# King's Research Portal

[Link to publication record in King's Research Portal](#)

# End of life care and place of death in adults with serious mental illness: a systematic review and narrative synthesis

Rebecca Wilson[1], rebecca.wilson@kcl.ac.uk*

Nilay Hepgul[1], nilay.hepgul@kcl.ac.uk

Irene J Higginson[1], irene.higginson@kcl.ac.uk

Wei Gao[1], wei.gao@kcl.ac.uk

[1] Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation

Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care

King's College London

Bessemer Road

London

SE5 9PJ

* Corresponding author

# Abstract

## Background

People with serious mental illness have greater mortality risk than the general population. They experience health care inequalities throughout life; it is not clear if this persists to end of life.

## Aim

Assess the empirical evidence describing end of life care and place of death for people with serious mental illness.

## Design

A systematic review of original, peer-reviewed research, following PRISMA guidelines. Data were analysed using a narrative synthesis approach.

## Data sources

Five online databases (Embase, PsycArticles, PsycInfo, Medline, PubMed) and additional sources were searched (without time restriction) for primary research reporting health care utilisation in the last year of life or place of death in adults with serious mental illness.

## Results

After full text screening, 23 studies were included. We found studies reporting hospital admissions, emergency department care, palliative care and GP visits at end of life. We found conflicting evidence for the association between serious mental illness and end of life care, although different patient groups, settings and measures were used across studies. People with serious mental illness were more likely to die in care homes than the general population. There were no patterns for other places of death.

## Conclusions

The evidence was sparse and heterogeneous, demonstrating variability in patterns and reporting of health care use and with little consensus on where people with serious mental illness are likely to

die. Given that people with serious mental illness have increased mortality risk, this gap in the knowledge around end of life care outcomes is concerning; this area of research needs further development.

Key words: mental disorders; systematic review; death; terminal care; delivery of health care

## Key statements

### What is already known about the topic?

- People with serious mental illness have increased mortality risk and have worse experience of and access to health care
- Little is known about the end of life care experiences of people with serious mental illness

### What this paper adds?

- There has not been a systematic review of the evidence describing the end of life care of people with serious mental illness
- This review shows that research in this topic has grown in recent years but there is lack of consensus among the literature
- There is a conflict in the literature between what care is considered good and bad end of life in this population

### Implications for practice, theory or policy

- Research in end of life care for people with serious mental illness is emerging but needs to develop consistent hypotheses around what good end of life care comprises in this population
- Some of the assumptions for what represents good end of life care  in the general population (eg, place of death, hospitalisation at the end of life) may not be transferable to people with serious mental illness

# Background

It is well documented that people with serious mental illness have a lower life expectancy than the general population (1–4). Whilst people with serious mental illness are at greater risk of death from unnatural causes (including homicide, suicide and accidents) (5,6), most of the mortality gap is explained by deaths from natural causes (7–9). This suggests that people with serious mental illness might have a high need for palliative and end of life care. Inequalities in access to and provision of health care for people with serious mental illness have been previously reported (10–13), yet it is not clear if this inequity persists to end of life. Several reviews and theoretical papers have discussed end of life care for people with serious mental illness and have generally concluded that this population are underserved, yet acknowledge that there is a limited scientific evidence base to illustrate the health care circumstances and outcomes at end of life for these patients (14–17). A systematic review of empirical research is needed to evaluate and summarise the results and assess the quality of the existing evidence on end of life care outcomes in people with serious mental illness.

# Methods

The aim of this study was to systematically review the empirical evidence assessing end of life care and place of death for people with serious mental illness. It was intended that exploring the health care people with serious mental illness receive at the end of life would highlight any end of life care inequalities this population face. Specifically, we aimed to explore what health care services people with serious mental illness utilised in the last 12 months of life and where deaths occurred.

## Study design

A systematic literature review was conducted using the Centre for Reviews and Dissemination guidelines (18) and reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework (19). Due to anticipated heterogeneity of the evidence, data

were analysed using a narrative synthesis approach (20). This study protocol is registered with the PROSPERO database (registration number: CRD42017072604).

## Eligibility criteria

Inclusion criteria were: adults (18+ years) with a diagnosis of serious mental illness, who had died or were in the last year of life; reported either health care access/utilisation in the last year of life or place of death; original research published in peer reviewed journals; and full-texts articles available in English language.

Studies were excluded if they reported only one place of death (eg, the sample all died in hospital) and if actual health care access/utilisation was not reported (eg, only hypothetical or preferred care was reported). Conference abstracts were excluded as adequate information was required to judge quality. Reviews, case reports/studies and grey literature were not included as previous reviews (14,15,17) have included such literature and the aim and novelty of this review was to review only empirical, primary evidence. Studies from low-income countries were excluded as health care systems are not comparable and people with serious mental illness are likely to face additional barriers to end of life care not present in middle and high income countries.

## Data sources

The database interface OvidSP was used to jointly search Embase, PsycArticles, PsycInfo and Medline from inception to search date (March 2019) in an advanced keyword search. PubMed was also searched using free-text search terms (truncated if necessary, "*") and Boolean operators ("OR", "AND"). Free-text keyword search terms were used to run a standardised search strategy. The medical subject headings (MeSH terms) and synonyms were used in combination with the keywords where available. Minor adjustments were made for different databases. Search terms were limited to titles or abstracts. The search terms used for PubMed are included in the supplementary material. Hand searches were used to search the reference lists of any relevant reviews found throughout the search and any relevant references identified in eligible papers.

## Study selection

Published original research articles meeting the inclusion criteria were identified in the search. Duplicate references were removed using referencing software (Endnote X8).

Title and abstract screening and full text screening were performed independently by two researchers (RW and NH). Any disagreements, at each stage, were resolved following discussion. Data extraction and quality assessment of included studies was then completed by two researchers (RW and NH). A standard data extraction form was used for all included studies (see supplementary material).

## Data analysis and synthesis

Using the data extraction form, a comprehensive table of study characteristics and results was populated. Details of the study results of interest (health care use in the last year of life and/or place of death) were identified, from the table Results column, and used to inform the synthesis of the evidence. A narrative synthesis approach was used to describe the results of the included studies. Narrative synthesis has been described as a process of summarising and explaining the results of a systematic review; it aims to "tell the story" of the evidence found using text (20). Using this approach we collated and summarised the evidence for (1) health care in the last year of life and (2) place of death. Within each of these two outcomes, results were grouped and summarised by either type of health care service or by place of death, thus results across studies describing utilisation of a particular health service or a place of death are described collectively.

## Quality assessment

Although studies were not excluded on the basis of quality, the quality of individual studies was assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (21), as a tool appropriate for use on a heterogeneous collection of studies. For this quality measure, the 14 items are indicators of meeting different quality criteria, scored as "yes" (2), "partly" (1), "no" (0), or "not applicable". The summary scores for each study were derived by calculating the total

score of relevant items (ie, all those not scored as "not applicable") and dividing it by the total possible score (excluding "not applicable" items). Quality ratings ranged from 0-1.0. The assessment was completed independently by two researchers (RW and NH). Where scores differed, the central value was taken. Quality ratings were expressed as a percentage; over 80% was considered strong, above 70%, good, 50% or above, adequate, and below 50%, limited (22). Quality scores were compared across studies.

# Results

## Search results

The literature search yielded 3625 references (after excluding duplicates). Following title and abstract screening, 180 full texts were assessed for eligibility. Twenty-three studies were included in the review (see Figure 1).

*Figure 1 PRISMA flow diagram of included studies*

## Study characteristics

Characteristics of the 23 included studies are presented in Table 1. Fourteen studies reported health care at end of life (23–36) and 13 studies reported place of death in patients with a serious mental illness (13,28,34–44) and. Four studies reported both outcomes (28,34–36).

All studies were observational by design and were published between 1977 and 2019. All but two studies (28,40) used a comparator to assess place of death or end of life care, generally a cohort without serious mental illness, although two studies (24,32) used cohorts with serious mental illness not at the end of life as comparators. There was great variability in the size of the study sample from which the sample of people with serious mental illness. In two studies (28,32), the whole sample comprised eligible adult subjects with serious mental illness, whom were included in the synthesis of results, whilst other studies presented results for subsamples with serious mental illness from a

much larger denominator, for example, N=1746 cases with serious mental illness from a total sample of N=733904 (13).

Most studies were from the USA (13,24,30–32,34,35,38) and Canada (29,36,43); the remaining studies were from Denmark (41,42), the UK (28,44), France (39), the Netherlands (25), Australia (27,33), New Zealand (23), Japan (40) and Taiwan (26,37). The mean/median age of subjects ranged between 47 and 79. Although adult subjects was an inclusion criteria for the review, two studies (29,36) included subjects aged 10 and over and one (25) included cases aged 17 and over. These studies were included as the majority of subjects were adults. Most studies' samples had a male majority. The highest proportions of male subjects were 97% and 93% (31,34), however both of these studies used veteran populations. Only three studies had female majorities (36,39,44).

Mental illness diagnoses were mixed and it was not feasible to restrict the review to studies that included only patients with a diagnosis of serious mental illness. Nine studies included only patients with schizophrenia spectrum disorders (13,26,27,29–31,34,36,37), one included only patients with bipolar disorder (44) and all others were mixed samples.

Four studies reported outcomes for deaths from natural causes (34,35,38,42), two for unnatural deaths (33,43) and six for a mixed sample of natural and unnatural deaths (24,28,36,40,41,44). One study described the sample's cause of death as "non-sudden", which was an inclusion criteria (25). The remaining studies did not report cause of death.

