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ISSN 2755-0060

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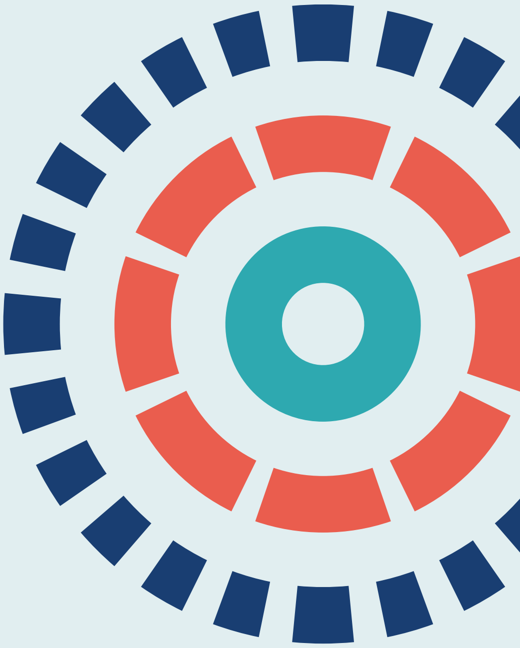

DOI 10.3310/ULTI9178

End-of-life care for people with severe mental illness: the MENLOC evidence synthesis

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Declared competing interests of authors: none

Published March 2022
DOI: 10.3310/ULTI9178

This report should be referenced as follows:

Hannigan B, Edwards D, Anstey S, Coffey M, Gill P, Mann M, Meudell A. End-of-life care for people with severe mental illness: the MENLOC evidence synthesis. *Health Soc Care Deliv Res* 2022;**10**(4).

Health and Social Care Delivery Research

ISSN 2755-0060 (Print)

ISSN 2755-0079 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

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This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number 17/100/15. The contractual start date was in November 2018. The final report began editorial review in February 2020 and was accepted for publication in October 2020. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HSDR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HSDR programme or the Department of Health and Social Care.

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Abstract

End-of-life care for people with severe mental illness: the MENLOC evidence synthesis

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Background: People with severe mental illness have significant comorbidities and a reduced life expectancy. This project answered the following question: what evidence is there relating to the organisation, provision and receipt of care for people with severe mental illness who have an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months?

Objectives: The objectives were to locate, appraise and synthesise relevant research; to locate and synthesise policy, guidance, case reports and other grey and non-research literature; to produce outputs with clear implications for service commissioning, organisation and provision; and to make recommendations for future research.

Review methods: This systematic review and narrative synthesis followed international standards and was informed by an advisory group that included people with experience of mental health and end-of-life services. Database searches were supplemented with searches for grey and non-research literature. Relevance and quality were assessed, and data were extracted prior to narrative synthesis. Confidence in synthesised research findings was assessed using the Grading of Recommendations, Assessment, Development and Evaluation and the Confidence in the Evidence from Reviews of Qualitative Research approaches.

Results: One hundred and four publications were included in two syntheses: 34 research publications, 42 case studies and 28 non-research items. No research was excluded because of poor quality. Research, policy and guidance were synthesised using four themes: structure of the system, professional issues, contexts of care and living with severe mental illness. Case studies were synthesised using five themes: diagnostic delay and overshadowing, decisional capacity and dilemmas, medical futility, individuals and their networks, and care provision.

Conclusions: A high degree of confidence applied to 10 of the 52 Grading of Recommendations, Assessment, Development and Evaluation and Confidence in the Evidence from Reviews of Qualitative Research summary statements. Drawing on these statements, policy, services and practice implications are as follows: formal and informal partnership opportunities should be taken across the whole system, and ways need to be found to support people to die where they choose; staff caring for people with severe mental illness at the end of life need education, support and supervision; services for people with severe mental illness at the end of life necessitate a team approach, including advocacy; and the

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timely provision of palliative care requires proactive physical health care for people with severe mental illness. Research recommendations are as follows: patient- and family-facing studies are needed to establish the factors helping and hindering care in the UK context; and studies are needed that co-produce and evaluate new ways of providing and organising end-of-life care for people with severe mental illness, including people who are structurally disadvantaged.

Limitations: Only English-language items were included, and a meta-analysis could not be performed.

Future work: Future research co-producing and evaluating care in this area is planned.

Study registration: This study is registered as PROSPERO CRD42018108988.

Funding: This project was funded by the National Institute for Health Research (NIHR) Health and Social Care Delivery Research programme and will be published in full in *Health and Social Care Delivery Research*; Vol. 10, No. 4. See the NIHR Journals Library website for further project information.

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List of abbreviations

aHR	adjusted hazard ratio
AMED	Allied and Complementary Medicine Database
aOR	adjusted odds ratio
aRR	adjusted relative risk
ASSIA	Applied Social Sciences Index and Abstracts
CASP	Critical Appraisal Skills Programme
CENTRAL	Cochrane Central Register of Controlled Trials
CERQual	Confidence in the Evidence from Reviews of Qualitative Research
CI	confidence interval
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CPR	cardiopulmonary resuscitation
DARE	Database of Abstracts of Reviews of Effects
ED	emergency department
EoL	end of life
EPPI	Evidence for Policy and Practice Information
GP	general practitioner
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
HCP	health-care professional
HR	hazard ratio
HSDR	Health and Social Care Delivery Research
ICU	intensive care unit
LYoL	last year of life
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
OR	odds ratio
PEER	Patient Experience and Evaluation in Research
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTSD	post-traumatic stress disorder
RR	relative risk
SAG	stakeholder advisory group
SMI	severe mental illness

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Plain English summary

In this study we brought together evidence from research, policies, guidance and case studies in the area of end-of-life care for people with severe mental illness. End-of-life care refers to the help given to people with life-threatening conditions in their expected last 12 months of life. Severe mental illness refers to a range of issues for which care is usually provided by specialist mental health services.

An advisory group, which included people who had experience of mental health and end-of-life care, helped us throughout our project. We searched research databases, journals and online sources. We assessed research articles for their quality and summarised their content. In one review we combined content from research with content from policy and guidance. In another review we combined the content of the case studies. We wrote synthesis statements summarising the research evidence, and assessed how much confidence decision-makers should have in these statements.

We included 104 documents overall. We synthesised research, policy and guidance under themes reflecting their content: the structure of mental health and end-of-life care services; professional practice; providing and receiving care; and living with severe mental illness. We synthesised case studies under themes relating to delays in diagnosis, making decisions, treatment futility, supporting people and the experience of care.

Our project has implications for care. The evidence suggests that partnerships should be built between mental health and end-of-life care staff, and that people should be supported to die where they choose. Care staff need education, support and supervision. A team approach is needed, including support for advocacy. Physical health care for people with severe mental illness needs to be improved so that life-threatening conditions can be recognised sooner.

Future research should involve people with severe mental illness at the end of life and their carers. Research is also needed to evaluate new ways of providing and organising care.

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Scientific summary

Background

People with severe mental illness such as schizophrenia, bipolar disorder and major depression have significant comorbidities and experience higher mortality rates and reduced life expectancy than the general population. Policy across the UK includes a focus on improving end-of-life care where diagnosis is immaterial, and requires the introduction of palliative and supportive care earlier in the dying trajectory. In the context of calls for parity of esteem, referring to the expectation that care for people with mental health problems should be of the same quality as care for all other people, this project aimed to synthesise relevant research and other evidence relating to end-of-life care for people with severe mental illness. It set out to answer the question 'what evidence is there relating to the organisation, provision and receipt of care for people with severe mental illness who have an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months?'.

Objectives

The detailed objectives were to:

1. use internationally recognised, transparent, literature review approaches to locate, appraise and synthesise the relevant research evidence relating to the organisation, provision and receipt of care in the expected last year of life for people with severe mental illness who have additional diagnoses of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months
2. locate and synthesise policy, guidance, case reports and other grey and non-research literature relating to the organisation, provision and receipt of care in the expected last year of life for people with severe mental illness who have additional diagnoses of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months
3. produce outputs with clear implications for service commissioning, organisation and provision
4. make recommendations for future research designed to inform service improvements, guidance and policy.

Methods

The protocol for this evidence synthesis was registered with the International Prospective Register of Systematic Reviews, and the project followed guidance for undertaking reviews in health care published by the Centre for Reviews and Dissemination at the University of York.

All relevant English-language evidence was sought that specifically related to adults (> 18 years of age) with severe mental illness who had an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who were likely to die within the next 12 months. All citations were considered that addressed service organisation and provision and receipt of end-of-life care for people with severe mental illness irrespective of care setting. Citations reporting the views and experiences of service users, families and health and social care staff were also included. Following consultation with members of a project stakeholder advisory group, 'severe mental illness' was defined as including those with (but was not limited to) schizophrenia, schizophrenia spectrum and other psychotic

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disorders, schizotypal and delusional disorders, bipolar affective disorder, bipolar and related disorders, major depressive disorder and disorders of adult personality and behaviour. Searches were not made for studies into mental and behavioural disorders due to psychoactive substance use or for studies into dementia or other neurodegenerative diseases, and materials reporting on mental health problems experienced subsequent to receipt of a terminal illness diagnosis were excluded. Types of evidence sought included quantitative research, qualitative research and relevant non-research material, including UK policies and guidelines and reports of international practice initiatives and clinical case studies.

Following the development and testing of a search strategy, comprehensive searches were conducted across 10 databases: MEDLINE, PsycInfo, EMBASE, Health Management Information Consortium, Allied and Complementary Medicine Database, Cumulative Index to Nursing and Allied Health Literature, Cochrane Central Register of Controlled Trials, Applied Social Sciences Index and Abstracts, Database of Abstracts of Reviews of Effects and the Web of Science. Supplementary searching was undertaken to identify additional material including grey literature. This included the use of online searches and the targeted searching of organisational websites and of journal tables of contents. Reference lists of included studies were scanned, and forward citation tracking was performed using the Web of Science.

All citations were independently assessed for relevance by two members of the review team using titles and abstracts, with disagreements resolved through discussion with a third reviewer. When a citation appeared to meet the inclusion criteria, or where a definite decision could not be made based on the title and/or abstract alone, the full text was retrieved. Two reviewers screened each retrieved citation for inclusion using a purposely designed form, with disagreements resolved through discussion with a third reviewer.

Included research items and case studies were appraised by two reviewers using Critical Appraisal Skills Programme checklists, or alternatives, if necessary, to reflect the type of material retrieved. Disagreements were resolved following discussion with a third reviewer. Policy and guidance documents retrieved were not appraised for quality. Following appraisal, demographic data from research items and case studies were extracted into tables and checked by a second reviewer. The full text of research items and case studies, and relevant extracts from policy and guidance documents, were uploaded to the software program NVivo 12 (QSR International, Warrington, UK). All items uploaded were subjected to line-by-line coding followed by two thematic syntheses: the first drawing on included research, policy and guidance items and the second drawing on included case studies. As no intervention studies were included in the review, no meta-analyses were performed. In the case of research items, confidence in synthesised findings was assessed by two reviewers, using the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) and the Confidence in the Evidence from Reviews of Qualitative Research (CERQual) approaches.

Results

A total of 11,904 citations were initially retrieved through database searching and other methods. Following screening and the addition of relevant grey literature, a total of 104 publications were included in the final synthesis, comprising 34 research publications, 42 case studies and 28 non-research items. Twenty-five of the 42 case studies met either seven or all eight of the quality criteria, with eight meeting half or fewer. All included cohort studies were of acceptable quality, as was the quality of most of the descriptive studies and the survey components of the included mixed-methods studies. The quality of the majority of the qualitative studies, and of the qualitative component of the mixed-methods studies, was high.

Research, policy and guidance material was synthesised using four themes:

1. Structure of the system, which addressed the broad shape and structure of the mental health and end-of-life care systems and had four subthemes – policy and guidance; separate commissioning, management and organisation; partnership; and no right place to die.
2. Professional issues, which addressed professional practice and had four subthemes – relationships between health-care professionals and people with severe mental illness, mental health professionals doing end-of-life care, end-of-life care professionals doing mental health care, and training and education.
3. Contexts of care, which addressed the organisation, provision and receipt of care and had three subthemes – managing the interface between mental health and end-of-life care, health-care services and treatment utilisation in the last year of life, and meeting individual and family needs.
4. Living with severe mental illness, which addressed the individual and social characteristics of patients and had three subthemes – complexities of end-of-life care, familiarity and trust, and recognising physical decline.

Case study material was synthesised using five themes:

1. diagnostic delay and overshadowing
2. decisional capacity and dilemmas
3. medical futility
4. individuals and their networks
5. care provision.

Conclusions

A high degree of confidence was judged to apply to 10 out of the 52 GRADE and CERQual synthesis summary statements associated with the included research material, distributed across all four major themes (structure of the system, professional issues, contexts of care and living with severe mental illness). All 10 were summary statements synthesised from generally well-conducted, relevant studies in which there was a high degree of coherence. A moderate degree of confidence was judged to apply to 32 of the statements, denoting concerns relating to one or more of the dimensions assessed in the underpinning evidence (methodology, coherence, relevance and adequacy), with the confidence in the remaining 10 summary statements judged as being either low or very low. The purpose of assessing confidence in summaries of synthesised findings is to better support decisions by policy-makers, managers and senior practitioners, including in the areas of policy and guideline development. Drawing on the evidence summary statements for which there was a high degree of confidence, the key implications for policy, services and practice are as follows:

1. This evidence synthesis points with a high degree of confidence to the importance of formal and informal partnership opportunities being taken and encouraged. Partnerships can involve the building of coalitions across the whole system, including mental health, end-of-life, primary care, social care and other services. This is necessary to support the exchange of information during the integrated care of people with severe mental illness at the end of life. In a context in which there is often 'no right place to die' and in which mental health staff are often poorly equipped to care for people at the end of life, and in which people with severe mental illness at the end of life face frequent moves between services, finding ways of supporting people to die in the locations of their choice is a priority.
2. This synthesis also has implications for professional practice. Many people with severe mental illness have limited social networks and little or no family contact, but even though mental health staff value the quality of their relationships with patients, some find it difficult to invest in

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relationships with people with severe mental illness at the end of life because of the upset caused when patients are transferred to other facilities for end-of-life care. Mental health staff, many of whom find talking with patients about death and dying difficult, find that when opportunities to discuss these topics are found patients are receptive. In the case of health-care professionals working in end-of-life care, stigmatising and prejudicial attitudes towards people with severe mental illness and people who are homeless can affect end-of-life decision-making. All of these summary statements have clear implications for the future education, support and supervision of all care staff working across both the mental health and the end-of-life care systems.
3. A high-confidence synthesis summary from the contexts of care domain is that programmes and services for people with severe mental illness at the end of life require a comprehensive team approach incorporating symptom relief, psychological and psychosocial support, and spiritual care. Comprehensive services of this type are exactly as should be expected by all members of the population, but the importance of this for people with severe mental illness at the end of life is worth restating for the purposes of promoting parity of esteem. Capable advocates are able to increase the referral of people with severe mental illness at the end of life to palliative care services, and to help make sure that palliative care is provided and received. Not having an advocate means that people with severe mental illness who lack social and family support risk becoming 'lost in the system'. Taken together, these synthesis summaries have important implications for the identification of roles for members of the care team in co-ordinating services across boundaries, advocating for and on behalf of patients, and providing direct care.
4. A final high-confidence summary statement is derived from the evidence synthesised in the area of living with severe mental illness. This review has found that the timely provision of palliative care can be hindered when people with severe mental illness, and particularly those who are homeless, receive delayed diagnoses of their end-of-life-related conditions. This has implications for the proactive provision of physical health care to groups of people who might not recognise the seriousness of their condition and who might miss out on routine health assessments.

Few UK studies have been conducted into end-of-life care for people with severe mental illness, and, internationally, few studies have included patients, family members or other unpaid carers. No intervention studies were found for inclusion in this synthesis. In this context of a relative paucity of research evidence, the key recommendations for future studies are as follows:

1. Patient and family-facing studies should be commissioned to examine the experiences of people with severe mental illness at the end of life, and the experiences of their surrounding paid and unpaid carers and those important to them, to establish the factors helping and hindering care in the specific UK context.
2. A programme of research should be commissioned comprising studies that explicitly co-produce, introduce and evaluate new ways of providing and organising end-of-life care for people with severe mental illness with both cancer and other life-threatening conditions. This programme should include studies involving support for structurally disadvantaged groups, including people with severe mental illness at the end of life who are also homeless or who are in prison. Candidate interventions include advanced care planning, advocacy and improved education for professionals, along with the development of new or enhanced roles for practitioners and the introduction of models of integrated provision spanning the mental health, end-of-life and related care systems.

Limitations

Only English-language items were included, and a meta-analysis could not be performed.

Future work

This project is intended as the start of a programme of research into an important, but perhaps neglected, area.

Study registration

This study is registered as PROSPERO CRD42018108988.

Funding

This project was funded by the National Institute for Health Research (NIHR) Health and Social Care Delivery Research programme and will be published in full in *Health and Social Care Delivery Research*; Vol. 10, No. 4. See the NIHR Journals Library website for further project information.

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Chapter 1 Background and rationale

In this project, we undertook a rigorous synthesis of research and other evidence in the area of end-of-life (EoL) care for people with severe mental illness (SMI), conducted according to internationally agreed quality standards. The project has been within the remit of the National Institute for Health Research (NIHR) Health and Social Care Delivery Research (HSDR) programme in addressing quality, organisation and access in health services. In the context of calls for parity of esteem between mental health and physical health care,[1] the health problem this project has addressed is a highly relevant but perhaps neglected one.

In preparing the original proposal supporting this project, an initial scoping review of literature was undertaken (with updated searches run in July 2018), and a targeted search was made for relevant policy documents across the four UK nations. A search of the database of NIHR projects was conducted to check for overlapping or related studies. Preliminary searches of four databases (combining 'palliative care', 'mental health' and 'service provision' terms) produced 4754 citations, within which were a number of relevant papers, including two previous literature reviews (from the UK and Canada, respectively), both now out of date, having been published over a decade ago.[2,3] Items discovered in this scoping search confirmed the timeliness and feasibility of a new, rigorous evidence synthesis, and particularly an EPPI (Evidence for Policy and Practice Information)-Centre-style review that is sensitive to the needs of stakeholders and that includes grey and non-research materials.[4] Items from this initial search, combined with general material addressing what is known about the burden of disease and the physical health of people living with mental health difficulties, have been used to inform this background and rationale (and subsequent) sections of this project report.

Burden of disease and costs

The overarching background for this project includes what is already known about the burden of SMI, cancer and end-stage lung, heart, renal or liver failure. Mental ill-health is a leading cause of years lived with disability around the world, with major depressive disorder the leading cause of years lived with disability in 56 countries and the second leading cause in a further 56.[5] Specific cancers, along with mental ill-health, neurological conditions, drug use disorders and specific organ diseases, all feature in the leading 20 causes of disability adjusted life-years in England for 2013.[6] The wider economic costs of mental illness in England were recently estimated at £105.2B each year.[7] This figure combines the direct costs of services, lost productivity at work and reduced quality of life, with the annual costs of the same in Wales estimated at £7.2B.[8]

Meeting the physical health needs of people living with severe mental illness

The term 'severe' (or, often used interchangeably, 'serious', 'serious and enduring' or 'serious and persistent') mental illness, as used throughout this project, has longstanding currency in the fields of mental health policy, services and practice, dating back in the UK at least as far as the publication of *Building Bridges: A Guide to Arrangements for Interagency Working for the Care and Protection of Severely Mentally Ill People*.[9] It continues to be used in research[10] and has currency with the NIHR Dissemination Centre, which published a themed review on SMI in 2018.[11] *Building Bridges* recognised the imprecision of the term 'severe mental illness' and endorsed a multidimensional framework definition encompassing five areas: safety, need for informal or formal care, disability, diagnosis and duration. Diagnosis is, therefore, an important, but not the only, dimension used in the identification of people with SMI and includes the *International Classification of Diseases*, Tenth Revision, diagnoses of schizophrenia, schizotypal and delusional disorders, bipolar affective disorder, and disorders of adult personality and behaviour,[12] along with similar

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Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, diagnoses, including schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, and major depressive disorder.[13]

The particular focus in this project on EoL care can also be set in the context of people with SMI having high comorbidities[2] and experiencing higher mortality rates and reduced life expectancy than the general population.[14] Higher mortality and morbidity rates for this group have been found across all age groups,[15] with a 10- to 20-year reduction in life expectancy reported.[16] Inequities, not limited to care at the EoL specifically, can be explained with reference to individual- and system-level factors. People with SMI are less likely to attend health screenings and may respond to symptoms differently.[17] They may delay or avoid seeking help, and are more likely to exhibit disruptive behaviours or miss contacts with health professionals,[3,18] putting them at risk of delayed disease detection.[2] Inadequate support systems are also common among those with SMI, affecting their ability to access appropriate clinical care and navigate complex health systems.[19] Other factors influencing variations in mortality and morbidity for people living with SMI include poor previous experiences of seeking help from health-care professionals (HCPs), care staff's incorrect attribution of physical symptoms to psychiatric disorder and the lack of experience by mental health professionals in determining how and when to refer people onwards to other appropriate services.[3,20]

End-of-life care for people with severe mental illness

In this study, following the definition used by the General Medical Council,[21] EoL care is used to refer to the care of people who have diagnoses of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and are likely to die within the next 12 months. It includes care provided in hospitals, hospices and other institutional settings (e.g. care homes, prisons and hostels) and care provided in the home and via outreach to people who may also be homeless.

Beyond the inequities identified above, commitments to parity of esteem demand that EoL care for people with SMI should be as timely and as high quality as it is for others. However, early evidence gathered in support of this initial project proposal suggests that this group is poorly served, with England's Cancer Strategy 2015–20[22] recognising that people with SMI need to be the focus of improvements diagnosis and care. Although the incidence of cancer among people living with SMI is similar to that of the general population, mortality rates among those with SMI are double.[23,24] This disparity may be related in part to late presentation and reduced use of interventions such as surgery, chemotherapy or radiotherapy.[25,26] The experience of SMI can delay detection and treatment of life-threatening physical disorders as people are less likely to seek treatment, to verbalise pain and to access timely health care.[27] Consequently, this patient cohort is more likely to present with more advanced cancers that are invariably more complex and costly to treat, with patients less likely to undergo invasive treatments and more likely to die.[28] Some cancers, other terminal conditions and/or related treatments may also compound mental illness and precipitate potential 'problematic' behaviours.[29] For many patients, therefore, palliative care is often the only meaningful treatment option available.

The original case for this evidence synthesis also built on the observation that, once people with SMI are in touch with EoL services, their symptoms may be poorly recognised and undertreated, with staff working in EoL services lacking knowledge, training and experience in this area.[30] Undetected and hence untreated mental illness can jeopardise treatment outcomes, reduce patient satisfaction and increase health-care costs.[31] Variable adherence can be a complicating factor,[19] compounded by comorbid disorders, such as substance misuse, and social factors, such as homelessness, isolation or lack of transportation, all of which can exert an impact on planning for EoL care and treatment.[3,15] Assumptions about the capacity of people with SMI to make EoL decisions, and concerns that EoL discussions would be too distressing or would exacerbate mental health problems, may lead to inadequate consultation and advance care planning.[32] The case for this project included reference to the fact that people with SMI have a higher percentage of 'do not resuscitate' orders than other groups and are less likely to have had discussions about their explicit wishes for EoL care.[33]

Palliative care

Although not all people at the EoL need palliative care, a review of the evidence[34] confirmed inequities in palliative care provision for both cancer and non-cancer patient populations. In Wales, an estimated 24,000 of the 32,000 people who die per year would benefit from palliative care, but over one-quarter do not have access to it.[34,35] Access to palliative care services among people who die from cancer is 46%, compared with 5% among those dying from other conditions,[36] including end-stage lung, heart, renal or liver failure.

The case for this project recognised that people with mental illness and advanced incurable cancer and/or lung, heart, renal or liver failure face inequities and discrimination[35] and a lack of integrated care.[2] Some may be excluded from EoL care planning[3], and even from hospitals or hospices entirely.[29] They may be referred back to mental health services, where staff are often inadequately prepared to provide appropriate EoL care.[3] Difficulties accessing appropriate services mean that for people with mental illness and a life-threatening disease palliative care may be the first line of treatment.[2] The specific provision of palliative care for people with SMI is known to be poorer than for the general population. People with SMI are approximately 50% less likely to access appropriate palliative care, including symptom control and pain relief.[3,20] Palliative care and hospice staff often feel unskilled,[20] lacking confidence and training in conducting discussions about EoL care with people SMI.[32] Evidence gathered to inform the proposal for this synthesis also indicates that there is a lack of co-ordinated EoL care, and that access to appropriate psychosocial support is often limited.[2,3] Medical and nursing staff working in hospices have also been shown to be unprepared for working with people with SMI, basing their assessments on instinct rather than using evidence-based approaches.[37] In a survey of psychological services in hospices in the UK and the Republic of Ireland, only 30% of hospices had access to a psychiatrist, 41% had access to a clinical psychologist and 45% had neither.[38] Patient experience data underscore these observations, with England's National Cancer Patient Experience Survey showing that people with a long-term mental health condition (2% of those surveyed; $n = 1184$) reported less positive experiences of cancer care.[39] In Wales, the most recent National Cancer Patient Experience Survey[40] found that the lowest proportion of respondents reporting positive experiences of their cancer care were those identifying as also having mental health problems.

Evidence explaining why this research was needed

Research at the interface of physical and mental health care is recognised as a UK priority.[41] Against the background presented above, this project has created generalisable knowledge to improve EoL care and services for an underserved group. Policies from the four UK governments focus on improving EoL care, where diagnosis is immaterial.[42–50] These policies require the introduction of palliative and supportive care earlier in the illness trajectory, with patient surveys showing that this is rated very highly by those receiving it.[51] The charity Marie Curie (London, UK) identified triggers that should initiate palliative care for people with diagnoses other than cancer,[52] but, apart from dementia, it does not mention those with pre-existing SMI. In national policy the needs of people with SMI who develop advanced incurable cancer and/or end-stage lung, heart, renal or liver failure are acknowledged poorly, or not at all. This group face the prospect of 'disadvantaged dying'[53,54] at a time when quality of care in the last months of life should be uniformly high for all groups.

Uniquely among the cancer, palliative and EoL strategies developed across the four countries of the UK, the Independent Cancer Taskforce's *Achieving World-class Cancer Outcomes: A Strategy for England 2015–2020*[22] makes the specific recommendation that the NIHR commission research in the area of cancer care for people living with SMI. This project has responded to this call, and expanded it to also cover EoL care for people living with SMI and facing end-stage lung, heart, renal or liver failure.

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It has answered a question that is both timely and relevant: what evidence is there relating to the organisation, provision and receipt of care for people with SMI who have an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months?

This rigorously conducted evidence synthesis has brought together reports of approaches to service organisation, processes and interventions shown to both facilitate and hinder the provision of high-quality, accessible, equitable and acceptable EoL care to people with SMI. The project team has also gathered research and other evidence reporting the views and experiences of service users, families, and health and social care staff. Outputs from the project are intended to have an impact on services and practice, and plans are in place to present findings in accessible ways to NHS and other managers, practitioners and educators. It is anticipated that findings will inform future National Institute for Health and Care Excellence (NICE) guidelines, and thereby help shape the provision of services. Current relevant NICE guidance[55–59] lacks standards or recommendations that particularly address EoL care for people with SMI.

A pre-project search of NIHR databases found studies that have investigated the physical health of people with SMI (e.g. Health Technology Assessment 12/28/05[60]), services for this group across organisations (e.g. HSDR 11/1023/13[61]) and care for people experiencing mental health difficulties after receiving cancer diagnosis (e.g. Health Technology Assessment 09/33/02[62]). As no research has been commissioned in the area addressed here, this project has effectively opened a new and important programme of work with value to the NHS and its partners. Having used a methodical, systematic and transparent approach, the MENLOC project team now plans to use this synthesis as the starting point for a programme of research that builds on what is already known, is designed with people who have experience of mental health difficulties and with people who have lived with cancer and have cared for family at the EoL, and generates new evidence of what works with value to the NHS and other relevant organisations.

Chapter 2 Working with stakeholders and defining parameters

In this chapter, the approach taken to working with stakeholders, including members of the public and people with personal experience of mental health and/or EoL care, is described. Reporting of this section is completed with reference to GRIPP2-SF standards.[63] The proposal for this evidence synthesis was shaped by people with experience of mental health problems, cancer and other long-term conditions, and by people with experience of caring. The original idea for the study arose following sustained and critical discussions between two co-investigators, Roger Pratt and Sally Anstey, who together identified that individuals with SMI are disadvantaged when diagnoses of advanced cancer or end-stage organ failure are made. Roger is a retired mental health social worker who lives with lymphoma (in long-term remission) and heart failure. He cared for his wife who died from advanced peritoneal cancer; she received specialist palliative care in the last year of her life and died in a hospice. This discussion observed that professional perceptions and misperceptions such as stigma and fear have an impact on management (e.g. pain control, supporting choice and place of care/death) in the case of people with SMI receiving EoL care. Alan Meudell later joined the project team as a mental health service user consultant and researcher. He has worked on two previous NIHR studies[64,65] and one Health and Care Research Wales study[66] and has led training for Health and Care Research Wales on involving service users in research. He is also interested in the physical health care of people living with mental health difficulties and in the provision of equitable services.

Throughout the project, building on these beginnings, the aim of public and patient involvement was to embed public and patient involvement perspectives into all aspects of the project, from the definition of search terms and parameters onwards to impact and dissemination. The role Alan Meudell played was equal partner in all stages of the research process except the literature search (which was led, uniquely, by Mala Mann as the team's information services specialist). At his request, once the project had started, Roger contributed at stakeholder advisory group (SAG) meetings only, although both he and Alan Meudell participated in initial training that other investigators joined. They also contributed to the task of identifying carers and service users to join the project stakeholder group. Alan Meudell advised on the ongoing focus and direction of the study, and directly contributed to the screening of items for possible inclusion, the synthesis of materials and the accessible writing-up of this final report. In preparing an initial project proposal for submission to the HSDR programme, plans were also presented to the Patient Experience and Evaluation in Research (PEER) group at Swansea University (www.swansea.ac.uk/humanandhealthsciences/research-at-the-college-of-human-and-health/patientexperienceandevaluationinresearchpeergroup/; accessed 14 February 2020). The PEER group comprises people with experience of using health-care services and of caring and exists to provide a public and patient view of research proposals before they are submitted for funding. When the proposal was considered by the PEER group, members gave it a very positive response, stating that this was a much-needed project in an area that is largely ignored. People were particularly interested in plans for choosing members of the SAG and advised the project team to engage with charities such as Macmillan Cancer Support (London, UK), with hospices and with palliative care staff such as nurses. They also recognised the difficulty of actually recruiting SAG members from the target population but believed an attempt should be made to engage by offering opportunities for people with SMI and EoL diagnoses to participate in any way feasible for them. This advice was noted, and services in South Wales were approached to seek their agreement in principle to help put project team members in touch with service users and carers (as well as managers and practitioners) able to advise the study.

Populating the SAG was accomplished during the project set-up phase, with representatives drawn from the mental health and EoL fields. Members included professionals from a range of practitioner backgrounds based in NHS and charitable organisations, policy advisers and people with lived experience of mental health difficulties and of life-threatening disease. The full membership of the SAG is found in

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Appendix 1, and over the life of the study the combined project team and SAG met, in Cardiff, at three strategic time points. The first meeting was scheduled at the commencement of the project, with the focus on agreeing terms of reference (see *Appendix 2*) and then refining database search terms and wider search strategies, including the identification of online sources for the team to consult (see *Appendix 3*). The second meeting took place after the evidence searching and screening had been completed, which provided an opportunity to share work in progress (see *Appendix 4*). The final meeting was scheduled at the commencement of the whole-project synthesis and report-writing phase, with a focus on sharing preliminary findings and discussing plans for dissemination and maximising impact (see *Appendix 5*).

Defining the project's parameters: 'severe mental illness' and 'end of life' (and related)

At the first, key, combined project team and SAG meeting, candidate database search strategies and search terms developed by the project team for both SMI (see *Appendix 6*) and EoL care (see *Appendix 7*) were distributed and discussed at length with the purpose of refinement.

Severe mental illness

Project team and SAG members recognised the imprecise nature of the phrase 'severe mental illness', but also the everyday currency of the term. It was recognised that the focus of this study was broadly on EoL care for adults over the age of 18 years who have used secondary, specialist, inpatient and/or community mental health services. At the meeting participants also discussed the inclusion of additional diagnoses [e.g. anorexia and post-traumatic stress disorder (PTSD)] not listed in the MENLOC protocol. It was noted that diagnostic manuals are extensive, and that listing new individual diagnoses at this point would open the door to including all diagnoses, making for unmanageable searches. It was decided, therefore, not to include such terms.

An intense dialogue was held around the diagnosis of depression as a result of the large numbers of outputs initially retrieved via the scoping search reporting on depression as a consequence of receiving an EoL diagnosis, as opposed to preceding such a diagnosis. The continuum of depression was also noted, and the project team agreed that outputs concentrating on people with mild, commonly experienced depression (and, by extension, anxiety) should be excluded. A consensus was to remove 'depression' as a search term or MeSH (medical subject headings) term but instead use 'depression' in conjunction with other terms such as 'psychosis' or 'pre-existing' or 'severe'. This meant, therefore, using adjacency searching to retrieve accurate results. Project information specialist Mala Mann confirmed that older terms such as 'melancholia' would not need to be searched for, because database indexing combines outputs using these phrases with outputs using more contemporary terminology.

Project members reported that not all initial EoL care outputs retrieved made clear whether or not the mental health problems experienced preceded EoL diagnosis. Some discussion also took place on whether or not a fourth arm should be added to the search strategy, capturing the use of secondary services, in recognition of the fact that people with SMI are overwhelmingly people who use secondary mental health services. It was noted that a four-arm search would be too narrow, and that citations containing such terms would already be identified using the existing three-arm search (see *Chapter 3*).

A decision was made not to search specifically for the search terms 'suicide', 'assisted death', 'assisted suicide' and 'euthanasia' (noting that euthanasia may be seen by some people using services as the only possible option when all else fails), as papers in these areas would be found through existing search strategies.

End-of-life care

Suggestions from SAG members for search terms related to the EoL were noted, including 'thanatology' (the study of the theory, philosophy and doctrine of death); 'best supportive care'/'enhanced supportive care' (these being relatively new terms currently in use); 'end-stage', as a term to represent dying with chronic conditions; and ‘conservative management’ or ‘conservative treatment’. A consensus was to exclude ‘self-poisoning’ or ‘self-inflicted injuries’, as the goal of treatment likely to be reported in outputs was to sustain life. A consensus was also *not* to add into the search strategies terms attempting to establish the reasons for EoL care, but to *include* terms reflecting the closing down of active treatments: ‘withdrawing active treatment’, ‘withdrawing’ or ‘refusing’ treatments such as dialysis and ‘moribund’. It was noted that the ‘expected last six months of life’ is a term used in the USA and should be included.

At this first combined project team and SAG meeting, participants identified a group of conditions not previously considered by the project team, covering (for example) conditions broadly referred to in the meeting as ‘brain failure’. It was noted that ‘brain failure’ outputs would be captured under the term ‘organ failure’, and that a separate funding proposal was being prepared to synthesise the evidence in the area of EoL care for people with neurodegenerative conditions.

Finding grey literature, including non-research material

Websites to search that had already been identified by the project team were circulated (see *Appendix 8*), and in this first, key, meeting SAG members were invited to identify additional online sites. Suggestions made in the meeting or received thereafter included a Hospice UK (London, UK) report (KC), deaths in custody (SP), palliative care in prisons (NP) and searches on institutional repositories.

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Chapter 3 Methods and description of included materials

This chapter describes the methods used in this evidence synthesis, and the materials finally included. At the commencement of the project a protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO CRD42018108988).[67] The synthesis was conducted with the co-investigator involvement of an expert from the Cardiff Specialist Unit for Review Evidence (SURE). It followed guidance for undertaking reviews in health care published by the Centre for Reviews and Dissemination[68] and in incorporating stakeholder views and non-research material used methods informed by the EPPI-Centre.[4] To ensure rigour, the review is reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.[69] Factors facilitating and hindering high-quality EoL care for people with SMI were identified, as was evidence relating to services, processes, interventions, views and experiences.

Aims and objectives

The aim of this project was to synthesise relevant research and other appropriate evidence relating to the organisation, provision and receipt of EoL care for people with SMI (including schizophrenia, bipolar disorder and other psychoses, major depression and personality disorder). Specifically, it answered the following question: what evidence is there relating to the organisation, provision and receipt of care for people with SMI who have an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months?

The specific objectives were to:

1. use internationally recognised, transparent literature review approaches to locate, appraise and synthesise the relevant research evidence relating to the organisation, provision and receipt of care in the expected last year of life (LYoL) for people with SMI who have additional diagnoses of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months
2. locate and synthesise policy, guidance, case reports and other grey and non-research literature relating to the organisation, provision and receipt of care in the expected LYoL for people with SMI who have additional diagnoses of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months
3. produce outputs with clear implications for service commissioning, organisation and provision
4. make recommendations for future research designed to inform service improvements, guidance and policy.

Inclusion criteria

Types of participants

This evidence synthesis considered all relevant evidence specifically relating to adult participants (> 18 years of age) with SMI who have an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months. SMI was defined as including but not limited to schizophrenia, schizophrenia spectrum and other psychotic disorders, schizotypal and delusional disorders, bipolar affective disorder, bipolar and related disorders, major depressive disorder and disorders of adult personality and behaviour.

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Types of intervention and phenomena of interest

All citations were considered that addressed service organisation and the provision and receipt of EoL care for people with SMI who have an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months. Citations reporting the views and experiences of service users, families and health and social care staff were also included.

Context

All citations were considered with regard to organisation, provision and receipt of EoL care provided in hospitals, hospices and other institutional settings (e.g. care homes, prisons and hostels) and care provided in the home and via outreach to people who may also be homeless.

Types of evidence

Types of evidence sought included quantitative research, qualitative research and non-research material (e.g. policies, guidelines, reports of practice initiatives and clinical case studies). Searches were conducted for UK-only grey literature, including policies, guidance and related information, in recognition of the fact that the primary audience of decision-makers interested in the study's key findings and implications is likely to be UK based. Materials published in the English language since the inception of databases were considered.

Exclusion criteria

- As confirmed in a first combined project team and SAG meeting, where reporting allowed the distinction to be made, evidence relating to mental health problems (e.g. depression) as a consequence of terminal illness (e.g. cancer or chronic organ failure).
- Evidence relating to EoL care for people with mental and behavioural disorders due to psychoactive substance use, except where these coexisted with SMI as specified above.
- Evidence relating to EoL care for people with dementia or other neurodegenerative diseases, except where these coexisted with SMI as specified above.
- Evidence from animal studies.

Developing the search strategy

The focus of the search strategy was to achieve high sensitivity and specificity for retrieving studies relevant to the review question. The search strategy was comprehensive and designed to ensure that all relevant literature was obtained, with the precise emphasis on concepts associated with the research question discussed in the first combined project team and SAG meeting, described in *Chapter 2*. Although some terminology remains equivocal in this area, the search strategy as it became finalised was designed to identify all relevant evidence relating to EoL care (i.e. in the LYoL) in those with SMI. Reflecting the importance of diagnosis in the framework definition of SMI,[9] diagnostic terms included in the search strategy included schizophrenia, schizophrenia spectrum and other psychotic disorders, schizotypal and delusional disorders, bipolar affective disorder, bipolar and related disorders, major depressive disorder and disorders of adult personality and behaviour. Reflecting prevailing definitions of SMI (e.g. as used by the NIHR Dissemination Centre[11]), searches were not made for studies into mental and behavioural disorders due to psychoactive substance use or for studies into dementia or other neurodegenerative diseases, and items in these areas were not included in the review, except where participants' diagnoses co-existed with the disorders included above.

Preliminary searching

Preliminary database searching using MEDLINE was carried out as part of initial scoping undertaken in preparation of the proposal for funding, with material from this drawn on in *Chapter 1*. The preliminary keywords that were used to inform these searches included the following:

> Palliative care OR Hospice care OR Terminal care OR Terminally ill OR End of life care OR Last year of life
>
> AND
>
> Neoplasms OR Cancer OR heart failure, lung failure, liver failure or renal failure
>
> AND
>
> Mental health OR Depression OR Mental disorders OR Depressive disorder OR Personality disorders OR Bipolar disorder OR Schizophrenia OR Mental illness

An analysis of the text words contained in the titles and abstracts, and of the index terms used to describe each article, was undertaken. As a result of this, the search strategy was further developed, and in July 2018 the opportunity was undertaken to update and extend the preliminary scoping exercise across four databases. These were, on Ovid, MEDLINE® ALL, MEDLINE Epub Ahead of Print, In-Process and Other Non-Indexed Citations, PsycInfo and EMBASE. The MEDLINE search can be found in *Appendix 9*.

Comprehensive searching

A comprehensive search strategy was developed by Mala Mann following discussion at the first combined project team and SAG meeting (see *Chapter 2*). This search strategy was initially developed for MEDLINE (see *Appendix 10*) and PsycInfo (see *Appendix 11*). As a means of testing and refining this search strategy before applying it across multiple databases, Deborah Edwards first screened the citations retrieved across MEDLINE and PsycInfo to ensure relevance and to assess that the strategy was neither too broad nor too narrow. Once the project team was satisfied with the search strategy, this was tailored to the remaining eight databases, with searches run from each database's inception. Databases searched included:

- on the Ovid platform – MEDLINE ALL, EMBASE, HMIC (Health Management Information Consortium), PsycInfo and AMED (Allied and Complementary Medicine Database)
- on the EBSCO*host* platform – CINAHL (Cumulative Index to Nursing and Allied Health Literature) and CENTRAL (Cochrane Central Register of Controlled Trials)
- on the ProQuest platform – ASSIA (Applied Social Sciences Index and Abstracts)
- others – DARE (Database of Abstracts of Reviews of Effects) and the Web of Science.

Supplementary searches were undertaken to identify additional papers, information on studies in progress, unpublished research, research reported in the grey literature and personal blogs. Members of the SAG advised the project team as to which relevant websites to search (see *Chapter 2*), and a full list of websites searched along with the search terms utilised can be found in *Appendix 12*. Members of the SAG were also asked to inform the research team of any other publications of which they were aware that they thought might be relevant to the review. The principal investigator (BH) and the project manager (DE) followed a number of key EoL and mental health authors and organisations on Twitter (Twitter, Inc., San Francisco, CA, USA) to identify any material that could be potentially relevant to the evidence synthesis.

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Searches were also conducted using Google (Google Inc., Mountain View, CA, USA), as described by Mahood *et al.*[70] The first 10 pages of each Google output were screened using the following terms:

- "palliative care" and "mental illness"
- "end of life" and "mental illness"
- "end of life" and schizophrenia (searching the first five pages of output)
- "end of life" and bipolar (searching the first five pages of output).

To identify published resources that had not yet been catalogued in electronic databases, recent editions of the *Journal of Pain and Symptom Management*, *Cancer*, *Psycho-Oncology* and *BMJ Supportive & Palliative Care* were hand searched. These journals were selected because a large number of outputs identified in database searches had been published in them. Reference lists of included studies were scanned and forward citation tracking was performed using the Web of Science.

Primary research citations retrieved from database searches

All citations retrieved from the 10 database searches were imported or entered manually into EndNote™ (Thomson Reuters, CA, USA) and duplicates were removed. The total numbers of hits retrieved for each database are displayed in *Table 1*.

Primary research citations identified from supplementary searching

All primary research citations identified as potentially relevant from across all supplementary sources (*Table 2*) were entered manually into EndNote. A total of 128 citations were identified.

TABLE 1 Number of citations retrieved by database

Database	Search interface	Hits
AMED	Ovid	196
ASSIA	ProQuest	836
CINAHL	EBSCO*host*	361
CENTRAL	Wiley	958
DARE	CRD	263
EMBASE	Ovid	7033
HMIC	Ovid	39
MEDLINE all[a]	Ovid	1302
PsycINFO	Ovid	663
Web of Science	Clarivate Analytics	125
Total		11,776

CRD, Centre for Reviews and Dissemination.
a Includes MEDLINE e-publications.

TABLE 2 Number of citations retrieved from supplementary searching

Source	Number of citations
Reference lists of included studies	88
Forward citation tracking of included studies	15
Twitter	4
Google	8
SAG	2
Trial registers	0
Hand-searching	11
Total	128

Removing irrelevant citations

Once all of the primary research citations had been imported into EndNote, irrelevant citations were removed by searching for keywords in the title using the search feature of the EndNote software. The project team had previously agreed which keywords to use to identify papers that did not meet the review's inclusion criteria. All hits for each keyword were screened by Deborah Edwards to ensure that they were, in fact, irrelevant before they were removed. The following keywords were used:

- Abuse/substance
- Adolescence/adolescent/youth
- AIDS/HIV
- Alcohol
- Anxiety
- Assessment
- Bereav*
- Bipolar diathermy/electrocautery
- Book review
- Child
- Dementia/Alzheimer's
- Depression
- Diabetes
- Diagnos*
- Fatigue
- Grief
- Incidence
- Instrument/tool
- Letter
- Neonate/neonatal
- Parent
- Predict*
- Prevalence
- Prognosis/prognostic
- Psychometric
- Scale
- Screen*
- Sleep/insomnia

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- Smoking/tobacco
- Spiritual/religious
- Survival
- Thesis
- Validity/reliability/validation
- Version.

At the end of this process, the remaining citations were exported as an XML file and then imported into the software package Covidence™ (Melbourne, VIC, Australia).

Title and abstract screening

All citations were independently assessed for relevance by two members of the review team using the information provided in the title and abstract using Covidence. Disagreements were resolved through discussion with a third reviewer, and, where needed for further clarity, the full text was retrieved to aid this discussion. Particular care was taken with citations referencing people experiencing depression. Depression is a commonly experienced mental health problem, but it is also one that can manifest as a severe mental health problem, requiring an urgent and potentially life-saving intervention. As our focus was on EoL care for people with pre-existing SMI, we excluded citations reporting on prior experiences of mild depression, and excluded items reporting on the identification of depression and its treatment among people who had experienced psychological distress subsequent to their EoL diagnosis. Only citations clearly reporting on EoL care for people who had pre-existing severe depression were included.

For citations that appeared to meet the inclusion criteria, or in cases in which a definite decision could not be made based on the title and/or abstract alone, the full texts of all citations that appeared to meet the review's inclusion criteria by title and abstract screening were retrieved.

Full-text screening

To achieve a high level of consistency, two reviewers screened each retrieved citation for inclusion using a purposely designed form (see *Appendix 13*). Disagreements were resolved through discussion with a third reviewer. All English-language items relating to the provision of EoL care to and the receipt of EoL care by people with SMI and an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure were included at this stage. The flow of citations through each stage of the review process is displayed in the PRISMA flow chart in *Figure 1*.[69]

Grey literature identified from supplementary searching

Sixty-eight grey literature citations were identified as potentially relevant from across all supplementary searches (*Table 3*), and these were all entered manually into EndNote. Policies and guidance, reports and other non-research materials found in the grey literature were also read by two members of the project team and considered against the topic inclusion criteria, with disagreements resolved as above. Forty were excluded (see *Appendix 15*), leaving a total of 28 that were assessed as relevant to the review (see *Appendix 16*). A test search for relevant information in renal-specific documents produced no material suitable to be included in the review. The decision was therefore made by the project team not to search within (the large number of) disease-specific policy and guidance documents for material concerned with the management of EoL care for people also with SMI.

