom clusters identified in individuals with cancer, physical symptoms observed in individuals with a diagnosis of schizophrenia (including symptoms of common comorbid conditions and physical symptoms associated with use of neuroleptic medications), physical illnesses observed in individuals with schizophrenia, and descriptions of physical, emotional, and behavioral occurrences in individuals with schizophrenia undergoing cancer treatment were reviewed. Publications written in languages other than English were excluded. A total of 18 publications deemed to be relevant were reviewed. The publications dated from 2010 to 2020, and included study articles from the United States, Taiwan, Poland, Japan, Belgium, and South Korea.

## **Results**

No publications focusing exclusively on cancer symptom clusters in individuals with schizophrenia were identified. The publications which were identified through the literature search were found to describe three broad phenomena that have been observed in individuals with schizophrenia and cancer: physical health conditions known to affect individuals with



schizophrenia and potentially impact cancer risk and outcomes; physical experiences of cancer among individuals with schizophrenia, including pain perception; emotional and behavioral symptoms of schizophrenia that may influence the ability of an individual to tolerate or complete cancer treatments. While direct reports of symptom clusters affecting individuals with schizophrenia who have cancer are lacking, the information found through the literature review may provide important clues about symptom clusters experienced by individuals with schizophrenia—a step in understanding an underrepresented problem in clinical research and care.

### **Physical Health Conditions Affecting Individuals with Schizophrenia and Connection to Cancer Risk and Outcomes**

Physical symptoms which have been associated with schizophrenia include symptoms of health conditions that are prevalent in this population and adverse effects of antipsychotic medications used to treat schizophrenia. These physical symptoms may provide insight into cancer risk factors, including increased or decreased cancer risk, and cancer-related morbidity and mortality.

Obesity and metabolic syndrome have been recognized as common in individuals with schizophrenia (Correll, et al., 2017). The risk for obesity in individuals with schizophrenia may be four times higher than in the general population (Mazereel et al., 2020). Obesity and its related conditions have been attributed to use of antipsychotic medications (Mazereel et al., 2020) as well as psychosocial factors such as a more sedentary lifestyle and low socioeconomic status (Vancampfort et al., 2017). Obesity has been linked to an increased risk for multiple

cancer types, including liver, colorectal, breast, and ovarian cancers (Arnold et al., 2016).

However, currently, a consensus regarding the incidence of these cancers in individuals with schizophrenia is lacking, owing to disparate findings from the studies performed to date (Chou et al., 2016). Obesity is suspected to negatively influence cancer outcomes, with data suggesting higher mortality rates for colorectal and pancreatic cancers in obese individuals compared to normal-weight patients (Lee et al., 2016; Yuan et al., 2013). It should be noted that the exception to disparate data on cancer incidence and mortality is lung cancer, which has been shown to disproportionately affect individuals with schizophrenia, likely due in part to high rates of smoking in this population (Irwin et al., 2019b).

Physical sequelae of commonly used antipsychotic medications affect many individuals with schizophrenia, and have been suspected to impact the incidence of certain cancers and responses to cancer treatments (Cole & Padmanabhan, 2012; Johnston et al., 2018). While antipsychotic medications, particularly second-generation antipsychotics, have helped many individuals with schizophrenia to effectively manage symptoms of the illness (Moore et al., 2015), these medications are not without adverse effects (Read & Williams, 2019). Among the potential adverse effects of antipsychotic medications is hyperprolactinemia, an increase in serum prolactin levels caused by dopamine antagonists, which include risperidone, quetiapine, and olanzapine. Hyperprolactinemia associated with the use of antipsychotic medications has been linked to increased breast cancer risk (Hodgson et al., 2010). In addition to the risk for hyperprolactinemia secondary to antipsychotic use, women with schizophrenia may be at an increased risk for breast cancer due to reduced parity (Grassi & Riba, 2020). Reduced parity, or having fewer pregnancies, as well as not having breastfed, have been associated with an

increased risk of breast cancer due to increased lifetime exposure to hormones (Fortner et al., 2019).

Antipsychotic medication use while undergoing chemotherapy has been examined as a cause of chemotherapy complications (Cole & Padmanabhan, 2012). Many chemotherapeutic agents cause myelosuppression (Epstein et al., 2020). Since some antipsychotic medications carry a risk of blood dyscrasias, including neutropenia (Jombo & Ekwere, 2018), the use of antipsychotic medication while undergoing chemotherapy may subsequently increase the risk of infection and the development of sepsis under such circumstances may be life-threatening (Cole & Padmanabhan, 2012).

### **Physical Symptoms and Experiences of Cancer**

Some findings from studies examining symptoms of physical illnesses in individuals with schizophrenia have posed the question of whether individuals with schizophrenia may have a decreased perception or awareness of physical changes related to illness, including pain (Shinden et al., 2017; Nishihira et al., 2017). This phenomenon has implications for both the recognition or awareness of a physical illness in the individual with schizophrenia, and the physical symptoms that are experienced by the ill individual.

A population-based retrospective cohort study of 1001 individuals with schizophrenia and a cancer diagnosis and 4004 matched individuals with cancer and without schizophrenia found lower rates of opioid usage and lower doses of opioid used in the last months of life among individuals with terminal cancer and schizophrenia (Lin et al., 2020). Reasons behind the discrepancy in pain medication usage were conjectured to be both altered pain sensitivity among individuals with schizophrenia, as well as misunderstanding and under-treatment of pain in this population (Lin et al., 2020). The presence of hypoalgesia, or a decreased sensitivity to pain, in individuals with schizophrenia, has been proposed by some researchers as a symptom specific to

schizophrenia (Lin et al., 2020; Singh et al., 2006). This symptom has been speculated to contribute to both the physical experience of cancer and timing of the cancer diagnosis.

Hypoalgesia in individuals with schizophrenia has also been noted in the case of other physical illnesses. A retrospective cohort study of patients in Japan presenting for medical care with appendicitis found that perforation of the appendix (a complication associated with late diagnosis) was much more common among individuals with schizophrenia as compared to patients without schizophrenia (53% vs. 17%;  $p$ -value  $< 0.01$ ) (Nishihira et al., 2017). This observation suggests that potentially serious, life-threatening sequelae may result from diminished pain perception, highlighting the significance of its recognition in individuals at risk for poor disease outcomes, specifically cancer.

### **Emotional and Behavioral Symptoms of Schizophrenia Influencing Ability to Tolerate Cancer Treatments**

Individuals living with schizophrenia may experience difficulties tolerating or completing cancer treatments due to schizophrenia-related cognitive and psychiatric symptoms (Cole & Padmanabhan, 2012; Farasatpour et al., 2012). A study examining disruptions in breast cancer treatment found that disruptions in care were common in patients with schizophrenia, and are associated with adverse cancer outcomes (Irwin, et al., 2017). Half of the 95 women in the study experienced at least one disruption in cancer care, among them, interruptions in cancer treatment and deviations from stage-appropriate cancer treatment (Irwin et al., 2017). Lack of psychiatric treatment (defined as documentation of having a psychiatric provider and a record of being on antipsychotic medication) was found to be associated with cancer treatment disruptions, as were psychiatric hospitalizations after cancer diagnosis (Irwin et al., 2017). In a retrospective study of

56 patients with breast cancer and schizophrenia, Farasatpour et al. (2012) found that delays in breast cancer diagnosis and in beginning treatment were common (Farasatpour et al., 2012).

Among reasons for late diagnoses and delays in beginning treatment, the authors speculate that negative symptoms of schizophrenia, including alterations in ability to process sensory information, may decrease sensitivity to pain (Farasatpour et al., 2012; Singh et al., 2006).

A case study involving three women with SMI (diagnoses of schizophrenia and bipolar disorder) and diagnoses of breast cancer closely examined specific factors influencing the womens' cancer treatment trajectories. The authors identified multiple challenges to successful completion of cancer treatment for these individuals, including patients' reported lack of understanding of the cancer diagnosis and communication problems between the patients and their physicians (Cole & Padmanabhan, 2012). Communication difficulties were described as challenges potentially related to "diagnostic overshadowing" due to providers misattribution of physical symptoms to psychiatric causes, their uncertainties about communicating with patients with severe mental illness, and patient's mistrust of health care providers (Cole & Padmanabhan, 2012). These findings suggest that features of schizophrenia affecting communication may lead to both diminished understanding of a cancer diagnosis for individuals with schizophrenia and blinded recognition of a cancer on the part of healthcare providers.

More overt behavioral manifestations of schizophrenia have been also been described as potential barriers to individuals completing cancer treatments. In a study of 56 patients with

schizophrenia or schizoaffective disorder who developed cancer, Farasatpour et al. (2012) described instances of verbal and physical aggression toward medical staff as well as self-harming behaviors among the patients (Farasatpour et al., 2012). A case study published by Tylec et al. (2015) described a patient with schizophrenia and laryngeal cancer who exhibited significant difficulties in tolerating a tracheotomy tube—a life-preserving measure selected due to the determination that the patient would not be capable of completing radiation therapy or postoperative care (Tylec et al., 2015). The patient repeatedly removed the tracheotomy tube and became agitated when medical personnel reinserted the tube. Behaviors related to schizophrenia, particularly displays of agitation and aggression, present during encounters for medical treatment, have been noted to be detriments to both completing treatment and maintaining a trusting relationship with health care providers—ultimately, a factor which can impact all aspects of the individual’s treatment and disease course (Grassi & Riba, 2020).

### **Discussion**

Individuals with schizophrenia suffer from poorer cancer outcomes compared to the general population. Disparities in receiving care as well as social and lifestyle factors are known to contribute to this population’s overall poorer health and shorter lifespans, yet specific factors affecting the experience and trajectory of cancer remain unexplored for individuals living with schizophrenia. This narrative review sought to identify information on cancer-related symptom clusters in this population, as symptom cluster research in cancer has offered insight into the physical and emotional experiences of cancer and its treatment, as well as direction for symptom interventions in other populations (Lee et al., 2014; Miaskowski et al., 2017).

The current literature is lacking data specifically pertaining to cancer and cancer treatment-related symptoms in individuals living with schizophrenia. Publications identified through this literature search offer information describing more general physical and psychological symptoms that have been observed in individuals with schizophrenia who are diagnosed with cancer. Phenomena described in the current literature include physical conditions affecting individuals with schizophrenia, which affect cancer risk and outcomes, physical perceptions and experiences of cancer, and emotional and cognitive symptoms of schizophrenia that may impact ability to accept cancer treatment. This information provides preliminary data that can be used to build foundational knowledge of symptom clusters in this currently understudied population.

Physical health conditions affecting individuals with schizophrenia as described in the current literature reveal health challenges and inequities experienced by this population, and may provide clues to incidence rates and outcomes for certain cancers. Obesity and its related health problems disproportionately affect individuals with schizophrenia, and the link to increased risk for some cancers and lower cancer survival warrant attention to obesity and metabolic diseases in this population. While the prevalence of obesity among individuals with schizophrenia has been recognized, a dedicated focus on the potential for increased cancer risk and poorer cancer outcomes may help healthcare providers to focus preventative efforts on reducing the risk for cancer. Additional research on the potential adverse effects of antipsychotic medications and their link to cancer incidence and treatment complications may also be instructive for clinicians; monitoring and preventative measures, as well as protocols for managing cancer treatment complications for patients taking antipsychotic medications, could improve health, quality of life, and cancer survival for individuals with schizophrenia.

The physical experience of cancer for individuals with schizophrenia may be shaped by an altered awareness of the signs of physical illness and pain. This phenomenon has been conjectured to contribute to later presentation to care and diagnoses of cancer (Farasatpour et al., 2012), which ultimately contributes to a decreased long-term survival (Flores et al., 2019). Compounding an impaired recognition of physical signs of disease, individuals with schizophrenia may encounter difficulties in communicating with healthcare providers due to stigma and diagnostic overshadowing—both phenomena that result from misunderstanding and inadequate knowledge of the individual presenting for care. Awareness of the possibility that expected cancer-related symptoms may not manifest in or be reported by individuals with schizophrenia may encourage providers to observe and evaluate these patients more carefully for untreated symptoms. This includes potential cancer-related symptoms that may cause physical pain. Importantly, the possibility of altered pain perception or hypoalgesia in individuals with schizophrenia should not create the expectation of reduced pain or a need for less pain control, but rather, openness to the possibility of cancer-related symptoms that do not coincide with expected physical presentations.

The emotional and psychiatric symptoms related to schizophrenia may make it difficult for individuals living with this condition to tolerate recommended cancer treatments. The available literature suggests that not having established psychiatric care can contribute to disruptions in cancer treatment (Irwin et al., 2017). Considering the potential for treatment disruptions due to symptoms of schizophrenia, as well as data pointing to affected individuals' inadequate understanding of cancer diagnoses and lack of trust in medical providers, having psychiatric care in place to help manage schizophrenia symptoms may facilitate improved rates of cancer treatment acceptance, tolerance, and completion. Additionally, facilitators of trust and



effective communication with medical providers should be explored and promoted in an effort to bridge potential gaps between individuals' with schizophrenia and their providers' understanding of a cancer diagnosis.

Ultimately, improved patient-provider communication and collaboration may help healthcare providers to provide appropriate guidance around preventative care to reduce cancer risk, recognize signs and symptoms related to cancer, and engage in dialogue about cancer treatments and their potential side effects for their patients living with schizophrenia. The Bridge trial, a person-centered, team-based trial of collaborative care tested a model in which persons with SMI, oncologists, mental health clinicians, and patient caregivers collaborate to deliver and manage cancer care for individuals with SMI and cancer (Irwin et al., 2019a). The trial found that engagement of individuals with SMI in their cancer treatment improved, as did their reported quality of life (Irwin et al., 2019a). Perhaps most significantly, through this program, individuals with SMI such as schizophrenia and bipolar disorder who had previously been unable to complete recommended cancer treatments were able to start and complete recommended cancer treatments (Irwin et al., 2019a). The expansion of such care models may ultimately foster improved symptom management and ultimately, better treatment outcomes for individuals with schizophrenia and cancer.

While individuals with schizophrenia experience greater morbidity and mortality from cancer and other serious medical conditions, they are commonly excluded from clinical research (Humphreys et al., 2015). Reasons for this include concerns about decisional capacity and fears that experimental treatments may place excessive stress on individuals with schizophrenia and exacerbate symptoms (Humphreys et al., 2015). While research protections aim to shield vulnerable populations from harm, data on symptoms of illnesses such as cancer in individuals

with schizophrenia will remain limited with restrictions on their ability to participate in research—a potential factor contributing to perpetuation of an inequity in care. Additionally, this prevents these individuals from potentially being able to benefit from therapies available through clinical trials. Data on evaluations of capacity to consent to treatment and research have suggested that psychiatric diagnoses may be used as presumptive criteria for determining ability to consent, potentially placing unnecessary limits on opportunities for treatment (Appelbaum, 2007). This is especially problematic, given that measures to evaluate capacity to consent to treatment are available (Hostiuc et al., 2018).

At the core of symptoms witnessed in individuals with schizophrenia and cancer are the persons themselves. Understanding the experience of cancer in this population must thus begin with an understanding of the individuals, and ultimately, a person-centered approach—one that is respectful of, and responsive to, the individuals’ unique needs and preferences. An understanding of cancer-related symptom clusters experienced by these individuals can provide important insights into their physical and emotional health needs. From this knowledge can come strategies and interventions to facilitate care that is acceptable, appropriate, and feasible for them. The gap in cancer outcomes for this population can perhaps ultimately be bridged by closing the gap in knowledge between what is known and what remains to be understood about the experience of cancer for individuals with schizophrenia.

### **Limitations**

This narrative review encompassed the identification and review of currently available literature pertaining to symptom clusters in individuals with schizophrenia and cancer. The sparse amount of data specific to this phenomenon in the literature limited the scope of this review, and did not lend itself to a systematic analysis or synthesis. The data identified through

this narrative review may serve as a starting point for more focused research on symptom clusters in this population. Ultimately, such research may generate much-needed information on cancer symptoms in this understudied and underrepresented population, and contribute to improved cancer care and outcomes.

### **Conclusion**

Little is currently known about symptom clusters in individuals with schizophrenia and cancer. Inequities in care and disproportionately poor cancer outcomes for individuals with schizophrenia speak to a need for dedicated research in this area. Studies focusing specifically on the unique symptoms, presentations, and experiences of cancer in this population will augment current knowledge in this area and build a foundation for improved disease management, survival, and improved outcomes such as quality of life, dignity, and respect.