The results are summarised in Table 2.

## Health care utilisation in the last year of life

Studies describing health care utilisation in the last year of life for patients with serious mental illness encompassed various types of health care including: hospitalisation, clinic visits, general practice and palliative care. Three studies presented results describing general practice attendance at the end of life for patients with serious mental illness (29,33,36) with conflicting evidence for

rates of attendance. More evidence was found for hospital and emergency department use and palliative care.

## Hospital use

Studies describing utilisation of hospital care in the last year of life offered mixed results. Assessing acute care in the last month of life, one study found 44.7% patients who died from natural causes and 18.7% who died from unnatural causes were admitted to hospital in the last month of life (28). Another study reported hospitalisations in the last month of life were more likely to be admitted through accident and emergency, compared to admissions prior to the last month of life (32).

Comparing acute care in patients with serious mental illness to the general population, two studies reported that patients with serious mental illness were more likely to have hospital admissions in the last year of life (24,30). However, Cohen et al (30) reported that rates of admissions to a general medical facility, were comparable in patients with and without schizophrenia (51% and 50%, respectively). Furthermore, there was no significant difference in the length of hospital stay in the last month of life between cancer patients with and without schizophrenia (26).

Several studies reported the opposite association; patients with serious mental illness were less likely to be admitted to hospital in the last six months (29) and the last month (35) of life, and were in hospital for shorter stays (29,31,32) than patients without serious mental illness. Patients who had schizophrenia and who died in hospital or at home were less likely to have been admitted in the last six months of life than decedents without schizophrenia (36). Assessing gender differences, Spilsbury et al (27) reported that female patients with schizophrenia were less likely to be admitted to hospital in the last year of life than female patients without schizophrenia (72.6% compared with 81.1%, p<0.001), although admission rates were generally high. However, this difference was not observed in men, although male patients with schizophrenia had longer inpatient stays ($\tilde{x}$ 8.1 days compared with $\tilde{x}$ 4.5 days); a pattern than was not seen in female patients.

Results were also mixed regarding intensive care unit care. Two studies found that patients with serious mental illness were more likely to receive care in an intensive care unit in the last month of life, one which compared intensive care with that for patients with serious mental illness not at the end of life (32) and the other compared with decedents without serious mental illness (26). These findings were supported by Spilsbury et al (27), but in male patients only. Conversely, Lavin et al (35) reported that patients with serious mental illness were less likely to receive intensive care in the last 30 days of life. Mixed findings were also evident for other hospital intervention. In one study, there was no significant difference in unanticipated surgery or invasive surgery in the last 30 days of life or prior to the last 30 days of life (OR=0.8, 95% CI 0.3-2.2) (32). However, Huang et al (26) reported than patients with serious mental illness were more likely to undergo invasive interventions (such as cardiopulmonary resuscitation, endotracheal intubation, mechanical ventilation, urinary catheterisation and feeding tube) in the last month of life than patients without serious mental illness, but were less likely to receive chemotherapy and generally less likely to receive diagnostic examinations (excluding panendoscopy).

## Emergency department

One study reported that people with serious mental illness were more likely to visit the emergency department at the end of life than the general population (35) and two studies found no significant difference (24,27). Lavin et al (35) reported that patients with psychiatric illness were more likely to visit the emergency department at least once in the last 30 days of life than patients without (OR=1.64, 95% CI 1.30-2.08) and were more likely to have more emergency department visits (RR=1.38, 95% CI 1.02-1.88). In a study that stratified by gender, there was no significant difference between rates of emergency department attendance in the last year of life for patients with and without schizophrenia, although, for male patients, those without schizophrenia were more likely to make visits to the emergency department considered urgent, rather than non-urgent (27). Chang et al (24) reported that patients with serious mental illness had a median of two emergency

department visits (IQR 0-5) in the last 12 months of life, though this was not significantly different to the number of visits reported in patients with serious mental illness not in the last year of their life.

Taking into consideration the cause of death, a study of acute care utilisation in the last month of life in patients with a variety of psychiatric diagnoses reported that 45.6% patients who died from natural causes and 26.6% patients who died from unnatural causes visited the emergency department in the last month of life (28).

## Palliative care

Six studies reported receipt of palliative care (23,25–27,29,34), notably four of these were among the most recent studies found in this systematic review of the evidence. Results regarding palliative care were particularly mixed.

From a sample of decedents who died non-sudden deaths, 14.9% received palliative care in the last month of life, however of those who had "psychiatric disorder", 8.5% received palliative care (25). The rate of receipt of specialist palliative care in patients with serious mental illness was 0.5%, compared to 1.72% of the general population (23).

Spilsbury et al (27) reported that patients with schizophrenia were less likely to be registered with specialist palliative care than patients without schizophrenia and were less likely to receive palliative care if they had died from cancer, chronic obstructive pulmonary disease or certain types of organ failure or neurological disorder. After adjusting for patient socioeconomic factors and cause of death, one study found that patients with schizophrenia were less likely to receive palliative care than those without schizophrenia (29). Mixed evidence was provided by Huang et al (26); cancer patients with schizophrenia were no more or less likely than cancer patients without schizophrenia to receive palliative care or hospice ward care in the last month of life, however patients with schizophrenia were less likely to have a palliative care consultation (OR=0.59, 95% CI 0.43-0.82).

One study found no significant difference in rates of hospice enrolment in patients with and without schizophrenia, however, patients with schizophrenia had longer hospice stays (mean number of days=107) than patients without schizophrenia (mean number of days=63), which approached statistical significance (p=0.05) (34).

## Place of death

### Hospital deaths

In the 11 studies that reported place of death, hospital was the most prominent location mentioned in the evidence. This was partly because five studies compared deaths in hospital in-patients with serious mental illness with the general population (13,37–39,44). Though these papers explored in-hospital mortality, where in-hospital deaths were compared with patients without serious mental illness, these comparative figures were extracted and studies included as descriptors of place of death. Several studies reported that patients with serious mental illness were more likely to die in hospital than patients without (13,38,44). This pattern was found for both patients with schizophrenia (5.2% patients with schizophrenia died in hospital compared with 3% patients without schizophrenia) (13) and bipolar disorder (9.7% of patients with bipolar disorder compared to 8.4% of patients without) (44). Sohn et al (38) also reported that, following acute myocardial infarction, patients with schizophrenia were more likely to die in hospital, after adjusting for patient-related factors (OR=1.72, 95% CI 1.02-2.90). Patients with schizophrenia were also more likely to die in an intensive care unit than patients without (24.1% compared to 14.1%, OR=1.56, 95% CI 1.08-2.24) (37). However, not all evidence supported this trend. In a mixed psychiatric population, patients with serious mental disorder were found to be less likely to die in hospital, although this association was somewhat attenuated by patient sociodemographic and clinical factors (OR=0.92, 95% CI 0.84-1.01) (38). Also in a mixed sample, Gervaix et al (39) reported that patients with serious mental disorder were less likely die in hospital, after adjusting for patient factors, including physical comorbidities (OR=0.87, 95% CI 0.86-0.87).

Other studies looking more widely at place of death also demonstrated conflicting conclusions around hospital deaths. In one study, patients with psychiatric illness were less likely to die in hospital than patients without (37% compared to 40%, OR=0.67 95% CI 0.60-0.75) (35). In another, patients with schizophrenia were significantly less likely, than patients without, to die in hospital (55.5% compared to 70.5% in a matched cohort, p<0.001); this pattern was evident for all causes of death except suicide (36). However, evidence was often weak or in support of no difference between patients with and without serious mental illness. In cancer patients, rates of hospital deaths were comparable in those with and without schizophrenia (27% and 26%, respectively) (34). Another study found no significant difference between patients with and without psychiatric disorders for deaths in the emergency department (4% and 6%, respectively) or deaths in hospital (11% and 7%, respectively) (42).

Two studies assessed place of death in serious mental disorder populations without comparing with data from non-psychiatric samples (28,40). Hospital was the second most common place of death in a sample of patients with a range of psychiatric diagnoses (14%), after home deaths (62%) (40). Hitosugi et al (28) reported that, of these hospital deaths, 48% resulted from natural causes (40). In a sample of patients that died from natural causes, hospital was the most common place of death (52.7%).

## Home deaths

Rates of home deaths varied in the studies between 2.2% (in cancer deaths) (36) and 74% (in sudden cardiac deaths) (42). Hitosugi (40) made no comparison with other patient groups but reported that 62.4% of patients with a history of mental illness died at home. In a more recent study, home deaths were reported in 31.2% of adults with serious mental disorder who died from natural causes (28).

There was mixed evidence demonstrating whether patients with serious mental illness were more or less likely to die at home than other populations. Small differences in home deaths between cancer patients with and without schizophrenia (33% compared with 36%, respectively) were reported by

Ganzini et al (34). In one study, the difference in home deaths between patients with and without "psychiatric illness" (35.6% and 34.1%, respectively) did not reach significance (OR=1.02, 95% CI 0.92-1.14) (35) and in another, patients with "neuroses and character disorders" were more likely to die at home than all decedents (40% compared with 27%, respectively) and this difference was not statistically significant (41). However, in patients who died from sudden cardiac death, 74% of patients with serious mental illness died at home, compared to 62% of patients without serious mental illness, which approached statistical significance (p=0.06) (42).

One study reported that although home deaths from all-cause mortality were comparable in patients with and without schizophrenia (8.8% and 8.2%, respectively), and rates of home deaths were comparable for deaths from respiratory and circulatory diseases, home deaths in cancer patients were lower in those with schizophrenia than without (2.3% compared with 6.3%, respectively) (36).

