End-of-life care for people with severe and persistent mental illness: an umbrella review

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ABSTRACT

Background

Although there is sufficient evidence that disparities in health care access and provision contribute to poor physical health outcomes in people with a severe and persistent mental illness (SPMI), very little is known about the quality of end-of-life (EoL) care and palliative sedation in these people.

Methods

A comprehensive and systematic literature search in PubMed, Embase, Web of Science, Scopus, and CINAHL electronic databases (from inception to November 2023) was conducted, without language restriction, for reviews on the EoL-care and/or palliative sedation for people with SPMI. Critical appraisal of the selected reviews was performed. Data were analyzed according to 4 principles of biomedical ethics.

Results

Ten reviews were included. From the analysis, it became clear that people with SPMI are at risk of suboptimal EoL-care. Stigma among healthcare professionals, lack of integrated care policies, absence of advanced care planning, and insufficient expertise and training in palliative care of psychiatrists have been identified as key challenges to the provision of adequate EoL-care for people with SPMI. No data were found about palliative sedation.

Conclusions

To optimize palliative and EoL-care for SPMI patients and a life-limiting disease, a policy of coordinated and integrated mental and physical healthcare is needed. Moreover, education and training initiatives to reduce stigma and discrimination among all healthcare workers and to enhance palliative care skills in psychiatrists should be offered. Finally, more research is needed on EoL and particularly on palliative sedation for people with SPMI.

Keywords

End-of-Life Care; Severe and Persistent Mental Illness; Bipolar Disorder; Schizophrenia; Advanced Care Planning; Integration of Care; Stigma.

INTRODUCTION

Severe and persistent mental illness (SPMI), most commonly including schizophrenia, bipolar disorder, and recurrent or currently severe major depressive disorder, is defined by the National Institute of Mental Health (NIMH) as a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities [1–3]. Between 5% and 10% of adults in the United States live with an SPMI [4–6]. In Europe, approximately 27.5 million people have a depressive, bipolar or schizophrenia spectrum disorder [3].

People with SPMI have a higher risk of serious somatic comorbidities, such as cardiovascular disease, respiratory disease or cancer [6–10]. They tend to die 20-30 years earlier than the general population [11–13]. Contributing factors to these issues are unhealthy lifestyle behaviors, long-term intake of psychotropic drugs, but also disparities in healthcare access and provision [7,14]. Moreover, people with SPMI may have difficulty communicating their symptoms and avoid seeking medical help [15–17]. Finally, it is not unusual that healthcare professionals (HCPs) misattribute physical health problems to the psychiatric illness [15,18].

Palliative care is a type of healthcare that serves people with a serious medical condition, for which curative treatment is no longer possible. The purpose is to maintain an optimal well-being when the end-of-life (EoL) is approaching. This is achieved by managing symptoms (e.g. pain) and by providing psychosocial and spiritual support [19]. Palliative sedation is an integral part of palliative care. It is a measure of last resort, aimed to relieve suffering and reduce consciousness through the administration of sedative medication.

Although there is sufficient evidence that disparities in health care access and provision contribute to poor physical health outcomes in people with SPMI, very little is known about the quality of EoL care in these people [20]. We therefore conducted an umbrella review to summarize the state of the art regarding the organization of palliative care and palliative sedation for people with SPMI and to identify any gaps.

METHODS

Search Strategy

A comprehensive and systematic literature search in PubMed, Embase, Web of Science, Scopus, and CINAHL electronic databases (from inception to November 2023), without language restriction, was conducted. Databases were searched for systematic reviews (scoping reviews, mapping reviews, meta-analyses, integrative reviews and umbrella reviews), examining the organization of palliative/hospice/EoL care for people with an SPMI. JD constructed search strings for the different databases. Full search strategies are available as supplementary material. Duplicates were removed by JD, using Endnote X9 and Rayyan. After removing duplicates, titles and abstracts were screened by JW and JDD, using Rayyan. JDD did the full-text screening. Articles that were deemed potentially relevant according to the selection criteria were included. Any disagreements were solved by consensus or by decision of a second reviewer (MDH). References of the selected studies and pertinent reviews were carefully cross-checked for other relevant studies.

Eligibility criteria

Any review systematically researching literature on EoL-care and/or palliative sedation for people with SPMI in the context of a life-limiting physical illness was included.