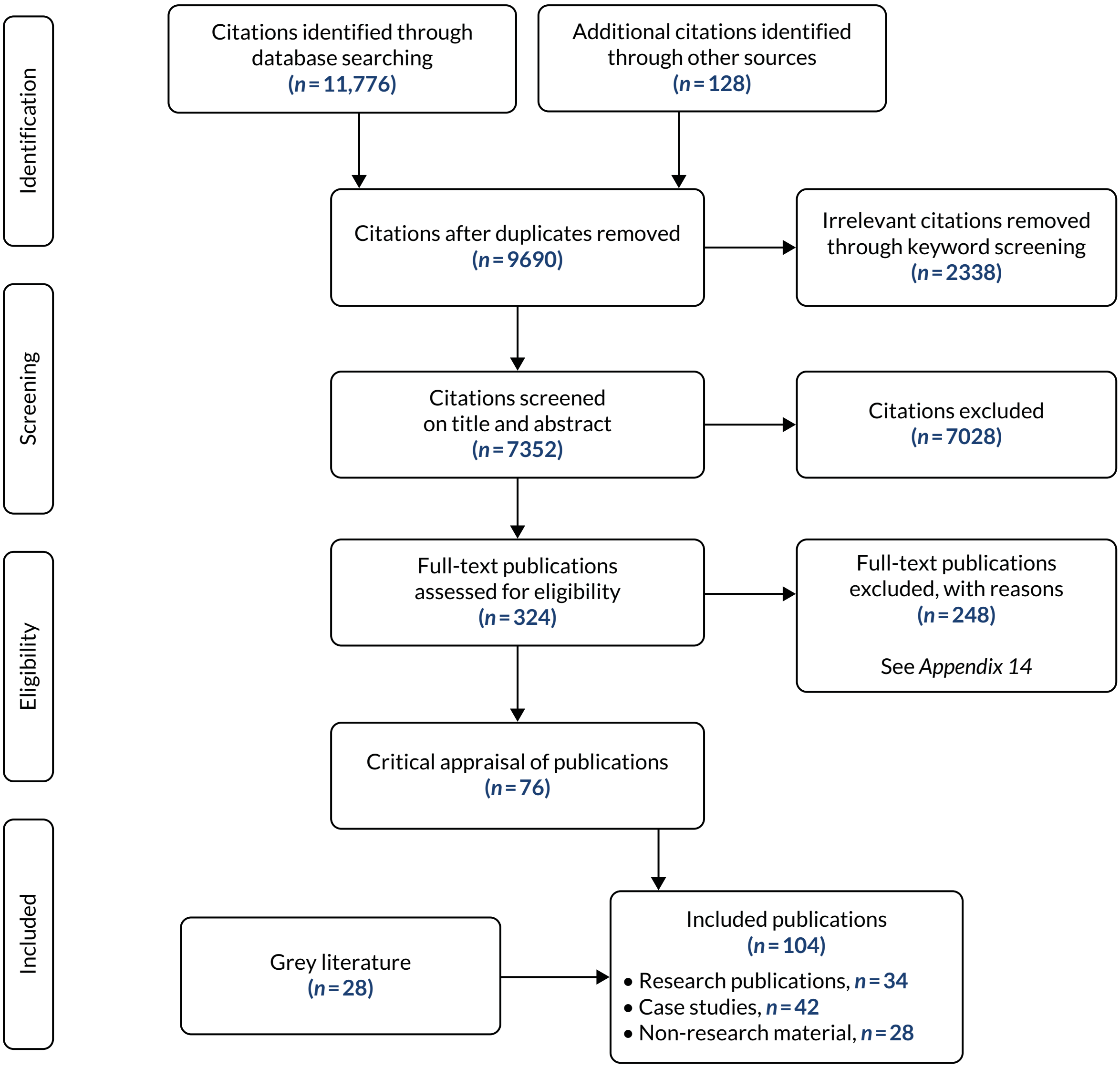

FIGURE 1 The PRISMA flow chart. Reproduced with permission from Edwards *et al.*[71] © The Author(s) 2021 This article is distributed under the terms of the Creative Commons Attribution 4.0 License (https://creativecommons.org/licenses/by/4.0/) which permits any use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage).

TABLE 3 Number of pieces of grey literature retrieved from supplementary searching

Source	Number of citations
Organisation websites	47
SAG	16
Google	3
E-mail alert for HQIP	1
Reference lists of included studies	1
Total	68

HQIP, Healthcare Quality Improvement Partnership.

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Materials included in evidence synthesis

One hundred and four publications were included in the evidence synthesis, which consisted of research publications ($n = 34$), case studies ($n = 42$) and non-research policy and guidance material ($n = 28$).

Terminology and language use

Language is important (and sometimes contentious), and, as described in *Chapter 2*, *Defining the project's parameters: 'severe mental illness' and 'end of life' (and related)*, the variety of terms used in the mental health and EoL fields and in the materials included in this synthesis were recurring items at combined project team and SAG meetings. Across the items located and included in the synthesis, no agreed definitions could be discerned relating to the precise meanings of SMI or the content of EoL care or palliative care. Specialist palliative care could refer, particularly in the UK context, to care provided in any setting (hospice, home, care home or hospital) by a dedicated specialist team with additional education and skills in palliative care that enables them to support those at the EoL with any diagnosis who have complex, high-level needs, whatever the cause. Palliative care, however, could refer to care provided by all HCPs to those who are at the EoL (across all care settings) and do not have the additional complex needs that require additional specialist support. This clinical distinction may be similar across many countries with similarly developed health systems (e.g. the USA, Australia and Canada), but, in each case, the project team, having finalised the materials to include, noted the existence of different funding and organisational arrangements and varying standards for eligibility to access services. Discussion also took place between project team and SAG members on the language to be used in this report to describe people with SMI at the EoL. In recognition of people's receipt of (or need for) integrated care crossing mental health and palliative care system boundaries, a decision was made at the third combined project team and SAG meeting to use the word 'patient'.

Quality appraisal

Following searching and screening, information from research and case study publications was assessed independently for methodological quality by two reviewers using one of a number of agreed appraisal checklists. Alternative tools, which reflected the specific design and methods used in individual research outputs, were used as necessary when suitable Critical Appraisal Skills Programme (CASP) tools were not available. Any disagreement on quality was resolved through discussion with a third reviewer. No research items were judged to have been fatally flawed, and all were included. The policy and guidance documents and non-research reports were not subject to quality appraisal.

For qualitative studies, the appropriate checklist available from CASP was used.[72] For cross-sectional designs, the Specialist Unit for Review Evidence 12-item checklist[73] (with responses 'yes', 'no', 'can't tell') was used and an overall score reflecting the number of items answered 'yes' was generated.

Retrospective cohort studies were appraised using the Scottish Intercollegiate Guidelines Network's *Methodology Checklist 3: Cohort Studies*.[74] This is a 14-item checklist (with responses 'yes', 'no', 'can't say' and 'does not apply'). Six items do not apply to this type of study design (statements 1.3, 1,4, 1,5, 1.6, 1.8 and 1.12). The overall assessment reflects how well a study has sought to minimise the risk of bias or confounders. The final rating is high quality (++), acceptable (+) or low quality (–).

- *High quality (++): Majority of criteria met. Little or no risk of bias. Results unlikely to be changed by further research.*
- *Acceptable (+): Most criteria met. Some flaws in the study with an associated risk of bias. Conclusions may change in the light of further studies.*

- *Low quality (–): Either most criteria not met, or significant flaws relating to key aspects of study design. Conclusions likely to change in the light of further studies.*

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As retrospective designs are generally regarded as weaker, the authors of the checklist suggest that these should not receive a rating higher than '+'.

For case studies, the Joanna Briggs Institute critical appraisal checklist for case reports was used.[75] This is an eight-item checklist (with responses 'yes', 'no', 'unclear', 'not applicable') from which an overall score is generated reflecting the number of items answered 'yes'.

Data extraction

All demographic data from the 76 research and case study publications were extracted directly into tables based on study design (see *Appendices 17–20*), following the format recommended by the Centre for Reviews and Dissemination.[68] The work was allocated to a member of the research team who extracted the relevant data, and a second reviewer (DE) independently checked the data extraction forms for accuracy and completeness. A record of corrections was kept. Where multiple publications from the same study were identified, data were extracted and reported as if from a single study.

Data analysis and synthesis

Following discussion at the second of the three combined project team and SAG group meetings, the decision was made to conduct a first analysis and synthesis for the combined research studies ($n = 34$) and policy and guidance documents ($n = 28$), and a second analysis and synthesis for the case studies ($n = 42$). The project protocol stated an intention to perform meta-analyses of data for included intervention studies. However, no intervention studies were found. All synthesised findings are therefore presented as narrative syntheses in *Chapters 4* and *5*.

All research papers were available in full-text form, and each was uploaded to a project created using the software package NVivo 12 (QSR International, Warrington, UK). All policy and guidance documents were available as electronic documents, and the content of each was searched using keywords relevant to the review ('mental illness' and 'end of life'). Data retrieved in this way were extracted and entered verbatim into Microsoft Word (Microsoft 365 Apps for Enterprise; Microsoft Corporation, Redmond, WA, USA) documents, one for each policy and guidance item. Microsoft Word files containing the extracted data were then uploaded to the same NVivo project as the research items in preparation for analysis. All case studies were available in full-text form and were uploaded to a second NVivo project.

A thematic approach was employed to analyse and synthesise both sets of data,[76] with work on the combined research and policy data set led jointly by Ben Hannigan and Deborah Edwards and work on the case study data set led by Michael Coffey. Using NVivo, in both cases inductive data-driven codes were generated and attached to segments of material through the line-by-line reading of documents. To aid discussion and refinement, and to support a visual appreciation of the overall character of the developing research and policy synthesis, codes and their relationships to each other were also reproduced on large sheets of display paper. In both thematic syntheses, codes were grouped into meaningful candidate themes (and, in the case of the research and policy synthesis, subthemes) reflecting the material being synthesised

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and the overarching objectives of the project.[4] These were shared with all members of the project team for review and further refinement, with no major disagreements noted. Themes and subthemes were then tabled at the third combined project team and SAG meeting, where the overarching thematic structure of both syntheses was discussed and approved. Both syntheses aimed to bring together reports of approaches to service organisation, processes and interventions shown to both facilitate and hinder the provision of high-quality, accessible, equitable and acceptable EoL care to people with SMI. The reporting of the separate analysis and synthesis of the combined research, policy and guidance items is contained in *Chapter 4*, and the reporting of the analysis and synthesis of the case study items is contained in *Chapter 5*. *Figure 6* in *Chapter 6* provides a visual overview of both thematic syntheses as a whole.

Assessing confidence

The assessment of the quality of evidence for retrospective cohort studies was conducted using the GRADE (Grading of Recommendations, Assessment, Development and Evaluation) approach,[77] and was conducted by Deborah Edwards and checked by Ben Hannigan. This approach rates the quality of a body of evidence as 'high', 'moderate', 'low' or 'very low' (*Figure 2*).[77] Explicit criteria, including study design, risk of bias, impression, inconsistency, indirectiveness and magnitude of effect, are used. As the studies retrieved for this evidence synthesis were observational as opposed to interventional, the initial quality of the body of evidence overall started off as low.[78] When the evidence base was rated specifically on study design (in particular retrospective cohort studies), this led to the ratings for all evidence generated using material from these types of study being downgraded from 'low quality' to 'very low quality'.

The strength of the synthesised qualitative and non-intervention findings was assessed using the CERQual (Confidence in the Evidence from Reviews of Qualitative Research) approach,[79] and this was again led by Deborah Edwards and Ben Hannigan. The original CERQual approach was designed for qualitative findings, but in this project a process previously used by members of the research team in HSDR 11/1024/08[80] and in HSDR 08/1704/211[81] was used. This approach involved using CERQual for the additional purpose of assessing confidence in findings synthesised from surveys and other non-intervention quantitative studies. The confidence in individual synthesised review findings is based on the assessment of four components: coherence, methodological limitations, relevance and adequacy. Overall assessments of confidence are then described using four levels – high, moderate, low or very low – as summarised in *Figure 3*, which draws on and adapts material previously published.[82]

High quality	Further research is very unlikely to change our confidence in the estimate of effect
Moderate quality	Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate
Low quality	Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate
Very low quality	Any estimate of effect is very uncertain

FIGURE 2 The GRADE quality of evidence and definitions. Reproduced from GRADE: an emerging consensus on rating quality of evidence and strength of recommendations, Guyatt G, Oxman AD, Vist GE, Kunz R, Falck-Ytter Y, Alonso-Coello P, *et al.*, volume 336, pp. 924–6, 2008, with permission from BMJ Publishing Group Ltd.[77]

High confidence	Highly likely that the review finding is a reasonable representation of the phenomenon of interest	⇧ ⇧
Moderate confidence	Likely that the review finding is a reasonable representation of the phenomenon of interest	⇧ ⇩
Low confidence	Possible that the review finding is a reasonable representation of the phenomenon of interest	⇩ ⇩
Very low confidence	Not clear whether the review finding is a reasonable representation of the phenomenon of interest	⇩ ⇩
Coherence	An assessment of how clear and cogent the fit is between the data from the primary studies and the review finding	
Methodological limitations	The extent to which there are concerns about the design or conduct of the primary studies supporting a reviewing finding	
Relevance	The extent to which the body of data from the primary studies supporting a review finding is applicable to the context specified in the review question	
Adequacy	The degree of richness and quantity of data supporting a review finding	

FIGURE 3 The CERQual: applying high, moderate, and low confidence to evidence. Reproduced with permission from Lewin *et al.*[82] This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The Creative Commons Public Domain Dedication waiver (https://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated. The figure includes minor additions and formatting changes to the original figure.

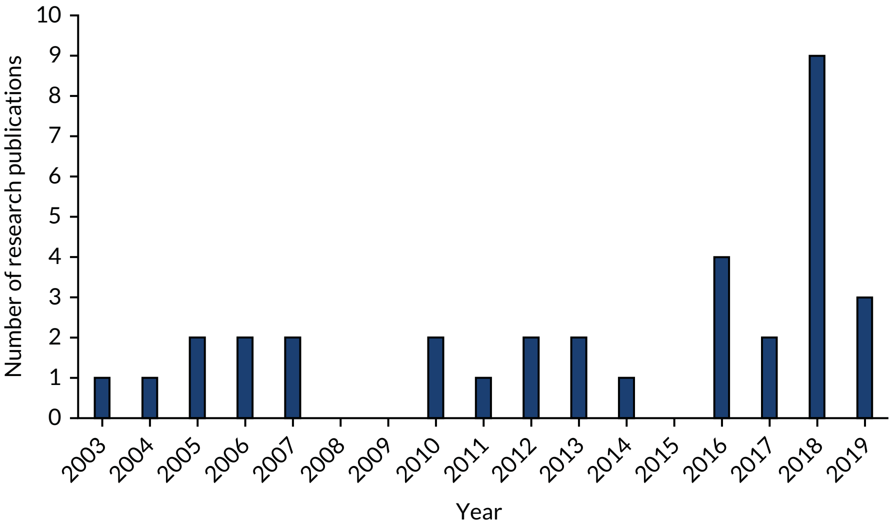

FIGURE 4 Histogram of year of publication of research studies.

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Description of research studies

Thirty-four publications covering 30 research studies were deemed suitable for inclusion in the review: 19 quantitative studies (reported across 21 publications), nine qualitative studies (reported across 11 publications) and two mixed-methods studies. Demographic information on the characteristics of included research studies is given in *Appendices 17–20*.

Country of research

Data were retrieved from 10 countries: the USA ($n = 12$, across 13 publications[32,83–94]), Canada ($n = 4$, across five publications[95–99]), New Zealand ($n = 1$[100]), Taiwan (Province of China) ($n = 1$[101]), Australia ($n = 4$, across six publications[102–107]), France ($n = 1$[108]), Belgium ($n = 1$[109]), the Netherlands ($n = 2$[109–111]), the UK ($n = 3$[37,112,113]) and the Republic of Ireland ($n = 1$[114]).

Year of publication

Figure 4 displays the year of publication of the 34 research study publications.

Study designs and methods

Among the quantitative studies, 12 studies (across 13 publications) were retrospective cohort studies,[84,88–92,95,97,98,100,101,107,108] seven studies (across eight publications) were descriptive surveys[83,85–87,93,94,96,111] and nine studies (across 11 publications) used a qualitative design.[32,37,99,102–106,109,112,113] Among the qualitative studies, five studies (across seven publications) were described as using a non-specific qualitative descriptive approach,[102–106,112,113] two utilised grounded theory,[37,109] one used ethnography[99] and one used phenomenology.[32] Specific methods used to collect qualitative data included interviews ($n = 6$,[32,37,102–106,109] across eight publications), focus groups ($n = 1$[112]), a combination of interviews and focus groups ($n = 1$[113]) and a combination of observation and interviews.[99] One mixed-methods study consisted of a retrospective review of patients' medical records and a post-test evaluation of educational/training initiatives with HCPs, descriptive surveys and non-specific qualitative descriptive approaches using interviews.[110] The other mixed-methods study consisted of a descriptive survey and a qualitative descriptive approach using interviews.[114]

Settings

The settings in which research studies were undertaken were described as follows: specialist palliative care services;[100] palliative care consultation services;[93] acute and psychiatric care;[85,108] Veterans Administration medical centres/nursing homes;[83,88,90] all medical care covered by one insurance company;[101] acute care;[91,92,96] all hospital and community based palliative care ($n = 2$ studies, across three publications);[95,97,107] homeless/vulnerably housed;[99,113] shelter-based hospice for the homeless;[98] general practices and psychiatric practices;[114] nursing/care homes;[84,111] mental health and hospice/palliative care services[32,94,112] including community, residential homes, supported accommodation and psychiatric hostels;[106] mental health services (hospital and/or community based) ($n = 5$ studies, across eight publications);[86,87,102–105,109,111] hospices;[37] and not stated.[89]

Participant characteristics

In 11 studies (across 12 publications) participants were decedents (people who had died) who were described as having had a diagnosis of severe and persistent mental illness,[100] schizoaffective disorders,[88,95,97,101,107,108] a pre-existing psychiatric illness,[91] a mental health diagnosis,[89] pre-cancer depression[92] or PTSD.[90] One further study explored the views of family members of decedents who had PTSD.[83]

Seven studies (across eight publications) directly involved patients and included:

- residents in a nursing home with schizophrenia, bipolar disorder, or other psychosis[84]
- homeless patients admitted to a shelter-based hospice with a range of mental health diagnoses[98]

- homeless or vulnerably housed individuals (inferred that some would have had a mental health diagnosis) who were on a palliative trajectory and their support workers and formal service providers[99]
- current or previous homeless individuals (inferred that some would have had a mental health diagnosis) and their health and social care providers, hostel and outreach staff[113]
- adults with schizophrenia or other psychosis, mood disorders (major depression and bipolar disorder), personality disorders or PTSD who were receiving community-based services[86,87]
- patients with severe and persistent mental illness[96] or schizophrenia[109] who were not at the EoL, but the study focused on future care preferences.

The remaining 12 studies (across 14 publications) were conducted with HCPs who worked with patients with SMI at EoL[32,37,85,93,94,102–106,110–112,114] and these included mental health HCPs,[85,102–104] EoL HCPs,[37] mental health and EoL HCPs,[32,94,106,112] psychiatrists[105,114] and general practitioners (GPs).[114]

Terminal or chronic condition/s or cause of death

A large number of research studies ($n = 16$, across 19 publications[32,37,83–87,93,94,99,100,102–105,109,111,112,114]) explored the perspectives of HCPs who cared for those with SMI at EoL and as a result did not refer to any specific terminal or chronic condition. The remaining studies reported cause of death ($n = 6$ studies across seven publications[88,95,97,98,101,108,110]), terminal condition(s) ($n = 6$[89,90,92,96,106,113]) or chronic condition(s) ($n = 2$[91,107]) and included the following:

- cancer ($n = 10$ studies, across 11 publications)[88–91,95,97,98,101,107,108,110]
- chronic obstructive pulmonary disease/chronic lower respiratory disease/chronic pulmonary disease ($n = 5$[90,91,98,107,110])
- liver failure/chronic liver disease ($n = 4$[90,91,107,110])
- congestive heart failure/chronic heart disease ($n = 4$[89–91,107])
- chronic renal disease ($n = 3$[90,91,107])
- advanced life-limiting illness ($n = 2$[106,113])
- chronic medical illness ($n = 1$[96]).

Definition of end-of-life time frame

Eleven studies predefined the time frame over which they measured the outcomes of interest at the EoL, which were within 1 month of death,[91,92,101] within 6 months of death,[88,95,97] within 12 months of death[100,107] and in the last 7 days of life.[89]

Description of case studies

Forty-two publications consisted of 51 case studies of individuals who had an existing mental illness diagnosis and who went on to develop an EoL condition (see *Appendix 20*). In four case studies the purpose of the paper was to show the application of a particular model of care, such as dynamic system analysis[115] or stepwise psychosocial palliative care.[116,117] Most of the case studies were published in peer-reviewed research journals ($n = 38$), along with two conference abstracts,[118,119] one that appeared in a report[120] and one that was in a first-person-account blog.[121] The case studies ranged in depth from discursive papers with little direct detail about the individuals involved, to those that focused mainly on the patient's or patients' physical illness and a substantive number that discussed issues of mental capacity and the ability of the person to express their choice to accept, refuse or abandon treatments.

Country of research

The majority of case study papers were published in the USA ($n = 28$[26,116,117,121–145]); followed by the UK ($n = 4$[120,146–148]), Canada ($n = 3$[149–151]), Australia ($n = 1$[15]), France ($n = 1$[152]), Israel ($n = 1$[153]), Mexico ($n = 1$[119]), the Netherlands ($n = 1$[115]) and Singapore ($n = 1$[154]), with one conference abstract not stating the country in which the case study was located.[118]

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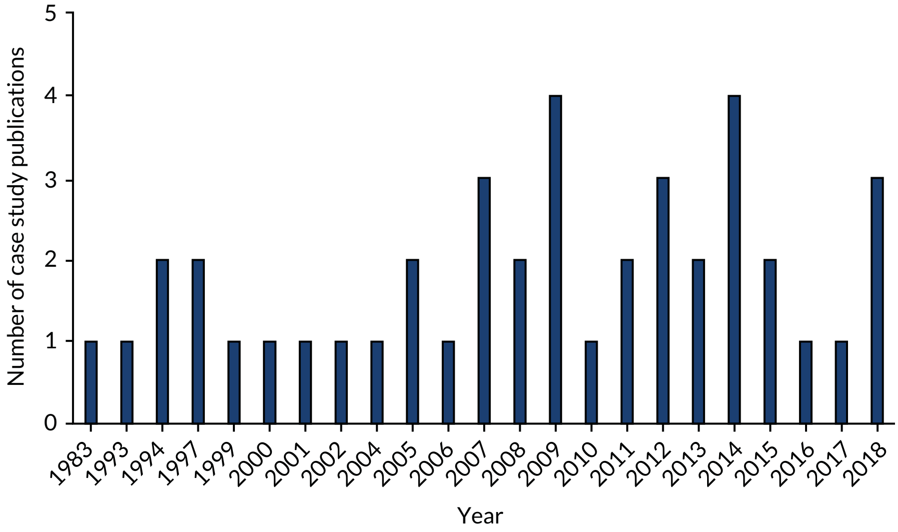

FIGURE 5 Histogram of year of publication of case studies.

Year of publication

The earliest case study was published in 1983[133] and outputs appeared regularly up until the end of the search period in 2019.[118,119,150] *Figure 5* displays the year of publication of the 42 research study publications.

Attributes of service users

The case studies outlined, sometimes in very sparse detail, the individual attributes of the people with pre-existing mental health problems who were in the EoL trajectory. The age range across the case studies was 20–91 years (mean age 55 years) and was provided in all except two of the studies.[121,143] Women were the focus of 24 case studies. Diagnosis was reported for all case study individuals and included psychotic-type diagnoses (schizophrenia, psychosis, schizoaffective and bipolar conditions) (31 publications reporting 35 case studies[15,26,115,118–121,124,127–130,132,133,135–147,149–154]), personality disorder (five publications reporting five case studies[122,123,125,131,132]), PTSD (three publications reporting

TABLE 4 Critical appraisal scores for cohort studies

Study (authors and year)	Q1	Q2	Q7	Q9	Q10	Q11	Q13	Q14	Overall assessment
Butler and O'Brien 2018[100]	Y	Y	Y	Y	Y	Y	Y	N	Acceptable
Chochinov *et al.* 2012;[95] Martens *et al.* 2013[97]	Y	Y	Y	Y	Y	Y	Y	Y	Acceptable
Ganzini *et al.* 2010[88]	Y	Y	Y	Y	Y	Y	N	N	Acceptable
Huang *et al.* 2017[89]	Y	Y	Y	Y	Y	Y	Y	N	Acceptable
Huang *et al.* 2018[101]	Y	Y	Y	Y	Y	Y	Y	Y	Acceptable
Lavin *et al.* 2017[91]	Y	Y	Y	Y	Y	Y	Y	N	Acceptable
McDermott *et al.* 2018[92]	Y	Y	Y	Y	Y	Y	Y	Y	Acceptable
Podymow *et al.* 2006[98]	Y	Y	Y	Y	Y	Y	N	N	Acceptable
Spilsbury *et al.* 2018[107]	Y	Y	Y	Y	Y	Y	N	N	Acceptable
Fond *et al.* 2019[108]	Y	Y	Y	Y	Y	Y	Y	Y	Acceptable
Cai *et al.* 2011[84]	Y	Y	Y	Y	Y	Y	Y	Y	Acceptable
Kelley-Cook *et al.* 2016[90]	Y	Y	Y	Y	Y	Y	Y	N	Acceptable

N, no; Q, question; Y, yes.

three case studies[116,117,126]) and anorexia nervosa ($n = 2$[134,148]). In the papers discussing the individuals with anorexia, the EoL condition was a direct result of that condition, leading to chronic fractures and organ failure.[134,148] These are then two outliers in that the EoL condition was a direct result of the mental health issue for those individuals. The vast majority of EoL conditions presented in the case study papers were cancer-related diagnoses, and organ failure [heart ($n = 3$ (across four publications[115,126,129,130]), liver ($n = 1$[122]) and kidney ($n = 5$[131,139,146,150,154])] made up the remainder.

Results of quality appraisal

Critical appraisal scores for cohort studies

The methodological quality of each of the 12 cohort studies was judged against the relevant eight quality criteria derived from the Scottish Intercollegiate Guidelines Network's *Methodology Checklist 3: Cohort Studies* checklist,[74] and each study is summarised in *Table 4*. All the studies were judged to be of acceptable quality, indicating that some flaws in the study design were present, with an associated risk of bias. Seven studies did not provide confidence intervals (CIs) as part of the statistical analysis.[88–91,98,100,107]

Critical appraisal scores for descriptive surveys

The methodological quality of seven descriptive studies and the survey component of two mixed methods studies[110,114] were judged against the 12 quality criteria used in the SURE tool, and each study is summarised in *Table 5*. The authors of one study, reported in two companion papers,[86,87] did not state the type of study that they had undertaken and were reporting on, but from the description of the methods this was classified as a quantitative descriptive project and, thus, was included in this section with other studies of this type. The quality of 9 of these 11 descriptive studies was high, with all nine meeting either 11 or all 12 criteria. The quality of the other two studies was significantly lower, with either the majority of quality criteria not being met or the account in the published paper being unclear.[85,94]

Critical appraisal scores for qualitative studies

The methodological quality of each of the nine qualitative studies and the qualitative component of two mixed-methods studies[110,114] were judged against the 10 quality criteria used in the CASP qualitative checklist,[72] and each study is summarised in *Table 6*. In the case of two studies,[106,113] the authors did not include a description of the type of study conducted, but from the description of the methods used these were classified as examples of qualitative descriptive studies. The quality of these 11 studies was high, with all bar one[106] of the studies meeting at least 9 of the 10 quality criteria.

TABLE 5 Critical appraisal scores for descriptive studies

Study (authors and year)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12
Alici *et al.* 2010[83]	Y	Y	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Elie *et al.* 2018[96]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Evenblij *et al.* 2016[110]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Evenblij *et al.* 2019[111]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Foti 2003[85]	Y	Y	Y	U	N	Y	N	N	N	N	N	N
Foti *et al.* 2005;[87] Foti *et al.* 2005[86]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Patterson *et al.* 2014[93]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sheridan *et al.* 2018[114]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Taylor *et al.* 2012[94]	Y	Y	N	N	U	N	N	N	N	N	Y	N

N, no; Q, question; U, unclear; Y, yes.

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TABLE 6 Critical appraisal scores for qualitative studies

Study (authors and year)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Evenblij *et al.* 2016[110]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hackett and Gaitan 2007[37]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jerwood 2018[112]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
McGrath and Forrester 2006;[104] McGrath and Holewa 2004;[102] McGrath and Jarrett 2007[103]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
McKellar *et al.* 2015[105]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
McNamara *et al.* 2018[106]	Y	Y	Y	U	Y	N	Y	Y	Y	Y
Morgan 2016[32]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Sheridan *et al.* 2018[114]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Shulman *et al.* 2018[113]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Stajduhar *et al.* 2019[99]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sweers *et al.* 2013[109]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

N, no; Q, question; U, unclear; Y, yes.

Critical appraisal scores for case studies

The methodological quality of each case study was judged against the eight quality criteria used in the Joanna Briggs Institute case report checklist,[75] and each study is summarised in *Table 7*. As this shows, the quality of the studies varied overall. Twenty-five of the 42 case studies met either seven or all eight criteria; the single criterion missing from the majority of papers in this group related to the description of diagnostic tests or assessment methods and their results. Eight of the 42 studies met half or fewer of the eight quality criteria, but for the purposes of inclusivity all 42 studies were included in the subsequent narrative synthesis (see *Chapter 5*).

TABLE 7 Critical appraisal scores for case studies

Study (authors and year)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Score
Ang *et al.* 2009[154]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Badger and Ekham 2011[122]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Bakker 2000[115]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Boyd *et al.* 1997[123]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Cabaret *et al.* 2002[152]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Candilis and Foti 1999[124]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Clements-Cortes 2004[149]	Y	Y	Y	N	Y	Y	N	Y	6/8
Doron and Mendlovic 2008[153]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Feely *et al.* 2013[125]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Feldman and Petriyakoil 2006[126]	Y	U	Y	N	N	Y	Y	N	4/8
Feldman *et al.* 2014[116]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Feldman *et al.* 2017[117]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Geppert *et al.* 2011[127]	Y	Y	Y	Y	Y	Y	Y	Y	8/8

TABLE 7 Critical appraisal scores for case studies (*continued*)

Study (authors and year)	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Score**
Gonzelez *et al.* 2009[128]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Griffith 2007[129]	Y	Y	N	Y	Y	Y	Y	Y	7/8
Griffith 2007[130]	Y	Y	N	Y	Y	Y	Y	Y	7/8
Hill 2005[131]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Irwin *et al.* 2014[26]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Kadri *et al.* 2018[150]	Y	N	Y	N	Y	N	Y	Y	5/8
Kennedy *et al.* 2013[120]	Y	U	Y	N	Y	Y	Y	Y	6/8
Kunkel *et al.* 1997[132]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Levin and Feldman 1983[133]	Y	Y	Y	N	Y	N	Y	Y	6/8
Lopez *et al.* 2010[134]	Y	Y	Y	N	Y	Y	N	Y	6/8
Maloney *et al.* 2014[121]	Y	Y	Y	N	Y	Y	Y	Y	7/8
Mason and Bowman 2018[118]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
McCasland 2007[135]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
McKenna *et al.* 1994[136]	Y	N	U	N	Y	N	Y	Y	4/8
Mogg and Bartlett 2005[146]	Y	N	N	N	Y	N	N	Y	2/8
Moini and Levenson 2009[137]	Y	Y	Y	N	N	N	Y	Y	5/8
Monga *et al.* 2015[138]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Muhtaseb *et al.* 2001[147]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
O'Neill *et al.* 1994[148]	Y	N	Y	N	Y	N	N	N	2/8
Picot *et al.* 2015[15]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Rice *et al.* 2012[139]	Y	N	Y	N	Y	Y	Y	Y	6/8
Rodriguez-Mayoral 2018[119]	Y	N	N	N	N	Y	Y	Y	5/8
Romm *et al.* 2009[140]	Y	N	Y	N	N	N	Y	Y	3/8
Shah *et al.* 2008[141]	Y	N	Y	Y	Y	Y	Y	Y	7/8
Stecker 1993[142]	Y	N	Y	N	N	N	Y	Y	4/8
Steves and Willliams 2016[143]	Y	N	N	N	Y	Y	Y	Y	4/8
Terpstra *et al.* 2014[144]	Y	Y	Y	Y	Y	Y	Y	Y	8/8
Thomson and Henry 2012[145]	Y	Y	N	N	N	N	N	Y	2/8
Webber 2012[151]	Y	N	N	N	N	Y	Y	Y	3/8

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Chapter 4 Thematic synthesis of policy, guidance and research

This chapter presents a synthesis of policy, guidance and research included in the overall review. Material from the research studies and policy and guidance documents has been synthesised into four themes: structure of the system, professional issues, contexts of care and characteristics of people with SMI.

Structure of the system

Twenty-six policy and guidance documents[22,30,55,120,155–176] and 18 research outputs[32,85,88,91–94,97–99,103,105,106,108,110,112–114] contribute to this theme, which addresses the broad shape and structure of the EoL and mental health care systems. Material is organised under four subthemes: policy and guidance; separate commissioning, management and organisation; partnership; and no right place to die.

Policy and guidance

Nineteen policy and guidance documents[22,30,156–161,163–170,172,174,175] and one research output contribute to this subtheme.[112]

People with SMI are recognised as a group needing particular attention in the provision of EoL care in multiple independent UK reports and consultations,[22,156–158,161,163–165] with the Care Quality Commission[158] suggesting that many health-care providers have focused efforts on reducing premature death among people with a mental health condition rather than properly considering EoL care needs.

There is a lack of national and local policy guidance in the UK that addresses the EoL care of people with SMI;[112] however, isolated examples of local policy do exist.[170] Evidence[166] also exists that a majority (62%) of mental health providers have produced action plans to promote improvement in EoL care. Where this is in place, 92% of mental health providers have also reported forwarding this to clinical teams, and three-quarters (75%) have reported forwarding this to the trust/university health board. In the context of a lack of specific national and local policy, both mental health and palliative care nurses report concern about their legislative responsibility.[112]

Standards of care for people with mental health problems should be the same as those for people with physical health problems, and this ideal is strongly emphasised across generic UK health policies,[160,167–169] national mental health-specific policies[159,172,175] and independent reports and guidance documents.[157,164] By extension, EoL care for people with SMI should be as good as the EoL care provided to others.[30] Aspirations that high-quality EoL care should specifically apply to people with SMI are found in Scottish mental health policy,[172] and in Wales the current mental health strategy[175] refers to supporting recovery and enablement through to the EoL with recent whole-system policy referring to equitable services for people with mental health difficulties and specifically improving EoL care.[174] Northern Ireland's mental health service has a standard that people with incurable conditions should be supported at the EoL and to die in their preferred place of care.[159] English strategy identifies that there is a need to improve the provision of EoL care information in unscheduled care settings,[168] and targets additional resources at homeless people.[167]

Separate commissioning, management and organisation

Eleven policy and guidance documents[30,120,157,158,162,164,166,169,170,173,176] and 11 research outputs[32,85,93,94,99,103,106,110,112–114] contribute to this subtheme.

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Accessing and navigating the system

All national health-care systems have obligations to provide access to palliative care for people with disabilities, including those associated with existing mental health difficulties.[176] In relation to access to hospice care specifically, a specific aim of the UK charity Hospices UK to make their services more available to people with serious mental illness.[162] Data reported in the *National Audit of Care at the End of Life* report,[166] however, show that only 10% of mental health service providers have their own specialist palliative care service, in comparison with 95% of English and Welsh acute care providers. A majority of mental health providers report having access to specialist palliative care beyond their own hospital, however, with 16% having access to at least one EoL care facilitator, of which 40% are contained within a specialist palliative care team. Availability of specialist palliative care HCPs to mental health providers include 60% having face-to-face access to nursing staff during usual working hours across the whole week, and 49% having the same access to doctors. Other means of access to specialist palliative care reported include telephone contact, with doctors available at any hour to 57% of mental health providers and nurses available at any hour to 42% of mental health providers.[166]

The separate organisation of mental health and EoL services means that many people with existing mental health issues do not receive treatment that is appropriate for them when they are eventually admitted to hospital.[164] Treatment also becomes more complicated if patients are receiving analgesia and other EoL medication.[164] Evidence brought together by the Social Care Institute for Excellence 2013[173] is that people with mental health needs remain one of the groups missing out on equal access to EoL care. The needs of people with SMI are not always considered by commissioners and service planners, who have been described as lacking awareness of the EoL needs of people with SMI.[157]

Accessing adequate and timely palliative care at the EoL for those with mental health problems, including in general hospital settings, is described as difficult for staff.[103,106,114] Psychiatrists report barriers when accessing physical health and palliative care services, even when services are co-located, with difficulties including communicating with physicians, being blocked by administrative staff, having to deal with multiple departments and working in systems where no single patient identifier is used to join up record-keeping.[114] Referral and consultation are reported as often being affected by patients' past experiences of services and the impact of stigma.[106] Mental health staff have described people with mental illnesses at the EoL as not welcome in general hospitals, with the result that these patients are offered trial placements in appropriate settings but are then discharged or are simply refused care.[103]

A considerable number of people with SMI have limited contact with their GPs, families and wider networks, and may be socially isolated.[30,106,110,170] This can be a challenge for them in terms of accessing, navigating and/or receiving appropriate EoL care, including making practical arrangements, such as travelling long distances to appointments and having enough funds to make this possible.[114]

Access for homeless and vulnerable groups

Social isolation and disconnection from family, friends and services are particular concerns among people who are homeless, with around 50% of rough sleepers having mental health needs.[30,167] The social characteristics of homeless people include that they are unlikely to live in supported accommodation and may lead irregular lifestyles, with high levels of mental illness and drug and alcohol abuse, making them difficult for health and social care professionals to reach.[162]

Homeless people, many of whom have SMI, have particular problems accessing EoL services and are often excluded from hospices and care homes, where they do not fit the profile of most people using such services.[113,158] Professionals describe difficulties placing homeless people with cancer in care homes or hospices even when they have no history of substance misuse.[113] Social services provide care for the 'structurally vulnerable' but typically view the provision of EoL care as beyond their remit of responsibility or expertise,[99] and undertake assessments of need that take account only of homeless people's immediate, current, needs such as during hospital admission or following detox from alcohol.[113] Guidance from St Mungo's (London, UK), a charity for homeless people, is that hostel and project staff should carry out assessments supplementing those completed by HCPs and social care professionals in order that people can be supported as long as possible in their preferred place of care.[120]

The siloing effect of services also means that homeless people (who generally have lower levels of health literacy, cognitive capacity and access to material resources such as telephones, the internet and transportation) are often unable to successfully navigate their way through multiple departments and agencies. They are, therefore, less likely to receive any meaningful palliative care and support whatsoever,[99] and more likely to receive care in hostels where the support ethos is at odds with meeting needs at the EoL.[113]

The Help the Hospices report[162] suggests that people who are detained in prisons as a result of social exclusion and stigmatisation may have trouble accessing palliative care. Health care for prisoners has been described as focusing particularly on mental health and substance misuse programmes[162] as opposed to including EoL care. To our knowledge, no research exists in these areas, but guidance is clear that detained people should be cared for with respect and dignity and should have choice.[161]

Care co-ordination across systems

Separate commissioning, management and ways of organising both services and professionals create challenges for both mental health and EoL HCPs to co-ordinate high-quality care across mental health and EoL care systems.[112] National policy in England is clear on the importance of organising integrated services around the patient,[169] and in Scotland clear emphases have been placed on services taking responsibility for care, negotiating working partnerships across palliative and mental health systems and involving families.[30] One example of local policy from NHS Lothian identifies the importance of strong linkages between different services in order that the wishes and needs of people with SMI at the EoL are considered and met.[170] This creates multiple co-ordination difficulties at a time when speed is critical so that people receive the care and support they need.[164]

Lacking personal and material resources, homeless and vulnerable people at the EoL who require access to multiple health and social care services typically have to act as their own care co-ordinators to navigate the system.[99] The invisibility of vulnerable people means that they are liable to fall through the cracks between professional boundaries, with practitioners failing to take responsibility for meeting and co-ordinating palliative care needs and patients missing out on palliative care because they do not know where to go, who to see or when to find support[99] or because professionals continue to work in 'silos'.[112] Problems of fragmented services and a lack of continuity found in the care of homeless people are also associated with a lack of trust between practitioners and people using services.[113]

Formal proposals to improve the organisation and coordination of care across palliative and mental health services include the following:

- Identifying lead clinicians.[114]
- Having 'liaison portfolios' for designated members of existing care staff with specific responsibilities to advocate and act as a resource, to link mental health and palliative care services, to open channels of communication, to record-keep, to facilitate access to services for practitioners and to co-ordinate education sessions.[94]
- Designating link workers to develop care protocols and education and awareness-raising sessions crossing the mental health and EoL care systems.[30]
- Locating liaison mental health nurses, and resident mental health nurses in palliative care services, with liaison staff described as particularly well placed to develop close partnerships across services, broker collaborative care and offer support, education and supervision.[30]
- In circumstances such as these, supervision would be helpful.[32] One example of good practice reported in the Scottish system is a registered mental health nurse who provides clinical supervision for other members of the multidisciplinary team.[30]

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Resources

The lack of sufficient or suitably qualified staff in the usual residences of people with SMI drives people at the EoL to either acute hospital or nursing home care, and the strategy of employing non-professionals in community services is suggested as having depleted the capability of staff to care for people at the EoL.[114] A general absence of services and programmes to meet the EoL needs of people with SMI has been found in parts of the USA,[85] alongside evidence of insufficient psychiatrist availability and inadequate resources to support people.[93]

Partnership

Seven policy and guidance documents[30,55,155,163,168,170,171] and seven research outputs[85,103,105,106,110,112,114] contribute to this subtheme.

Funding and flexibility to work in partnership

Working in partnership across EoL and mental health services is important and when strong formal and informal partnerships between staff across the different settings exist then people with existing mental illnesses at EoL can be practically assisted with their palliative care needs.[85] However, some mental health and EoL HCPs report that they believe that the flexibility to work in partnership with other agencies has declined, with this attributed to reductions in funding and competitive commissioning arrangements.[112] This under-resourcing often means that EoL HCPs, including those working in hospitals, are not aware of the needs of people with SMI.[106] Funding systems requiring quick decisions also inhibit good care in the context of needs assessments taking time.[106]

A lack of good relationships and partnership between mental health and EoL services specifically prevents adequate pain management[85,112] and assessment of mental capacity.[112] Different approaches to improving this exist, which include building on the importance of identifying lead clinicians to improve care management, with one proposal being that the lead be whoever is best-placed: a GP, or a practitioner working in the area of the 'dominant condition'.[114] Other flexible approaches include EoL services specifically training mental health staff to work full-time in their services, or vice versa.[30,103]

Multidisciplinary teamwork

Interagency and interprofessional team working at the EoL is important[30,55,163,168,170,171] and high levels of multidisciplinary care have been reported in the last days of life.[110] Mental health and EoL services have both been characterised as benefiting from a democratic multidisciplinary team ethos.[102] Outcomes have been found to improve when interprofessional care is in place, drawing on the contributions of staff in both mental health and palliative services with partnership and advocacy, ensuring that complex needs are met.[106]

However, mental health staff report a lack of information on services provided by EoL HCPs, and vice versa,[85] and consultant-level mental health staff are not always directly involved in the provision of EoL care, with junior staff leading instead.[105] Hospice staff have been advised to particularly focus their energies on the needs of people with the most complex problems[155] and to improve communication and joint working across team boundaries.[163] However, in the absence of systems or structures designed to facilitate partnership, qualitative data show how ongoing mainstream service support for people with mental illnesses at the EoL is often accomplished only because of the ad hoc efforts of individuals.[103] Even in these cases, however, partnership working is described as limited to advice-giving or telephone support rather than the provision of hands-on care.[103]

Ongoing interprofessional communication

Communication among practitioners working together to provide mental health and EoL care varies in intensity and effectiveness. Ongoing communication between partners in care is frequently given as a prerequisite for high-quality provision,[30,55,164] with qualitative research pointing to the value of open and clear decision-making and interprofessional case conferences as a place for discussion of key issues such as advance care planning.[106] Practical examples of how 'coalition building' has benefited individual patients exist.[85] Missed opportunities have also been reported, with participants in one study describing limited or no space for health, social care, housing and other staff to meet, and a generally low quality of information being shared across boundaries, including in initial referrals.[112] GPs report rarely receiving updates from palliative care services.[114]

No right place to die

Seven policy and guidance documents[30,120,156–159,162] and 14 research outputs[32,88,91,92,97–99,105,106,108,110,112–114] contribute to this subtheme.