## Care home deaths

Studies consistently reported the increased likelihood of dying in a nursing home/care home (terminology and setting varied across studies; nursing homes, care homes and other residential health and social care settings are collectively referred to as care homes here) in patients with serious mental illness.

In the oldest of the included studies, Nielsen et al (41) reported that 17% of people with functional psychoses died in a care home, compared with 2% of all decedents. More recently, this pattern remained unchanged, as patients with serious mental illness who died from natural causes were found to be more likely to die in a care home than those without a diagnosis of serious mental illness (15% compared with 11% (OR=1.27, 95% CI 1.09-1.49)) (35).

In all-cause deaths, patients with schizophrenia were more likely to die in a nursing home compared to a matched cohort of patients without schizophrenia (29.7% compared with 13.9%, respectively) (36). This pattern was seen in deaths from circulatory disease, cancer and respiratory disease. In

14

cause of death specific studies, patients with schizophrenia who died from cancer and sudden cardiac death were more likely to die in a care home than patients without a diagnosis of schizophrenia (34,42).

In the studies that described care home deaths without a comparator, 4.3% of all-cause deaths in patients with various psychiatric diagnoses were reported to occur in a 'healthcare facility' that was not a hospital (40) and 10.4% of deaths from natural causes in patients with serious mental disorder were in a care home (28).

## Other places

In patients with a range of psychiatric diagnoses, Hitosugi (40) reported that 20% died in 'other locations' whilst Wilson et al (28) found that 2.2% of deaths from natural causes occurred in 'other locations'. One study reported that 1.7% of patients with psychiatric illness died in 'other locations' (35), and that this was the same for patients without psychiatric illness. However, another study reported lower rates of death in an unknown location in patients with schizophrenia compared to patients without schizophrenia (5% compared with 18%, respectively) (34). Similarly, patients with previous psychiatric disorder who died from sudden cardiac death were significantly less likely to die in a public place than those without a psychiatric disorder (3% compared to 19%, p<0.01) (42).

## Unnatural deaths

Four studies reported place of death exclusively for deaths from unnatural causes (28,36,40,43). One study reported that, of the 25 patients in their sample with various psychiatric diagnoses who died in hospital or other healthcare facility, over half of deaths were the result of an accident (N=7), homicide (N=4) or suicide (N=2) (40). Martens et al (36) compared place of death in patients who died by suicide with and without a diagnosis of schizophrenia. Nearly half of patients with schizophrenia who died by suicide died in their home (47.8%) and a third (33.3%) died in hospital; this was not significantly different to patients who died from suicide without a diagnosis of schizophrenia. In a study describing place of death for patients who died by suicide and had had

contact (in the 12 months prior to death) with a mental health professional, 'own home' was the most common place of death (61.7%); this was the same for people who hadn't had contact with a mental health professional (43). In a study with mixed psychiatric diagnoses, most patients who died from unnatural causes died at home (39.6%) or in 'other' places (described as outdoor spaces, addresses other than their home and other institutional buildings) (36.0%); no patients died in a hospice and only one died in a care home (28).

## Quality of studies

The quality of studies was variable. The mean quality score using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (21) ranged between 0.455-0.945. Notably, the lowest quality score was the oldest study (41). All but five studies (23,24,27,33,41) were judged to be of strong quality (>80%) using the thresholds described by Millard et al (22).

# Discussion

## End of life care

There was little consensus regarding an association between hospital in-patient care at the end of life in patients with serious mental illness, although more studies were found to support an association between less in-patient care at the end of life for patients with serious mental illness, than for patients without. However, due to the heterogeneity in the diagnoses, cause of death and type of hospital admission, it is not possible to conclude that patients with serious mental illness are less likely to be hospitalised in at the end of life.

The lack of literature reporting palliative care in patients with serious mental illness corroborated previous reviews of the literature (45). Although, notably, the evidence that was found which described hospice and palliative care for patients with serious mental illness were published more recently, which suggests that this is an emerging area of research.

On the whole, little evidence was found to support differences between patients with and without serious mental illness in health care utilisation near the end of life, however, this is largely due to a lack of evidence and great heterogeneity in the literature. The inconsistencies found in this systematic review mirrors those found by the scoping review performed by Relyea et al (46), who concluded that that inconsistencies in practice and implementation signal a lack of policy development.

## Place of death

Mixed results were observed for place of death in patients with serious mental illness. There was variety across these studies in terms of the diagnoses included in the samples, causes of death and setting and study design. We found studies that reported associations between serious mental illness and increased likelihood of dying in hospital, decreased likelihood and no association between serious mental illness and hospital deaths. One common feature amongst studies reporting an increased likelihood of dying in hospital (13,37,38,44) was that they were all investigating the risk of in-hospital mortality in patients with serious mental illness. Whereas, most studies that found a negative or no association between serious mental illness and hospital-deaths were studies where all cases and all controls were deceased and place of death was the outcome rather than in-hospital mortality. Two exceptions to this were Sohn et al (38), who reported differences between diagnoses in place of death and Gervaix e al (39), where no difference between hospital mortality in patients with and without serious mental disorder was reported. A potential explanation for these mixed results is the different perspectives on hospital deaths. The authors of one of the included studies stated that "less hospital care suggests these patients are most likely being underserved" (36). This challenges the perception that dying in hospital represents poor end of life care. The mixed results describing hospital deaths in patients with serious mental illness found in this review illustrate the variation in whether authors were investigating hospital deaths as a 'bad death' or as a marker of poor end of life care. Whilst hospital is the most common place of death for the general population

17

(47) and is generally considered a negative outcome, this is not transferable to patients with serious mental illness, as hospital deaths are linked with cause of death (28,40).

One consistent finding regarding place of death was concerning care homes, which included nursing home and supported care facilities. Care home deaths were more common in patients with serious mental illness, for all causes. One potential explanation for this is, for many people with serious mental illness a care homes or similar institutional care setting is their usual place of care, and may be more likely to be their place of death, than the general population, who may be more likely to reside at home until their death or nearer to the end of life. However, though studies indicated care home deaths were higher in this population, on comparing rates with those of the general population reported in other studies (eg, in 2014, over 20% of deaths in England and Wales occurred in care homes (48)), the rates of care home deaths reported in the studies included in this review are considerably lower for patients with serious mental illness. This discrepancy points to the various definitions of care home used in the serious mental illness literature and that from the wider population, perhaps indicating that care home deaths cannot be directly compared in the two patient populations. Furthermore, age at death may play a role in the association between serious mental illness and care home deaths. In the general population, care home deaths usually occur in older age (49,50). As the average age at death is lower in people with serious mental illness than the general population (9,51) care home deaths may be comparatively lower in people with serious mental illness.

Most studies did not report significant associations between serious mental illness and home deaths. Rates of home deaths varied greatly between studies and did not appear to be associated with population or setting. The evidence did indicate that dying in the home was associated with cause of death. Deaths from unnatural causes, including suicide, were associated with more home deaths (28,36,43). These results would suggest that assessment of place of death in this patient population should consider cause of death, as, due to the increased risk of unnatural death (1), place of death is

not an appropriate proxy measure for end of life care across all-cause mortality in this patient group. Furthermore, no consistent findings were found for 'other' places of death, which was likely to refer to a wide variety of settings across the different studies. One place of death notably missing from the literature was hospice.

## Strengths and limitations

We aimed to identify the peer-reviewed, primary evidence describing place of death and end of life care in adults with serious mental illness but did not exclude studies whose aim did not mirror or own. As such, we included any study that measured either of these two outcomes. We were able to include data from studies not purposefully designed to report place of death or end of life care. Although this has implications for the interpretation of these data, as discussed above (eg, in-hospital mortality) this widened the breadth of the included studies and enriched our data synthesis.

It was decided to exclude grey literature from the review. Although this may be considered a limitation, this decision was taken because, first, previous reviews have included and been dominated by grey literature, guidelines and case studies (14,15,45,46). Second, our intention was to identify empirical, peer-reviewed evidence describing end of life care outcomes for patients with serious mental illness and assess whether this is or has been a research priority in the fields of psychiatry or palliative care research. Thus, we believe this review is novel in including only primary evidence, of which we were able to assess the quality using a methodological tool. The exclusion of non-English literature also presents a limitation to the review.

One of the main limitations of the review is the heterogeneity and diversity of the included studies. Comparisons between study results were not always possible and, with the lack of consensus, it is not possible to explicitly answer the research question 'where do people with serious mental illness die?', rather, we achieved the aim of identifying the evidence and our review is a comprehensive synthesis and description of the results from the literature. Furthermore, one limitation was the range of diagnoses included. In order not to exclude some relevant studies, we took an inclusive

approach and there is variation amongst the populations included in this review. Some samples (35,39,43) included patients who had a psychiatric admission, contact or prescription, although these may have not been a diagnosis we initially intended to limit the review to, they were serious enough to warrant inpatient care, thus were included as they were considered serious mental illness. We restricted our search strategy to middle and high income countries to avoid making comparisons between countries with different economic resources and priorities. However, using a threshold of middle and high income counties, we included countries that were culturally diverse (eg, countries dichotomised by other labels, such as 'East' and 'West'), which may have contributed to the heterogeneity amongst the results.

