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Maun, E., Gardiner, C., McConnell, T. et al. (2026) Loneliness among adults at the end of life: a systematic review of prevalence and correlates. Palliative Medicine. ISSN: 0269-2163

https://doi.org/10.1177/02692163261428936

PALLIATIVE MEDICINE

Review article

Palliative Medicine
1–16

DOI: 10.1177/02692163261428936
journals.sagepub.com/home/pmj
Mary Ann Liebert
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Loneliness among adults at the end of life: A systematic review of prevalence and correlates

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Abstract

Background: Loneliness has been linked to poorer quality of life and worse symptoms in the final weeks prior to death. However, research on prevalence at end of life has yet to be systematically reviewed.

Aim: To synthesise evidence of prevalence and correlates of loneliness among adults at the end of life.

Design: Systematic review without meta-analysis, due to high study heterogeneity, registered on PROSPERO (CRD42024581962).

Data sources: OVID Medline, PsycInfo, Web of Science, PubMed, Social Policy and Practice and Health Management Information Consortium databases were searched up to April 2025. Studies estimating prevalence of loneliness were eligible where the sample (or identifiable sub-sample) were adults with a terminal illness, receiving palliative care or retrospectively identified with a loneliness measure less than 12 months prior to death.

Results: Fifteen eligible studies were included. Most studies were North American or European, with samples based on clinical diagnosis or palliative care receipt. Prevalence estimates of moderate or worse loneliness ranged from 20% to 73% and high loneliness from 8% to 33% in studies sampling based on clinical diagnosis or care receipt, and 7%–12% and 18.6% respectively, in studies sampling retrospectively based on time to death. However, findings are presented with caution due to significant heterogeneity across studies.

Conclusions: Evidence suggests loneliness may be a difficulty faced by a significant minority of people at the end of life, requiring support for individuals, within services and communities. Research is needed in a wider range of countries, and to develop and assess effective interventions.

Keywords

systematic review, loneliness, terminally ill, palliative care, prevalence

What is already known about the topic?

- Loneliness has been linked to poorer quality of life and worse symptoms at end of life.
- Terminally ill people may experience loneliness related to deteriorating mobility and changes in the quality of important relationships.
- Evidence of loneliness prevalence at end of life is needed to inform commissioning of initiatives to address loneliness as a potentially modifiable factor.

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What this paper adds

- Fifteen studies estimated loneliness prevalence among those at end of life, across a range of conditions, care settings and countries.
- Prevalence ranged from 20% to 73% (moderate or worse loneliness) and from 8% to 33% (high loneliness) for studies based on diagnosis or receipt of care.
- Results are presented cautiously as studies were heterogeneous in their size, design, sample and setting characteristics.

Implications for practice, theory or policy

- More consistent analysis of correlates, and more research across different countries and conditions, would be beneficial.
- Loneliness should be considered as a potential difficulty contributing to worse quality of end of life.
- Initiatives to prevent and reduce loneliness at end of life in individuals, within services and communities should be commissioned and evaluated.

Introduction

Loneliness can be defined as the subjective negative feelings that stem from perceived disparities between expected and actual social relationships.[1] Though the mechanisms translating the experience of loneliness to health and wellbeing are the subject of research,[2] loneliness has been linked to reduced quality of life,[3] increasing depressive symptoms,[4] frailty,[5] disturbed sleep,[6] and increased risk of heart failure[7] and other causes of mortality.[8] Community-based healthcare professionals supporting people at the end of life cite loneliness as a common concern in their caseloads,[9,10] with implications for their experiences at end of life. For instance, associations have been found between loneliness and use of life support in the last 2 years of life,[11] pain, anxiety and trouble breathing in the last month of life,[12] and greater likelihood of admission to, and dying in, a care home compared to a private home.[11,13]

End of life is difficult to define and can include individuals with advanced progressive terminal conditions, people who are frail with coexisting conditions and adults who experience a sudden crisis in a pre-existing condition.[14–16] Loneliness is common among people with conditions that are major causes of death, such as cancer,[17] dementia[18] and chronic obstructive pulmonary disease.[19] Circumstances that frequently occur near the end of life are also general risk factors for loneliness, including presence of multiple conditions,[20,21] deteriorating health and reducing social networks[13]. Experiencing advanced frailty or terminal illness can change social relationships, increase feelings of disconnect with others, and difficulties expressing concerns.[22] For instance, reducing mobility and functional limitations can limit social interactions, or change their quality due to the need to depend on others, introducing the potential for loneliness even in the presence of others.[23] Although loneliness differs from social isolation or living alone, they are related objective measures and are potential risk factors for loneliness.[24,25] For instance, having no informal caregiver in the last 6 months of life has been linked to becoming lonely.[26]

Loneliness prevalence and risk factors have been recently reviewed among the general and older population[21,27–31] and different patient groups,[32] however, only two reviews have addressed these aspects specifically related to end of life. A recent scoping review identified a handful of studies estimating prevalence of loneliness, ranging from 10% to 50%, with limited generalisability due to small samples or limited age range, concluding that there was "*no reliable population-based data about the prevalence of loneliness at EOL*" [33](p. 6191). As appropriate for a scoping review, minimal quality assessment of included studies was carried out and new studies have since been published. With regard to correlates of loneliness, limited evidence has been synthesised of at-risk population groups,[33] but there has been greater focus on beliefs, emotional and social support.[33,34] A recently developed framework for the causes of loneliness in advanced illness encompasses psychological and existential micro level factors, physical function, mobility and social meso level factors and environmental and societal macro level factors.[34] This provides a structure for understanding potential causes of loneliness among those with advanced terminal illness. However, a gap exists to undertake a systematic review of prevalence data and understand population-based correlates of loneliness among those at end of life, assessing measurement and study quality. This review therefore aimed to 1. synthesise evidence of loneliness prevalence and 2. identify the correlates of loneliness among adults at the end of life.