Dying at home

Nurses have talked about there being 'no right place to die'[32] and that care for people with SMI at the EoL is lacking in all settings: psychiatric units, general medical units, and older people's mental health and hospice/palliative care settings.[32] System features combine to prevent people with SMI at the EoL from dying in the place, and manner, of their choice, which for a lot of people with SMI and palliative care needs is at home[158] or in a 'home-like' environment such as community-supported accommodation.[106,114] This is despite evidence that, with the right support from community-based services, people with SMI at EoL are able to stay at home.[157]

Studies have explored whether decedents with SMI were more or less likely than those without SMI to have died at home,[88,91,97] and have produced mixed findings. When all causes of death were considered, there were no differences in the likelihood of home deaths between decedents with and decedents without previous mental illness [odds ratio (OR) 1.02, 95% CI 0.92 to 1.14].[91] For Lavin *et al.*[91] all causes of death included cancer, chronic obstructive pulmonary disease, coronary artery disease, congestive heart failure, peripheral vascular disease, liver failure, diabetes and renal failure. The evidence for cancer-specific deaths is contradictory, however, with the results of a smaller study demonstrating no differences in the likelihood of home deaths between decedents with and decedents without schizophrenia diagnoses (OR 0.88, 95% CI 0.48 to 1.62),[88] whereas in a further study it was shown that decedents with schizophrenia diagnoses were 65% less likely to have died in a nursing home than decedents without (OR 0.35, 95% CI 0.28 to 0.44).[97]

Dying in a mental health hospital

Opportunities for EoL care to be provided in mental health facilities are limited.[110] Older people's mental health wards rarely include people with schizophrenia diagnoses, and few examples exist of people being cared for until death in mental health units.[32] One example shows a person with bipolar disorder, dementia and cardiac disease being repeatedly moved between services at the EoL.[32] Irrespective of any patient preferences on where they might be cared for, staff describe inpatient mental health services as poorly equipped to meet the EoL care needs of those with SMI.[112]

Dying in a hostel

Many homeless people have combinations of long-term physical, mental health and substance misuse problems and have difficulties engaging with health-care practitioners.[120] Although the preference for many homeless people is to receive EoL care in a hostel setting, several challenges make this difficult to achieve.[98,99,113,156] Hostel staff express concern over the suitability of residents with advanced ill-health to receive support in hostel accommodation until death, with specific concerns including limited access to adequate support,[113] lack of staff confidence,[113] burden on staff,[113] safeguarding concerns,[113] no pain or symptom management[98] and the fact that hostels are often noisy and chaotic.[113] Staff may also have concerns about providing hostel-based care because of the perceived risks associated with poor living conditions, overcrowding, drug or alcohol use and violence, even when such risks are probably negligible.[98,99,112] Storing and administering medication, particularly opiates, in hostels where many residents may have substance misuse problems and staff lack sufficient training or experience is also problematic.[99,113]

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Several models of good practice are reported in the literature.[98,99,162] The Mission Hospice Programme in Canada provided dedicated palliative care to homeless people in a shelter, where people could spend their remaining days surrounded by family, friends and volunteers.[162] This demonstrates what can be achieved with sufficient resources, training and support. One further study described a specific shelter-based hospice care programme, reporting that 57% of homeless individuals received a palliative care consultation; the programme achieved success in optimising pain and symptom management and was shown to save money compared with likely alternative care locations.[98]

Dying in an acute hospital

National standards state that all people with advanced and incurable conditions should be able to die in their preferred place,[159] but evidence from official reports includes the illustrative case study of a woman at the EoL being moved repeatedly between services before dying in an unfamiliar acute hospital environment.[158]

Acute general hospitals often have a role in the EoL care provided to people with SMI, even though care in this context is described as in need of improvement.[30] Staff in acute hospitals report that they are often under-resourced and lack awareness of the particular needs of people with SMI at the EoL,[106] or describe acute hospital admissions [particularly via emergency departments (EDs)] as undesirable and often explained by difficulties in accessing hospice care or physical care in mental health settings.[112]

Many adults with SMI are ultimately transferred at the EoL to acute hospitals for EoL care,[30,32,98,99,105,110,166] for care within palliative medical settings[105] or for care in EDs,[105,112] often because of the limited expertise of staff in mental health settings in EoL care[114] or because patients' physical health care needs cannot be met in a mental health establishment.[112] On other occasions patients may move from the community[105] or from homeless shelters[98,99] because of a lack of adequate support.[98,99,105] Many staff feel that transferring people at the EoL in this way leads to discontinuity and disruption.[105]

Mixed results were observed across studies regarding the likelihood of dying in a hospital.[88,91,92,97,108] When all causes of death are considered, having a pre-existing mental illness was associated with a 33% lower chance of dying in a hospital than not having one (OR 0.67, 95% CI 0.60 to 0.75).[91] In the case of cancer-specific deaths, those with pre-cancer depression had 25% lower odds of dying in hospital than those without [adjusted odds ratio (aOR) 0.75, 95% CI 0.64 to 0.87],[92] and those with a diagnosis of schizophrenia had 48% lower odds of dying in hospital than those without (OR 0.52, 95% CI 0.47 to 0.57).[97] One further study explored rates of death from cancer in the ED or intensive care unit (ICU), finding that having a schizophrenia diagnosis was associated with a 35% lower odds of dying in the ED or ICU than not having that diagnosis (aOR 0.65, 95% CI 0.56 to 0.76).[108] In comparison, findings from a smaller study found that rates of hospital deaths for those who died of lung cancer were comparable in those with and without schizophrenia diagnoses (OR 1.06, 95% CI 0.55 to 2.05).[88]

Dying in a nursing home or residential facility

Consistent findings were reported across three studies[88,91,97] regarding the increased likelihood of dying in a nursing home or residential facility among decedents with SMI. When all causes of death were considered, having any type of pre-existing mental illness was associated with 27% higher odds of dying in a nursing home than not having one (OR 1.27, 95% CI 1.09 to 1.49).[91] In the case of cancer-specific deaths, having a schizophrenia diagnosis was associated with significantly higher odds of dying in a nursing home than not having one (OR 49.33 95% CI 43.89 to 55.45).[97] In the case of lung cancer deaths, having a schizophrenia diagnosis was associated with higher odds than not having that diagnosis of dying in an assisted living facility (OR 3.16, 95% 1.33 to 7.49) or a skilled nursing unit (OR 1.31, 95% CI 0.59 to 2.89).[88]

Dying in a hospice

One study[91] found no significant differences in the likelihood of dying in a hospice between those with and those without a history of previous mental illness (OR 0.98, 95% CI 0.79 to 1.22).

Many hospices are not able to cope with the needs of homeless people as a result of complex behaviours related to chaotic lifestyles and substance abuse issues[113,156] and the inexperience of staff.[113] Such issues often lead to homeless people leaving the ward setting, making delivering care difficult.[113] Care home and hospice staff find it challenging to find provision catering for this population group because of their typically young age, meaning that access to these services is uncommon.[99,113]

Professional issues

Ten policy and guidance documents[30,156,162–166,171,176,177] and 16 research outputs (reporting 14 studies)[32,37,85,93,94,99,102–106,110–114] contribute to this theme, which addresses professional and practitioner issues. Material is organised under four subthemes: relationships between HCPs and people with SMI, mental health professionals doing EoL care, EoL care professionals doing mental health care, and training and education.

Relationships between health-care professionals and people with severe mental illnesses

Three policy and guidance documents[30,164,176] and 11 research outputs (reporting nine studies)[32,37,99,102–104,106,111–114] contribute to this subtheme.

Connecting relationships

Mental health nurses value connectedness. They emphasise the importance of building nurturing relationships that go beyond the usual nurse–patient relationship.[102,110] Nurses often describe themselves as a substitute family,[32,104] especially when people with SMI have been receiving care for a long time, sometimes years.[102] Nurses describe this as part of their daily interactions, and that in their work they attend to patients' daily needs.[102] Mental health nurses report that some people with SMI have limited social networks and, in some circumstances, no family contact.[104,110] In these circumstances mental health staff state that they often represent the interests of people living with mental health problems and do work that goes beyond health-care provision, such as assisting with money, shopping for clothing and looking after the home environment.[110] They have satisfaction and a belief that they make a difference.[102] However, some nurses also choose not to form close relationships of this type[102] and staff who have built such relationships are reported as often being upset when people they have been caring for need to be relocated because of their increasing palliative care needs.[114]

Talking about death and dying

Place of care and desired place of death are important topics of discussion between mental health staff and people with SMI,[106] with global guidance recognising that people with life-limiting illnesses (including SMI) should be supported to make decisions at the EoL.[176] However, concerns over talking about EoL care, death and dying lead to the avoidance of such conversations.[112] This is particularly so with people who have histories of thinking about suicide and of attempting to take their own lives,[112] as staff fear upsetting them and creating emotional instability or distress.[112] Some staff working in mental health facilities feel confident about their ability to engage in EoL communication with patients and their families.[111] Staff in care homes describe themselves as needing greater confidence in EoL communication.[111] Determinants of high self-efficacy in EoL care communication among staff are reported to include age (older), formal training in palliative care, number of years working in direct care (> 10 years) and knowledge of the definition of palliative care.[111]

Good communication is vital when discussing care and support for people living with a terminal illness.[164] However, owing to the lack of appropriate skills and competence, staff are not always comfortable discussing EoL or mental health issues. Palliative care and mental health nurses report

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that when conversations arise about EoL care planning, patients appear to be willing and able to have conversations with them.[112] This supports the person to have choice and to die in a safe, home-like environment.[106] It is recognised that communicating about the EoL can be difficult and takes effort, time and experience, although in one study nurses stated that helpful EoL conversations are nonetheless possible.[110]

Attitudes and beliefs of health-care professionals

Nurses and psychiatrists report that physical care providers are often unable or unwilling to deal with people living with SMI and that they are generally resistant to accepting those who are diagnosed with a mental illness and display an unwillingness to admit people with SMI to acute care hospitals.[110,114] In some cases people with mental disorders are reported to be unsuitable for hospices.[110] In other instances some mental health facilities have arrangements with nursing homes or hospices specialising in mental health care.[110]

The negative views about people with SMI held by the general population may be held by staff working in palliative care and hospice services.[30,112] The underlying attitudes of HCPs serve as barriers to the provision of effective care, and are associated with prejudice and stigma about mental illness and death.[32,37,103,112] Caring for a person with SMI at the EoL is often associated with stigma and an inability among HCPs to see the person behind the illness.[103] Stigma manifests in how people with SMI are spoken with or written about, and underlying beliefs affect the exchange of information, care planning, involvement and management of risk.[112] Stigma and prejudice also influence care for those who are homeless or vulnerably housed,[99,113] resulting in a lack of compassion.[113]

Stigma is also reported to be attached not only to people with mental health problems but also to the HCPs who care for them.[103] Sometimes this stigma is generated by fear that the person with mental illness is going to be dangerous to themselves,[32,103] leading to a fear of providing EoL care.[32] It is also associated with a lack of understanding about mental illness, especially schizophrenia.[32] Stigma also works in the opposite direction, with mental health staff holding stigmatising views about EoL care.[103]

Professionals also hold particular views about people with mental health problems and their experiences of pain. Mental health nurses are reported as believing that people with anxiety disorders have a much lower pain tolerance, leading to a very high demand for care, and that people with SMI might express pain differently, hampering the interpretation of physical complaints by doctors.[110] They state that people living with schizophrenia often have a much higher pain tolerance and might not even recognise pain as such, meaning that they are at risk of waiting too long to visit a doctor.[110]

Mental health professionals doing end-of-life care

One policy and guidance document[30] and 10 research outputs (reporting eight studies)[32,37,93,102–105,110–112] contribute to this subtheme.

Experience, knowledge and skills

One study reports that just over one-third of mental health nurses have experience of providing care to people living with mental illness at the EoL in the past 2 years.[110] A further study suggested that the willingness of mental health staff to be involved with people with SMI at EoL, and their ability to be compassionate, may also be related to personal as well as professional qualities.[102]

Many mental health staff may know little about how EoL care is provided,[30] how and when to refer, and how services are funded.[112] Although studies have shown that some mental health staff have a general understanding and awareness of what is involved in EoL care,[102,111] others have found that they do not.[112] In terms of practical clinical skills to care for people with SMI at the EoL, mental health staff have questioned their ability to effectively deliver pain management or to provide psychosocial-spiritual support.[102,111]

End-of-life care not being mental health work

Mental health staff have expressed a desire not to care for medically unwell patients at EoL,[32,105] feeling that EoL care 'falls outside the remit of a mental health service'[112] and that it is not something that should be managed within specialised mental health services.[105] Some psychiatrists have been reported to display a lack of interest in working with palliative care services, or the observation has been made that the general approach that psychiatrists take to people with SMI may not always be appropriate for people receiving palliative care.[178] Specifically, in the Dutch health-care system, with the focus moving away from care in hospitals towards recovery-oriented care in the community, fewer people are now being admitted to mental health facilities, and when they are admitted they have a shorter length of stay. Consequently, palliative care is no longer seen as core business in mental health facilities.[110] A further factor eroding mental health staff members' confidence in EoL care in Australia is that, to avoid investigations by coroners, people with SMI are transferred away from older adult mental health services to non-mental health clinical environments.[105] This is because laws require a coroner to investigate a death in psychiatric facilities, and the possibility of an inquiry causes anxiety about scrutiny, prompting staff to avoid patient deaths in their part of the health-care system. This avoidance compromises care for people at the EoL, and some psychiatrists feel frustrated and constrained in their roles.[105] Other mental health staff, however, see death as part of life and take the view that people with SMI should be supported from birth to death, which means embracing EoL care and not treating all psychological responses to impending death as evidence of mental illness.[105]

Emotional distress

Staff who provide care over long periods to individuals with SMI need support in the face of terminal illness, and in bereavement.[30] Caring for individuals at the EoL can be stressful for mental health nurses,[30,103] demonstrated in the way mental health nurses use words such as 'hard', 'traumatising', 'angst' and 'stress' to describe the experience.[103] Some nurses' distress is exacerbated by issues of loss associated with the strong relationships that they develop with people with SMI, added to which are bureaucratic difficulties and a lack of resources.[103] In the hospice environment, mental health staff report becoming emotionally involved[37] and find caring exhausting to the point that they have a sense of relief when people die.[32] Conversely, others who have long-term involvement with people with SMI report that they experience distress associated with grief.[104] For staff working in mental health institutions, stress is compounded when post-death inquiries (including those involving the police) are initiated, at exactly the time staff are already dealing with the grief of loss.[104] This knowledge that actions may be legally scrutinised increases the stress felt by staff, some of whom have reported traumatic coroners' inquests.[104] Staff also report that they fear that providing the appropriate amount of pain relief could be seen as accelerating death rather than relieving pain and that they would then have to explain any decisions to a coroner's inquest.[104]

End-of-life health-care professionals doing mental health care

Two policy and guidance documents[30,171] and five research outputs[32,37,103,110,112] contribute to this subtheme.

It has been observed that people with SMI who develop cancer or other life-threatening conditions have insufficient attention paid to their palliative care needs.[30] Education, knowledge and skills are important, and in the case of EoL HCPs it is recognised that they must be prepared to fulfil roles caring for people with SMI even though they may not have the required skills,[30] lack confidence[37] and are not necessarily equipped for the task ahead[106] in terms of training[37,112] and experience.[103] This is particularly so in the case of new nurses who have yet to gain relevant experience.[32] EoL HCPs who report prior experience or training in mental health issues are more confident in dealing with this population group.[37]

Staff in palliative care services feel poorly prepared to provide care and treatment to patients with long-term psychosis or active bipolar mood disorder, even though the underpinning principles applying to the care of these groups are similar to those applying to all other groups, with the consequence that

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the needs of these patients are not always well met.[171] One study reported that most nurses involved in palliative care (60%) had provided care to between one and three people living with mental illnesses in the past 2 years.[110] Staff are often unable, unwilling or not comfortable to deal with people with SMI[178] and are reported to be sometimes ignorant of the needs of such people.[30,103]

Many EoL HCPs report that they have limited understanding of the structure of their local mental health system, of different mental health diagnoses and how these may affect patients, and of how to contact relevant teams for additional information following referral.[112] They are also unfamiliar with the differences between a clinical psychologist and a counsellor.[37] It has been recommended that all hospices and palliative care staff become conversant with the major mental illnesses, including how they present, the signs of deterioration, the basics of care provision and how to assess people with SMI in emergencies.[30] It is also recommended that EoL staff be aware of the specific needs that present in this group of people at the EoL, and in doing so work closely with both mental health and social services.[30]

Training and education

Eight policy and guidance documents[30,156,162–166,177] and eight research outputs (reporting seven studies)[32,37,85,93,94,102,104,106] contribute to this subtheme.

Educational needs

Similarities have been claimed in the ideals underpinning mental health and EoL care nursing, with both sharing commitments to holistic and non-judgemental care.[102,104] However, professionals also lack education, understanding and resources to make sure that people with SMI at the EoL are not lost to services.[106] These observations add to the case that education and training are important to better support the development of skills and collaborative working in palliative care among mental health staff, and to improve palliative care staff members' understanding of mental health needs.[30,106,162] This is particularly the case for staff caring for homeless people at the EoL, who have significant training and personal support needs that enable them to provide personalised care in conjunction with relevant multidisciplinary teams.[156]

General areas that education and training could focus on have been highlighted across the literature and include:

- communication skills between HCPs and those with SMI at the EoL[164]
- communication and shared understanding across EoL and mental health care teams[32,163,165]
- palliative care skills for mental health staff,[162–165] especially with regard to advance care planning skills among the mental health workforce[85,162–165]
- addressing stereotypical beliefs about those with SMI[30,32,106]
- mental health education to EoL HCPs that provides them with the basic skills needed for providing care.[30,37,162]

More specific training needs have also been identified, for example formal differential diagnoses in the mental health field,[37] cognitive–behavioural techniques and communication skills,[37] and approaches to working with people with SMI and family members whose behaviour is seen as difficult to manage.[32,37] Differentiations have also been made between the training needs of nurses and the training needs of medical staff, with the latter requiring more detailed material to reflect their existing education.[37] Specific recommendations on education have been made for GPs, for whom continuing professional education might include the principles of palliative care to better enable them to provide high-quality primary care for people with SMI.[30]

Core professional preparation

Education and training are important and offer ways of improving how different professionals work together.[30,164] This is particularly so in the context of core professional preparation, which lacks detail in some areas. An example is in psychiatry training, and programme directors of palliative care consult services have suggested that psychiatry training is inadequate in the categories of EoL care and issues related to death and dying.[178] The Leadership Alliance for the Care of Dying People sets out the underpinning competencies that it suggests should be part of the curriculum for doctors in training, including being able to address ethical and legal issues arising in the context of care for people with medical or mental health problems.[177] In one study, when talking about their core mental health training, some mental health staff pointed to their underpinning, person-centred training, and skills enabling them to be sensitive to individual needs, including at the EoL,[102] and others spoke of how their preparation enables them to care for people with SMI, including during periods of physical illness.[103] In a further study, mental health nurses propose that their core education should consider how mental health practice might be adapted to medical and surgical areas.[32]

In-service education

The Royal College of Physicians[171] recommends improved training, including to better enable EoL care to be provided to vulnerable people who have pre-existing mental illnesses. This includes investing in liaison psychiatry, in education for specialist palliative care staff and in training to meet needs in the case of mental health emergencies.[171] Hospices have been described as focusing on education and training that remove barriers to access,[162] and it has been suggested that hospices should develop training that equips staff and volunteers to better care for people with SMI, in the knowledge that education can improve services.[30]

Marie Curie suggests that improvements are needed and that EoL care and bereavement training should be provided to all health and social care students and practitioners as routine both in core preparation and through ongoing post-qualification education.[164,165] Investments in education of this type are championed with the aim of developing all members of care staff to provide services to people with mental illness at the EoL.[164] However, education and training opportunities are patchy. One report[166] found that, between 2017 and 2018, only 6% of mental health providers included EoL care training as part of their staff induction programme, with 13% saying that they included EoL care in their mandatory/priority training and 91% saying that they offered EoL care communication training. By contrast, among acute and community providers, 47% reported including EoL care in their mandatory training.

End-of-life and mental health staff learning from each other

End-of-life and mental health staff working together can improve knowledge and awareness, such as through the establishment of dedicated link positions with roles including the provision of education[30] or through cross-training.[85,94] Hospice trainers can teach mental health providers about EoL care,[85] and mental health providers use case examples to expose hospice and palliative care providers to typical mental health issues.[85,94] Evaluations from cross-training initiatives demonstrate that both mental health and EoL participants have greater confidence in their skills after the training,[85,94] and palliative care staff report that they have a more positive regard for the lived experience of people with SMI.[94] In terms of approaches to learning, staff report valuing the use of real-life vignettes to illustrate practical approaches to complex problems.[85] Particularly appreciated by EoL HCPs is the chance to learn about commonly made mental health diagnoses, approaches to communicating bad news and how to manage mental health emergencies in people at the EoL.[85] Mental health staff feel that cross-training improved their confidence in caring for people at the EoL,[94] giving them key insights, including into the importance of advance care planning.[85]

Contexts of care

Eleven policy and guidance documents[21,30,156,161–166,170,176] and 31 research outputs[32,37,83–93,95–102,104–110,112–114] (reporting 28 studies) contribute to this theme, which addresses the organisation, provision and receipt of care. Material is organised under three subthemes: managing the interface between mental health and EoL care; health-care services and treatment utilisation in the LYoL, and meeting individual and family needs.

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Managing the interface between mental health and end-of-life care

Two policy and guidance documents[30,164] and eight research outputs[37,93,95,105,106,110,112,114] contribute to this subtheme.

General practitioners managing care

Evidence suggests that GPs are the gatekeepers of enabling or hindering access to palliative care services, and in some instances manage the palliative care needs of people with SMI within their practice.[30,110,114] One study showed that just one-quarter of people with SMI were referred by a GP for palliative care assessment,[114] and referrals to specialist palliative care services were mainly related to achieving admission to hospice, nursing home and intermediate care beds for further investigations or for community/specialist palliative care.[114]

The role of medical specialists

The different types of specialists that people with SMI visit at the EoL include hospital specialists (medical, general surgery and surgical)[95,110,114] as well as psychiatrists.[93,95,110,164] Palliative care HCPs are significantly more likely to refer people living with mental illnesses such as depression ($r = 0.25$; $p < 0.01$) and personality disorders ($r = 0.23$; $p < 0.01$) at the EoL to psychiatrists when their own comfort level with mental health is low.[93] The services psychiatrists provide include informal or 'kerb-side' consultations for the palliative care team without having patient contact, therapy, capacity evaluations and the management of delirium or behavioural disturbances.[93]

Referral

When dealing with terminal illness, speed is of the essence. Whether someone has only a few years or, in many cases, a matter of months to live, they cannot afford to wait to get the support they need. Wherever possible, this means that support for people living with mental health issues and approaching the EoL must be fast-tracked or prioritised.[164] This is essential, given the importance of trusting relationships and mutual understanding for people with SMI.[106] However, staff acknowledge that referrals are not straightforward, particularly in the case of people with schizophrenia lacking someone to speak with and for them, or not having settled accommodation.[106] Inadequate quality of referrals of people with SMI can result in staff being unaware of vital information that would aid effective communication between them and the person using services.[112] Types of missing information include discussion of a patient's mental ill-health, mental health history, symptoms, risk information relating to EoL care and advice on how best to work with the patient.[112]

Mental health assessment at the end of life

Skilled assessment and care planning are important, as people with SMI require expert advice to manage their medication, to prevent crises and to receive appropriate help when crises do happen.[30] These are all areas in which staff can gain knowledge and skills.[30] Within mental health facilities, psychiatric assessment for those at the EoL is an important aspect of participants' work, involving assessing patients for treatable psychiatric illness,[112] decision-making capacity,[105,112] pain[112] and risks of harm.[105,112] Psychiatrists are described as working in a system that is focused on facilitating recovery and in supporting people at the EoL.[105] Evidence exists that people with SMI are not always offered assessments of their mental health needs in hospices.[37] It is important that hospices and specialist palliative care services have policies and procedures in place for assessing those with SMI at EoL so that there are no delays in accessing emergency psychiatric support if it is needed,[30] and so that problems are not underdetected.[106,114] For those working in hospices, mental health issues are seen as a challenge, and staff express several fears and uncertainties acting as barriers influencing the assessment process for people with mental health difficulties at the EoL.[37] These barriers include separating physical and psychological symptoms, fear and limited ability to communicate. Time, trust and collegial support are facilitators of assessment and treatment processes.[37]

Health-care services and treatment utilisation in the last year of life

Thirteen research outputs[88–92,95,97,100,101,104,107,108,112] (reporting 12 studies) contribute to this subtheme.

Ambulatory visits to general practitioners or medical specialists

One retrospective cohort study[95] explored the rates of ambulatory visits to the GP and medical specialists, and whether this was higher or lower for those with and those without schizophrenia diagnoses who had died from cancer. No differences were observed in rates of ambulatory visits to the GP within 6 months of death [adjusted relative risk (aRR) 1.03, 95% CI 0.96 to 1.11].[95] However, in the 6 months to death decedents with schizophrenia diagnoses were 39% less likely than those without to visit medical specialists (aRR 0.61, 95% CI 0.54 to 0.69).[95]

Palliative care services

Three studies compared rates of utilisation of palliative care among decedents with and decedents without schizophrenia diagnoses who died from cancer at different time points throughout the LYoL. One study conducted in New Zealand showed that decedents with SMI were 71% less likely to access specialist palliative care services (community and inpatient services) than those without SMI in the LYoL [relative risk (RR) 0.29, 95% CI 0.24 to 0.34].[100] Huang *et al.*[101] found, in a nationwide population-based cohort from Taiwan (Province of China), no significant differences in the overall utilisation of palliative care services (hospice ward care, palliative care consultation and hospice home care) between those with schizophrenia diagnosis and those without at 3 months before death (OR 1.03, 95% CI 0.090 to 1.18) or at 1 month before death (OR 1.03, 95% CI 0.99 to 1.33).[101] However, they also demonstrated that people with SMI were 31% less likely to receive a palliative care consultation than those without during the last month of life (OR 0.59, 95% CI 0.43 to 0.82).[101] In a study from France, decedents with schizophrenia diagnoses and cancer were 61% more likely to have frequent admissions to palliative care units in the last 31 days before death (OR 1.61, 95% CI 1.45 to 1.80), 152% more likely in the last 3 days before death (OR 2.52, 95% CI 2.25 to 2.82) and to have had 36% more time from initiation of palliative care to death (ß 0.36; standard deviation 0.03) than matched controls.[108]

Rates of hospice enrolment for people dying of cancer vary depending on the nature of the patient's SMI. One study demonstrates no significant differences in the rates of hospice ward care between decedents with schizophrenia diagnoses and those without within 1 month of death (RR 1.15, 95% CI 0.99 to 1.33),[101] and another found the same pattern regarding hospice enrolment for decedents with schizophrenia diagnoses and those without within 6 months of death (RR 11.3, 95% CI 0.63 to 2.01).[88] However, having depression ahead of a cancer diagnosis was found to be associated with a 19% higher hazard of hospice enrolment than not having depression ahead of a cancer diagnosis within the 30 days of death (subhazard ratio 1.19, 95% CI 1.11 to 1.28).[92] When looking at the length of stay once enrolled in hospice care, decedents with schizophrenia diagnoses had significantly longer hospice stays than those without (mean difference 44, 95% CI 5.16 to 82.84).[88] Having depression ahead of a cancer diagnosis has also been found to be associated with a 29% increased likelihood of longer hospice stays of $\geq$ 90 days than not having this (aOR 1.29, 95% CI 1.06 to 1.58).[92]

General practitioners and psychiatrists believe that people with SMI are less likely than other groups to have their palliative needs identified, are less likely to be referred to specialist palliative care and are less likely to engage with or to use specialist palliative care services once they are referred.[114] Conflicting findings are found across studies exploring the rates of the use of specialist palliative care in the community for decedents with a schizophrenia diagnosis who died from cancer, depending on the time frame for which EoL care is measured. One study shows that decedents with schizophrenia diagnoses (where the cause of death meant that they were amenable to palliative care) were 66% less likely to receive hospital-based specialist palliative care (RR 0.34, 95% CI 0.26 to 0.44)[107] and 62% less likely to have received specialist palliative care in the community than those without in the LYoL (OR 0.38, 95% CI 0.30 to 0.48).[107] Further analysis found that being enrolled in community-based specialist palliative care was associated with a 50% increased rate of hospital admission [hazard ratio (HR) 1.5, 95% CI 1.1 to 2.1] but no change in the rate of ED presentation (HR 1.2, 95% CI 0.8 to 1.7). Among decedents in the matched cohort, being enrolled in the service was associated with a 60% lower rate of emergency department admission (HR 1.6, 95% CI 1.2 to 2.4) but no difference in the rate of hospital admissions (HR 0.8, 95% CI 0.6 to 1.0).[107]

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Decedents with schizophrenia diagnoses who died of cancer were 29% less likely to have used specialist palliative care in the community than decedents without within 6 months of death (aRR 0.71, 95% CI 0.62 to 0.81)[95] and also to have received significantly fewer days of specialist palliative care in the community on average (59.3 days compared with 76.2 days).[95] However, when looking within 1 month or 3 months of death, one study[101] found no significant differences in rates between decedents with schizophrenia diagnoses for whom the cause of death was cancer and those without (OR 1.11, 95% CI 0.89 to 1.39, and OR 1.21, 95% CI 0.99 to 1.48, respectively).[101]

Long-term institutional care

One study (reporting across two publications) explores the use of long-term institutional care (nursing homes, care homes) for those with and those without SMI at the EoL.[95,97] Decedents with schizophrenia diagnoses who died of cancer had a significantly increased rate of use of long-term institutional care than decedents without within 6 months of death, as demonstrated by a higher percentage residing in a nursing home (aRR 4.28, 95% CI 3.55 to 5.16).[95] They also had significantly longer lengths of stay than those without schizophrenia diagnoses in the 6 months before death, as demonstrated by the rate of days residing in a nursing home (per person) (aRR 5.19, 95% CI 3.60 to 7.78).[95] Decedents with schizophrenia diagnoses who died in a nursing home had significantly lower rates of inpatient hospital days than those without within with 6 months of death (aRR 0.80, 95% CI 0.67 to 0.95).[97] However, no significant differences were shown between cohorts for rates of GP visits (aRR 1.14, 95% CI 0.89 to 1.20),[97] specialist visits (aRR 1.14, 95% CI 0.97 to 1.33) or hospital separation rates (RR 0.93, 95% CI 0.82 to 1.06) [separation from a health-care facility occurs any time a patient (or resident) leaves because of death, discharge, sign-out against medical advice or transfer. The number of separations is the most commonly used measure of the utilisation of hospital services].[97]

Acute care

With regard to inpatient separations, decedents with schizophrenia diagnoses who died of cancer had a significant reduction in the rate of inpatient hospital separations compared with decedents without such diagnoses within the 6 months before death (aRR 0.79, 95% CI 0.73 to 0.86).[95] Across all causes of death, one study[91] found that decedents with pre-existing psychiatric illnesses were 41% less likely to have a hospital admission than those without within 1 month of death (OR 0.59, 95% CI 0.51 to 0.68).[91] A similar pattern was found when looking at cancer-specific deaths. Decedents with schizophrenia diagnoses were 27% less likely to have had more than one admission to acute care during the last 31 days of life (aOR 0.73, 95% CI 0.67 to 0.80).[108] In an exploration of rates of admission within 6 months of death, decedents with schizophrenia diagnoses had a 21% reduction in the rate compared with decedents without schizophrenia diagnoses (aRR 0.85, 95% CI 0.77 to 0.94).[95] Decedents with a schizophrenia diagnosis had a 40% reduction in the rate of admission compared with those without schizophrenia diagnoses (except for breast cancer) within the LYoL (aHR 0.6, 95% CI 0.5 to 0.8).[107] Lower rates of hospital admission were also observed for decedents with schizophrenia diagnoses who had heart failure (aHR 0.6, 95% CI 0.5 to 0.8),[107] cirrhosis/liver disease (aHR 0.5, 95% CI 0.3 to 1.2)[107] or renal disease/dialysis (aHR 0.6, 95% CI 0.3 to 1.2),[107] but no differences were found for those who had died from chronic lower respiratory disease (HR 0.7, 95% CI 0.4 to 1.2).[107]

With regard to length of stay, two studies showed no statistically significant differences between those with and those without SMI at EoL,[91,95] and another showed that length of stay was longer for those with SMI than for those without SMI.[108] In the studies that showed no difference, the populations were those with schizophrenia diagnoses and those without schizophrenia diagnoses who died of cancer in the 6 months before death (aRR 1.00, 95% CI 0.85 to 1.19),[95] and those with pre-existing mental illness and those without within 1 month of death across all causes of death (RR 0.93, 95% CI 0.86 to 1.00).[91] Conversely, Fond *et al.*[108] found that the median length of stay in acute care during the last 31 days of life was higher for decedents with schizophrenia diagnoses who died of cancer {median length of stay in acute care during the last 31 days of life [median (interquartile range) 16 (8–28), vs. 22 (11–31); $p < 0.0001$]}.

Intensive care unit admissions

When all causes of death were considered, decedents with pre-existing psychiatric illnesses were 59% less likely to be have been admitted for care in an ICU than those without pre-existing psychiatric illnesses within 1 month before death (OR 0.41, 95% CI 0.35 to 0.48).[91] This was also seen, albeit to a lesser extent (22%), for decedents with pre-cancer depression compared with those without pre-cancer depression within 1 month before death when the cause of death was lung cancer (aOR 0.78, 95% CI 0.67 to 0.90).[92] Conversely, it was found that having schizophrenia diagnoses and having died of cancer was associated with a 21% increased likelihood of having been admitted for care in an ICU compared with those without within 1 month of death (OR 1.21, 95% CI 1.07 to 1.36).[101] However, one further study found no association between having schizophrenia diagnoses and having died of cancer and at least one ICU admission during the last 31 days of life (aOR 0.92; 95% CI 0.91 to 1.09).[108] With regard to length of stay in the ICU, decedents with pre-existing mental illnesses spent significantly fewer days admitted than those without pre-existing mental illness in the 1 month prior to death (RR 0.88, 95% CI 0.79 to 0.97).[91]

Emergency department visits

Studies investigated rates of visits to the ED and, again, the results were mixed.[91,92,107,108] Across all causes of death, having pre-existing psychiatric illnesses was associated with a 64% increased likelihood of visiting the ED at least once compared with not having one, within 1 month of death (OR 1.64, 95% CI 1.30 to 2.08).[91] One study demonstrated that having pre-cancer depression was associated with a 22% reduction in the likelihood of visiting the ED at least once compared with those without pre-cancer depression within 1 month of death (aOR 0.78, 95% CI 0.62 to 0.98),[92] whereas another found no associations between having a schizophrenia diagnosis and attending the ED at least once during the last 31 days before death (OR 0.93, 0.91 to 1.09).[108]

Where disease-specific analyses in relation to cause of death have been undertaken for decedents with schizophrenia diagnoses compared with those without, significantly higher rates of attending the ED within 1 month of death have been found for those dying from ischaemic heart disease (HR 1.1, 95% CI 1.0 to 1.4),[107] heart failure (HR 1.0, 95% CI 0.8 to 1.3),[107] chronic lower respiratory disease (HR 1.1, 95% CI 0.8 to 1.3),[107] renal disease/dialysis (HR 1.1, 95% CI 0.8 to 1.5),[107] cirrhosis/liver disease (HR 1.0, 95% CI 0.8 to 1.2)[107] and cancer (HR 1.2, 95% CI 1.1 to 1.4).[107]

Invasive interventions

End-of-life HCPs working in the UK feel that there is a lack of standard guidance on resuscitation,[112] whereas staff in Australia report a legal requirement to always engage in cardiopulmonary resuscitation (CPR) in mental health settings. This is because of concerns about the validity of 'do not resuscitate' orders for people with SMI who may be judged as unable to consent to advance directives that might stipulate otherwise.[104] However, in one study it was found that no significant difference in orders about CPR existed between decedents with schizophrenia diagnoses and those without within 6 months of death at a Veterans Administration medical centre, in whom the cause of death was cancer (aRR 1.03, 95% CI 0.96 to 1.11).[88]

Mixed findings were evident for a range of invasive interventions across studies.[101,108] In the month before death, decedents with schizophrenia diagnoses in whom the cause of death was cancer were significantly more likely than those without schizophrenia diagnoses to have had CPR (OR 1.34, 96% CI 1.15 to 1.57), endotracheal intubation (OR 1.22, 95% CI 1.08 to 1.38), mechanical ventilation (OR 1.15, 95% CI 1.03 to 1.29), urinary catheterisation (OR 1.19, 95% CI 1.07 to 1.32), or feeding tubes (OR 1.41, 95% CI 1.26 to 1.58).[101] However, in a second study[108] no significant differences were found in artificial nutrition, tracheal intubation, mechanical ventilation, gastrostomy, dialysis, CPR and having at least one air extraction (sterile) chamber admission during the 31 days before death between those with schizophrenia diagnoses and those without. With regard to other procedures, the same study[108] showed that decedents with schizophrenia diagnoses and cancer were less likely to have undergone

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surgery (aOR 0.71, 95% CI 0.63 to 0.80) or to have had blood transfusions (aOR 0.72, 95% CI 0.64 to 0.83) in the 31 days before death.

Veterans with existing, but unspecified, mental health conditions, among whom over half had a terminal condition of cancer (30.1%) or heart disease (20.1%) at the time of death, were 20% less likely to have an intravenous infusion (OR 0.80; $p = 0.001$) than those without and 23% more likely to have both a do-not-resuscitate order (OR 1.23; $p = 0.002$) and physical restraints (OR 1.23; $p = 0.004$) than those without.[89]

Physician orders for life-sustaining treatment are orders that stay with the patient regardless of care setting and are most often used to limit life-sustaining treatments, artificially delivered nutrition and even transport to hospital.[88] Decedents with schizophrenia diagnoses who died of cancer were 267% more likely to have physician orders for life-sustaining treatment in place (OR 3.67, 95% CI 1.38 to 9.72).[88]

Chemotherapy

Findings are mixed relating to chemotherapy presented across studies.[89,92,108] Decedents with schizophrenia diagnoses in whom the cause of death was cancer were 45% less likely to have chemotherapy than those without within 1 month of death (OR 0.55, 95% CI 0.48 to 0.63)[89] or 47% less likely in the last 14 days of life (aOR 0.53, 95% CI 0.46 to 0.62).[108] In a study of people dying of lung cancer, no association was found between having depression ahead of a cancer diagnosis and not having depression ahead of diagnosis in the use of chemotherapy in the last 14 days of life (aOR 0.89, 95% CI 0.74 to 1.07).[92]

Advanced diagnostic examinations

Studies investigated whether those with SMI at the EoL were more or less likely to have received a number of different advanced diagnostic examinations.[101,108] Decedents with schizophrenia diagnoses in whom the cause of death was cancer were less likely to have had computed tomography, magnetic resonance imaging/sonography (OR 0.80, 95% CI 0.71 to 0.89), bone scans (OR 0.62, 95% CI 0.50 to 0.76) or positron emission tomography scans (OR 0.37, 95% CI 0.15 to 0.96) than those without within 1 month of death.[101] There were no differences in the use of pan-endoscopy (OR 0.98, 95% CI 0.84 to 1.15) or colonoscopy (OR 1.02, 95% CI 0.74 to 1.41) between the groups.[101] Decedents with schizophrenia diagnoses and cancer were less likely to have had imaging (OR 0.66, 95% CI 0.59 to 0.73) or endoscopy (OR 0.85, 95% CI 0.74 to 0.97) in the 31 days before death.[108]

Use of medications at the end of life

Decedents with schizophrenia diagnoses who died of cancer were 44% less likely to have used analgesia than those without in the 6 months prior to death, as demonstrated by the total days and rate per person-year of receiving analgesics (aRR 0.66, 95% CI 0.54 to 0.81).[95] However, there was no significant difference in the number of different drugs used between those with schizophrenia diagnoses who died from cancer and those without within 6 months of death as demonstrated by the number of different drugs (per person-year, for those on at least one prescription in the 6 months) (aOR1.02, 95% CI 0.96 to 1.08).[95]

Contrary to one study's hypothesis, veterans with schizophrenia diagnoses where the cause of death was cancer were no less likely than those without to receive opioid medications before hospice enrolment in the last 6 months of life (73% vs. 81%; OR 0.64, 95% CI 0.33 to 1.26).[88] A further study showed a significant association between a lifetime diagnosis of PTSD and the medications needed at the EoL, where there was found to be a higher use of medications (in particular hypnotics and antidepressants) at the EoL among terminally ill veterans with PTSD than among those without PTSD.[90]

Meeting individual and family needs

Eleven policy and guidance documents[21,30,156,161–166,170,176] and 20 research outputs (reporting 18 studies)[32,37,83–88,90,93,96,98,99,102,104,106,109,110,112,113] contribute to this subtheme.

Spiritual and psychosocial support

It is recognised that people with SMI have particular vulnerabilities arising from their mental health experiences, and will often lack support from personal networks.[176] This means that programmes and services for people with SMI at the EoL require a comprehensive team approach incorporating symptom relief (pain control),[30,37,98,110] psychological support (clinical psychology, counsellors and support groups),[37,164] psychosocial support (social worker)[30,90,102,104,106,110] and spiritual care (chaplain or spiritual counsellors),[30,90,98,102,104,106,110] whether in the mental health or the EoL setting. Nurses working in mental health settings highlight the importance of spiritual care for a peaceful death. They report that at the EoL many people with SMI tend to reflect on the meaning of their lives and frequently aim to resolve old issues.[110] One study shows that there are no significant differences in the likelihood of receiving a social work, chaplain or psychologist visits between veterans with and veterans without PTSD.[90]

Families and their involvement

In the mental health setting, HCPs report on the impact and challenges of chaotic family systems,[32,110,112] prior family estrangement[98,102,104,106,110] and family members also having a mental health diagnosis.[32] Attempting to negotiate contact with estranged family members is an important aspect of palliative care[98,102,104,110] as people with SMI often have less family support. This has implications for reduced advocacy and for reduced liaison with staff in the context of making shared treatment decisions, both of which serve as barriers to good EoL care.[112]

Among veterans with and veterans without PTSD, the majority (72%) received consultations before being referred for hospice care, including a family meeting. These consultations included most aspects of advance care planning, such as pain concerns, goals of care, feeding, hydration and symptom management. No significant differences were reported in the likelihood of family meetings occurring between veterans with and veterans without PTSD.[90] However, some family members of veterans with PTSD reported unmet needs for emotional support, especially in the last month of life, linked to poor communication with care providers. Family members also felt that their relatives were not treated with dignity and they were generally not satisfied with the level of care that their relative had received.[83]

Advocacy

Having an advocate that can support a person with SMI throughout their cancer journey, including at the EoL, is important.[30,162] Staff report that people with SMI being referred to palliative care and receiving services, such as pain control, is not straightforward and appears to be based on the presence or absence of a strong advocate.[32,106,112] HCPs have suggested that an advocate can be a family member, friend, health professional (e.g. a GP or a member of mental health staff), a public advocate,[106] an identifiable carer[32] or a case manager who has a history with the person using services.[112] People fulfilling this role can ensure that the needs of people with SMI at the EoL are recognised and met,[30] can support the development of palliative care skills among mental health staff and can improve the palliative care team's understanding of people's mental health needs.[162] Without such advocates, people with SMI may become 'lost in the system'.[106,156] Palliative care experts have a responsibility to act as advocates for people with SMI at the EoL, ensuring that they are not passed across agencies and do not fall through the gaps.[30]

Not having strong external social supports, and possibly having experienced family estrangement, means that people with SMI can lack access to advocacy to help navigate the complex EoL trajectory.[30,32,106,110,112,156,161,162] Those most at risk may have additional vulnerabilities, including being homeless or living on their own in boarding house accommodation,[106,156] or having mental health and/or learning disabilities.[161] In these circumstances, when admitted to hospital in crisis they may have nobody to speak on their behalf or to give their history and background,[156] and, as a result, 'ill-informed decisions are made about their care and discharge'(p. 8; contains public sector information licensed under the Open Government Licence v3.0).[156]

End-of-life care preferences

All countries are expected to have mechanisms in place to support people with disabilities to make decisions, and to use these mechanisms in preference to substitute decision-making processes.[176]

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It is in this context particularly that anticipatory, or advance, planning for people with mental health issues at the EoL is important,[164,165] along with the need for improved working across palliative care and mental health services and better education and training to support anticipatory care-planning skills.[163] Ninety per cent of mental health providers in England and Wales report having advance care planning processes in place, with 75% saying that they have a care plan that supports priorities for care compared with 97% of acute and community providers.[166] However, discussing EoL care wishes is often problematic for people who have SMI,[32,106,110,113,156,170] especially for those who are homeless.[113,156] Nursing staff report that it is sometimes difficult to have realistic conversations[32] and to distinguish reality from delusions when trying to explore the EoL care wishes of those with SMI.[110] Nursing staff have also expressed concerns that some patients with SMI may react differently to 'bad news' and, consequently, establishing EoL care preferences may be difficult.[110] It is therefore essential for HCPs to take sufficient time to assess the person properly, particularly if that person is unable to express their needs clearly.[106]

It is important not to assume that mental capacity is lacking;[21] however, the fluctuating or limited capacity of people with SMI at the EoL can challenge care,[106,112] and EoL HCPs are not always comfortable determining patients' capability to make medical decisions.[93] As a consequence, both palliative care and mental health nurses have a tendency to assume that mental capacity is lacking, with the consequence that discussions around advance care planning are avoided.[112]

Three studies examined scenario-based preferences regarding medical advance care planning among persons with SMI who were not at the EoL.[86,87,96] People with SMI were able to designate treatment preferences in response to EoL health state scenarios and felt comfortable talking about EoL matters.[86,96] Some people with SMI had thought about their medical treatment preferences in the event that they became seriously medically ill, but very few had discussed these preferences.[87] Others believed that someone should be designated to make medical health-care decisions for a person who is too sick to make or communicate these decisions themselves.[87] A further study into the EoL care perspectives of people with schizophrenia diagnoses (including those experiencing cognitive and emotional deficits) found that they were open to the idea of talking about EoL care and found this reassuring and sometimes beneficial.[109]

A retrospective medical records review[85] in the USA shows that, despite federal legislation being in place to support the use of a health proxy for patients with SMI, only 1 out of 344 patients whose care records were examined had a proxy in place. As a result, people were not assisted with advance care planning or with their preferences for medical treatment if they became seriously ill, despite this being identified as a right for persons with mental illness. Mental health and EoL nurses who work with people with SMI at the EoL report that people are capable of completing advance care planning documents without undue distress[85,110] and are able to make advanced decisions about medical treatments and decide who should make decisions if they become unable.[110] This is more likely to occur when open communication exists between people with SMI and practitioners.[106] However, professionals working with the homeless population at EoL (many of whom also have SMI) report that they often lack confidence in having such conversations and express concerns regarding the fragility and vulnerability of many homeless people.[113] Stajduhar *et al.*[99] report that homeless people are likely to experience oppression, poverty and inadequate housing, which usually makes the 'survival imperative' more important than accessing palliative care, and, as a result, advance care planning, the provision of palliative care or discussions about death and dying are not issues of importance in their everyday lives.[99] When EoL care was discussed with those residing in a homeless shelter-based hospice, most requested or agreed do-not-resuscitate orders and specifically declined emergency ambulance and hospital transfer.[98]

The authors of one study[88] hypothesised that veterans with schizophrenia diagnoses and advanced cancer would be less likely than those without schizophrenia diagnoses to complete advance directives. However, no differences were found (OR 1.29, 95% CI 0.72 to 2.32). Findings from another study[84] found that having a diagnosis of SMI was significantly associated with 24% lower odds of having any advance directives in a nursing home after controlling for a variety of resident and family characteristics (aOR 76, 95% CI 0.66 to 0.87).

Living with severe mental illness

Eight policy and guidance documents[22,30,156–158,161,162,170] and 11 research outputs[32,37,85,99,102,103,106,110,112–114] (reporting 10 studies) contribute to this theme, which addresses the individual and social characteristics of patients with SMI. Material is organised under three subthemes: complexities of EoL care, familiarity and trust, and recognising physical decline.

Complexities of end-of-life care

Two policy and guidance documents[156,170] and seven research papers[32,37,103,106,110,112,113] contribute to this subtheme.

Providing EoL care to people with SMI is challenged by patients' behaviour associated with their mental health difficulties.[32,37,103,106,110,112,113,156,170] Many HCPs often find it difficult to address mental health issues at the EoL, particularly if the person affected demonstrates complex or interpersonally challenging behaviour, anger or aggression, hostility or paranoia[32,37,112,113,156] and/or are uncommunicative or have limited communication.[37,106,110,112,156,170] EoL care HCPs typically report that they are challenged by both care-seeking and care-rejecting behaviours, unusual presentations, and angry and aggressive outbursts.[112] Unpredictable and potentially dangerous side effects arising from combined medications associated with SMI and EoL management are also challenges in EoL care for people with SMI.[106]

Familiarity and trust

Four policy and guidance documents[156,161,162,170] and nine research outputs[32,85,99,102,103,106,112–114] (reporting eight studies) contribute to this subtheme.

Trust and rapport

Early referral to palliative care services is important so that health-care staff can build trust and rapport with people with SMI.[106] There is also a need for greater integrated care, shared care-planning and better communication between specialist health and social care services to ensure that appropriate EoL care is provided in a familiar environment (where practicably possible) for those with SMI.[85,170] People with SMI who are living in supported accommodation, living in community-based residences, receiving institutional mental health care and/or are homeless may see 'home'[99,102,103,112,114] as linked with staff and residents they know and trust.[103,114]

Supporting people in familiar environments

People with SMI benefit from care in environments with which they are familiar, surrounded by people they know and trust. However, they often need to leave their familiar, supported accommodation at the EoL.[114] It is likely that staff offering usual mental health support will not be suitably qualified to provide EoL care.[99,102,103,113,114] Studies give examples of how staff in mental health establishments are able to care for people with SMI at EoL in mental health establishments. One showed how mental health staff sought advice from colleagues at local hospice/palliative care organisations so that patients could die in a familiar environment.[85] Another reported how opportunities for palliative care staff to visit people in mental health facilities were preferable to transferring people for palliative care because it prevented the problem of people becoming distressed in an unfamiliar environment.[102,103] Staff also talked about becoming a substitute family to the person with SMI and appreciated being able to care for them at the EoL.[102]

Providing palliative care in hostels is challenging, but as residents see these as 'home' this may make them a better choice than hospital at the EoL on the grounds of compassion and choice.[113] However, some residential staff have been reported as ignoring the subsequent pressure to transfer residents to acute care settings, often putting themselves at significant risk, simply to ensure that residents can, where possible, remain in an environment familiar to them at the EoL.[99] In the case of homeless people, even though hospitals are better suited to meet the physical needs of dying people, the benefits of enabling a person with SMI at the EoL to remain in a familiar hostel often outweigh the challenges.[113]

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However, significant deteriorations in EoL-related physical health commonly result in the homeless person being admitted to hospital in a crisis, when they may be unable to advocate for themselves and have nobody to speak on their behalf, and may also be experiencing language barriers, substance misuse problems, emotional volatility, social anxiety and other mental health issues.[156] Consequently, ill-informed decisions may be made about their care and subsequent discharge.[156] Furthermore, as and when the homeless person enters the EoL phase, hospitals and hospices may be unable to adequately support their complex physical and mental health needs and any associated issues such as chaotic lifestyles and addictions.[113,156]

Recognising physical decline

Six policy and guidance documents[22,30,156–158,161] and six research[99,106,110,112–114] outputs contribute to this subtheme.