## References

- Al Qadire, M., Shamieh, O., Abdullah, S., & Albadainah, F. (2020). Symptom clusters' content, stability and correlation with the quality of life in a heterogeneous group of cancer patients: A large-scale longitudinal study. *Clinical Nursing Research, 29*(8), 561–570.  
<https://doi.org/10.1177/1054773820933449>
- Appelbaum, P. S. (2006). Decisional capacity of patients with schizophrenia to consent to research: Taking stock. *Schizophrenia Bulletin, 32*(1), 22–25.  
<https://doi.org/10.1093/schbul/sbi063>
- Arnold, M., Leitzmann, M., Freisling, H., Bray, F., Romieu, I., Renehan, A., & Soerjomataram, I. (2016). Obesity and cancer: An update of the global impact. *Cancer Epidemiology, 41*, 8–15. <https://doi.org/10.1016/j.canep.2016.01.003>
- Baethge, C., Goldbeck-Wood, S., & Mertens, S. (2019). SANRA—a scale for the quality assessment of narrative review articles. *Research Integrity and Peer Review, 4*(1), 2–8.  
<https://doi.org/10.1186/s41073-019-0064-8>
- Charlson, F. J., Ferrari, A. J., Santomauro, D. F., Diminic, S., Stockings, E., Scott, J. G., McGrath, J. J., & Whiteford, H. A. (2018). Global epidemiology and burden of schizophrenia : Findings from the global burden of disease study 2016. *Schizophrenia Bulletin, 44*(6), 1195–1203. <https://doi.org/10.1093/schbul/sby058>

- Chou, F. H. C., Tsai, K. Y., Wu, H. C., & Shen, S. P. (2016). Cancer in patients with schizophrenia: What is the next step? *Psychiatry and Clinical Neurosciences*, *70*(11), 473–488. <https://doi.org/10.1111/pcn.12420>
- Cole, M., & Padmanabhan, A. (2012). Breast cancer treatment of women with schizophrenia and bipolar disorder from Philadelphia, PA: Lessons learned and suggestions for improvement. *Journal of Cancer Education*, *27*(4), 774–779. <https://doi.org/10.1007/s13187-012-0391-7>
- Correll, C. U., Solmi, M., Veronese, N., Bortolato, B., Rosson, S., Santonastaso, P., Thapa-Chhetri, N., Fornaro, M., Gallicchio, D., Collantoni, E., Pigato, G., Favaro, A., Monaco, F., Kohler, C., Vancampfort, D., Ward, P. B., Gaughran, F., Carvalho, A. F., & Stubbs, B. (2017). Prevalence, incidence and mortality from cardiovascular disease in patients with pooled and specific severe mental illness: a large-scale meta-analysis of 3,211,768 patients and 113,383,368 controls. *World Psychiatry*, *16*(2), 163–180. <https://doi.org/10.1002/wps.20420>
- Dodd, M.J., Miaskowski, C., & Paul, S.M. (2001). Symptom clusters and their effect on the functional status of patients with cancer. *Oncology Nursing Forum*, *28*, 465-470.
- Domino, M. E., Wells, R., & Morrissey, J. P. (2015). Serving persons with severe mental illness in primary care-based medical homes. *Psychiatric Services*, *66*(5), 477–483. <https://doi.org/10.1176/appi.ps.201300546>
- Donovan, K. A., & Jacobsen, P. B. (2007). Fatigue, depression, and insomnia: Evidence for a symptom cluster in cancer. *Seminars in Oncology Nursing*, *23*(2), 127–135. <https://doi.org/10.1016/j.soncn.2007.01.004>

- Epstein, R. S., Aapro, M. S., Basu Roy, U. K., Salimi, T., Krenitsky, J. A., Leone-Perkins, M. L., Girman, C., Schlusser, C., & Crawford, J. (2020). Patient burden and real-world management of chemotherapy-induced myelosuppression: Results from an online survey of patients with solid tumors. *Advances in Therapy*, 37(8), 3606–3618. <https://doi.org/10.1007/s12325-020-01419-6>
- Esper, P. (2010). Symptom clusters in individuals living with advanced cancer. *Seminars in Oncology Nursing*, 26(3), 168–174. <https://doi.org/10.1016/j.soncn.2010.05.002>
- Fan, G., Filipeczak, L., & Chow, E. (2007). Symptom clusters in cancer patients: A review of the literature. *Current Oncology*, 14(5), 173-179. <https://doi.org/10.3747/co.2007.145>
- Farasatpour, M., Janardhan, R., Williams, C. D., Margenthaler, J. A., Virgo, K. S., & Johnson, F. E. (2013). Breast cancer in patients with schizophrenia. *American Journal of Surgery*, 206(5), 798–804. <https://doi.org/10.1016/j.amjsurg.2012.06.013>
- Flores, E. J., Park, E. R., & Irwin, K. E. (2019). Improving lung cancer screening access for individuals with serious mental illness. *Journal of the American College of Radiology*, 16(4), 596–600. <https://doi.org/10.1016/j.jacr.2018.12.045>
- Fortner, R. T., Sisti, J., Chai, B., Collins, L. C., Rosner, B., Hankinson, S. E., Tamimi, R. M., & Eliassen, A. H. (2019). Parity, breastfeeding, and breast cancer risk by hormone receptor status and molecular phenotype : Results from the nurses' health studies. *Breast Cancer Research*, 21(40),1–9. <https://doi.org/10.1186/s13058-019-1119-y>
- Grassi, L., & Riba, M. (2020). Cancer and severe mental illness: Bi-directional problems and

potential solutions. *Psycho-Oncology*, 29(10), 1445–1451.

<https://doi.org/10.1002/pon.5534>

Hirtschritt, M.E. & Binder, R.L. (2017). Interrupting the mental illness-incarceration-recidivism cycle. *Journal of the American Medical Association*, 317(7), 695-696. <https://doi.org/doi:10.1001/jama.2016.20992>

Hodgson, R., Wildgust, H. J., & Bushe, C. J. (2010). Cancer and schizophrenia: is there a paradox? *Journal of Psychopharmacology*, 24(4 Suppl), 51–60.

<https://doi.org/10.1177/1359786810385489>

Hostiuc, S., Rusu, M. C., Negoii, I., & Drima, E. (2018). Testing decision-making competency of schizophrenia participants in clinical trials. A meta-analysis and meta-regression. *BMC Psychiatry*, 18(1), 2. <https://doi.org/10.1186/s12888-017-1580-z>

Howard, E. P., Martin, L., Heckman, G. A., & Morris, J. N. (2021). Does the person-centered care model support the needs of long-term care residents with serious mental illness and intellectual and developmental disabilities? *Frontiers in Psychiatry*, 12, 1–9.

<https://doi.org/10.3389/fpsy.2021.704764>

Humphreys, K., Blodgett, J. C., & Roberts, L. W. (2015). The exclusion of people with psychiatric disorders from medical research. *Journal of Psychiatric Research*, 70, 28–32.

<https://doi.org/10.1016/j.jpsychires.2015.08.005>

Irwin, K. E., Henderson, D. C., Knight, H. P., & Pirl, W. F. (2014). Cancer care for individuals with schizophrenia. *Cancer*, 120(3), 323–334. <https://doi.org/10.1002/cncr.28431>

- Irwin, K. E., Park, E. R., Shin, J. A., Fields, L. E., Jacobs, J. M., Greer, J. A., Taylor, J. B., Taghian, A. G., Freudenreich, O., Ryan, D. P., & Pirl, W. F. (2017). Predictors of disruptions in breast cancer care for individuals with schizophrenia. *The Oncologist*, *22*(11), 1374–1382. <https://doi.org/10.1634/theoncologist.2016-0489>
- Irwin, K. E., Park, E. R., Fields, L. E., Corveleyn, A. E., Greer, J. A., Perez, G. K., Callaway, C. A., Jacobs, J. M., Nierenberg, A. A., Temel, J. S., Ryan, D. P., & Pirl, W. F. (2019a). Bridge: Person-centered collaborative care for patients with serious mental illness and cancer. *The Oncologist*, *24*(7), 901–910. <https://doi.org/10.1634/theoncologist.2018-0488>
- Irwin, K. E., Steffens, E. B., Yoon, Y. J., Flores, E. J., Knight, H. P., Pirl, W. F., Freudenreich, O., Henderson, D. C., & Park, E. R. (2019b). Lung cancer screening eligibility, risk perceptions, and clinician delivery of tobacco cessation among patients with schizophrenia. *Psychiatric Services*, *70*(10), 927–934. <https://doi.org/10.1176/appi.ps.201900044>
- Johnston, A. N., Bu, W., Hein, S., Garcia, S., Camacho, L., Xue, L., Qin, L., Nagi, C., Hilsenbeck, S. G., Kapali, J., Podsypanina, K., Nangia, J., & Li, Y. (2018). Hyperprolactinemia-inducing antipsychotics increase breast cancer risk by activating JAK-STAT5 in precancerous lesions. *Breast Cancer Research*, *20*(42), 1–13. <https://doi.org/10.1186/s13058-018-0969-z>
- Jombo, H., & Ekwere, T. (2018). A cross-sectional study of the impact of antipsychotic medications on the hematological profile of patients with schizophrenia in a tertiary health facility in Uyo, South-South, Nigeria. *International Neuropsychiatric Disease Journal*, *11*(2), 1–9. <https://doi.org/10.9734/indj/2018/40894>



- Kwekkeboom, K. L. (2016). Cancer symptom cluster management. *Seminars in Oncology Nursing*, 32(4), 373–382. <https://doi.org/10.1016/j.soncn.2016.08.004>
- Lee, C. S., Gelow, J. M., Denfeld, Q. E., Mudd, J. O., Burgess, D., Green, J. K., Hiatt, S. O., & Jurgens, C. Y. (2014). Physical and psychological symptom profiling and event-free survival in adults with moderate to advanced heart failure. *Journal of Cardiovascular Nursing*, 29(4), 315–323. <https://doi.org/10.1097/JCN.0b013e318285968a>
- Lee, J., Meyerhardt, J. A., Giovannucci, E., & Jeon, J. Y. (2015). Association between body mass index and prognosis of colorectal cancer: A meta-analysis of prospective cohort studies. *PLoS ONE*, 10(3). <https://doi.org/10.1371/journal.pone.0120706>
- Lin, G. M., Chen, Y. J., Kuo, D. J., Jaiteh, L. E. S., Wu, Y. C., Lo, T. S., & Li, Y. H. (2013). Cancer incidence in patients with schizophrenia or bipolar disorder: A nationwide population-based study in Taiwan, 1997-2009. *Schizophrenia Bulletin*, 39(2), 407–416. <https://doi.org/10.1093/schbul/sbr162>
- Lin, H. Y., Hsieh, J. G., Hsieh, C. J., & Wang, Y. W. (2020). Differences in the opioid consumption of terminally ill schizophrenic and nonschizophrenic cancer patients: Analysis of secondary national population data. *Journal of Pain and Symptom Management*, 59(6), 1232–1238. <https://doi.org/10.1016/j.jpainsymman.2019.12.360>
- Mazereel, V., Detraux, J., Vancampfort, D., van Winkel, R., & De Hert, M. (2020). Impact of psychotropic medication effects on obesity and the metabolic syndrome in people with serious mental illness. *Frontiers in Endocrinology*, 11(October), 1–10. <https://doi.org/10.3389/fendo.2020.573479>

McCasland, L. (2016). *Reproductive history and cancer risk*. National Cancer Institute.

<https://www.cancer.gov/about-cancer/causes-prevention/risk/hormones/reproductive-history-fact-sheet>

Miaskowski, C., Barsevick, A., Berger, A., Casagrande, R., Grady, P.A., Jacobsen, P., Kutner, J.,

Patrick, D., Zimmerman, L., Xiao, C., Matocha, M., & Marden, S. (2017). Advancing symptom science through symptom cluster research: Expert panel proceedings and recommendations, *JNCI: Journal of the National Cancer Institute*, *109*(4),

djw253. <https://doi.org/10.1093/jnci/djw253>

Moore, S., Shiers, D., Daly, B., Mitchell, A. J., & Gaughran, F. (2015). Promoting physical health for people with schizophrenia by reducing disparities in medical and dental care.

*Acta Psychiatrica Scandinavica*, *132*(2), 109–121. <https://doi.org/10.1111/acps.12431>

Nishihira, Y., McGill, R. L., & Kinjo, M. (2017). Perforated appendicitis in patients with schizophrenia: A retrospective cohort study. *BMJ Open*, *7*(9), 1–5.

<https://doi.org/10.1136/bmjopen-2017-017150>

Read, J., & Williams, J. (2019). Positive and negative effects of antipsychotic medication: An international online survey of 832 recipients. *Current Drug Safety*, *14*(3), 173–181.

<https://doi.org/10.2174/1574886314666190301152734>

Shinden, Y., Kijima, Y., Hirata, M., Nakajo, A., Tanoue, K., Arigami, T., Kurahara, H.,

Maemura, K., & Natsugoe, S. (2017). Clinical characteristics of breast cancer patients with mental disorders. *The Breast*, *36*, 39-43. <https://doi.org/10.1016/j.breast.2017.01.010>

- Singh, M.K., Giles, L.L., Nasrallah, H.A. (2006). Pain insensitivity in schizophrenia: trait or state marker? *Journal of Psychiatric Practice*, *12*, 90-102.
- Tylec, A., Baran, T., Wojciechowska, K., Ślemp, H. D., & Kucharska, K. (2015). Complications after the treatment of laryngeal cancer in a paranoid schizophrenia patient. *Acta Neuropsychologica*, *13*(3), 293–300. <https://doi.org/10.5604/17307503.1184041>
- Vancampfort, D., Firth, J., Schuch, F. B., Rosenbaum, S., Mugisha, J., Hallgren, M., Probst, M., Ward, P. B., Gaughran, F., De Hert, M., Carvalho, A. F., & Stubbs, B. (2017). Sedentary behavior and physical activity levels in people with schizophrenia, bipolar disorder and major depressive disorder: a global systematic review and meta-analysis. *World Psychiatry*, *16*(3), 308–315. <https://doi.org/10.1002/wps.20458>
- Yuan, C., Bao, Y., Wu, C., Kraft, P., Ogino, S., Ng, K., Qian, Z. R., Rubinson, D. A., Stampfer, M. J., Giovannucci, E. L., & Wolpin, B. M. (2013). Prediagnostic body mass index and pancreatic cancer survival. *Journal of Clinical Oncology*, *31*(33), 4229–4234. <https://doi.org/10.1200/JCO.2013.51.7532>

Table 1

Reference	Country of Origin	Purpose/Study Design	Major Findings
Chou et al. (2016)	Taiwan	Narrative review of studies examining cancer incidence and mortality among individuals with schizophrenia	Inconsistencies in reported cancer incidence and mortality rates in individuals with schizophrenia may be due to diversity in studies' settings, populations, and types of cancers examined. Increased cancer mortality in individuals with schizophrenia is common; contributing factors may include lower cancer screening rates, psychiatric symptoms complicating treatment, and physician factors.
Cole & Padmanabhan (2012)	United States	3 case studies involving women with schizophrenia and breast cancer	Barriers to completing cancer treatment include difficulties understanding a cancer diagnosis and adhering to medications and appointment schedules, and complications of schizophrenia. Longer patient visits, use of social support services, and consultations with a psychiatrist are needed to successfully treat cancer patients with schizophrenia.
Correll et al. (2017)	United States	Meta-analysis to assess incidence and prevalence rates of cardiovascular disease (CVD) and mortality rates for CVD in individuals with vs. without SMI	Individuals with SMI had a higher incidence of CVD compared to individuals without SMI. Individuals with SMI were also at increased risk for CVD-related death. CVD incidence was found to increase with antipsychotic medication use ( $p = 0.008$ ).
Farasatpour et al. (2012)	United States	Retrospective cohort study examining breast cancer treatment and outcomes for women with schizophrenia who were diagnosed with breast cancer and treated at a Department of Veterans Affairs medical center.	48% of the women with schizophrenia delayed seeking medical treatment after breast cancer diagnosis. Women with schizophrenia tended to have larger tumors at the time of diagnosis and more had metastasis at presentation compared to women without schizophrenia. Disorganized thought process was associated with a delay in seeking medical attention ( $p < 0.04$ ) and disruptive behavior ( $p < 0.004$ ).

