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

Accessible summary

Background

People with severe mental illness often have significant physical health problems, and reduced life expectancy. Against this background, in this project 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 cancer or other life-threatening conditions in their expected last 12 months. Severe mental illness refers to a range of issues for which care and treatment is usually provided by specialist mental health services.

Methodology

An advisory group, including people with experience of mental health and end of life care, helped us throughout our project. We searched research databases and supplementary sources (including relevant journals, websites of government departments, charities and other organisations) for relevant evidence published in the English language. We assessed research articles and case studies for their quality, and summarised their content. In the first of two syntheses we combined content from the research articles with content from the policy and guidance documents. In a second synthesis we combined content from the case studies. We assessed how confident decision-makers should be in our summaries of the research evidence, and identified the implications of our review for health care policy, services, practice and research.

Research findings

We included 104 documents in our overall review, comprising 34 research publications, 42 case studies and 28 non-research items. The majority of the research items and the case studies were of acceptable or high quality.

Research, policy and guidance material was synthesised using four themes and case study material was synthesised using five themes. These are summarised below:

Summary of thematic syntheses

Structure of the system

Policy and guidance

Separate commissioning, management and organisation

- Accessing and navigating the system
- Access for homeless and vulnerable groups
- Care coordination 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 severe mental illness

Complexities of end of life 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 EoLC trajectory forthose who are homeless**

Professional issues

Relationships between health care professionals and people with severe mental illnesses

- Connecting relationships
- Talking about death and dying
- Attitudes and beliefs of health care professionals

Mental health professionals doing end of life care

- Experience, knowledge and skills
- End of life care not being mental health work
- Emotional distress

End of life care professionals doing mental health care

Training and education

- Educational needs
- Core professional preparation
- In-service education
- End of life and mental health staff learning from each other

Diagnostic delay and overshadowing

Receiving late diagnoses

Decisional capacity and dilemmas

Capacity, consent and dilemmas in care and treatment

Contexts of care

Managing the interface between mental health and end of life care

- General practitioners managing care
- The role of medical specialists
- Referral
- Mental health assessment at the end of life

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 end of life

Meeting individual and family needs

- Spiritual and psychosocial support
- Families and their involvement
- Advocacy
- End of life care preferences

Medical futility

Exhausting the optimism of health professionals

Individuals and their networks

The importance of support in the community

Care provision

Care across different settings and by different groups of professionals

Key

Evidence from synthesis of research, policy and guidance

Evidence from synthesis of case studies

What are the implications for policy, services and practice?

The implications of our project's findings are:

1. Formal and informal partnership opportunities should be taken and encouraged across the whole system, and ways should be found to support people to die where they choose.
2. Education, support and supervision for all staff caring for people with severe mental illness at the end of life is needed.
3. Programmes and services for people with severe mental illness at the end of life require a team approach, including advocacy.
4. Proactive physical health care for people with severe mental illness is needed to challenge the problem of delayed diagnosis.

What are the recommendations for future research?

Recommendations for future research are:

1. Patient and family-facing studies are needed to establish factors helping and hindering care in the UK context.
2. Studies are needed which explicitly co-produce and evaluate new ways of providing and organising end of life care for people with severe mental illness, including for people who are structurally disadvantaged.

Publications and further information

Complete monograph
Hannigan B., Edwards D., Anstey S., Coffey M., Gill P., Mann M. and Meudell A. (2022) End of life care for people with severe mental illness: the MENLOC evidence synthesis. Health Services and Delivery Research 10 (4)

https://doi.org/10.3310/ULTI9178

Derived article: case studies
Coffey M., Edwards D., Anstey S., Gill P., Mann M., Meudell A. and Hannigan B. (2022) End of life care for people with severe mental illness: mixed methods systematic review and thematic synthesis of published case studies (the MENLOC study). BMJ Open 12 e053223

http://dx.doi.org/10.1136/bmjopen-2021-053223

Derived article: research, and UK policy and guidance
Edwards D., Anstey S., Coffey M., Gill P., Mann M., Meudell A. and Hannigan B. (2021) End of life care for people with severe mental illness: mixed methods systematic review and thematic synthesis (the MENLOC study). Palliative Medicine 35 (10) 1747-1760

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Gofal diwedd oes i bobl â salwch meddwl difrifol: cyfosodiad o dystiolaeth (astudiaeth MENLOC)

Crynodeb hwylus

Cefndir

Mae gan bobl â salwch meddwl difrifol broblemau iechyd corfforol sylweddol yn aml, a disgwyliad oes is. Yn erbyn y cefndir hwn, yn y prosiect hwn daethpwyd â thystiolaeth ynghyd o ymchwil, polisïau, canllawiau ac astudiaethau achos ym maes gofal diwedd oes i bobl â salwch meddwl difrifol. Mae gofal diwedd oes yn cyfeirio at y cymorth a roddir i bobl â chanser neu gyflyrau eraill sy'n bygwth bywyd yn ystod eu 12 mis olaf disgwyliedig. Mae salwch meddwl difrifol yn cyfeirio at amrywiaeth o faterion y darperir gofal a thriniaeth ar eu cyfer fel arfer gan wasanaethau iechyd meddwl arbenigol.