Identifying signs of declining health

A key to good palliative care is the early recognition of declining physical health and a gradual awareness of the impending potential of death. However, the physical health needs of those with pre-existing SMI may not be identified and, as a result, care is often inadequate.[30,161] Death is often perceived as sudden, but in reality there are usually missed signs of deterioration,[156] including on the part of patients themselves.

People with schizophrenia often find it difficult to articulate their physical health needs to those who care for them, and they may not identify the significance of escalating physical symptoms that indicate a decline in their own health,[106,114] causing them to present late to services.[106,110] Access to quality health care is often diminished[114] and the commonality of previously unsatisfactory health-care encounters adds to delays in medical help-seeking.[106] This typically affects disease progression, delays the diagnosis process and has an impact on treatment and outcomes.[22,112] Many people with SMI die within 2 years of presentation with a serious physical health issue and initial deterioration.[114] Not only do those with SMI often not recognise the decline of their own health, but when they do they often experience difficulty in having their physical symptoms taken seriously[30,110] and, because of a history of such experiences, they end up making limited contact with primary care.[106]

The impact of late diagnosis

All of the factors cited above can, in turn, lead to a delayed/late diagnosis for people with SMI, and this presents a challenge in organising and providing quality EoL care as people are often not identified as approaching the EoL until a late stage of life-limiting physical disease such as cancer.[106,158] As a result, the timely provision of palliative care is hampered,[30,110] which ultimately results in people with SMI having little time to plan their EoL care.[157] This is particularly an issue for those who are homeless, as symptoms are not recognised by staff and it is difficult to predict disease trajectories as their health is often poor and their needs complex.[113]

Identifying an end-of-life care trajectory for those who are homeless

People who are homeless do not always see accessing EoL care and/or attending medical appointments as a priority, and HCPs often do not appreciate this, as the priority for patients is more about simply surviving.[99] Given the large number of fatalities from substance misuse among this group, death is often normalised, and as a result palliative care needs are relatively invisible.[99] Given this, and the chaotic lifestyle of many homeless people, predicting and even identifying an EoL care trajectory is problematic, especially when care is provided outside the formal health-care system, where workers have very little health or palliative care knowledge, experience and training.[99]

However, identifying deteriorating health in a timely manner is essential to allow time to plan appropriate care and support and may help to avoid crisis-driven hospital deaths.[156] Hostel staff and HCPs are reported as answering ‘no’ to what has been described as the ‘surprise question’ (‘Would you be surprised if this person were to die in the next 6–12 months?') asked about many homeless people.[113] This is in the context of homeless people being hard to assess for palliative care because of their complex needs and generally poor health, with prognostically uncertain conditions commonly experienced by many, including liver disease resulting from substance misuse or hepatitis C.[113] There is also evidence to suggest that when a homeless person is identified as dying (primarily from cancer) by health-care providers who better understand the social determinants of health, access to and provision of palliative care is improved.[99]

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Chapter 5 Thematic synthesis of case studies

This chapter thematically synthesises material from included case studies. Many of these report on key episodes, or critical junctures,[179] in the lives of people with SMI at the EoL. They include instances of people presenting to health services and then disappearing again, or pivotal decisions being made with profound impact for patients and others. Material from the case studies has been synthesised into five themes as follows: diagnostic delay and overshadowing, decisional capacity and dilemmas, medical futility, individuals and their networks, and care provision.

Diagnostic delay and overshadowing

Although the case studies ranged across many countries, they nevertheless show a consistent picture of delayed or late diagnosis and what might be termed diagnostic overshadowing. Complex and enduring mental health problems are often described as contributing to this. This is signalled in case studies as arising from the mental illness of the individual who fails to recognise the seriousness of their plight, and presents to services only when their condition is advanced and treatment options are limited.[124,132,133,137,144] Kunkel *et al.*[132] present four case examples of individuals with existing mental health problems, including that of Ms A, a 38-year-old African American woman with an unspecified psychosis presenting with a 20 cm mass in her right breast that was adhering to the chest wall. Investigations revealed a significant cancer with lymph node involvement but, despite the late presentation, there were no metastases. Ms A was treated with chemotherapy and surgery but then failed to attend for radiation treatment and considered the new lesions as nothing more than 'haematoma'. She later presented to the ED in respiratory distress and with large, presumably malignant, effusions, asked not to be resuscitated and died soon after. The case study paper labels Ms A's difficulty with accepting her situation and similar behaviours as 'maladaptive denial'.

This tendency to impute the mental conditions of individuals as a source of late presentation, or indeed of deciding not to continue with treatment, is a recurring feature of this literature. Other case study examples suggest how diagnosis and treatment of serious life-threatening or life-limiting physical conditions are complicated by untreated mental illness and the beliefs and behaviours arising from this.[132,133,137] A number of papers also appear to elide behavioural aspects of presentations with mental ill-health and position these as problematic in the delivery of care and treatment, with terms used such as 'malingering', 'manipulative', 'dominance and aggression' and 'demanding',[115,122,123,125] or problems for staff who 'struggled with how best to provide care'.[126]

Denial by people with SMI, or seeming to have a lack of insight, is a possible complicating factor. It is not unknown for any persons diagnosed with serious conditions to deny the gravity of their situation, and for people with pre-existing mental health conditions it appears that this is no different.[132] Feldman and Periyakoil[126] note that specific issues arise in cases of people with PTSD, where 'the threat to life inherent in terminal illness may mimic the original trauma', leading to an exacerbation of the psychological symptoms associated with the condition, including anxiety, anger, denial, avoidance and distrust of authority, impeding medical adherence and resulting in the refusal of treatment.

There are also examples of individuals with long histories of pre-existing mental health problems, often in long-stay facilities, who, despite their access to HCPs, experience delayed or late diagnosis of conditions that placed them on the EoL trajectory.[26,119,127,138,151–153] Terpstra *et al.*[144] present the case of a 61-year-old man with a longstanding diagnosis of schizophrenia, living in an adult foster home and under legal guardianship. The man was seen every 2 weeks at a mental health clinic and attended a primary care provider to report a new-onset cough. His examination was documented as benign, but 1 week later he complained of hypotension and left-sided weakness. A detailed examination revealed advanced bladder cancer and multiple brain metastases that had not been spotted until this last presentation.

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The authors locate the problem in the mental condition of the person and suggest that people with conditions such as schizophrenia do not willingly verbalise pain or related symptoms. It is, however, difficult to escape the issue that extended contact with health-care services could have included some monitoring of the physical health of the person.

Decisional capacity and dilemmas

Many of the case studies feature a concern about the decisional capacity of individuals to consent to treatment and/or to refuse treatments offered, and implicate professional dilemmas of determining the value of attempting curative treatments compared with palliation.[118,120,122,127,132,133,146,147,154] Romm *et al.*[140] argue that mental health staff have a particular duty to ensure that the interests of people with SMI are defended via treatments targeting potentially distorted states of mind, adding that although SMI can impair decisional capacity this should not be assumed and should be thoroughly assessed.[140] In some case study examples, the conclusion arrived at was that the person retained the capacity to determine their treatment choices, and that these choices were then respected.[120]

Treatment refusal is highlighted numerous times.[120,124,127,128,133,136,139,140,143,145–147] Past refusals seem to prompt treatment teams to impute future problems.[139] For example, Gonzalez *et al.*[128] present the case of an 86-year-old with a 20-year history of mastectomy for cancer and refusal of medical care who re-presented with a bleeding and ulcerating mass on the chest wall. The case study reported that the patient was not a case for curative treatment even though there was no evidence of metastases. The reasons for lack of curative efforts were indicated as:

> *curative treatment was not feasible based on a geriatric evaluation, which considered the patient's severe cognitive decline, advanced age of the patient's caregiver, and the expectations of the patient and his family.*
>
> *Gonzalez* et al.[128]

In some cases, treatment refusal is reported as arising from psychiatric symptomatology, such as fixed beliefs about damnation or that thoughts could be read by physicians, rather than being related to capacity to understand and make decisions based on available information.[26]

Approaching the courts for guidance is reportedly made in a variety of contexts, including where major concerns exist relating to a patient's capacity or best interests and for declarations on treatment in the case of patients lacking decision-making capacity.[146]. Shah *et al.*[141] report an example of treatment refusal by a man with decisional incapacity where the review of the medical ethics committee concluded that even with full decision-making capacity a person might refuse the radical procedures being proposed because of the risks involved and the deforming nature of the surgery.

Fluctuating mental capacity requiring multiple assessments[118,146] is also reported. In some reports, the option to review and return to previous decisions is implied in case examples.[141]

The absence of previously declared wishes on life-saving treatments appears to be a recurring issue and suggests one area for future intervention testing.[150] The absence of any declaration on treatment may mean that teams seek agreement of a substitute decision-maker, such as a family member,[139,140] sometimes with power of attorney, but the patient may indicate their refusal in their actions, for example repeatedly removing life-saving treatments such as catheters in renal dialysis[150] or not agreeing to take medication.[132] Enforcing medical treatment of a person who is actively refusing is not supported in this literature and it is argued that doing so may complicate future alliance building.[139]

Medical futility

Some case studies reveal, in the example of people with anorexia nervosa, how experience of this condition can exhaust the optimism of those doing the caring, and the language used, such as 'refractory' and 'incurable', reflects this.[148] Lopez *et al.*[134] describe the case of Ms A, a 30-year-old woman with a diagnosis of anorexia nervosa, where 'neither forcing her into involuntary treatment nor waiting for her to voluntarily engage in treatment appeared likely to resolve her illness, return her to a state of life-sustaining clinical stability or provide her a decent quality of life'.[134] The paper invokes the concept of medical futility, and the case demonstrates an example of the use of palliation and referral to hospice care for this psychiatric condition. In this case, it is also reported that the option of an out-of-state eating disorder treatment programme, which was acceptable, was eventually rejected on cost grounds, implying that perhaps the situation was less futile than indicated. Nevertheless, the treatment team and the ethics committee concluded 'that her physical and psychiatric impairments were likely to lead to her death, despite any plausible attempts at aggressive intervention'.[134] The palliative care team therefore commenced involvement with the consent of both the patient and the family.

Individuals and their networks

For many people with SMI the availability of support networks in their communities is crucial, and the absence of these supports is implicated in delayed treatment seeking. Some case studies refer to family involvement,[115,129,130,135,145,154] whereas others indicate the lack or absence of such support.[122,124,180] The EoL condition in some circumstances appears to have led to the re-emergence of family support,[152] or that teams actively support the person to reconnect with distant family.[120] In some instances, tensions in family involvement are reported,[123,131] and in one example family dynamics are situated as the source of subsequent mental health-related troubles.[148] Other case studies identify the reciprocal nature of support, and report the concerns of the individual with the EoL condition for their family.[129,130] EoL care places an additional set of demands on families, such as learning to manage symptoms,[116] and some conditions appear to result in exhausted or burned-out family members.[134] An additional demand on support networks can arise from the absence of advance decisions or where decisional capacity is in question so that, for instance, families may be involved in discussions on treatment and with do-not-resuscitate decisions for which they may be ill-prepared.[127,132,139,140,150] Families also show some concern that their family member's mental health problems are overlooked by the palliative care team.[145]

Care provision

Where case studies report on the ongoing delivery of care to individuals with pre-existing SMI and subsequent EoL condition, they advocate the benefits of a transdisciplinary approach involving palliative care specialists, psychiatric specialists (preferably the team whose members already know the person) and wider community members (e.g. religious ministers).[15,26,119,120,134,140,148] Stecker[142] provides an example of drawing on a specialist in both oncology and psychiatry to advise an inpatient mental health nursing team.

Liaison consultation and collaboration is reported as beneficial for hospice staff. Examples include learning from psychiatric consultation,[125] learning from psychologists on how to alter the environment to reduce distress[116] and a hospice nurse being supported by a psychiatric nurse.[131] Case reports note the mutual benefits of hospice and mental health nurses working together in EoL care, and the similarities in their work, but they also note a need for hospice staff to be better informed about mental health conditions.[145] Case studies also demonstrate the interest that mental health teams have in learning from their colleagues working in palliative care.[152]

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Some case study papers present models of care, although these are small scale and may not indicate either transferability or generalisability. Examples include treatment models such as dynamic system analysis,[115] stepwise psychosocial palliative care[116,117] and the patient, provider, systems model.[26]

Case studies reveal issues in the provision of care for treatment teams, such as how to handle psychiatric presentations.[115,123,139,145] Case studies also report examples of what has worked in supporting people with mental health problems at the EoL, including building rapport and trust, especially with people with PTSD;[116] using music therapy at the EoL;[149] having conversations about death;[26,129,130,152] initiating hospice at home;[26,129,130] and providing multidisciplinary mental health care and palliative care at home.[120]

An array of places for the provision of EoL care is proposed and supported in case studies. In almost every example the place of care and treatment is positioned as one arising from the preferences of the individual. These include palliative care provision in mental health institutions,[127,152,153] hospice care for mental health patients,[125,135,144,148] acute hospital[15] and home care.[120] Repeated transfer between settings related to psychiatric and/or physical symptomatology is also evident,[139] suggesting potential challenges to continuity of care.

Challenges reported in this literature include mental health staff being emotionally unprepared for caring for people who are terminally ill,[142] an observation that it is suggested supports the need for staff to become aware of feelings that may interfere with their therapeutic functioning. Where people with SMI receive EoL care in hospices, palliative care staff are reported as experiencing strong emotions, such as anger and frustration.[116] Case study papers also occasionally offer psychodynamic interpretations of staff–patient interactions and care.[115,131,142]

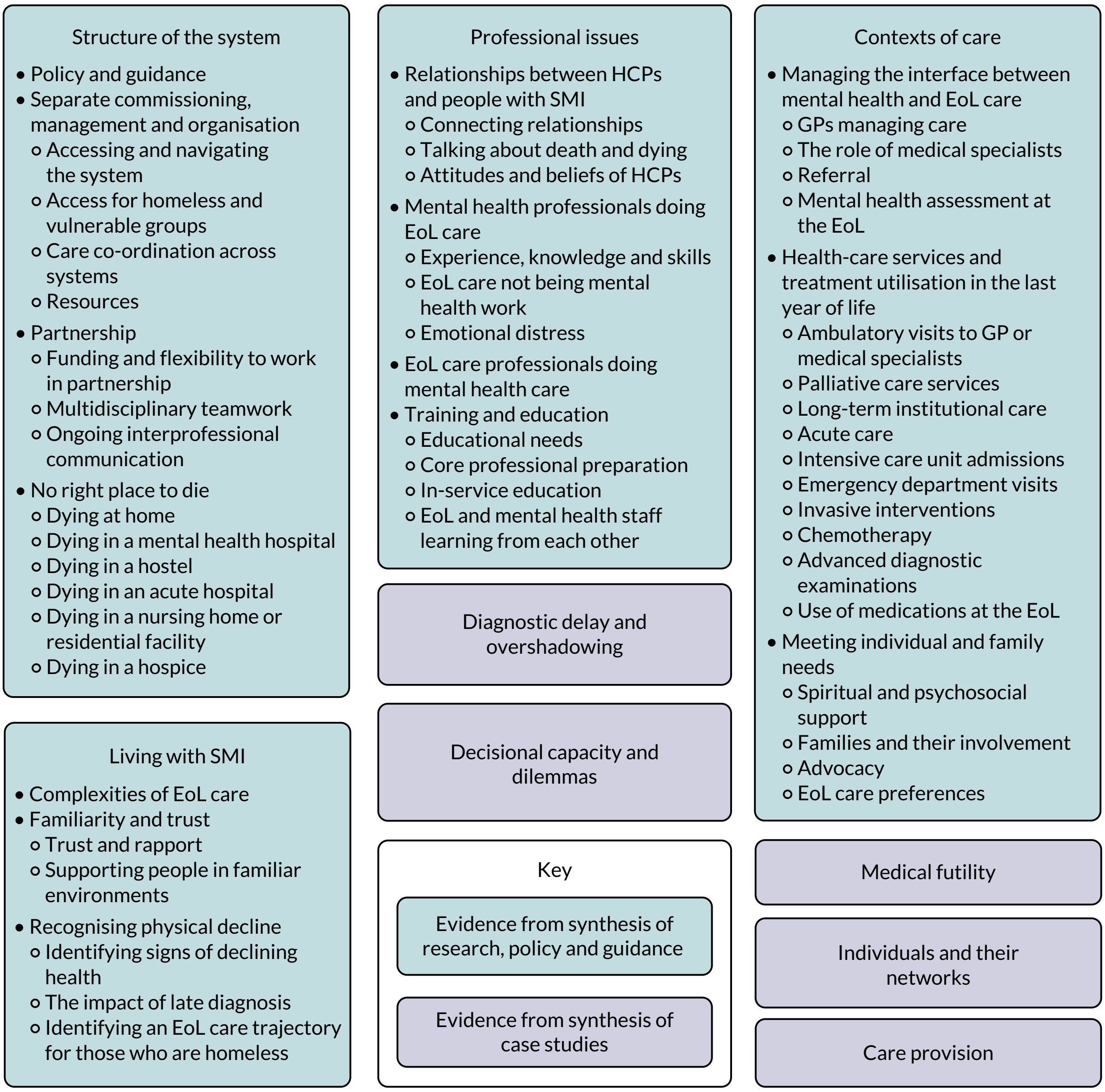
Treatment challenges are reported in managing some mental health-related medication alongside the provision of chemotherapy. Two case study papers report issues with the prescription of clozapine, as this is implicated in depressing white blood cell counts, which, in consequence, could precipitate a life-threatening infection.[136,138] Treatment challenges also arise from people with SMI at the EoL absconding or being lost to follow-up.[137,147] One paper reports a concern regarding suicide risk assessment in EoL care, although this is not a feature directly relevant in the case presented.[145] A further challenge is in providing palliative care to patients who, despite being provided with careful explanation, continue to believe that they are not going to die.[134]

Chapter 6 Overarching summary and conclusion

This chapter summarises the main findings from both of the thematic syntheses and presents assessments of the confidence in the summaries of the synthesised findings reported in *Chapter 4*. Implications for service commissioning, organisation and provision are outlined and recommendations are made, drawing on both syntheses, for future research.

Summary of what has been learned

Figure 6 summarises the main findings from the two thematic syntheses, the first drawing on research, policy and guidance and the second drawing on case studies.



Structure of the system

- Policy and guidance
- Separate commissioning, management and organisation
  - Accessing and navigating the system
  - Access for homeless and vulnerable groups
  - Care co-ordination across systems
  - Resources
- Partnership
  - Funding and flexibility to work in partnership
  - Multidisciplinary teamwork
  - Ongoing interprofessional communication
- No right place to die
  - Dying at home
  - Dying in a mental health hospital
  - Dying in a hostel
  - Dying in an acute hospital
  - Dying in a nursing home or residential facility
  - Dying in a hospice

Living with SMI

- Complexities of EoL care
- Familiarity and trust
  - Trust and rapport
  - Supporting people in familiar environments
- Recognising physical decline
  - Identifying signs of declining health
  - The impact of late diagnosis
  - Identifying an EoL care trajectory for those who are homeless

Professional issues

- Relationships between HCPs and people with SMI
  - Connecting relationships
  - Talking about death and dying
  - Attitudes and beliefs of HCPs
- Mental health professionals doing EoL care
  - Experience, knowledge and skills
  - EoL care not being mental health work
  - Emotional distress
- EoL care professionals doing mental health care
- Training and education
  - Educational needs
  - Core professional preparation
  - In-service education
  - EoL and mental health staff learning from each other

Diagnostic delay and overshadowing

Decisional capacity and dilemmas

Key

Evidence from synthesis of research, policy and guidance

Evidence from synthesis of case studies

Contexts of care

- Managing the interface between mental health and EoL care
  - GPs managing care
  - The role of medical specialists
  - Referral
  - Mental health assessment at the EoL
- Health-care services and treatment utilisation in the last year of life
  - Ambulatory visits to GP or medical specialists
  - Palliative care services
  - Long-term institutional care
  - Acute care
  - Intensive care unit admissions
  - Emergency department visits
  - Invasive interventions
  - Chemotherapy
  - Advanced diagnostic examinations
  - Use of medications at the EoL
- Meeting individual and family needs
  - Spiritual and psychosocial support
  - Families and their involvement
  - Advocacy
  - EoL care preferences

Medical futility

Individuals and their networks

Care provision

FIGURE 6 Summary of thematic syntheses.

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Overarching summary of first synthesis

This section presents an overarching summary of the first synthesis (see *Chapter 4*) complete with an assessment of confidence. The qualitative and non-intervention findings were assessed for confidence using the CERQual (*Table 8*) approach. The quality of evidence derived from retrospective cohort studies also included in this first synthesis was assessed using the GRADE approach. *Appendices 21–24* include the detail of how the CERQual statements were generated, along with the detail of the ungraded summary statements derived from policy and guidance material.

TABLE 8 The CERQual summary of findings table

Summary of review finding	Studies contributing to review finding	CERQual confidence
Synthesis 1: structure of the system *Policy and guidance*		
1. Owing to a lack of national and local guidance regarding EoL care and mental health care, palliative care nurses report concerns about their legislative responsibility	112	VL
Separate commissioning, management and organising		
2. HCPs recognise that accessing and navigating EoL care for those with SMI is a challenge and many obstacles exist	102–104,106,114	M
3. Homeless people are often excluded from hospices and care homes, and HCPs report difficulties in placing homeless people with cancer	99,113	M
4. Separate commissioning, management and ways of organising both services and professionals creates challenges for both mental health and EoL HCPs to co-ordinate high-quality care across mental health and EoL care systems	112	VL
5. The invisibility of homeless and vulnerable people, and the fragmented character of care systems, means that they often have to act as their own care co-ordinators	99,112,113	M
6. Multiple proposals have been made to improve the co-ordination of care for people with SMI at the EoL, mostly involving the identification of staff with clear responsibilities	32,94,114	M
7. HCPs feel that there is a lack of resources in terms of services and trained professionals who are able to meet the needs of those with SMI at EoL	85,93,114	M
Partnership		
8. Working in partnership across EoL and mental health services is important, and when flexibility and solutions to work in partnership across agencies exist then EoL care for those with SMI can be facilitated	85	M
9. A lack of good relationships and partnership working, influenced by reductions in funding and competitive commissioning, inhibit good care, especially with regard to pain management, needs assessments and assessment of mental capacity	106,112,114	M
10. HCPs report that formal (and sometimes ad hoc) multidisciplinary teamwork can improve patient outcomes	85,102–106	M
11. Coalition-building and formal opportunities to meet and discuss care are essential and must ensure that information is made available to primary care and social services partners	85,93,112,114	H

TABLE 8 The CERQual summary of findings table (*continued*)

Summary of review finding	Studies contributing to review finding	CERQual confidence
No right place to die		
12. Mental health and EoL staff recognise that allowing people to die in the location of their choice (which is often a home or home-like environment) is important, but staff also talk about how appropriate care is often lacking in all settings	32,106,114	H
13. Mental health services rarely care for people with SMI at the EoL as they are poorly equipped to meet their needs, and as a result patients are frequently moved between services	32,110,112	H
14. Multiple challenges exist for EoL care to take place in a hostel, including a lack of staff preparedness, the chaotic environment, and concerns over risks and the safe storage of medication	98,113	M
15. Providing EoL care in the community, in mental health settings or in homeless shelters can be difficult and as a result those with SMI are often transferred into acute settings at the EoL, but providing mental health care in acute settings also poses challenges	32,105,106,110,112,114	M
16. Staff working in hospices report that hospices are ill-prepared to care for the needs of homeless people at the EoL and require more help in dealing with substance misuse and the alternative lifestyles of what is mostly a younger age group	99,113	M
Synthesis 2: professional issues *Relationships between HCPs and people with SMI*		
1. Some mental health staff feel that building nurturing relationships is important, especially for those with limited social networks and no family contact. However, others choose not to form such relationships, finding it too upsetting when patients are transferred for EoL care	32,102–104,106,110,114	H
2. Some mental health staff find conversations about death and dying challenging, but those who feel able to have these have found that patients are receptive	106,110,112,114	H
3. The underlying stigmatising and prejudicial attitudes of EoL HCPs towards those with SMI, including those who are homeless, can affect decisions around EoL care	32,37,99,102–104,112–114	H
Mental health professionals doing EoL care		
4. Mental health staff feel that they have limited experience of caring for patients with SMI at the EoL, and although some feel able to deliver care others feel that they lack the knowledge and skills, particularly with regard to pain management and psychosocial or spiritual support	102–104,110,112	M
5. Some mental health staff report that they do not feel able, are not interested or avoid caring for people with SMI at the EoL, whereas others embrace caring for them	32,93,105,110,112	M
6. Mental health staff report that caring for those with SMI at EoL can be distressing and emotionally draining, and some fear being scrutinised following the death of patients	32,37,102–104	M
EoL HCPs doing mental health care		
7. EoL HCPs feel that they lack knowledge and understanding of mental health diagnoses and services. As a result, they report that they are not always confident, willing or comfortable to care for patients with SMI at the EoL	32,37,93,102–104,106,110,112	M

continued

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TABLE 8 The CERQual summary of findings table (*continued*)

Summary of review finding	Studies contributing to review finding	CERQual confidence
Training and education		
8. Mental health and EoL HCPs have highlighted a wide range of educational needs	37,85,102–104	M
9. Palliative care programme directors have suggested that psychiatry training is inadequate in the categories of EoL care and issues related to death and dying	93	VL
10. Although some mental health nurses feel that that their core professional preparation enables them to care for people with SMI during periods of physical illness and at the EoL others feel that this is something that can be improved	32,102–104	M
11. EoL and mental health staff learning from each other, such as through cross-training, has been positively evaluated	85,95	VL
Synthesis 3: contexts of care *Managing the interface between mental health and EoL care*		
1. GPs are the gatekeepers in enabling or hindering access to palliative care services and in some instances they manage the palliative care needs of people with SMI within their practice	110,114	M
2. People with SMI are reported to visit a number of different types of physician specialists as well as psychiatrists at EoL	93,110,114	M
3. Both EoL and mental health staff acknowledge that referrals are often complicated and lack vital information that would facilitate communication between themselves and those with SMI at the EoL	106,112	L
4. Both EoL and mental health HCPs across a variety of settings report that mental health assessments at the EoL can be a challenge and that they need help to deal with their fears and uncertainties	37,105,112,114	M
Health-care services and treatment utilisation in the LYoL		
5. GPs and psychiatrists believe that people with SMI are less likely than other groups to make use of specialist palliative care	110	VL
6. EoL HCPs working in the UK feel that standard guidance on resuscitation is lacking for people with SMI at EoL	112	VL
7. EoL professionals in Australia have concerns about capacity to consent in relation to resuscitation orders for people with SMI at EoL	102–104	VL
Meeting individual and family needs		
8. Programmes and services for people with SMI at EoL require a comprehensive team approach incorporating symptom relief, psychological and psychosocial support, and spiritual care	37,90,98,102–104,106,110	H
9. HCPs report challenges in handling contact with families, especially when years of estrangement have occurred or where family members also have mental health conditions	32,98,102–104,110,112	M
10. Veterans with a diagnosis of PTSD were just as likely to receive a family consultation regarding advance care planning as those without a diagnosis of PTSD	90	VL
11. When families were involved in the care of veterans with a diagnosis of PTSD, they reported unmet needs for emotional support and felt generally that their relatives were not treated with dignity and were unsatisfied with the level of care received	83	VL
12. HCPs report that being referred to palliative care and receiving services appears to be based on the presence or absence of a strong advocate	32,106,112	H

TABLE 8 The CERQual summary of findings table (*continued*)

Summary of review finding	Studies contributing to review finding	CERQual confidence
13. People with SMI can lack access to advocacy to help navigate the complex EoL trajectory because of limited social and family support and, as a result, they can become 'lost in the system'	32,106,110,112	H
14. HCPs have concerns about negotiating EoL care preferences with people with SMI for fear that mental health symptoms may influence understanding and expectations or that such discussions may lead to further distress	32,106,110,113	M
15. HCPs report that they are not always comfortable with determining patients' capability to make medical decisions and that they tend to assume that mental capacity is lacking and as a result discussions around advance care planning are avoided	93,106,112	M
16. Findings from scenario-based preferences regarding medical advance care planning suggest that people with SMI are able to designate treatment preferences in response to the EoL and are open to discussing EoL care	86,96,109	M
17. People with SMI conditions are capable of completing advance care plans for the EoL but even where legislation is in place to support this it rarely appears to be standard practice	85,98,110	M
18. A lack of confidence to have open communication and experience among HCPs, especially when working with homeless people, may explain the absence of advance care planning for those with SMI at the EoL	98,99,106,113	M
Living with SMI *Complexities of EoL care*		
1. Challenging behaviours, communication issues and side effects of combining SMI and EoL medications make it difficult to address mental health issues at the EoL	32,37,102–104,106,110,112	M
Familiarity and trust		
2. Early referral to palliative care helps build trust and rapport between staff and people with SMI at the EoL	37,85,99,102–104,112,114	M
3. Although people with SMI often leave environments with which they are familiar at the EoL, mental health and palliative care staff can work together to support people without the need for moving	99,102–104,113,114	M
4. Hostel staff report that they try to ensure that palliative care can be provided in a familiar environment for as long as possible as they feel that the benefits outweigh the challenges	99,113	M
Recognising physical decline		
5. Staff report that people with SMI are not always able to recognise their own declining health, and it is felt that, because of previous unsatisfactory health-care encounters, they often present late to services	106,110,112,114	M
6. The timely provision of palliative care can be hampered when people with SMI (especially those who are homeless) are not identified as approaching the EoL until the late diagnosis of life-limiting physical disease	106,110,113	H
7. People who are homeless are often more concerned with day-to-day survival than with keeping appointments with HCPs, and this makes it difficult to identify EoL trajectories and to provide palliative care	99,113	M

H, high confidence; L, low confidence; M, moderate confidence; VL, very low confidence.

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A high degree of confidence was judged to apply to 10 of the 52 synthesis summary statements, distributed across all four major themes (*Structure of the system*, *Professional issues*, *Contexts of care* and *Living with severe mental illness*). All 10 were summary statements synthesised from generally well-conducted, relevant studies in which there was a high degree of coherence. A moderate degree of confidence was judged to apply to 32 of the statements, denoting concerns relating to one or more of the dimensions assessed in the underpinning evidence (methodology, coherence, relevance and adequacy), with the confidence in the remaining 10 summary statements judged as being either low or very low.

Structure of the system: confidence in the evidence

This evidence synthesis found that there is a lack of national and local guidance in the UK regarding EoL care and mental health care, and that palliative care nurses report concerns about their legislative responsibility (CERQual – very low).

Health-care professionals recognise that the separate commissioning, management and organisation of mental health and EoL services often result in those with SMI having trouble accessing and navigating the system (ungraded – non-research) and that many obstacles exist (CERQual – moderate). Access to health care is particularly difficult for homeless and vulnerable groups, who are often isolated and disconnected from family and friends (ungraded – non-research). Homeless people are also often excluded from hospices and care homes, and HCPs report difficulties in finding suitable placements for homeless people who have cancer (CERQual – moderate).

It is important that care is co-ordinated and integrated across services so that the needs of those with SMI at the EoL are met, although it is acknowledged that this is difficult to achieve (ungraded – non-research). The separate commissioning, management and ways of organising both services and professionals create challenges for both mental health and EoL HCPs in co-ordinating high-quality care across mental health and EoL care systems (CERQual – very low). The invisibility of homeless and vulnerable people, and the fragmented character of care systems, means that they often have to act as their own care co-ordinators (CERQual – moderate). Multiple proposals have been made to improve the co-ordination of care for people with SMI at the EoL, mostly involving the identification of staff with clear responsibilities (CERQual – moderate). HCPs feel that a barrier to being able to meet the needs of those with SMI at the EoL is a lack of resources in terms of appropriate services and trained professionals (CERQual – moderate).

Working in partnership across EoL and mental health services is important, and when flexibility and solutions to work in partnership across agencies exist then EoL care for those with SMI can be facilitated (CERQual – very low). However, a lack of good relationships and partnership working, influenced by reductions in funding and competitive commissioning, inhibit good care, especially with regard to pain management, needs assessments and the assessment of mental capacity (CERQual – moderate). Interagency and interprofessional team working at the EoL is important (ungraded – non-research) and HCPs report that formal (and sometimes ad hoc) multidisciplinary teamwork can improve patient outcomes (CERQual – moderate). Ongoing communication between partners is a key element of high-quality care (ungraded – non-research) and coalition-building and formal opportunities to meet and discuss care are essential and must ensure that information is made available to primary care and social services partners (CERQual – high).

With the right support from community-based services, people with SMI at the EoL are able to stay at home, and both mental health and EoL staff recognise that allowing people to die in the location of their choice (which is often home or a home-like environment) is important, but staff also talk about how appropriate care is often lacking in all settings (CERQual – high). However, results across the retrospective cohort studies are mixed regarding the likelihood of decedents with SMI having died at home compared with that of those without SMI at the EoL (GRADE – very low), but studies consistently report that decedents with SMI were significantly more likely than those without SMI to have died in a nursing home or residential facility (GRADE – very low). Results across the retrospective cohort studies were mixed regarding the likelihood of decedents with SMI having died at home compared with those without SMI (GRADE – very low). Retrospective cohort studies consistently reported that decedents with SMI were significantly more likely to have died in a nursing home or residential facility than those without SMI (GRADE – very low). In reality, people with SMI at the EoL are often moved between services and mental health services rarely care for them as they are poorly equipped to meet their needs (CERQual – high).

With regard to those who are homeless with SMI at the EoL, although one shelter-based hospice care programme was cost-effective and successful in delivering EoL care,[98] it is acknowledged that multiple challenges exist for EoL care to take place in a hostel, including lack of staff preparedness, the chaotic environment, and concerns over risks and the safe storage of medication (CERQual – moderate). Providing EoL care in the community, within mental health settings or homeless shelters, can be difficult and, as a result, those with SMI are often transferred into acute settings at the EoL, but providing mental health care in acute settings also poses challenges (CERQual – moderate). However, results across retrospective cohort studies are mixed regarding the likelihood of decedents with SMI having died in a hospital compared without SMI at the EoL (GRADE – very low). Staff working in hospices report that hospices are ill prepared for caring for the needs of homeless people at the EoL, and require more help in dealing with substance misuse and the alternative lifestyles of what is mostly a younger age group (CERQual – moderate). For people with SMI more generally, one retrospective cohort study found no significant differences in the likelihood of dying in a hospice between those with and those without a history of mental illness (GRADE – very low).

Professional issues: confidence in the evidence

A number of different aspects of the relationships between HCPs and people with SMI have been explored. Mental health staff feel that building nurturing relationships between HCPs and people with SMI is important, especially for those who have limited social networks and no family contact. However, others choose not to form such relationships, finding it too upsetting when patients are transferred for EoL care (CERQual – high). Being able to talk about death and dying is crucial if people with life-limiting illnesses (including people also living with SMI) are to be supported to make decisions at the EoL, and good communication is an important aspect of this (ungraded – non-research). Even though some mental health staff find conversations about death and dying challenging, those who feel able to do so have found that patients are receptive (CERQual – high). Relationships, however, can be hindered by the attitudes and beliefs of HCPs. This includes the underlying stigmatising and prejudicial attitudes of EoL HCPs towards those with SMI, including those who are homeless, which can affect decisions around EoL care (CERQual – high).

Mental health staff feel that they have limited experience of caring for patients with SMI at the EOL and although some feel able to deliver care others feel that they lack the knowledge and skills, particularly with regard to pain management and psychosocial or spiritual support (CERQual – moderate). Some feel that EoL care is not mental health work and they report that they do not feel able to, are not interested in or avoid caring for people with SMI at the EoL, whereas others embrace caring for people with SMI at the EoL. They also report that caring for those with SMI at the EoL can be distressing and emotionally draining, and some fear being scrutinised following the death of patients (CERQual – moderate). It is recognised that staff who provide care to this group of patients will need support (ungraded – non-research). When it comes to EoL HCPs delivering care to those with SMI, they feel that they lack knowledge and understanding of mental health diagnoses and services. As a result, they report that they are not always confident, willing or comfortable to care for patients with SMI at the EoL (CERQual – moderate). As a consequence of this, the needs of people with SMI at the EoL are not always well met (ungraded – non-research). It is widely recognised that education and training opportunities across professional groups who care for people with SMI at the EoL are important, that core professional preparation could be improved (ungraded – non-research) and that greater opportunities could be provided for in-service education (ungraded – non-research).

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Mental health and EoL HCPs have highlighted a wide range of educational needs (CERQual – moderate). With regard to core professional preparation, palliative care programme directors have suggested that psychiatry training is inadequate in the categories of EoL care and issues related to death and dying (CERQual – very low). Although some mental health nurses feel that that their core professional preparation enables them to care for people with SMI during periods of physical illness and at the EoL, others feel that this is something that could be improved (CERQual – moderate). However, it is recognised that in-service education opportunities for HCPs to develop skills and knowledge in EoL care are patchy, particularly in organisations providing mental health care, and could be developed (ungraded – non-research). One solution is for EoL and mental health staff to work together so that knowledge and awareness can be improved, such as through the establishment of dedicated link positions with roles including the provision of education (ungraded – non-research). Another solution that has been positively evaluated is EoL and mental health staff learning from each other through initiatives, such as cross-training (CERQual – very low).

Contexts of care: confidence in the evidence

General practitioners are the gatekeepers at the interface between mental health and EoL care and can enable or hinder access to palliative care services and, in some instances, manage the palliative care needs of people with SMI in their practice (CERQual – moderate). However, one study showed no significant differences in the rates of ambulatory visits to the GP within 6 months of death between those with schizophrenia and those without schizophrenia who died from cancer (GRADE – very low). People with SMI are also reported to visit a number of different types of physician specialists as well as psychiatrists at the EoL (CERQual – moderate), and one study showed that decedents with schizophrenia were significantly less likely to visit a medical specialist than those without schizophrenia (GRADE – very low). Regardless of the initial point of contact, support for people living with mental health issues and approaching the EoL must be fast-tracked or prioritised (ungraded – non-research). Both EoL and mental health staff acknowledge that referrals are often complicated and lack vital information that would facilitate communication between professionals and people with SMI at the EoL (CERQual – low). Once a person with SMI has been referred successfully, skilled mental health assessment at the EoL is required so that care can be planned and they can be helped to manage their symptoms and other needs (ungraded – non-research). Both EoL and mental health HCPs across a variety of settings report that mental health assessments at the EoL can be a challenge and that they need help to deal with their fears and uncertainties (CERQual – moderate).

With regard to health-care service utilisation at the EoL, GPs and psychiatrists believe that people with SMI are less likely than other groups to make use of specialist palliative care (CERQual – very low). However, findings across retrospective cohort studies are inconsistent regarding the rates of utilisation of palliative care or specialist palliative care in the community among decedents with and decedents without schizophrenia diagnoses who died from cancer at different time points throughout the LYoL (GRADE – very low). When looking at hospices, significant differences were seen in rates of enrolment for decedents with a schizophrenia diagnosis who died of cancer (GRADE – very low), although one study showed that having depression ahead of a cancer diagnosis was associated with a significantly increased rate in hospice enrolment and in length of stay (GRADE – very low).

At the EoL, people with SMI use long-stay, hospital, ED and ICU care in different ways from people without SMI, but findings from research in this area are inconsistent (GRADE – very low). One study shows that decedents with a schizophrenia diagnosis who died of cancer had a significantly increased rate of use long-term institutional care and longer lengths of stay than those without within 6 months of death (GRADE – very low). However, studies consistently report that people with SMI who died from cancer, heart failure cirrhosis/liver disease or renal disease/dialysis were significantly less likely to have been admitted to hospital at the EoL than those without SMI, but no differences were noted for those who died from chronic lower respiratory disease (GRADE – very low).

At the EoL, people with SMI receive invasive interventions such as analgesia or opioid medication, chemotherapy and advanced diagnostic examinations in different ways from people without SMI, but findings from research in this area are inconsistent (GRADE – very low). One study shows that decedents with schizophrenia diagnoses who died of cancer were significantly more likely to have physician orders for life-sustaining treatment (GRADE – very low). A further study shows that veterans with pre-existing, but unspecified, mental health conditions where over half had a terminal condition of cancer or heart disease were more likely to receive care that was directed at controlling symptoms or supporting do-not-resuscitate orders (GRADE – very low). EoL HCPs working in the UK feel that standard guidance on resuscitation is lacking for people with SMI at EoL (CERQual – very low), and EoL professionals in Australia have concerns about capacity to consent in relation to resuscitation orders for people with SMI at the EoL (CERQual – very low). Only one study explored rates of CPR and found no significant differences between those with and those without SMI at the EoL (GRADE – very low).

Meeting individual and family needs is an area that has been explored. People with SMI have particular vulnerabilities arising from their mental health experiences, and programmes and services for people with SMI at the EoL require a comprehensive team approach (ungraded – non-research). Programmes and services for people with SMI at the EoL require a comprehensive team approach incorporating symptom relief, psychological and psychosocial support, and spiritual care (CERQual – high). On exploring families and their involvement, HCPs report challenges in handling contact with families, especially where years of estrangement have occurred or where family members also have mental health conditions (CERQual – moderate). Some work has been conducted with veterans with a diagnosis of PTSD at the EoL that shows that their families were just as likely to receive a consultation regarding advance care planning as those without a diagnosis of PTSD (CERQual – very low). However, when families were involved in the care of veterans with a diagnosis of PTSD they reported unmet needs for emotional support, felt generally that their relatives were not treated with dignity and were unsatisfied with the level of care received (CERQual – very low).

Having an advocate who can support a person with SMI throughout their cancer journey, including at the EoL, is important, and such advocates can prevent people with SMI from falling through gaps in the system (ungraded – non-research). HCPs report that whether or not people with SMI are referred to palliative care and receive services appears to be based on the presence or absence of a strong advocate (CERQual – high). However, people with SMI can lack access to advocacy to help them navigate the complex EoL trajectory owing to limited social and family support and, as a result, they can become ‘lost in the system’ (CERQual – high).

End-of-life care preferences, such as advance care planning, for people with SMI at the EoL are important, and mechanisms should be in place to support these people to make their own decisions, although it is recognised that this can be problematic (ungraded – non-research). HCPs have concerns about negotiating EoL care preferences with people with SMI because of the fear that the person’s mental health symptoms may influence their understanding and expectations or that such discussions may lead to further distress (CERQual – moderate). Another issue with this population group is mental capacity and in the context of making decisions it is important not to assume that this is lacking (ungraded – non-research). HCPs report that they are not always comfortable with determining patients’ capability to make medical decisions and that they tend to assume that mental capacity is lacking and, as a result, discussions aound advance care planning are avoided (CERQual – moderate). Findings from scenario-based preferences regarding medical advance care planning suggest that people with SMI are able to designate treatment preferences in response to the EoL and are open to discussing EoL care (CERQual – moderate). People with SMI are capable of completing advance care plans for the EoL, but even where legislation is in place to support this it rarely appears to be standard practice (CERQual – moderate). Results from retrospective cohort studies are inconsistent regarding the likelihood of people with a diagnosis of SMI having completed an advance directive (GRADE – very low). A lack of confidence in having open communication and experience among HCPs, especially when working with homeless people, may explain the absence of advance care planning for those with SMI at the EoL (CERQual – moderate).

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Living with severe mental illness: confidence in the evidence

Providing EoL care to people with SMI can be challenged by patients' behaviour associated with their mental health difficulties (ungraded – non-research). The complexities of care for people living with SMI, such as challenging behaviours, communication issues and the side effects of combining SMI and EoL medications, make it difficult to address mental health issues at the EoL (CERQual – moderate). A number of factors can facilitate addressing mental health issues at the EoL and include the person with SMI being referred early to palliative care so that trust and rapport can be built between staff and people with SMI at the EoL (CERQual – moderate). Another facilitator is the ability to support people with familiar environments and, although people with SMI often leave environments with which they are familiar at the EoL, mental health and palliative care staff can work together to support people without the need for movement (CERQual – moderate). For those who are homeless and vulnerable this is not as easy as deteriorations in EoL-related physical health commonly results in the homeless person being transferred to hospital in crisis, where their needs are poorly met (ungraded – non-research). However, hostel staff report that where possible they try to ensure that palliative care can be provided in a familiar environment for as long as possible, as they feel that the benefits outweigh the challenges (CERQual – moderate).

It is acknowledged that not being able to recognise the physical health needs of, and the signs of physical deterioration in, those with pre-existing SMI can be a barrier to the receipt of adequate EoL care (ungraded – non-research). Staff report that people with SMI are not always able to recognise their own declining health and because of previous unsatisfactory health-care encounters it is felt that they often present late to services (CERQual – moderate). As a result, the timely provision of palliative care can be hampered when people with SMI (especially those who are homeless) are not identified as approaching the EoL until the late diagnosis of life-limiting physical disease (CERQual – high). People who are homeless are often more concerned with day-to-day survival than with keeping appointments with HCPs, and this makes it difficult to identify EoL trajectories and to provide palliative care (CERQual – moderate).

Implications for policy, services and practice

The purpose of assessing confidence in summaries of synthesised findings is to better support decisions by policy-makers, managers and senior practitioners, including in the areas of policy and guideline development.[82] The GRADE and CERQual assessments presented above are explicitly drawn on in this section. Particular weight is given to the 10 GRADE and CERQual summary statements, derived uniquely from research studies included in the review, and therefore not from case studies, policy or guidance, in which there is a high degree of confidence.

The key implications are as follows:

1. This evidence synthesis points with a high degree of confidence to the importance of formal and informal partnership opportunities being taken and encouraged. Partnerships can involve the building of coalitions across the whole system, including mental health, EoL, primary care, social care and other services. This is necessary to support the exchange of information in the integrated care of people with SMI at the EoL. In a context in which there is often 'no right place to die' and in which mental health staff are often poorly equipped to care for people at the EoL, and where people with SMI at the EoL face frequent moves between services, finding ways of supporting people to die in the location of their choice is a priority.
2. This synthesis also has implications for professional practice. Many people with SMI have limited social networks and little or no family contact, but even though mental health staff value the quality of their relationships with patients, some find it difficult to invest in relationships with people with SMI at the EoL because of the upset caused when patients are transferred to other facilities for EoL care. Mental health staff, many of whom find talking about death and dying with patients difficult, find that when opportunities are found patients are receptive. In the case of HCPs working in EoL care, stigmatising and prejudicial attitudes towards people with SMI and people who are homeless can affect EoL decision-making. All of these summary statements have clear implications for the future education, support and supervision of all care staff working across both the mental health and the EoL care systems.