Methods

Study design

This systematic review followed a published protocol (https://www.crd.york.ac.uk/PROSPERO/view/CRD42024581962), the Preferred Reporting Items for

Systematic Reviews and Meta-Analyse, PRISMA, 2020 reporting guidance[35] and as a meta-analysis was not possible due to high study heterogeneity, the Synthesis without Meta-Analysis reporting guideline.[36]

Eligibility criteria

Studies were included which were (i) English language primary research studies in any geographic region or setting (ii) where the sample was of adults aged 18 or over and (iii) included a quantitative estimate of loneliness prevalence using any question or scale. Eligibility criteria relating to end of life spanned several different groups aligning to broad definitions used elsewhere.[14,15] Eligible studies sampled (iv) adults explicitly defined as end of life, receiving palliative or hospice care or having a terminal diagnosis. Conditions normally considered terminal were confirmed by a clinical researcher with expertise in end-of-life care, including metastatic cancer, end stage liver disease and amyotrophic lateral sclerosis. Retrospective studies of individuals who had died were included where loneliness was measured within the 12 months prior to death.

For studies including only a continuous score for loneliness measured using a validated scale, the author was contacted to request the raw data for estimating prevalence to meet criteria (iii). Studies with samples including a subpopulation of people meeting criteria (iv) were included where the authors could be contacted and agreed to send relevant sub-sample data.

Articles focussed on children and young people under 18 years or measuring living alone, social isolation or social participation, but not loneliness were excluded. Further exclusions included study designs addressing prevalence of loneliness for groups other than patients, for instance carers of people with terminal illness and articles other than empirical research, such as theses or conference abstracts. One original exclusion in the review protocol was removed after searches had been completed: loneliness was not required to be the main outcome of each study.

Search strategy

Six databases were searched up to 29th April 2025 for academic studies (OVID Medline and PsycInfo, Web of Science and PubMed) and grey literature (Social Policy and Practice and Health Management Information Consortium). Scoping for the review established a search strategy including MeSH, subject headings and key words, translated for each database (Supplemental materials, Supplemental Figure S1). Forward and backward citation searching was conducted for included articles and for two relevant reviews.[33,37]

Screening

Search results were de-duplicated in EndNote then uploaded to Rayyan.ai systematic review screening software (https://www.rayyan.ai/) for independent blind screening of titles and abstracts by two researchers (EM, BH). Following discussion to reach consensus, full text articles were blind reviewed then discussed. Citation searching was undertaken by EM and identified articles reviewed by BH.

Data extraction and assessment of risk of bias

EM and BH undertook independent data extraction using an excel form including author, date, journal and title, stated aims, geography, study type and methodology, sample eligibility, and methodology. Loneliness measure used, statistical analyses, results including prevalence estimate, and where relevant, analysis of correlates were tabulated.

Quality of included studies was assessed by EM using Joanna Briggs Institute guidance for systematic reviews of prevalence and incidence[38] to identify risk of bias. The tool includes nine questions on the appropriateness of sampling frame, sampling method, sample size, response rate, subject and setting description, measure used and statistical analysis. Each study was scored 0–9 and categorised as lower risk of bias (score of 7–9), moderate risk (score of 4–6) or high risk of bias (score of 0–3), following other studies.[39] All studies were included, however, to explore the influence of study quality on prevalence, the range of prevalence estimates was reported first for all studies, then studies assessed as lower risk of bias.

Outcome measure - loneliness

There is no consensus on how loneliness should be measured but several validated scales are available such as the University of California Los Angeles (UCLA) loneliness scale[40] and the De Jong Gierveld Loneliness scale.[41] Scales vary in length and include items related to aspects of loneliness, indirectly asking whether a respondent is lonely. For instance, the three item short form of UCLA loneliness scale asks whether individuals lack companionship, feel left out and are isolated from others hardly ever, some of the time or often.[42] The De Jong Gierveld scale has 11 items relating to emotional and social aspects of loneliness.[43] Although these scales have acceptable reliability and validity,[43,44] there are no accepted cut off points to categorise differing intensities of loneliness. Therefore, differing cut-offs used by study authors were categorised according to their original description.[27,39] Categories were low loneliness (cut-offs described by study authors as no or low loneliness), moderate loneliness (mild or moderate loneliness) or high loneliness (cut-offs described as very, high, severe, clinically informative or frequent loneliness).

Single direct questions about feeling lonely are also commonly included in surveys, with slightly different wording and response categories, such as "*How often do you feel lonely?"* or "*Do you feel lonely?*."[44] Where loneliness was measured with a direct question and binary response, loneliness was considered to be moderate, following other studies.[39] Validated scale and direct measures of loneliness were analysed separately as low concordance has been found in responses.[45] For instance, men and women may differ in their responses to each question type,[46] and direct loneliness measures may underestimate loneliness due to social stigma.[10]

Data analysis

A synthesis without meta-analysis with a structured approach was carried out[36] as four of seven considerations for the appropriateness of meta-analysis were present in the identified studies.[47] Sources of clinical heterogeneity included differing loneliness measurement, study designs and populations (including age ranges, diagnoses, settings and indication of end of life), as well as assessing less than half the studies as lower risk of bias.