Studies on ‘palliative psychiatry’ in the sense of medical futility, euthanasia or medical assisted suicide, mental health problems as a consequence of EoL, neurodegenerative disease (such as dementia), intellectual disability or substance abuse (including alcohol abuse) as main diagnosis, or homeless people without SPMI, were excluded.

Quality Appraisal

Included studies were appraised by JDD, using the Joanna Briggs Institute (JBI) Critical Appraisal tool for Systematic Reviews [21].

Data Extraction

Data were extracted and mapped descriptively by JDD by using the JBI Data Extraction Form for Review for Systematic Reviews and Research Syntheses [21].

RESULTS

Search Strategy

The search in PubMed (n = 204), Embase (n = 534), Web of Science (n = 355), Scopus (n = 137), and CINAHL (n = 92) yielded a total of 1,322 reports. Of these, 596 duplicate reports were removed. Overall, 726 records were selected as potentially eligible, of which 10 original records met the inclusion criteria. The results of the study selection are shown in the PRISMA flow diagram (see Figure 1).

Study and patient characteristics

The search yielded 10 systematic reviews. Although three identified themselves as ‘scoping’ reviews [22–24], a scoping approach was used by all of them. None of the reviews was able to compare quantitative results or perform a meta-analysis. Five reviews included ‘grey literature’ [22–26].

All articles were published in English. Three studies were conducted in both Canada [23–25] and the USA [27–29], 2 in the UK [26,30], 1 in Australia [22] and 1 in the Netherlands [31]. Except for 1 [25], all articles were published in 2019 or later.

Eight reviews focused on people with an SPMI [22,23,25–28,30,31] While some did not further specify this term, others mentioned specific diagnoses. Two reviews only included people with schizophrenia [24,29].

One review searched for any specific tools or interventions to improve palliative care for people with SPMI [31]; 1 partly focused on the organization of the Australian ‘National Disability Insurance System’ (NDIS) [22]; and 1 limited their search to the place of death and healthcare utilization in the last year of life by people with SPMI [30]. None of the reviews reported on ‘palliative sedation’.

An overview of the study characteristics is presented in table 1.

Quality appraisal

Overall, 2 reviews had a negative score on at least 4 of the 11 criteria. One review did not use an appropriate search strategy [27]. Three reviews did not use a data extraction tool [27–29]; for 1 review it was unclear which methods were used to minimize errors in data extraction [25]. In general, the methods used to combine studies were appropriate. However, not all reviews made appropriate recommendations for future practice, policy or research: they were too brief, were not supported by the reported data, or were completely absent.

Results of the quality appraisal are available as supplementary material.

Main results

Data from the reviews are described according to the four principles of biomedical ethics [32]. The principle of justice constitutes the right of every patient to be treated equally, in daily practice and research. The principle of autonomy represents the right of the patient to make an informed decision about their own treatment. The principle of non-maleficence not only implies that clinicians need to refrain from actively harming the patient, but also need to avoid harm through neglect or ignorance. Finally, clinicians must actively act in the best interests of the individual patient (principle of beneficence). Some data, however, may be classified under multiple categories as there is obvious overlap between these principles.

Justice

<u>*Granting equal access*</u>

Several reviews indicate that people with SPMI do not have equal access to appropriate EoL-care, compared to the general population [22,23,26–30]. In the last month of life, patients with SPMI receive less chemotherapy and fewer diagnostic tests [30]. The figures regarding registrations to an emergency unit during this time period, however, are inconclusive [26,30].

Moreover, reviews indicate that, as a result of stigmatization and discrimination, people with SPMI are more vulnerable to social isolation, poverty, homelessness and incarceration in prison. These factors also contribute to inequality in care during EoL [22–24] The healthcare-avoiding behavior of people with SPMI equally gets worse if they have previously been confronted with negative experiences in healthcare, such as discrimination [22,23].

Reviews indicate that another possible cause of the above-mentioned inequalities is the way in which healthcare is organized. In most cases, there is no integration of mental health and palliative care [26,27]. Palliative care is usually linked to acute somatic care in general hospitals [26]. Resources and expertise in healthcare are often focused on clearly defined populations, explaining why this service is limited for people with complex health problems, such as people with SPMI [22,23,27,28]. In the absence of a policy of coordinated and integrated mental and somatic health care, people with SPMI and serious comorbid physical problems will fall through the cracks. This phenomenon is referred to as ‘system siloing’ [22–28].