3. A high-confidence synthesis summary from the contexts of care domain is that programmes and services for people with SMI at the EoL require a comprehensive team approach that incorporates symptom relief, psychological and psychosocial support, and spiritual care. Comprehensive services of this type are exactly as should be expected by all members of the population, but their importance for people with SMI at the EoL is worth restating for the purposes of promoting parity of esteem. Capable advocates are able to increase the numbers of people with SMI at the EoL who are referred to palliative care services, and to help make sure that palliative care is provided and received. Not having an advocate risks people with SMI who are lacking social and family support becoming 'lost in the system'. Taken together, these synthesis summaries have important implications for the identification of roles for members of the care team in co-ordinating services across boundaries, advocating for and on behalf of patients, and providing direct care.
4. A final high-confidence summary statement is derived from the evidence synthesised in the area of living with SMI. This review has found that the timely provision of palliative care can be hindered when people with SMI, and particularly those who are homeless, receive delayed diagnoses of their EoL-related conditions. This has implications for the proactive provision of physical health care to groups of people who might not recognise the seriousness of their condition and who might miss out on routine health assessments.

Recommendations for future research

The case studies synthesised in *Chapter 5* demonstrate the complexities and the ethical dilemmas associated with the provision of care to people with SMI at the EoL. Many are stark in revealing the challenges presented by delayed diagnosis, patients' fluctuating capacity to make decisions and the futility of treatment. Case studies also demonstrate, as does the included research, the unpreparedness of professionals to meet patients' multiple needs. Synthesised case study findings also show the dangers of ascribing delays in mobilising (or continuing with) palliative care services in response to what are often described, in written reports, as patients' challenging presentations, or even their wilfully difficult behaviour.

Among the research publications from which data were synthesised in *Chapter 4*, only three originate from the UK, and across all included research studies very few include either patients or family members as participants. The consequence of this is that information on the experiences of people with SMI at the EoL features most prominently in the synthesis of case studies, making this a wide-open area for future well-designed research. Significantly, none of the included research publications reported on intervention studies, and no research was found in the area of EoL care provided to people with SMI in the prison setting.

In this context of a paucity of research evidence, key recommendations for future studies arising from this evidence synthesis are as follows:

1. Patient- and family-facing studies should be commissioned to examine the experiences of people with SMI at the EoL, and the experiences of their surrounding paid and unpaid carers and those important to them, to establish the factors that help and hinder care in the UK-specific context.
2. A programme of research should be commissioned comprising studies that explicitly co-produce, introduce and evaluate new ways of providing and organising EoL care for people with SMI with both cancer and other life-threatening conditions. This programme should include studies involving support for structurally disadvantaged groups, including people with SMI at the EoL who are also homeless or who are in prison. Candidate interventions include advance care plans, advocacy and improved education for professionals, along with the development of new or enhanced roles for practitioners and the introduction of models of integrated provision spanning the mental health, EoL and related care systems.

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Limitations

All 30 research studies reported in 34 publications included in this review were undertaken in high-income countries with developed health systems, but only three were completed in the UK.[37,112,113] All three UK studies used qualitative methods, but only one[113] included people who had experience of using services and none evaluated interventions to improve care. Although implications for policy, services and practice arising from this project have been drawn from all 30 studies, it is recognised that contextual differences in global health and social care systems (e.g. relating to the funding of services) need to be borne in mind when the transferability of findings and summary evidence statements are considered. In addition, it is recognised that the search for policy and guidance was limited to the UK only, rather than being extended to other countries around the world, including those with broadly comparable health systems. With only English-language items included in this project, the possibility also exists that important research and other evidence of relevance has been neither identified nor included. Finally, as no intervention studies were located, no meta-analysis could be performed.

Conclusion

This rigorously conducted evidence synthesis has brought together policy, guidance, research and case studies in an important but neglected area: EoL care for people with SMI. Although findings from this review are of immediate and direct relevance in this very specific area, they also have relevance for the EoL care of other disadvantaged groups in which health inequalities persist. Reflecting approaches developed through the EPPI-Centre, a strength of this synthesis is the inclusion of both research and non-research material, coupled with the exclusive use of research evidence to inform the project's overall implications for policy, services and practice. The project was launched in response to a need identified by people with lived experience of mental health and EoL services, one of whom proceeded to work as a full member of the project team doing work that included reviewing and approving this full report and its Scientific and Plain English summaries. The establishment of a SAG populated by senior professionals, government advisors, and people with direct experience of service use and of caring was key, and this was a further vehicle for a public and patient voice to be heard at strategic points during the lifetime of the project.

Outputs written for internationally leading journals will follow, reporting main and other findings from this full NIHR Journals Library report along with the production of an accessible summary for wide dissemination. Presentations are planned at key conferences, and with help from the project's SAG key policy-makers, managers, professionals and organisations these will be targeted to make sure that the findings reach people who are able to make full use of them. With this evidence synthesis designed as the starting point for a programme of research, further projects are planned, including studies involving people with SMI at the EoL and their carers and studies evaluating new ways of providing and organising care.

Acknowledgements

The team is grateful to Roger Pratt for his contribution to generating the ideas underpinning this project, as reported in *Chapter 2*. The team is also grateful to all members of the SAG (named in *Appendix 1*), and particularly to the group's independent chairperson, Dr Nikki Pease, for their time, energy and expertise.

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Publications

Edwards D, Anstey S, Coffey M, Gill P, Mann M, Meudell A, Hannigan B. End of life care for people with severe mental illness: mixed methods systematic review and thematic synthesis (the MENLOC study). *Palliat Med* 2021;**35**:1747–60.

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Data-sharing statement

All available data can be obtained from the corresponding author.

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Appendix 1 List of stakeholder advisory group members

- Dr Nikki Pease (chairperson), Consultant in Palliative Medicine, Velindre University NHS Trust, Cardiff.
- Dr Idris Baker, Lead Palliative Care Clinician for Wales and Consultant in Palliative Care, Abertawe Bro Morgannwg University Health Board, Swansea.
- Dr Liz Davies, Head of Mental Health and Vulnerable Groups Division, Welsh Government.
- Hazel Powell, Nursing Officer for Mental Health and Learning Disability, Welsh Government.
- Pam Penman, Practice Development Facilitator, Marie Curie Hospice, Cardiff and the Vale.
- Dr Helen Noble, Reader, Queen's University Belfast.
- Professor Ian Jones, Director of the National Centre for Mental Health, Cardiff.
- Kathleen Caper, Head of Policy and Advocacy, Hospice UK, London.
- Niamh Brophy, previously Palliative Care Coordinator at St Mungo's, London.
- Dr Stephanie Perrett, Lead Nurse for Health and Justice, Public Health.
- Roger Pratt, public and patient representative.
- Sian Jones, public and patient representative.
- Huw Davies, public and patient representative.

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Appendix 2 Terms of reference for stakeholder advisory group

Background

MENLOC aims to synthesise relevant research and other appropriate evidence relating to the organisation, provision and receipt of end-of-life care for people with SMI who have an additional diagnosis of advanced incurable cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months.

Project team and stakeholder advisory group: membership

The MENLOC project team comprises people with backgrounds in mental health services and end-of-life care research and practice, health services research, evidence review and information sciences, and lived experience of mental health difficulties and of surviving cancer.

The MENLOC SAG comprises people drawn from communities with interests in the project and its findings, including HCPs, mental health and end-of-life care researchers, service managers from the NHS and charitable sector, and people with experience of using services and of caring for people using services.

Stakeholder advisory group: terms of reference

The SAG will be independently chaired and will provide guidance to the project team over the lifetime of the study. The SAG will specifically:

1. receive information on the aims and objectives of MENLOC, and provide guidance on key definitions (e.g. 'severe mental illness'), the corresponding refinement of search terms and strategies for evidence searching and review
2. review MENLOC's progress and receive preliminary findings and provide a final round of guidance on evidence searching and review
3. advise the project team on the dissemination of findings, the promotion of impact and the identification of future research questions.

Working together

It is anticipated that members of the MENLOC project team and the SAG will meet on three occasions in Cardiff. In addition to participating in these meetings, members of the SAG can expect to spend approximately 1–2 hours in preparation. Members of the SAG will also be welcomed to the MENLOC end-of-project launch event.

Funding acknowledgement

MENLOC is funded by the NIHR Health and Social Care Delivery Research programme (project number 17/100/15).

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The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Appendix 3 Notes from first combined project team and stakeholder group meeting

End of Life Care for People with Severe Mental Illness: an Evidence Synthesis (the MENLOC study)

Project Team and Stakeholder Advisory Group Meeting

Tuesday 04 December 2018
12:00 – 15:00
Room 609 Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB

Meeting notes

Record of attendance

Project team		
	Position	**Present**
Prof Ben Hannigan (chief investigator)	Professor of Mental Health Nursing	Yes
Deborah Edwards (project manager)	Research Fellow	Yes
Dr Sally Anstey (co-investigator)	Senior Lecturer	Yes
Dr Paul Gill (co-investigator)	Senior Lecturer	Yes
Mala Mann (co-investigator)	Information Specialist	Yes
Prof Michael Coffey (co-investigator)	Professor of Mental Health Care	Yes
Alan Meudell (co-investigator)	Public and Patient Project Member	Yes
Roger Pratt (co-investigator)	Public and Patient Project Member	Yes
Stakeholder advisory group		
	Position	**Present**
Dr Nikki Pease (independent chair)	Consultant in Palliative Medicine, Velindre NHS Trust	Yes
Dr Idris Baker	Lead Palliative Care Clinician for Wales and Consultant in Palliative Care, Abertawe Bro Morgannwg University Health Board	Apologies given
Dr Liz Davies	Head of Mental Health and Vulnerable Groups Division, Health and Social Services Group, Welsh Government	Yes
Hazel Powell	Nurse Director Mental Health and Learning Disability, Abertawe Bro Morgannwg Health Board and Chair of the All Wales Senior Nurse Advisory Group for Mental Health	Apologies given
Pam Penman	Practice Development Facilitator, Marie Curie Hospice, Cardiff and the Vale	Yes
Dr Helen Noble	Lecturer, Queen's University Belfast and expert in end of life care for people	Yes (via videoconference)
Prof Ian Jones	Director of the National Centre for Mental Health and Professor of Psychiatry, Cardiff University	Yes
Kathleen Caper	Head of Policy and Advocacy, Hospice UK	Yes

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Niamh Brophy	Palliative Care Coordinator at St Mungo's	Apologies given
Dr Stephanie Perrett	Lead Nurse for Health and Justice, Public Health Wales	Yes
Sian Jones	Public and patient representative	Yes
Huw Davies	Public and patient representative	Yes

1. **Welcome, introductions and apologies**
   Stakeholder advisory group (SAG) and project team members were welcomed by the chair, Nikki Pease, and the chief investigator Ben Hannigan.

2. **MENLOC project team and project advisory group: terms of reference**
   Proposed terms of reference for the SAG were tabled and discussed, and it was agreed to amend these to include an estimation of the time commitment for SAG members. [document: *MENLOC project team and SAG - terms of reference v2*]

3. **Introducing the MENLOC project**
   Ben Hannigan introduced the MENLOC project, noting that this is funded through an award from the NIHR HS&DR Programme. As a preamble to a more detailed discussion of search terms SAG members commented on the aims of the study, though the meeting also noted that any change to these would require the approval of the funder. It was agreed to confine suggestions and advice to the inclusion and exclusion criteria for the selection of outputs, and to specific search strategies and terms.

   Early discussions included the project's exclusion of outputs relating to end of life care for people living with dementia. It was identified that in the case of outputs focusing on end of life care for people with both severe mental illness *and* dementia that these would be included, but that outputs relating to people with *only* dementia would be excluded.

   Discussions also centred on the identification of specific types of organ failure, and suggestions were received to also include genetic conditions, irreversible progressive conditions, permanent vegetative states and the potential of adding the word 'chronic' in front of the different types of organ failure described and included.

4. **Defining the project's parameters: 'severe mental illness' *and* 'end of life' (and related)**
   Search strategies and terms developed by the project team were distributed for discussion, and for welcome suggestions from SAG members. Specifically:

   Severe mental illness
   The imprecise nature of 'severe mental illness' was noted, though the everyday currency of the term was also recognised along with the recognition that MENLOC is broadly focusing on end of life care for people who have used secondary, specialist, inpatient and/or community mental health services.

   SAG members proposed, and meeting participants discussed, the inclusion of additional diagnoses (e.g., anorexia and PTSD) not listed in the MENLOC protocol. It was noted that diagnostic manuals are extensive and that listing new individual diagnoses at this point opened the door to including *all* diagnoses, making for unmanageable searches. It was decided therefore not to include such terms.

   A particular discussion was held around the diagnosis of depression, in the context of large numbers of outputs reporting depression as a *consequence* of receiving an end of life diagnosis, as opposed to *preceding* this. The continuum of depression was also noted, and meeting participants agreed that outputs concentrating on people with mild, commonly experienced, depression (and by extension, anxiety) should not be included. A consensus was to remove 'depression' as a search term or MeSH heading (particularly given that Deborah Edwards' screening of hundreds of papers identified in this way produced no outputs meeting MENLOC's inclusion criteria), but to instead to use 'depression' in conjunction with other terms such as 'psychosis' or 'pre-existing' or 'severe'.

Mala Mann confirmed that older terms such as 'melancholia' do not need to be searched for because database indexing groups together outputs using these phrases with outputs using more contemporary terminology.

Project members reported that not all end of life care outputs retrieved make clear whether or not the mental health problems experienced *preceded* end of life diagnosis.

Some discussion was also had on whether a fourth arm should be added to the search strategy, capturing use of secondary services in recognition of the fact that people with severe mental illness are overwhelmingly people using secondary mental health services. It was noted that using a four-arm search would be too narrow, and that citations containing such terms will already be identified using the existing three-arm search.

Neurological and neurodegenerative conditions
SAG members identified a group of conditions not previously considered by the project team, covering (for example) 'brain failure'. It was noted that 'brain failure' outputs would be captured under the term 'organ failure', and that a separate funding proposal is being prepared to synthesise the evidence in the area of end of life care for people with neurodegenerative conditions.

End of life care
Suggestions from SAG members for end of live related search terms were noted, including: 'thanatology' (the study of the theory, philosophy, and doctrine of death); 'best supportive care'/'enhanced supportive care' (these being new terms currently in use); 'end-stage' as a term to represent dying with chronic conditions; and 'conservative management' or 'conservative treatment'. A consensus was to exclude 'self-poisoning' or 'self-inflicted injuries' where the goal of treatment likely to be reported in outputs is to sustain life. A consensus was also *not* to add into search strategies terms attempting to establish the reasons for end of life care, but to *include* terms reflecting the closing down of active treatments: 'withdrawing active treatment'; 'withdrawing' or 'refusing' treatments such as dialysis; and 'moribund'. It was noted that the expected last six months of life is a term used in the US, and should be included.

It was agreed not to search for 'suicide', 'assisted death', 'assisted suicide' and 'euthanasia' (noting that euthanasia may be seen by some people using services as the only possible option when all else fails) as papers in these areas should be found through existing search strategies.

5. Finding grey literature, including non-research material
   Websites to search which have already been identified by the project team were circulated, and SAG members were invited to identify more in the meeting or to forward these to Deborah Edwards via email after the close of the meeting. Suggestions made in the meeting included: a Hospice UK report (Kathleen Caper); deaths in custody (Steph Perrett); palliative care in prisons (Nikki Pease); searches on institutional repositories.

   SAG members encouraged the project team to consider including outputs focusing on caregiver perspectives, and indeed the MENLOC protocol includes this as part of the project plan.

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6. Summary of meeting
   Discussions were recapped, and SAG members were thanked for their time and valued contributions.

7. Future meetings
   The MENLOC timeline suggests a meeting in March 2019, to be scheduled via online poll.

8. Close

Ben Hannigan
Deborah Edwards

Appendix 4 Notes from second combined project team and stakeholder group meeting

End of Life Care for People with Severe Mental Illness: an Evidence Synthesis (the MENLOC study)

Project Team and Stakeholder Advisory Group Meeting

Friday 08 March 2019
12:00 – 14:00
Room 704/705 Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB

Meeting notes

Record of attendance

Project team		
	Position	**Present**
Prof Ben Hannigan (chief investigator)	Professor of Mental Health Nursing	Yes
Deborah Edwards (project manager)	Research Fellow	Yes
Dr Sally Anstey (co-investigator)	Senior Lecturer	Yes
Dr Paul Gill (co-investigator)	Senior Lecturer	Yes
Mala Mann (co-investigator)	Information Specialist	Yes
Prof Michael Coffey (co-investigator)	Professor of Mental Health Care	Yes
Alan Meudell (co-investigator)	Public and Patient Project Member	Yes
Roger Pratt (co-investigator)	Public and Patient Project Member	Yes
Stakeholder advisory group		
	Position	**Present**
Dr Nikki Pease (independent chair)	Consultant in Palliative Medicine, Velindre NHS Trust	Yes
Dr Idris Baker	Lead Palliative Care Clinician for Wales and Consultant in Palliative Care, Abertawe Bro Morgannwg University Health Board	Yes
Dr Liz Davies	Head of Mental Health and Vulnerable Groups Division, Health and Social Services Group, Welsh Government	Apologies given
Hazel Powell	Nurse Director Mental Health and Learning Disability, Abertawe Bro Morgannwg Health Board and Chair of the All Wales Senior Nurse Advisory Group for Mental Health	Apologies given
Pam Penman	Practice Development Facilitator, Marie Curie Hospice, Cardiff and the Vale	Apologies given
Dr Helen Noble	Senior Lecturer, Queen's University Belfast and expert in end of life care for people	Yes (via videoconference)
Prof Ian Jones	Director of the National Centre for Mental Health and Professor of Psychiatry, Cardiff University	Apologies given

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Kathleen Caper	Head of Policy and Advocacy, Hospice UK	Apologies given
Jane Cook	National Health Advisor for Ministry of Housing, Communities and Local Government's Rough Sleeper Initiative	Apologies given
Dr Stephanie Perrett	Lead Nurse for Health and Justice, Public Health Wales	Yes
Sian Jones	Public and patient representative	Apologies given
Huw Davies	Public and patient representative	Yes

1. **Welcome, introductions and apologies**
   Stakeholder advisory group (SAG) and project team members were welcomed by the chair, Nikki Pease, and the chief investigator Ben Hannigan.

2. **MENLOC project team and project advisory group: terms of reference v2**
   Revised terms of reference for the SAG were tabled, which now include an estimation of the expected length of time SAG members can expect to spend reading papers ahead of meetings.
   [document: *MENLOC project team and SAG - terms of reference v2*]

3. **Minutes of the meeting held on the 04 December 2018, and recap of decisions made**
   Notes from the last meeting were reviewed, and key decisions (particularly on search parameters and search terms) were recapped. It was noted that Dr Helen Noble is a *Senior* Lecturer at QUB.

4. **MENLOC progress update: searching, screening and finalising included citations**
   Deborah Edwards presented an update on project progress since the December 2018 SAG meeting. It was noted that the project team had reviewed 7,830 citations having searched multiple databases, websites, tables of contents and other sources. Citations had been screened by two team members, with differences in the review of full-text items being referred to a third member. It was noted that team members had also convened during the morning before this SAG meeting to discuss citations for which there was still uncertainty, and to identify outstanding issues for tabling with stakeholders to agree a definitive judgment. Key areas discussed, and decisions made, were:

   Case studies
   Forty percent of the citations found addressing end of life care for people with pre-existing severe mental illness are single case studies. Mala Mann advised that including these in an evidence synthesis would be unusual, and following a suggestion from Michael Coffey it was agreed by participants that case studies could be subjected to a separate thematic synthesis to be included in the final report submitted to the to the HS&DR Journal.

   Advance care planning and advance decision-making
   Sally Anstey reminded participants that there is a difference between advance care planning and advanced decision-making, although some papers appear to use these terms interchangeably. A number of papers located explore end of life treatment preferences for those living with severe mental illness (SMI), but who are not currently at the end of life (EoL) (e.g. Foti et al 2005a), or advance care planning for those living with SMI but not currently at the EoL (Foti et al 2005b). These papers address hypothetical, rather than actual, end of life scenarios. It was agreed that even though they do not meet the review's inclusion criteria they should be referred to and used in a non-systematic section of the final report and be written up separately.

Eating disorders
Reflecting decisions made at the December 2018 SAG meeting, 'eating disorders' was not used as a specific search term. However, using other search strategies it was noted that one relevant paper in this area was retrieved (Lopez et al 2010) with another identified through back chaining (O'Neill et al 1994). Deborah Edwards reported on the project team's uncertainty as to whether a separate search in this field should be conducted, with the literature showing this to be a highly controversial area (including whether or not people with eating disorders should be considered as receiving 'palliative' care). Idris Baker agreed with this from his experience, and meeting participants were invited to guide the project team via further discussion. It was noted that all of the papers located falling into the eating disorders field were case studies, and reflecting the agreement noted above would therefore not be included in the main evidence synthesis but can be included in a separate thematic synthesis. Idris Baker also pointed out there is a difference between the physical sequalae (e.g. organ failure) of mental health problems such as eating disorders, and additional diagnoses (e.g. cancer) otherwise unrelated to mental illness. This distinction relates to a number of other (non-eating disorder) papers that the team have also been unsure of, and which can therefore be ruled out of the review as they do not focus on *additional* diagnoses.

Refusing treatment/non-compliance
Participants discussed whether an end-stage renal patient with pre-existing SMI refusing to have more dialysis was an example of EoL care in the context of this project. Paul Gill informed the meeting that a person in this position would only live for two weeks or so after stopping dialysis, and that therefore these are indeed people at the end of life. Discussion at the SAG meeting confirmed this, and Idris Baker observed that many people making the decision to refuse treatment do so because they have already learned that their treatment has ceased to be effective. The meeting also noted that all of the papers exploring these issues are case studies, and would therefore not be included in the main evidence synthesis as per decisions recorded above.

Suicide
It was decided that to be included a paper had to be about a person with severe mental illness who also had an additional end of life diagnosis. Papers about people with SMI who had attempted suicide, and who were then at EoL because of their injuries, would therefore not be included.

Severe mental illness
It was noted that the project team may need to revisit the inclusion of papers to make sure they relate to people with pre-existing *severe* mental illness. It was also reported that not all end of life care outputs retrieved make clear whether or not the mental health problems experienced *preceded* end of life diagnosis.

5. Policy documents and grey literature: progress update and finalising documents for inclusion

Policy documents from other countries
At the project team's pre-stakeholder meeting Deborah Edwards reported that a number of policy documents had been retrieved via online searching for NSW Australia that covered both mental illness and EoL care. Sally Anstey reported that Australian EoL care is highly regarded in the global context, and if it is ranked as the world's best then an option would be to refer to this as a context-setter in the final project report.

Policy, guidance and grey literature for chronic conditions
Prior to the SAG meeting Paul Gill and Helen Noble had provided the project team with a list of documents relating to renal/kidney disease at EoL. However, there were no references to mental illness within any of these documents. Mala Mann and Deborah Edwards expressed confidence that the search techniques employed across each of the charitable and organisational websites, covering specific chronic conditions using EoL and mental illness, would have retrieved any documents that covered both these subject areas. Using renal disease as an example to test this out the team has decided that they will not search any further.

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Generic policy documents

Deborah Edwards asked the SAG whether searching should include national generic healthcare policy documents such as England's Five Year Forward. The SAG felt that this would be a worthwhile exercise but Steph Perrett reminded the team to be mindful that they should not always expect to find references to mental illness and/or EoL care specifically as these documents relate to high-level strategy.

Prison and Probation Ombudsman reports

Deborah Edwards introduced these, which report on deaths in prison, where the team has reviewed one year's worth of reports. At the SAG meeting it was suggested that the team include them as a type of output in the non-systematic part of the project along with the case studies. Nikki Pease informed the meeting that she knew of a Master's student who has looked at palliative care in prisons, and will forward contact details.

Context of care

Sally Anstey proposed a section in the final report called 'context of care', to include papers that explore caring for people with SMI at EoL in hospices, palliative care units or psychiatric wards along with those papers that explore issues for homeless people with SMI at EoL. The SAG agreed with this decision, with Idris Baker pointing out that in the UK the term 'hospice' has changed over the years. Where it used to refer to a building it now refers more to care the community setting, In the US the term 'hospice' tends to mean community.

Charities and organisations

SAG members were asked to review lists of charities and organisations whose websites have been searched. Additional sites to search were suggested:
Samaritans: https://www.samaritans.org/
Llanmau: https://www.llamau.org.uk/
SSAFA: https://www.ssafa.org.uk/
Community Housing Cymru: https://chcymru.org.uk/
National Housing Federation: https://www.housing.org.uk/
Shelter Cymru: https://sheltercymru.org.uk/
Shelter: https://www.shelter.org.uk/
Gofal: http://www.gofal.org.uk/
Compassionate communities: https://www.compassionate-communitiesuk.co.uk/
Byw Nawr: https://www.dyingmatters.org/wales
Combat Stress: https://www.combatstress.org.uk/
Royal British Legion: https://www.britishlegion.org.uk/

[all websites last accessed 08th March 2019]

Team members also noted an additional Welsh Assembly report into inequalities in palliative care, and a Welsh Government response to this, which should be reviewed in the policy section of the final report.

6. Summary of meeting

   Main points addressed, and decisions made, were reviewed and thanks were expressed to SAG and project team members for their valued contributions.

7. Future meeting

   The next combined project team/SAG meeting will be on 18 December 2019, 12.00 to 14.00, in Eastgate House (room to be confirmed). The agenda will include updates on further progress, dissemination and impact.

8. Close

Deborah Edwards
Ben Hannigan

Appendix 5 Notes from third combined project team and stakeholder group meeting

End of Life Care for People with Severe Mental Illness: an Evidence Synthesis (the MENLOC study)

Project Team and Stakeholder Advisory Group Meeting

Wednesday 18 December 2019
12:00 – 14:00
Room 506/507 Eastgate House, 35-43 Newport Road, Cardiff, CF24 0AB

Meeting notes

Record of attendance

Project team		
	Position	Present
Prof Ben Hannigan (chief investigator)	Professor of Mental Health Nursing	Yes
Deborah Edwards (project manager)	Research Fellow	Yes
Dr Sally Anstey (co-investigator)	Senior Lecturer	Yes
Dr Paul Gill (co-investigator)	Senior Lecturer	Yes
Mala Mann (co-investigator)	Information Specialist	Yes
Prof Michael Coffey (co-investigator)	Professor of Mental Health Care	Yes
Alan Meudell (co-investigator)	Public and Patient Project Member	Yes
Stakeholder advisory group		
	Position	Present
Dr Nikki Pease (independent chair)	Consultant in Palliative Medicine, Velindre NHS Trust	Yes
Dr Idris Baker	Lead Palliative Care Clinician for Wales and Consultant in Palliative Care, Abertawe Bro Morgannwg University Health Board	Yes
Dr Liz Davies	Head of Mental Health and Vulnerable Groups Division, Health and Social Services Group, Welsh Government	Apologies given
Hazel Powell	Nurse Director Mental Health and Learning Disability, Abertawe Bro Morgannwg Health Board	Apologies given
Pam Penman	Practice Development Facilitator, Marie Curie Hospice, Cardiff and the Vale	Apologies given
Dr Helen Noble	Senior Lecturer, Queen's University Belfast and expert in end of life care for people	Yes (via videoconference)
Prof Ian Jones	Director of the National Centre for Mental Health and Professor of Psychiatry, Cardiff University	Yes
Kathleen Caper	Head of Policy and Advocacy, Hospice UK	Apologies given

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Jane Cook	National Health Advisor for Ministry of Housing, Communities and Local Government's Rough Sleeper Initiative	Apologies given
Dr Stephanie Perrett	Lead Nurse for Health and Justice, Public Health Wales	Apologies given
Roger Pratt	Public and Patient Project Member	Yes
Sian Jones	Public and patient representative	Yes
Huw Davies	Public and patient representative	Yes
Dr Julia Terry	Senior Lecturer, Swansea University (observer)	Yes

1. **Welcome, introductions and apologies**
   Stakeholder advisory group (SAG) and project team members were welcomed by the chair, Nikki Pease.
2. **Recap of study aims and objectives**
   Ben Hannigan presented a brief recap of the aims and objectives of the MENLOC study.
3. **Recap of decisions made by group in previous meetings (BH)**
   With reference to the minutes from the last SAG meeting held on March 8th 2019, Ben Hannigan summarised the discussion and decisions made.
4. **Summary of findings**
   Deborah Edwards presented details of the search strategy, Michael Coffey presented a summary of findings from the case study thematic synthesis and Ben Hannigan presented a summary of themes from the synthesis of policy, guidance and research. It was noted that case studies appear in the literature before research.
5. **Observations on 'last year of life' (LYoL)**
   Sally Anstey led a discussion on how care in the LYoL varies, and/or how the content of care in the LYoL is unspecified, in material retrieved for the synthesis, and on how material retrieved for this evidence synthesis has revealed (for example) differences in the meanings attached to the word 'hospice' ('hospice' as a place, or 'hospice' as care provided at home). Project team and SAG members discussed how the final report for the NIHR might usefully include a commentary on this.
6. **CerQual and GRADE**
   Deborah Edwards provided an overview of plans to use CerQual and GRADE, as a key task for the new year.
7. **Clarification of terminology for final report**
   Following a discussion It was agreed to use the term 'patients with severe mental illness' but to add a note in the final report that the project team recognise that differences in terms used are found across the literature.
8. **Dissemination/Accessible summary/Impact/Publications**
   Ben Hannigan opened a discussion on strategies to share findings from the MENLOC study. Members of the SAG agreed to receive and comment on the accessible summary (or equivalent) when it is produced, and to provide details of people and organisations who might be sent a copy. There was agreement to 'aim high' with journal papers, with *BMJ Supportive and Palliative Care* as a possible target. With the MENLOC grant award including support for open access papers the meeting noted the value of developing a publication strategy, potentially including the preparation of a research/policy paper and the preparation of a case study paper. Idris Baker informed the meeting of the high level of policymaking interest in Wales in end of life care, and project team and SAG members noted that the SAG includes people with access to government and cross-party AM groups. Idris is a member of the End of Life Board, which is a key group to which findings should be brought. Potential conferences for dissemination were discussed, including the Palliative Care Congress, the European Association of Palliative Care, the International Congress of the Royal College of Psychiatrists, the Wales Palliative Care Conference and the International Mental Health Nursing Research Conference. Ian Jones suggested a blog piece for the NCMH and Cardiff University mental health site.

9. **End of project event**
   Ben Hannigan reminded people present that the MENLOC award includes a sum for a report launch event, to be organised once the NIHR Journal Library publication is published. Ideas discussed included an evening event sponsored by the Welsh Government
10. **Future work/ideas**
    Ongoing plans to initiate new research building on the MENLOC study were shared and discussed.
11. **Close**
    SAG members were thanks for their time and contributions at this and earlier meetings, and Nikki Pease was thanked by Ben Hannigan for serving as independent chair. The meeting closed with all present reminded that they will be welcomed to the launch event in the future.

Deborah Edwards
Ben Hannigan

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Appendix 6 Definitions and search terms: ‘severe mental illness’

From the MENLOC protocol:

The term ‘severe [or, often used interchangeably, ‘serious’ or ‘serious and enduring’] mental illness’ (SMI) as used throughout this project proposal has longstanding currency within the fields of MH policy, services and practice dating back at least as far as the publication of *Building Bridges* (Department of Health 1995). It continues to be used in research (see for example: Kronenberg, Doran et al. 2017), and has currency with the NIHR Dissemination Centre which published a Themed Review into Severe Mental Illness in 2018 (National Institute for Health Research 2018). *Building Bridges* recognised the imprecision of the term ‘severe mental illness’, and endorsed a multidimensional framework definition encompassing five areas: safety; need for informal or formal care; disability; diagnosis; and duration. Diagnosis is therefore an important, but not the only, dimension used in the identification of people with SMI and includes ICD-10 diagnoses of schizophrenia, schizotypal and delusional disorders, bipolar affective disorder, and disorders of adult personality and behaviour (World Health Organization 1992) along with similar DSM-V diagnoses including schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, and major depressive disorder (American Psychiatric Association 2014).

Inclusion	Exclusion
Relevant evidence specifically relating to adult participants (>18 years of age) with SMI (including schizophrenia, schizophrenia spectrum and other psychotic disorders, schizotypal and delusional disorders, bipolar affective disorder, bipolar and related disorders, major depressive disorder and disorders of adult personality and behaviour) who have an additional diagnosis of advanced, incurable, cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months. Published in English Language only.	Where reporting allows the distinction to be made, MH problems (e.g. depression) as a consequence of terminal illness (e.g., cancer or chronic organ failure). Evidence relating to EoLC for people with mental and behavioural disorders due to psychoactive substance use, except where these coexist with disorders included in the column to the left. Evidence relating to EoLC for people with dementia or other neurodegenerative diseases except where these coexist with disorders included in the column to the left. Evidence from animal studies.

Search terms: ‘severe mental illness’

These are the search terms that we will be including when looking for literature:

- severe and persistent mental illness / SPMI
- severe mental illness / SMI
- (chronic or severe or serious or persistent) NEXT TO (mental* or psychological*) NEXT to (ill* or disorder*)
- mental health condition*
- mental illness / mental disorder
- mental health

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- major depression
- mentally Ill Persons
- mental disorders
- psychiatric illness*

- Bipolar Disorder / bipolar
- Schizophrenia / schizoaffective disorder

- psychiatric disorder
- mood disorder*
- personality disorder*

- depression disorder*
- Major depressive disorder

- psychotic* or psychosis or psychoses or
- mania
- psychotic disorders
- Paranoid Disorders

Are there any other terms that we have missed and that you think it would be useful to add?

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American Psychiatric Association (2014). Diagnostic and statistical manual of mental disorders (DSM-V). Arlington, American Psychiatric Publishing.
Department of Health (1995). Building bridges: a guide to arrangements for interagency working for the care and protection of severely mentally ill people. London, Department of Health.
Kronenberg, C., T. Doran, M. Goddard, T. Kendrick, S. Gilbody, C. R. Dare, L. Aylott and R. Jacobs (2017). "Identifying primary care quality indicators for people with serious mental illness: a systematic review." British Journal of General Practice **67**(661): e519-e530.
National Institute for Health Research (2018). Forward thinking: NIHR research on support for people with severe mental illness. Southampton, National Institute for Health Research.
World Health Organization (1992). The 10th revision of the international classification of diseases and rFIC

Appendix 7 Definitions and search terms: 'end of life'

From the MENLOC protocol:

In this study EoLC is used to refer to the care of people with diagnoses of advanced, incurable, cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months. It includes care provided in hospitals, hospices and other institutional settings (such as prisons and hostels) and care provided in the home and via outreach to people who may also be homeless.

Inclusion	Exclusion
Relevant evidence specifically relating to adult participants (>18 years of age) with SMI (including schizophrenia, schizophrenia spectrum and other psychotic disorders, schizotypal and delusional disorders, bipolar affective disorder, bipolar and related disorders, major depressive disorder and disorders of adult personality and behaviour) who have an additional diagnosis of advanced, incurable, cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months. Published in English Language only.	Where reporting allows the distinction to be made, MH problems (e.g. depression) as a consequence of terminal illness (e.g., cancer or chronic organ failure). Evidence relating to EoLC for people with mental and behavioural disorders due to psychoactive substance use, except where these coexist with disorders included in the column to the left. Evidence relating to EoLC for people with dementia or other neurodegenerative diseases except where these coexist with disorders included in the column to the left. Evidence from animal studies.

Search terms: 'end of life'

These are the search terms that we will be including when looking for literature:

- Palliative care
- Hospice care / caring
- Terminal Care / caring
- end of life / end-of-life / end of their lives
- Terminally ill
- Terminal illness
- last year of life / LYoL

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Are there any other terms that we have missed and that you think it would be useful to add?

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Appendix 8 Searching for grey literature and non-research material

From the MENLOC protocol:
Objective 2 in full says we will:

- locate and synthesise policy, guidance, case reports and other grey and non-research literature relating to the organisation, provision and receipt of care in the expected LYoL for people with SMI who have additional diagnoses of advanced, incurable, cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months.

Inclusion	Exclusion
Relevant evidence specifically relating to adult participants (>18 years of age) with SMI (including schizophrenia, schizophrenia spectrum and other psychotic disorders, schizotypal and delusional disorders, bipolar affective disorder, bipolar and related disorders, major depressive disorder and disorders of adult personality and behaviour) who have an additional diagnosis of advanced, incurable, cancer and/or end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months. Published in English Language only.	Where reporting allows the distinction to be made, MH problems (e.g. depression) as a consequence of terminal illness (e.g., cancer or chronic organ failure). Evidence relating to EoLC for people with mental and behavioural disorders due to psychoactive substance use, except where these coexist with disorders included in the column to the left. Evidence relating to EoLC for people with dementia or other neurodegenerative diseases except where these coexist with disorders included in the column to the left. Evidence from animal studies.

Supplementary searches will be undertaken to identify additional papers, information on studies in progress, unpublished research or research reported in the grey literature.

Relevant websites and trial registers will be searched e.g.

NIH ClinicalTrials.gov (http://www.clinicaltrials.gov),

MetaRegister of Controlled Trials (http://www.controlled-trials.com),

WHO International Clinical Trials Registry Platform (ICTRP)

(http://www.who.int/ictrp/en).

[all websites last accessed 8th March 2019]

To identify published resources that have not yet been catalogued in the electronic databases, recent editions of key journals will be hand-searched. Reference lists of included studies will be scanned, experts contacted, and forward citation tracking performed using ISI Web of Science.

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Reflecting EPPI Centre (Gough, Oliver et al. 2017) methods, searches will be conducted for non-research material (e.g., social media, personal accounts, policies) using transparent, clearly described, approaches (Mahood, Van Eerd et al. 2014). With advice being taken from members of a project stakeholder advisory group, relevant websites will be searched using search terms and strategies carefully tested and refined as necessary to ensure that all items relevant to the care of people with SMI and (a) advanced, incurable, cancer and/or (b) end-stage lung, heart, renal or liver failure and who are likely to die within the next 12 months are equally included.

Candidate websites for searching include:

British Heart Foundation (https://www.bhf.org.uk/),
British Liver Trust (https://www.britishlivertrust.org.uk/),
British Lung Foundation (https://www.blf.org.uk/),
British Renal Society (http://britishrenal.org/),
Cancer Research UK (http://www.cancerresearchuk.org/),
Cancer Research Wales (https://www.cancerresearchwales.co.uk/),
Care Quality Commission (https://www.cqc.org.uk/),
Centre for Mental Health (https://www.centreformentalhealth.org.uk/),
Hospice UK (http://www.hospiceuk.org/),
Macmillan Cancer Support (http://www.macmillan.org.uk/)
Marie Curie (https://www.mariecurie.org.uk/),
Mental Health Foundation (https://www.mentalhealth.org.uk/),
National Council for Palliative Care (http://www.ncpc.org.uk/),
National Kidney Foundation (https://www.kidney.org/),
Scottish Partnership agency for Palliative Care
(https://www.palliativecarescotland.org.uk/).
St Mungo’s (https://www.mungos.org/),
Tenovus Cancer Care (http://www.tenovuscancercare.org.uk/),
The Renal Association (https://renal.org/),
[all websites last accessed 8th March 2019]

Are there any other websites that you think it would be useful to add?

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Gough, D., S. Oliver and J. Thomas, Eds. (2017). An introduction to systematic reviews. London, Sage.
Mahood, Q., D. Van Eerd and E. Irvin (2014). "Searching for grey literature for systematic reviews: challenges and benefits." Research Synthesis Methods **5**(3): 221-234.

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Appendix 9 Ovid MEDLINE® all: initial search strategy

Date range searched: 1946 to 5 July 2018. Last date searched: 6 December 2019

1. exp Palliative care/ (48,615)
2. exp Hospice care/ (5807)
3. exp Terminal Care/ (47,347)
4. exp Terminally ill/ (6150)
5. ("palliative care" or "hospice care" or "end of life care" or end-of-life).tw. (38,005)
6. ((hospice or terminal*) adj3 (care or caring or ill*)).tw. (12,527)
7. ("last year of life" or LYOL or "end of life" or "end of their lives").tw. (19,101)
8. (end-stage disease* or end stage disease* or end-stage ill* or end stage ill*).tw. (1112)
9. or/1-8 (104,642)
10. exp Neoplasms/ (3,055,654)
11. (cancer* or tumo?r* or neoplas* or malignan* or carcinoma* or adenocarcinoma* or adeno? carcinoma* or choriocrcinoma* or leukemia* or leukaemia* or metastat* or sarcoma* or teratoma* or lymphoma).tw. (3,168,623)
12. exp Multiple Organ Failure/ (10,043)
13. Organ failure.tw. (16,597)
14. Pulmonary Disease, Chronic Obstructive/ (32,992)
15. (Chronic obstructive pulmonary disease or COPD).tw. (53,007)
16. Heart Failure/ (105,052)
17. Renal Insufficiency/ (14,550)
18. Liver Failure/ (6735)
19. ("cardiac failure" or "liver failure" or "kidney failure" or "renal failure").tw. (114,515)
20. Chronic Disease/ (248,675)
21. Health service utilization.mp. (1502)
22. lifestyle-related factor*.mp. (337)
23. or/10-22 (4,430,236)
24. exp Bipolar Disorder/ (37,229)
25. exp Schizophrenia/ (97,818)
26. (bipolar or mania or Schizophrenia).tw. (148,564)
27. exp Depression/ (102,372)
28. exp Mental Disorders/ (1,125,241)
29. ("mental illness" or "mental disorder*" or depression).tw. (333,320)
30. mental health condition*.tw. (1794)
31. exp Depressive Disorder/ (99,383)
32. exp Mental Health/ (31,108)
33. exp Personality Disorders/ (39,084)
34. (severe and persistent mental illness).mp. (304)
35. severe mental illness.mp. (3558)
36. or/24-35 (1,3902,77)
37. 9 and 23 and 36 (2648)
38. (dementia or Alzheimer).tw. (106,344)
39. (Algeria$ or Egypt$ or Liby$ or Morocc$ or Tunisia$ or Western Sahara$ or Angola$ or Benin or Botswana$ or Burkina Faso or Burundi or Cameroon or Cape Verde or Central African Republic or Chad or Comoros or Congo or Djibouti or Eritrea or Ethiopia$ or Gabon or Gambia$ or Ghana or Guinea or Keny$ or Lesotho or Liberia or Madagasca$ or Malawi or Mali or Mauritania or

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Mauritius or Mayotte or Mozambiq$ or Namibia$ or Niger or Nigeria$ or Reunion or Rwand$ or Saint Helena or Senegal or Seychelles or Sierra Leone or Somalia or South Africa$ or Sudan or Swaziland or Tanzania or Togo or Ugand$ or Zambia$ or Zimbabw$ or China or Chinese or Hong Kong or Macao or Mongolia$ or Taiwan$ or Belarus or Moldov$ or Russia$ or Ukraine or Afghanistan or Armenia$ or Azerbaijan or Bahrain or Cyprus or Cypriot or Georgia$ or Iran$ or Iraq$ or Jordan$ or Kazakhstan or Kuwait or Kyrgyzstan or Leban$ or Oman or Pakistan$ or Palestin$ or Qatar or Saudi Arabia or Syria$ or Tajikistan or Turkmenistan or United Arab Emirates or Uzbekistan or Yemen or Bangladesh$ or Bhutan or British Indian Ocean Territory or Brunei Darussalam or Cambodia$ or India$ or Indonesia$ or Lao or People's Democratic Republic or Malaysia$ or Maldives or Myanmar or Nepal or Philippin$ or Singapore or Sri Lanka or Thai$ or Timor Leste or Vietnam or Albania$ or Andorra or Bosnia$ or Herzegovina$ or Bulgaria$ or Croatia$ or Faroe Islands or Greenland or Liechtenstein or Lithuani$ or Macedonia or Malta or maltese or Romania or Serbia$ or Montenegro or Svalbard or Argentina$ or Belize or Bolivia$ or Brazil$ or Chilean or Colombia$ or Costa Rica$ or Cuba or Ecuador or El Salvador or French Guiana or Guatemala$ or Guyana or Haiti or Honduras or Jamaica$ or Nicaragua$ or Panama or Paraguay or Peru or Puerto Rico or Suriname or Uruguay or Venezuela or developing countr$ or south America$).ti,sh. (1,190,707)

40. Academic Dissertations/ (0)
41. thesis.tw. (7038)
42. book.pt. (0)
43. Books/ (3122)
44. or/38-43 (1,303,105)
45. 37 not 44 (2373)
46. limit 45 to (English language and humans and "all adult (19 plus years)") (1387)

Appendix 10 Ovid MEDLINE: final search strategy

Date range searched: 1946 to 6 December 2018. Last date searched: 6 December 2019

1. exp Palliative care/ (49,655)
2. exp Hospice care/ (5949)
3. exp Terminal Care/ (48,040)
4. exp Terminally ill/ (6227)
5. ("palliative care" or hospice or "end of life care" or end-of-life).tw. (43,896)
6. ((hospice or terminal*) adj3 (care or caring or ill*)).tw. (12,766)
7. ("Irreversible condition" or "terminal condition" or fatal illness).tw. (791)
8. ("last year of life" or LYOL or "end of life" or "end of their lives" or "last six months of life" or "last 6 months of life").tw. (19,924)
9. (end-stage disease* or end stage disease* or end-stage ill* or end stage ill* or end-stage or end stage).tw. (60,633)
10. (expected adj3 die).tw. (215)
11. (imminent adj3 death).tw. (561)
12. ("Dying soon" or "expected death" or "imminently dying" or Moribund).tw. (2493)
13. conservative treatment/ (1401)
14. (conservative adj2 (treatment or management)).tw. (42,831)
15. Withholding Treatment/ (10,909)
16. Treatment Refusal/ (11,477)
17. (Refus* adj3 (treat* or care or intervention or dialysis)).tw. (4855)
18. ((withdrew or withdraw* or withhold*) adj3 (treat* or car* or intervene* or therap* or dialysis or transplant*)).tw. (15,455)
19. or/1-18 (244,771)
20. exp Neoplasms/ (3,107,101)
21. (cancer* or tumo?r* or neoplas* or malignan* or carcinoma* or adenocarcinoma* or adeno? carcinoma* or choriocrcinoma* or leukemia* or leukaemia* or metastat* or sarcoma* or teratoma* or lymphoma).tw. (3,243,976)
22. ("Enzymatic disease*" or "enzyme disease*").tw. (25)
23. Genetic Disease, Inborn/ (13,207)
24. ("duchenne muscular dystrophy" or "amyotrophic lateral sclerosis" or ALS).tw. (40,207)
25. amyotrophic lateral sclerosis/ (16,921)
26. Muscular dystrophy, Duchenne/ (4706)
27. ("Genetic disease" or "genetic condition").tw. (7305)
28. Cystic Fibrosis/ (33,150)
29. ("cystis fibrosis" or CF).tw. (36,968)
30. exp Multiple Organ Failure/ (10,209)
31. ("Organ failure" or "chronic organ failure").tw. (17,137)
32. Pulmonary Disease, Chronic Obstructive/ (34,379)
33. ("renal insufficiency" or "serious physical illness").tw. (21,134)
34. (Chronic obstructive pulmonary disease or COPD).tw. (54,881)
35. (chronic adj3 (illness or condition or disease*)).tw. (250,692)
36. "chronic medical condition".tw. (382)
37. Heart Failure/ (107,446)
38. Renal Insufficiency/ (14,803)
39. Liver Failure/ (6828)