Flores et al. (2019)	United States	Overview of challenges to obtaining lung cancer screening by individuals with SMI	Individuals with SMI report difficulties in accessing lung cancer screening and fear of a lung cancer diagnosis. Barriers to shared decision-making (SDM) between individuals with SMI and their providers may also decrease lung cancer screening in this population. Radiologists can partner with primary care and psychiatric providers to facilitate increased lung cancer screening for individuals with SMI.
Grassi & Riba (2020)	United States	Narrative review of literature pertaining to cancer screening, incidence, mortality, and palliative care for individuals with SMI	Rates of cancer screening are lower among individuals with SMI compared to the general population. Cancer incidence among individuals with SMI varied between studies. Compared to the general population, fewer individuals with SMI received appropriate cancer treatment. Survival rates were lower, and use of palliative care was limited among individuals with schizophrenia.
Hodgson et al. (2010)	United Kingdom	Non-systematic review of studies examining data on cancer mortality rates in individuals with schizophrenia	Factors such as diet, exercise, use of antipsychotic medications, and access to health care may impact cancer incidence and mortality in individuals with schizophrenia. The interplay between these factors contributes to the complexity of assessing cancer incidence and mortality in this population.
Irwin et al. (2017)	United States	Retrospective chart review to characterize disruptions in breast cancer treatment and identify modifiable risk factors for treatment disruptions for women with schizophrenia and breast cancer	Half of the patients with schizophrenia experienced at least one disruption in breast cancer treatment. Lack of documentation of psychiatric care and antipsychotic medications predicted cancer treatment disruptions. Disruptions in treatment included delays in diagnosis and care, and deviations from stage-appropriate treatment.
Irwin et al. (2019a)	United States	Trial to assess feasibility and acceptability of a person-centered collaborative care model (BRIDGE) serving individuals with SMI and cancer.	BRIDGE increased access to psychiatric treatment for patients, fostered patient-clinician trust, and helped patients to start and complete cancer treatments. There was improvement in Brief Psychiatric Rating Scale (BPRS) scores on psychiatric for patients who participated in the BRIDGE trial.

Irwin et al. (2019b)	United States	Investigation of lung cancer screening eligibility and cancer risk perception among individuals with schizophrenia; smoking cessation interventions offered by health care providers to patients with schizophrenia. Cross-sectional survey and medical record review.	34% of older patients were eligible for lung cancer screening based on smoking history. More than half of the patients perceived their lung cancer risk as low. One in three patients who currently smoked reported being offered medications by a PCP or psychiatrist to assist with smoking cessation.
Johnston et al. (2018)	United States	Study examining the potential impact of antipsychotic medications on the development of breast tumors (mouse model)	Two antipsychotic medications known to cause hyperprolactinemia, risperidone and pimozide, prompted precancerous breast lesions to progress to cancer, while aripiprazole, which does not generally cause hyperprolactinemia, did not.
Lin et al. (2020)	Taiwan	Retrospective cohort study examining use of opioid pain medications by terminally ill cancer patients with and without schizophrenia	During the last month of life, opioid use was lower among patients with schizophrenia than without schizophrenia (odds ratio = 0.40). Cumulative dose of opioid medications used was also lower in patients with schizophrenia (2407 mg vs 3694 mg; $p < 0.05$ ).
Mazereel et al. (2020)	Belgium	Literature review examining impact of psychotropic medications on obesity and metabolic syndrome in individuals with serious mental illness (SMI)	Obesity and related metabolic abnormalities may be present in individuals with SMI independent of psychotropic medication use, due to lifestyle factors. Psychotropic medications, particularly second generation antipsychotics, contribute to weight gain in individuals with SMI, though effects vary among individuals. Higher doses of medications and use of multiple medications are associated with greater metabolic consequences.
Nishihara et al. (2017)	Japan	Retrospective cohort study examining individuals with and without schizophrenia presenting for care for appendicitis.	Perforation of the appendix at presentation was more common among patients with schizophrenia compared to patients without schizophrenia (53% vs. 17%; $p < 0.01$ ). Delayed presentation for care and decreased sensitivity to pain may contribute to the higher incidence of appendiceal perforation.

Shinden et al. (2017)	Japan	Retrospective cohort study examining awareness of breast cancer symptoms, extent of disease at diagnosis, treatment received, and survival in patients with and without mental illness (schizophrenia, dementia, or intellectual disability).	Patients with schizophrenia were less likely to be aware of breast cancer symptoms ( $p < 0.01$ ) and presented with more advanced disease at diagnosis. Patients with schizophrenia were more likely to undergo mastectomy and less likely to receive adjuvant chemotherapy or radiation. Difference in disease-free survival between patients with and without schizophrenia was not statistically significant.
Singh et al. (2006)	United States	Literature review to examine findings related to the nature of reported pain insensitivity in individuals with schizophrenia	Among studies examining pain insensitivity in individuals with schizophrenia, methodological cofounders limited the applicability of results. Preliminary findings suggest that the higher pain thresholds reported in some studies are multifactorial.
Tylec et al. (2015)	Poland	Case study of a patient with schizophrenia diagnosed with esophageal cancer.	The patient did not report physical symptoms related to cancer, though symptoms were present (choking, bleeding). The patient repeatedly removed his tracheostomy tube and exhibited aggressive behavior toward hospital staff; further surgical treatment and radiation were not offered due to concerns about patient's ability to cooperate with treatment.
Vancampfort et al. (2017)	Multinational	Systematic review and meta-analysis of studies examining sedentary behavior and physical activity levels in individuals with schizophrenia, bipolar disorder, and major depressive disorder	Individuals with schizophrenia, bipolar disorder, and major depressive disorder were found to be more sedentary than healthy age-matched peers ( $p = 0.003$ ). They were also less likely than healthy age-matched peers to meet guidelines for recommended amounts of physical activity ( $p < 0.001$ ). Lower physical activity levels were associated with male gender, longer duration of illness, higher body mass index, and unemployment.

## **Chapter IV**

### **Hospice Use Among Individuals with Severe Persistent Mental Illness**

Authors: Diana M. Hanan, RN, MSN, FNP-BC and Karen S. Lyons, PhD, FGSA

Full citation:

Hanan, D.M. & Lyons, K.S. (2021). Hospice use among individuals with severe persistent mental illness. *Journal of the American Psychiatric Nurses Association*, 27(3), 213-221.

<https://doi.org/10.1177/1078390320910482>

This manuscript was accepted for publication on March 6, 2020, in *Journal of the American Psychiatric Nurses Association*. Permission to print this manuscript has been obtained from Sage Publications (See Appendix p. 138).



## **Abstract**

**BACKGROUND:** Severe persistent mental illness (SPMI) currently affects an estimated 11.2 million adults in the United States (National Institute of Mental Health, 2019). Affected individuals are known to experience inequities in care, and on average, they die earlier than individuals without SPMI. Currently, little is known about hospice use among individuals with SPMI, including what factors contribute to the use of hospice services.

**AIMS:** The aim of this integrated review was to identify factors associated with the use of hospice services by individuals with SPMI.

**METHODS:** A review of the available literature on this topic was performed in accordance with PRISMA guidelines. The databases Cumulative Index to Nursing and Allied Health Literature, PubMed, and PsycInfo were searched, and relevant records were identified. Ultimately, eight studies were identified and selected for analysis.

**RESULTS:** Themes illustrating the factors associated with hospice use and, within them, challenges to obtaining hospice care were discovered. The three themes identified within the eight studies were fragmentation of care, inadequate communication, and the need for advance care planning. These patterns indicated that multiple barriers to utilizing hospice care exist for individuals with SPMI when compared with the general population.

**CONCLUSIONS:** By recognizing and addressing factors influencing the use of hospice care, as well as barriers to receiving hospice, improved provision of timely end-of-life care that is consistent with individuals' preferences may be facilitated.

**Keywords:** severe persistent mental illness, schizophrenia, hospice, end-of-life care

## **Introduction**

Little is currently understood about the care that individuals with severe persistent mental illness (SPMI) receive near the end of life, or the factors that influence that care. Hospice, a model of care whose focus is symptom management and comfort in the context of terminal illness, can benefit individuals with life-limiting diseases and promote responsible use of medical resources. Understanding factors associated with the use of hospice care by individuals with SPMI is essential at a time when discussions about end-of-life care and shared decision making are increasingly recognized as important to individual and public health. Individuals with SPMI, who have high rates of chronic diseases and die younger than the general population (Chochinov et al., 2012), are missing from the conversation. Through inclusive dialogue and identification of current trends, health care for these individuals may be delivered with greater efficacy, and mental health and hospice care providers may gain skill and confidence in meeting the needs of this vulnerable population.

### **Severe Persistent Mental Illness**

SPMI describes a subset of mental illnesses that typically have their onset in early adulthood and have profound effects on relationships, capacity for educational attainment and employability, and social functioning (Carey & Carey, 1999). Disorders typically included under the rubric of SPMI include schizophrenia, schizoaffective disorder, bipolar disorder, major depression, and obsessive–compulsive disorder (Carey & Carey, 1999). Among those classified as having SPMI, 90% have schizophrenia (McCasland, 2007). Individuals living with these illnesses experience disadvantages when it comes to health status and outcomes. Data suggest that individuals with serious mental illnesses have shorter life spans than unaffected individuals for multiple reasons, including prevalence of chronic diseases, access to services, and ability for self-care (Colton & Manderscheid, 2006; Irwin et al., 2014). Excess morbidity and mortality

among individuals with SPMI have been well documented in the health literature (Chochinov et al., 2012; Irwin et al., 2014). Incidence rates for cardiovascular disease, diabetes, and chronic obstructive pulmonary disease have been found to be higher among individuals with schizophrenia compared with the general population (Correll et al., 2017; Olfson et al., 2015), and these individuals also experience greater mortality from these chronic illnesses (Olfson et al., 2015). Additionally, if individuals with SPMI develop cancer, they are more likely to die from it (Irwin et al., 2014). Despite recognition of these inequities, information about the use of hospice among individuals with SPMI is scarce. Care planning and preferences, rates of hospice use, completion of advance directives, and communication around end-of-life care warrant reexamination, and the experiences of individuals with SPMI facing the end of life merit recognition and clear narration.

### **Hospice Care**

Hospice, a multidisciplinary care model, consists of medical treatment, symptom management, and emotional and spiritual support to individuals with limited life expectancies and their families (National Hospice and Palliative Care Organization [NHPCO], 2017). Benefits of hospice include improved physical comfort, access to support services, and reduction in hospitalizations and invasive treatments unlikely to benefit the terminally ill individual (NHPCO, 2017). Hospice care appears to be advantageous to both individuals and health care delivery as a whole. In addition to providing holistic, personalized care, use of hospice services has been associated with significant health care cost savings (Powers et al., 2015). Using data from U.S. Medicare beneficiaries in 2011, Powers et al. applied a regression model to estimate cost savings with use of hospice services. Annual national cost savings were estimated to range from 316 million to 2.43 billion dollars (Powers et al., 2015). This translates to approximately

355 million to 2.7 billion dollars in 2019 (<https://cpiinflationcalculator.com>). Medical interventions frequently used at the end of life, including intensive care unit (ICU) stays, are often invasive, costly, and may not be in alignment with patients' expressed wishes for care (Vig et al., 2010). While all treatment goals and preferences should be honored, it appears that curative treatment remains the focus of most hospital care provided to chronically and seriously ill individuals (Jenq & Tinetti, 2013).

Despite known benefits of hospice care, many eligible individuals—without respect to mental health conditions—do not enroll in hospice, and hospice stays are often short (Powers et al., 2015). In 2016, 1.43 Medicare beneficiaries were enrolled in hospice for 1 day or more (NHPCO, 2017). More than half of those served by hospice in 2017 received 30 days or less of care (NHPCO, 2017). Reasons for underutilization of hospice appear to be multifactorial, and several trends have been identified. A qualitative study conducted by Vig et al. (2010) found that reasons why patients and families choose not to enroll in hospice include the misconception that hospice care is only for the last few hours to days of life, the challenge of acknowledging death, concerns about losing connections to current health care providers, and delayed referrals to hospice by physicians. Examination of factors associated with obstacles to hospice use may offer direction for health care providers, who can help facilitate services for patients who would benefit from hospice. For individuals with SPMI, this support from health care providers may prove especially valuable, as available data have suggested that they have not routinely been included in national efforts to improve end-of-life care (Foti, 2003).

### **Hospice Care and Individuals With SPMI**

Multiple researchers have identified patterns in health care service use among individuals with SPMI that appear to differ from the general population (Huang et al., 2017; Irwin et al.,

2014). A seminal 2008 literature review examining palliative care for individuals with SPMI suggested that individuals with SPMI encounter multiple challenges to receiving appropriate palliative care (Woods et al., 2008). In the past 10 years, palliative and end-of-life care for individuals with SPMI have not been closely reexamined, and current trends in hospice use and the provision of end-of-life care for these individuals are not clearly understood. Care preferences and planning, understanding of and ability to acknowledge death, and perceptions about hospice among individuals with SPMI necessitate a comprehensive description. The examination of specific factors related to hospice use thus merit a closer look for the purpose of facilitating equitable and ethical care for this vulnerable population.

The purpose of this integrated review was to identify factors associated with use of hospice care by individuals with SPMI. Due to frequent overlapping use of the terms *hospice* and *palliative care* in the pertinent literature (a reflection of a common occurrence in clinical practice), data on the use of palliative care, when utilized for symptom management and comfort at the end of life, are also valuable in the investigation of current care trends. While hospice use is thus the focus of this review, literature describing use of palliative care in the context of life-limiting illness is also discussed.

### **Methods**

A comprehensive review of the available literature was conducted with the assistance of a research librarian. The electronic databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and PsycINFO were each searched using the search phrases “hospice” AND “psychiatric” and “mental illness” AND “hospice.” Additionally, an ancestry search was performed using the electronically identified articles. A total of 126 records was identified through the database and ancestry searches. Two additional records were obtained

through other sources. Of the 128 articles obtained, 53 were found to be duplicates. The remaining 75 articles were screened for pertinence to the subject of inquiry. Articles included were those describing research studies whose exclusive focus was on individuals with SPMI or specifically schizophrenia, and described use of hospice services or palliative care services, at the end of life. No time limit was imposed on the records reviewed. Editorials, case studies, and literature reviews were excluded from the analysis, and three articles written in languages other than English were excluded. Articles primarily describing the experiences of caregivers or substitute decision makers were also excluded, as the experience of individuals themselves was of primary interest. Eight studies ultimately met the inclusion criteria for analysis. The process of record identification is depicted in Figure 1.

## **Results**

The eight articles included in the analysis represented quantitative and mixed-methods studies pertaining to individuals with SPMI, and in some cases, to individuals with a specific diagnosis of schizophrenia. All studies examined use of hospice care, or palliative care services, when specifically utilized at the end of life. Of note, none of the studies specifically reported including homeless individuals with SPMI; this presents the possibility that a sector of individuals affected by current trends in hospice use were not examined. Four of the studies were conducted in the United States, two in Canada, one in Taiwan, and one in New Zealand. Two studies were described in more than one article (Chochinov et al., 2012; Foti, Bartels, Merriman, et al., 2005, Foti, Bartels, Van Citters, et al., 2005; Martens et al., 2013). Overlaps related to the findings within each of these publication dyads are considered in the analysis. A summary of the eight studies, including findings, is presented in Figure 1.

Through careful review and comparison of the eight articles, patterns and trends in hospice use, as well as potential factors limiting use of hospice services, were identified. Differences in access to or use of hospice and in utilization of care at the end of life were noted in the majority of the studies. While the identified differences varied across studies, most pointed out disparities in use of hospice services between individuals with SPMI and the general population. Within these, specific themes describing potential barriers to hospice use were discovered. Fragmentation of care, inadequate communication, and deficiencies in advance care planning emerged as significant factors affecting hospice utilization.

### **Discrepancies in Hospice Use**

Several studies conducted within the past decade describe discrepancies in use of hospice by individuals with SPMI as compared with the general population. In a matched cohort study conducted in Manitoba, Canada, Chochinov et al. (2012) found out that individuals with schizophrenia were less likely to receive palliative care services and more likely to die in nursing homes compared with those in the matched cohort. In this study, individuals with schizophrenia were also less likely to see specialist health care providers. The authors note that while the majority of individuals who die of cancer die in an acute care hospital, the rates of in-hospital deaths in this study were 75.9% for individuals with cancer and schizophrenia, compared with 85.9% of individuals with cancer who did not have schizophrenia (Martens et al., 2013).

Similarly, in a cohort study in New Zealand, Butler and O'Brien (2018) found that individuals with SPMI were 3.5 times less likely than matched peers to receive specialist palliative care services, as measured by palliative care referrals. The authors note that this finding is not reflective of the expectation that individuals with SPMI might actually warrant *more* referrals to palliative care services, given that this population has higher rates of



morbidity and mortality than seen in the general population (Butler & O'Brien, 2018). In this study, the proportion of individuals in the SPMI cohort who identified as Maori was 1.2 times higher than in the comparison group, and these individuals were also older, on average (Butler & O'Brien, 2018); these between-group differences underscore the discrepancies between needs and service utilization.

In a population-based cohort study conducted in Taiwan, Huang et al. (2017) found no significant differences in overall use of palliative care or hospice between individuals with and without schizophrenia in the last month of life; however, individuals with schizophrenia had fewer consultations with palliative care providers. Individuals with schizophrenia were also found to have a higher rate of ICU utilization and were more likely to receive interventions such as cardiopulmonary resuscitation, intubation, mechanical ventilation, and feeding tubes in the month preceding death (Huang et al., 2017).