To enable different measures to be compared, in addition to translating each loneliness measure to low, moderate and high loneliness, estimates were synthesised separately for studies using validated scales and those using single direct questions, following other systematic reviews of loneliness.[27,39] As studies were identified measuring patient loneliness via different groups, a decision was made to analyse studies measuring loneliness by the patient separately from studies using family or health professional proxies, as estimates are influenced by the differing perspectives of these groups.[48] Following initial synthesis, studies were subsequently separated into those identifying their samples by clinical diagnosis or care receipt, and those retrospectively identifying their samples via time to death without other diagnosis or care criteria. This post-hoc grouping enabled separation of studies where not all sample members would know they were nearing the end of life. Prevalence was also narratively summarised by diagnosis where available given known differences in end-of-life experiences between those with malignant and non-malignant disease.[49] The presence or absence and direction of multivariable associations between potential correlates and loneliness for relevant studies were summarised.

Results

Included study characteristics

Database searches identified 668 unique records, see Figure 1. After title and abstract screening, 619 records were excluded leaving 49 articles for full text review and a further 13 from reference and citation searching. Reasons for exclusion with examples are presented in Supplemental Table S1. Following full text review, a total of 15 studies were included.[50–64] Risk of bias assessment identified seven studies as having lower risk (scoring 7–8) and eight having moderate risk (scoring 4–6), Supplemental Table S2. The most common sources of bias in the studies were using a single direct question rather than a validated scale measure of loneliness, small sample size and providing no information on response rate.

Table 1 provides details of included study characteristics for studies with samples identified by diagnosis or care receipt. Table 2 provides study details for studies with samples retrospectively identified by time to death. In each table, studies are separated into three categories: patient reported loneliness using 1. scale loneliness measures and 2. direct loneliness measures; and 3. family or health professional reported loneliness. Studies are ordered alphabetically within each category. Across all included studies, most addressed prevalence in North America or Europe: Canada (*n* = 2), United States (*n* = 5), Italy (*n* = 1), Netherlands (*n* = 3) and Turkey (*n* = 1), with three studies from other regions: Hong Kong, Israel and South Africa, Tables 1 and 2. Data sources included surveys in hospices and outpatient clinics (*n* = 9), routinely collected homecare data, including two using similar data (*n* = 3), nationally representative longitudinal survey data (*n* = 1) and baseline data for a randomised controlled trial (*n* = 2). Nine studies were published within the last decade. Relevance to end of life eligibility criterion included prognosis of less than 3 months (*n* = 1) or 6 months to live (*n* = 2), receipt of hospice services or palliative care (*n* = 3), terminal diagnosis (*n* = 6) and length of time from loneliness measure to death of less than 30 days (n=1), less than 6 months (n=1) and less than 12 months (*n* = 1). Four of 15 studies aimed to investigate a wide range of symptoms including loneliness, while 11 included loneliness as a specific focus. Study sample size ranged from 37 dying oncology hospice patients to 27,295 cancer decedents who used home care services in their final 6 months of life.

Study population characteristics included disease type: cancer patients (*n* = 6), patients with end stage liver disease (*n* = 1), HIV/AIDS (*n* = 1) and Amyotrophic lateral sclerosis (*n* = 1) and six studies not including details of patient diagnosis or including mixed diagnoses. The proportion of women among the sample, ranged from 36% to 100%