Representing the vulnerable

Reviews indicate that, both at the policy and the individual level, patients with SPMI are insufficiently represented. The MENLOC study, a mixed methods systematic review and thematic synthesis, state that there is not much attention for agents to help the patient in making healthcare decisions during EoL. Although the law states that everyone is entitled to a 'healthcare proxy', they found, for example, that only 1 of 334 patients with SPMI actually has a proxy [26]. People with SPMI have a smaller personal network that can represent their interests, making them even more vulnerable [22–28]. Although a professional can be called upon to assist a person with SPMI, they are not always well aware of the personal wishes and specific needs of the patient, and does not always act with the same commitment [22–25,27]. This increases the risk of ill-informed decisions, or decisions that the patient wouldn’t support [22,25–27]. Other reviews mention a lack of legal and institutional guidelines regarding palliative care in psychiatric hospitals [22,23,28,29]. Mental health professionals themselves indicate they are not equipped with a sufficient framework to provide qualitative EoL care [22,26].

Doing research

When it comes to EoL-care, there is a clear research gap regarding people with SPMI [22]. One systematic review showed that research conducted at the interface between cancer and mental health primarily focuses on the mental impact of cancer on individuals without pre-existing SPMI [29]. Another review showed that existing research on EoL-care in people with SPMI is very disparate, making it difficult to draw major conclusions [28]. Moreover, very little research has been done on the patient's perspective [22,25].

Several reviews mention the few studies conducted on the development of appropriate clinical or policy tools in the context of EoL-care for people with SPMI [22–25,28,31]. Two of these discuss the Health Care Preferences Questionnaire (HCPQ), a tool to identify needs and preferences of the patient concerning EoL-care and making an advanced care planning (ACP). However, figures on the impact of using these instruments on the quality of EoL-care are still lacking [31].

Respect for autonomy

Starting the conversation

Reviews point out that professionals often tend to avoid talking about the approaching EoL with SPMI patients [22,24–26]. They fear these conversations can be emotionally destabilizing and induce suicidal thoughts [22,25,26] In addition, it is often thought that the patient will not fully understand the message. People with SPMI, however, don’t experience these conversations as more disturbing and share the same concerns as others [23,25,28,29,31].

Respecting another point of view

Reviews indicate that, although patients with SPMI generally are able to have EoL conversations, they sometimes, depending on their health state, can react in an unpredictable or unexpected way [24,25,29]. They can act extremely dependent or very dismissive towards the caregiver, or may even be aggressive. It is possible that they refuse to make contact at all [22–29].

However, not every patient who refuses contact or further (curative) treatment can be classified as 'inadequate'. The refusal can indeed be well-considered and well-founded [22,24–26,29]. Some reviews recommend that in cases where there is a genuine lack of clarity about the patient's decision-making capacity, it may be appropriate to consult an ethics committee [26,29]. Nevertheless, the MENLOC study mentions that it is important for the HCP to always be aware of their own emotions when evaluating patients' decisions about the EoL process, as it can affect clinical and therapeutic functioning [26].

Giving the patient control

Several reviews point to the fact that it must always be assumed that a person has decision-making capacity until proven otherwise. Moreover, every effort must be made to promote decision-making capacity [24,26,31].

In daily practice, HCPs sometimes assume the patient is incompetent to make decisions solely on the basis of their psychiatric diagnosis. As a result, people with SPMI are less likely to be involved in conversations about making medical decisions or ACP than the average population. In these cases, HCPs address their relatives or substitute decision-makers (SDMs) directly [22–27]. Some reviews state, however, that it is important to realize that decision-making capacity is always linked to specific decisions and situations, not to medical diagnoses [25,29]. Data from reviews also demonstrate that patients with SPMI want to be involved in decisions about EoL [22,24–27], but rarely start the conversation about this subject [26,27].

Letting the patient be at home

Reviews clearly indicate that people with SPMI, like the general population, want to spend the end of their life at home or in a familiar environment [22,26]. EoL-care can take place in any setting that the person with SPMI considers their home: a sheltered housing initiative, nursing home, homeless shelter…[24].

Several reviews report data of studies concerning the place of death and the use of healthcare by people with SPMI during the last months of their life. It remains unclear whether the number of deaths in hospital, in comparison to the numbers of death at home, are greater in the SPMI population than the general population [26,30]. Nevertheless, there is clear evidence that people with schizophrenia are admitted to intensive care units and receive invasive treatment (cardiopulmonary resuscitation, mechanical ventilation, parenteral nutrition) more often during their last months of life, than people from the general population [22,27,29,30]. This can be due to a lack of ACP [27]. Another clear statistic reported by reviews is that people with SPMI die in a nursing home more often than the general population [24,26–30].