## Implications and recommendations

Although a number of studies were found in this review, there was great discrepancy in the objectives of these studies and whether acute health care at the end of life is a favourable outcome or not in this patient group. Studies have explored patients' preferences for end of life care in serious mental illness populations. One study concluded that, just as the general population have a wish to and are able to express their end of life care preferences, so too do patients with serious mental illness (52). In another study, no differences were observed between the end of life care preferences (regarding terminal cancer care and artificial life support) between patients with and without serious mental disorder (53). Research assessing both patient preferences and health care outcomes is needed in this patient population, this would help to address the divide between the two schools of thought regarding acute health care at the end of life and to ensure patients' preferences are being met. Severity of mental disorder should also be considered as it may be associated with both preferences and access to services.

## Conclusion

We found a lack of literature describing end of life care and place of death in patients with serious mental illness and little consensus among the published primary evidence. Given that patients with

serious mental illness have increased mortality risk, both from natural and unnatural causes, the fact that little is known about their care at end of life is particularly concerning. In order to ensure this vulnerable population do not face health care inequality at the end of life, a robust evidence base is needed urgently. We conclude that, although research in this area is gaining momentum, end of life care in people with serious mental illness has not been a research priority and a homogenous research strategy, with standardised definitions and objectives is needed.

# Declarations

## Competing interests

The authors have no conflicts of interest to declare.

## Funding

## Authors' contributions

RW conceived the study. RW and WG designed the search strategy. RW and NH screened studies and extracted the data. RW wrote the manuscript with substantial contributions from NH, IJH and WG. All authors have read and approved the final manuscript.

# References

1.    Reisinger Walker E, McGee RE, Druss BG. Mortality in mental disorders and global disease burden implications: a systematic review and meta-analysis. JAMA Psychiatry. 2015 Apr 1;72(4):334–41.

2.    Hjorthøj C, Stürup AE, McGrath JJ, Nordentoft M. Years of potential life lost and life expectancy in schizophrenia: a systematic review and meta-analysis. The Lancet Psychiatry. 2017;4(4):295–301.

3.    Hoang U, Goldacre MJ, Stewart R. Avoidable mortality in people with schizophrenia or bipolar disorder in England. Acta Psychiatr Scand. 2013 Mar 1;127(3):195–201.

4.    Hayes JF, Marston L, Walters K, King MB, Osborn DPJ. Mortality gap for people with bipolar disorder and schizophrenia: UK-based cohort study 2000-2014. Vol. 211, British Journal of Psychiatry. The Royal College of Psychiatrists; 2017. p. 175–81.

5.    Crump C, Sundquist K, Winkle MA, Sundquist J. Mental disorders and vulnerability to homicidal death: Swedish nationwide cohort study. BMJ. 2013 Mar 4;346(7898):f557.

6.    Hiroeh U, Appleby L, Mortensen PB, Dunn G. Death by homicide, suicide, and other unnatural causes in people with mental illness: A population-based study. Lancet. 2001 Dec;358(9299):2110–2.

7.    Hiroeh U, Kapur N, Webb R, Dunn G, Mortensen PB, Appleby L. Deaths from natural causes in people with mental illness: A cohort study. J Psychosom Res. 2008 Mar 1;64(3):275–83.

8.    Lawrence D, Hancock KJ, Kisely S. The gap in life expectancy from preventable physical illness in psychiatric patients in Western Australia: retrospective analysis of population based registers. BMJ. 2013;346(may21 1):f2539–f2539.

9.    Nordentoft M, Wahlbeck K, Hällgren J, Westman J, Ösby U, Alinaghizadeh H, et al. Excess

Mortality, Causes of Death and Life Expectancy in 270,770 Patients with Recent Onset of Mental Disorders in Denmark, Finland and Sweden. Burne T, editor. PLoS One. 2013 Jan 25;8(1):e55176.

10.     Moore S, Shiers D, Daly B, Mitchell AJ, Gaughran F. Promoting physical health for people with schizophrenia by reducing disparities in medical and dental care. Vol. 132, Acta psychiatrica Scandinavica. 2015. p. 109–21.

11.     Ringen PA, Engh JA, Birkenaes AB, Dieset I, Andreassen OA. Increased mortality in schizophrenia due to cardiovascular disease - a non-systematic review of epidemiology, possible causes and interventions. Front Psychiatry. 2014;5(SEP).

12.     Laursen TM, Mortensen PB, Maccabe JH, Cohen D, Gasse C. Cardiovascular drug use and mortality in patients with schizophrenia or bipolar disorder: A Danish population-based study. Psychol Med. 2014;44(8):1625–37.

13.     Daumit GL, Pronovost PJ, Anthony CB, Guallar E, Steinwachs DM, Ford DE. Adverse Events During Medical and Surgical Hospitalizations for Persons With Schizophrenia. Arch Gen Psychiatry. 2006 Mar 1;63(3):267.

14.     Woods A, Willison K, Kington C, Gavin A. Palliative care for people with severe persistent mental illness: a review of the literature. Can J Psychiatry. 2008 Nov;53(11):725–36.

15.     Baker A. Palliative and End-of-Life Care in the Serious and Persistently Mentally Ill Population. J Am Psychiatr Nurses Assoc. 2005 Oct 1;11(5):298–303.

16.     Lloyd-Williams M, Abba K, Crowther J. Supportive and palliative care for patients with chronic mental illness including dementia. Curr Opin Support Palliat Care. 2014 Sep;8(3):303–7.

17.     Donald EE, Stajduhar KI. A scoping review of palliative care for persons with severe persistent mental illness. Palliative and Supportive Care. Cambridge University Press; 2019. p. 1–9.

18.	University of York. Systematic Reviews: CRD's guidance for undertaking reviews in health care. 2009.

19.	Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med. 2009 Jul 21;6(7).

20.	Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. A Product from the ESRC Methods Programme. 2006.

21.	Kmet LM, Lee RC, Cook LS. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Edmonton, AB, Canada; 2004.

22.	Millard T, Elliott J, Girdler S. Self-Management Education Programs for People Living with HIV/AIDS: A Systematic Review. AIDS Patient Care STDS. 2013 Feb 1;27(2):103–13.

23.	Butler H, O'Brien AJ. Access to specialist palliative care services by people with severe and persistent mental illness: A retrospective cohort study. Int J Ment Health Nurs. 2017;27(2):737–46.

24.	Chang BP, Pany MJ, Obermeyer Z. Early death after emergency department discharge in patients with psychiatric illness. Am J Emerg Med. 2017;35(5):784–6.

25.	Evenblij K, Pasman HRW, van der Heide A, Hoekstra T, Onwuteaka-Philipsen BD. Factors associated with requesting and receiving euthanasia: a nationwide mortality follow-back study with a focus on patients with psychiatric disorders, dementia, or an accumulation of health problems related to old age. BMC Med. 2019;1–12.

26.	Huang HK, Wang YW, Hsieh JG, Hsieh CJ. Disparity of end-of-life care in cancer patients with and without schizophrenia: A nationwide population-based cohort study. Schizophr Res. 2018;195:434–40.

27. Spilsbury K, Rosenwax L, Brameld K, Kelly B, Arendts G. Morbidity burden and community-based palliative care are associated with rates of hospital use by people with schizophrenia in the last year of life: A population-based matched cohort study. PLoS One. 2018;13(11):1–21.

28. Wilson R, Gaughran F, Whitburn T, Higginson IJ, Gao W. Place of death and other factors associated with unnatural mortality in patients with serious mental disorders: population-based retrospective cohort study. BJPsych Open. 2019 Mar 4;5(2):e23.

29. Chochinov HM, Martens PJ, Prior HJ, Kredentser MS. Comparative health care use patterns of people with schizophrenia near the end of life: A population-based study in Manitoba, Canada. Schizophr Res. 2012;141(2–3):241–6.

30. Cohen ME, Dembling B, Schorling JB. The association between schizophrenia and cancer: A population-based mortality study. Schizophr Res. 2002;57(2–3):139–46.

31. Copeland LA, Mortensen EM, Zeber JE, Pugh MJ, Restrepo MI, Dalack GW. Pulmonary disease among inpatient decedents: Impact of schizophrenia. Prog Neuro-Psychopharmacology Biol Psychiatry. 2007;31(3):720–6.

32. Daumit GL, McGinty EE, Pronovost P, Dixon LB, Guallar E, Ford DE, et al. Patient Safety Events and Harms During Medical and Surgical Hospitalizations for Persons With Serious Mental Illness. Psychiatr Serv. 2016;67(10):1068–75.

33. De Leo D, Draper BM, Snowdon J, Kõlves K. Contacts with health professionals before suicide: Missed opportunities for prevention? Compr Psychiatry. 2013;54(7):1117–23.

34. Ganzini L, Socherman R, Duckart J, Shores M. End-of-Life Care for Veterans With Schizophrenia and Cancer. Psychiatr Serv. 2010 Jul;61(7):725–8.

35. Lavin K, Davydow DS, Downey L, Engelberg RA, Dunlap B, Sibley J, et al. Effect of Psychiatric Illness on Acute Care Utilization at End of Life From Serious Medical Illness. J Pain Symptom Manage. 2017;54(2):176–85.

36.     Martens PJ, Chochinov HM, Prior HJ. Where and how people with schizophrenia die: A

        population-based, matched cohort study in Manitoba, Canada. J Clin Psychiatry.

        2013;74(6):551–7.

37.     Shen H-N, Lu C-L, Yang H-H. Increased Risks of Acute Organ Dysfunction and Mortality in

        Intensive Care Unit Patients With Schizophrenia: A Nationwide Population-Based Study.

        Psychosom Med. 2011;73(7):620–6.

38.     Sohn M, Moga DC, Talbert J. Mental disorder comorbidity and in-hospital mortality among

        patients with acute myocardial infarction. Geriatr Ment Heal Care. 2015;3(1):7–11.