In contrast to the cohort studies, a cross-sectional study of U.S. veterans with cancer, both with and without schizophrenia, found that veterans with a diagnosis of schizophrenia received end-of-life care that in terms of quality was rated to be as good as or better than care received by individuals without schizophrenia (Ganzini et al., 2010). More than half (55%) of veterans with schizophrenia who died of cancer were enrolled in hospice at the time of death (Ganzini et al., 2010). This study differed from the others analyzed, for the care environment was a U.S. Veterans Health Administration (VHA) facility rather than a civilian hospital; as such, the coordination of care and service provision were likely substantially different from those seen in non-VHA health care setting. A VHA directive issued in 2008 reiterated the 1996 Veterans Health Care Reform Act, which stated that the VHA is obligated to provide hospice and palliative care to eligible veterans (U.S. Department of Veterans Affairs, 2008).

## **Inadequate Communication About End-of-Life Care**

Communication about preferences for end-of-life care is essential in facilitating care that is in accordance with patients' wishes and values and appropriate to the prognosis. Open communication about end-of-life care may allow for implementation of hospice services when they are desired. All the authors of the reviewed articles suggest that inadequate communication about preferences for end-of-life care are a barrier to receipt of hospice or palliative care. Communication barriers take multiple forms and may be due to both psychiatric symptoms themselves and health care provider factors. Chochinov et al. (2012) report that the disorganized thought patterns that typify schizophrenia may lead to inadequate communication of symptoms by individuals with schizophrenia and cancer, potentially hindering palliative care referrals. Similarly, Butler and O'Brien (2018) suggest that behaviors and symptoms associated with SPMI may complicate the assessment and interpretation of physical symptoms, potentially affecting the care delivered to these individuals, including hospice care. Trust and a therapeutic alliance with health care providers are integral to adequate management of SPMI, and symptoms of schizophrenia may impede development of such an alliance, particularly if providers are not willing to engage with these individuals during symptomatic periods. In the absence of a feeling of safety for both patient and provider, discussions about symptom management and advance care planning may not occur (Ganzini et al., 2010). Further research on patient-provider communication may elucidate the specific and most significant barriers to effective dialogue. Empirical evidence from the research done to date has suggested that individuals with schizophrenia may be excluded from end-of-life care decisions due to concerns about competency and emotional vulnerability (Candilis et al., 2004). The role of families and caregivers, who may be absent or unavailable to advocate for individuals with SPMI, should also

be explored, as family involvement and caregiver resources could prove significant in how and if end-of-life care discussions occur.

### **Need for Advance Care Planning**

Foti (2003), in describing the challenges inherent in discussing end-of-life care for adults with SPMI, cites family communication problems and estrangement, guardianship status, and assumptions regarding capacity to participate in end-of-life care decision making as obstacles to communication about health care preferences. Underlying these issues is the question of competency; in the instance of an individual with a serious mental illness being judged incompetent to make medical decisions, a health care proxy or guardian may be appointed to communicate end-of-life care preferences (Foti, 2003). Such a representative must be knowledgeable about both end-of-life care and the feelings and values of the individual. The absence of a representative to facilitate communication about care preferences may result in a conversation not taking place, or occurring late in the course of an illness, when advance care planning becomes an imminent and stressful endeavor.

In their nationwide population-based cohort study, Huang et al. (2017), citing prior evidence, posit that higher rates of ICU utilization and invasive procedures such as cardiopulmonary resuscitation and intubation may be in part related to a decreased frequency of having completed advance directives (Cai et al., 2011). The authors suggest that lack of sufficient communication about advance directives may be due to multiple factors, including the difficulty of establishing rapport between individuals with SPMI and their health care providers, individuals' potential inability to refuse invasive procedures, and lack of caregivers or advocates due to frequently being single and being estranged from family (Foti, Bartels, Merriman, et al., 2005; Pollio et al., 2002). Martens et al.'s (2013) findings that individuals with schizophrenia

are much more likely than age-matched peers without schizophrenia to die in nursing homes also suggests that lack of family support may be associated with lower rates of referrals to palliative care.

Foti, Bartels, Van Citters, et al. (2005) found that individuals with serious mental illness are capable of providing input and expressing preferences around end-of-life care decisions. In this study of 150 community-dwelling adults with serious mental illness diagnoses, Foti, Bartels, Van Citters, et al. found that most individuals with serious mental illness were able to express care preferences in response to hypothetical scenarios. Examining the same population, the authors found that very few individuals with serious mental illness had discussed their preferences for end-of-life care, and only 5% reported having had a conversation with their physicians about this. These findings were discordant with the fact that more than one fourth of the individuals in the sample reported having thought about their preferences for medical treatment in the event of serious illness (Foti, Bartels, Van Citters, et al., 2005). Most of the individuals expressed the belief that someone should be appointed to make medical decisions on behalf of individuals who are too ill to do so (Foti, Bartels, Van Citters, et al., 2005). Specific reasons for the disconnect between preferences for end-of-life care and completing advance directives according to one's preferences are not defined, though the authors speculate that for individuals with SPMI, hospitalization, an event that may provide an opportunity for discussion of care preferences, can be destabilizing, and makes this a challenging time for discussions around end-of-life care. Foti, Bartels, Merriman, et al. (2005) stress that due to the trend of lower life expectancies for individuals with SPMI, health care providers should be prepared to have discussions about end-of-life care preferences with them.

### **Fragmentation of Care**

Fragmentation of care is a third theme that emerged within the descriptions of end-of-life care for individuals with SPMI. Inadequate coordination of care and lack of clarity about patients' preferences and plans for care may hinder referrals to hospice or palliative care services. Butler and O'Brien (2018) identify fragmentation of health care as a major barrier to individuals with SPMI receiving adequate care for physical health problems. They specifically cite a "single-disease framework" as a precipitant to the delays in, or lack of care, that individuals with SPMI experience (Butler & O'Brien, 2018). Both Chochinov et al. (2012) and Martens et al. (2013) describe inconsistencies in how and what type of care is delivered to individuals near the end of life, suggesting discontinuity in service delivery. In the Canadian matched cohort study, individuals with schizophrenia were found to have made more visits to general practitioners and psychiatrists, though lower rates of seeing other specialists, receiving opioids for pain relief, and receiving palliative care than matched peers (Chochinov et al., 2012). Thus, despite evidence of significant interaction with the health care system near the end of life, individuals with schizophrenia did not have frequent encounters with services that might have offered a path to palliative or hospice care. In their 2008 literature review, Woods et al. (2008) pointed out that providers outside psychiatry or hospice care may be reluctant to care for individuals with SPMI due to inexperience and discomfort. The more recent studies by Chochinov et al. (2012), Martens et al. (2013), and Butler and O'Brien (2018) suggest that this trend toward separation of health care needs, which may promote fragmented care, has not abated.

## **Discussion**

The analysis of eight studies examining the use of hospice services by individuals with SPMI has revealed themes that illustrate factors and barriers related to receiving hospice care

(see Table 1). Collectively, discrepancies in end-of-life care between individuals with SPMI and the general are apparent. Inadequate communication, the need for advance care planning, and fragmentation of care appear to affect the ways in which hospice care is accessed, utilized, and missed. The interaction of these factors likely further influences hospice use among individuals with SPMI, as communication and coordination of care ultimately inform care delivery. With awareness of these issues, clinicians and community caregivers can be proactive in addressing the disparities in care and working toward solutions to close the gaps.

Initiating conversations about care preferences and completing advance directives can provide clarity about an individual's treatment preferences and facilitate improved care coordination. Shared decision making, a process by which determinations about preferences and goals of care may be established, has been promoted by the Agency for Healthcare Research and Policy as an ideal means of establishing treatment plans (U.S. Department of Health and Human Services, 2016). In shared decision making, the patient and health care provider work together to make health care decisions that are in the best interest of the patient (U.S. Department of Health and Human Services, 2016). This process has the potential to yield important information for individuals with SPMI and their health care providers, bringing preferences and perspectives to light. The importance of open communication with health care providers may carry even greater weight for individuals with SPMI, as relationships with family, who are often tasked with contributing to end-of-life care needs and decisions, may be strained or nonexistent. More advocates for individuals with SPMI, both within and outside the medical system, are needed to help ensure that this important communication takes place.

It is important to note that the differences in hospice use between individuals with SPMI and the general population did not appear to be country- specific. The studies conducted in

Canada, Taiwan, and New Zealand, all of which employ national public health services, identified phenomena similar to those seen in the United States in terms of perception of SPMI and use of end-of-life care. This suggests that access to and affordability of care, known barriers to obtaining health services in the United States, cannot be assumed to be the primary drivers of inequities in care when it comes to services at the end of life; rather, fragmentation of care appears to be pervasive. It is significant that the only study showing equal or superior receipt of hospice care involved individuals who received treatment in an environment in which the provision of hospice and palliative care were obligatory. This care, which was provided in a VHA medical setting, may suggest a model for non-VHA medical centers.

A potential limitation of the studies analyzed is sample size, which may have yielded insufficient representation of individuals with SPMI. The four studies conducted in the United States utilized small samples, representing limited sectors of individuals with SPMI. The studies involving community-dwelling individuals may have provided data on a subset of individuals with SPMI who are less affected by symptoms related to mental illness and therefore not necessarily representative of this population as a whole. It should be noted that community-dwelling individuals with SPMI may live with or have access to family, which could influence or change the experience of accessing or receiving hospice care. Clearly, further research is needed to fully understand the role of family in this area. A significant challenge inherent in studying this marginalized population is whether some of the sickest individuals with SPMI are accounted for in these studies. Homelessness, a significant problem among individuals with SPMI (Podymow et al., 2006), can make the causes and circumstances surrounding death harder to determine, and inevitably, some deaths will be missed. The condition of homelessness also represents the socioeconomic inequalities that exist for many individuals with SPMI, and which,

for some, may be prohibitive of securing hospice services. The problem, which is multifactorial, must be addressed on both a local and a national level and will require both the material resources and clinical acumen to reach these individuals. Psychiatric and mental health nurses, with their skill and expertise in reaching mentally ill individuals who may otherwise avoid care, may be particularly suited to serve as advocates and leaders in this endeavor. Inclusion of homeless individuals with SPMI in future studies would add to the depth of information on this marginalized population.

Clarification and consistency around use of the terms *hospice* and *palliative care* may improve accessibility to specific data on hospice use, particularly when information about underrepresented populations is sought. When more information related to individuals with SPMI and their use of hospice use is brought to light, directions for future research into the experiences and challenges faced by these individuals will become clearer. In light of the currently limited material conveyed through the voices of individuals with SPMI, qualitative studies may initially provide the strongest direction for the journey toward improved knowledge and understanding.

### **Conclusions**

The current literature reveals discrepancies in use of hospice services between individuals with SPMI and the general population. This chasm, which has been observed internationally and is likely multifactorial, may be closed if specific factors affecting use of hospice by individuals with SPMI can be clarified and addressed. Additional focused research is imperative to define effective means for the equitable provision of end-of-life care.



## References

- Butler, H., O'Brien, A. J. (2018). Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study. *International Journal of Mental Health Nursing, 27*(2), 737-746. <https://doi.org/10.1111/inm.12360>
- Cai, X., Cram, P., & Li, Y. (2011). Origination of medical advance directives among nursing home residents with and without serious mental illness. *Psychiatric Services, 62*(1), 61–66. [https://doi.org/10.1176/ps.62.1.pss6201\\_0061](https://doi.org/10.1176/ps.62.1.pss6201_0061)
- Candilis, P.J., Foti, M., & Holzer, J. (2004). End-of-life care and mental illness: A model for community psychiatry and beyond. *Community Mental Health Journal, 40*(1), 3-16. <https://doi.org/10.1023/b:comh.0000015214.24404.cc>
- Carey, M.P., & Carey, K.B. (1999). Behavioral research on the severe and persistent mental illnesses. *Behavioral Therapy, 30*(3), 345-353.
- Chochinov, H. M., Martens, P. J., Prior, H. J., & Kredentser, M. S. (2012). Comparative health care use patterns of people with schizophrenia near the end of life : A population-based study in Manitoba, Canada. *Schizophrenia Research, 141*(2–3), 241–246. <https://doi.org/10.1016/j.schres.2012.07.028>
- Colton, C. W., & Manderscheid, R. W. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease, 3*(2), 1–14.

- Correll, C. U., Solmi, M., Veronese, N., Bortolato, B., Rosson, S., Santonastaso, P., Thapa-Chhetri, N., Fornaro, M., Gallicchio, D., Collantoni, E., Pigato, G., Favaro, A., Monaco, F., Kohler, C., Vancampfort, D., Ward, P. B., Gaughran, F., Carvalho, A. F., & Stubbs, B. (2017). Prevalence, incidence and mortality from cardiovascular disease in patients with pooled and specific severe mental illness: a large-scale meta-analysis of 3,211,768 patients and 113,383,368 controls. *World Psychiatry, 16*(2), 163–180.  
<https://doi.org/10.1002/wps.20420>
- Foti, M.E. (2003). Do it your way: A demonstration project on end-of-life care for persons with serious mental illness. *Journal of Palliative Medicine, 6*(4), 661-668. <https://doi.org/10.1089/109662103768253830>
- Foti, M. E., Bartels, S. J., Van Citters, A. D., Merriman, M. P., & Fletcher, K. E. (2005a). End-of-life treatment preferences of persons with serious mental illness. *Psychiatric Services, 56*(5), 585–591. <https://doi.org/10.1176/appi.ps.56.5.585>
- Foti, M. E., Bartels, S. J., Van Citters, A. D., Merriman, M. P., Fletcher, K. E. (2005b). End of-life treatment preferences of persons with serious mental illness. *Psychiatric Services, 56*(5), 585-591. <https://doi.org/10.1176/appi.ps.56.5.585>
- Ganzini, L., Socherman, R., Duckart, J., Shores, M. (2010). End-of-life care for veterans with schizophrenia and cancer. *Psychiatric Services, 61*(7), 725-728. <https://doi.org/10.1176/ps.2010.61.7.725>

- Huang, H.-K., Wang, Y.-W., Hsieh, J.-G., & Hsieh, C.-J. (2018). Disparity of end-of-life care in cancer patients with and without schizophrenia: A nationwide population-based cohort study. *Schizophrenia Research, 195*, 434–440. <https://doi.org/10.1016/j.schres.2017.10.029>
- Irwin, K. E., Henderson, D. C., Knight, H. P., & Pirl, W. F. (2014). Cancer care for individuals with schizophrenia. *Cancer, 120*(3), 323–334. <https://doi.org/10.1002/cncr.28431>
- Jenq, G., Tinetti, M. E. (2013). Changes in end-of-life care over the past decade: More not better. *Journal of the American Medical Association, 309*(5), 489-490. <https://doi.org/10.1001/jama.2013.73>
- Martens, P. J., Chochinov, H. M., & Prior, H. J. (2013). Where and how people with schizophrenia die: A population-based, matched cohort study in Manitoba, Canada. *Journal of Clinical Psychiatry, 74*(6), 551–557. <https://doi.org/10.4088/JCP.12m08234>
- McCasland, L. A. (2007). Providing hospice and palliative care to the seriously and persistently mentally ill. *Journal of Hospice & Palliative Nursing, 9*(6), 305–313. <https://doi.org/10.1097/01.NJH.0000299313.99514.0c>
- National Hospice and Palliative Care Organization. (2017). Hospice care. <https://www.nhpco.org/hospice-care-overview>
- National Institute of Mental Health. (2019). Mental illness. <https://www.nimh.nih.gov/health/statistics/mental-illness.shtml>

- Olfson, M., Gerhard, T., Huang, C., Crystal, S., & Stroup, T. S. (2015). Premature mortality among adults with schizophrenia in the United States. *JAMA Psychiatry*, 72(12), 1172–1181. <https://doi.org/10.1001/jamapsychiatry.2015.1737>
- Podymow, T., Turnbull, J., Coyle, D., Yetisir, E., Wells, G. (2006). Shelter-based managed alcohol administration to chronically homeless people addicted to alcohol. *Canadian Medical Association Journal*, 174(1), 45-49. <https://doi.org/10.1503/cmaj.1041350>
- Pollio, D. E., North, C. S., & Osborne, V. A. (2002). Family-responsive psychoeducation groups for families with an adult member with mental illness: Pilot results. *Community Mental Health Journal*, 38(5), 413-421. <https://doi.org/10.1023/A:1019812512926>
- Powers, B. W., Makar, M., Jain, S. H., Cutler, D. M., & Obermeyer, Z. (2015). Cost savings associated with expanded hospice use in medicare. *Journal of Palliative Medicine*, 18(5), 400-401. <https://doi.org/10.1089/jpm.2015.0014>
- U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality. (2016). The SHARE approach: A model for shared decision making-fact sheet. <https://www.ahrq.gov/professionals/education/curriculumtools/shareddecisionmaking/tools/sharefactsheet/index.html>
- U.S. Department of Veterans Affairs. (2008, August). Hospice and palliative care workload capture, 10NC-4-geriatrics and extended care operations (VHA Directive 2008-041 August 4, 2008). <https://www.va.gov/vhapublications/publications.cfm?pub=1&order=asc&orderby=issue>