Reviews point to the fact that SPMI people, who have been in a mental health facility for a large part of their lives, cannot stay in this facility when EoL is approaching. In these circumstances, they are referred to somatic services, where specialized care can be provided [22,26]. Not only are these people displaced from their familiar environment, they also have to part from the care staff who in many cases are their main confidants [22–24,29]. In the most unfortunate cases, patients are referred back and forth between mental and somatic care settings, because of the complex care needs [22–26,28].

Non-maleficence

Referring to specialized care

Reviews indicate that HCPs experience difficulties in referring a patient with SPMI to specialized EoL care in a timely and adequate manner. Besides stigma and prejudice (see above) [22,24–27], lack of psychiatric knowledge and feeling for psychiatric patients, challenging communication and data transfer problems (absence of information on the psychiatric history of the patient) further complicate adequate EoL-care after referral [22,23,26,28].

Teaching your colleagues

Only a minority of mental health professionals has experience with EoL-care. As a consequence, they are insecure about providing EoL-care and tend to avoid it. Moreover, they are afraid of doing things that fall outside the legal framework, because they lack the required knowledge [22,24–26,28].

Palliative care providers, on the other hand, are uncertain when it comes to supporting people with SPMI. They feel uncomfortable and find they lack knowledge, training, skills and experience to cope with these patients [22,24–26,28]. They also experience difficulties in dealing with behavioral problems [23].

Various reviews argue that there is great benefit in cross-training between HCPs [23–26]. Appointing a psychiatric liaison worker to a palliative care unit, or vice versa, can help to increase the expertise and self-confidence of HCPs, through support, education and supervision [22,23,25,26,28]. Specific training for palliative care providers can focus on knowledge of the most common psychiatric syndromes, skills for a global psychiatric assessment, debunking prejudice and dealing with difficult behavior [24–26]. Training for mental health professionals can focus on making an ACP and on grief counseling for bereaved relatives [24,26]. The MENLOC study suggests it is preferable that the liaison worker has direct contact with the patient and is an integral part of daily clinical practice [26].

Working in team

Besides cross-training between services, several reviews suggest that an intrinsic understanding between mental health and palliative care facilities – both intramural and extramural – and the integration of team members from both healthcare services also benefit the patient with SPMI [24–26]. One suggestion is a regular multidisciplinary meeting in order to discuss specific cases [23,24,26,29]. An even bigger step is an integrated unit involving all relevant specializations (e.g. psychiatrist, oncologist) [22,23,25,26,29].

Beneficence

Acting with medical expertise

Several reviews point out that the complex clinical picture of people with SPMI and serious somatic comorbidities make heavy demands on the available time of HCPs. Broad medical expertise is therefore recommended [23,29]. However, the growing fragmentation of medicine into ever more specialized sub-disciplines adds to the difficulty in the provision of adequate care.

There is a greater risk that physical deterioration is not noticed in time, because some SPMI patients have a disturbed body perception (reduced pain sensitivity) and communication deficits [22–27,29], or because HCPs misattribute physical symptoms to the mental illness [22,24,25,29].

Several reviews indicate that special attention should be paid by the clinician to the adequate management of medication. The interaction between palliative medication (pain control, chemotherapy) and psychotropic drugs (antipsychotics, antidepressants) can potentially cause serious side effects [23,24,26].

Supporting relatives

Some reviews emphasize that special attention needs to be paid to the support of relatives [23]. Families including a person with SPMI are often characterized by more family conflicts, a complex family structure, and family members who are struggling with mental illnesses themselves [26,28]. Sometimes, relatives are designated as SDMs and are in need of support by HCPs when they are in the position to effectively make important decisions on behalf of the patient [22,24,26,29].

Family members, as well as the patient, want to stay in touch with the same team that has already been caring for the patient for years, and not having to discuss EoL problems or issues with other care providers. In this way, concerns are more easily discussed and solved [24].

Some literature also mentions the importance of providing appropriate support groups for bereaved relatives, following the death of the patient with SPMI [24].