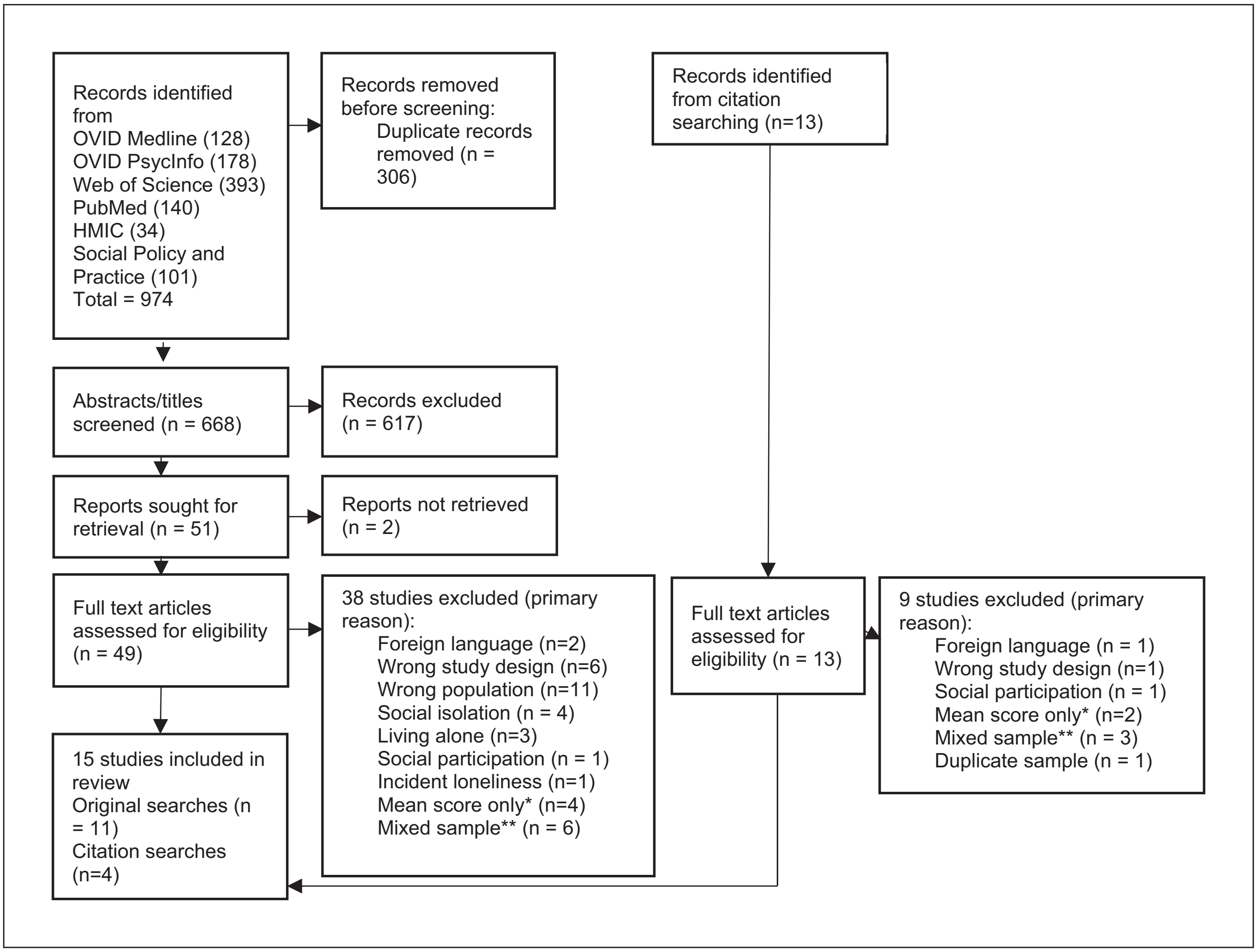

Figure 1. PRISMA diagram literature search.
*Studies reported loneliness as a mean score and raw data to calculate prevalence was not available.
**Studies included individuals at end of life but disaggregated data was not available.

(weighted proportion 50%). Weighted mean age was 70.7 years (data available from seven studies). Ethnicity and socioeconomic status data where available is reported in Supplemental Table S3.

Measurement of loneliness

Among studies of patient-reported loneliness (*n* = 13, total of 47,588 patients), scale measures were used in 7 studies: three-item UCLA loneliness scale (*n* = 5), 20-item UCLA loneliness scale (*n* = 1), and 11-item De Jong Gierveld loneliness scale (*n* = 1). Six studies used patient-reported direct questions asking about being or feeling lonely with binary response options. Studies measuring loneliness via health professional or family-respondent used direct questions with 3 or 5 response options (*n* = 2) estimated from 85 professionals and 292 family members, Table 1. Supplemental Table S4 presents the mapping of each study's loneliness measure to the framework of low, moderate and high loneliness.

Studies with samples identified by diagnosis/care receipt and patient-reported prevalence – validated scale measure

Four out of six studies estimating patient-reported prevalence using a scale measure were assessed as having lower risk of bias (scores of 7) and two studies a moderate risk of bias (scores of 4), Supplemental Table S2. Prevalence of moderate or worse loneliness ranged from 26% to 73% (26%–58% among studies with a lower risk of bias), Table 1. There was less variation in estimates of high loneliness, ranging from 8% to 33%.

Two studies of baseline data from a randomised controlled trial comparing models of palliative care addressed prevalence estimates by disease type[60] and for multimorbidity.[63] The first study found patients with non-cancer diagnoses (congestive heart failure, end stage renal disease or chronic obstructive pulmonary disease) reported the three items in the UCLA scale more frequently than patients with cancer diagnoses. For

Table 1. Studies with samples identified by disease or prognosis: Study characteristics, loneliness measure and prevalence estimate.