39.     Gervaix J, Haour G, Michel M, Chevreul K. Impact of mental illness on care for somatic

        comorbidities in France: a nation-wide hospital-based observational study. Epidemiol

        Psychiatr Sci. 2018;1–13.

40.     Hitosugi M. Retrospective analysis of the forensic autopsy cases of psychiatric patients. Med

        Sci Law. 1999;39(4):293–301.

41.     Nielsen J, Homma A, Biorn-Henriksen T. Follow-up 15 years after a geronto-psychiatric

        prevalence study. Conditions concerning death, cause of death, and life expectancy in

        relation to psychiatric diagnosis. Journals Gerontol. 1977;32(5):554–61.

42.     Risgaard B, Waagstein K, Winkel BG, Jabbari R, Lynge TH, Glinge C, et al. Sudden cardiac death

        in young adults with previous hospital-based psychiatric inpatient and outpatient treatment:

        a nationwide cohort study from Denmark. J Clin Psychiatry. 2015;76(9):e1122–9.

43.     Schaffer A, Sinyor M, Kurdyak P, Vigod S, Sareen J, Reis C, et al. Population-based analysis of

        health care contacts among suicide decedents: Identifying opportunities for more targeted

        suicide prevention strategies. World Psychiatry. 2016;15(2):135–45.

44.     Schoepf D, Heun R. Bipolar disorder and comorbidity: Increased prevalence and increased

        relevance of comorbidity for hospital-based mortality during a 12.5-year observation period

in general hospital admissions. J Affect Disord. 2014;169:170–8.

45.     Ellison N. Mental Health and Palliative Care - Literature Review. Ment Heal Found. 2008;1–23.

46.     Relyea E, MacDonald B, Cattaruzza C, Marshall D. On the Margins of Death: A Scoping Review on Palliative Care and Schizophrenia. Journal of Palliative Care. 2018 Jan 10;62–9.

47.     Morin L, Aubry R, Frova L, MacLeod R, Wilson DM, Loucka M, et al. Estimating the need for palliative care at the population level: A cross-national study in 12 countries. Palliat Med. 2017;31(6):526–36.

48.     Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FE, Evans CJ, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliat Med. 2018 Feb 10;32(2):329–36.

49.     Larsson K, Kåreholt I, Thorslund M. Care utilisation in the last years of life in relation to age and time to death: results from a Swedish urban population of the oldest old. Eur J Ageing. 2008 Dec 31;5(4):349–57.

50.     Lock A, Higginson I. Patterns and predictors of place of cancer death for the oldest old. BMC Palliat Care. 2005 Dec 8;4(1):6.

51.     Jayatilleke N, Hayes RD, Dutta R, Shetty H, Hotopf M, Chang CK, et al. Contributions of specific causes of death to lost life expectancy in severe mental illness. Eur Psychiatry. 2017;43:109–15.

52.     Foti ME, Bartels SJ, Van Citters AD, Merriman MP, Fletcher KE. End-of-life treatment preferences of persons with serious mental illness. Psychiatr Serv. 2005 May;56(5):585–91.

53.     Elie D, Marino A, Torres-Platas S, Noohi S, Semeniuk T, Segal M, et al. End-of-life care preferences in patients with severe and persistent mental illness and chronic medical conditions: a comparative cross-sectional study. Am J Geriatr Psychiatry. 2018;26(1):89–97.

Additional materials

Additional file 1 -  PRISMA checklist

Additional file 2 - Search terms

Additional file 3 - Data extraction form

Additional file 4 - Table 1 - Data extracted from included studies

Table 1 – Data extracted from included studies

| Reference | Country | Date data collection | Study sample[1] | Patient characteristics[2] (N MH patients; MH diagnosis; N (%) deceased) | Design/Setting | Cause of death (natural/ unnatural/ mixed) | Key findings | Notes on comparator | Quality |
|---|---|---|---|---|---|---|---|---|---|
| **Health care utilisation in last year of life** | | | | | | | | | |
| Butler & O'Brien (2017) (23) | New Zealand | 2008-2014 | N=230708 | N=29712; Mixed sample of adults with primary diagnosis of "serious and persistent mental illness"; Mortality not reported | Retrospective study | Unknown | • Rate of SPC receipt in adults with SMI was 0.5%, compared to 1.72% in general population. <br>• Rate ratio for palliative care receipt for people with SMI, compared to general population = 0.29. ie, people with SMI are 3.51 times less likely to receive SPC than general population. | N=230571 adults from general population, without SPMI diagnosis | 0.695 |
| Chang, Pany & Obermeyer (2017) (24) | USA | 2005-2011 | N=920223 emergency department patients | N=92 cases died within 15 days of discharge; Mixed sample including patients with depression, schizophrenia/ | Retrospective case-control study using hospital data | Mixed | • Cases (psychiatric patients that died within 15 days ED discharge) had a median of 2 (IQR 0-5) ED visits in last 12 months of life. This was not significantly higher than the number of ED visits controls had in the 12 months prior to ED discharge (median=1, IQR=0-2) (OR=1.10, p=0.063). <br>• Cases had a median of 7 (IQR 2-15) clinic visits in the last 12 months of life. This was not | N=92 patients with psychiatric illness who did not died within 15 days discharge | 0.640 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | psychosis, mood disorders; All deceased | | | • significantly higher than the number of clinic visits controls had in the 12 months prior to ED discharge (median=6, IQR=3-10.25) (OR=1.01, p=0.405). <br>• Cases had a median of 1 (IQR 0-3.25) inpatient admissions in the last 12 months of life. This was significantly higher than the number of inpatient admissions controls had in the 12 months prior to ED discharge (median=1, IQR=0-2) (OR=1.14, p=0.0355). | | |
| Chochinov et al (2012) (29) | Canada | 1995-2008 | N=15770 decedents | N=3943; Patients with schizophrenia; All deceased | Matched cohort study using routine health data (age 10+) | Not reported | • GP visits **in last 6 months of life** higher in patients **with** schizophrenia after adjusting for geography, age at death, sex, cause of death, year of death (Adjusted Relative Risk=1.15, 95% CI 1.10-1.20) <br>• Physician specialist visits higher in patients without schizophrenia after adjustments(ARR=0.72, 95% CI 0.67-0.77) <br>• Hospitalisations higher in patients without schizophrenia after adjustment (ARR=0.79, 95% CI 0.75-0.83) <br>• Rate of inpatient hospital days higher in patients without schizophrenia after adjustment (ARR=0.80, 95% CI 0.73-0.87) <br>• Home care higher in patients without schizophrenia after adjustment (ARR=0.56, 95% CI 0.52-0.60) | N=11827 decedents without schizophrenia | 0.865 |