DISCUSSION

We conducted this umbrella review to synthesize all relevant reviews concerning EoL-care for people with SPMI and a life-limiting disease. We used the four principles of biomedical ethics to sort the findings [32]. From this analysis, it has become clear that several issues complicate the application of ethical principles in EoL-care for these people. Stigma among HCPs, lack of integrated care policies, absence of ACP, and insufficient expertise and training of psychiatrists in palliative care have been identified as key challenges to the provision of adequate EoL-care for people with SPMI.

The ***stigmatization and discrimination of SPMI patients*** remains to be a problem [33–36]. “Psychiatric patients lack the capacity to understand their illness or to make adequate decisions about their treatment”, “psychiatric patients are not able to communicate with HCPs”, “psychiatric patients are unpredictable or dangerous”, and “psychiatric patients already have a low QoL” are common stigmatizing assumptions [34,37,38]. These assumptions can result in SPMI patients not getting equal access to EoL-care [38–40]. Indeed, stigmatizing views may lead to the misattribution of physical symptoms to mental illness (‘diagnostic overshadowing’), to the avoidance of direct contact with psychiatric patients, or to a paternal approach bypassing the patient’s perspectives [38–42]. To address the issue of stigma, it is, above all, important to make HCPs aware of their prejudices and discriminating behavior, as most stigma is implicit (i.e. stigma occurring outside of conscious control) [37,43,44]. Several stigma-reducing interventions have been introduced [33,40,43,45]. The most effective interventions are the contact-based interactions between HCPs and individuals with SPMI [33,39,43,46,47]. Besides these interventions, it has been proposed that the discussion of specific cases by interdisciplinary and multidisciplinary teams, including mental and medical health professionals, can help tackle stigma and discrimination [40,41].

The ***lack of integrated care policies*** has serious consequences for the provision of different kinds of care and interventions, including EoL-care**.** A fragmented service delivery system (‘system siloing’) [22,23,27,28,38,48] partly explains why SPMI patients have 2-3 times less access to palliative care than the general population [49,50], and why referral of SPMI patients from mental healthcare setting or community care to specialized palliative care is delayed, or accurate patient information is not provided [22,23,26,28,38]. In order to prevent people with SPMI from falling through the cracks of the fragmented healthcare system, several interventions are proposed. A personal care-coordinating professional (e.g. a social worker) can be appointed to the patient to bridge the gap between services. The implementation of a Flexible Assertive Community Treatment (FACT)-team also enhances continuity of care [22,25,51–55]. Interdisciplinary meetings between mental and physical HCPs on a regular basis stimulate cooperation [51,53,56,57]. On system level, shared digital information platforms are needed to guarantee no patient information is lost during referral [52,53,56–59]. For community-dwelling SPMI patients, a good coordination between primary care physician and psychiatrist is needed [34,51–53,56,57].

The ***absence of ACP*** has been identified as another barrier to good EoL-care. As a result of the above mentioned stigmatization by HCPs, conversations about ACP often bypass the patient [60]. The absence of ACP can pose significant risks to patients, as they are more likely to receive ineffective or unwanted interventions when approaching the EoL. Research has shown that patients with SPMI receive more invasive procedures in the last month of their life [22,27,29,30], and die more often in a nursing home than the general population [24,26–30]. Although the use of palliative sedation at the EoL is one important aspect to be discussed in ACP, data about palliative sedation in SPMI patients are lacking. In order to promote decision-making capacity and enable people with SPMI to engage in discussions about ACP, a number of suggestions have been made. First of all, if the psychiatric condition of the patient is fluctuating it is advisable to have the conversation at various points of time [23,25–27]. Efforts should be made in building a therapeutic relationship, in which 'non-abandonment', honesty and the dignity are central virtues [24,25,27,29,61,62]. Professionals should be trained in specific communication techniques [26,60,62]. During the process of care planning, it is desirable for the patient to be accompanied by a relative or informal carer who can act as an SDM [26,55,63].

Finally, there is ***insufficient expertise and training of psychiatrists in palliative care***. Patients, their informal carers, as well as psychiatric professionals all point out that professional expertise in handling these cases is missing [55,64]. Specific educational training can help address this issue [65]. Psychiatrists can be offered education about basic palliative care interventions, such as on how to do

ACP or to fill out a healthcare proxy form [23,26,66]. Practical experience can be integrated into the psychiatry residency program, or psychiatrists can take a fellowship in palliative care [66]. Fellowship-trained psychiatrists in palliative care have additional skills, like pain and symptom management and prognostication during EoL-care [66]. Moreover, they can act as ambassadors and train colleague psychiatrists [66]. Additionally, other clinicians with expertise in palliative care can be involved in mental healthcare settings, such as primary care providers or medical specialists [15,64].