Author/s, year, country	Stated aim/s of study	Study type and data source	Sample *N*, end of life eligibility, gender, age, diagnosis characteristics	Loneliness measure used and categories/ scoring	Prevalence estimate from study (and comparison group if available)[a,b]	Prevalence estimate converted to no/low; moderate; high loneliness (Supplemental Table S4) [a]
Patient-reported prevalence – validated scale measure						
Berry et al., 2022, USA	Investigate the prevalence of and factors associated with loneliness in liver transplant candidates	Cross-sectional survey	454 patients with end stage liver disease awaiting liver transplant; Women 36%; Median age 60 years (IQR 53–64); 100% end stage liver disease	UCLA loneliness scale, 3 item (range 3–9). Scored: not lonely (3–4)/ lonely (5–9)	26% lonely (*n* = 118)	No/low: 74% Moderate or worse: 26% High: not included
Consonni et al., 2024, Italy	Investigated the degree of loneliness feelings in ALS and its correlations with clinical and neuropsychological profiles, and cortical involvement.	Cross sectional questionnaire, MRI, genetic tests	200 patients with amyotrophic lateral sclerosis[a]; Women 49.5%; Mean age 59.74 years (sd 11.7), range 22–88 years; 100% amyotrophic lateral sclerosis	UCLA loneliness scale, 3 item (range 3–9). Scored: no loneliness (3)/ mild loneliness (4–5)/ clinically informative loneliness (6–9)	62% no loneliness (*n* = 125); 21% mild loneliness (*n* = 42)[c]; 16% clinically informative loneliness (*n* = 33)	(as provided in published study) No/low: 62% Moderate or worse: 37% High: 16%
de Boer et al., 2020, Netherlands	To assess the prevalence of psychosocial problems, and to assess longitudinal changes in functional status, psychosocial functioning, and quality of life.	Longitudinal questionnaire and medical records	85 patients with metastatic breast cancer; Women 100%; Median age 77 years (IQR: 73–82); 100% metastatic cancer	De Jong Gierveld loneliness scale, 11 items, (range 0–11). Scored: no loneliness (0–2)/ moderate loneliness (3–8)/ severe loneliness (9–11)	36% lonely (28% moderately lonely and 8% severe loneliness)	No/low: 64% Moderate or worse: 36% High: 8%
Kaymak et al., 2022, Turkey	Investigate death anxiety, hopelessness and loneliness levels of distant metastatic cancer patients who underwent palliative radio therapy; relationship between these and predisposing factors.	Cross-sectional study survey	40 patients with metastatic cancer receiving palliative radio therapy; Women 17.5%; Median age 60 years, range 43–87 years; 100% metastatic cancer	UCLA loneliness scale, 20 item, (range 20–80); Turkish version. Scored: low loneliness (score 20–34)/ moderate (35–48)/ high (49 or more)	57.5% moderate loneliness; 15% high loneliness	No/low: 27.5% Moderate or worse: 72.5% High: 15%
Maloney et al., 2025, USA	To examine the association between comorbid illnesses in patients with serious life-limiting illnesses and loneliness.	Cross-sectional secondary analysis of RCT baseline data baseline interview	1212 patients with advanced cancer (metastatic solid tumour) or end stage organ failure registered in the EMPallA RCT cohort, April 2018 and June 2022; Women 52%; Mean age 67 years, sd 10; Mixed diagnosis[d]: Cancer only 35%; CHF only 22%; ESRD only 19%; COPD only 14%; Non-cancer, multiple illness 8%; Cancer, multiple illness 2%	UCLA loneliness scale, 3 item (range 3–9). Scored: not lonely (3–6)/ very lonely (7–9)	78% not very lonely (*n* = 946); 22% very lonely (*n* = 266) By comorbidity: 21% very lonely – one diagnosis; 33% very lonely – two or more advanced illnesses	No/low: not provided Moderate or worse: not provided High: 22% By comorbidity: high loneliness – One advanced illness: 21% high loneliness – Two or more advanced illnesses: 33%
Schmucker et al., 2021, USA	To report baseline demographic and quality of life (QOL) data for the EMPallA cohort, identify the association between illness type and baseline QOL while controlling for other factors, and explore baseline relationships between illness type, symptom burden, and loneliness.	Cross-sectional baseline for RCT baseline interview	500 patients with advanced cancer (metastatic solid tumour) or end stage organ failure registered in the EMPallA RCT cohort, April 2018 and April 2020; Women 54%; Mean age 67 years, sd 10; Mixed diagnosis: Cancer 41%; End-stage renal disease 20%; Chronic obstructive pulmonary disease 27%; Congestive heart failure 25%	3 item UCLA loneliness – individual items/answer distributions. Categories: hardly ever/some of the time/ often	Patients with organ failure/COPD more likely to respond “often” to each question than patients with cancer: Feel isolated Cancer hardly ever (57%), some of the time (33%), often (10%) Not cancer hardly ever (47%), some of the time (29%), often (25%) Feel left out Cancer hardly ever (58%), some of the time (34%), often 9%) Not cancer hardly ever (42%), some of the time (32%), often 26%) Lack companionship Cancer hardly ever (59%), some of the time (28%), often 13%) Not cancer hardly ever (44%), some of the time (31%), often (25%)	Feel isolated Cancer No/low: 57% Moderate or worse: 43% High: 10% Not cancer No/low: 47% Moderate or worse: 54% High: 25% Feel left out Cancer No/low: 58% Moderate or worse: 43% High: 9% Not cancer No/low: 42% Moderate or worse: 58% High: 26% Lack companionship Cancer No/low: 59% Moderate or worse: 41% High: 13% Not cancer No/low: 44% Moderate or worse: 56% High: 25%

(continued)

Table 1. (continued)