Vig, E., Starks, H., Taylor, J., Hopley, E., & Fryer-Edwards, K. (2010). Why don't patients enroll in hospice? Can we do anything about it? *Journal of General Internal Medicine*, 25(10), 1009–1019. <https://doi.org/10.1007/s11606-010-1423-9>

Woods, A., Willison, K., Kington, C., & Gavin, A. (2008). Palliative care for people with severe persistent mental illness: A review of the literature. *Canadian Journal of Psychiatry*, 53(11), 725–736. <https://doi.org/10.1177/070674370805301104>

**Figure 1**

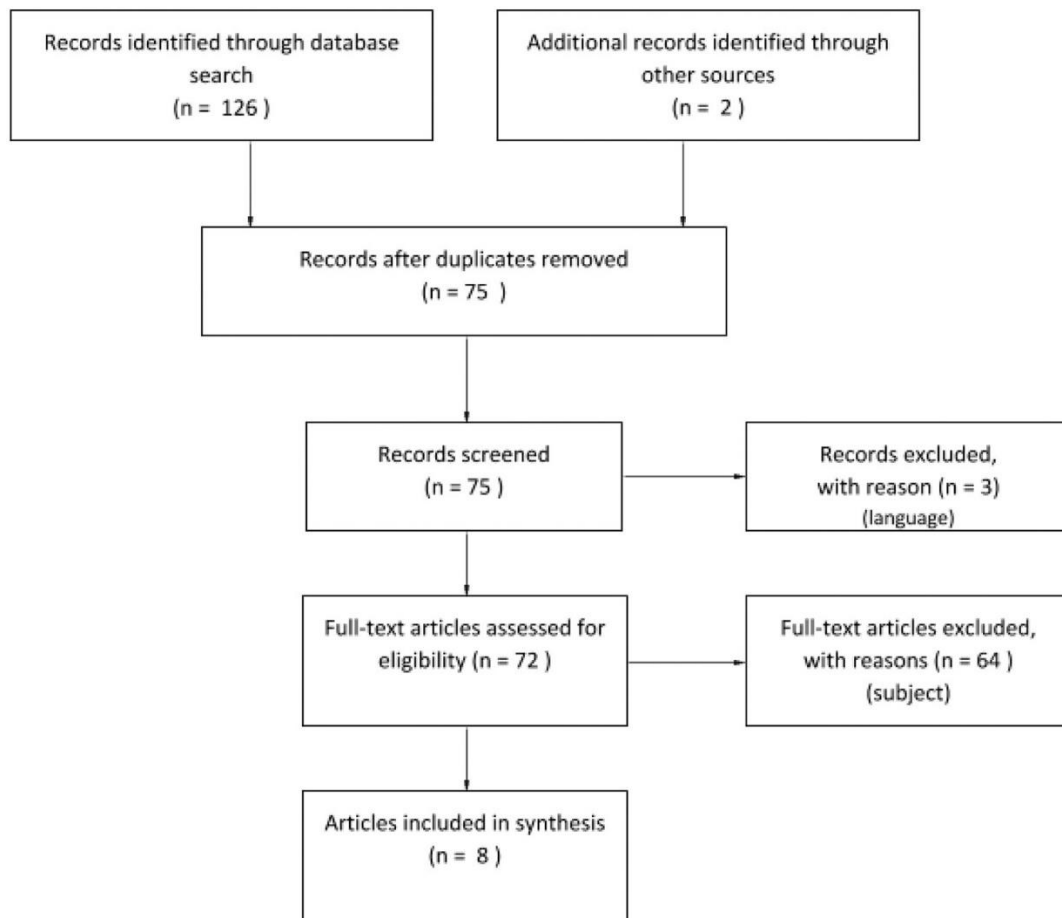


Table 1 Studies Examining Hospice Use and End-of-Life Care Trends Among Individuals with SPMI

Source	Purpose	Design	Sample	Summary of Findings
Butler et al. 2018	Examine access to palliative care by individuals with SPMI	Retrospective cohort study	Individuals with and without SPMI utilizing palliative care resources in one health district in New Zealand (n = 4103; SPMI = 147)	Individuals with SPMI were 3.5 times less likely than the general population to access specialist palliative care services (rate ratio = 0.29).
Chochinov et al. 2012	Compare utilization of health services, including palliative care, in the last 6-24 months of life by individuals with vs. without schizophrenia	Retrospective matched cohort study	Individuals with and without a diagnosis of schizophrenia in Manitoba, CA. Data obtained from National Repository. (n = 14889; schizophrenia = 3943)	Compared to the matched cohort, individuals with schizophrenia spent more days in nursing homes (p < 0.01), and were less likely to see specialists (p < 0.01), receive opioid analgesia (p < 0.01) or receive palliative care (OR = 0.48).
Foti 2003	Improve access to advanced care planning resources and end-of-life care	Demonstration project involving individuals with SMI, healthcare providers, and community stakeholders	Adults served by the Massachusetts Department of Mental Health Services; medical charts reviewed (n = 344)	Cross-training of healthcare providers led to improved coordination of care. An increased number of individuals with SMI went on to complete health care proxy forms.
Foti et al. 2005a	Examine interest in and ability to express preferences about advance care planning among individuals with SPMI	Structured interview, including use of hypothetical health scenarios	150 adults with SMI living in the community (Massachusetts, USA)	Most individuals with SMI were able to express preferences for care when given hypothetical scenarios. Individuals endorsed preferences similar to those in general population.
Foti et al. 2005b	Examine preferences regarding end-of-life care among individuals with SPMI	Health Care Preferences Questionnaire administered to individuals with SPMI	150 community dwelling adults in Massachusetts, USA with serious mental illness (SMI).	Individuals with serious mental illness were able to identify treatment preferences in response to end-of-life health scenarios.
Ganzini et al. 2010	Compare quality of end-of-life care between individuals with and without schizophrenia	Cross-sectional study	Veterans with and without schizophrenia (n = 256; schizophrenia = 60) in a VHA medical center in Oregon, United States	Veterans with schizophrenia had longer hospice stays (p = 0.05) and had more orders for life-sustaining treatment (p < 0.01) than veterans without schizophrenia.
Huang et al. 2017	Compare treatments received near the end of life in individuals with cancer and with vs. without schizophrenia	Nationwide population-based cohort study	Individuals > 20 years old in Taiwan with and without schizophrenia, newly diagnosed with cancer (n = 9,555; schizophrenia = 1911)	No significant difference in rates of admission to hospice. In the month before death, individuals with schizophrenia had more ICU admissions (OR = 1.21), were less likely to receive chemo (OR = 0.60), and more likely to undergo invasive procedures.

Martens et al. 2013	Compare causes and places of death for individuals with/without schizophrenia	Retrospective matched cohort study	Decedents in Manitoba, CA with and without schizophrenia (n = 15,770; schizophrenia = 3943)	Individuals with schizophrenia were more likely to die of lung cancer than matched controls (p < 0.04). Individuals with schizophrenia were much more likely to die in nursing homes (p < 0.0001).
---------------------	---	------------------------------------	---	---



## **Chapter V**

### **Summary and Discussion**

Severe persistent mental illness (SPMI), also referred to as serious mental illness (SMI) is a major cause of morbidity and disability both in the United States and worldwide (National Institute of Mental Health, 2018). Individuals living with SPMI experience poorer health outcomes and have lower life expectancies compared to the general population (Irwin et al., 2017; Weinstein et al., 2016). Underlying these disproportionately poor outcomes are stigma related to mental illness (Irwin et al., 2014), difficulties accessing health care (Irwin et al., 2019), and barriers to effective communication between individuals with SPMI and health care providers (Cole & Padmanabhan, 2012; Irwin et al., 2017). These inequities can be seen in the care that individuals with SPMI receive, the challenges they face in obtaining necessary medical care, and how and where they live and die (Chochinov et al., 2012).

This dissertation had three aims. The first aim was to identify facilitators and barriers to providing adequate care to older adults with SPMI who reside in long-term care facilities. The second aim was to describe the current data on symptom clusters identified in individuals with schizophrenia and cancer. The third aim was to identify current trends in hospice use among individuals with SPMI and explore potential challenges that individuals with SPMI face when identifying options for care at the end of life.

### **Qualitative Study: Findings**

Health care professionals who care for older adults with serious mental illness and chronic medical conditions residing in long-term care facilities encounter barriers meeting the needs of these residents. The health care providers who were interviewed for the qualitative

descriptive study, which included nurse practitioners, physical and occupational therapists, a registered nurse, social worker, and a primary care physician, described the barriers they encounter, and also noted beneficial and effective approaches perspectives which helped them to provide person-centered care for these residents. Within the interviews, several important themes were identified. These were: coming to know the individual and their unique needs takes time; being flexible and adapting approaches facilitates trust; respecting the inherent worth of each person promotes caring.

Positive relationships with health care providers and caregivers may help facilitate meeting the needs of individuals with SPMI and chronic medical conditions. Respect, taking the time to get to know and build trust with residents living with SPMI, and willingness to adapt care for individuals with SPMI may facilitate the provision of optimal care for these individuals. A specific means of respect for individuals with SPMI is a willingness to “get into their world”-- to consider the perspectives and perceptions of individuals living with serious mental illness and medical conditions. Barriers to meeting the needs of individuals with SPMI, particularly those who are also living with chronic medical conditions, include inadequate/limited time, challenges in communicating with these residents, and the symptoms related to mental illness, which may contribute to difficulties accepting care.

Long-term care facilities in the United States may lack the resources needed to adequately care for older adults with SPMI (Birtley & Phillips, 2020). Long-term care residents with SPMI have a complex set of needs, including management of chronic medical conditions as well as care and support for psychiatric conditions (Van der Wolf et al., 2019). Data show that the number of individuals with SPMI living in long-term care facilities has been increasing

(Fullerton et al., 2009; Hua et al., 2020). Given this trend, an examination of care for long-term care residents living with SPMI and medical conditions is prudent.

### **Symptom Clusters in Individuals with Schizophrenia and Cancer: Findings**

Individuals living with schizophrenia are known to experience higher rates of diseases that have been linked to increased incidences of certain cancers. Some of the chronic diseases more prevalent among individuals with schizophrenia include cardiovascular disease and diabetes (Mazereel et al., 2020; Vancampfort et al, 2017), which are more commonly found in individuals who are obese. While antipsychotic medications may be of great benefit in helping individuals with schizophrenia to manage symptoms, the potential adverse effects of some antipsychotic medications may contribute to health conditions such as obesity and related metabolic diseases (Mazereel et al., 2020), which may ultimately affect cancer risk and outcomes. Additionally, hematologic effects of some antipsychotic medications may complicate cancer treatment, increasing the risk for potentially serious reactions to treatments such as immunosuppressive chemotherapy (Cole & Padmanabhan, 2012).

Individuals with schizophrenia may experience cancer symptoms, as well as symptoms of physical illnesses in general, differently than individuals without schizophrenia. This can contribute to under-recognition of illness, in some cases delaying diagnosis until the disease is in a later stage (Farasatpour et al., 2012). Decreased perception of pain, or hypoalgesia, has specifically been proposed as a potential factor contributing to late cancer diagnoses (Farasatpour et al., 2012; Singh et al., 2006). However, physiological mechanisms behind this phenomenon do not appear to be well understood, and the phenomenon itself cannot be viewed as an expected occurrence in individuals with schizophrenia.

The psychiatric and cognitive symptoms of schizophrenia may also influence cancer

diagnosis, treatment, and outcomes. Difficulties fully understanding a cancer diagnosis due to disorganized thought process can contribute to delays in starting treatment (Irwin et al., 2017) or ability to accept and complete treatment (Cole & Padmanabhan, 2012). Such symptoms may contribute to difficulties communicating with health care providers, further hindering referrals for and initiation of stage-appropriate treatment (Irwin et al., 2017). More visible psychiatric symptoms of schizophrenia such as paranoia, agitation, and aggressive behaviors may limit opportunities for communication and discourage medical providers from engaging with individuals with schizophrenia (Farasatpour et al., 2012). Disengagement with individuals with schizophrenia may ultimately preclude the recognition of illness and symptom clusters related to cancer in this population.

#### **Hospice Use Among Individuals with Serious and Persistent Mental Illness: Findings**

Individuals with serious and persistent mental illness have shorter lifespans and are disproportionately affected by many chronic medical conditions, but little attention has been focused on end of life care for this population. An integrated review of the literature to date has revealed current trends in hospice use in this population as well as several specific challenges constitute major barriers to hospice use in this population.

Communication about end-of-life care is essential in facilitating care that reflects the preferences and values of the patient. For individuals with SPMI, communication with health care providers around end-of-life care may be hindered by symptoms related to mental illness; individuals may have difficulty describing symptoms due to disorganized thought process, and providers may be reluctant to engage with individuals with SPMI when cognitive and psychiatric symptoms are present (Chochinov et al., 2012). When a sense of safety, trust, and a therapeutic alliance have not been established, discussions around end-of-life care are less likely to transpire

(Ganzini et al., 2010). Concerns about the cognitive and emotional capacities of individuals with SPMI may also deter medical providers from initiating conversations about end-of-life care (Foti, 2003).

Advance care planning helps to facilitate end-of-life care that is congruent with individuals' preferences and values. However, data suggest that advance care planning often does not occur for individuals with SPMI (Huang et al., 2017). Reasons for this include an assumption that individuals with SPMI are unable to participate in advance care planning or express their preferences (Foti, 2003), difficulty establishing rapport with health care providers, which enables discussions around end-life-care (Ganzini et al., 2010; Huang et al., 2017), and hospitalizations, which, while they serve as opportunities for advance care planning, can be destabilizing for individuals with SPMI (Foti et al., 2005).

Fragmentation of care may create barriers to receiving desired end-of-life care, which may include hospice services. Lack of care coordination and uncertainty around care preferences may hinder referrals to services such as palliative care and hospice for individuals with SPMI. Chochinov et al. found that individuals with SPMI and diagnoses of life-limiting conditions had lower rates of receiving palliative care and interventions such as opioids for pain relief, despite having more visits with both primary care providers (Chochinov et al., 2012). Factors such as access to services and lack of comfort among providers outside of psychiatry and hospice care in caring for individuals with SPMI have been identified as barriers to connecting these individuals with hospice and palliative care services (Woods et al., 2008).

### **Overarching Themes**

Across the three investigations compiling this dissertation, three major themes were revealed: communication challenges between individuals with SPMI and their health care

providers negatively impact health outcomes; fragmentation of care creates barriers to communication and collaboration; and stigma and assumptions about individuals with SPMI have led to exclusion in the health care system and missed opportunities for care.

### **Communication**

Clear and effective communication between individuals with SPMI and their health care providers is necessary to facilitate adequate assessment and treatment of medical conditions and ensure that the needs and preferences of the individual are understood. Miscommunication has been shown to result in missed symptoms and opportunities for care as well as the potential omission of care options.

Individuals with SPMI—specifically, individuals with schizophrenia—who experience symptoms of physical health conditions may have difficulties communicating their symptoms to their medical providers. These difficulties may stem from cognitive impairment related to schizophrenia and/or psychiatric symptoms such as disorganized thought process, paranoia, or delusions. When such symptoms are present, physical symptoms may be more difficult for providers to assess and interpret (Butler & O'Brien, 2018). Additionally, mistrust of medical providers and hospitals, which in some cases is related to paranoia (Irwin et al., 2019a) may discourage open dialogue with medical providers. Non-psychiatric providers may feel unsure about communicating with patients with SPMI (Cole & Padmanabhan, 2012), and as a result, necessary conversations may not take place. Hence, health care providers may inadvertently contribute to and perpetuate inadequate communication with patients living with schizophrenia by not fully engaging with these patients. Additionally, diagnostic overshadowing—the misattribution of physical illness symptoms to psychiatric causes—may prevent discussions about medical problems and delay diagnoses (Cole & Padmanabhan, 2012).

Individuals living with SPMI and facing terminal diagnoses may miss opportunities to receive palliative or hospice care due to being excluded from conversations around end-of-life care planning. This can occur due to individuals' difficulty communicating due to the presence of psychiatric symptoms (Chochinov et al., 2012) and responses of health care providers to patients exhibiting these psychiatric symptoms. Additionally, while evidence suggests that many individuals living with SPMI are able to express preferences about their care in response to hypothetical scenarios (Foti et al., 2005), discussions about end of life care often do not occur.