This umbrella review has ***strengths and limitations***. A key strength of this analysis certainly are the extensive search strategies including several databases (see Supplementary Material). However, all reviews included in this umbrella review are based on studies that have been conducted in high income countries with developed health systems. Moreover, none of these addressed the use of palliative sedation among SPMI patients. We conducted an additional search for individual empirical studies on this subject, but found no relevant articles. Finally, although umbrella reviews certainly represent one of the highest levels of evidence synthesis currently available, a major limitation is that these reviews only report what researchers have systematically reviewed [67]. Therefore, more recent articles or empirical studies might have been missed.

CONCLUSION

EoL care for people with SPMI and a life-limiting disease is a multifaceted and complex problem. HCPs, in various settings, may face many ethical challenges in dealing with these patients. Although in recent years multiple systematic reviews have pointed to the same issues, no real changes have been noticed. There is still an urgent need for a policy of coordinated and integrated mental and physical healthcare for persons with SPMI and a life-limiting disease. Moreover, education and training initiatives to address blind spots of psychiatric as well as palliative care providers need to be developed. Finally, we specifically draw attention to the fact that no scientific data on the use of palliative sedation in the SPMI population were found. Therefore, more research is needed, especially in relation to the practice of ACP.

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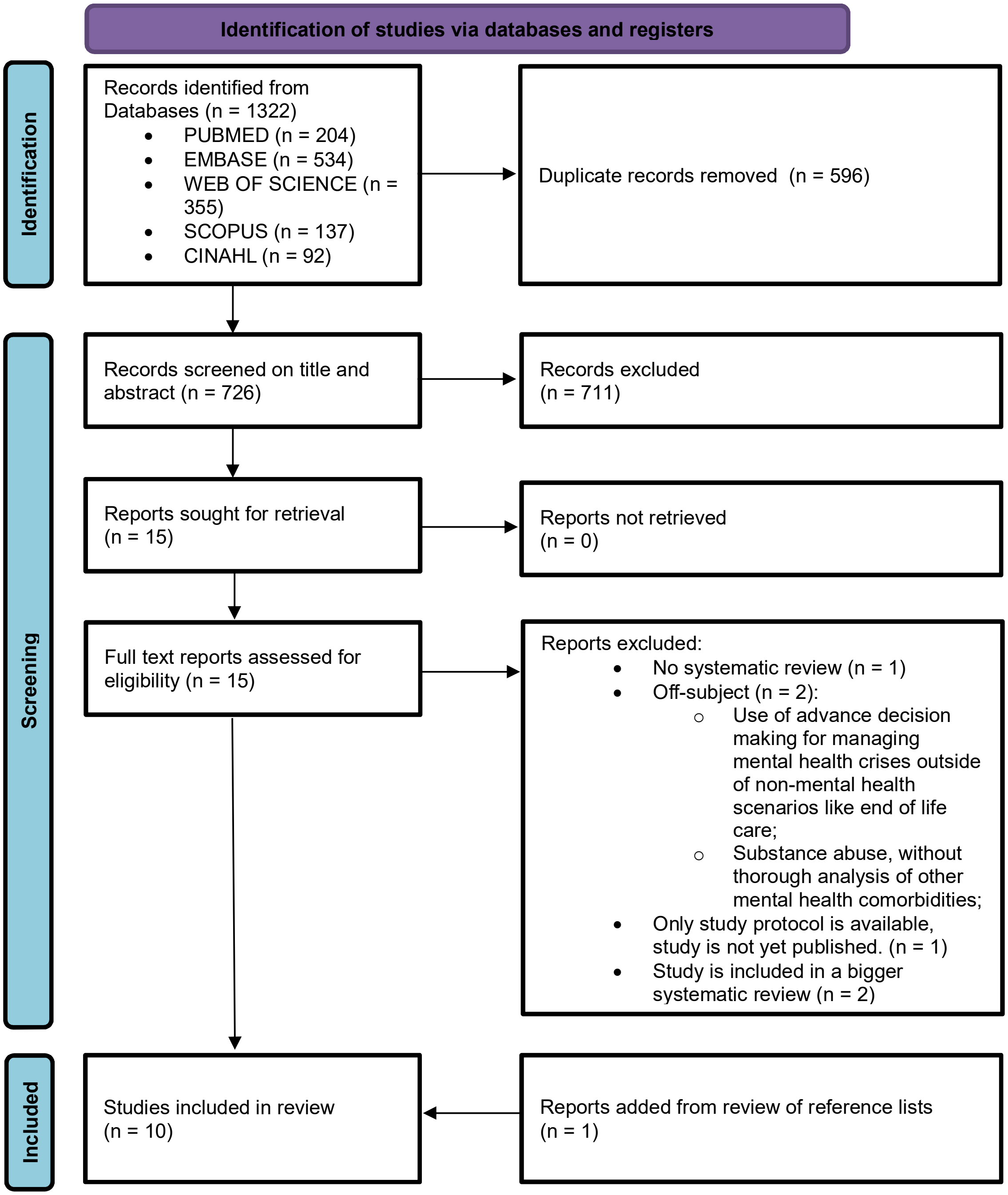
Figure 1 Primsma Flow chart