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40. (chronic adj2 (“cardiac failure” or “liver failure” or “kidney failure” or “end-stage renal disease” or ESRD or “renal failure” or “heart failure”)).tw. (44,143)
41. Chronic Disease/ (251,517)
42. Health service utilization.mp. (1569)
43. lifestyle-related factor*.mp. (354)
44. or/20-43 (4,717,135)
45. exp Bipolar Disorder/ (37,764)
46. exp Schizophrenia/ (99,011)
47. (schizo* or “mood disorder*” or “personality disorder*” or psychotic* or psychosis or psychoses).tw. (197,049)
48. (bipolar or mania or Schizophrenia).tw. (151,754)
49. (Depression adj2 (psychosis or psychotic or severe or major)).tw. (28,840)
50. exp Mental Disorders/ (1,143,274)
51. mental health condition*.tw. (1954)
52. exp Personality Disorders/ (39,433)
53. exp psychotic disorders/ (48,805)
54. exp schizoaffective disorder/ (48,805)
55. exp psychosis/ (48,805)
56. Paranoid Disorders/ (3987)
57. (“severe mental illness” or “persistent mental illness”).tw. (3969)
58. ((chronic* or sever* or serious or persistent* or enduring or debilitating) adj2 (mental* or psychological*) adj2 (ill* or disorder* or health)).tw. (12,556)
59. exp Mentally Ill Persons/ (5926)
60. (SPMI or SMI).tw. (3830)
61. or/45-60 (1,239,759)
62. (dementia or Alzheimer).ti. (52,380)
63. (bipolar electrocoagulation or bipolar radiofrequency or bipolar tumour probe or bipolar diathermy).tw. (1123)
64. (“respiratory depression” or “marrow depression” or “hematologic* depression”).tw. (6399)
65. (child* or adoles* or pediatric or paediatric).tw. (1,520,041)
66. (Algeria$ or Egypt$ or Liby$ or Morocc$ or Tunisia$ or Western Sahara$ or Angola$ or Benin or Botswana$ or Burkina Faso or Burundi or Cameroon or Cape Verde or Central African Republic or Chad or Comoros or Congo or Djibouti or Eritrea or Ethiopia$ or Gabon or Gambia$ or Ghana or Guinea or Keny$ or Lesotho or Liberia or Madagasca$ or Malawi or Mali or Mauritania or Mauritius or Mayotte or Mozambiq$ or Namibia$ or Niger or Nigeria$ or Reunion or Rwand$ or Saint Helena or Senegal or Seychelles or Sierra Leone or Somalia or South Africa$ or Sudan or Swaziland or Tanzania or Togo or Ugand$ or Zambia$ or Zimbabw$ or China or Chinese or Hong Kong or Macao or Mongolia$ or Taiwan$ or Belarus or Moldov$ or Russia$ or Ukraine or Afghanistan or Armenia$ or Azerbaijan or Bahrain or Cyprus or Cypriot or Georgia$ or Iran$ or Iraq$ or Jordan$ or Kazakhstan or Kuwait or Kyrgyzstan or Leban$ or Oman or Pakistan$ or Palestin$ or Qatar or Saudi Arabia or Syria$ or Tajikistan or Turkmenistan or United Arab Emirates or Uzbekistan or Yemen or Bangladesh$ or Bhutan or British Indian Ocean Territory or Brunei Darussalam or Cambodia$ or India$ or Indonesia$ or Lao or People’s Democratic Republic or Malaysia$ or Maldives or Myanmar or Nepal or Philippin$ or Singapore or Sri Lanka or Thai$ or Timor Leste or Vietnam or Albania$ or Andorra or Bosnia$ or Herzegovina$ or Bulgaria$ or Croatia$ or Faroe Islands or Greenland or Liechtenstein or Lithuani$ or Macedonia or Malta or maltese or Romania or Serbia$ or Montenegro or Svalbard or Argentina$ or Belize or Bolivia$ or Brazil$ or Chilean or Colombia$ or Costa Rica$ or Cuba or Ecuador or El Salvador or French Guiana or Guatemala$ or Guyana or Haiti or Honduras or Jamaica$ or Nicaragua$ or Panama or Paraguay or Peru or Puerto Rico or Suriname or Uruguay or Venezuela or developing countr$ or south America$).ti,sh. (1,225,437)
67. Academic Dissertations/ (0)
68. thesis.tw. (7167)

69. book.pt. (0)
70. Books/ (3174)
71. or/62-70 (2,653,676)
72. 19 and 44 and 61 (2434)
73. 72 not 71 (2126)
74. limit 73 to (english language and humans and “all adult (19 plus years)”) (1217)

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Appendix 11 Ovid PsycInfo: final search strategy

Date range searched: 1806 to December week 1 2018. Last date searched: 6 December 2019

1. exp Palliative Care/ (11,016)
2. Hospice/ (3062)
3. exp Terminally Ill Patients/ (4562)
4. exp HOSPICE/ (3062)
5. ("palliative care" or "hospice care" or "end of life care" or end-of-life).tw. (15,589)
6. ((hospice or terminal*) adj3 (care or caring or ill*)).tw. (6333)
7. ("Irreversible condition" or "terminal condition" or fatal illness).tw. (216)
8. ("last year of life" or LYOL or "end of life" or "end of their lives" or "last six months of life" or "last 6 months of life").tw. (9038)
9. (end-stage disease* or end stage disease* or end-stage ill* or end stage ill* or end-stage or end stage).tw. (2002)
10. (expected adj3 die).tw. (44)
11. (imminent adj3 death).tw. (272)
12. ("Dying soon" or "expected death" or "imminently dying" or Moribund).tw. (235)
13. (conservative adj2 (treatment or management)).tw. (460)
14. Treatment Withholding/ (462)
15. Treatment Refusal/ (730)
16. (Refus* adj3 (treat* or care or intervention or dialysis)).tw. (1811)
17. ((withdrew or withdraw* or withhold*) adj3 (treat* or car* or intervene* or therap* or dialysis or transplant*)).tw. (3579)
18. or/1-17 (28,620)
19. exp NEOPLASMS/ (47,829)
20. (cancer* or tumo?r* or neoplas* or malignan* or carcinoma* or adenocarcinoma* or adeno? carcinoma* or choriocrcinoma* or leukemia* or leukaemia* or metastat* or sarcoma* or teratoma* or lymphoma).tw. (76,722)
21. ("Enzymatic disease*" or "enzyme disease*").tw. (0)
22. Genetic Disorders/ (4048)
23. ("duchenne muscular dystrophy" or "amyotrophic lateral sclerosis" or ALS).tw. (13,477)
24. Amyotrophic Lateral Sclerosis/ (3551)
25. Muscular Dystrophy/ (1293)
26. ("Genetic disease" or "genetic condition").tw. (611)
27. Cystic Fibrosis/ (854)
28. ("cystis fibrosis" or CF).tw. (3217)
29. "Multi* Organ Failure*".tw. (71)
30. ("Organ failure" or "chronic organ failure").tw. (203)
31. exp Chronic Obstructive Pulmonary Disease/ (1272)
32. ("renal insufficiency" or "serious physical illness").tw. (319)
33. (Chronic obstructive pulmonary disease or COPD).tw. (2277)
34. (chronic adj3 (illness or condition or disease*)).tw. (28,394)
35. "chronic medical condition".tw. (196)
36. Heart Disorders/ (8989)
37. Kidney Diseases/ (2001)
38. Liver Disorders/ (1145)
39. (chronic adj2 ("cardiac failure" or "liver failure" or "kidney failure" or "end-stage renal disease" or ESRD or "renal failure" or "heart failure")).tw. (866)

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40. Chronic Illness/ (10,804)
41. lifestyle-related factor*.mp. (51)
42. or/19-41 (139,563)
43. exp Bipolar Disorder/ (25,413)
44. exp SCHIZOPHRENIA/ (85,758)
45. (schizo* or “mood disorder*” or “personality disorder*” or psychotic* or psychosis or psychoses).tw. (208,100)
46. (bipolar or mania or Schizophrenia).tw. (137,089)
47. (Depression adj2 (psychosis or psychotic or severe or major)).tw. (34,922)
48. exp Mental Disorders/ (566,262)
49. mental health condition*.tw. (1698)
50. exp Personality Disorders/ (33,638)
51. exp Schizoaffective Disorder/ (2961)
52. exp Psychosis/ (109,879)
53. “Paranoia (Psychosis)”/ (1215)
54. “Severity (Disorders)”/ (15,885)
55. “severe mental illness”.tw. (4681)
56. “persistent mental illness”.tw. (799)
57. ((chronic* or sever* or serious or persistent* or enduring or debilitating) adj2 (mental* or psychological*) adj2 (ill* or disorder* or health)).tw. (16,725)
58. Mentally Ill Persons.mp. (805)
59. (SPMI or SMI).tw. (1991)
60. or/43-59 (637,058)
61. (dementia or Alzheimer).ti. (30,336)
62. (bipolar electrocoagulation or bipolar radiofrequency or bipolar tumour probe or bipolar diathermy).tw. (5)
63. (“respiratory depression” or “marrow depression” or “hematologic* depression”).tw. (407)
64. (child* or adoles* or pediatric or paediatric).tw. (811,926)
65. (Algeria$ or Egypt$ or Liby$ or Morocc$ or Tunisia$ or Western Sahara$ or Angola$ or Benin or Botswana$ or Burkina Faso or Burundi or Cameroon or Cape Verde or Central African Republic or Chad or Comoros or Congo or Djibouti or Eritrea or Ethiopia$ or Gabon or Gambia$ or Ghana or Guinea or Keny$ or Lesotho or Liberia or Madagasca$ or Malawi or Mali or Mauritania or Mauritius or Mayotte or Mozambiq$ or Namibia$ or Niger or Nigeria$ or Reunion or Rwand$ or Saint Helena or Senegal or Seychelles or Sierra Leone or Somalia or South Africa$ or Sudan or Swaziland or Tanzania or Togo or Ugand$ or Zambia$ or Zimbabw$ or China or Chinese or Hong Kong or Macao or Mongolia$ or Taiwan$ or Belarus or Moldov$ or Russia$ or Ukraine or Afghanistan or Armenia$ or Azerbaijan or Bahrain or Cyprus or Cypriot or Georgia$ or Iran$ or Iraq$ or Jordan$ or Kazakhstan or Kuwait or Kyrgyzstan or Leban$ or Oman or Pakistan$ or Palestin$ or Qatar or Saudi Arabia or Syria$ or Tajikistan or Turkmenistan or United Arab Emirates or Uzbekistan or Yemen or Bangladesh$ or Bhutan or British Indian Ocean Territory or Brunei Darussalam or Cambodia$ or India$ or Indonesia$ or Lao or People’s Democratic Republic or Malaysia$ or Maldives or Myanmar or Nepal or Philippin$ or Singapore or Sri Lanka or Thai$ or Timor Leste or Vietnam or Albania$ or Andorra or Bosnia$ or Herzegovina$ or Bulgaria$ or Croatia$ or Faroe Islands or Greenland or Liechtenstein or Lithuani$ or Macedonia or Malta or maltese or Romania or Serbia$ or Montenegro or Svalbard or Argentina$ or Belize or Bolivia$ or Brazil$ or Chilean or Colombia$ or Costa Rica$ or Cuba or Ecuador or El Salvador or French Guiana or Guatemala$ or Guyana or Haiti or Honduras or Jamaica$ or Nicaragua$ or Panama or Paraguay or Peru or Puerto Rico or Suriname or Uruguay or Venezuela or developing countr$ or south America$).ti,sh. (128,851)
66. thesis.tw. (24,537)
67. book.pt. (476,469)
68. exp BOOKS/ (6110)
69. or/61-68 (1,332,511)
70. 18 and 42 and 60 (838)
71. 70 not 69 (609)

Appendix 12 Supplementary searches

All websites last accessed 8 March 2019.

Trial registers

Trial register	Search terms
ClinicalTrials.gov	"end of life" or palliative and mental
*meta*Register of Controlled Trials	Not applicable
UK Clinical Trials Gateway	"last year of life" or LYOL or "end of life" or "end of their lives" in mental
WHO ICTRP Search Portal International (www.who.int/ictrp/en/)	"end of life" or "end of their lives" and mental

Charity websites

Website	Search type	Search terms
Cancer Research UK (www.cancerresearchuk.org/)	Electronic search: main website	"end of life" and "mental illness/health" "palliative care" and mental illness/health"
Cancer Research Wales (www.cancerresearchwales.co.uk/)	Electronic search: main website	"end of life" and "mental illness/health" "palliative care" and mental illness/health"
Tenovus Cancer Care (www.tenovuscancercare.org.uk/)	Electronic search: main website	"end of life" and "mental illness"
Mental Health Foundation (www.mentalhealth.org.uk/)	Electronic search: main website	"end of life" and "mental illness/health" "palliative care" and mental illness/health"
	Manual search: policy publications	As per reviews inclusion criteria
Centre for Mental Health (www.centreformentalhealth.org.uk/)	Electronic search: policy publications	"end of life" and "mental illness/health" "palliative care" and mental illness/health"
National Kidney Foundation (www.kidney.org/)	Electronic search: main website	"end of life" and "mental illness/health" "palliative care" and mental illness/health"
	Manual search: policy publications	As per reviews inclusion criteria
British Liver Trust (www.britishlivertrust.org.uk/)	Electronic search: publications	"end of life" and "mental illness" "palliative care" and mental illness" (mental health too broad a term)
British Renal Society (http://britishrenal.org/)	Electronic search: conference abstracts	"end of life" and "mental illness/health" "palliative care" and "mental illness/health"
The Renal Association (http://britishrenal.org/)	Electronic search: main website	"end of life" and "mental illness/health" "palliative care" and "mental illness/health"
British Heart Foundation (http://britishrenal.org/)	Electronic search: main website	"last year of life" or LYOL or "end of life" or "end of their lives" and "severe mental" and "Healthcare professionals" "palliative care" and "mental illness" (mental health too broad)

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Website	Search type	Search terms
British Lung Foundation (www.blf.org.uk/)	Electronic search: main website	“end of life” and “mental illness/health” “palliative care” and “mental illness/health”
Hospice UK (www.hospiceuk.org/)	Electronic search: main website	“end of life” and “mental illness/health” “palliative care” and “mental illness/health”
Marie Curie (www.mariecurie.org.uk/)	Electronic search: main website Manual search: briefings	“end of life” and “mental illness/health” “palliative care” and “mental illness/health” As per reviews inclusion criteria
Macmillan Cancer Support (www.macmillan.org.uk/)	Electronic search: main website	“last year of life” or LYOL or “end of life” or “end of their lives” and “severe mental” “palliative care” and mental illness/health”
Bipolar UK (www.bipolaruk.org/)	Electronic search: main website	“end of life” and “mental illness/health” Palliative
MIND (www.mind.org.uk/)	Electronic search: main website	“end of life care” and “mental illness/health” Palliative
Rethink Mental Illness (www.rethink.org/)	Electronic search: main website	“end of life care” and “mental illness/health” Palliative
Sova (www.sova.org.uk/)	Electronic search: main website	“end of life care” and “mental” Palliative
Hafal: for recovery for serious mental illness (www.hafal.org)	Electronic search: main website	“end of life care” and “mental” Palliative and mental
Age Concern (www.ageuk.org.uk)	Electronic search: main website	“end of life care “ and “mental” Palliative and mental
Salvation Army (https://salvationarmy.org.uk)	Electronic search: main website	“end of life care” and “mental” Palliative and mental
Dying Matters (www.dyingmatters.org/)	Electronic search: main website	“end of life “ and “mental” “palliative care” and “mental illness/health”
Care Not Killing (www.carenotkilling.org.uk/)	Electronic search: main website	“end of life care” and then searched within results for the term “mental” “palliative care” and then searched within results for the term “mental”
Northern Ireland Hospice (www.nihospice.org/)	Electronic search: main website	“end of life care” and “mental” Palliative
Mental Health UK (www.mentalhealth-uk.org/)	No search facility or publications page	
Heads Together (www.headstogether.org.uk/)	No search facility or publications page	
Kidney Research UK (www.kidneyresearchuk.org/)	Electronic search: main website	“end of life care” and “mental” Palliative
National Kidney Federation (www.kidney.org.uk/)	Electronic search: main website	“end of life care” and “mental” Palliative

Website	Search type	Search terms
St Mungo's (www.mungos.org/)	Electronic search: main website	"end of life" Palliative "mental illness"
Samaritans (www.samaritans.org/)	Electronic search: main website	"end of life" and "severe mental" Palliative and "severe mental"
Llanmau (www.llamau.org.uk/)	Electronic search: main website	
SSAFA (www.ssafa.org.uk/)	Electronic search: main website	
Community Housing Cymru (https://chcymru.org.uk/)	Electronic search: main website	
National Housing Federation (www.housing.org.uk/)	Electronic search: main website	
Shelter Cymru (https://sheltercymru.org.uk/)	Electronic search: main website	
Shelter (www.shelter.org.uk/)	Electronic search: main website	
Gofal (www.gofal.org.uk/)	No search function checked projects and services page but no relevant reports	As per reviews inclusion criteria
Compassionate Communities (www.compassionate-communitiesuk.co.uk/)	No search function checked projects but no relevant reports	As per reviews inclusion criteria
Byw Nawr (www.dyingmatters.org/wales)	Electronic search: main website	
Combat Stress (www.combatstress.org.uk/)	Electronic search: main website	
Royal British Legion (www.britishlegion.org.uk/)	Electronic search: main website	

SSAFA, the Soldiers, Sailors, Airmen and Families Association.

Organisation websites

Website	Search type	Search terms
NHS England (www.england.nhs.uk/cancer/strategy/; www.england.nhs.uk/EoLC/resources/-; http://endoflifecareambitions.org.uk/)	Electronic search: main website	"mental illness"
NHS Wales (www.wales.nhs.uk/)	Electronic search: main website	"end of life" and "mental illness/health"
	Advanced search: title field only	"palliative care" and "mental illness/health"
Welsh Government (https://gov.wales/)	Electronic search: main website	"end of life" and "mental illness/health"
	Advanced search: limited to health and social services	"palliative care" and "mental illness/health"
Department of Health and Social Care (www.gov.uk/)	Electronic search: publications	"end of life" and "mental illness/health"
	Limited by: Department of Health and Social Care	"palliative care" and "mental illness/health"
	Topic: Health and Social Care	
	Subtopic: end of life	

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Website	Search type	Search terms
Department of Health: Northern Ireland (www.health-ni.gov.uk/)	Electronic search: publications	"end of life" and "mental illness/health" "palliative care" and "mental illness/health"
Department of Health, Social Services and Public Safety: Northern Ireland (www.health-ni.gov.uk/)	Electronic search: publications	"end of life" and "mental illness/health" "palliative care" and "mental illness/health"
Ministry of Justice (www.gov.uk/)	Electronic search: publications Limited by: Ministry of Justice Topic: health and social care Subtopic: end of life	"end of life" and "mental illness/health" "palliative care" and "mental illness/health"
Care Inspectorate Wales (www.qcs.co.uk/wale)s/	Searching available only with practitioner registration E-mailed – no relevant publications	
Care Quality Commission (www.cqc.org.uk/)	Electronic search: publications	"end of life" and "severe mental" "palliative care" and "mental illness"
Prisons and Probation Ombudsman (www.ppo.gov.uk)	Electronic search: main website Manual search: fatal incident reports over a 1-year period between June 2017 and 2018 Limited by: deaths of natural causes	"end of life" As per reviews inclusion criteria
Royal College of Psychiatrists (www.rcpsych.ac.uk/)	Manual search: college reports	As per reviews inclusion criteria
Royal College of Physicians (www.rcplondon.ac.uk/)	Electronic search: main website	"end of life" and "mental illness/health" "palliative care" and "mental illness/health"
The Worldwide Hospice and Palliative Care Alliance (www.thewhpca.org/)	Manual search: resources	As per reviews inclusion criteria
European Association of Palliative Care (www.eapcnet.eu/)	Manual search: national guidelines (UK countries only)	As per reviews inclusion criteria
Scottish Partnership Agency for Palliative Care (www.palliativecarescotland.org.uk/)	Electronic search: main website	"end of life care" and "mental illness" and evaluation "palliative care" and "mental illness/health"
National Council for Palliative Care (www.ncpc.org.uk/)	Electronic search: main website	"end of life" and "mental illness/health" "palliative care" and "mental illness/health""
Social Care Institute for Excellence (www.scie.org.uk/)	Electronic search: main website	"end of life" and "mental illness" "palliative care" and "mental illness"
Health Improvement Scotland (www.healthcareimprovementscotland.org/)	Electronic search: main website	"end of life" and "mental illness" "palliative care" and "mental illness"

Website	Search type	Search terms
Covers publications by NHS Scotland, Scottish Government and Healthcare Improvement Scotland		
NICE (www.nice.org.uk/guidance)	Electronic search: main website	“end of life” or “palliative care”
		“mental illness”
Royal College of Nursing (www.rcn.org.uk/clinical-topics/end-of-life-care)	Manual search through section on clinical topics end of life	As per reviews inclusion criteria
Gold Standards Framework (www.goldstandardsframework.org.uk/)	Manual search through library resources	As per reviews inclusion criteria

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Appendix 13 Screening tool

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Author/s (year): Country:

Reviewer: Date Reviewed:

Participants are adults with **pre-existing Severe Mental Illness**
(Place an X in the relevant box, by clicking the mouse on the box)

Yes ☐ If yes, continue with screening No ☐ If no, STOP screening and EXCLUDE

Participants are adults with the following **terminal illnesses**
(Place an X in the relevant box, by clicking the mouse on the box)

Cancer ☐
End stage heart failure ☐
Chronic conditions (not specified) ☐
Other ☐

End stage lung failure ☐
End stage liver failure ☐
End stage kidney failure ☐

If other, please specify

The focus of paper is about **End of Life** care
(Place an X in the relevant box, by clicking the mouse on the box)

Yes ☐ If yes, continue with screening

No ☐ f no, STOP screening and EXCLUDE

The focus of the paper is also about one of the following the **areas**
(Place an X in the relevant **boxes,** by clicking the mouse on the boxes)

Organisation of care / services ☐
Access to care / services ☐
Treatment / Management ☐

Provision of care / services ☐
Utilization of services ☐
Views and experiences ☐

Preferences	☐	
Other	☐	If other, please specify

What is your **decision** regarding this paper? (Place an X in the relevant box)

Include ☐

Exclude ☐

Not Sure ☐

Comments

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Appendix 14 Table of studies excluded from the review

Study	Reason for exclusion
Abdullah *et al.* 2015[181]	Not about EoL care – radiotherapy
Ahearn 2015[182]	No evidence of any participants with pre-existing SMI
Akechi *et al.* 2002[183]	No evidence of any participants with pre-existing SMI
Akechi *et al.* 2004[184]	Prevalence of mental health concerns post-cancer diagnosis
Alexander 2004[185]	Patterns of referral to a hospice and not about EoL care
Alexopoulos 2008[186]	Not about EoL care – problem-solving therapy
Ann-Yi *et al.* 2018[187]	No evidence of any participants with pre-existing SMI
Anquinet *et al.* 2014[188]	Pre-existing psychological problems, namely depression and anxiety, and not SMI
Aragona 2007[189]	Not about EoL care – tolerability and efficacy of aripiprazole
Atkin *et al.* 2017[190]	Anxiety assessment and management as a consequence of advanced life-limiting illness
Azhar *et al.* 2018[191]	No evidence of any participants with pre-existing SMI
Azuero *et al.* 2014[192]	No evidence of any participants with pre-existing SMI
Baile *et al.* 1993[193]	No evidence of any participants with pre-existing SMI
Baker 2016[194]	Review article – all relevant citations screened
Balaban *et al.* 2017[195]	Not about EoL care – haemodialysis
Balogun and Abdel-Rahman 2009[196]	No evidence of any participants with pre-existing SMI
Bang *et al.* 2005[197]	No evidence of any participants with pre-existing SMI
Bannink *et al.* 2000[198]	No evidence of any participants with pre-existing SMI
Barth *et al.* 2013[199]	No evidence of any participants with pre-existing SMI
Bartlett *et al.* 2010[200]	Not about expected LYoL – normal health until emergency
Bassirpour *et al.* 2011[201]	Review article – all relevant citations screened
Battersby *et al.* 2018[202]	Not about expected LYoL – cardiovascular health
Bauer 2016[203]	Review article – all relevant citations screened
Baumrucker *et al.* 2009[204]	No evidence of any participants with pre-existing SMI
Beechem 1995[205]	No evidence of any participants with pre-existing SMI
Beernaert *et al.* 2015[206]	Dementia; no other SMI
Bekelman *et al.* 2018[207]	No evidence of any participants with pre-existing SMI
Bekelman *et al.* 2018[208]	No evidence of any participants with pre-existing SMI
Bergquist and Hammerlid 2007[209]	No evidence of any participants with pre-existing SMI
Berlim *et al.* 2006[210]	No evidence of any participants with pre-existing SMI
Bernard *et al.* 2016[211]	No evidence of any participants with pre-existing SMI
Black *et al.* 2001[212]	Employing registered mental health nurses in palliative care settings
Block and Billings 1994[213]	Review article all relevant citations screened
Block 2001[214]	Focuses on one person who does not have any pre-existing SMI

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Study	Reason for exclusion
Block 2006[215]	No evidence of any participants with pre-existing SMI
Bloomer and O'Brien 2013[216]	Review article – all relevant citations screened
Borowiak *et al.* 2009[217]	Excluded patients with psychiatric disorders
Bove *et al.* 2018[218]	Palliative care for people with COPD and not SMI
Bradley *et al.* 2005[219]	No evidence of any participants with pre-existing SMI
Braiteh *et al.* 2007[220]	No evidence of any participants with pre-existing SMI
Bramstedt and Arroliga 2004[221]	No evidence of any participants with pre-existing SMI
Brandt *et al.* 2005[222]	No evidence of any participants with pre-existing SMI
Braverman *et al.* 2017[223]	HCPs' attitudes towards physician-assisted suicide
Breitbart and Jacobsen 1996[224]	No evidence of any participants with pre-existing SMI
Breitbart *et al.* 1995[225]	No evidence of any participants with pre-existing SMI
Breitbart *et al.* 2010[226]	No evidence of any participants with pre-existing SMI, and participants with psychosis excluded
Breitbart *et al.* 2012[227]	No evidence of any participants with pre-existing SMI, and participants with psychosis excluded
Breitbart *et al.* 2018[228]	No evidence of any participants with pre-existing SMI, and participants with psychosis excluded
Brennan *et al.* 2015[229]	No evidence of any participants with pre-existing SMI
Brown *et al.* 2019[230]	Review article – all relevant citations screened
Browne 2017[231]	Not about expected LYoL – treatment
Bruhn *et al.* 2013[232]	Not about expected LYoL – pain management
Buda *et al.* 2012[233]	No evidence of any participants with pre-existing SMI
Buss *et al.* 2011[234]	Not about meeting the needs of people with pre-existing SMI at the EoL
Byock *et al.* 2006[235]	Review article – all relevant citations screened
Calderón *et al.* 2018[236]	No evidence of any participants with pre-existing SMI at the EoL
Campo-Engelstein *et al.* 2016[237]	Not about meeting the needs of people with pre-existing SMI at the EoL
Candilis *et al.* 2004[238]	Not about meeting the needs of people with pre-existing SMI at the EoL
Capozzo *et al.* 2009[239]	No evidence of any participants with pre-existing SMI
Carter *et al.* 2007[240]	No evidence of any participants with pre-existing SMI
Check *et al.* 2019[241]	The paper addresses post-cancer diagnosis depression
Chochinov 2004[242]	Review article – all relevant citations screened
Chou *et al.* 2016[243]	Not about EoL care – general discussion about cancer in patients with schizophrenia
Choudry *et al.* 2015[244]	No evidence of any participants with pre-existing SMI
Close *et al.* 2014[245]	Not about expected LYoL – lithium exposure and renal failure in people with bipolar disorder
Cohen *et al.* 2002[246]	Not about EoL care – association schizophrenia and cancer
Craun *et al.* 1997[247]	Review article – all relevant citations screened
Crump *et al.* 2013[248]	Not about EoL care – comorbidities and mortality in bipolar disorder
Crump *et al.* 2013[249]	Not about EoL care – comorbidities and mortality in schizophrenia
Davie 2006[250]	No evidence of any participants with pre-existing SMI

Study	Reason for exclusion
den Boer *et al.* 2019[251]	Review article – all relevant citations screened
Dinnen *et al.* 2018[252]	No evidence of any participants with pre-existing SMI
Doering 2018[253]	Review article – all relevant citations screened
Donald and Stajduhar 2019[254]	Review article – all relevant citations screened
Dube 2013[255]	Not about EoL care – kidney transplants
Ita *et al.* 2003[256]	Prevalence study
Evenblij 2018[257]	Prevalence study
Fairman and Irwin 2013[258]	Review article – all relevant citations screened
Farasatpour *et al.* 2013[259]	Not about EoL care – treatment delay
Feldman 2011[260]	Review article – all relevant citations screened
Filiberti *et al.* 2001[261]	Psychological autopsy but none of the cases had obvious pre-existing SMI
Flick 2018[262]	No evidence of any participants with pre-existing SMI
Forster *et al.* 2017[263]	No evidence of any participants with pre-existing SMI
Frei *et al.* 2001[264]	Prevalence study
Fried and Gillick 1994[265]	No evidence of any participants with pre-existing SMI
Fujioka *et al.* 2018[266]	A scoping review of the perspectives of professionals on assisted dying. Nothing about SMI
Fukunishi *et al.* 2002[267]	Not about EoL care – haemodialysis
Ganzini 2018[88]	No evidence of any participants with pre-existing SMI
Gao *et al.* 2019[268]	No evidence of any participants with pre-existing SMI
Gardner-Sood *et al.* 2015[269]	Not about EoL care – cardiovascular risk factors and metabolic syndrome in people with established psychotic illnesses
Garrido *et al.* 2017[270]	Not about EoL care – serious physical illness
Gill *et al.* 2010[271]	Prevalence study
Gillick and Mendes 1996[272]	No evidence of any participants with pre-existing SMI other than dementia
Ginieri-Coccossis *et al.* 2008[273]	No evidence of any participants with pre-existing SMI
Glick *et al.* 2018[274]	Review article – all relevant citations screened
Granek *et al.* 2019[275]	Not EoL care – emotional distress and suicidal ideations
Grigoletti *et al.* 2009[276]	Prevalence study
Groenewoud *et al.* 1997[277]	Not about EoL care –incidence study of assisted suicide
Güth *et al.* 2011[278]	Not about EoL care – suicide
Habraken *et al.* 2009[279]	No evidence of any participants with pre-existing SMI
Harris *et al.* 2019[280]	Not EoL care – incidence of gastrointestinal cancers
Hawkins 2016[281]	Opinion/review article – all relevant citations screened
Hay and Passik 2000[282]	Not about EoL care – symptom management
Henderson and Ord 1997[283]	No evidence of any participants with pre-existing SMI
Henoch *et al.* 2007[284]	Excluded patients with psychiatric disorders
Henriksson *et al.* 1995[285]	Not about EoL care – suicide
Hietanen *et al.* 1994[286]	Not about EoL care – suicide
Hindley *et al.* 2019[287]	Not about EoL care – advance decision-making for mental health crisis

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Study	Reason for exclusion
Hinton 1972[288]	Psychological problems arose during their terminal illness
Holmes *et al.* 2015[289]	No evidence of any participants with pre-existing SMI
Howard *et al.* 2010[23]	Review article – all relevant citations screened
Hwang *et al.* 2012[290]	Not about EoL care – chemotherapy
Iachina *et al.* 2019[291]	Not about EoL care – treatment
Inagaki *et al.* 2006[292]	Not about EoL care – treatment
Iordanidis *et al.* 1993[293]	Older people with end-stage renal disease
Irwin *et al.* 2008[294]	No evidence of any participants with pre-existing SMI
Irwin *et al.* 2011[295]	Psychiatry resident education in palliative care
Irwin *et al.* 2017[296]	Not about EoL care – treatment
Ishikawa *et al.* 2016[28]	Not about EoL care – screening, treatment and 30-day mortality
Jackson *et al.* 2018[297]	Not about EoL care – dialysis
Jamison and Holmes 2018[298]	No evidence of any participants with pre-existing SMI
Jarero *et al.* 2016[299]	No evidence that PTSD was pre existing
Jeffery *et al.* 2019[300]	Not about meeting needs of people with pre-existing SMI at the EoL
Jones *et al.* 2008[301]	Not about EoL care – diagnostic overshadowing
Kadan-Lottick *et al.* 2005[302]	Not about EoL care – access to mental health services after cancer diagnosis
Kaerlev *et al.* 2018[303]	Not about EoL care – chemotherapy
Kardinal and Porter 1981[304]	No evidence of any participants with pre-existing SMI
Kaufman 2010[305]	Not about EoL care – haemodialysis
Kelly and Shanley 2000[306]	Frailty associated with terminal illness
Kim *et al.* 2016[307]	Psychiatric patients with no other chronic health condition
Kimmel *et al.* 1998[308]	Prevalence study
King *et al.* 2005[309]	Discussion article about assessing depression in patients with cancer and no mention of previous SMI
Kisely *et al.* 2008[310]	Not about EoL care – cancer-related mortality
Kisely *et al.* 2013[311]	Not about EoL care – cancer-related mortality
Kisely *et al.* 2016[312]	Not about EoL care – cancer-related mortality
Kissane and Smith 1996[313]	Not about EoL care – psychosocial morbidity in women with breast cancer
Kissane *et al.* 2004[314]	Not about EoL care – referrals to liaison psychiatry
Kleiboer *et al.* 2011[315]	Depression within previous month and having cancer for over 6 months
Lacy and Higgins 2005[316]	Not about EoL care – psychotherapy
Lamers 2005[317]	No evidence of any participants with pre-existing SMI
Lawrence and Kisely 2010[318]	Review article – all relevant citations screened
Legler *et al.* 2011[319]	No patients with previous SMI – comorbidities that the paper refers to are other medical conditions and dementia
Lehto *et al.* 2019[320]	Review article – all relevant citations screened
Lent and Brown Bradley 1999[321]	Not about expected LYoL – treatment
Levine *et al.* 1978[322]	No evidence of any participants with pre-existing SMI
Levinson 1975[323]	No evidence of any participants with pre-existing SMI

Study	Reason for exclusion
Lichtenthal *et al.* 2009[324]	Prevalence of mental disorder and closeness to death
Liu *et al.* 2017[325]	Not about EoL care – suicide
Lloyd-Williams *et al.* 1999[326]	No evidence of any participants with pre-existing SMI
Lloyd-Williams *et al.* 2014[327]	Review article – all relevant citations screened
Macleod 2013[328]	Not about meeting needs of people with pre-existing SMI at the EoL
Madeira *et al.* 2011[329]	No evidence of any participants with pre-existing SMI
Madrigal 2010[330]	Discussion paper – all relevant citations retrieved
Maguire *et al.* 1999[331]	No evidence of any participants with pre-existing SMI
Martiny *et al.* 2012[332]	Prevalence study
Masel *et al.* 2016[333]	Not about EoL care – consumption of pain medication
Maull 1991[334]	No evidence of any participants with pre-existing SMI and also not about expected LYoL
McCormack and Sharp 2006[29]	Discussion paper on palliative care for people with mental health problems, some of whom would have had previous SMI, but no further details provided
McDaniel *et al.* 1992[335]	Not about meeting needs of people with pre-existing SMI at the EoL
Medenica *et al.* 2014[336]	Not about meeting needs of people with pre-existing SMI at the EoL
Meyer and Block 2011[337]	Not about EoL care – discussion on personality disorder in oncology settings
Meyer *et al.* 2013[338]	Not about EoL care – behaviour of patients with schizophrenia and metastatic breast cancer
Miller 2018[339]	Poster presentation no outcome data presented
Millman *et al.* 2016[18]	Protocol paper – no outcome data
Miovic and Block 2007[340]	Discussion paper – all relevant citations screened
Morasso *et al.* 1999[341]	Not about meeting needs of people with pre-existing SMI at the EoL
Moskowitz 1997[342]	Suicidality and responses to people who wish to die, including those who are critically ill
Moss 1980[343]	Not about meeting needs of people with pre-existing SMI at the EoL
Mucsi *et al.* 2017[344]	Not about EoL care – kidney transplant
Muir-Cochrane 2006[345]	Not about EoL care – barriers to care
Mulder *et al.* 2012[346]	Not about meeting needs of people with pre-existing SMI at the EoL
Myhill 2014[347]	Editorial – all relevant citations screened
Nash 2017[348]	Not about meeting needs of people with pre-existing SMI at the EoL
Neely and Roxe 2000[349]	Not about meeting needs of people with pre-existing SMI at the EoL
Ng 2012[350]	Clinical trial protocol and a full report was not published
Ng *et al.* 2013[351]	Prevalence study
Ng *et al.* 2014[352]	Patients were excluded if they had other comorbid psychiatric diagnoses or if they were already treated with antidepressants
Nipp *et al.* 2017[353]	Not about meeting needs of people with pre-existing SMI at the EoL
O'Connor *et al.* 2006[354]	Not about EoL care – pain management
Ogawa *et al.* 2010[355]	States no previous psychiatric history
O'Mahony *et al.* 2018[356]	Not about EoL care – pain management
Onishi *et al.* 2006[357]	Not about meeting needs of people with pre-existing SMI at the EoL

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Study	Reason for exclusion
Owen *et al.* 1994[358]	Not about meeting needs of people with pre-existing SMI at the EoL
Ozenli *et al.* 2010[359]	Not about meeting needs of people with pre-existing SMI at the EoL
Paice 2002[360]	Not about meeting needs of people with pre-existing SMI at the EoL
Parkerson and Gutman 1997[361]	Not about meeting needs of people with pre-existing SMI at the EoL
Payne and Haines 2002[362]	No evidence of any participants with pre-existing SMI
Payne *et al.* 2004[363]	No evidence of any participants with pre-existing SMI
Pengelly and Purnell 2009[364]	Not about EoL care – psychological support for cancer patients
Perr 1985[365]	Not about meeting needs of people with pre-existing SMI at the EoL
Peteet 2009[366]	No evidence of any participants with pre-existing SMI
Phongtankuel *et al.* 2018[367]	No evidence of any participants with pre-existing SMI
Popa-Velea *et al.* 2010[368]	No evidence of any participants with pre-existing SMI, and those with psychoses excluded
Price *et al.* 2006[38]	No evidence of any participants with pre-existing SMI
Quentzel and Levine 1997[369]	Not about EoL care – haemodialysis
Quipourt *et al.* 2011[370]	No evidence of any participants with pre-existing SMI
Rajmohan and Kumar 2013[371]	Not about EoL care – psychological factors and pain management
Ramos and Fulton 2017[372]	No evidence of any participants with pre-existing SMI
Rasmussen and Richardson 2011[373]	Not about EoL care – ECT therapy
Rayner *et al.* 2004[374]	No evidence of any participants with pre-existing SMI
Rayner *et al.* 2011[375]	No evidence of any participants with pre-existing SMI
Reeve *et al.* 2007[376]	Prevalence study
Reinke *et al.* 2011[377]	No evidence of any participants with pre-existing SMI
Relyea *et al.* 2019[378]	Review article – all relevant citations screened
Rhondali *et al.* 2013[379]	Not an English-language full-text article
Riquin *et al.* 2017[380]	Not an English-language full-text article
Sanders *et al.* 2019[381]	No evidence of any participants with pre-existing SMI
Saracino *et al.* 2018[382]	Not about EoL care – those awaiting liver transplant
Sato *et al.* 2004[383]	Not about EoL care – milnacipran treatment for major depressive disorder
Scott *et al.* 2018[384]	Not about meeting needs of people with pre-existing SMI at the EoL
Shalev *et al.* 2017[20]	Review article – all relevant citations screened
Shalev *et al.* 2017[385]	Review article – all relevant citations screened
Sharma *et al.* 2010[386]	Not about meeting needs of people with pre-existing SMI at the EoL
Sharma *et al.* 2012[387]	Not about meeting needs of people with pre-existing SMI at the EoL
Shipman *et al.* 2008[388]	General discussion on EoL based on a survey of professionals and academics
Snyder and Whisman 2004[389]	Not about expected LYoL
Spencer *et al.* 2012[390]	No participants with pre-existing SMI – assessed as having MDD, PTSD, PD, GAD within the last 30 days
Stedeford and Bloch 1979[391]	Not about meeting needs of people with pre-existing SMI at the EoL
Stein *et al.* 2018[392]	Abstract of conference presentation – no outcome data presented
Talbott and Linn 1978[393]	Not about expected LYoL

Study	**Reason for exclusion**
Tate and Longo 2005[394]	Not about meeting needs of people with pre-existing SMI at the EoL
Taylor *et al.* 2013[395]	Not about EoL care – surgical treatment of cancer
Taylor *et al.* 2018[396]	Not about expected LYoL – self-injury that led to death
Terpstra and Terpstra 2012[397]	Review article – all relevant citations screened
Trachsel 2018[398]	Discussion article – all relevant citations screened
Trachsel *et al.* 2016[399]	Not about expected LYoL – palliative psychiatry
Trachsel *et al.* 2019[400]	Not about expected LYoL – palliative psychiatry
Udo 2012[401]	No evidence of any participants with pre-existing SMI
Unseld *et al.* 2018[402]	No evidence of any participants with pre-existing SMI
van der Lee *et al.* 2005[403]	No evidence of any participants with pre-existing SMI
Vehling *et al.* 2017[404]	Not about meeting needs of people with pre-existing SMI at the EoL
Verschuur *et al.* 2014[405]	Not about meeting needs of people with pre-existing SMI at the EoL
Walker *et al.* 2014[406]	Not about expected LYoL – cost-effectiveness of identification and treatment of major depression
Walling *et al.* 2018[407]	Not about meeting needs of people with pre-existing SMI at the EoL
Ward and Smith 2009[408]	Not about expected LYoL
Warmenhoven *et al.* 2013[409]	Prevalence study
Waterman *et al.* 2016[410]	No evidence of any participants with pre-existing SMI – dementia
Wei *et al.* 2013[411]	Not about expected LYoL
Weinstein *et al.* 2016[412]	Review article – all relevant citations screened
Wen *et al.* 2018[413]	No evidence of any participants with pre-existing SMI
White 1985[414]	Not about meeting needs of people with pre-existing SMI at the EoL
Wilson *et al.* 2007[415]	No evidence of any participants with pre-existing SMI
Wilson *et al.* 2007[416]	No evidence of any participants with pre-existing SMI
Wilson *et al.* 2016[417]	No evidence of any participants with pre-existing SMI
Wilson *et al.* 2019[418]	Review article – all relevant citations screened
Woersching *et al.* 2019[419]	Review article on health-care utilisation but not at the EoL
Woodhead *et al.* 2016[420]	Not about EoL care – data linkage study, SMI and cardiovascular disease
Woods *et al.* 2008[3]	Review article – all relevant citations screened

COPD, chronic obstructive pulmonary disease; ECT, electroconvulsive therapy; GAD, general anxiety disorder; MDD, major depressive disorder; PD, personality disorder.

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Appendix 15 Table of excluded grey literature

All websites last accessed 14 February 2020.

