

Review Article

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Abstract

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

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

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

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

Introduction

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

Unequal access to care and disparities in health outcomes are key indicators of inequity of healthcare for people with SPMI. Although there is evidence that these inequities persist for those approaching end-of-life (Chochinov et al., 2012), very little is known about palliative care for those with SPMI (Woods et al., 2008). Scoping reviews allow the researcher to “...‘map’ relevant literature in the field of interest” (Arksey & O’Malley, 2005). In 2008, Woods et al. conducted a scoping review identifying four themes related to palliative care

for people with SPMI: decision-making capacity and advance care planning, access to care, provision of care (both illness- and healthcare provider-related issues), and vulnerability. To update this review and capture new knowledge, a systematic scoping review was undertaken to determine the extent, range, and nature of research activity about those with SPMI requiring palliative care and to identify gaps and opportunities for future research.

Methods

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

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

To identify relevant studies, the following databases were searched during September 2017 and again in May 2018: Web of Science, PubMed, Medline (EBSCO), CINAHL, Healthsource, Academic Search Complete, PsycInfo, PsycArticles, Cochrane Database of Systematic Reviews, and Cochrane Central Register of Controlled Trials. Search terms were drawn from two concept groups: mental illness and end-of-life. Specific terms included were: "mental health," "mental illness," "schizophrenia," "major depression," "bipolar disorder"; and "palliative," "end of life," "end-of-life," "hospice," "end stage," and "end-stage." The reference lists of included articles were also searched. Original searches produced 1,401 articles after duplicates were removed. Title and abstract reviews followed by full-text reading produced 32 articles. The reference lists of these articles were searched for relevant articles, resulting in the inclusion of a further five articles for a total of 37 articles. An updated search in May 2018 identified an additional nine articles for a total of 46 (Figure 1).

Articles were coded using NVivo 10 to chart the data and identify key issues and themes (Arksey & O'Malley, 2005). An iterative codebook was developed to act as an analytical framework and inform a narrative review of the data (Arksey & O'Malley, 2005). Codes were then grouped to identify and articulate themes and to reveal gaps. Greenhalgh et al. (2018) describe narrative review as "a scholarly summary along with interpretation and critique" (p. 2). Using a scoping review methodology, a narrative approach to analysis draws on published literature not only to provide a synopsis, but also to examine critically how information has been presented, built up, and how it may be useful to

advancing health systems and clinical practice (Greenhalgh et al., 2018). Suggestions for practice resulting from narrative review are evidence-informed rather than evidence-based; this approach to analysis is especially relevant for bodies of research containing very few, if any, clinical trials (Arksey & O'Malley, 2005; Greenhalgh et al., 2018).

Results

Description of identified studies

Forty-six eligible articles were identified after excluding duplicates and determining the relevance of the articles (Figure 1). Descriptive studies made up the majority of included articles (18 total: nine quantitative, eight qualitative, and one mixed-methods) followed by qualitative case studies (nine), literature reviews (eight), intervention studies (five articles representing three studies; two of which used mixed-methods evaluation and one of which used quantitative methods alone), and other (six, including discussion and theoretical analysis). Articles originated in the United States (20), Australia (seven), Europe (five), Canada (six), the United Kingdom (five), New Zealand (one), Taiwan (one), and South Africa (one). The majority of articles featured all SPMIs (31), with 14 focused on schizophrenia. With the exception of one article on posttraumatic stress disorder, no other specific SPMIs were addressed. Profession of the first author included physician (MD; 21), nursing (11), social work (five), and other or unknown (nine). The majority of articles were published in mental health journals (26), with 14 appearing in palliative care journals. General or other journal types composed the remaining six articles. Forty-four articles have been published since 2000 and more than half of all included articles (27) published since 2010.

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

Complexity of care

People with SPMI at the end of the life are part of a highly complex population. Studies showing early mortality reveal that those with SPMI are approaching end-of-life early, and late presentation often results in high needs and a short timeline for care (Baker, 2005; Moini & Levenson, 2009). Reviews and case studies found that late presentation can be due to both disease and system issues, resulting in overlapping and interacting health effects with high symptom burden and treatment interactions (Baker, 2005; Davie, 2006; Terpstra et al., 2014; Woods et al., 2008). The coexistence of physical and psychological illnesses can create confusion about symptoms and etiology, for example when unusual behaviors convey or obscure the presence of symptoms, including pain (Baker, 2005; Griffith, 2007b; Kelly & Shanley, 2000; Morgan, 2016). Nurses in qualitative studies report that cooccurring disorders such as substance abuse can make pain management challenging because of both physiological factors and provider stigma (Evenblij et al., 2016; Morgan, 2016). People with schizophrenia are thought to have a decreased response to pain, which can mask illness (Evenblij et al., 2016; Terpstra et al., 2014; Webber, 2012). Treatment for one illness may influence the other, including medication interactions, as identified in an intervention study by Picot et al. (2015) and a case study analysis by Terpstra et al. (2014). Changes during