Health care professionals working in long-term care settings, who regularly witness the communication challenges experienced by residents with SPMI, described the barriers to effective communication with these individuals. Communicating with individuals with SPMI can take more time, and time was noted to be in limited supply by long-term care staff. Willingness to find and take the time to listen, ask questions, re-explain health information, and demonstrate investment in residents living with SPMI can foster effective communication and build trust—the foundation for relationships with vulnerable individuals.

### **Care Fragmentation**

The treatment of physical and mental health conditions as separate tasks to attend to may contribute to poor care coordination and perpetuate the perception of an absolute division between physical and mental health. When care is not well coordinated, particularly for individuals with SPMI and physical health conditions, pertinent medical information may be missed, or may not be communicated to all treatment providers (Irwin et al., 2017). The end results can include lower quality of care and care that is less likely to meet the needs of individuals with SPMI (Cole & Padmanabhan, 2012; Irwin et al., 2017).

Individuals living with SPMI and facing a cancer diagnosis may not be well-connected to



primary care physicians or medical specialists other than psychiatrists (Farasatpour et al., 2012). Reasons for this include difficulty accessing care due to financial burden and social isolation (Irwin et al., 2019a) and in some cases, avoidance of contact with the health care system (Grassi & Riba, 2020). Limited and ineffective interactions with medical providers can contribute to delays in cancer diagnoses and the initiation of treatment (Irwin et al., 2014), both of which contribute to poorer cancer outcomes (Farasatpour et al., 2012; Grassi & Riba, 2020). In addition to less contact with health care providers outside of psychiatry, the segregation of cancer care from mental health services may mean that oncologists do not have access to patients' full psychiatric and medical histories; this can mean that treatment recommendations and decisions are made without consideration of all aspects of patients' health and needs (Irwin et al., 2017).

The physical separation of psychiatric care from medical services—by location, department, organizational structure, or academic medical track—may reflect the perception and treatment of mental illness, and particularly SPMI, as beyond the scope of primary care and other non-psychiatric providers. Feelings of uncertainty among medical providers when communicating with patients with SPMI (Cole & Padmanabhan, 2012) suggest potential knowledge deficits and a need for additional training and support for providers. Education on psychiatric disorders has been identified as a need among physicians who do not practice psychiatry, such as oncologists (Irwin et al., 2019a) and women's health providers (Garbarino et al., 2019).

Disparities in the provision of end-of-life care reflect care fragmentation and gaps in services for individuals with SPMI facing terminal diagnoses. In a matched cohort study, Chochinov et al. (2012) found that individuals with schizophrenia nearing the end of life had

fewer visits with medical specialists and lower rates of receiving palliative care, despite having more contact with psychiatrists and general practitioners (Chochinov et al., 2012). In addition to lower rates of receiving palliative care, data suggest that individuals with SPMI are more likely than individuals without SPMI to die in nursing homes (Martens et al., 2013), and may have pain at the end of life inadequately treated (Lin et al., 2020). Care setting and symptom management at the end of life are in part reflective of care preferences and communication with health care providers. The discrepancies noted may indicate significant gaps in coordination of care for individuals with SPMI.

In long-term care settings, the separation of care into medical and psychiatric can create barriers to addressing the overall health needs of long-term care residents living with SPMI. Long-term care residents living with SPMI and chronic medical conditions constitute a growing proportion of the long-term care population (Hua et al., 2021), yet evidence suggests that many long-term care facilities are not prepared to meet the mental health needs of these individuals (Grabowski et al., 2010; Kaldy, 2018). While management of medical conditions is routinely provided in facilities by physicians or nurse practitioners, residents with SPMI have a complex set of needs, including psychiatric care, which require care coordination across specialties (Birtley & Philips, 2020).

Health care professionals who care for these individuals in long-term care describe the imposed schism between physical health management and psychiatric care, and the consequences for residents with SPMI. Further complicating the care of persons with SPMI, is the issue that individuals with psychiatric diagnoses, particularly schizophrenia, may not be accepted to long-term care facilities and additionally, if a person with SPMI develops acute medical problems requiring treatment, health care providers may be hesitant to treat them due

to concerns, assumptions, and potential implications of the psychiatric diagnosis and their capacity to care for these individuals (Noble et al., 2017).

### **Stigma and Assumptions**

Underlying miscommunication, missed opportunities for care, and disconnections between mental and physical health services is stigma surrounding SPMI and assumptions about the individuals living with them. Stigma and assumptions ultimately do harm to the mental and physical health of individuals with SPMI by making access to care more difficult, discouraging providers from providing appropriate care, and limiting opportunities for individuals to participate in and receive care that is most appropriate to their needs.

When individuals living with schizophrenia develop cancer, the cancer diagnoses are more likely to be later stage compared to the general population (Chou et al., 2016; Irwin et al., 2014). Among factors contributing to late stage diagnoses are disparities in access to and quality of care (Grassi & Riba, 2020; Irwin et al., 2017). Barriers to obtaining care may result from both individuals' avoidance of the health care system (Grassi & Riba, 2020) and health care providers' concerns and difficulties around engaging with individuals with SPMI (Cole & Padmanabhan, 2012; Irwin et al., 2014).

Evidence suggests that underlying this disconnect are mistrust and fear. Individuals with SPMI may distrust clinicians and hospitals due to distressing or traumatic experiences during hospitalizations, particularly involuntary admissions (Berry et al., 2013). Medical providers may fear interactions with patients with SPMI due to a lack of preparedness and a false perception that these individuals are violent (Giandinato et al., 2018; Grassi & Riba, 2020). Despite media images which may suggest this, the absolute risk of violence among individuals with schizophrenia is low (Irwin et al., 2014). A focus on or expectation of psychiatric symptoms

of schizophrenia may contribute to diagnostic overshadowing, in which symptoms related to physical illness are attributed to a psychiatric condition (Cole & Padmanabhan, 2012). This phenomenon suggests a perception of individuals with SPMI as one-dimensional—characterized solely by psychiatric symptoms.

Cancer treatment provided to individuals with SPMI similarly reflects assumptions about these individuals' capacity to engage in treatment. Evidence reveals that cancer care received by individuals with SPMI is of lower quality, in that in many cases, it may be less aggressive and deviate from established stage-appropriate care (Irwin et al., 2014; Irwin et al., 2017). While disruptions in cancer treatment may occur due to symptoms such as difficulty comprehending a cancer diagnosis (Cole & Padmanabhan, 2012) or refusal of treatment (Chou et al., 2016), studies examining collaborative care models suggest that individuals with SPMI who develop cancer can engage in cancer treatment when appropriate support is provided (Irwin et al., 2019a).

Assumptions about capacity of individuals with SPMI to engage in conversations around terminal diagnoses and end-of-life care may impact if and how often these discussions occur (Butler & O'Brien, 2018). While research to date suggests that many individuals living with SPMI are capable of expressing preferences for end-of-life care, discussions around advance care planning between health care providers and patients can be hindered by the assumption that these individuals do not have the capacity to participate in these discussions (Candilis et al., 2004; Foti, 2003). While trust can facilitate a therapeutic relationship and open up dialogue between patients and providers, patients' propensity to distrust medical providers due to a history of negative experiences, and gaps in providers' understanding of the needs and experiences of individuals with SPMI, can preclude or hinder trust and open dialogue between patients and providers.

Individuals with SPMI and chronic medical conditions who live in long-term care are vulnerable to misunderstanding and isolation. As residents of facilities which were largely not designed to provide for their needs, individuals with SPMI, though currently more commonly housed in long-term care facilities, may be perceived as distinct from more typical long-term care resident, such as those with dementia or other neurocognitive disorders (van der Wolf et al., 2019). With the focus on psychiatric symptoms exhibited by residents with SPMI and medical conditions, physical health needs may be neglected. Nurses who care for these residents described instances of long-term care residents with SPMI having physical symptoms such as pain and infection overlooked and confounded by psychiatric symptoms such as anxiety, agitation, paranoia, and social withdrawal potentially impacting the treatment of cancer. Beyond the symptoms that indicated psychiatric illness were the individuals themselves, with all of the needs and complexities inherent to their humanity.

### **Research Implications**

Individuals with SPMI are commonly excluded from participating in research due to assumptions about competency to participate and concerns about the need to protect vulnerable individuals from potential harm (Humphreys et al., 2015; Irwin et al., 2014). This has contributed to the limited amount of data on physical illnesses—both chronic medical conditions and specific diseases such as cancer in this population. Increased inclusion of individuals with serious and persistent mental illness in medical research, and particularly in clinical trials, has the potential to expand current knowledge of the health needs of this population and increase clinicians' understanding of the complex interplay between mental illness and physical health conditions. Opportunities to participate in research may also expand treatment options for individuals living with SPMI, providing them with more and possibly improved treatment

options (Irwin et al., 2019a). The ethical principle of beneficence includes the protection of vulnerable individuals from potential harm in research, yet endeavoring to protect them from potential harm may ultimately result in the systematic exclusion of these individuals from research (Humphreys et al., 2015). For individuals with SPMI, this can preclude access to specialized care and ultimately worsen the existing health disparities that they face.

To address inequities in health outcomes for individuals living with SPMI, future research examining health factors specific to this population is needed. Currently, knowledge of cancer symptom clusters in individuals with SPMI is limited. Studies to date suggest that presentations of cancer-related symptoms and responses to cancer diagnoses may differ in clinically significant ways from those experienced by individuals without SPMI. To better understand these phenomena and develop effective interventions to improve cancer diagnosis, treatment, and outcomes for individuals with SPMI, studies focused on cancer symptom clusters for these individuals are necessary.

Inequities in care delivered later in life for individuals living with SPMI speak to a need for further investigation into care for older adults with SPMI and chronic medical conditions, including those who reside in long-term care. Qualitative data point to time, trust, and empathy as vital for fostering understanding of the needs of these individuals, who, by virtue of their place of residence, are a less visible population. With insight into how older adults with SPMI and medical conditions may understand their health conditions and respond to interactions with providers, health care professionals can adopt approaches that are more likely to be acceptable to individuals with SPMI, and more likely to facilitate effective dialogue about symptoms and problems impacting health and quality of life. Qualitative data from the individuals themselves

may provide direction for studies examining measurable interventions to improve care options and delivery for older adults in long-term care living with SPMI and chronic medical conditions. Policies informing care for older adults with SPMI must take into consideration the needs of this growing population. Long-term care facilities, brought into the spotlight in the wake of the Covid-19 pandemic, may experience pressure to evolve as care delivery in long-term care receives increased attention from concerned consumers and policymakers.

Studies examining the provision of end-of-life care for individuals living with SPMI are currently limited. An integrated review of research to date indicated specific challenges to accessing palliative and hospice care for individuals with SPMI. The identification of barriers to receiving appropriate end-of-life care can direct potential solutions, including research into interventions to improve the provision of palliative care and hospice when desired by the individual. The need for improved communication about serious illness, end-of-life care, and advance directives, as well as better care coordination, suggest a role for trials of collaborative care models specifically designed to support individuals with SPMI facing life-limiting illnesses. A recent trial of a person-centered collaborative care model for individuals with SPMI and cancer found that such a model was well-received by patients, caregivers, and oncologists, and that both cancer treatment completion and psychiatric symptoms for enrolled patients with SPMI were positively impacted (Irwin et al., 2019a).

### **Clinical Implications**

The insights gained from the perspectives of health care professionals who care for adults with SPMI in long-term care, examination of the available data on symptom clusters in individuals with schizophrenia and cancer, and an integrated review of the literature in hospice use among individuals with SPMI all speak to the need for greater collaboration between health

care providers when caring for this population. Communication, coordination of care, and understanding of the needs of individuals with SPMI can all benefit from a collaborative approach to care.

Research to date investigating collaborative care models used to provide medical care to individuals with SPMI suggests that the integration of psychiatric and medical care can be highly beneficial to both patients with SPMI and their providers. A trial testing the feasibility and acceptability of a person-centered collaborative care model for individuals with SPMI and cancer found that such an approach, with structured communication between patients, caregivers, oncologists, psychiatrists, and case managers, was perceived as beneficial for all parties (Irwin et al., 2019a). More specifically, patients with SPMI and cancer were more likely to complete cancer treatments, and psychiatric symptoms improved (Irwin et al., 2019a).

In addition to improving communication and collaboration, ensuring that the needs of individuals with SPMI are appropriately addressed in clinical settings includes implementing assessment methods that are appropriate for them. With the knowledge that individuals with SPMI may have difficulty recognizing physical illness symptoms or communicating symptoms, health care providers can pay careful attention to changes in physical presentation, take the time to ask patients with SPMI about their symptoms, and consider alternative methods for symptom assessment. The inclusion of caregivers and family members in the individual's care should also be considered when appropriate, as it may help providers to better understanding the individuals' history and build rapport. Individuals with schizophrenia are vulnerable to having their pain undertreated, particularly near the end of life (Chochinov et al., 2012). Screening for pain using alternative measures, such as non-verbal pain scales, may be helpful in evaluating pain in individuals with schizophrenia when communication skills are compromised by cognitive or



psychiatric symptoms (Lin et al., 2020).

### **Theoretical Implications**

Person-centered care, a model of care characterized by a focus on the individual and specifically, the individual's needs, preferences, and values, has been promoted as an optimal approach to care in nursing, medicine, and long-term care (Mestagh & Hansen, 2014; Yoon, 2018). While Kitwood first described person-centered care in the context of caring for individuals with dementia (Kitwood, 1997), the benefits of person-centered care have been demonstrated for other populations, including individuals with SPMI and intellectual and developmental disabilities living in long-term care (Howard et al., 2021).

The concept of personhood has proved to be an apt lens through which to more clearly view the circumstances encountered by individuals with SPMI as they experience illness, aging, and the end of life. Across examinations of health care for individuals living with SPMI—cancer care, care delivered in long-term care facilities, and end-of-life care—the core elements of person-centered care emerged as prerequisites for improving care for these individuals and resolving inequities in health outcomes. Respect, trust, inclusion, open communication, and a willingness to put oneself in the place of an individual living with SPMI have been identified as specific facilitators to delivering care that is appropriate and beneficial for these individuals. The relevance of personhood to the care of individuals with SPMI suggests a wider scope for the concept of personhood. Personhood can inform understanding of the needs of individuals with SPMI, and the challenges underlying caring for this population—communication, fragmented care, and stigma—demonstrate what must be acknowledged and overcome by honoring personhood and delivering person-centered care.

### **Limitations**

Individuals living with SPMI in addition to medical conditions are currently underrepresented in medical and nursing literature; as such, the foundations for research are still being established. The available information on this population largely exists in pockets within the literature on general mental illness, chronic medical conditions, older health, and end of life care.

The qualitative study was limited by the inability to obtain information from long-term care residents themselves. While the data that were obtained from health care providers who care for individuals with SPMI and chronic medical conditions provided valuable insight into barriers and facilitators to providing good/adequate care for this population, insights from individuals with SPMI who live in long-term care would contribute unprecedented information to the body of literature on the needs of this commonly unseen population. Future qualitative studies with individuals with SPMI can be directed by the insights gained from the interviews with the providers who care for them. Ultimately, quantitative research measuring specific factors influencing the care received by individuals with SPMI in long-term care may be guided by first-hand knowledge and insights into these factors.

### **Conclusion**

Individuals living with SPMI experience inequities in health outcomes, access to care, and life expectancy. These inequities, rooted in a history of segregation by institutionalization and stigmatization of individuals with SPMI, have impacted their experiences of care for serious medical illnesses, chronic conditions, and care near the end of life. Improved communication and coordination of care can enhance health services utilized by individuals with SPMI, improving their chances for positive health outcomes. Inclusion in research can both expand opportunities for these individuals to gain access to important treatments and contribute to a

better understanding of medical conditions in individuals with SPMI. Reversing health inequities for individuals living with SPMI will necessitate multidisciplinary collaboration and investment in the well-being of this often overlooked population.

Examining the inequities experienced by individuals living with SPMI through the lens of personhood reveals fundamental issues surrounding autonomy, dignity, and stigma. Overcoming these barriers demands a person-centered approach, a recognition of the inherent worth of each individual—recognizing the person behind the illness.