Author/s, year, country	Stated aim/s of study	Study type and data source	Sample *N*, end of life eligibility, gender, age, diagnosis characteristics	Loneliness measure used and categories/ scoring	Prevalence estimate from study (and comparison group if available)[a,b]	Prevalence estimate converted to no/low; moderate; high loneliness (Supplemental Table S4) [a]
Patient-reported prevalence – direct measure – disease or prognosis identified sample						
Chan et al., 2014, Hong Kong	Examine the relationship between depression and pain in terminally ill Chinese elders in Hong Kong and explore the moderating effect of psychosocial factors such as loneliness, communication and being at ease interacting with others.	Cross-sectional administrative assessment data	312 older adults having first long term care assessment with prognosis of $<$ 6 months to live; Women 47.8%; Mean age 77.4 (sd 7.3); Mixed diagnosis, 64.1% cancer	Single item, feel lonely Y/N on the Minimum Data Set for Home Care, MDS-HC. Response options: not feeling lonely/ feeling lonely	42.95% feeling lonely (*n* = 134)	No/low: 57.05% Moderate or worse: 42.95%
Rokach et al., 2007, Israel	To explore the qualitative aspects of the loneliness experienced by the dying and by their attending caregivers.	Cross-sectional questionnaire	37 dying oncology hospice patients[a]; Women 70%; Mean age 62 years, sd 11.56, range 36–87 years; 100% cancer	Current loneliness, exact question not specified. Categorised: not currently lonely/ currently lonely	46% patients were currently lonely. In comparison 22% lonely in general population sample, 33% carers lonely	No/low: 54% Moderate or worse: 46%
Ruijs et al., 2014, Netherlands	Investigation of the presence and nature of unbearable suffering and its relationship to requests for euthanasia.	Cross- sectional questionnaire	64 patients with prognosis of less than half a year to live Women 51.6% (calculated) Mean age 70 years (calculated); 100% cancer	Feeling lonely (intrapersonal) measured through the State-of-Suffering V (SOS-V) instrument. Presence (main effect extracted) and extent symptom causes unbearable suffering (five-point scale). Categorised: Not lonely/ Lonely; Suffering unbearable: scores 4,5.	20% felt lonely (*n* = 12); 10% felt unbearable loneliness (*n* = 6); Of 60 patients with measurements	No/low: 80% Moderate or worse: 20%
Shawn et al., 2005, South Africa	To describe the frequency and severity of symptoms as well as the physical discomfort and psychological distress associated with those symptoms among 64 HIV-positive South African patients enrolled in a rural palliative care programme	Cross-sectional questionnaire	64 patients receiving treatment from HIV/AIDS palliative care programme; Women 69%; Mean age of 32, range 20–45 years; 100% HIV/AIDS	Feelings of loneliness, question not specified from HIV symptom list. Categorised: no feelings of loneliness/ Feelings of loneliness	50% feelings of loneliness (*n* = 32)	No/low: 50% Moderate or worse: 50%
Family or health professional-reported prevalence – direct measure						
Baer and Hanson, 2000, USA	To determine if family members perceive that hospice improves the care of dying nursing home residents during the last 3 months of life.	Cross-sectional survey	292 family members reported on hospice decedents (Decedents) Women: not reported; Mean age 79.5 years; Mixed diagnosis	On a typical day in last 3 months of life did your family member experience any loneliness? Response options: none/ mild/ moderate/ severe	None 26% mild 39% moderate 26% severe 9%	No/low: 65% Moderate or worse: 35% High: 9% Family perception
Georges et al., 2005, Netherlands	Describe the symptoms, their treatment during the final months of life of terminally ill cancer patients and to assess characteristics of the dying process.	Longitudinal survey	85 physicians identified a terminally ill patient with cancer (patients); Women 46% Mean age not reported, $<$ 45 years 5%, 45–60 years 19%, 60–75 years 48%, $>$75 years 28%; 100% cancer	Feelings of loneliness (question not provided, range 1–5). Scored not lonely (1)/ moderate (2–3)/ severe (4–5)	At inclusion in study: Moderate loneliness 22% Severe loneliness 5% Before death: Moderate loneliness 32% Severe loneliness 5%	No/low: 73% Moderate or worse: 27% High: 5% Physician perception at study inclusion

[a] Two studies included comparison groups: Consonni et al., 49 healthy controls and Rokach et al., 78 caregivers and 128 participants from general population;

[b] Percentages may not sum to 100 due to rounding in original published paper;

[c] Figures in published paper add to 110%, author clarification of correct figures, therefore differ to publication;

[d] CHF: chronic heart failure; ESRD: end stage renal disease; COPD: chronic obstructive pulmonary disease.

Table 2. Studies with retrospectively identified samples based on time to death: Study characteristics, loneliness measure and prevalence estimate.

Author/s, year, country	Stated aim/s of study	Study type and data source	Sample *N*, end of life eligibility, gender, age, diagnosis characteristics	Loneliness measure used and categories/ scoring	Prevalence estimate from study (and comparison group if available)[a]	Prevalence estimate converted to No/low; Moderate; High loneliness (Supplemental Table S4) [a]
Patient-reported prevalence – validated scale measure						
Kotwal et al., 2021, USA	To determine the prevalence and correlates of social isolation and loneliness among older adults in the last years of life	Pooled cross- sectional health and retirement study	743 decedents with a loneliness measure $<$12 months before death (subsample provided by authors); Women 50.4%; Mean age 79.6 years, sd 11.9, range 52–100 years; Diagnosis not reported	UCLA loneliness scale, 3 item, (range 0–6). Scored: No loneliness (0)/ any loneliness (1–3, not provided for subsample)/ frequent loneliness (4–6)	Frequent loneliness 18.6% (*n* = 123) for author-provided subsample with a loneliness measure 1 year or less before death; In comparison 11% loneliness among respondents who lived longer than 4 years	No/low: not provided Moderate or worse: not provided High: 18.6%
Patient-reported prevalence – direct measure						
Mofina et al., 2025, USA	How to define and quantify a bad death in palliative home care? Across-sectional and exploratory study using Canadian interRAI data	Cross-sectional administrative assessment data	16,586 homecare recipients who had a loneliness measure 30 days or less before their death; Women 54.7%; Median (IQR) 83 years (13.0) 18–64 years 8.1%, 65–74 years 11.8%, 75–84 years 29.2%, 85+ years 50.9%; Mixed diagnosis, 26.5% cancer[b]	Resident Assessment Instrument for Home Care (RAI-HC), a standardised assessment tool based on the MDS-HC. Categorised: not lonely/Lonely	12.2% lonely (*n* = 2029)	No/low: 87.8% Moderate or worse: 12.2%
Seow et al., 2020, Canada	To describe the trajectory of psychosocial symptoms in the 6 months before death among a population-based cohort of patients with cancer living at home and receiving home care services	Cross-sectional administrative assessment data	27,295 cancer decedents who used home care services in their final 6 months of life; Women 47%; Mean age not reported, 18–64 years 22.1%, 65–74 years 22%, 75–84 years 32.9%, 85+ years 23%; 100% cancer	Resident Assessment Instrument for Home Care (RAI-HC), a standardised assessment tool based on the MDS-HC. Categorised: not lonely/Lonely	7.04% lonely (*n* = 1192 of 16,933 included in loneliness prevalence estimate)	No/low: 92.96% Moderate or worse: 7.04%

[a] Percentages may not sum to 100 due to rounding in original published paper;