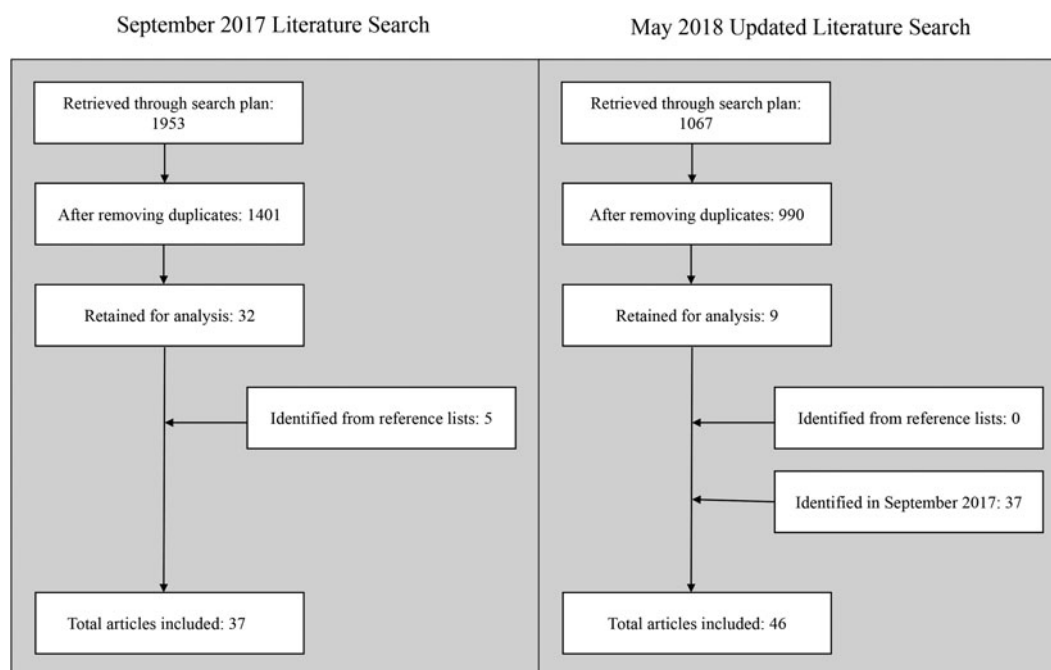


Fig. 1. Article selection process.

decline in health may influence the physical as well as the psychological state and cause complications, including changes in drug metabolism (Craun et al., 1997; Picot et al., 2015; Terpstra et al., 2014). In the discussion of end-of-life care for people with posttraumatic stress disorder, Feldman (2017) reminds readers that “[t]he treatment of psychosocial issues at the end-of-life is not a straightforward extension of evidence-based approaches for physically healthy individuals” (p. 117), and emphasizes attention to the complex nature of the illness experience for people with SPMI and the importance of making decisions for care with an understanding of this context.

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

such as smoking may provide challenges for staff and facilities that are increasingly adopting smoke-free policies or require staff accompaniment for people leaving the unit (Griffith, 2007b; Terpstra et al., 2014).

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

Additional complexities reported in the literature seem to result from social disadvantages experienced by people with SPMI, including stigma, discrimination, isolation, and poverty (Baker, 2005; Bloomer & O’Brien, 2013; Candilis et al., 2004; Craun et al., 1997; Morgan, 2016). Alienation from friends and family members places people with SPMI at a disadvantage in palliative care settings that rely on lay caregivers, such as community-based hospice care (Baker, 2005; Craun et al., 1997). Special populations, such as those who are homeless or incarcerated, are reported to experience additional complexities from systems that are not prepared to care for them (Baker, 2005; Wright

et al., 2017). According to Baker's (2005) literature review, follow-up and continuity of care are particularly challenging for people with SPMI who are homeless, and those suffering from SPMI and terminal illness who are incarcerated are increasingly vulnerable to the harsh environment found in prisons, where adequate pain and symptom management is often not provided.

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

Limited access to care

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

System challenges

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

reported feeling concern that routine actions such as giving morphine might be perceived under inquiry as hastening death, resulting in criminal charges (McGrath & Forrester, 2006). These types of guidelines are examples of system contributions that limit access to appropriate care for people with SPMI at end-of-life.