## Master Reference List

Al Qadire, M., Shamieh, O., Abdullah, S., & Albadainah, F. (2020). Symptom clusters' content, stability and correlation with the quality of life in a heterogeneous group of cancer patients: A large-scale longitudinal study. *Clinical Nursing Research, 29*(8), 561–570.  
<https://doi.org/10.1177/1054773820933449>

American Psychiatric Association (2019). *Diagnostic and statistical manual of mental disorders* (5th ed).  
<https://dsm.psychiatryonline.org/doi/book/10.1176/appi.books.9780890425596>

Appelbaum, P. S. (2006). Decisional capacity of patients with schizophrenia to consent to research: Taking stock. *Schizophrenia Bulletin, 32*(1), 22–25.  
<https://doi.org/10.1093/schbul/sbi063>

Arnold, M., Leitzmann, M., Freisling, H., Bray, F., Romieu, I., Renehan, A., & Soerjomataram, I. (2016). Obesity and cancer: An update of the global impact. *Cancer Epidemiology, 41*, 8–15. <https://doi.org/10.1016/j.canep.2016.01.003>

Baethge, C., Goldbeck-Wood, S., & Mertens, S. (2019). SANRA—a scale for the quality assessment of narrative review articles. *Research Integrity and Peer Review, 4*(1), 2–8.  
<https://doi.org/10.1186/s41073-019-0064-8>

Baker, A. (2005). Palliative and end-of-life care in the serious and persistently mentally ill population. *Journal of the American Psychiatric Nurses Association, 11*(5), 298–303.  
<https://doi.org/10.1177/1078390305282209>

- Bartels, S. J., Aschbrenner, K. A., Rolin, S. A., Hendrick, D. C., Naslund, J. A., & Faber, M. J. (2013). Activating older adults with serious mental illness for collaborative primary care visits. *Psychiatric Rehabilitation Journal*, *36*(4), 278–288.  
<https://doi.org/10.1037/prj0000024>
- Bergamo, C., Sigel, K., Mhango, G., Kale, M., & Wisnivesky, J. P. (2017). Inequalities in lung cancer. *Physiology & Behavior*, *176*(5), 139–148.  
<https://doi.org/10.1016/j.physbeh.2017.03.040>
- Berry, K., Ford, S., Jellicoe-Jones, L., & Haddock, G. (2013). PTSD symptoms associated with the experiences of psychosis and hospitalisation: A review of the literature. *Clinical Psychology Review*, *33*(4), 526–538. <https://doi.org/10.1016/j.cpr.2013.01.011>
- Birtley, N. M., & Phillips, L. (2020). The business and practice of psychiatric advanced practice nursing in long term care. *Archives of Psychiatric Nursing*, *34*(5), 288–296.  
<https://doi.org/10.1016/j.apnu.2020.07.007>
- Butler, H., & O'Brien, A. J. (2018). Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study. *International Journal of Mental Health Nursing*, *27*(2), 737–746. <https://doi.org/10.1111/inm.12360>
- Cai, X., Cram, P., & Li, Y. (2011). Origination of medical advance directives among nursing home residents with and without serious mental illness. *Psychiatric Services*, *62*(1), 61–66.  
[https://doi.org/10.1176/ps.62.1.pss6201\\_0061](https://doi.org/10.1176/ps.62.1.pss6201_0061)

Candilis, P.J., Foti, M., & Holzer, J. (2004). End-of-life care and mental illness: A model for community psychiatry and beyond. *Community Mental Health Journal*, 40(1), 3-16.

<https://doi.org/10.1023/b:comh.0000015214.24404.cc>

Carey, M.P., & Carey, K.B. (1999). Behavioral research on the severe and persistent mental illnesses. *Behavioral Therapy*, 30(3), 345-353.

Centers for Disease Control and Prevention (2020, February). *Leading causes of death*.

Retrieved from Centers for Disease Control and Prevention website:

<https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>

Charlson, F. J., Ferrari, A. J., Santomauro, D. F., Diminic, S., Stockings, E., Scott, J. G.,

McGrath, J. J., & Whiteford, H. A. (2018). Global epidemiology and burden of

schizophrenia: Findings from the global burden of disease study 2016. *Schizophrenia*

*Bulletin*, 44(6), 1195–1203. <https://doi.org/10.1093/schbul/sby058>

Chochinov, H. M., Martens, P. J., Prior, H. J., & Kredentser, M. S. (2012). Comparative health care use patterns of people with schizophrenia near the end of life : A population-based study in Manitoba, Canada. *Schizophrenia Research*, 141(2–3), 241–246.

<https://doi.org/10.1016/j.schres.2012.07.028>

Chou, F. H. C., Tsai, K. Y., Wu, H. C., & Shen, S. P. (2016). Cancer in patients with

schizophrenia: What is the next step? *Psychiatry and Clinical Neurosciences*, 70(11), 473–

488. <https://doi.org/10.1111/pcn.12420>

- Cole, M., & Padmanabhan, A. (2012). Breast cancer treatment of women with schizophrenia and bipolar disorder from Philadelphia, PA: Lessons learned and suggestions for improvement. *Journal of Cancer Education, 27*(4), 774–779. <https://doi.org/10.1007/s13187-012-0391-7>
- Colton, C. W., & Manderscheid, R. W. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease, 3*(2), 1–14. <http://www.cdc.gov/pcd/issues/2006/apr/>
- Council of Economic Advisors. (2019, September). *The state of homelessness in America*. Retrieved from <https://www.whitehouse.gov/wp-content/uploads/2019/09/The-State-of-Homelessness-in-America.pdf>
- Correll, C. U., Solmi, M., Veronese, N., Bortolato, B., Rosson, S., Santonastaso, P., Thapa-Chhetri, N., Fornaro, M., Gallicchio, D., Collantoni, E., Pigato, G., Favaro, A., Monaco, F., Kohler, C., Vancampfort, D., Ward, P. B., Gaughran, F., Carvalho, A. F., & Stubbs, B. (2017). Prevalence, incidence and mortality from cardiovascular disease in patients with pooled and specific severe mental illness: A large-scale meta-analysis of 3,211,768 patients and 113,383,368 controls. *World Psychiatry, 16*(2), 163–180. <https://doi.org/10.1002/wps.20420>
- Dodd, M.J., Miaskowski, C., & Paul, S.M. (2001). Symptom clusters and their effect on the functional status of patients with cancer. *Oncology Nursing Forum, 28*, 465-470.
- Domino, M. E., Wells, R., & Morrissey, J. P. (2015). Serving persons with severe mental illness in primary care-based medical homes. *Psychiatric Services, 66*(5), 477–483. <https://doi.org/10.1176/appi.ps.201300546>

- Donovan, K. A., & Jacobsen, P. B. (2007). Fatigue, depression, and insomnia: Evidence for a symptom cluster in cancer. *Seminars in Oncology Nursing*, 23(2), 127–135.  
<https://doi.org/10.1016/j.soncn.2007.01.004>
- Epstein, R. S., Aapro, M. S., Basu Roy, U. K., Salimi, T., Krenitsky, J. A., Leone-Perkins, M. L., Girman, C., Schlusser, C., & Crawford, J. (2020). Patient burden and real-world management of chemotherapy-induced myelosuppression: Results from an online survey of patients with solid tumors. *Advances in Therapy*, 37(8), 3606–3618.  
<https://doi.org/10.1007/s12325-020-01419-6>
- Esper, P. (2010). Symptom clusters in individuals living with advanced cancer. *Seminars in Oncology Nursing*, 26(3), 168–174. <https://doi.org/10.1016/j.soncn.2010.05.002>
- Farasatpour, M., Janardhan, R., Williams, C. D., Margenthaler, J. A., Virgo, K. S., & Johnson, F. E. (2012). Breast cancer in patients with schizophrenia. *American Journal of Surgery*, 206(5), 798–804. <https://doi.org/10.1016/j.amjsurg.2012.06.013>
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *Gerontologist*, 58, S10–S19.  
<https://doi.org/10.1093/geront/gnx122>
- Flores, E. J., Park, E. R., & Irwin, K. E. (2019). Improving lung cancer screening access for individuals with serious mental illness. *Journal of the American College of Radiology*, 16(4), 596–600. <https://doi.org/10.1016/j.jacr.2018.12.045>



- Fortner, R. T., Sisti, J., Chai, B., Collins, L. C., Rosner, B., Hankinson, S. E., Tamimi, R. M., & Eliassen, A. H. (2019). Parity, breastfeeding, and breast cancer risk by hormone receptor status and molecular phenotype: Results from the nurses' health studies. *Breast Cancer Research, 21*(1), 1–9. <https://doi.org/10.1186/s13058-019-1119-y>
- Foti, M.E. (2003). Do it your way: A demonstration project on end-of-life care for persons with serious mental illness. *Journal of Palliative Medicine, 6*(4), 661-668. <https://doi.org/10.1089/109662103768253830>
- Foti, M. E., Bartels, S. J., Merriman, M. P., Fletcher, K. E., & Van Citters, A. D. (2005a). Medical advance care planning for persons with serious mental illness. *Psychiatric Services, 56*(5), 576–584. <https://doi.org/10.1176/appi.ps.56.5.576>
- Foti, M. E., Bartels, S. J., Van Citters, A. D., Merriman, M. P., & Fletcher, K. E. (2005b). End-of-life treatment preferences of persons with serious mental illness. *Psychiatric Services, 56*(5), 585–591. <https://doi.org/10.1176/appi.ps.56.5.585>
- Fullerton, C.A., McGuire, T.G., Feng, Z., Mor, V., & Grabowski, D.C. (2009). Trends in mental health admissions to nursing homes, 1999-2005. *Psychiatric Services, 60*(7), 965-971.
- Ganzini, L. (2010). End-of-life care for veterans with schizophrenia and cancer. *Psychiatric Services, 61*(7), 5–8. <https://doi.org/10.1176/ps.2010.61.7.725>
- Giandinoto, J. A., Stephenson, J., & Edward, K. L. (2018). General hospital health professionals' attitudes and perceived dangerousness towards patients with comorbid mental and physical

- health conditions: Systematic review and meta-analysis. *International Journal of Mental Health Nursing*, 27(3), 942–955. <https://doi.org/10.1111/inm.12433>
- Grassi, L., & Riba, M. (2020). Cancer and severe mental illness: Bi-directional problems and potential solutions. *Psycho-Oncology*, 29(10), 1445–1451. <https://doi.org/10.1002/pon.5534>
- Hirschtritt, M.E. & Binder, R.L. (2017). Interrupting the mental illness-incarceration recidivism cycle. *Journal of the American Medical Association*, 317(7), 695-696. <https://doi.org/doi:10.1001/jama.2016.20992>
- Hodgson, R., Wildgust, H. J., & Bushe, C. J. (2010). Cancer and schizophrenia: is there a paradox? *Journal of Psychopharmacology*, 24(4 Suppl), 51–60. <https://doi.org/10.1177/1359786810385489>
- Hostiuc, S., Rusu, M. C., Negoii, I., & Drima, E. (2018). Testing decision-making competency of schizophrenia participants in clinical trials. A meta-analysis and meta-regression. *BMC Psychiatry*, 18(1), 2. <https://doi.org/10.1186/s12888-017-1580-z>
- Howard, E. P., Martin, L., Heckman, G. A., & Morris, J. N. (2021). Does the person-centered care model support the needs of long-term care residents with serious mental illness and intellectual and developmental disabilities? *Frontiers in Psychiatry*, 12, 1–9. <https://doi.org/10.3389/fpsy.2021.704764>
- Hua, C. L., Cornell, P. Y., Zimmerman, S., Winfree, J., & Thomas, K. S. (2021). Trends in serious mental illness in US assisted living compared to nursing homes and the community:

2007-2017. *American Journal of Geriatric Psychiatry*, 29(5), 434–444.

<https://doi.org/10.1016/j.jagp.2020.09.011>

Huang, H.-K., Wang, Y.-W., Hsieh, J.-G., & Hsieh, C.-J. (2018). Disparity of end-of-life care in cancer patients with and without schizophrenia: A nationwide population-based cohort study. *Schizophrenia Research*, 195, 434–440. <https://doi.org/10.1016/j.schres.2017.10.029>

Humphreys, K., Blodgett, J. C., & Roberts, L. W. (2015). The exclusion of people with psychiatric disorders from medical research. *Journal of Psychiatric Research*, 70, 28–32. <https://doi.org/10.1016/j.jpsychires.2015.08.005>

Hwong, A.R. & Irwin, K.E. (2020). Reducing global disparities in cancer screening for people with mental illness. *Lancet Psychiatry*, 7(1), 4-6. [https://doi.org/10.1016/S2215-0366\(19\)30470-5](https://doi.org/10.1016/S2215-0366(19)30470-5)

Irwin, K. E., Henderson, D. C., Knight, H. P., & Pirl, W. F. (2014). Cancer care for individuals with schizophrenia. *Cancer*, 120(3), 323–334. <https://doi.org/10.1002/cncr.28431>

Irwin, K. E., Park, E. R., Shin, J. A., Fields, L. E., Jacobs, J. M., Greer, J. A., Taylor, J. B., Taghian, A. G., Freudenreich, O., Ryan, D. P., & Pirl, W. F. (2017). Predictors of disruptions in breast cancer care for individuals with schizophrenia. *The Oncologist*, 22(11), 1374–1382. <https://doi.org/10.1634/theoncologist.2016-0489>

Irwin, K. E., Park, E. R., Fields, L. E., Corveleyn, A. E., Greer, J. A., Perez, G. K., Callaway, C. A., Jacobs, J. M., Nierenberg, A. A., Temel, J. S., Ryan, D. P., & Pirl, W. F. (2019a).

- Bridge: person-centered collaborative care for patients with serious mental illness and cancer. *The Oncologist*, 24(7), 901–910. <https://doi.org/10.1634/theoncologist.2018-0488>
- Irwin, K. E., Steffens, E. B., Yoon, Y. J., Flores, E. J., Knight, H. P., Pirl, W. F., Freudenreich, O., Henderson, D. C., & Park, E. R. (2019b). Lung cancer screening eligibility, risk perceptions, and clinician delivery of tobacco cessation among patients with schizophrenia. *Psychiatric Services*, 70(10), 927–934. <https://doi.org/10.1176/appi.ps.201900044>
- Jenq, G., & Tinetti, M. E. (2013). Changes in end-of-life care over the past decade: More not better. *Journal of the American Medical Association*, 309(5), 489–490. <https://doi.org/10.1001/jama.2013.73>
- Jester, D.J., Hyer, K., & Bowblis, J.R. (2020). Quality concerns in nursing homes that serve large proportions of residents with serious mental illness. *The Gerontologist*, 60(7), 1312-1321. <https://doi.org/10.1093/geront/gnaa044>
- Johnston, A. N., Bu, W., Hein, S., Garcia, S., Camacho, L., Xue, L., Qin, L., Nagi, C., Hilsenbeck, S. G., Kapali, J., Podsypanina, K., Nangia, J., & Li, Y. (2018). Hyperprolactinemia-inducing antipsychotics increase breast cancer risk by activating JAK-STAT5 in precancerous lesions. *Breast Cancer Research*, 20(1), 1–13. <https://doi.org/10.1186/s13058-018-0969-z>
- Jombo, H., & Ekwere, T. (2018). A cross-sectional study of the impact of antipsychotic medications on the hematological profile of patients with schizophrenia in a tertiary health facility in Uyo, South-South, Nigeria. *International Neuropsychiatric Disease Journal*, 11(2), 1–9. <https://doi.org/10.9734/indj/2018/40894>

- Kaldy, J. (2018). When mental illness and aging make nursing homes necessary: What's next? *Caring for the Ages, 19*(5).
- Kilbourne, A., Almirall, D., Goodrich, D., Lai, Z., Abraham, K.M., Nord, K.M., & Bowersox, N.W. (2014). Enhancing outreach for persons with serious mental illness: 12-month results from a cluster randomized trial of an adaptive implementation strategy. *Implementation Science, 9*(163). <https://doi.org/10.1186/s13012-014-0163-3>
- Kim, D.-Y. (2016). Psychiatric deinstitutionalization and prison population growth: A critical literature review and its implications. *Criminal Justice Policy Review, 27*, 3-21. <https://doi.org/10.1177/0887403414547043>
- Kisely, S., Forsyth, S., & Lawrence, D. (2016). Why do psychiatric patients have higher cancer mortality rates when cancer incidence is the same or lower? *Australian & New Zealand Journal of Psychiatry, 50*(3), 254-263. <https://doi.org/10.1177/0004867415577979>
- Kitwood, T. (1997). *Dementia reconsidered*. Open University Press.
- Knapik, G.P. & Graor, C.H. (2013). Engaging persons with severe persistent mental illness into primary care. *The Journal for Nurse Practitioners, 9*(5), 283-287. <https://doi.org/10.1016/j.nurpra.2013.02.019>
- Kwekkeboom, K. L. (2016). Cancer symptom cluster management. *Seminars in Oncology Nursing, 32*(4), 373–382. <https://doi.org/10.1016/j.soncn.2016.08.004>

- Lee, C. S., Gelow, J. M., Denfeld, Q. E., Mudd, J. O., Burgess, D., Green, J. K., Hiatt, S. O., & Jurgens, C. Y. (2014). Physical and psychological symptom profiling and event-free survival in adults with moderate to advanced heart failure. *Journal of Cardiovascular Nursing, 29*(4), 315–323. <https://doi.org/10.1097/JCN.0b013e318285968a>
- Lee, J., Meyerhardt, J. A., Giovannucci, E., & Jeon, J. Y. (2015). Association between body mass index and prognosis of colorectal cancer: A meta-analysis of prospective cohort studies. *PLoS ONE, 10*(3). <https://doi.org/10.1371/journal.pone.0120706>
- Lichstein, J.C., Domino, M.E., Beadles, C.A., Ellis, A.R., Farley, J.F., Morrissey, J.P., Gauchat, G.W., DuBard, A., & Jackson, C.T. (2014). Use of medical homes by patients with comorbid physical and severe mental illness. *Medical Care, 52*, S85-S91.
- Lin, G. M., Chen, Y. J., Kuo, D. J., Jaiteh, L. E. S., Wu, Y. C., Lo, T. S., & Li, Y. H. (2013). Cancer incidence in patients with schizophrenia or bipolar disorder: A nationwide population-based study in Taiwan, 1997-2009. *Schizophrenia Bulletin, 39*(2), 407–416. <https://doi.org/10.1093/schbul/sbr162>
- Lin, H. Y., Hsieh, J. G., Hsieh, C. J., & Wang, Y. W. (2020). Differences in the opioid consumption of terminally ill schizophrenic and nonschizophrenic cancer patients: Analysis of secondary national population data. *Journal of Pain and Symptom Management, 59*(6), 1232–1238. <https://doi.org/10.1016/j.jpainsymman.2019.12.360>

Lopes, R., Soares, R., Figueiredo-Braga, M., & Coelho, R. (2014). Schizophrenia and cancer: Is angiogenesis a missed link? *Life Sciences*, *97*(2), 91–95.

