

End of life care for people with severe mental illness: an evidence synthesis (the MENLOC study)

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Scientific summary

Background

People with severe mental illness such as schizophrenia, bipolar disorder and major depression have significant co-morbidities and experience higher mortality rates and reduced life expectancy compared with 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

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 specifically relating to adults (>18 years of age) 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. All citations were considered which addressed service organisation, 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 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.

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 ten databases: MEDLINE, PsycINFO, EMBASE, HMIC, AMED, CINAHL, CENTRAL, ASSIA, DARE and Web of Science.

Supplementary searching was undertaken to identify additional material including grey literature. This included use of online searches, and the targeted searching of organisational websites and of journal tables of content. Reference lists of included studies were scanned, and forward citation tracking performed using 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. For citations appearing 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 reflecting 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. 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.

Findings

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, 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:

- *Structure of the system*, which addressed the broad shape and structure of the mental health and end of life care systems and had four sub-themes: *Policy and guidance; Separate commissioning, management and organisation; Partnership; and No right place to die.*
- *Professional issues*, which addressed professional practice and had four sub-themes: *Relationships between health care professionals and people with severe mental illnesses; Mental health professionals doing end of life care; End of life care professionals doing mental health care; and Training and education.*
- *Contexts of care*, which addressed the organisation, provision and receipt of care and had three sub-themes: *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.*
- *Living with severe mental illness*, which addressed the individual and social characteristics of patients and had three sub-themes: *Complexities of end of life care; Familiarity and trust; and Recognising physical decline.*

Case study material was synthesised using five themes:

- *Diagnostic delay and overshadowing.*
- *Decisional capacity and the dilemmas of active versus passive treatments.*
- *Medical futility.*
- *Individuals and their support networks.*
- *Features of care provided.*

Overarching summary and conclusions

A high degree of confidence was judged to apply to 10 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 ten 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 policymakers, managers and senior practitioners, including in the areas of policy and guideline development. Drawing on the evidence summary statements for which there is a high degree of confidence, key implications for policy, services and practice are:

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 in 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 where 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 relationships with people with severe mental illness at the end of life due to the upset caused when patients are transferred to other facilities for end of life 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 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 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 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 palliative care is provided and received. Not having an advocate risks people with severe mental illness, 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 coordinating 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, for groups of people who might not recognise the seriousness of their condition or who might miss out from routine health assessments.

Few UK studies have been conducted into end of life care for people with severe mental illness, and internationally few studies include 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 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, in order to establish factors helping and hindering care in the specific UK context.
2. A programme of research should be commissioned comprising studies which 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 meta-analysis could not be performed.

Future work

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

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