| | | | | | | | <ul><li>Length of home care in days higher in patients without schizophrenia after adjustment (ARR=0.74, 95% CI 0.57-0.96)</li><li>Nursing home residence higher in patients with schizophrenia after adjustment (ARR=2.13, 95% CI 2.01-2.25)</li><li>Patients with schizophrenia more likely to see GPs and psychiatrists (p<0.01); all other specialisms seen more by patients without schizophrenia (p<0.01)</li><li>After adjusting for age at death, sex, region of residence, SEP, cause of death, place of death, and date of death, patients with schizophrenia were less likely to receive palliative care **in last two years of life** than matched cohort (OR=0.48, 95% CI 0.41-0.56)</li></ul> | | |
|---|---|---|---|---|---|---|---|---|---|
| Cohen, Dembling & Schorling (2002) (30) | USA | 1986 | N=18733 decedents | N=130; Schizophrenia; All deceased | Data derived from National Mortality Followback Survey (deaths over 25 years) | Not reported | <ul><li>93% patients with schizophrenia hospitalised, compared to 65% of patients without schizophrenia (p<.001).</li><li>However, 51% were hospitalised to general medical facility, compared with 50% patients without schizophrenia.</li></ul> | N=18603 patients without schizophrenia | 0.865 |
| Copeland et al (2007) (31) | USA | 2001-2002 | N=27798 | N=943; Schizophrenia; All deceased | Inpatient decedents in Veterans hospitals derived from | Not reported | <ul><li>54.5% Patients without a schizophrenia diagnosis had a primary care clinic visit in last year of life, compared to 30.7% patients with a schizophrenia diagnosis (p<0.05)</li></ul> | N=26855 patients without schizophrenia | 0.945 |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | national veterans databases | | • 39.8% patients without a schizophrenia diagnosis had a speciality care clinic visit in last year of life, compared to 18.7% patients with a schizophrenia diagnosis (p<0.05)<br>• 28.8% patients with a schizophrenia diagnosis had minimal inpatient care (≤4 days) in last year of life, compared to 13.9% patients without a schizophrenia diagnosis (p<0.05) | | | |
| Daumit et al (2016) (32) | USA | 1994-2004 | N=253 patients who had hospital admissions | N=253; Serious mental illness defined as: schizophrenia, being disabled with diagnosis of bipolar disorder or major depression, or being disabled with another mental disorder and use of specialty mental health care; All deceased | Case-crossover study including patients discharged from acute care hospitals identified from cohort of Medicaid beneficiaries | Not reported | • Hospitalisations within 30 days of death were associated with being admitted through ED; 81% of admissions in last 30 days were admitted through ED, compared to 78% of admissions ≥30 days prior to death (p=0.05)<br>• Length of stay was shorter in the last 30 days (7.4) compared to prior to last 30 days (but within 5 years of death) (13.1) (p<0.001)<br>• Admissions in the last 30 days of life had higher associated Charlson Comorbidity Index than admissions prior to last 30 days of life (4.3 compared to 3.1, p<0.001)<br>• Patient safety events were more prevalent in hospitalisations that occurred within 30 days of death than in those not within 30 days of death. Any safety events were more common in last 30 days (OR=3.7, 95% CI 1.4-10.3), and after removing medication events – the most | Each participants' admissions in the last 30 days of life (cases) were compared with their own admissions prior to last 30 days of life (controls) | 0.915 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | • common type of events – the association was stronger (OR=5.9, 95% CI 3.2-10.7).<br>• Unanticipated transfer to intensive care unit more frequent in the last 30 days of life (OR=4.4, 95% CI 2.2-8.8)<br>• No significant difference in unanticipated surgery or invasive procedure | | |
| De Leo et al (2013) (33) | Australia | 2006-2008 | N=443 decedents | N=194; Patients with a "diagnosable psychiatric disorder", including mood, psychotic, substance use and anxiety disorders; All deceased | Case-control study of suicide deaths aged over 35; data collected from NOK and HCPs. | Unnatural | • In males, 77.5% of patients with any psychiatric diagnosis visited their GP ≤3 months prior to suicide, compared to 76.1% of males without a psychiatric diagnosis (OR=1.09, 95% CI 0.49-2.38).<br>• In females, 75.6% of patients with any psychiatric diagnosis visited their GP ≤3 months prior to suicide, compared to 75.0% of females without a psychiatric diagnosis (OR=1.03, 95% CI 0.28-3.86). | 25.1% of suicide deaths without psychiatric disorder | 0.665 |
| Evenblij et al (2019) (25) | Netherlands | 2015 | N=5361 decedents | N=183; Patients with "psychiatric disorder"; All deceased | Decedents with non-sudden deaths identified from national mortality data | "Non-sudden" | **NB - % weighted stratification (by diagnosis) and patient sex, age, ethnicity and place and cause of death, such that they were representation of all deaths (nationally) during the study period**<br>• 8.5% patients with psychiatric disorder received palliative care in last month of life, compared to 4.6% of patients with dementia, | • N=803 decedents with dementia<br>• N=918 patients with health problems related to ageing | 0.889 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | 7.5% patients with accumulation of health problems, 14.9% all deceased patients<br>• 1.5% patients with psychiatric disorder received care from pain specialist in last month of life, compared to 0.3% of patients with dementia, 1.1% patients with accumulation of health problems, 2.5% all deceased patients<br>• 34.7% patients with psychiatric disorder received care from psychiatrist/psychologist in last month of life, compared to 13.7% of patients with dementia, 5.7% patients with accumulation of health problems, 6.2% all deceased patients | • N=5361 all patients died a non-sudden death (included patients with psychiatric disorder, dementia and health problems) | |
| Ganzini et al (2010) (34) | USA | 2003-2008 | N=256 decedents | N=60;<br>Schizophrenia/ schizoaffective disorder;<br>All deceased | Cancer decedents identified from US veterans database | Natural | **NB – no timeframe specified**<br>• N=33 (55%) patients with schizophrenia were hospice enrolled, compared to N=102 (52%) patients without schizophrenia ($x^2$ = 0.161, p=0.69)<br>• Patients with schizophrenia had a mean hospice length of stay 107 days (SD 144) compared to 63 days (SD 96) for patients without schizophrenia (t= -1.97, p=0.05)<br>• N=35 (58%) patients with schizophrenia had advanced directive, compared to N=110 (56%) patients without schizophrenia ($x^2$ = 0.091, p=0.76) | N=196 cancer decedents without schizophrenia | 0.860 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | • N=22 (37%) patients with schizophrenia had CPR order, compared to N=80 (41%) patients without schizophrenia ($x^2$ = 0.33, p=0.51)<br>• N=9 (15%) patients with schizophrenia had Physician Orders for Life Sustaining Treatment, compared to N=9 (5%) patients without schizophrenia ($x^2$ = 7.61, p<0.01) | | |
| Huang et al (2018) (26) | Taiwan | 1999-2012 | N=8555 decedents | N=1911; Schizophrenia; All deceased | Decedents diagnosed with colorectal, liver, lung, breast, oral or prostate cancer identified from database of National Health Insurance claims | Not reported | • Patients with schizophrenia had a mean length of stay in an acute ward of 18.3 days (SD 10.10) in the last month of life, compared to 17.9 days (SD 9.8) for patients without schizophrenia (p=0.193)<br>• 26.7% patients with schizophrenia utilised ICU in last month of life, compared to 22.9% patients without schizophrenia (OR=1.21, 95% CI 1.07-1.36). The difference was significant for colorectal (OR=1.42, 95% CI 1.08-1.85) and liver cancer (OR=1.49, 95% CI 1.19-1.87) subgroups.<br>• 17.4% patients with schizophrenia used palliative care in last month of life compared to 18.9% patients without schizophrenia (OR=1.03, 95% CI 0.90-1.19). There were no significant differences for any of the cancer-specific subgroups.<br>• 15.7% patients with schizophrenia had hospice ward care in last month of life | N=7644 cancer decedents without schizophrenia | 0.85 |

| | | | | | | | compared to 15.6% patients without schizophrenia (OR=1.15, 95% CI 0.99-1.33). No significant difference for any of the cancer subgroups. <br><br> • 2.7% patients with schizophrenia had palliative care consultation in last month of life compared to 4.5% patients without schizophrenia (OR=0.59, 95% CI 0.43-0.82). The difference was significant for breast (OR=0.27, 95% CI 0.10-0.75) and oral cancer (OR=0.32, 95% CI 0.10-0.98) subgroups. <br><br> • 5.6% patients with schizophrenia had hospice home care in last month of life compared to 5.4% patients without schizophrenia (OR=1.11, 95% CI 0.89-1.39). No significant diff for any of the cancer subgroups <br><br> • 17.7% patients with schizophrenia had chemotherapy in last month of life compared to 28.1% patients without schizophrenia (OR=0.55, 95% CI 0.48-0.63). No significant difference for any of the cancer subgroups. <br><br> Invasive interventions <br><br> • Patients with schizophrenia more likely to have CPR (OR=1.34, 95% CI 1.15-1.57), endotracheal intubation (OR=1.22, 95% CI 1.08-1.38), mechanical ventilation (OR=1.15, 95% CI 1.03-1.29), urinary catheterisation | | |
|---|---|---|---|---|---|---|---|---|---|

| | | | | | | | (OR=1.19, 95% CI 1.07-1.32) and feeding tube (OR=1.41, 95% CI 1.26-1.58) in last month of life.<br><br>Advanced diagnostic examination<br>• Patients with schizophrenia less likely to have CT/MRI/ sonography (OR=0.80, 95% CI 0.71-0.89), bone scan (OR=0.62, 95% CI 0.50-0.76) and PET scan (OR=0.37, 95% CI 0.15-0.96) in last month of life. No difference found for panendoscopy. | | |
| Lavin et al (2017) (35) | USA | 2010-2014 | N=16214 decedents | N=1715; Mixed MH sample; patients had diagnosis of mood, anxiety and/or psychotic disorder or prescription medicines for psychiatric illness; All deceased | Cases selected from state database of past inpatients | Natural | In analyses adjusted for patient and health care factors:<br>• Compared to patients without psychiatric illness, patients with evidence of psychiatric illness were less likely to have any hospitalisation in the last 30 days of life (OR=0.59, 95% CI 0.51-0.68)<br>• Compared to patients without psychiatric illness, patients with evidence of psychiatric illness were less likely to have any ICU care (OR=0.41, 95% CI 0.35-0.48) and spent fewer days in ICU (RR=0.88, 95% CI 0.79-0.97) in the last 30 days of life<br>• Compared to patients without psychiatric illness, patients with evidence of psychiatric illness were more likely to have an ED visit (OR=1.64, 95% CI 1.30-2.08) and to have had | N=14499 patients without evidence of psychiatric illness | 0.945 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | more ED visits (RR=1.38, 95% CI 1.02-1.88) in the last 30 days of life | | |
| Martens, Chochinov & Prior (2013) (36) | Canada | 1995-2008 | N=15770 decedents | N=3943; Schizophrenia; All deceased | Cases and matched controls identified from routine health care system data repository | Mixed | **Health care utilisation stratified by place of death** <br> **NB – adjusted for patient factors** <br> For hospital deaths <br> • GP visits were higher in patients with schizophrenia (RR=1.12, 95% CI 1.07-1.18). Physician specialist visits (RR=0.69, 95% CI 0.64-0.75), inpatient hospital separation rate (RR=0.81, 95% CI 0.77-0.85) and inpatient hospital days (RR=0.90, 95% CI 0.80-1.00) were higher in patients without schizophrenia. <br> Home deaths <br> • GP visits were higher in patients with schizophrenia (RR=1.26, 95% CI 1.14-1.40). Inpatient hospital separation rate was higher in patients without schizophrenia (RR=0.82, 95% CI 0.68-0.99). <br> Deaths in nursing homes <br> • Inpatient hospital days were higher in patients without schizophrenia (RR=0.80, 95% CI 0.67-0.95). <br> Deaths in other locations <br> • GP visits were higher in patients with schizophrenia (RR=1.33, 95% CI 1.18-1.50) | N=11827 decedents without schizophrenia | 0.945 |