Authors, title of document, URL	Focus; reason for exclusion
Addicott R, Ross S. *Implementing the End of Life Care Strategy. Lessons for Good Practice*. London: The King's Fund; 2010. URL: www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Implementing-end-of-life-care-Rachael-Addicott-Shilpa-Ross-Kings-Fund-October2010_0.pdf	EoL care; no mention of care of patients with mental illness
Addicott, R. Hiley, J. *Issues Facing Commissioners in End-of-Life Care*. London: The King's Fund; 2011. URL: www.kingsfund.org.uk/sites/default/files/issues-facing-commissioners-end-of-life-care-report-september2011.pdf	EoL care; no mention of care of patients with mental illness
All Wales Palliative Care Planning Group. *Report to Minister for Health and Social Services on Palliative Care Services – Sugar Report*. 2008. URL: www.wales.nhs.uk/documents/Palliative-Care.pdf	EoL care; no mention of care of patients with mental illness
Cross Party Group Hospices and Palliative Care. *CPG Hospices and Palliative Care: Inquiry*. Inequalities in Access to Hospice and Palliative Care; 2018. URL: www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/cpg-report_english_web.pdf?sfvrsn=4	EoL care; no mention of care of patients with mental illness
Department of Health, Social Services and Public Safety. *Living Matters Dying Matters. A Palliative and End of Life Care Strategy for Adults in Northern Ireland*. 2010. URL: www.health-ni.gov.uk/sites/default/files/publications/dhssps/living-matters-dying-matters-strategy-2010.pdf	EoL care; no mention of care of patients with mental illness
Department of Health. *End of Life Care Strategy. Fourth Annual Report*. 2012. URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf	EoL care; no mention of care of patients with mental illness
Department of Health. *Our Commitment to You for End of Life Care the Government Response to the Review of Choice in End of Life Care*. 2016. URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf	EoL care; no mention of care of patients with mental illness
Hall S, Petkova H, Tsouros AD, Costantini M, Higginson IG. *Palliative Care for Older People: Better Practices*. Copenhagen: World Health Organization, Regional Office for Europe; 2011. URL: www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf	EoL care; no mention of care of patients with mental illness
Healthcare Improvement Scotland. *Palliative and EoL Care Indicators*. 2013. URL: www.healthcareimprovementscotland.org/his/idoc.ashx?docid=ab6bef0f-48d4-4409-baf0-d15297469599%26version=-1	EoL care; no mention of care of patients with mental illness
Mental Health Foundation. *Mental Health and Palliative Care*. 2008. URL: www.mentalhealth.org.uk/file/1207/download?token=kMrNYnE-	EoL care and mental health; review article all relevant citations included
National Institute for Health and Care Excellence. *Psychosis and Schizophrenia in Adults: Prevention and Management*. Clinical Guideline 178. 2014. URL: www.nice.org.uk/guidance/cg178	Psychosis and schizophrenia; no mention of care of patients at the EoL
National Institute for Health and Care Excellence. *Bipolar Disorder: Assessment and Management*. Clinical Guideline 184. 2014. URL: www.nice.org.uk/guidance/cg184	Bipolar; no mention of care of patients at the EoL
National Institute for Health and Care Excellence. *Psychosis and Schizophrenia in Adults*. Quality Standard 80. 2014. URL: www.nice.org.uk/guidance/qs80	Psychosis and schizophrenia; no mention of care of patients at the EoL
National Institute for Health and Care Excellence. *Bipolar Disorder in Adults*. Quality Standard 95. 2014. URL: www.nice.org.uk/guidance/qs95	Bipolar; no mention of care of patients at the EoL

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Authors, title of document, URL	Focus; reason for exclusion
National Institute for Health and Care Excellence. *Care of Dying Adults in the Last Days of Life*. NICE Guideline 31. 2015. URL: http://wales.pallcare.info/files/NICE%20Care%20of%20dying%20adults%20in%20the%20last%20days%20of%20life%20NG31.pdf	EoL care; no mention of care of patients with mental illness
National Palliative and End of Life Care Partnership. *Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015–2020.* 2015. URL: http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf	EoL care; no mention of care of patients with mental illness
Naylor C, Parsonage M, McDaid D, Knapp M, Fossey M, Galea A. *Long-term Conditions and Mental Health. London: The Cost of Co-morbidities.* London: The King's Fund and Centre for Mental Health; 2012. URL: www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf	Long-term conditions and mental health; no mention of care of patients at the EoL
Naylor C, Das P, Ross S, Honeyman M, Thompson J, Gilburt H. *Bringing Together Physical and Mental Health: A New Frontier for Integrated Care.* London: The King's Fund; 2016. URL: www.kingsfund.org.uk/publications/physical-and-mental-health	Physical and mental health; no mention of care of patients at the EoL
NHS England. *The Five Year Forward View for Mental Health*. 2016. URL: www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf	Mental health; no mention of care of patients at the EoL
NHS England. *Achieving World-Class Cancer Outcomes: A Strategy for England 2015–2020 Progress Report.* 2017. URL: www.england.nhs.uk/wp-content/uploads/2017/10/national-cancer-transformation-programme-2016-17-progress.pdf	Cancer; no mention of the EoL care of patients with pre-existing SMI
NHS Scotland. *Clinical Standards Specialist Palliative Care.* 2002. URL: www.palliativecarescotland.org.uk/content/publications/ClinicalStandardforSPC.pdf	EoL care; no mention of care of patients with mental illness
NHS Scotland. *Living and Dying Well. A National Action Plan for Palliative and End of life Care in Scotland.* 2008. URL: www2.gov.scot/resource/doc/239823/0066155.pdf	EoL care; no mention of care of patients with mental illness
NHS Scotland. *Care in the Last Days of Life*. 2014. URL: www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/care-in-the-last-days-of-life.aspx	EoL care; no mention of care of patients with mental illness
Prisons and Probation Ombudsman for England and Wales. *Learning from PPO Investigations. End of Life Care.* 2013. URL: www.ppo.gov.uk/app/uploads/2014/07/Learning_from_PPO_investigations_-_End_of_life_care_final_web.pdf	EoL care; no mention of care of patients with mental illness
Public Health England. *What We Know Now 2014: New Information Collated by the National End of Life Care Intelligence Network*. URL: www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_201	EoL care; no mention of care of patients with mental illness
Public Health England. *Atlas of Variation for Palliative and End of Life Care in England.* 2018. URL: https://fingertips.phe.org.uk/profile/atlas-of-variation	EoL care; no mention of care of patients with mental illness
Royal College of Nursing. *Getting It Right Every Time. Fundamentals of Nursing Care at the End of Life*. 2015. URL: www.rcn.org.uk/professional-development/publications/pub-004871	EoL care; refers to psychological support but not specific to SMI
Royal College of Physicians. *National Care of the Dying Audit for Hospitals, England. National Report.* 2014. URL: www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals	EoL care; no mention of care of patients with mental illness
Royal College of Psychiatrists. *Liaison Psychiatry for Every Acute Hospital: Integrated Mental and Physical Healthcare.* 2013. URL: www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr183.pdf?sfvrsn=1c625881_2	Liaison psychiatry; no mention of care of patients at the EoL

Authors, title of document, URL	Focus; reason for exclusion
Scottish Government. *The Healthcare Quality Strategy for NHS Scotland*. 2010. URL: www.gov.scot/binaries/content/documents/govscot/publications/report/2010/05/healthcare-quality-strategy-nhsscotland/documents/0098354-pdf/0098354-pdf/govscot%3Adocument	General health care; some sections on EoL care but no mention of the EoL care of patients with pre-existing SMI
Scottish Government and NHS Scotland. *Achieving Sustainable Quality in Scotland's Healthcare. A '20:20' Vision*. 2011. URL: www2.gov.scot/Topics/Health/Policy/2020-Vision/Strategic-Narrative	General health care; no mention of the EoL care of patients with pre-existing SMI
Secretariat of the Commission of the Bishops' Conferences of the European Community. *Opinion of the Working Group on Ethics in Research and Medicine on Palliative Care in the European Union*. 2016. URL: www.comece.eu/dl/psqlJKJKooNNJqx4KJK/PalliativeCARE_EN.pdf	EoL care; no mention of care of patients with mental illness
The National Council for Palliative Care. *The End of Life Care Strategy: New Ambitions*. 2013. URL: www.ncpc.org.uk/sites/default/files/End%20of%20Life%20Care%20Strategy%20New%20Ambitions%20Report_WEB.pdf	EoL care; no mention of care of patients with mental illness
Scottish Government. *Strategic Framework for Action on Palliative and End of Life Care 2016–2021*. 2015. URL: www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/#res491388	EoL care; no mention of care of patients with mental illness
Wales Cancer Network. *Cancer Delivery Plan for Wales 2016–2020*. 2016. URL: www.walescanet.wales.nhs.uk/sitesplus/documents/1113/161114cancerplanen.pdf	Cancer; no mention of the EoL care of patients with pre-existing SMI
Welsh Government. *Together for Mental Health: Delivery Plan: 2016–10*. 2016. URL: https://gov.wales/docs/dhss/publications/161010deliveryen.pdf	Mental health; no mention of care of patients at the EoL
Welsh Government. *Together for Health: Delivering End of Life Care*. 2013. URL: https://gov.wales/docs/dhss/publications/130416careen.pdf	EoL care; no mention of care of patients with mental illness
Welsh Government. *Palliative and End of Life Care Delivery Plan*. 2017. URL: https://gov.wales/docs/dhss/publications/170327end-of-lifeen.pdf	EoL care; no mention of care of patients with mental illness
Worldwide Palliative Care Alliance. *Global Atlas of Palliative Care at the End of Life*. 2014. URL: www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf	EoL care; no mention of care of patients with mental illness
National Institute for Health and Care Excellence. *End of Life Care for Adults: Service Delivery*. 2019. URL: www.nice.org.uk/guidance/ng142	EoL care; no mention of care of patients with mental illness

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Appendix 16 Table of included grey literature

Study	Focus
Addicott and Ashton 2010[155]	EoL care Some sections on EoL care for people with pre-existing SMI
Care Quality Commission 2016[157]	EoL care and mental health Includes information on EoL care for those with pre-existing SMI
Care Quality Commission 2016[157]	EoL care Some sections on EoL care for people with pre-existing SMI
Care Quality Commission 2017[156]	EoL care Some sections on EoL care for people with pre-existing SMI
Department of Health 2008[161]	EoL care Some sections on EoL care for people with pre-existing SMI
Department of Health 2016[160]	General health care Some sections on mental health and physical health
Department of Health 2018[159]	Mental health Some sections on EoL care for people with pre-existing SMI
General Medical Council 2010[21]	EoL care Some sections on EoL care for people with pre-existing SMI
Help the Hospices 2006[162]	EoL care Some sections on EoL care for people with pre-existing SMI
Independent Cancer Taskforce 2015[22]	Cancer Some sections on EoL care for people with pre-existing SMI
Leadership Alliance for the Care of Dying People 2014[177]	EoL care Some sections on EoL care for people with pre-existing SMI
Marie Curie 2016[164]	EoL care and mental health Includes information on EoL care for those with pre-existing SMI
Marie Curie 2016[165]	EoL care and mental health Includes information on EoL care for those with pre-existing SMI
Marie Curie 2017[163]	EoL care and mental health Includes information on EoL care for those with pre-existing SMI
Addington-Hall 2000[30]	EoL care and mental health Includes information on EoL care for those with pre-existing SMI
NICE 2004[55]	Cancer Some sections on EoL care for people with pre-existing SMI
NHS England 2019[167]	General health care Some sections on EoL care or the care of people with SMI

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Study	Focus
NHS England 2014[1]	General health care Some sections on EoL care for people with mental health conditions
NHS England 2017[168]	General health care Some sections on EoL care for people with pre-existing SMI
NHS Lothian 2010[170]	EoL care Some sections on EoL care for people with pre-existing SMI
Royal College of Physicians 2007[171]	EoL care Some sections on EoL care for people with pre-existing SMI
Scottish Government 2017[172]	Mental health Some sections on EoL care for people with pre-existing SMI
Social Care Institute for Excellence 2013[173]	EoL care Some sections on EoL care for people with pre-existing SMI
Welsh Government 2012[175]	Mental health Some sections on EoL care for people with pre-existing SMI
Welsh Government 2018[174]	General health care Some sections on EoL care or the care of people with mental ill health
Worldwide Palliative Care Alliance 2017[176]	EoL care Some sections on EoL care for people with pre-existing SMI
Healthcare Quality Improvement Partnership 2019[421]	EoL care A section on mental health providers
Kennedy *et al.* 2013[120]	EoL care Some sections on EoL care for people with pre-existing SMI

Appendix 17 Characteristics of retrospective cohort studies included in the review

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
Butler and O'Brien 2018,[100] New Zealand **Aim** To compare the rate of access to palliative care services for people with SPMI with the rate for the general population **Mental health diagnosis** SPMI **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** Specialist palliative care services in the LYoL	**Setting** Specialist palliative care services within a district public health board **Participants** Decedents with SPMI utilising specialist palliative care services ($n = 147$); decedents from the general population utilising palliative care services ($n = 230{,}571$) **Age (years)** SPMI cohort: 18–24 (2%); 25–44 (16%); 45–64 (42%); 65–84 (31%); ≥ 85 (9%) General population: 18–24 (19%); 25–44 (36%); 45–64 (30%); 65–84 (13%); ≥ 85 (2%) **Gender** SPMI cohort: male (78%) General population: male (47.5%) **Ethnicity** SPMI cohort: European (79%); Maori (15%); Pacific (3%); Asian (2%) General population: European (65.5%); Maori (12.5%); Pacific (8%); Asian (14%)	**Design** Retrospective cohort (over 7 years) **Data sources** The mental health data came from the Programme for the Integration of Mental Health Data, which is a national mental health and addiction database of service activity and outcomes. The information on this database is collected from district health boards and non-governmental organisations Population information came from Ministry of Health reports and reported data limited to the Capital and Coast District Health Board region **Outcomes** Rate of access to palliative care services The rate ratio of specialist palliative care utilisation was calculated by dividing the rate of contacts for people with SPMI by the rate of contacts for the general population **Outcome measures** The number of specialist palliative care service contacts in the LYoL for people with SPMI was compared with the number of specialist palliative care service contacts within the general population Statistical analysis Descriptive statistics Rate ratios
Fond *et al.* 2019,[108] France	**Setting** French hospital care	**Design** Retrospective population-based cohort study (over 4 years)

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
Aim To establish whether or not the EoL care delivered to patients with schizophrenia and cancer differed from that delivered to patients with cancer who did not have a diagnosis of mental illness **Mental health diagnosis** Schizophrenia **Causes of death** Brain cancer, liver cancer or any metastatic solid cancer **Definition of EoL care/palliative care** Last 31 days of life	**Participants** Decedents with schizophrenia (*n* = 2481); decedents without mental illness (*n* = 222,477) **Age (years)** Matched cohort: 15–62 (22.2%); 63–71 (24.1%); 72–81 (28.4%); ≥ 82 (25.3%) Schizophrenia cohort: 15–62 (48.6%); 63–71 (24.7%); 72–81 (17.3%); ≥ 82 (9.4%) **Gender** Matched cohort: male (58%) Schizophrenia cohort: male (56%) **Ethnicity** No data reported	**Data sources** Data from Le Programme de Médicalisation des Systèmes d'Information, the French national hospital database, in which administrative and medical data are systematically collected for acute and psychiatric care **Outcomes** Health service utilisation in the 6 months prior to death for people with schizophrenia and cancer compared with those with cancer only and no schizophrenia diagnosis **Outcome measures** Access to palliative care in the last 31 days of life and the last 3 days of life Chemotherapy in the last 14 days of life Within the last 31 days of life Artificial nutrition (i.e. enteral or parenteral nutrition), tracheal intubation, mechanical ventilation, gastrostomy (or change in gastrostomy status), cardiopulmonary resuscitation, dialysis, blood transfusion, surgery, imaging, endoscopy At least one ED admission, one ICU admission, one air extraction chamber (i.e. sterile chamber) admission More than one admission to acute care unit Length of stay in acute care unit Death in ED ICU **Statistical analysis** Multivariate analysis presented as adjusted ORs [adjusted for social deprivation, year of death, time from cancer diagnosis to death, metastasis (yes vs. no), comorbidity, hospital category (specialist vs. non-specialist cancer centre]
Ganzini *et al.* 2010,[88] USA	**Setting** Veterans' Associations medical centres in north-west USA (Oregon, Washington and Alaska)	**Design** Retrospective cohort (over 6 years)

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
Aim To compare measures of quality of EoL care among veterans with and veterans without schizophrenia who died of cancer **Mental health diagnosis** Schizophrenia or schizoaffective disorder **Cause of death** Cancer **Definition of EoL/palliativecare** Last 6 months of life	**Participants** Veterans/decedents with schizophrenia or schizoaffective disorder who died of cancer ($n = 60$) were compared with veterans/ decedents with no major mental illness who died of cancer ($n = 196$) **Age (years), mean (SD)** Cancer and schizophrenia, 64.1 (11.5); cancer without schizophrenia, 70.5 (10.4) **Gender** Cancer and schizophrenia: male (93%) Cancer without schizophrenia: male (97%) **Ethnicity** No data reported	**Data sources** Data from the data management system of the US Department of Veterans Affairs Northwest Health Network–Veterans Integrated Service Network 20 were obtained along with medical record review **Outcomes** Quality of EoL care **Outcome measures** Enrolment in and length of hospice care Prescription of any opioids in the last 6 months of life but before hospice enrolment Presence of an advance directive or physician orders **Statistical analysis** *t*-tests and chi-squared tests
Huang *et al.* 2017,[89] USA **Aim** To gain knowledge on mental health disparities in EoL care; to identify at least three quality indicators of EoL care processes that are associated with mental health diagnoses **Mental health diagnosis** Any mental health diagnosis – not specified **Terminal conditions** Cancer (30.1%), heart disease (20.1%), other (not reported) **Definition of EoL/palliative care** Processes of care at the EoL; time frame not specified	**Setting** Not reported **Participants** Inpatient veterans/decedents ($n = 5476$) **Age (years), mean (SD)** 70.1 (22.5) **Gender** Male (98%) **Ethnicity** White (65%); black (34%)	**Design** Retrospective cohort (over 7 years) **Data sources** Data were drawn from the Best Practices for EoL care for Our Nation's Veterans (BEACON) trial conducted **Outcomes** Quality of EoL care **Outcome measures** Opioid order, do-not-resuscitate order, intravenous line infusing at time of death, nasogastric tube and physical restraints **Statistical analysis** Generalised equation modelling presented as ORs

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
Huang *et al.* 2018,[101] Taiwan (Province of China) **Aim** To compare the medical treatments received by cancer patients with and without schizophrenia within 1 and 3 months prior to their death **Mental health diagnosis** Schizophrenia **Terminal conditions** Cancer (breast, lung, liver, colorectal, oral, prostate) **Definition of EoL/palliative care** Within 1 month or 3 months of death	**Setting** All medical care covered by the National Health Insurance Program, which covers approximately 99% of the population and has contracts with 97% of the hospitals and clinics **Participants** Patients from 20 years old who were newly diagnosed as having one of six common cancers between 2000 and 2012 but who were not alive by the end of the study period Matched (ratio 1 : 4) sample decedents with no previous schizophrenia diagnoses ($n = 7644$) **Age (years)** < 50 (23.4%), 50–69 (44.8%), > 70 (31.7%) **Gender** Male (55%) **Ethnicity** Not reported	**Design** Retrospective cohort (over 12 years) **Data sources** Nationwide population-based cohort study based on the National Health Insurance Research Database of Taiwan **Outcomes** Medical treatments or interventions 1–3 months prior to their death Utilisation of medical care and palliative care 1–3 months prior to their death Advanced diagnostic examinations 1–3 months prior to their death **Outcome measures** Numbers receiving chemotherapy, invasive intervention and advanced diagnostic examination Number of inpatient days ICU utilisation (days) Palliative care and hospice ward care utilisation (days) Palliative care consultation and hospice home care **Statistical analysis** Multiple logistic regression analysis presented as ORs (adjusted for age, sex, type of primary cancer, comorbidity, year of death, time from cancer diagnosis to death, income, hospitalised in an acute ward in the month before death (yes vs. no)
Lavin *et al.* 2017,[91] USA **Aim** To examine whether or not having a psychiatric illness is associated with site of death or health-care utilisation in the last month of life	**Setting** UW Medicine health-care system, an integrated health-care system that includes four diverse academic and community hospitals **Participants** Decedents without psychiatric illness ($n = 14{,}499$) and decedents with psychiatric illness ($n = 1715$)	**Design** Retrospective cohort (over 4 years) **Data collection methods** Data were extracted from UW Medicine electronic health records and from Washington State death certificates

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
Mental health diagnosis Psychiatric illness (ICD-9) diagnosis of mood, anxiety and/or psychotic disorder or prescription medications for psychiatric illness prevalence 10.6% (5.6% based on documented diagnosis and 5.0% based on psychiatric medication prescription) **Chronic conditions (of relevance)** Non-haematological cancer, chronic obstructive pulmonary disease, congestive heart failure, chronic liver disease, chronic renal disease **Definition of EoL/palliative care** Last month of EoL	**Age (years), mean (SD)** Psychiatric illness: 61.3 (14.1) No psychiatric illness: 64.6 (12.3) **Gender** Psychiatric illness: male (50.3%) No psychiatric illness: male (53.8%) **Ethnicity (psychiatric illness cohort)** Hispanic ethnicity (1.7%); white (84.3%); black (7.4%); Native American (2.2%); Asian (3.3%); Pacific Islander (0.2%); other race (1.4%); mixed race (1.2%)	**Outcomes** Occurrence and length of non-surgical acute care hospitalisations Occurrence and number of ED visits that did not result in a subsequent non-surgical hospitalisation Occurrence and length of ICU stays Place of death **Statistical analysis** Logistic regression using zero-inflated negative binomial models presented as ORs (adjusted for a combination of age, race, insurance status, comorbidities, marital status, facility insurance status, cancer, chronic obstructive pulmonary disease, congestive heart failure, diabetes or chronic renal disease depending on the outcome of interest)
Martens *et al.* 2013,[97] **Chochinov *et al.* 2012,[95] Canada** **Aim** To compare place and cause of death of those with and those without schizophrenia in Manitoba, Canada[97] To compare rate of health-care services, including palliative care, used in the last 6–24 months of life for patients with and patients without schizophrenia[95] **Mental health diagnosis** Schizophrenia **Cause of death (of relevance)** Cancer **Definition of EoL/palliative care** Palliative care used in last 6–24 months of life	**Setting** All hospital- and community-based palliative care in the universal health-care system of the province of Manitoba **Participants** Decedents with schizophrenia diagnoses in 12 years prior to death ($n = 3943$); matched (ratio 1 : 3) decedents with no previous schizophrenia diagnoses ($n = 11,827$) **Age (years), mean (SD) (all)** 73.4 years (16.5 years) **Gender (all)** Male (43.3%) **Ethnicity** Not reported	**Design** Retrospective cohort (over 12 years) **Data sources** De-identified ('anonymised') administrative claims data were used from the Population Health Research Data Repository housed at the Manitoba Centre for Health Policy, University of Manitoba **Outcomes** Relationship between place of death by cause of death[97] Health service use patterns by place of death in last 6 months of life[97] Health service utilisation rates in the 6 months prior to death for decedents with and decedents without schizophrenia[95] **Outcome measures** Place of death: hospital, home, nursing home and other[97] GP visit rate per person[97] Physician specialist visit rate per person[97]

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
		Inpatient hospital separation rates per person[97] Rate of inpatient hospital days per person[97] Visits to GPs (family practice physician), specialists, inpatient stays in acute care hospitals, use of nursing homes (long-term institutional care, also referred to as personal care homes)[95] Use of palliatve care[95] Use of home care services[95] Utilisation of analgesics[95]
McDermott *et al.* 2018,[92] USA **Aim** To assess the relationship between depression and health-care utilisation at the EoL among older adults (aged ≥ 67 years) diagnosed with advanced non-small-cell lung cancer from 2009 to 2011 **Mental health diagnosis** Pre-cancer, diagnosis-time or post diagnosis depression **Terminal condition** Advanced non-small-cell lung cancer **Definition of EoL/palliative care** Last 30 days of life	**Setting** Acute health-care services and hospice care in the USA **Participants** Decedents with: • Pre-cancer depression ($n = 1485$) • Diagnosis-time depression ($n = 709$) • Post-diagnosis depression ($n = 1189$) • No depression at any time ($n = 10,444$) **Age (years), mean (SD) (pre-cancer depression cohort)** 77.4 (6.9) **Gender (pre-cancer depression cohort)** Male (35%) **Ethnicity (pre-cancer depression cohort)** White (90%); Hispanic (5%)	**Design** Retrospective cohort (over 3 years) **Data sources** SEER-Medicare Linked Database, comprising Medicare claims linked to clinical data for subjects in the National Cancer Institute's SEER data set **Outcomes** Health-care utilisation **Outcome measures** High-intensity EoL care as chemotherapy in the last 14 days of life Less than 3 days of hospice use or no hospice use Any ICU admission, > 1 inpatient hospitalisation admission, in-hospital death or > 1 ED visit in the last 30 days of life Length of hospice enrolment **Statistical analysis** Multivariable logistic regression presented as adjusted ORs (adjusted for days survived following diagnosis, race, Hispanic ethnicity, gender, age, socioeconomic status, marital status and rural residence)
Spilsbury *et al.* 2018,[107] Australia	**Setting** Acute health-care services and community-based health-care services use in Western Australia	**Design** Retrospective cohort (over 5 years)

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
Aim To describe the trajectory of acute health-care service use in the LYoL for people with schizophrenia and how this varied with receipt of community-based specialist palliative care and morbidity burden **Mental health diagnosis** Schizophrenia **Cause of death (of relevance)** Heart failure, cirrhosis/liver disease, renal disease/dialysis, chronic lower respiratory disease or cancer **Definition of EoL/palliative care** LYoL	**Participants** Decedents with a lifetime history of schizophrenia diagnoses ($n = 1196$); matched sample of decedents with no previous schizophrenia diagnoses ($n = 62312$) **Age (years), mean (SD) (schizophrenia cohort)** 20–29 years (4.3%); 30–39 years (7.4%) 30–39 years (10.9%); 50–59 years (14.2%) 60–69 years (17.7%); 70–79 years (19.1%) 80–89% (20.2%); ≥ 90 years (6.4%) **Gender (schizophrenia cohort)** Male (52%) **Ethnicity** Not reported	**Data sources** Data linkage and de-identified data extraction from the Western Australia Data Linkage System was performed **Outcomes** Acute care health service use Receipt of community-based specialist palliative care Morbidity burden **Outcome measure** Morbidity burden ED presentations over LYoL Number of hospitals admission in LYoL Community-based care in the LYoL **Statistical analysis** Regression analysis presented as HRs (adjusted for age, sex, accessibility, relative disadvantage, indigenous status, partner status, country of birth and number of comorbid conditions)
Kelley-Cook *et al.* 2016,[90] USA **Aim** To evaluate the clinical impact of palliative care in the treatment of terminally ill Vietnam veterans with a history of PTSD compared with those without PTSD, as it pertains to medications for symptom control at the EoL **Diagnosis** PTSD plus a range of other SMI or SMI-relevant symptoms (e.g. hallucinations) **Terminal conditions (of relevance)** Cancer, heart disease, liver disease, pulmonary disease and renal disease **Definition of EoL/palliative care** Use of medications at EoL; time frame not specified	**Setting** One US tertiary veterans' hospital **Participants** Veterans with PTSD ($n = 39$); veterans without PTSD ($n = 137$) **Age (years), mean (SD)** Mean age was 65.12 **Gender** Male (99%) **Ethnicity** Not reported	**Design** Retrospective cohort study **Data sources** Electronic medical records of a veterans' hospital **Outcomes** Social support, palliative care team interventions, family meeting interventions; medications **Outcome measures** Differences in pharmacologic treatment and non-pharmacological palliative care interventions between those with and those without PTSD **Statistical analysis** *t*-tests and chi-squared tests

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
Cai *et al.* 2011,[84] USA **Aim** To test whether or not persons with SMI were as likely as other nursing home residents to make informed choices about treatments through medical advance care planning **Mental health diagnosis** Schizophrenia, bipolar disorder or other psychosis **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** Medical ACP	**Setting** Nursing homes (*n* = 1174) **Participants** Residents with SMI (*n* = 1769) and residents with no SMI (*n* = 11,738) **Age (years), mean (SD)** SMI, 75.7 (5); no SMI, 81.1 (2) **Gender** SMI, male (32%); no SMI, male (28.4%) **Ethnicity (SMI)** Non-Hispanic white (80.2%); African American (13.3%); Hispanic (5.3%); other (1.2%)	**Design** Retrospective cohort study **Data sources** Data came from the 2004 National Nursing Home Survey that was conducted by the US Centers for Disease Control and Prevention **Outcomes** Whether or not sampled residents had any of the following advance care documents collected by the survey: living wills, DNR orders, do-not-hospitalise orders, and orders restricting feeding, medication or other treatments **Statistical analysis** *t*-tests and chi-squared tests Logistic regression analysis presented as adjusted ORs (adjusted for age, gender, race, marital status, being a veteran, length of stay, payment source, number of impairments of daily activities)
Podymow *et al.* 2006,[98] Canada **Aim** To improve health-care delivery to homeless adults **Mental health diagnosis** Depression (43%); schizophrenia (39%); anxiety (18%); none (14%) **Causes of death (of relevance)** Cancer (25%); chronic obstructive lung disease (4%) **Definition of EoL/palliative care** Palliative care delivery; time frame not specified	**Setting** 15-bed shelter-based palliative care/hospice pilot programme **Participants** Homeless patients who were admitted to the hospice, received terminal care and died between July 2001 and August 2003 (*n* = 28) **Age (years), mean (SD)** 49 (10.5) **Gender** Male (89%) **Ethnicity** Caucasian (89%); African American (7%); Aboriginal (4%)	**Design** Retrospective cohort (over 2 years) **Data sources** Data obtained from physician and nurse's patient intake history and medical transfer notes **Outcomes** Clinical course and care of the patients; costs **Outcome measures** Costs per patient stay, main symptoms, oxygen requirements, palliative care consults, number of medications, type of self-care assistance Pain management and type of pain management

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data sources; outcomes; outcome measures
		Religious counse
		Number of family visits
		Reasons precluding transfer to palliative care hospital
		Statistical analysis
		Descriptive statistics

DNR, do not resuscitate; ICD-9, *International Classification of Diseases*, Ninth Edition; SD, standard deviation; SEER, surveillance, epidemiology, and end results; SPMI, severe and persistent mental illness.

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Appendix 18 Characteristics of included qualitative studies

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	**Setting; patient characteristics**	**Design; data collection methods; data analysis**	**Thematic findings**
Jerwood *et al.* 2018,[112] UK **Aims** To examine the views of the clinical staff on the barriers to providing EoL care to people with SMI and to begin to consider how improvements can be made **Mental health diagnosis** SMI but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** General EoL care	**Setting** Mental health trust Hospice **Participants** Clinical staff ($n = 23$) who had some experience of working with the patient group and of the issues of EoL care No patient details reported	**Design** Qualitative descriptive **Data collection methods** Focus groups ($n = 4$) Cube ideas generation tool – participants wrote and drew on the Cube while the verbal discussion was taking place. In addition, paper and envelopes were made available to gather additional data from participants who felt uncomfortable sharing views in a group setting **Data analysis** Framework analysis	• The structure of the system • The presentation of the patient • The confidence of the clinician • The problem of partnership

McGrath and Holewa 2004,[102] McGrath and Jarrett 2007,[103] McGrath and Forrester 2006,[104] Australia
Aim of research project
To document the experience of providing EoL care to patients for health-care workers in an institutional mental health setting
	Setting
	Mental health institution
	Participants
	Those directly involved in the care of two patients who had died in the last year ($n = 8$)
	No patient details reported
		Design
		Qualitative phenomenology
		Data collection methods
		Interviews
		Participants were encouraged to talk about their experiences of caring for a terminally ill patient. Of particular interest was an exploration of factors that the participant believed either facilitated or hindered the provision of optimal EoL care
			McGrath and Holewa 2004[102]
			• Knowledge of palliative care
			• Definitions – educated guesses
			• Similarity to mental health philosophy and practice
			  ○ A person-centred practice
			  ○ Relationship-based connectedness
			  ○ Compassionate and holistic care
			  ○ Respect for autonomy and choice
			  ○ Concern for quality of life as defined by the client
			  ○ Focus on family as unit of care
			  ○ Multidisciplinary teamwork
			  ○ Ability to face and deal with dying

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data collection methods; data analysis	Thematic findings
Focus of individual publications To highlight the similarity in philosophy between palliative care and mental health practice[102] The findings presented here focus on one of the central problems impacting on EoL care, that of the stigma attached to mental health patients[103] To explore important ethicolegal issues at the interface of palliative care and institutional mental health[104] **Mental health diagnosis** Mental health patients but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** General EoL care		**Data analysis** Thematic analysis	○ Death with dignity ○ Concern to keep patient in familiar environment ○ Special attribute of staff McGrath and Jarrett 2007[103] ● The mental health stigma ○ Suggested causes for the mental illness stigma ○ Implications of mental illness stigma for EoL care ○ Trained HCPs accompanying patient to palliative care facility ○ The limited nature of positive assistance ○ Mental health staff stress in caring for dying patients McGrath and Forrester 2006[104] ● The legal dimension of care ○ The coronial inquest ○ Resuscitation vs. being allowed to die

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data collection methods; data analysis	Thematic findings
McNamara *et al.* 2018,[106] Australia **Aim** To address the paucity of research by documenting possible need, experiences of health-care service use and factors affecting palliative care use for people with schizophrenia who have advanced life-limiting illness **Mental health diagnosis** Schizophrenia but not linked to specific patients **Terminal condition** Advanced life-limiting illness **Definition of EoL/palliative care** General experiences of EoL care	**Setting** HCPs employed in government policy and management, palliative care, mental health, community service provision, clinical care, allied health care, high-care residential homes and community-based supported accommodation, including psychiatric hostels **Participants** HCPs (*n* = 16) who were caring for, or had experience of caring for, people with schizophrenia Three participants worked specifically in a role that covered both mental health and palliative care No patient details reported	**Design** Qualitative descriptive **Data collection methods** Interviews Three participants who worked in the same location were interviewed together An interview guide was used that focused on the EoL needs of people with schizophrenia, their experiences with health services and their possible need for palliative care **Data analysis** Thematic analysis	People with schizophrenia at the EoL: challenges of a vulnerable group • Individual factors that may affect people with schizophrenia at the EoL • Social factors that may affect people with schizophrenia at the EoL • Health-care factors that may affect people with schizophrenia at the EoL • The inter-relationship between factors that affect people with schizophrenia at the EoL Barriers to and facilitators of people with schizophrenia receiving palliative care • Recognising declining health, communication and planning • Collaboration and capacity building in the broader health, mental health and palliative care sectors
Morgan 2016,[32] USA **Aim** To explore the needs and attitudes of nurses in psychiatric/mental health settings towards patients who are in need of palliative and EoL care	**Setting** Hospice/palliative care Psychiatric/mental health care **Participants** Palliative care/HC nurses (*n* = 7)	**Design** Qualitative phenomenology described as a pilot study **Data collection methods** Interviews	• Stigma of mental illness • Effect of SMI symptoms on communication and trust • Chaotic family systems • Advocacy issues around pain, comfort care • Need for formal support and education for nurses • No right place to die

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data collection methods; data analysis	Thematic findings
Mental health diagnosis SMI but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** General experiences of EoL care	Psychiatric/mental health care ($n = 6$) Palliative care/HC and mental health nurses ($n = 2$) HIV/AIDS nurses, geriatric nurse practitioner, and working with homeless individuals All who had reported having worked with people with SMI at the EoL No patient details reported	An interview guide was used to elicit the participants' stories related to the nurses' experience with EoL and palliative care with patients with SMI. The questions in the interview helped explore topics related to the specific aims and capture the impact of contextual and individual factors that influenced the individual's thought process, behaviour and outcome **Data analysis** Thematic analysis	
Hackett and Gaitan 2007,[37] UK **Aim** To gain an understanding of the current practice of mental health assessments in the hospice service in two hospices in the UK **Mental health diagnosis** SMI but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** General experiences of EoL care	**Setting** Hospice **Participants** Nurses ($n = 6$), HCAs ($n = 1$) or doctors ($n = 2$) recruited from two hospice staff teams No further details reported	**Design** Qualitative grounded theory **Data collection methods** Interviews An interview guide was used, which focused on staff members' views on roles with regard to mental health assessments and the overall processes involved **Data analysis** Constructing networks of findings based on the interview questions (how staff members' feelings inform clinical practice and training needs)	• How is mental health assessed in the hospices? • What are the staff members' feelings about doing these assessments? • How does assessment information inform clinical practice? • What are the perceived training needs of staff?

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data collection methods; data analysis	Thematic findings
McKellar *et al.* 2016,[105] Australia **Aim** To explore how old-age psychiatrists approach and experience working with patients at the EoL **Mental health diagnosis** SMI but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** General experiences of EoL care	**Setting** Public mental health services for older people but most also maintained some private practice **Participants** Old-age psychiatrists recruited via e-mail sent to all members of the Australian Faculty of Psychiatry of Old Age and the New Zealand College of Psychiatrists ($n = 9$) No patient details reported	**Design** Qualitative descriptive **Data collection methods** Interviews A semistructured interview guide was developed, drawing on literature identifying the possible roles old-age psychiatrists may have at the EoL, to explore experiences working with patients at the EoL, approaches to this work and the impact of these experiences on participants **Data analysis** Thematic analysis	Death is not our business: working in a mental health framework • Death should not occur in psychiatry • Working in a psychiatric treatment mode • Keeping a distance from death • Unexpected death is a negative experience Death is our business: working in an aged care context • Death is part of life • Encountering the EoL through dementia care • Doing EoL work • Expected death is a positive experience
Stajduhar *et al.* 2019,[99] Canada **Aim** To identify barriers to accessing care among structurally vulnerable people at the EoL **Mental health diagnosis** Mental health issues **Terminal condition** Not linked to a specific terminal condition	**Setting** Homeless or vulnerably housed in a western Canadian province **Participants** Three participant groups: (1) those experiencing structural vulnerability and who were deemed to be on a palliative trajectory ($n = 25$); (2) their support ($n = 25$); and (3) their formal service providers (housing workers, clinicians) ($n = 69$)	**Design** Qualitative ethnographic **Data collection methods** Ethnographical observation and in-depth interviews informed by the critical theoretical perspective of equity and social justice Data collection for all groups was longitudinal, over 30 months, through repeated observation in homes, shelters, transitional housing units and community-based service centres, on the street and at health-care appointments	Barriers to accessing care • Survival imperative • Normalisation of dying • The problem of identification • Professional risk and safety management • Cracks of a ‘silo-ed’ care system

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data collection methods; data analysis	Thematic findings
Definition of EoL/palliative care General experiences of accessing EoL care	**Age (years) (group 1)** Mean 59, range 19–81 **Gender (group 1)** Male (64%) **Ethnicity (group 1)** White (52%); Indigenous (32%); African Canadian (4%)	Semistructured interviews and observational data (interviews: structurally vulnerable participants, $n = 19$; support persons, $n = 16$; service providers, $n = 23$) **Data analysis** Constant comparison analysis Thematic analysis	
Sweers *et al* 2013,[109] Belgium **Aim** To gain a better insight into the perspectives and expectations of patients with schizophrenia about EoL (care) **Mental health diagnosis** Schizophrenia: paranoid (65%); schizoaffective disorder (35%) **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** Future EoL perspectives and expectations	**Setting** Psychiatric hospital **Participants** Schizophrenic patients in remission with a minimum illness duration of 10 years ($n = 20$) **Gender** Male (60%) **Age (years)** Range 38–51; mean 47.3 + 6.9 **Ethnicity** Not reported	**Design** Qualitative grounded theory **Data collection methods** Interviews An interview guide was used; questions were broad and related to the experience of living with schizophrenia and EoL situations, and associated feelings and reactions, as well as the perceived impact of these experiences on the person's life and expectations about EoL (care) 5 out of 10 were interviewed twice – project was refined because of a lack of detailed information; next 10 had two interviews each **Data analysis** Constant comparison analysis	Note: study was conducted in Belgium, where euthanasia is legal • Patients' EoL perspectives and expectations • Fear of death • Skilled companionship • Quality of life ○ Physical well-being ○ Psychological well-being ○ Social concerns ○ Spiritual well-being

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; patient characteristics	Design; data collection methods; data analysis	Thematic findings
Shulman *et al.* 2018,[113] UK **Aim** To explore the views and experiences of current and formerly homeless people, front-line homelessness staff (from hostels, day centres and outreach teams) and health- and social-care providers, regarding challenges to supporting homeless people with advanced ill health, and to make suggestions for improving care **Mental health diagnosis** Background talks about trimorbidity drug and/or alcohol dependence and mental health problems in association with physical health issues **Terminal condition** Advanced life-limiting illness **Definition of EoL/palliative care** General experiences of EoL care	**Setting** Three London boroughs **Participants** Single homeless people ($n = 28$) Formerly homes people ($n = 10$) Health and social care providers ($n = 48$) Hostel staff ($n = 30$) Outreach staff ($n = 10$) **Gender** Male (54%) across all groups No further patient details reported	**Design** Qualitative descriptive **Data collection methods** Interviews ($n = 10$) Focus groups ($n = 28$) Use of case study vignette to generate discussion for all participants (no mental health focus) No details given about interviews **Data analysis** Thematic analysis	Complex behaviours in mainstream services • Behaviours related to complex trauma and substance misuse issues; inflexibility and inexperience Gaps in existing systems • Lack of appropriate alternatives • Need for holistic approach to care and support • Hostel as a place of care and death Uncertainty and complexity • Difficulty predicting illness trajectories • Advance care planning

AIDS, acquired immunodeficiency syndrome; HC, hospice care; HCA, health-care assistant; HIV, human immunodeficiency virus.

Appendix 19 Characteristics of descriptive cross-sectional surveys included in the review

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; place of death; patient characteristics	Design; data collection methods; outcomes
Alici *et al.* 2010,[83] USA **Aim** To define the frequency of PTSD-related symptoms among veterans who are near the EoL and to describe the impact that these symptoms have on patients and their families **Mental health diagnosis** PTSD-related symptoms (17%) **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** Last month of life	**Setting** VA medical centres and their affiliated nursing homes ($n = 5$) **Participants** Family members of patients ($n = 524$, rr 54%) who had received any inpatient or outpatient care from a participating VA medical centre in the last month of life. Among the 524 were patients with PTSD-related symptoms ($n = 89$) **Age (years)** Mean 71 (range 50–94) **Gender** Male (99%) **Ethnicity** African American (20%); white, non-Hispanic (78%); Hispanic (1%); other/unknown (1%)	**Design** Descriptive survey **Data collection methods** Questionnaire that assessed their perceptions of the quality of the care and services that the patients and the family members themselves received during the patient's last month of life and after the patient's death, administered 4–6 weeks post death The FATE survey has 32 items and evaluates outcomes by asking respondents for frequency ratings (e.g. 'How often did [the patient's] pain make him/her uncomfortable?') or yes/no responses (e.g. 'Do you think [the patient] died where he/she wanted to?'). For each symptom that family members reported, they were asked how often that symptom made the patient uncomfortable (never, 0; sometimes, 1; usually, 2; always, 3) **Outcomes** • Post-traumatic stress-related symptoms • PTSD-related symptoms and satisfaction with care
Patterson *et al.* 2014,[93] USA **Aim** To explore the current level of collaboration between psychiatrists and palliative care consult services across the USA and the factors that support or restrict such involvement **Mental health diagnosis** Personality disorders (as reported by palliative care services) as well as other mental health needs	**Setting** Inpatient and outpatient palliative care consult services within academic medical centres (non-profit, community hospitals private medical centres and VA hospitals) **Participants** Programme directors of palliative care consult services identified through the National Registry maintained by the Center to Advance Palliative Care ($n = 260$, rr 67%) No patient details reported	**Design** Descriptive survey **Data collection methods** A 36-item survey was developed following consultation with clinical and academic experts. The survey was divided into four areas: (1) demographic information about the programme director, (2) information about the facility and palliative care service composition, (3) patient mental health issues of concern and (4) psychiatrist involvement with the palliative care service

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; place of death; patient characteristics	Design; data collection methods; outcomes
Terminal condition Not linked to a specific terminal condition **Definition of EoL/palliative care** Use of palliative care services		**Outcomes** • Identified mental health needs of palliative care patients • How comfortable the programme directors reported being with treating mental health needs • Psychiatry involvement with palliative care services • Satisfaction with and desire for psychiatry involvement • Impediments to psychiatry involvement in palliative care services
Evenblij *et al.* 2016,[110] the Netherlands **Aim** To explore nurses' experiences with and to identify barriers to providing palliative care to psychiatric patients in Dutch mental health facilities **Mental health diagnosis** Psychiatric disorders, which included schizophrenic or other psychotic disorders (40%); personality or behavioural disorder (36%); mood disorder (30%); anxiety disorder (30%) **Causes of death (of relevance)** Cancer (35%), respiratory disorder (COPD) (4%), liver failure (4%) **Definition of EoL/palliative care** General experience of palliative care services	**Setting** Mental health facilities **Participants** Nurses registered in the Dutch Nurses' Association's division of psychiatric nursing who currently worked in a mental health facility and who had experience concerning palliative care provision ($n = 137$, rr 26%) No patient details reported	**Design** Mixed methods (descriptive survey and descriptive qualitative) **Data collection methods** An online survey based on pre-existing questionnaires. It was pilot tested and minor changes were made. Final survey consisted of two parts All nurses were asked to fill in questions about their knowledge, experience and needs concerning palliative care provision ($n = 137$), and nurses who had provided palliative care in the past 2 years were asked to fill in 27 additional case-specific questions about the care they had provided to the last patient who had died as a result of chronic physical comorbidity or old age ($n = 50$) Only the case-specific questions were reported in this publication Face-to-face interviews ($n = 9$) were conducted with a subset of the sample, which sought to identify nurses' personal experiences with palliative care provision in mental health facilities. Thematic analysis was conducted **Outcomes** • Elements of palliative care provided (survey) • Thematic areas (interviews) – barriers to palliative care provision/physical care domain/psychosocial care domain/organisation

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; place of death; patient characteristics	Design; data collection methods; outcomes
Sheridan *et al.* 2018,[114] Ireland **Aim** To examine how and by whom (GPs, psychiatrists, other HCPs) the need for palliative care is identified for people with a diagnosed mental illness To identify the referral pathways and access to physical health and palliative care services To identify how palliative care needs of people with SMI are managed once identified **Mental health diagnosis** SMI but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** General use of palliative care services	**Setting** General practice Psychiatric practice **Participants** GPs who were currently on the register of the Irish College of General Practitioners in both the Republic of Ireland ($n = 434$, rr 17.4%) and Northern Ireland ($n = 133$, rr 9%) Psychiatrists ($n = 80$, rr 26.2%) identified from the Irish Medical Directory No patient details reported	**Design** Mixed methods (descriptive survey and qualitative descriptive) **Data collection methods** A postal survey was conducted, and the questionnaire was based on a similar questionnaire utilised with GPs in the Republic of Ireland, which was adapted and piloted. Interviews with a subset of psychiatrists ($n = 6$). No GPs and their existing patients with SMI in receipt of palliative care ($n = 2$) agreed to take part **Outcomes** • Engagement with palliative care services (survey) • Opinions on needs and services (survey) • Palliative care needs (survey) • Thematic areas (interviews): ○ Psychiatry – not a unitary practice ○ Understanding and managing palliative care ○ Accessing and negotiating the system ○ Segregation, discrimination and stigma ○ Place of residence
Evenblij *et al.* 2019,[111] the Netherlands **Aim** To explore the differences between care staff in mental health facilities, nursing homes and care homes with regard to knowledge about palliative care, time pressure and self-efficacy in EoL communication, as well as aiming to identify determinants of high self-efficacy in EoL communication **Mental health diagnosis** SMI but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** EoL knowledge, self-efficacy, communication	**Setting** Mental health facilities (survey 1); nursing and care homes (survey 2) **Participants** Nurses and care assistants who worked in mental health facilities ($n = 137$, rr 29%), nursing and care homes ($n = 440$, rr 52%) Patient characteristics not reported	**Design** Descriptive survey **Data collection methods** Two descriptive surveys Survey 1: see Evenblij *et al.* 2016[110] Survey 2: Knowledge of palliative care was measured using the MOVE2PC questionnaire Satisfaction with the time available for giving care to patients was assessed using an existing a five-point scale tool developed by Ruijeters and Stevens Self-efficacy in EoL communication was measured using the communication subscale from the S-EoLC survey **Outcomes** • Knowledge of the definition of palliative care • Time pressures

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; place of death; patient characteristics	Design; data collection methods; outcomes
		- Confidence in staff's ability to engage in EoL communication - Determinants of high self-efficacy in EoL communication
Taylor *et al.* 2012,[94] Australia **Aim** To improve the quality of palliative care for people with a severe and persistent mental illness and those who develop mental health issues as a response to their diagnosis of a life-limiting illness **Mental health diagnosis** SMI but not linked to specific patients **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** Training in palliative care for mental health nurses	**Setting** A collaboration between one metropolitan palliative care service, the district nursing service, a mental health service and two regional palliative care services **Participants** Mental health workers (*n* = 68), including consultant psychiatrists, GPs, mental health nurses, RNs, ENs, social workers, OTs, counsellors, community outreach workers, paramedical assistants, and students of psychology and social work took part in palliative care workshops Palliative care professionals (*n* = 36), including RNs, ENs, social workers, OTs, a bereavement counsellor and an art therapist took part in mental health workshops Patient characteristics were not reported	**Design** Descriptive case study with post-test evaluation **Intervention** Cross–training mental health workshops for palliative care workers and palliative care workshops were given to mental health workers Pre- and post-evaluations were conducted by an independent evaluator **Data collection methods** Self-assessment survey with open-ended questions **Outcomes** - Participants' knowledge before and after the workshop - The areas of learning considered to be of most importance
Foti 2003,[85] USA **Aim** To better understand advance care planning processes for those with SMIs; to explore EoL care preferences among those with SMIs **Mental health diagnosis** SMI but not linked to specific patients **Terminal condition or cause of death** Not linked to a specific terminal condition **Definition of EoL/palliative care** Advance care planning	**Setting** Two state hospitals and one acute community mental health centre **Participants** Hospital patient records (*n* = 328) and community mental health inpatient records (*n* = 16) Mental health providers (nurse managers, *n* = 4; nurses, *n* = 7; case managers, *n* = 14; community provider staff members, *n* = 10 and supervisors, *n* = 6) Hospice and pastoral care providers (clinical staff, *n* = 15; hospice directors, *n* = 3; pastoral care providers, *n* = 3) **EoL care preferences** People with SMI (no participant details reported) **Education and training** HCPs (no participant details reported)	**Design** Mixed methods (descriptive survey consisting of a retrospective review of patients' medical records and a post-test evaluation of educational/training initiatives with HCPs) **Intervention** 'Do It your Way' project involved education, training and outreach The educational and training initiatives involved cross training, neighbour to neighbour initiative and the development of education and training curricula. The outreach involved professional outreach to medical professionals, mental health advocacy groups, and family and consumer groups and patient outreach **Data collection methods for needs assessment** Cross-sectional survey of patients' medical records, survey of providers and a post-test evaluation of educational/training initiatives with HCPs

Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; place of death; patient characteristics	Design; data collection methods; outcomes
	Professional outreach Medical professionals, mental health advocacy groups and family and consumer groups (no participant details reported) No further details reported	**Data collection methods for 'Do It your Way' project** EoL care preferences To explore EoL care preferences among those with SMI, the team developed the 21-item HCPQ. To specifically evaluate the subject's capacity to select a health-care agent, the team developed the CAT-HCP **Education and training** Post-cross-training core competency assessments **Professional outreach** Project staff developed a survey of attitudes and perceptions regarding advance care planning for persons with SMI **Outcomes for needs assessment** Evidence of actually having completed a proxy designation Formal education as well as personal and professional experiences regarding advance care planning and EoL care/improvements for care **Outcomes for the 'Do It your Way' project** • Number of people receiving assistance with advance care planning • Project impact in the form of preliminary findings • Comfort and confidence in skills after cross training
Foti *et al.* 2005,[86] USA **Aim** To ascertain preferences for EoL care among persons with serious mental illness; to examine preferences regarding medical advance care planning among persons with SMI, specifically experience, beliefs, values and concerns about health-care proxies and EoL issues	**Setting** Five community mental health agencies. Two agencies were located in suburban settings and three in urban environments **Participants** Adults with SMI who were receiving community-based services ($n = 150$) **Age (years), mean (SD)** 42 (10)	**Design** Descriptive survey **Data collection methods** HCPQ: see Foti 2003[85] Two hypothetical health state scenarios were adapted from standard scenarios in which patients have conditions that prevent them from expressing a choice between different types of palliative care, aggressive treatments and life support. The authors anticipated that hypothetical health state scenarios

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Author, year, country; aim; mental health diagnosis; terminal/chronic condition or cause of death; definition of EoL/palliative care	Setting; place of death; patient characteristics	Design; data collection methods; outcomes
Mental health diagnosis Schizophrenia or other psychosis (66%), mood disorders (major depression and bipolar disorder) (28%), personality disorders or PTSD (6%) **Terminal condition** Not linked to a specific terminal condition **Definition of EoL/palliative care** Preferences for EoL care; advance care planning	**Gender** Male (55%) **Ethnicity** Caucasian (91%); other (9%)	would enable us to learn about the advance care planning preferences of persons with serious mental illness, as they have for the general population **Outcomes** • EoL care preferences under the scenario of terrible pain from terminal metastatic cancer • Preferences for life support in the event of brain damage with little chance of recovery, both for an imaginary other patient and for the respondent (self), among persons with SMI experience with advance care planning • Beliefs, values and EoL concerns • Characteristics associated with EoL preferences
Elie *et al.* 2018,[96] Canada **Aim** To compare SPMI and CMI patients' EoL care preferences and comfort level with EoL care discussion To identify potential predictors of interest in requesting medical assistance in dying at the EoL **Mental health diagnosis** SPMI (53%) **Terminal condition** Not linked to a specific terminal condition for those with SPMI; however, 47% were chronically medically ill **Definition of EoL/palliative care** Preferences and comfort level with EoL care discussion Medical assistance in dying	**Setting** Jewish General Hospital **Participants** Patients attending the hospital between May and July 2016 Study group: patients diagnosed with a SPMI by their treating psychiatrist and without severe behavioural disturbances (*n* = 106, rr 83%) Comparator group: patients diagnosed with at least one chronic medical illness for > 2 years (*n* = 95, rr 89%) **Age (years), mean (SD)** SPMI: 65.5 (12.6); CMI: 63.3 (12.6) **Gender** SPMI: male (33%); CMI: male (43%) **Ethnicity** SPMI: Caucasian (80%); non-Caucasian (20%) CMI: Caucasian (58%), non-Caucasian (42%)	**Design** Descriptive survey **Data collection methods** The authors conducted a 20-minute semistructured interview based on the HCPQ to gather information on different EoL care topics, such as treatment preferences and comfort level about EoL discussion. Two imaginary scenarios were also explored with participants (see Foti *et al.* 2005[86]) **Outcomes** • Patients' agreement to use pain medication, palliative sedation and medical assistance in dying in case of terminal cancer • Preferred disposition regarding artificial life support in case of permanent brain damage

CAT-HCP, Competency Assessment Tool-Health Care Proxy; CMI, chronic medically ill; COPD, chronic obstructive pulmonary disease; CVA, cardiovascular accident; EN, enrolled nurse; FATE, Family Assessment of Treatment at End of life; HCPQ, Health Care Preferences Questionnaire; OT, occupational therapist; rr, response rate; RN, registered nurse; SD, standard deviation; SEER, surveillance, epidemiology, and end results; SPMI, severe and persistent mental illness; VA, Veterans Affairs.

