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

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

**Person-Level Factors**

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

**Gender and Sexuality Considerations**

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

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

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

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

**Racial and Ethnic Considerations**

 Systemic racism permeates all aspects of the healthcare system. It effects minority populations seeking health care, and should be considered by all healthcare professionals when providing care (Feagin & Bennefield, 2014). Mental health and palliative/EOL care are no exception. The impact of race on EOL care for persons with SPMIs can be found when examining the influence of race on EOL services in general. There are significant considerations for both EOL attitudes as well as access to EOL care. Rosenfeld et al. (2007) identified racial attitudinal differences, as White patients may accept hospice services, particularly in the home setting, while African American patients may prefer aggressive treatment choices. Race has been shown to influence EOL care preferences, EOL spirituality needs, and cultural considerations, which are larger ignored in research (Krakauer et al., 2002).

 Furthermore, minority populations may have different attitudes due to the communication styles of majority White providers with minority populations (Rosenfeld et al.). In a study of differences between White, Hispanic, and African American hospice patients, 20% of African American patients believed their care would be better if they were of a different race (Rosenfeld et al., 2007). Moreover, it has been shown that the treatment of minority patients in EOL care differs. For example, less analgesia is utilized in minority populations, despite similar EOL pain levels (Krakauer et al., 2002).

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

**Socioeconomic Status**

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

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

**Symptom Burden**

 Type of physical illness can clinically define symptoms that may contribute to extraneous symptom burden at the EOL. Persons with chronic respiratory diseases, for example, may experience aggravated shortness of breath at the EOL, which can be challenging to manage, particularly in the last week of life (Kinkenberg et al., 2004). Additionally, polypharmacy, often associated with the treatment of SPMIs, can aggravate symptoms at the EOL and should be considered when evaluating symptom presentation (Schenker et al., 2019).

 However, mental health symptoms, such as anxiety and depression, are prevalent at the EOL, regardless of mental health history (Kozlov et al., 2019). It is known that the quality of life of persons with SPMIs is decreased throughout a lifetime (Sagayadevin et al., 2018), which can complicate exacerbated EOL mental health symptoms. Symptom burden and symptom severity of both mental and physical symptoms is a clinically complicating factor at the EOL. Fox et al. (2018) identified that the severity of mental health symptoms often reduces treatment-seeking by persons with SPMIs, due to internalized stigma (or self-stigma) and fear of repercussions from health care workers. Furthermore, typical palliation does not account for persons with mental health histories, such as substance abuse or psychiatric medications, who may react differently to palliative medicines and receive sub-optimal symptom control (de Veer et al., 2018).

**Preferences for Care**

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

**Veteran Status**

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

**Environmental Factors**

**Setting of Care**

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

 **Homelessness.** Approximately one-third of homeless individuals suffer from an SPMI (Harvard Health, 2014), or about one-sixth of the SPMI population, making it necessary to discuss homelessness in EOL care provision when discussing the SPMI population. De Veer et al. (2018) identified significant implications in EOL care for persons experiencing homelessness, including complex care trajectories and access issues. Late, if any, access to palliative care is common due to both patient and provider factors. Palliative care clinicians are often unprepared in providing EOL care to PEH, and PEH are often distrustful of the healthcare system or experience a need for enhanced autonomy. The combination of these factors creates a vicious cycle of lapsed care provision (de Veer et al., 2018). Furthermore, PEH may put off care or avoid healthcare professionals due to a fear of not being treated with dignity or respect at the EOL because of their housing status (Klop et al., 2018). Other complicating factors included: proper identification for care, unwillingness to accept growing health issues, lack of transportation, active psychosis or addictions, risks to personal safety, and social support groups not recognized by healthcare providers (Klop et al., 2018; van Dongen et al., 2020).

Social Support

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

**Stigma**

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

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

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

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

**COVID-19**

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

**Conclusions**

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

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