| Spilsbury et al (2018) (27) | Australia | 2009-2013 | N=63508 decedents | N=1194; Schizophrenia; All deceased | Decedents and matched cohort identified from national database | Mixed | Emergency department attendance<br>• 73.1% female decedents with schizophrenia presented at ED in last year of life, compared with 76.1% female decedents without schizophrenia (p=0.11). Also no significant difference in urgency between those with/without schizophrenia.<br>• 72.7% male decedents with schizophrenia presented at ED in last year of life, compared to 72.5% male decedents without schizophrenia (p=0.93). Males without schizophrenia more likely to be urgent/emergency, less likely to be semi-urgent/non-urgent (p<0.001).<br>Hospital admissions<br>• 72.6% female decedents with schizophrenia admitted compared to 81.1% female decedents without schizophrenia (p<0.001). 71.9% male decedents with schizophrenia admitted compared to 70.2% male decedents without schizophrenia (p=0.410).<br>• Female decedents with schizophrenia had longer stays (mean 7.7 days (SE 0.4)) compared with 5.1 days (SE 0.1) (p<0.001). Male decedents with schizophrenia had longer stays (mean 8.1 days (SE 0.5)) compared with 4.5 days (SE 0.1) (p<0.001) | N=39265 matched decedents without schizophrenia | 0.75 |

| | | | | | | | • Female decedents with schizophrenia less acute care (94.5% vs 96.4%), palliation (1.8% vs 2.9%), more likely to have psychogeriatric care (2.2% vs 0.2%) (p<0.001). Male decedents with schizophrenia less acute care (96.8% vs 97.2%), palliation (1.9% vs 2.3%), more likely to have psychogeriatric care (0.7% vs 0.2%) (p<0.001)<br>• Female decedents with schizophrenia more likely to have emergency admission (54.4% vs 31.8%, p<0.001). Male decedents with schizophrenia more likely to have emergency admission (56.5% vs 30.6%, p<0.001).<br>• 1.9% Female decedents with schizophrenia stayed in ICU compared to 1.5% pts without schizophrenia (p=0.193). Female decedents with schizophrenia more likely to have ventilator support (1.4% vs 0.8%) (p=0.018). 3.0% male decedents with schizophrenia stayed in ICU compared to 2.0% male decedents without schizophrenia (p=0.002). Male decedents with schizophrenia more likely to have ventilator support (1.9% vs 1.5%) (p=0.074).<br>Specialist palliative care<br>• Decedents with schizophrenia less likely to be registered with specialist palliative care (6.5% | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | vs 15.8%, p<0.001), less likely to receive longer hours of care (mean 13.2 hrs/decedent vs 23.3 hrs/decedent, p<0.001), less likely to receive specialist palliative care if they had cause of death amenable to specialist palliative care (11.9% vs 24.7%, p<0.001) and were less likely to receive specialist palliative care if they had cancer (27.5% vs 40.4%, p<0.001).<br><br>Non-palliative care<br>• Patients with schizophrenia more likely to use centre based day care (11.1% vs 8.3%, p<0.001), client care coordination (11.1% vs 8.3%, p=0.003), counselling (13.6% vs 11.1%, p=0.009), personal care (13.3% vs 11.3%, p=0.034) and social support (16.8% vs 10.9%, p<0.001). No significant difference for allied health care, assessment, domestic assistance, home maintenance, nursing care or respite care | | |
| Wilson et al (2019) (28) | England | 2007-2013 | N=1029 decedents | N=1029; Mixed sample including; Schizophrenia, schizoaffective disorder, bipolar affective | Data drawn from linked clinical records, hospital data and mortality data | Mixed | *Natural cause of death*<br>• 47.3% had no admissions or A&E visits in last month of life, 37.6% both visited A&E and were admitted, 8% visited A&E and were not admitted, 7.1% did not visit A&E and were admitted<br>*Unnatural cause of death* | N/A | 0.9 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | disorder, substance use disorders, depressive episode or recurrent depressive disorder; All deceased | | | • 70.5% had no admissions or A&E visits in last month of life, 15.8% both visited A&E and were admitted, 10.8% visited A&E and were not admitted, 2.9% did not visit A&E and were admitted | | |

**Place of death**

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Daumit et al (2006) (13) | USA | 2001-2002 | N=733904 patients who had hospital admissions | N=1746; Schizophrenia; 5.2% deceased | Patients had medical/ surgical hospitalisations for primary diagnoses other than schizophrenia | Not reported | • Hospital deaths were more common in patients with schizophrenia (5.2%) than patients without schizophrenia (3.0%), following medical or surgical admission. | N=732158 hospitalised patients without schizophrenia (3.0% deceased) | 0.945 |
| Ganzini et al (2010) (34) | USA | 2003-2008 | N=256 decedents | N=60; Schizophrenia/ schizoaffective disorder; All deceased | Cancer decedents identified from US veterans database | Natural | • 33% of patients with schizophrenia died at home, compared to 36% of patients without schizophrenia;<br>• 27% of patients with schizophrenia died in hospital, compared to 26% of patients without schizophrenia;<br>• 17% of patients with schizophrenia died in a skilled nursing unit, compared to 13% of patients without schizophrenia; | N=196 cancer decedents without schizophrenia | 0.86 |

43

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | • 18% of patients with schizophrenia died in an assisted living facility, compared to 7% of patients without schizophrenia; <br> • 5% of patients with schizophrenia died in an unknown location, compared to 18% of patients without schizophrenia | | |
| Gervaix et al (2018) (39) | France | 2009-2013 | N=17620770 patients who had hospital admissions | N=1159672; Mixed MH sample; patients who had been admitted to hospital at least once for MH illness; 7.2% deceased | Patients hospitalised for somatic reasons identified in hospital discharge database | Not reported | • 7.57% all patients with mental illness had in-hospital deaths, compared with 7.44% all patients without a mental illness (Ratio=1.02) <br> • 23.08% cancer patients with a mental illness had in-hospital deaths, compared with 25.75% cancer patients without a mental illness (Ratio=0.90) <br> • 12.45% diabetes patients with a mental illness had in-hospital deaths, compared with 13.11% diabetes patients without a mental illness (Ratio=0.95) <br> • 13.00% cardiovascular patients with a mental illness had in-hospital deaths, compared with 13.13% cardiovascular patients without a mental illness in-hospital deaths (Ratio=0.99) <br> • In a multivariable model, adjusted for sex, age, cardiovascular disease, diabetes, cancer, no of hospitalisations, severity of hospitalisations and deprivation, mental illness was associated with lower likelihood of in-hospital death (OR=0.87, 95% CI 0.86-0.87) | • N=1225396 patients without mental illness died in hospital <br> • N=561543 patients with cancer and without mental illness died in hospital <br> • N=247894 patients with diabetes and without mental illness died in hospital | 0.8 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | • N=940376 patients with cardiovascular disease and without mental illness died in hospital | |
| Hitosugi (1999) (40) | Japan | 1990-1997 | N=1107 decedents | N=141; Mixed MH sample including schizophrenia (27%), mood disorders (23%), amongst others; All deceased | Cases selected from forensic autopsy cases of sudden or unnatural deaths | Mixed 28% natural; 67% unnatural; 5% unknown | • 62% patients died at home, 14% in hospital, 4% in other healthcare facilities and 20% in 'other locations' <br>• Psychiatric diagnosis was not significantly associated with place of death (p>.05) <br>• N=25 patients died in hospital/other healthcare facilities; N=12 (48%) of these patients died from natural deaths, N=13 (52%) from unnatural causes | N/A | 0.825 |
| Lavin et al (2017) (35) | USA | 2010-2014 | N=16214 decedents | N=1715; Mixed MH sample; patients had diagnosis of mood, anxiety and/or psychotic disorder or prescription | Cases selected from state database of past inpatients | Natural | • Compared to patients without MH diagnosis, MH patients more likely to die in nursing home (15 % compared to 11%, OR=1.27, 95% CI 1.09-1.49) and less likely to die in hospital (37% compared to 40%, OR=0.67, 95% CI 0.60-0.75). No significant differences between MH and non-MH patients in deaths at home, in hospice, or other locations. | N=14499 patients without evidence of psychiatric illness | 0.945 |