Appendix 20 Characteristics of case studies included in the review

Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Ang *et al* 2009,[154] Singapore; addresses the challenge of what should be done in the case of people with chronic conditions that impair their capacity	Emergency hospital care of a 41-year-old woman with schizoaffective disorder since the age of 21 years and with end-stage renal failure since the age of 40 years	Ethical issues in EoL care for people lacking capacity to make decisions	Autonomy of a patient with regard to medical treatment, assessment of the patient's decisional capacity, and the process of deciding on the appropriate course to take for a patient without the mental capacity to give consent for required treatment in a potentially life-threatening situation Legal frameworks, tools to assess capacity and the use of advanced ('Ulysses') contracts are all addressed
Badger and Ekham 2011,[122] USA; ethical conflicts at the EoL for patients with personality disorder, substance misuse and self-harming behaviour	A case of a 41-year-old man with long-term mental health problems whose physical health declined (liver and respiratory failure) and whose care presented an ethical challenge to practitioners	Ethical issues in EoL care for people lacking capacity to make decisions	Decision-making for people lacking capacity is difficult in the absence of advance directives and in the case of people with complex mental health and substance misuse problems
Bakker 2000,[115] the Netherlands; focuses on the palliative care of patients in a 'reactivation program', this being a service for older people with complex health problems	A residential service using DSA for older people with complex mental and physical health problems, in which the case is a 91-year-old woman	The use of the DSA approach, including in the example of people who end their lives in the DSA service, illustrating the phases of the approach in action	The DSA approach is offered as a psychosocial counterbalance to more exclusively biomedically oriented approaches to care
Boyd *et al.* 1997,[123] USA; the process of care for a hospice patient described as manipulating family, friends and hospice staff during her EoL care	A hospice service for people at the EoL, with the case being a 52-year-old woman with breast cancer who is described as having a pre-existing (but not clearly described) severe mental health problem characterised by 'manipulative' behaviour	The challenges faced by hospice staff in providing care to someone perceived as being manipulative, and how these can be addressed using practices informed by psychodynamic thinking	Hospice staff can provide care for people with 'troubled personality' using psychodynamic approaches, including supporting ego functioning, supporting autonomy, setting limits, and assessing and managing staff emotional responses
Cabaret *et al.* 2002,[152] France; the provision of EoL care in an inpatient psychiatric hospital setting	An inpatient psychiatric hospital, with the case being a 45-year-old man with schizophrenia and lung cancer	The provision of humane, palliative care in a mental health hospital	Inpatient mental health staff are able to provide humane, dignified care until the EoL for people with SMI
Candilis and Foti 1999,[124] USA; EoL care for someone with psychosis and cancer, where the patient's preferences are not clearly known	A case study beginning in an ED and moving to a mental health unit, focused on the care of a 70-year-old woman with cancer and psychosis	Decision-making in the context of EoL care and psychosis, where the patient's understanding and preferences are not clearly known	Differences in view can exist over the best course of action in cases where patients refuse treatment but do not elaborate – supportive, palliative, care or more aggressive intervention

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Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Clements-Cortes 2004,[149] Canada; the use of music therapy in the emotional care of people who are at the EoL	A discussion on the value of music therapy, followed by three case studies all of people using an older people's palliative care inpatient service, of which two (a 71-year-old woman and a 72-year-old woman) had pre-existing mental health problems	The value of music in providing emotional support to people with terminal illnesses	Music therapy can facilitate emotional expression, including in people with SMI
Doron and Mendlovic 2008,[153] Israel; EoL care in inpatient mental health wards	Two case studies of people, one aged 45 years at the time of her death and the other a woman whose age at death is not stated, cared for near to the EoL in inpatient mental health settings, where both had SMI and cancer	The challenges for both patients and staff of care during a terminal illness in a mental health inpatient setting	Information on the patient's condition and prognosis should be given in the context of their capacity to understand; decisions should be made by patients where possible or otherwise by clinicians; and home is where people should die, meaning that if this is a psychiatric ward staff should be supported to provide care for as long as possible
Feely *et al* 2013,[125] USA; EoL care in a hospice for people with borderline personality disorder	A case study of a 44-year-old woman with borderline personality disorder and terminal metastatic pancreatic cancer who was being cared for in a hospice	The difficulties for staff in hospices of providing care for people with complex mental health problems characterised by impulsive behaviour and difficulties in relationships	There is a lack of evidence to support interventions with people with borderline personality disorder at the EoL, but behavioural interventions should be tailored to the person based on the creation of genuine, respectful, relationships
Feldman and Petriyakoil 2006,[126] USA; PTSD at the EoL	A case study of a 61-year-old male veteran with heart failure and acute onset of PTSD symptoms	Challenges of recurrence of latent PTSD symptoms seemingly triggered by the threat to life of terminal illness mimicking previous experiences	Specific challenges in EoL care for people with PTSD may mean they experience psychological symptoms that have been dormant, become anxious and angry, avoid health care and distrust medical recommendations, leading to non-adherence to and refusal of treatment
Feldman *et al.* 2014,[116] USA; the provision of palliative care to people with PTSD at the EoL	A re-presentation of a new model of care to people with PTSD, either pre-existing or post-EoL diagnosis, illustrated by three case studies (men aged 65, 65 and 61 years) in diverse palliative care settings	An illustrated model of care for people with PTSD at the EoL, involving therapy over three distinct stages: palliate immediate discomfort and provide social supports, provide psychoeducation and enhance coping skills, and treat specific trauma issues	The SPPC model can be used to support terminally ill patients with PTSD where conventional PTSD interventions are challenged by limited life expectancy, fatigue and other concerns
Feldman *et al.* 2017,[117] USA; the provision of palliative care to people with PTSD at the EoL	A case of a 72-year-old veteran with PTSD and multiple myeloma, admitted for inpatient hospice care at the EoL	How a staged approach to PTSD care is helpful for people at the EoL	A further illustration of how the SPPC model can be used to support terminally ill patients with PTSD where conventional PTSD interventions are challenged by limited life expectancy, fatigue and other concerns

Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Geppert *et al.* 2011,[127] USA; palliative care and capacity in the context of people with psychosis and terminal cancer	A detailed case study of a 58-year-old man with a pre-existing schizoaffective disorder who had terminal laryngeal cancer and was admitted to hospital	The ethical issues around treatment when people have psychosis and lack decisional capacity	Psychosis raises ethical issues for EoL care as it undermines decisional capacity and raises questions about the use of proxies and additional questions about where care ought to be provided (mental health services or EoL services)
Gonzalez *et al.* 2009,[128] USA; hospice care of a man with breast cancer and bipolar disorder	A medical case study of an 86-year-old man with complex health needs who received inpatient care, and who has bipolar disorder, dementia and breast cancer first treated 20 years previously	The complexity of providing care for people with multiple needs, in the context of family members also having significant health needs	Curative care is difficult to provide if treatment is not consistently provided and accepted, and palliative care is appropriate particularly when caregivers have health needs of their own
Griffith 2007,[129] USA; palliative and EoL care for a man with heart and lung failure and schizophrenia (part 1 of 2)	An extended case study of a 67-year-old man, focusing on his schizophrenia and his lung and heart disease and his care at home until death	The role of the psychiatrist in the provision of integrated care, including at the EoL, to people with SMI and multiorgan failure	Psychiatrists have an important part to play in treating people who have both severe mental health and terminal physical health problems
Griffith 2007,[130] USA; palliative and EoL care for a man with heart and lung failure and schizophrenia (part 2 of 2)	An extended case study of a 67-year-old man, focusing on his schizophrenia and his lung and heart disease and his care at home until death	The role of the psychiatrist in the provision of integrated care, including at the EoL, to people with SMI and multiorgan failure	Psychiatrists should have cultural and religious competence and be able to work with families
Hill 2005,[131] USA; hospice at home care for a person with borderline personality disorder	A case of an 83-year-old woman described as having borderline personality disorder and receiving hospice care at home	EoL care for people with borderline personality disorder and complex physical health problems and family histories	Nurses should develop therapeutic relationships, have good supervision, be consistent in caregiving, and have good working relationships with families and psychiatrists
Irwin *et al.* 2014,[26] USA; cancer care, including to EoL, for people with schizophrenia	A detailed review of literature followed by a case study of a 66-year-old woman with paranoid schizophrenia and terminal cancer, whose care moved from home to inpatient hospice	Health inequalities for people with schizophrenia and cancer	Practitioners need improved understanding of health disparities experienced by people with schizophrenia and cancer, research is needed to examine factors influencing survival and quality of life, and better integration is required between oncology and psychiatric services
Kadri *et al.* 2014,[150] Canada; care for a person with schizophrenia and advanced kidney disease who lacks capacity and resists treatment	A case of a 53-year-old woman with schizophrenia and advanced chronic kidney disease admitted to hospital as an emergency and who refused dialysis and then received supportive care	Ethical issues in the case of people with SMI and who are unable to make decisions but actively resist treatment	Two ethical issues are highlighted: the lack of acceptance of treatment, and the risk of doing immediate harm if treatment is continued nonetheless

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Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Kennedy *et al.* 2013,[120] UK; homelessness and EoL care	A case study of a 52-year-old woman with diagnosis of schizophrenia and cervical cancer living semi-independently in a one-bedroom flat	Treatment refusal in someone with SMI who has the capacity to make decisions and her determination to return home to live	Providing care for a person in their own home involving multiple professional teams in support of her autonomous decision to remain out of hospital and considering her refusal of active treatment
Kunkel *et al.* 1997,[132] USA; denial of cancer and non-compliance with treatment	A discussion of denial of cancer followed by five illustrative cases: 1. A 38-year-old woman with psychosis and breast cancer, who missed treatment and died following an emergency admission 2. A 52-year-old woman with presumed 'organic personality syndrome' and squamous cell carcinoma who was psychotic and who died in hospital 3. A 73-year-old man with presumptive pancreatic cancer and pre-existing organic delusional disorder and major depression with psychosis, who had home hospice care 4. A 75-year-old woman with dementia and breast cancer 5. A 73-year-old woman with schizophrenia, superimposed dementia and lung cancer	A review of factors associated with non-compliance in people with cancer, specifically psychoses and cognitive impairment; both are shown to play a role in delayed help-seeking and non-compliance with cancer, and EoL, care	Key issues affecting cancer treatment are competence, the place for legal intervention, ambivalence towards health-care providers and the importance of early psychiatric intervention
Levin and Feldman 1983,[133] USA (the authors are based in South Africa); ethical issues surrounding the care of people with psychosis and terminal cancer	A case of a 31-year-old woman with schizophrenia and terminal breast cancer who was described as wanting to leave hospital without medical care following the treatment of an acute episode of her mental illness	A discussion of ethical issues associated with the care of people with SMI and terminal illnesses when treatment is refused	People have a right to refuse high-powered medicine at the EoL
Lopez *et al.* 2010,[134] USA; explores how medical futility and principles of palliation may contribute to the management of treatment refractory anorexia nervosa	The case of a 30-year-old woman with chronic anorexia nervosa, treated unsuccessfully for several years	Discussion of ethical and legal issues associated with caring for a person with a psychiatric condition who is not helped by treatment, where the condition ultimately leads to her death	Refusal of treatment can be irrational but must be weighed against workers obligations and duty of care and the autonomy of the individual. Two broad options are considered: (1) involuntary treatment or (2) attempting to motivate the person until such time as they are willing to engage in treatment. The first option may have kept her alive in the short term but seemed unlikely to reverse the underlying condition

Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Maloney 2014,[121] USA (blog: www.thejournal.ie/readme/bipolar-ii-disorder-denial-mental-health-1467162-May2014); a wife's experiences of her husband's bipolar disorder and terminal cancer	A personal blog post recording a woman's experiences of her husband's diagnosis with bipolar disorder, his subsequent terminal cancer and his death at home	A first-hand, narrative account of long-term experiences ending in the death of a loved one	SMI changes people's lives and can cause people to lose touch with reality. People affected (patients and families) need support
Mason and Bowman 2018,[118] country unknown (conference abstract); the challenges of providing cancer care at the EoL to people with SMI and fluctuating capacity	A conference proceedings abstract describing the care of a 77-year-old man with schizophrenia and fluctuating capacity admitted to hospital for investigations and care into prostate cancer and metastases	An account of the challenges for people with SMI and fluctuating capacity in the context of EoL cancer care	Determining capacity in the context of SMI and acute physical illness is difficult, where standardisation in capacity assessment may help
McCasland 2007,[135] USA; the care and treatment of people with SMI and cancer, including at the EoL	A case of a 53-year-old woman with schizoaffective disorder, alcohol problems, liver damage and breast cancer who was cared for in the community until dying in a hospice	Hospice nurses need better preparation to look after people at the EoL who also have SMI	Communication skills are important for hospice nurses caring for people with SMI at the EoL, and hospice nurses need more training to care for this group of people
McKenna *et al.* 1994,[136] USA; the treatment with clozapine of people with SMI and cancer, where treatment also includes antineoplastic medication	A letter to the editor describing a 49-year-old man with schizophrenia and lung cancer with a poor prognosis, treated with clozapine, whose care was transferred from a mental health to a medical care institution	The combination of clozapine with anti-tumour drugs	Guidance is needed on the combination of clozapine (an antipsychotic drug) with anti-cancer drugs
Mogg and Bartlett 2005,[146] UK; the care and treatment of a man with treatment-resistant psychosis and life-threatening renal failure	The case is a man in his forties with a 30-year history of psychosis and multiple admissions to mental health hospital, who was then discovered to have life-threatening renal disease requiring regular dialysis	Different approaches to the assessment of capacity (outcome, status, functional), set in the context of the legal framework	Capacity can fluctuate, and 'best interests' need to be considered, which can mean guidance needing to be sought from the courts
Moini and Levinson 2009,[137] USA; the care and treatment of people with simple schizophrenia and medical conditions	A case of a 40-year-old woman with simple schizophrenia who was lost to services following diagnosis of breast cancer with metastases, and who was located at a later point at the terminal stage of her illness	Approaches to working with people with simple schizophrenia and medical problems	Proactive care is needed so that people stay in touch with services, although people with simple schizophrenia are also likely to have capacity to decide on their courses of treatment
Monga *et al.* 2015,[138] USA; the use of clozapine in people with psychosis who are also receiving chemotherapy	The case is of a 70-year-old man with schizophrenia, treated with clozapine, who continued his antipsychotic medication while receiving hospice care and treatment for oesophageal cancer	The use of clozapine as an atypical antipsychotic alongside the use of chemotherapy	There is limited information to guide the management of clozapine treatment during chemotherapy, and close co-operation between psychiatrists and oncologists is needed

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Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Muhtaseb *et al.* 2001,[147] UK; the treatment of people with SMI and advanced terminal cancer	The case is of a 76-year-old man with schizophrenia and advanced basal cell carcinoma, who refused active intervention	Treatment of advanced life-threatening cancer in people with SMI who refuse active intervention	Consent must be freely given, and people (including people with SMI) should be considered able to decide for themselves
O'Neill *et al.* 1994,[148] UK; hospice care for women with anorexia nervosa	The case of a 24-year-old woman with anorexia admitted to a hospice in poor physical condition after 7 years of anorexia nervosa that was not helped by treatment	Discusses the treatment and rapid decline to eventual death of a 24-year-old woman from the complications associated with anorexia nervosa	Recognises that psychiatric units do not have relevant expertise to provide complex physical health care. Says that her condition was identified as incurable by the psychiatric team and when the patient and her family accepted this she was then able to access appropriate care. Says hospice staff are familiar with other EoL care and that this largely worked for this woman, helped by an excellent referral letter (no clue how this is judged) and ongoing support from the psychiatrist. They conclude that there is a role for carefully selected non-cancer patients to be cared for in specialist palliative care centres
Picot *et al.* 2015,[15] Australia; the IMhPaCT programme, designed to improve care for people with SMI and life-limiting illnesses	The case is of a 46-year-old woman who had bipolar disorder and metastatic breast cancer, who received integrated mental health and palliative care at home before dying in hospital	An illustrative case showcasing the work of nurse practitioners involved in the IMhPaCT programme, which is designed to bring together mental health and palliative care for people with SMI	People with SMI at the EoL face additional problems of isolation, declining physical abilities, pain and disintegrating selfhood. Collaboration across specialities can enhance outcomes, and mental health nurses have a role to play
Rice *et al.* 2012,[139] USA; patient-provider communication in EoL care	The case of a 58-year-old male veteran with renal disease and schizophrenia who refused dialysis treatment	The case provides an example of a man refusing treatment in line with his previous history and is found to lack capacity to decide in his best interests. Involvement of his sister who is ill-prepared to take on proxy decisions	Discussion hinges on challenges of enforcing physical treatments on a person who is refusing, handling autonomy vs. coercion, recognition of need for building therapeutic alliances with the person and their surrogates
Rodriguez-Mayoral 2018,[119] Mexico; integrating mental health and palliative care for people with SMI and cancer	A short conference abstract describing a 72-year-old woman with bipolar disorder and advanced, untreated colon cancer from which she died	The case briefly describes how the woman was cared for until her death, free from symptoms of her mental illness	Cancer care regardless of disease stage should be integrated with palliative and mental health care to control symptoms and quality of life and death

Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Romm *et al.* 2009,[140] USA; managing cancer care for people using inpatient mental health services	The case is a 40-year-old man with schizophrenia and osteosarcoma for which amputation was indicated, and who refused surgical treatment but who was judged to lack capacity. His mother assumed decision-making responsibility and concurred with her son, and palliative care was initiated	Treatment of people with acute mental health problems and life-threatening cancer, and patients' capacity to understand and make decisions	Psychiatrists have responsibilities to represent the interests of people who are 'mentally compromised', including those who are also irreversibly medically compromised. Collaboration with palliative care practitioners is important, and although SMI can impair capacity this is not necessarily so
Shah *et al.* 2008,[141] USA; the treatment of people with SMI and advanced terminal cancer	The case is a 68-year-old homeless man with schizophrenia and neglected basal cell carcinoma, and who refused treatment in the context of a lack of capacity and was then treated for his mental illness	Informed consent is key to the provision of cancer treatment, and in cases where people lack capacity additional care needs to be taken	In the absence of the ability to give informed consent, interprofessional teams need to be involved, along with independent ethics committees
Stecker 1993,[142] USA; caring for young people with life-threatening cancer on an acute psychiatric ward	The case is of a 21-year-old man with presumed bipolar disorder and sarcoma who was admitted to an inpatient psychiatric unit and who caused staff to struggle with the acceptance of death	Staff in mental health wards do not routinely care for young people at the EoL, and this case challenged staff	Mental health nurses need to be able to identify feelings preventing them from working therapeutically with patients
Steves and Williams 2016,[143] USA; EoL care for people with terminal illnesses and SMI	A very brief case of a man, of unknown age, who had schizophrenia and terminal lung cancer but who had capacity and refused treatment prior to his death	Services for people with SMI at the EoL are in short supply, mental health nurses need training in EoL care, attention needs to be paid to the environment, communication needs to be effective, caregivers needs to be supported, family members may be resistant and other inpatients need to be supported following a death	Investments are needed in services and staff to care for increasing numbers of people with SMI who also have terminal medical conditions
Terpstra *et al.* 2014,[144] USA; EoL hospice care for people with SMI	The case is of a 61-year-old man with schizophrenia living in adult foster care who reported physical symptoms and was found to have bladder cancer and brain masses, who moved to an open hospice and whose care and treatment is then described	The complexity of providing hospice care for people with SMI and terminal cancer, and the role of nurses	People with schizophrenia are often medically undertreated, have shortened life expectancies, and have care that is challenged by their placements, poor communication and symptom management

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Author, year, country; purpose of article	Setting; demographic characteristics	Focus of case study	Discussion
Thomson and Henry 2012,[76] USA; the challenge for oncology nurses of caring for people with SMI and cancer	A paper on oncology nursing for people with pre-existing SMI, including a series of brief case studies: a 33-year-old woman with major depression and then breast cancer, a 43-year-old man with bipolar disorder and advanced pancreatic cancer and a 25-year-old woman with schizophrenia and breast cancer	Care and treatment of people with pre-existing SMI at the EoL, with a particular emphasis on understanding mental illnesses and its treatment	Medical professionals need to be aware of premature mortality in people with SMI, and need to develop skills and knowledge in caring for people with SMI as an underserved group. Practice is advancing in the areas of drug treatments, case management, family work and social support
Webber 2012,[151] Canada; caring for a man with SMI in his supported home prior to hospice care	A brief case study of a man of unknown age (but at least 31 years old) who had schizophrenia and metastatic gastric cancer and who was cared for in his supported home for as long as possible until being transferred to a hospice, where he died	Pain control, control over of levels of intervention, control over maintaining meaningful, relationships, outcomes of lost autonomy, lack of resources, restoring justice for patients with SMI and terminal illness, and innovation are all discussed	Autonomy has been diminished for people with SMI and palliative illness, yet people with SMI at the EoL want the same things as everyone else. Services and care need to improve

DSA, dynamic system analysis; IMhPaCT, Integrated Mental Health and Palliative Care Task; SPPC, stepwise psychosocial palliative care.

Appendix 21 CERQual qualitative evidence profile, synthesis 1: structure of the system

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Structure of the system: policy and guidance					
1. Owing to a lack of national and local guidance regarding EoL care and mental health care, palliative care nurses report concerns about their legislative responsibility Study 13	No methodological limitations	Serious concerns about relevance, as only one study representing one country contributed to this finding	No concerns about coherence	Serious concerns about adequacy (only one study offering data)	Very low confidence
Structure of the system: separate commissioning, management and organisation *Accessing and navigating the system*					
The separate commissioning, management and organisation of mental health and EoL often result in those with SMI having trouble accessing and navigating the system[157,164,422]					Ungraded – non-research
2. HCPs recognise that accessing and navigating EoL care for those with SMI is a challenge and many obstacles exist Studies 14, 15, 25	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were Ireland and Australia)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (three studies with moderately rich data overall)	Moderate confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Access for homeless and vulnerable groups					
Access to health care is particularly difficult for homeless and vulnerable groups, who are often isolated and disconnected from family and friends[30,162,167]					Ungraded – non-research
3. Homeless people are often excluded from hospices and care homes, and HCPs report difficulties in placing homeless people with cancer Studies 19, 21	No or very minor methodological limitations (one study with very minor and one study with no methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were the UK and Canada)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Very minor concerns about adequacy (two studies with rich data)	Moderate confidence
Care co-ordination across systems					
It is important that care is co-ordinated and integrated across services so that the needs of those with SMI at the EoL are met, although it is acknowledged that this is difficult to achieve[30,164,169,170]					Ungraded – non-research
4. Separate commissioning, management and ways of organising both services and professionals create challenges for both mental health and EoL HCPs to co-ordinate high-quality care across mental health and EoL care systems Study 13	No methodological limitations	Serious concerns regarding relevance as only one study representing one country contributed to this finding	No concerns about coherence	Serious concerns about adequacy (only one study offering data)	Very low confidence

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
5. The invisibility of homeless and vulnerable people, and the fragmented character of care systems, means they often have to act as their own care co-ordinators Studies 13, 19, 21	No or very minor methodological limitations (two studies with no and one study with very minor methodological limitations	Moderate concerns about relevance (partial relevance, as the studies were from the UK only)	No concerns about coherence	Minor concerns about adequacy (two studies with rich data and one study with thin data)	Moderate confidence
6. Multiple proposals have been made to improve the co-ordination of care for people with SMI at the EoL, mostly involving the identification of staff with clear responsibilities Studies 16, 25, 27	Minor methodological limitations (two studies with very minor and one study with serious methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Ireland, Australia and the USA)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (two studies with rich data and one study with thin data)	Moderate confidence
Resources					
7. HCPs feel that there is a lack of resources in terms of services and trained professionals that are able to meet the needs of those with SMI at the EoL Studies 23, 25, 28	Minor methodological limitations (one study with no, one study with very minor and one study with serious methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were Ireland and Australia)	No concerns about coherence	Minor concerns about adequacy (two studies with rich data and one study with thin data)	Moderate confidence
Structure of the system: partnership *Funding and flexibility to work in partnership*					
8. Working in partnership across EoL and mental health services is important and when flexibility and solutions to work in partnership across agencies exist then EoL care for those with SMI can be facilitated Study 28	No methodological limitations	Serious concerns regarding relevance, as only one study representing one country contributed to this finding	No concerns about coherence	Serious concerns about adequacy (only one study offering data)	Very low confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
9. A lack of good relationships and partnership working, influenced by reductions in funding and competitive commissioning, inhibit good care, especially with regard to pain management, needs assessments and assessment of mental capacity Study 13, 15, 25	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Ireland, Australia and the UK)	No concerns about coherence	Minor concerns about adequacy (two studies with rich data and one study with thin data)	Moderate confidence
Multidisciplinary teamwork					
Interagency and interprofessional team working at the EoL is important[30,55,163,168,170,171]					Ungraded – non-research
10. HCPs report that formal (and sometimes ad hoc) multidisciplinary teamwork can improve patient outcomes Study 14, 15, 18, 28	Minor methodological limitations (one study with one with no, one study with very minor, one study with minor and one study with serious methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were Australia and the USA)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (three studies with rich data and one study with thin data)	Moderate confidence
Ongoing interprofessional communication					
Ongoing communication between partners is a key element of high-quality care[30,55,164]					Ungraded – non-research
11. Coalition building and formal opportunities to meet and discuss care are essential and must ensure that information is made available to primary care and social services partners Studies 13, 15, 25, 28	Minor methodological limitations (one study with no methodological limitations, two studies with very minor methodological limitations and one study with serious methodological limitations)	Minor concerns about relevance (studies of HCPs representing a variety of settings and from across four countries, which were Ireland, Australia, the UK and the USA, covering three continents)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (two studies with rich data and two studies with thin data)	High confidence

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Structure of the system: no right place to die *Dying at home*					
With the right support from community-based services, people with SMI at the EoL are able to stay at home[157]					Ungraded – non-research
12. Mental health and EoL staff recognise that allowing people to die in the location of their choice (which is often a home or home-like environment) is important, but staff also talk about how appropriate care is often lacking in all settings Studies 15, 16, 25	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, Ireland and the USA)	No concerns about coherence	No concerns	High confidence
Dying in a mental health hospital					
13. Mental health services rarely care for people with SMI at the EoL as they are poorly equipped to meet their needs, and as a result patients are frequently moved between services Studies 13, 16, 24	No or very minor methodological limitations (one study with no and two studies with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were the UK, the USA and the Netherlands)	No concerns about coherence	Minor concerns about adequacy (two studies with rich data and one study with thin data)	High confidence
Dying in a hospice					
14. Multiple challenges exist for EoL care to take place in a hostel, including lack of staff preparedness, the chaotic environment, concerns over risks and the safe storage of medication Studies 12, 21	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were the UK and Canada)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Very minor concerns about adequacy (two studies with rich data)	Moderate confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Dying in acute settings					
15. Providing EoL care in the community, within mental health settings or homeless shelters can be difficult and as a result those with SMI are often transferred into acute settings at the EoL but providing mental health care in acute settings also poses challenges Studies 13, 15, 16, 18, 19, 24, 25	No or very minor methodological limitations (three studies with no and five studies with very minor methodological limitations)	Minor concerns about relevance (studies of HCPs representing a variety of settings and from across five countries, which were Ireland, Australia, the UK, the USA and the Netherlands, across three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (seven studies with rich data and one study with thin data)	Moderate confidence
Dying in hospice					
16. Staff working within hospices report that hospices are ill-prepared for caring for the needs of homeless people at the EoL and require more help in dealing with substance misuse and the alternative lifestyles of what is mostly a younger age group Studies 19, 21	No or very minor methodological limitations (one study with no and one study with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as studies were from two countries only, which were the UK and Canada)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Very minor concerns about adequacy (two studies with rich data)	Moderate confidence

The synthesis findings presented here are drawn from the wider thematic synthesis undertaken for this review. The themes identified were summarised into evidence statements, as illustrated in this table.

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Appendix 22 CERQual qualitative evidence profile, synthesis 2: professional issues

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Professional issues: relationships between HCPs and people with SMI *Connecting relationships*					
1. Some mental health staff feel that building nurturing relationships is important, especially for those with limited social networks and no family contact. However, others choose not to form such relationships, finding it too upsetting when patients are transferred for EoL care Studies 14–16, 24, 25	Very minor methodological limitations (all studies had very minor methodological limitations)	Minor concerns about relevance (studies of HCPs representing a variety of settings and from across four countries, which were Ireland, Australia, the Netherlands and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	No concerns	High confidence
Talking about death and dying					
People with life-limiting illnesses (including SMI) should be supported to make decisions at the EoL and good communication is important[164,176]					Ungraded – non-research
2. Some mental health staff find conversations about death and dying challenging; those who feel able have found that patients are receptive Studies 13, 15, 24, 26	No or very minor methodological limitations (two studies with very minor and one study with no methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, the Netherlands and the UK)	No concerns about coherence	Minor concerns about adequacy (three studies with rich data and one study with thin data)	High confidence
Attitudes and beliefs of HCPs					
3. The underlying stigmatising and prejudicial attitudes of EoL HCPs towards those with SMI including those who are homeless can affect decisions around EoL care Studies 13, 14, 16, 17, 19, 21, 25	No or very minor methodological limitations (five studies with very minor and three studies with no methodological limitations)	No concerns	No concerns about coherence	Minor concerns about adequacy (seven studies with rich data and one study with thin data)	High confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Professional issues: mental health professionals doing EoL care					
4. Mental health staff feel that they have limited experience of caring for patients with SMI at the EoL, and although some feel able to deliver care others feel that they lack the knowledge and skills, particularly with regard to pain management and psychosocial or spiritual support Studies 13, 14, 24	No or very minor methodological limitations (two studies with very minor and one study with no methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, the Netherlands and the UK)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (two studies with rich data and one study with thin data)	Moderate confidence
EoL care not being mental health work					
5. Some mental health staff report that they do not feel able, are not interested or avoid caring for people with SMI at the EoL, whereas others embrace caring for them Studies 13, 16, 18, 23, 24	No or very minor methodological limitations (two studies with very minor and three studies with no methodological limitations)	Minor concerns about relevance (studies of HCPs representing a variety of settings and from across four countries, which were the Netherlands, Australia, the UK and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (four studies with rich data and one study with thin data)	Moderate confidence
Emotional distress					
6. Mental health staff report that caring for those with SMI at the EoL can be distressing and emotionally draining, and some fear being scrutinised following the death of patients Studies 14, 16, 17	No or very minor methodological limitations (two studies with very minor and one study with no methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, the USA and the UK)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	No concerns	Moderate confidence
Staff who provide care over long periods to individuals with SMI need support in the face of terminal illness, and in bereavement[30]					Ungraded – non-research

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Professional issues: EoL HCPs doing mental health care *Experience, knowledge and skills*					
7. EoL HCPs feel that they lack knowledge and understanding of mental health diagnoses and services. As a result, they report that they are not always confident, willing or comfortable to care for patients with SMI at the EoL Studies 13–17, 23, 24	No or very minor methodological limitations (four studies with very minor and three studies with no methodological limitations)	Minor concerns about relevance (studies of HCPs representing a variety of settings and from across four countries, which were the Netherlands Australia, the UK and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (six studies with rich data and one study with thin data)	Moderate confidence
As a consequence of this, the needs of people with SMI at the EoL are not always well met[30,423]					Ungraded – non-research
EoL HCPs should become conversant with the needs of people with SMI and work closely with mental health services[30]					Ungraded – non-research
Professional issues: training and education					
8. Mental health and EoL HCPs have highlighted a wide range of educational needs Studies 14–17, 28	Minor methodological limitations (one study with no, three studies with very minor and one study with serious methodological limitation)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, the USA and the UK)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (three studies with rich data and one study with thin data)	Moderate confidence
Education and training opportunities in EoL care across professional groups who care for people with SMI at the EoL are important[30,156,162–165,177]					Ungraded – non-research
9. Palliative care programme directors have suggested that psychiatry training is inadequate in the categories of EoL care and issues related to death and dying Study 23	No minor methodological limitations	Serious concerns regarding relevance as only one study representing one country contributed to this finding	No concerns about coherence	Serious concerns about adequacy (only one study offering data)	Very low confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
10. Although some mental health nurses feel that that their core professional preparation enables them to care for people with SMI during periods of physical illness and at that EoL, others feel that this is something that could be improved Studies 14, 16	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were Australia and the USA)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Very minor concerns about adequacy (two studies with rich data)	Moderate confidence
In-service training opportunities for HCPs to develop skills and knowledge in EoL care are patchy, particularly in mental health-care-providing organisations and could be improved[30,162,164–166,171]					Ungraded – non-research
EoL and mental health staff working together can improve knowledge and awareness, such as through the establishment of dedicated link positions with roles including the provision of education[30]					Ungraded – non-research
11. EoL and mental health staff learning from each other such as through cross-training has been positively evaluated Studies 27, 28	Serious methodological limitations (two studies with serious methodological limitations)	Serious concerns regarding relevance as only two studies representing one country contributed to this finding	No concerns regarding coherence	Serious concerns about adequacy (two studies offering thin data)	Very low confidence

The synthesis findings presented here are drawn from the wider thematic synthesis undertaken for this review. The themes identified were summarised into evidence statements, as illustrated in this table.

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Appendix 23 CERQual qualitative evidence profile, synthesis 3: contexts of care

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Contexts of care: managing the interface between mental health and EoL care *GPs managing care*					
1. GPs are the gatekeepers in enabling or hindering access to palliative care services and in some instances manage the palliative care needs of people with SMI within their practice Studies 24, 25	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were the Netherlands and Ireland)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Very minor concerns about adequacy (two studies with rich data)	Moderate confidence
The role of medical specialists					
2. People with SMI are reported to visit a number of different types of physician specialists as well as psychiatrists at the EoL Studies 23–25	No or very minor methodological limitations (one study with no and two studies with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were the USA, the Netherlands and Ireland)	Minor concerns about coherence (data reasonably consistent within and across all studies)	No concerns about adequacy	Moderate confidence
Referral					
Support for people living with mental health issues and approaching the EoL must be fast-tracked or prioritised[164]					Ungraded – non-research
3. Both EoL and mental health staff acknowledge that referrals are often complicated and lack vital information that would facilitate communication between themselves and those with SMI at the EoL Studies 13, 15	No or very minor methodological limitations (one study with no and one study with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were Australia and the UK)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Moderate concerns about adequacy (one study offering moderately rich data and one study offering thin data)	Low confidence
Mental health assessment at the EoL					
Skilled mental health assessment at the EoL is required for people with SMI so that care can be planned and they can be helped to manage their symptoms and other needs[30]					Ungraded – non-research

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
4. Both EoL and mental health HCPs across a variety of settings report that mental health assessments at the EoL can be a challenge and that they need help to deal with their fears and uncertainties Studies 13, 17, 18, 25	No or very minor methodological limitations (three studies with no and two studies with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, the UK and Ireland)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (four studies with rich data and one study with thin data)	Moderate confidence
Health-care services and treatment utilisation in the LYoL *Palliative care*					
5. GPs and psychiatrists believe that people with SMI are less likely than other groups to make use of specialist palliative care Study 25	No methodological limitations	Serious concerns about relevance as only one study representing one country contributed to this finding	No concerns about coherence	Serious concerns about adequacy (only one study offering data)	Very low confidence
Invasive interventions					
6. EoL HCPs working in the UK feel that standard guidance on resuscitation is lacking for people with SMI at the EoL Study 13	No methodological limitations	Serious concerns about relevance as only one study representing one country contributed to this finding	No concerns about coherence	Serious concerns about adequacy (only one study offering data)	Very low confidence
7. EoL professionals in Australia have concerns about capacity to consent in relation to resuscitation orders for people with SMI at the EoL Study 14	Very minor methodological limitations	Serious concerns about relevance as only one study representing one country contributed to this finding	No concerns about coherence	Serious concerns about adequacy (only one study offering data)	Very low confidence

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Contexts of care: meeting individual and family needs *Spiritual and psychosocial support*					
People with SMI have particular vulnerabilities arising from their mental health experiences and programmes and services for people with SMI at the EoL require a comprehensive team approach[30,164,176]					Ungraded – non-research
8. Programmes and services for people with SMI at the EoL require a comprehensive team approach incorporating symptom relief, psychological and psychosocial support, and spiritual care Studies 10, 12, 14, 15, 17, 24	No or very minor methodological limitations (one study with no and five studies with very minor methodological limitations)	Minor concerns about relevance (studies of HCPs and families representing a variety of settings and from across four countries, which were the Netherlands, Australia, the UK and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	No concerns	High confidence
Families and their involvement					
9. HCPs report challenges in handling contact with families, especially where years of estrangement have occurred or where family members also have mental health conditions Studies 12–16, 24	No or very minor methodological limitations (one study with no and five studies with very minor methodological limitations)	Minor concerns about relevance (studies of HCPs representing a variety of settings and from across four countries, which were the Netherlands, Australia, the UK and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (five studies with rich data and one study with thin data)	Moderate confidence
10. Veterans with a diagnosis of PTSD were just as likely to receive a family consultation regarding advance care planning as those without a diagnosis of PTSD Study 10	Very minor methodological limitations	Serious concerns about relevance as only one study representing one country contributed to this finding	Serious concerns about adequacy (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very low confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
11. When families were involved in the care of veterans with a diagnosis of PTSD they reported unmet needs for emotional support, and felt generally that their relatives were not treated with dignity and were unsatisfied with the level of care received Study 22	Very minor methodological limitations	Serious concerns about relevance as only one study representing one country contributed to this finding	Serious concerns about adequacy (only one study offering data)	Serious concerns about adequacy (only one study offering data)	Very low confidence
Advocacy					
Having an advocate that can support a person with SMI throughout their cancer journey, including at the EoL, is important and such advocates can prevent people with SMI from falling through gaps in the system[30,156,161,162]					Ungraded – non-research
12. HCPs report that being referred to palliative care and receiving services appears to be based on the presence or absence of a strong advocate Studies 13, 15, 16	No or very minor methodological limitations (one study with no and two studies with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were the UK, the USA and Australia)	No concerns about coherence	Minor concerns about adequacy (two studies with moderately rich data and one study with thin data)	High confidence
13. People with SMI can lack access to advocacy to help navigate the complex EoL trajectory due to limited social and family support and as a result they can become 'lost in the system' Studies 13, 15, 16, 24	No or very minor methodological limitations (one study with no and two studies with very minor methodological limitations)	Minor concerns about relevance (studies of HCPs representing a variety of settings and from across four countries, which were the Netherlands, Australia, the UK and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (three studies with moderately rich data and one study with thin data)	High confidence

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
EoL care preferences					
Advance care planning for people with SMI at the EoL is important and mechanisms should be in place to support such people to make their own decisions, although it is recognised that this can be problematic[156,163–165,170,176]					Ungraded – non-research
14. HCPs have concerns about negotiating EoL care preferences with people with SMI for fear that mental health symptoms may influence understanding and expectations or that such discussions may lead to further distress Studies 15, 16, 21, 24	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Ireland, the USA and Australia)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	No concerns	Moderate confidence
It is important not to assume that mental capacity is lacking[21]					
15. HCPs report that they are not always comfortable with determining patients' capability to make medical decisions and that they tend to assume that mental capacity is lacking and as a result discussions around advance care planning are avoided Studies 13, 15, 23	No or very minor methodological limitations (two studies with no and one study with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, the UK and the USA)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (two studies with moderately rich data and one study with thin data)	Moderate confidence
16. Findings from scenario-based preferences regarding medical advance care planning suggest that people with SMI are able to designate treatment preferences in response to the EoL and are open to discussing EoL care Studies 20, 29, 30	No or very minor methodological limitations (two studies with no and one study with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Belgium, the USA and Canada)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	No concerns	Moderate confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
17. People with SMI conditions are capable of completing advance care plans for the EoL but even where legislation is in place to support this it rarely appears to be standard practice Studies 12, 24, 28	Minor methodological limitations (two studies with very minor and one study with serious methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were the Netherlands and the USA)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (two studies with moderately rich data and one study with thin data)	Moderate confidence
18. A lack of confidence to have open communication and experience among HCPs, especially when working with homeless people, may explain the absence of advance care plans for those with SMI at the EoL Studies 12, 15,19, 21 Results across studies were mixed regarding the likelihood of people with a diagnosis of SMI having completed an advance directive (GRADE – very low)	No or very minor methodological limitations (one study with no and three studies with very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were Australia, the UK and Canada)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	No concerns	Moderate confidence

The synthesis findings presented here are drawn from the wider thematic synthesis undertaken for this review. The themes identified were summarised into evidence statements, as illustrated in this table.

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Appendix 24 CERQual qualitative evidence profile, synthesis 4: living with severe mental illness

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Living with SMI: complexities of EoL care					
Providing EoL care to people with SMI is challenged by patients' behaviour associated with their mental health difficulties[156,170]					Ungraded – non-research
1. Challenging behaviours, communication issues and side effects of combining SMI and EoL medications make it difficult to address mental health issues at the EoL Studies 13–17, 24	Very minor methodological limitations (all studies had very minor methodological limitations)	Minor concerns about relevance (studies of HCPs and patients representing a variety of settings and from across four countries, which were the Netherlands Australia, the UK and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (six studies with rich data and one study with thin data)	Moderate confidence
Living with SMI: familiarity and trust *Trust and rapport*					
2. Early referral to palliative care helps build trust and rapport between staff and people with SMI at the EoL Studies 13–15, 17, 19, 25, 28	No or very minor methodological limitations (four studies with very minor and three studies with no methodological limitations)	Minor concerns about relevance (studies of HCPs and patients representing a variety of settings and from across five countries, which were Canada, Australia, Ireland, the UK and the USA, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (six studies with rich data and two studies with thin data)	Moderate confidence

Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
Supporting people in familiar environments					
3. Although people with SMI often leave environments with which they are familiar at the EoL, mental health and palliative care staff can work together to support people without the need for moving Studies 14, 19, 21, 25	No or very minor methodological limitations (three studies with very minor and one study with no methodological limitations)	Minor concerns about relevance (studies of HCPs and patients representing a variety of settings and from across four countries, which were Canada, Australia, Ireland and the UK covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	No concerns	Moderate confidence
Deteriorations in EoL-related physical health commonly results in the homeless person being transferred to hospital in crisis where their needs are poorly met[156]		Moderate concerns about relevance (partial relevance, as the studies were from two countries only)			Ungraded – non-research
4. Hostel staff report that they try to ensure that palliative care can be provided in a familiar environment for as long as possible as they feel the benefits outweigh the challenges Studies 19, 21	No or very minor methodological limitations. Moderate confidence (one study with very minor and one study with no methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were the UK and Canada)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Very minor concerns about adequacy (two studies with rich data)	Moderate confidence
Living with SMI: recognising physical decline *Identifying signs of declining health*					
The physical health needs and signs of physical deterioration of those with pre-existing SMI may not be identified and as a result care is often inadequate[30,156,161]					Ungraded – non-research
5. Staff report that people with SMI are not always able to recognise their own declining health and because of previous unsatisfactory health-care encounters it is felt that they often present late to services Studies 13, 15, 24, 25	No or very minor methodological limitations (three studies with very minor and one study with no methodological limitations)	Minor concerns about relevance (studies of HCPs and patients representing a variety of settings and from across four countries, which were Australia, Ireland, the Netherlands and the UK, covering three continents)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Minor concerns about adequacy (three studies with rich data and one study with thin data)	Moderate confidence

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Review finding and studies contributing to the review finding	Assessment of methodological limitations	Assessment of relevance	Assessment of coherence	Assessment of adequacy	Overall CERQual assessment of confidence
The impact of late diagnosis					
6. The timely provision of palliative care can be hampered when people with SMI (especially those who are homeless), are not identified as approaching the EoL until late diseases of life-limiting physical disease Studies 15, 21, 24	Very minor methodological limitations (all studies had very minor methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from three countries only, which were the Netherlands, Australia and the USA)	No concerns about coherence	No concerns about adequacy	High confidence
Identifying an EoL care trajectory for those who are homeless					
7. People who are homeless are often more concerned with day-to-day survival than with keeping appointments with HCPs and this makes it difficult to identify EoL trajectories and to provide palliative care Studies 19, 21	No or very minor methodological limitations (one study with very minor and one study with no methodological limitations)	Moderate concerns about relevance (partial relevance, as the studies were from two countries only, which were the UK and Canada)	Moderate concerns about coherence (data more varied and this finding is oversimplified)	Very minor concerns about adequacy (two studies with rich data)	Moderate confidence

The synthesis findings presented here are drawn from the wider thematic synthesis undertaken for this review. The themes identified were summarised into evidence statements, as illustrated in this table.

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