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

Analyses of palliative care use and related indicators show that those with SPMI are not receiving the same palliative care services as their counterparts without an SPMI. A quantitative descriptive study by Chochinov et al. (2012) compared a Canadian provincial cohort of people with schizophrenia against those without and found that people with schizophrenia had lower rates of seeing nonpsychiatric specialists, were less likely to receive opioid analgesia, and were less likely to receive palliative care. Similar results were reflected in New Zealand, where Butler and O'Brien (2018) found that people with schizophrenia in a region well-populated with healthcare resources were 3.5 times less likely to access specialist palliative care. A study in Taiwan identified that people with schizophrenia and cancer were less likely than people without schizophrenia in a matched cohort to receive chemotherapy, but more likely to receive invasive treatments and be admitted to the intensive care unit in the final month of life (Huang et al., 2017). Patients in an institutionalized setting may not be entitled to the same services as someone dying at home, such as specialist palliative nursing care management provided by hospice organizations in the United States (McGrath & Jarrett, 2007). It is not yet known why these disparities in treatment exist, but some articles addressing general system issues in access to care provide further information. A person with an SPMI who has experienced barriers to healthcare access in the past, such as discrimination, may be hesitant to attempt to seek care again (Bloomer & O'Brien, 2013; Jerwood et al., 2018; McNamara et al., 2018). In addition, ethical issues arise when a patient with an SPMI who lacks competence and does not have a substitute decision-maker refuses treatment, and providers must decide whether to impose guardianship and force treatment (Harman, 2017; Levin & Feldman, 1983).

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

Challenges with healthcare providers

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

Competence and autonomy

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

In cases in which people with SPMI are unable to make their own healthcare decisions (either temporarily or long term), a proxy decision-maker is often sought. People with SPMI may be estranged from friends or family, or may have their strongest relationships with healthcare providers, who are restricted from

acting as proxy decision-makers, making it difficult to find someone to fill this role (Candilis et al., 2004; Foti, 2003). People with SPMI who do not have a close friend or family member lack not only a substitute decision-maker, but an advocate for end-of-life care wishes (Jerwood et al., 2018; McNamara et al., 2018). Third-party decision-makers such as public trustees or guardians may have strict limits to their decision-making capacities, such as the need to seek (and await) a court order for the withdrawal of life-sustaining treatments or permission to forgo resuscitation (Harman, 2017).

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

Relationships between mental health and palliative care

Mental health and palliative care are divided by siloing, yet share many similarities in treatment philosophy and approaches to caring (McGrath & Holewa, 2004; Terpstra & Terpstra, 2012; Wright et al., 2017). Both mental health and palliative care are person-centered (McGrath & Holewa, 2004; Wright et al., 2017), focused on the therapeutic relationship (Baker, 2005; McGrath & Holewa, 2004; Picot et al., 2015; Sweers et al., 2013), share hope for a good outcome regardless of prognosis (Wright et al., 2017), and are centered on compassionate and holistic care (McGrath & Holewa, 2004; Picot et al., 2015). Respect for autonomy is important in both mental health and a palliative care (McGrath & Holewa, 2004; Webber, 2012) as is concern for quality of life as defined by the person receiving care (Griffith, 2007a; McGrath & Holewa, 2004). Both specialties aim to provide continuity of care (Baker, 2005) and to anticipate future needs to prevent crises (Bloomer & O'Brien, 2013). Lack of familiarity with mental health or palliative care breeds stigma, fear, and emotional distress in providers (Jerwood et al., 2018; McGrath & Jarrett, 2007).

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

Two intervention studies identified by the review are examples of such collaborations (Byock et al., 2006; Foti, 2003; Picot et al., 2015; Taylor et al., 2012). The Integrated Mental Health and

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

Discussion

In spite of the publication of twenty-nine new articles since Woods et al. (2008)’s scoping review, this comprehensive review of the literature identified similar themes. Although this speaks to the validity of the findings of this review, it also reveals that the scope and lay of the literature as well as the clinical settings being investigated, have not made significant progress since the original review was done. This body of evidence does not develop in sophistication until very recently, because studies cite each other but rarely build on previous findings. Particularly lacking were more rigorous and advanced investigative study designs as well as a lack of intervention studies informed by previous findings. Although some progress has been made in the past year toward more rigorous investigation of the current state of palliative care for people with SPMI, studies continue to draw on large administrative data and healthcare provider perspectives, excluding people with SPMI and their caregivers as expert data sources in their own experience. It is likely that a combination of stigma against mental illness in funding bodies, challenges in accessing this population because of disparities in location and access to care, gatekeeping on the part of organizations, and

conservative requirements for capacity to consent from ethics review boards have all contributed to the limited progress in this field (Bloomer & O’Brien, 2013; Carlsson et al., 2017; Keogh & Daly, 2009; McNamara et al., 2018). Although research with people with SPMI and with those in the palliative phase can be challenging because of diminished capacity for communication and other barriers, existing bodies of research in both mental illness and palliative care attest to the possibility of including such people in research and their perspectives are invaluable for informing care (Carlsson et al., 2017).