<https://doi.org/10.1016/j.lfs.2013.12.023>

Luciano, A. & Meara, E. (2014). The employment status of people with mental illness: National survey data from 2009 and 2010. *Psychiatric Services*, *65*(10), 1201-

1209. <https://doi.org/10.1176/appi.ps.201300335>

Martens, P. J., Chochinov, H. M., & Prior, H. J. (2013). Where and how people with schizophrenia die: A population-based, matched cohort study in Manitoba, Canada. *Journal of Clinical Psychiatry*, *74*(6), 551–557. <https://doi.org/10.4088/JCP.12m08234>

Mazereel, V., Detraux, J., Vancampfort, D., van Winkel, R., & De Hert, M. (2020). Impact of psychotropic medication effects on obesity and the metabolic syndrome in people with serious mental illness. *Frontiers in Endocrinology*, *11*, 1–10.

<https://doi.org/10.3389/fendo.2020.573479>

McCasland, L. A. (2007). Providing hospice and palliative care to the seriously and persistently mentally ill. In *Journal of Hospice & Palliative Nursing*, *9*(6), 305–313.

<https://doi.org/10.1097/01.NJH.0000299313.99514.0c>

McCormack, B. & McCance, T. (2017). *Person-centred practice in nursing and health care*.

Wiley Blackwell.

Mesdagh, A. & Hansen, B. (2014). Stigma in patients with schizophrenia receiving community mental health care: a review of qualitative studies. *Social Psychiatry and Psychiatric*

*Epidemiology*, 49, 79-87. <https://doi.org/10.1007/s00127-013-0729-4>

Miaskowski, C., Barsevick, A., Berger, A., Casagrande, R., Grady, P. A., Jacobsen, P., Kutner, J., Patrick, D., Zimmerman, L., Xiao, C., Matocha, M., & Marden, S. (2017). Advancing symptom science through symptom cluster research: Expert panel proceedings and recommendations. *Journal of the National Cancer Institute*, 109(4), 1–9.

<https://doi.org/10.1093/jnci/djw253>

Mitchell, A.J., Vancampfort, D., Sweers, K., van Winkel, R., Yu, W., & De Hert, M. (2013). Prevalence of metabolic syndrome and metabolic abnormalities in schizophrenia and related disorders—a systematic review and meta-analysis. *Schizophrenia Bulletin*, 39, 306-318. <https://doi.org/10.1093/schbul/sbr148>

Moore, S., Shiers, D., Daly, B., Mitchell, A. J., & Gaughran, F. (2015). Promoting physical health for people with schizophrenia by reducing disparities in medical and dental care. *Acta Psychiatrica Scandinavica*, 132(2), 109–121. <https://doi.org/10.1111/acps.12431>

National Hospice and Palliative Care Organization (2017). Hospice care. Retrieved from <https://www.nhpco.org/about/hospice-care>

National Institute of Mental Health. (2018). *Schizophrenia*. <https://www.nimh.nih.gov/health/statistics/schizophrenia>

National Institute of Mental Health (2019). Mental illness. Retrieved from <https://www.nimh.nih.gov/health/statistics/mental-illness.shtml>



- Nishihira, Y., McGill, R. L., & Kinjo, M. (2017). Perforated appendicitis in patients with schizophrenia: A retrospective cohort study. *BMJ Open*, 7(9), 1–5.  
<https://doi.org/10.1136/bmjopen-2017-017150>
- Noblett, J., Caffrey, A., Deb, T., Khan, A., Lagunes-Cordoba, E., Gale-Grant, O., & Henderson, C. (2017). Liaison psychiatry professionals' views of general hospital care for patients with mental illness. The care of patients with mental illness in the general hospital setting. *Journal of Psychosomatic Research*, 95, 26-32.  
<http://dx.doi.org/10.1016/j.jpsychores.2017.02.004>
- Olfson, M., Gerhard, T., Huang, C., Crystal, S., & Stroup, T. S. (2015). Premature mortality among adults with schizophrenia in the United States. *JAMA Psychiatry*, 72(12), 1172–1181. <https://doi.org/10.1001/jamapsychiatry.2015.1737>
- Podymow, T., Turnbull, J., & Coyle, D. (2006). Shelter-based palliative care for the homeless terminally ill. *Palliative Medicine*, 20(2), 81-86.  
<https://doi.org/10.1191/0269216306pm1103oa>
- Pollio, D.E., North, C.S. & Osborne, V.A. (2002). Family-responsive psychoeducation groups for families with an adult member with mental illness: Pilot results. *Community Mental Health Journal*, 38, 413–421. <https://doi.org/10.1023/A:1019812512926>
- Powers, B. W., Makar, M., Jain, S. H., Cutler, D. M., & Obermeyer, Z. (2015). Cost savings associated with expanded hospice use in medicare. *Journal of Palliative Medicine*, 18(5), 4–401. <https://doi.org/10.1089/jpm.2015.0014>

- Powers, R. (2017). *No one cares about crazy people: The chaos and heartbreak of mental health in America*. Hatchette Books.
- Read, J., & Williams, J. (2019). Positive and negative effects of antipsychotic medication: An international online survey of 832 recipients. *Current Drug Safety, 14*(3), 173–181.  
<https://doi.org/10.2174/1574886314666190301152734>
- Reddy, F., Reavis, E., Polon, N., Morales, J., & Green, M. (2017). The cognitive costs of social exclusion in schizophrenia. *Schizophrenia Bulletin, 43*(S1), S54.  
<https://doi.org/10.1093/schbul/sbx021.14>
- Ritchie, H. & Roser, M. (2018). Mental Health. Retrieved from  
<https://ourworldindata.org/mental-health>
- Rodgers, M., Dalton, J., Harden, M., Street, A., Parker, G., & Eastwood, A. (2018). Integrated care to address the physical health needs of people with severe mental illness: A mapping review of the recent evidence on barriers, facilitators and evaluations. *International Journal of Integrated Care, 18*(1), 9. <https://doi.org/10.5334/ijic.2605>
- Saha, S., Chant, D., & McGrath, J. (2007). A systematic review of mortality in schizophrenia. *Archives of General Psychiatry, 64*(10), 1123-1131.
- Saks, E. (2007). *The center cannot hold: My journey through madness*. Hyperion.

- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334–340.  
[https://doi.org/10.1002/1098-240x\(200008\)23:4<334::aid-nur9>3.0.co;2-g](https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g)
- Scull, A. (2021). “Community care”: Historical perspectives on deinstitutionalization. *Perspectives in Biology and Medicine*, 64(1), 70-81.  
<https://doi.org/10.1353/pbm.2021.0006>
- Singh, M.K., Giles, L.L., Nasrallah, H.A. (2006). Pain insensitivity in schizophrenia: trait or state marker? *Journal of Psychiatric Practice*, 12, 90-102.
- Sisti, D.A., Segal, A.G., & Emanuel, E.J. (2015). Improving long-term psychiatric care: Bring back the asylum. *Journal of the American Medical Association*, 313(3), 243-244.  
doi:10.1001/jama.2014.16088
- Slovenko, R. (2002). The transinstitutionalization of the mentally ill. *Ohio Northern University Law Review*, 29, 641-660.
- Sofronas, M., Wright, D.K., & Carnevale, F. A. (2018). Personhood: An evolutionary concept analysis for nursing ethics, theory, practice, and research. *Nursing Forum*, 53, 406-415.  
<https://doi.org/10.1111/nuf.12267>
- Sokol-Hessner, L., Zambeaux, A., Little, K., Macy, L., Lally, K., & Adams, K.M. (2015). “Conversation Ready”: A framework for improving end-of-life care (2<sup>nd</sup> ed.). Boston, MA: Institute for Healthcare Improvement

- Solmi, M., Firth, J., Miola, A., Fornaro, M., Frison, E., Fusar-Poli, P., Dragnioti, E., Shin, J., Carvalho, A.F., Stubbs, B., Koyanagi, A., Kisely, S., & Correll, C.U. (2020). Disparities in cancer screening in people with mental illness across the world versus the general population: Prevalence and comparative meta-analysis including 4717839 people. *Lancet Psychiatry*, *7*, 52-63. [https://doi.org/10.1016/S2215-0366\(19\)30414-6](https://doi.org/10.1016/S2215-0366(19)30414-6)
- Tran, E., Rouillon, F., Loze, J. Y., Casadebaig, F., Philippe, A., Vitry, F., & Limosin, F. (2009). Cancer mortality in patients with schizophrenia: An 11-year prospective cohort study. *Cancer*, *115*(15), 3555–3562. <https://doi.org/10.1002/cncr.24383>
- Tylec, A., Baran, T., Wojciechowska, K., Ślemp, H. D., & Kucharska, K. (2015). Complications after the treatment of laryngeal cancer in a paranoid schizophrenia patient. *Acta Neuropsychologica*, *13*(3), 293–300. <https://doi.org/10.5604/17307503.1184041>
- van der Wolf, E., van Hooren, S. A. H., Waterink, W., & Lechner, L. (2019). Well-being in elderly long-term care residents with chronic mental disorder: a systematic review. *Aging and Mental Health*, *23*(3), 287–296. <https://doi.org/10.1080/13607863.2017.1408773>
- Vancampfort, D., Firth, J., Schuch, F. B., Rosenbaum, S., Mugisha, J., Hallgren, M., Probst, M., Ward, P. B., Gaughran, F., De Hert, M., Carvalho, A. F., & Stubbs, B. (2017). Sedentary behavior and physical activity levels in people with schizophrenia, bipolar disorder and major depressive disorder: a global systematic review and meta-analysis. *World Psychiatry*, *16*(3), 308–315. <https://doi.org/10.1002/wps.20458>

- Vig, E., Starks, H., Taylor, J., Hopley, E., & Fryer-Edwards, K. (2010). Why don't patients enroll in hospice? Can we do anything about it? *Journal of General Internal Medicine*, 25(10), 1009–1019. <https://doi.org/10.1007/s11606-010-1423-9>
- Wainberg, M.L., Scorza, P., Shultz, J. M., Helpman, L., Mootz, J.J., Johnson, K.A., Neria, Y., Bradford, J.E., Oquendo, M.A., Arbuckle, M.R. (2017). Challenges and opportunities in global mental health: A research-to-practice perspective. *Current Psychiatry Reports*, 19(28). <https://doi.org/10.1007/s11920-017-0780-z>
- Weinstein, L.C., Stefancic, A., Cunningham, A.T., Hurley, K.E., Cabassa, L.J., & Wender, R.C. (2016). Cancer screening, prevention, and treatment in people with mental illness. *CA*, 66(2), 133–151. <https://doi.org/10.3322/caac.21334>.
- White, F.J. (2013). Personhood: An essential characteristic of the human species. *Linacre Quarterly*, 80(1), 74-97. <https://doi.org/10.1179/0024363912Z.00000000010>
- Woods, A., Willison, K., Kington, C., & Gavin, A. (2008). Palliative care for people with severe persistent mental illness: A review of the literature. *Canadian Journal of Psychiatry*, 53(11), 725–736. <https://doi.org/10.1177/070674370805301104>
- World Health Organization (2015a). Cancer. Retrieved from [https://www.who.int/health-topics/cancer#tab=tab\\_1](https://www.who.int/health-topics/cancer#tab=tab_1)
- World Health Organization (2015b). WHO global strategy on people-centred and integrated health services: Interim report. Retrieved from

[https://apps.who.int/iris/bitstream/handle/10665/155002/WHO\\_HIS\\_SDS\\_2015.6\\_eng.pdf;jsessionid=7C9EFD2192529AF8C9CA118CE4F95F48?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/155002/WHO_HIS_SDS_2015.6_eng.pdf;jsessionid=7C9EFD2192529AF8C9CA118CE4F95F48?sequence=1)

Yoon, J. Y. (2018). Relationships among person-centered care, nursing home adjustment, and life satisfaction: A cross-sectional survey study. *International Psychogeriatrics*, 30(10), 1519–1530. <https://doi.org/10.1017/S1041610218000194>

Yuan, C., Bao, Y., Wu, C., Kraft, P., Ogino, S., Ng, K., Qian, Z. R., Rubinson, D. A., Stampfer, M. J., Giovannucci, E. L., & Wolpin, B. M. (2013). Prediagnostic body mass index and pancreatic cancer survival. *Journal of Clinical Oncology*, 31(33), 4229–4234. <https://doi.org/10.1200/JCO.2013.51.7532>

Zuckerman, R. B., Stearns, S.C., & Sheingold, S.H. (2016). Hospice use, hospitalization, and medicare spending at the end of life. *The Journals of Gerontology: Series B*, 71(3), 569-580. <https://doi.org/10.1093/geronb/gbv109>

## Appendix A

### Qualitative Interview Guide

*In answering these questions, I would like you to answer based on your experiences caring for residents with serious mental illness and cancer/cardiovascular disease/other medical condition.*

1. As a provider who has cared for these residents, what do you see as the physical needs of the residents?
2. Can you describe how you think these physical needs are met in a way that respects the individuals' dignity and choices?

Prompt:

- If you could, would you change anything specific to the physical care of these residents? If so, what would it look like?
3. Now I would like you to think about the emotional needs of these residents. What do you see as their emotional needs?
  4. Can you describe how you think these residents' emotional needs are met in a way that respects their dignity and choices?

Prompt:

- If you could, would you change anything specific to the emotional care of these residents? If so, what would it look like?
5. In what ways do you think that the overall care needs of these residents differ from the needs of residents with cancer who do not have a serious mental illness?

Prompts:

- When providing care for these residents, what do you do differently to provide care in a way that shows appreciation for their specific needs?

- Tell me how you try to individualize the care you provide to these residents in order to show an appreciation for their personhood/individuality.
6. Please describe the things that you feel are barriers to your ability to respectfully meet the needs of these residents.

Prompt:

- What would make it easier for you to respectfully meet the needs of these residents?
7. How can individuals who work in long-term care settings help to ensure that these residents are cared for in a way that is person-centered and focuses on the residents' individual needs?

Prompts:

- If you could change things, what would you change to ensure that these residents are cared for in a way that is person-centered and focuses on their individual needs?
- In thinking about this population, what things do you do now to ensure that person-centered care is delivered, that you want to never change?

Is there anything else that you think would be important for me to know?



## Appendix B

Dear Diana Hanan,

Thank you for your email. You may include the Final Published PDF (or Original Submission or Accepted Manuscript) in your dissertation or thesis, which may be posted in an Institutional Repository or database as specified in our [journal author reuse policy](#).

**Please accept this email as permission for your request. Permission is granted for the life of the edition on a non-exclusive basis, in the English language, throughout the world in all formats provided full citation is made to the original SAGE publication with a link to the appropriate DOI where possible. Permission does not include any third-party material found within the work.**

Please contact us for any further use of the material and good luck on your dissertation!

Kind regards,

Mary Ann Price  
*(she/her/hers)*  
Senior Rights Coordinator  
SAGE Publishing  
2600 Virginia Ave NW, Suite 600  
Washington, DC 20037  
USA  
[www.sagepublishing.com](http://www.sagepublishing.com)