Methodoleg

Bu grŵp cynghori, gan gynnwys pobl â phrofiad o iechyd meddwl a gofal diwedd oes, o gymorth i ni drwy gydol ein prosiect. Buom yn chwilio cronfeydd data ymchwil a ffynonellau atodol (gan gynnwys cyfnodolion perthnasol, gwefannau adrannau'r llywodraeth, elusennau a sefydliadau eraill) am dystiolaeth berthnasol a gyhoeddwyd yn Saesneg. Fe wnaethom asesu erthyglau ymchwil ac astudiaethau achos am eu hansawdd, a chrynhoi eu cynnwys. Yn y cyntaf o ddau gyfosodiad, gwnaethom gyfuno cynnwys o'r erthyglau ymchwil gyda chynnwys o'r dogfennau polisi a chanllawiau. Mewn ail gyfosodiad, cyfunwyd cynnwys o'r astudiaethau achos. Aseswyd pa mor hyderus y dylai'r rhai sy'n gwneud penderfyniadau fod yn ein crynodebau o'r dystiolaeth ymchwil, a nodwyd goblygiadau ein hadolygiad ar gyfer polisi, gwasanaethau, ymarfer ac ymchwil gofal iechyd.

Canfyddiadau'r ymchwil

Gwnaethom gynnwys 104 o ddogfennau yn ein hadolygiad cyffredinol, a oedd yn cynnwys 34 o gyhoeddiadau ymchwil, 42 o astudiaethau achos a 28 o eitemau nad oeddent yn ymwneud ag ymchwil. Roedd y rhan fwyaf o'r eitemau ymchwil a'r astudiaethau achos o ansawdd derbyniol neu uchel.

Cafodd deunydd ymchwil, polisi a chanllawiau ei gyfosod gan ddefnyddio pedair thema a chafodd deunydd astudiaeth achos ei gyfosod gan ddefnyddio pum thema. Crynhoir y rhain isod.

Crynodeb o gyfosodiadau thematig

Strwythur y system

Polisi a chanllawiau
comisiynu, rheoli a threfnu ar Wahân

Cael hyd i'r system a llywio'r ffordd drwyddi
- Mynediad i grwpiau digartref a bregus
- Cydlynu gofal ar draws systemau
- Adnoddau

Partneriaeth
- Cyllid a hyblygrwydd i weithio mewn partneriaeth
- Gwaith tîm amlddisgyblaethol
- Cyfathrebu rhyngbroffesiynol parhaus

Dim lle iawn i farw
- Marw gartref
- Marw mewn ysbyty iechyd meddwl
- Marw mewn hostel
- Marw mewn ysbyty acíwt
- Marw mewn cartref nyrsio neu gyfleuster preswyl
- Marw mewn hosbis

Byw â salwch meddwl difrifol

Cymhlethdodau gofal diwedd oes. Cynefindra ac ymddiriedaeth
- Ymddiriedaeth a chydberthynas
- Cefnogi pobl mewn amgylcheddau cyfarwydd

Cydnabod dirywiad corfforol
- Adnabod arwyddion o ddirywiad iechyd
- Effaith diagnosis hwyr
- Nodi llwybr gofal diwedd oes i'r rhai sy'n ddigartref

Materion proffesiynol

Perthnasoedd rhwng gweithwyr gofal iechyd proffesiynol a phobl â salwch meddwl difrifol
- Cysylltu perthnasoedd
- Siarad am farwolaeth a marw
- Agweddau a chredoau gweithwyr gofal iechyd proffesiynol

Gweithwyr iechyd meddwl proffesiynol sy'n rhoi gofal diwedd oes
- Profiad, gwybodaeth a sgiliau
- Gofal diwedd oes nad yw'n waith iechyd meddwl
- Trallod emosiynol

Gweithwyr gofal diwedd oes proffesiynol sy'n rhoi gofal iechyd meddwl
Hyfforddiant ac addysg
- Anghenion addysgol
- Paratoad proffesiynol craidd
- Addysg mewn gwasanaeth
- Staff diwedd oes ac iechyd meddwl yn dysgu oddi wrth ei gilydd