[b] Diagnosis mix for Mofina et al., 2025: Alzheimer's 7.0%, Other 24.3%, Multiple sclerosis 0.7%, Parkinson's disease 4.9%, Cancer 26.5%, Congestive heart failure 26.5%, Chronic obstructive pulmonary disease 27.6%, Renal failure 15.3%, Stroke 20.4%, Coronary artery disease 33.0%, Arthritis 51.7%, Hemiplegia 2.5%, Any psychiatric diagnosis (incl depression) 16.0%.

instance, feeling isolated often, 10% for cancer patients and 25% for non-cancer patients, Table 1.[60] The second study found higher prevalence of high loneliness among patients with two or more of cancer or end stage organ failures (33%), compared to patients with only one condition (21%).[63] However, the same pattern was not found when comparing estimates from studies of single diseases. Two small studies of cancer patients (*N* = 40 and 80) estimated moderate or worse loneliness as 36%–73% and high loneliness 8%–15%. Two studies of end stage liver disease patients and patients with amyotrophic lateral sclerosis estimated moderate or worse loneliness as 26%–37% and high loneliness 16%. Studies differed by country, setting, design and sample characteristics.

Studies with samples identified by diagnosis/care receipt and patient-reported prevalence – direct measure

All four studies estimating patient-reported prevalence using a direct loneliness question were assessed as having a moderate risk of bias (scores of 4–6), Supplemental Table S2. Prevalence of moderate or worse loneliness ranged from 20% to 50%, Table 1. Only one study compared loneliness prevalence to those not at the end of life, finding higher loneliness among oncology hospice patients (46%) compared to the general population (22%) and carers (33%).[58] Prevalence ranged from 20% to 46% in studies of cancer patients and was 50% in patients with HIV/AIDS.

Studies with samples identified by diagnosis/care receipt and family or health professional-reported prevalence – direct measure

Both studies estimating family or health professional-reported prevalence with a direct loneliness question were assessed as having a moderate risk of bias (scores of 5), Supplemental Table S2. Studies estimated moderate or worse loneliness among patients at 27%–35% and high loneliness between 5% and 9%, Table 1.

Studies with retrospective samples identified by time to death

One of three studies with retrospective samples estimated patient-reported prevalence using a scale measure. The study was assessed as having lower risk of bias (score of 8), Supplemental Table S2, and prevalence of high loneliness was estimated at 18.6%, Table 2. This study compared loneliness prevalence to those not at the end of life, finding significantly lower loneliness among an age- and sex-matched group living for more than 4 years after their loneliness measurement (11%).[57] The remaining two studies estimated patient-reported prevalence using a direct measure and were assessed as lower risk of bias (scores of 7), Supplemental Table S2. Prevalence of moderate or worse loneliness was estimated as 7%–12% in these studies, Table 2.

Correlates of loneliness

Seven studies carried out multivariable analysis of correlates of loneliness. The presence, absence and direction of the associations found are presented in Figure 2. Four studies were rated lower risk of bias (scores of 7) and three rated moderate risk of bias (scores of 4 or 5). There was little consistency in covariates analysed, though sociodemographic, physical and mental health and social factors were most frequently included. Analytic methods included multiple linear and logistic regression.

Sociodemographic factors included age, gender and ethnicity, with no consistent associations found across all studies. However, women were more often lonely than men in studies assessed as having lower risk of bias. Few physical health factors were included in more than one study, with the exceptions of various disease stage measures (predominantly not associated with loneliness), arthritis and pain (both associated with being lonely). All studies including measures of poorer mental health (such as depression, anxiety and apathy) found associations with loneliness. Associations were also found between social factors such as not being married and experiencing social decline, but consistency across studies was again limited and no studies included living arrangements, such as lone living or living in a care home in their analyses.

Discussion

This review synthesised evidence from 15 studies, encompassing a variety of conditions, care settings and countries, and indicating loneliness may be experienced by a significant minority of people at the end of life, though with wide variation. Prevalence of moderate or worse loneliness was estimated to be 20% or over in all except two studies. Among studies with samples based on diagnosis or care receipt, prevalence ranged from 26% to 73% (mid-range or higher loneliness scale scores) and 20%–50% (based on answering yes to a direct loneliness question). High loneliness estimates ranged from 8% to 33% in these studies (upper range loneliness scale scores). Among studies based on samples identified retrospectively by time to death, respective estimates were 7%–12% and 18.6%. Where directly compared, loneliness was more common among patients with non-cancer diagnoses compared to cancer diagnoses, and multiple conditions compared to one condition. The same pattern was not found when comparing estimates from studies

	Berry et al., 2022	Consonni et al., 2024	Maloney et al., 2025	Mofina et al., 2025	Rokach et al., 2007	Seow et al., 2020	Shawn et al., 2005
	Lonely UCLA scale	UCLA scale score	Very lonely, UCLA scale	Lonely	Currently lonely	Lonely	Feeling lonely
Sociodemographic							
Age (increasing)	–	NS	–		NR		NS
65–74 years (ref cat <65 years)				NS		NS	
75–84 years (ref cat <65 years)				–		+	
85+ years (ref cat <65 years)				NS		+	
Women (ref cat men)	+	NS	+	+	NR	+	NS
Black ethnicity (ref cat white non-Hispanic)	–						
Non-white ethnicity (ref cat white)			NS				
Spanish speaking (ref cat English speaking)			NS				
Socioeconomic circumstances							
In work (compared to not in work)	–						
Education (highest)			–				NS
Suburban (ref cat urban)			–				
Immigrant status (ref cat non-immigrant)			NS				
Physical health							
Disease stage (various)	NS	NS		–			NS
Uncontrolled pain (ref cat no uncontrolled pain)				+		+	
Pain horrible/excruciating (ref cat not)				+			
ADL/IADL impairment (ref cat no impairment)						–	
High health instability (ref cat low instability)						–	
Frailty (frail, score of 4 or more on Liver Frailty Index)	+						
Weight (increasing)	NS						
BMI (increasing)	NS						
Cancer (ref cat organ failure)			–				
Alzheimer's/dementia/Parkinson's (ref cats none)				–			
Multiple sclerosis (ref cat none)				NS			
Arthritis (ref cat none)				+			
Co-morbidities (ref cat[a])			+	+			