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

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

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

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

Recommendations

Two sets of recommendations are presented here: recommendations from the included articles and recommendations from the researchers conducting this review. As mentioned previously, a partnership approach between mental health and palliative care is promoted by the authors of many included articles (Bloomer & O'Brien, 2013; Butler & O'Brien, 2018; Candilis et al., 2004; Davie, 2006; Elie et al., 2018; Griffith, 2007b; Harman, 2017; Jerwood et al., 2018; McGrath & Jarrett, 2007; McNamara et al., 2018; Terpstra & Terpstra, 2012; Woods et al., 2008). Providers are urged to be aware of the medical and psychiatric complexity, to know symptoms of both psychiatric and chronic life-limiting illnesses and to know how to react to those symptoms, and to be alert to changes (Baker, 2005; Candilis et al., 2004; Feldman, 2017; Griffith, 2007a; Moini & Levenson, 2009; Woods et al., 2008). Providers are also encouraged to respect the patient, build therapeutic relationships, and make full use of the multidisciplinary healthcare team as well as any existing relationships with healthcare providers the person with SPMI may have (Baker, 2005; Bloomer & O'Brien, 2013; Butler & O'Brien, 2018; Craun et al., 1997; Griffith, 2007a, 2007b; McNamara et al., 2018; Terpstra & Terpstra, 2012; Woods et al., 2008). Existing relationships with healthcare providers are opportunities for collaboration to maintain continuity of care, minimize adverse events, and capitalize on connections to established support systems (Bloomer & O'Brien, 2013; Craun et al., 1997). Also recommended in the included articles was a reduction in siloing in all specialties and primary care to ensure access to care wherever it is needed, and to collaborate with existing services (such as street nurses or community outreach workers who may already be in contact with people with SPMIs) (Baker, 2005; Bloomer & O'Brien, 2013; Candilis et al., 2004; Jerwood et al., 2018; Moini & Levenson, 2009). Some authors recommended NPs as an ideal role to provide coordination and care for people with SPMIs at end-of-life (Baker, 2005; McGrath & Jarrett, 2007). Providers are encouraged to engage in end-of-life care conversations with those with SPMIs (Baker, 2005; Butler & O'Brien, 2018; Elie et al., 2018; Foti, 2003; Foti et al., 2005b; Terpstra & Terpstra, 2012). More research is encouraged to develop the field, overcome barriers, identify strategies, and learn more about the current state of care for people with SPMIs (Baker, 2005; Bloomer & O'Brien, 2013; Elie et al., 2018; Foti et al., 2005b; Griffith, 2007b; Jerwood et al., 2018; Lavin et al., 2017; Lloyd-Williams et al., 2014; Terpstra & Terpstra, 2012; Woods et al., 2008). It is important to recognize the heterogeneity in this population and to seek diversity when investigating the experiences of people with SPMIs (Woods et al., 2008). More research into advance care planning was also called for (Bloomer & O'Brien, 2013; Candilis et al., 2004; Elie et al., 2018; Foti et al., 2005a; Lavin et al., 2017). Studies by Nahm (2009) and Nahm et al. (2012) examined potential shifts in psychiatric symptoms at end-of-life and suggested studying the experiences of people with SPMI at end-of-life as a way to better understand SPMI and develop new options for treatment. Some authors called for a greater commitment to providing care and redressing injustice for people with SPMIs at end-of-life (Baker, 2005; Davie, 2006; Webber, 2012).

Recommendations from the researchers conducting this review include a call for more research targeting system issues and leadership. Although this review did not assess for quality, it is clear that more rigorous quantitative and qualitative study designs are needed to move this field forward. Follow-up is needed for

successful intervention studies with rigorous patient, family, provider, and system outcome measurements. New interventions including treatment plans, collaborative team approaches, and system shifts should be developed and tested based on what is already known. Further research needs to involve people with SPMIs and their caregivers to capture their perspective and input in the study design, implementation, and analysis process.

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

Conclusion

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

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