| | | | | medicines for psychiatric illness; All deceased | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Martens, Chochinov & Prior (2013) (36) | Canada | 1995-2008 | N=15770 decedents | N=3943; Schizophrenia; All deceased | Cases identified from routine health care system data repository | Mixed | • Compared to decedents without schizophrenia, decedents with schizophrenia were more likely to die in a nursing home (30% compared to 14%) and less likely to die in hospital (56% compared to 71%) (p<.01). Deaths in homes and other locations were comparable.<br>• Decedents with schizophrenia who died from circulatory disease were more likely to die in a nursing home (34% compared to 17%) and less likely to die in hospital (54% compared to 69%) (p<.01). Deaths in homes and other locations were comparable.<br>• Decedents with schizophrenia who died from cancer were more likely to die in a nursing home (20% compared to 5%) and less likely to die in hospital (76% compared to 86%) or at home (2% compared to 6%) (p<.01). Deaths in other locations were comparable.<br>• Most deaths from suicide occurred in hospital or in the home, there was no significant difference between patients with or without schizophrenia (p=.16). | N=11827 decedents without schizophrenia | 0.945 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | • Decedents with schizophrenia who died from respiratory disease were more likely to die in a nursing home (33% compared to 20%) and less likely to die in hospital (61% compared to 74%) ($p<.01$). Deaths at home or in other locations were comparable.<br>• For all other causes of death, decedents with schizophrenia were more likely to die in a nursing home (32% compared to 19%) and less likely to die in hospital (50% compared to 59%) or in other places (11% compared to 15%) ($p<.01$). | | |
| Nielsen, Homma & Biorn-Henriksen (1977) (41) | Denmark | 1961-1976 | N=738 decedents | Mixed MH sample: functional psychoses (N=29), neurosis & other character disorders (N=43) and other mental disorders (N=42); All deceased | Deceased cases aged 65+ identified from a local database | Mixed | • 40% of patients with "neuroses and character disorders" died at home, compared with 27% of all decedents<br>• 17% of patients with "functional psychoses" died in an "old people's home", compared with 2% of all decedents, 13% of patients with dementia, 20% of patients with cerebrovascular disorders, 5% of patients with no mental illness | • N=738 decedents (this includes MH patients)<br>• N=170 patients with dementia, N=25 patients with cerebrovascular disease, N=429 patients with no mental illness | 0.455 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Risgaard et al (2015) (42) | Denmark | 2000-2006 | N=395 sudden cardiac decedents | N=77; Mixed sample including schizophrenia and related disorders (40%) amongst others; All deceased | National registry data used to identify sudden cardiac deaths in young adults (18-35) | Natural | • Psychiatric patients significantly more likely to die in an "institution" (8% compared to 3% non-psychiatric patients, p=0.02) and less likely to die in a "public place" (3% compared to 19%, p<0.01). <br> • Compared to non-psychiatric patients, more psychiatric patients died at home (74% compared to 62%), more died during hospitalisation (11% compared to 7%) and less died in the emergency department (4% compared to 6%) – these differences were not significant | N=318 non-psychiatric sudden cardiac deaths | 0.915 |
| Schaffer et al (2016) (43) | Canada | 1998-2011 | N=2835 suicide decedents | N=1883; Mixed sample described as: Patients with a 'mental health contact' in the 12 months prior to death, including: a mental health related primary care outpatient physician contact, an outpatient | Cases of suicide extracted from national registry data | Unnatural | • 62% of psychiatric patients died (from suicide) at home, compared to 69% of patients who had contact with a non-MH professional and 65% of patients who had no health contacts <br> • 3% of psychiatric patients died (from suicide) at 'other residences', compared to 2% of patients who had contact with a non-MH professional and 5% of patients who had no health contacts <br> • 12% of psychiatric patients died (from suicide) outdoors, compared to 11% of patients who had contact with a non-MH professional and 16% of patients who had no health contacts <br> • 8% of psychiatric patients died (from suicide) at a subway/railway, compared to 4% of | Compared with suicide completers who: <br> • Had only non-mental health care contact in last year of life (N=716) <br> • Had no health care contacts in last year of life (N=236) | 0.945 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | psychiatric contact, a mental health related emergency department visit, a mental health related hospitalisation; All deceased | | | • patients who had contact with a non-MH professional and 4% of patients who had no health contacts<br>• 16% of psychiatric patients died (from suicide) at 'other' locations, compared to 15% of patients who had contact with a non-MH professional and 9% of patients who had no health contacts | | |
| Schoepf & Heun (2014) (44) | UK | 2000-2012 | N=6831 patients who had hospital admissions | N=621; Bipolar disorder; N=60 (9.7%) deceased | Admissions for ≥24 hours extracted from hospital records for three local hospitals | Mixed | • 9.7% patients with bipolar disorder who had had at least one general hospital admission died in hospital, compared to 8.4% patients without bipolar disorder<br>• Patients with bipolar disorder who died in hospital had higher prevalence of hypertension, COPD, pneumonia, bronchitis, ischemic stroke than patients without bipolar disorder who died in hospital | Compared to N=520 matched controls without bipolar disorder | 0.94 |
| Shen, Lu & Yang (2011) (37) | Taiwan | 2005-2007 | N=2239 intensive care patients | N=203; Schizophrenia; 24.1% deceased | Study cohort of intensive care patients drawn from subset of the National Health Insurance Research | Not reported | • Patients with schizophrenia were more likely to die in ICU than patients without schizophrenia (24.1% compared to 14.1% of patients without schizophrenia, OR=1.56, 95% CI 1.08-2.24) | Compared to N=2036 matched controls, intensive care patients without schizophrenia diagnosis | 0.94 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | Database, the Longitudinal Health Insurance Database of 2005 | | | | |
| Sohn et al (2015) (38) | USA | 2010 | N=42416 patients with acute myocardial infarction | N=16140; Mixed sample including: Schizophrenia Major affective disorders Substance abuse disorders Other mental disorders (excluding organic disorders, eg dementia) N=715 (4%) deceased | Data drawn from Health Cost and Utilisation Project | Natural | • 4% patients with mental disorder died in hospital, compared to 6% patients without mental disorder<br>• In bivariate analysis, having any mental disorder was associated with lower odds of in-hospital mortality (unadjusted OR=0.71, 95% CI 0.65-0.78), but was attenuated by gender, race, primary payer source, income, admission type and comorbidity index (adjusted OR=0.92, 95% CI 0.84-1.01)<br>• Schizophrenia is a significant risk factor of in-hospital mortality in acute myocardial infarction patients (after adjusting for covariates) (AOR=1.72, 95% CI 1.02-2.90), whereas substance abuse disorder has a protective effect (AOR=0.80, 95% CI 0.70-0.91). Major affective disorders and other mental disorders not associated with in-hospital mortality. | N=26276 (N=715, 4% deceased) patients without mental disorder diagnosis | 0.865 |
| Wilson et al (2019) (28) | England | 2007-2013 | N=1029 decedents | N=1029; | Data drawn from linked | Mixed | *Natural cause of death* | N/A | 0.9 |

| | | | | Mixed sample including; Schizophrenia, schizoaffective disorder, bipolar affective disorder, substance use disorders, depressive episode or recurrent depressive disorder; All deceased | clinical records, hospital data and mortality data | | • Hospital most common place of death (52.7%), followed by home (31.2%), care home (10.4%), hospice (3.4%) and 'other' (2.2%)<br>*Unnatural cause of death*<br>• Home most common place of death (39.6%), followed by 'other' (36.0%), hospital (23.7%), care home (0.7%) and hospice (0%) | | |

[1] Information on the entire sample reported in the study
[2] Information on the relevant patients included the review

Abbreviations

MH = mental health
SPMI = serious persistent mental illness
COPD = chronic obstructive pulmonary disorder
ICU = intensive care unit
SPC = specialist palliative care
ED = emergency department
A&E = accident & emergency
SEP = socioeconomic position
NOK = next of kin

HCP = health care professional

Table 2 - Summary of results found for each outcome (health care use in the last year of life and place of death)

| Health care use in the last year of life (23,24,33–36,25–32) | Hospital (including ICU) (24,26–32,35,36) | • Rates of hospital admission in the last year of life ranged from 18.7% to 72.6%<br>• Two studies (24,30) reported that people with SMI were more likely to be admitted in the last year of life whilst six studies (27,29,31,32,35,36) reported lower hospital care, although there was great heterogeneity amongst these studies<br>• Mixed evidence was found describing ICU care and other interventions at end of life |
|---|---|---|
| | Emergency department (24,27,28,35) | • ED attendance varied according to cause of death and urgency of visit<br>• One study (35) reported more ED attendance in people with SMI and two studies (24,27) reported no difference |
| | Palliative care (23,25–27,29,34) | • Four studies (23,25,27,29) reported that people with SMI were less likely to receive palliative care; mixed findings were reported by two studies (26,34) |
| | GP visits (29,33,36) | • Two studies (29,36) reported that people with SMI were more likely to visit their GP; one study (33) reported no association |

| Place of death (13,28,42–44,34–41) | Hospital (13,28,44,34–40,42) | • Between 4% and 61% deaths occurred in hospital<br>• Four studies (13,37,38,44) reported an increased likelihood of dying in hospital for people with SMI and three studies (35,36,39) reported a lower likelihood of dying in hospital; two (34,42) reported no association<br>• These associations varied by SMI diagnosis and by cause of death |
|---|---|---|
| | Home (28,34–36,40–43) | • Very mixed evidence describing likelihood of dying at home, depending on population and cause of death<br>• Wide variety in rates home deaths, ranging from 2.2% to 74% |
| | Care home (28,34–36,40–42) | • Between 4.3% and 29.7% deaths occurred in a care home<br>• Studies consistently reported increased likelihood of dying in a care home (34–36,41,42) |
| | Other (28,34–36,40,42,43) | • Between 1.7% and 20% deaths occurred in other locations<br>• Great variability largely depending on cause of death |

Figure 1



```
┌─────────────────────────────────────┐      ┌─────────────────────────────────────┐
│ Records identified through database  │      │ Records identified through other     │
│ searching (N=5356)                   │      │ sources (N=30)                       │
└─────────────────────────────────────┘      └─────────────────────────────────────┘

              ┌──────────────────────────────────────────────┐
              │ Records screened after duplicates            │
              │ removed (N=3625)                             │
              └──────────────────────────────────────────────┘

                                            ┌──────────────────────────────────┐
                                            │ Records excluded (N=3445)        │
                                            └──────────────────────────────────┘

              ┌──────────────────────────────────────────────┐
              │ Full text articles assessed for              │
              │ eligibility (N=180)                          │
              └──────────────────────────────────────────────┘

                               ┌─────────────────────────────────────────────────┐
                               │ Full text articles excluded (N=157)             │
                               │                                                 │
                               │   -   No relevant outcome (N=118)               │
                               │   -   Conference abstract only (N=22)           │
                               │   -   Full text not available in English (N=9)  │
                               │   -   Ineligible population (N=5)               │
                               │   -   Not primary research (N=2)                │
                               │   -   Duplicate (N=1)                           │
                               └─────────────────────────────────────────────────┘

              ┌──────────────────────────────────────────────┐
              │ Included in data synthesis (N=23)            │
              └──────────────────────────────────────────────┘
```