Oedi a chysgodi diagnostig
Derbyn diagnosisau hwyr

Gallu gwneud penderfyniadau a chyfyng-gyngor
Galluedd, cydsyniad a chyfyng-gyngor mewn gofal a thriniaeth

Allwedd

Tystiolaeth o gyfosodiad o ymchwil, polisi a chanllawiau

Tystiolaeth o gyfosodiad o astudiaethau achos

Cyd-destunau gofal

Rheoli'r rhyngwyneb rhwng iechyd meddwl a gofal diwedd oes
- Meddygon teulu'n rheoli gofal
- Rôl arbenigwyr meddygol
- Atgyfeirio
- Asesiad iechyd meddwl ar ddiwedd oes

Gwasanaethau gofal iechyd a'r defnydd o driniaeth yn ystod blwyddyn olaf bywyd
- Ymweliadau symudol â meddyg teulu neu arbenigwyr meddygol
- Gwasanaethau gofal lliniarol
- Gofal sefydliadol hirdymor
- Gofal acíwt
- Derbyniadau i unedau gofal dwys
- Ymweliadau ag adrannau brys
- Ymyriadau mewnwthiol
- Cemotherapi
- Archwiliadau diagnostig uwch
- Defnydd o feddyginiaethau ar ddiwedd oes

Diwallu anghenion unigolion a theuluoedd
- Cymorth ysbrydol a seicogymdeithasol
- Teuluoedd a'u cyfranogiad
- Eiriolaeth
- Dewisiadau gofal diwedd oes

Oferedd meddygol
Dihysbyddu optimistiaeth gweithwyr iechyd proffesiynol

Unigolion a'u rhwydweithiau
Pwysigrwydd cymorth yn y gymuned

Darpariaeth gofal
Gofal ar draws gwahanol leoliadau a chan wahanol grwpiau o weithwyr proffesiynol

Beth yw'r goblygiadau i bolisi, gwasanaethau ac ymarfer?

Goblygiadau canfyddiadau ein prosiect yw:

1. Dylid achub ar gyfleoedd partneriaeth ffurfiol ac anffurfiol a'u hannog ar draws y system gyfan, a dylid dod o hyd i ffyrdd o gynorthwyo pobl i farw lle maent yn dewis.
2. Mae angen addysg, cymorth a goruchwyliaeth ar gyfer yr holl staff sy'n gofalu am bobl â salwch meddwl difrifol ar ddiwedd eu hoes.
3. Mae rhaglenni a gwasanaethau i bobl â salwch meddwl difrifol ar ddiwedd oes yn gofyn am ddull tîm, gan gynnwys eiriolaeth.
4. Mae angen gofal iechyd corfforol rhagweithiol ar gyfer pobl â salwch meddwl difrifol i herio'r broblem o oedi cyn cael diagnosis.

Beth yw'r argymhellion ar gyfer ymchwil yn y dyfodol?

Argymhellion ar gyfer ymchwil yn y dyfodol:

1. Mae angen astudiaethau sy'n wynebu cleifion a theuluoedd i ddeall ffactorau sy'n helpu ac yn llesteirio gofal yng nghyd-destun y DU.
2. Mae angen astudiaethau sy'n cyd-gynhyrchu ac yn gwerthuso ffyrdd newydd o ddarparu a threfnu gofal diwedd oes i bobl â salwch meddwl difrifol, gan gynnwys ar gyfer pobl sydd o dan anfantais strwythurol.

Cyhoeddiadau a rhagor o wybodaeth

Cwblhau monograff
Hannigan B., Edwards D., Anstey S., Coffey M., Gill P., Mann M. and Meudell A. (2022) End of life care for people with severe mental illness: the MENLOC evidence synthesis. Health Services and Delivery Research 10 (4)

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Erthygl deilliedig: astudiaethau achos
Coffey M., Edwards D., Anstey S., Gill P., Mann M., Meudell A. and Hannigan B. (2022) End of life care for people with severe mental illness: mixed methods systematic review and thematic synthesis of published case studies (the MENLOC study). BMJ Open 12 e053223

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Erthygl deilliedig: ymchwil, a pholisi a chanllawiau'r DU
Edwards D., Anstey S., Coffey M., Gill P., Mann M., Meudell A. and Hannigan B. (2021) End of life care for people with severe mental illness: mixed methods systematic review and thematic synthesis (the MENLOC study). Palliative Medicine 35 (10) 1747-1760

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