634 Table 1 Study Characteristics

Source	Country	Phenomenon of Interest	Type of Literature Included	Number of Literature	Chronological Range of Literature	Country of Included Literature	Patient Age	Patient Diagnosis
Boschen et al. (2022)	Australia	Death, dying, and palliative care experiences (with special attention to Australian NDIS participants)	'Academic and grey literature'	66	2013-2021	Not Specified	>18 years old	SPMI, bipolar disorder, schizophrenia, schizo-affective disorder, psychosocial disability
Hannigan et al. (2022)	UK	End of Life Care	Empirical literature, case report, grey literature	104	1983-2019	USA (40), Canada (7), UK (7), Australia (5), Netherlands (3), France (2), Belgium (1), Ireland (1), Israel(1), Mexico(1), New Zealand (1), Singapore(1), Taiwan(1), Unknown (1). Policy and guidance	>18 years old	SMI. Including but not limited to schizophrenia, schizophrenia spectrum and other psychotic disorders, schizotypal and delusional disorders, bipolar affective disorder, bipolar and related disorders,

						material was UK only		major depressive disorder and disorders of adult personality and behaviour.
Riley et al. (2022)	USA	End of Life Care	Empirical literature only	9	2005-2019	USA (3), Australia (1), Canada (1), New Zealand (1), Netherlands (1), Switzerland (1), UK (1)	No age limit	SPMI, not further specified
Baruth et al. (2021)	USA	End of Life Care	Empirical literature, review, case report	33	2008-2018	USA (13), Canada (4), Australia (2), Belgium (2), Japan (2), Taiwan (2), UK (2), Austria (1), France (1), Netherlands (1), Poland (1), Sweden (1)	No age limit	Schizophrenia
Hanan et al. (2021)	USA	End of Life Care	Empirical literature only	8	2003-2018	USA (4), Canada (2), New Zealand	No age limit	SPMI or specifically schizophrenia

						(1), Taiwan (1)		
Wilson et al. (2020)	UK	Health care utilization in last year of life/Place of death	Empirical literature only	23	1977-2019	USA (8), Canada (3), Australia (2), Denmark (2), Taiwan (2), UK (2), France (1), Japan (1), Netherlands (1), New Zealand (1)	>18 years old	SMI, not further specified
Den Boer et al. (2019)	Netherlands	Tools or interventions for optimalization of end of life care	Empirical literature only	4	2005-2016	USA (3), Netherlands (1)	No age limit	SPMI. Focus on psychotic disorders, bipolar disorder, mood disorders.
Donald et al. (2019)	Canada	End of Life Care	Empirical literature, review, case report, theoretical analysis	46	2000-2018	USA (20), Australia (7), Canada (6), Europe (5), UK (5), New Zealand (1), South Africa (1), Taiwan (1)	>18 years old	SPMI. Including schizophrenia, bipolar disorder, major depression.
Relyae et al. (2019)	Canada	End of Life Care	Empirical literature, review, case report,	32	1983-2017	Not Specified	No age limit	Schizophrenia or schizo-affective disorder

			editorial, grey literature					
Woods et al. (2008)	Canada	End of Life Care	Empirical literature, narrative review, case report, expert opinion, editorial, commentary	68	1979-2007	USA (38), UK (10), Canada (9), Australia (2), other (9)	No age limit	Mental disorders. Focus on schizophrenia, bipolar disorder, and severe depression. Comments on personality disorder, PTSD, anorexia nervosa, and alcoholism were also included.