Figure 2. *(continued)*

	Berry et al., 2022	Consonni et al., 2024	Maloney et al., 2025	Mofina et al., 2025	Rokach et al., 2007	Seow et al., 2020	Shawn et al., 2005
	Lonely UCLA scale	UCLA scale score	Very lonely, UCLA scale	Lonely	Currently lonely	Lonely	Feeling lonely
Mental health							
Depression (ref cat not depressed)				+		+	
Depression (scale scores, increasing symptoms)		+					
Anxiety (scale scores, increasing symptoms)		+					
Apathy (scale scores, increasing symptoms)		+					
Any psychiatric diagnosis (ref cat none)				+			
Quality of life							
Quality of life (increasing)		–					
Cognition and behaviour							
Behaviour change (scale, increasing symptoms)		+					
Emotional regulation (scale, increasing symptoms)		NS					
Cognitive impairment (ref cat no impairment)						+	
Psychological factor**s** (scale scores, increasing symptoms)							
Empathy		NS					
Self-alienation					NS		
Emotional distress					NS		
Social inadequacy and alienation					NS		
Growth and discovery					NS		
Social factors							
Married/partnered (ref cat unmarried)	–				NR		
Social decline (ref cat no decline)						+	
Social decline with distress (ref cat no decline)				+			
Social decline with no distress (ref cat no decline)				NS			
Interpersonal isolation					+		
Conflict with family (ref cat no conflict)				+			
Caregiver distress/burden (as measured in study)				–		NS	
Presence of caregiver (ref cat no caregiver)			–				
Circumstances of death							
5–12 weeks before deaths (ref cat 1–4 weeks)						NS	
Location of death in hospital (ref cat home)						+	

ref cat: reference category; NS: not significant; NR: coefficients not reported but covariates in multivariable analysis; – = decreasing loneliness (loneliness scale outcome), lower odds of loneliness (lonely binary outcome); + = increasing loneliness (loneliness scale outcome), greater odds of loneliness (lonely binary outcome);
[a]Multiple morbidity defined as two or more conditions[63] and five or more conditions.[64]

Figure 2. Correlations with loneliness: Presence or absence of association and direction.

of single diseases, though the samples, countries and methods also differed. There was no clear difference in estimates from direct or scale measurements. However, direct loneliness estimates from two studies with retrospective samples based on time to death were notably lower (7% and 12%) compared to estimates from studies with clinically identified samples (20%–50%). Caution is required in interpreting these findings due to heterogeneity in measurement of loneliness and study details such as sample size and characteristics, country and care setting.

These findings can be viewed in the context of the many changes to individuals' physical, social and internal worlds with approaching end of life. Although individuals respond in different ways, declining health and mobility can impose unpredictable constraints on social activities, roles and relationships.[65] Indirect pressures arise through uncertain trajectories of illness and care[66] and fragmented support.[67,68] Approaching end of life may lead to feelings of separateness, lost connections, regrets or shame, connected to existential loneliness – deeper feelings of aloneness.[22,65,69] However, these deeper feelings are not captured in widely used short loneliness measures, though longer scales do exist.[70]

Comparing prevalence of loneliness among people at end of life and among those living longer can provide insights into differing needs across life stages. In this review, one study found higher loneliness among those in their last year of life compared to those living for more than 4 years.[57] In the wider literature, a recent systematic review found pooled prevalence of loneliness among older adults ranged from 11.1% in western Europe to 27.7% in eastern European countries, measured as 6 or more on the de Jong Gierveld loneliness scale.[27] This is equivalent to moderate loneliness for scale measures in this review and lower than our estimation of 26%–73% among those at end of life. Similar pooled prevalence was found for high loneliness among older adults, measured as 6 or more on the UCLA loneliness scale, as among adults at end of life in this review (6%–19% for older adults; 8%–26% for people at end of life in this review). These comparisons give some indication that loneliness among people at the end of life may be higher than among the general older adult population, at least at moderate levels. However, general prevalence estimates vary across and between regions, likely influenced by differing demographic, health, social and welfare contexts.[27] Future studies could compare people at end of life with general population estimates within the same country.

Differing loneliness prevalence by diagnosis was found in two studies of baseline data from a randomised controlled trial.[60,63] Greater prevalence of loneliness was found among patients with non-cancer diagnoses compared to cancer diagnoses, and with multimorbidity compared to one diagnosis. However, the same pattern was not seen when comparing prevalence across studies of patients with single diseases. People with cancer are more likely to be referred to, or die in, hospices compared to people with non-cancer end stage disease.[71] This may mean people with cancer receive more support to maintain important relationships and find meaning towards the end of their lives.[72] Differing symptoms and management of illnesses also vary in their impact on an individual's life and social functioning.[34] In relation to multimorbidity, the challenges of managing multiple conditions may reduce opportunities to meet others or increase perceived differences with others.[21,23] More studies are needed comparing prevalence by diagnosis to add to this emerging evidence base and to carry out multivariable analysis of correlates to help disentangle the effects of underlying individual differences between patients, disease-specific factors and potentially modifiable aspects such as access to support.

Few studies carried out multivariable analysis of correlates of loneliness and there was limited consistency in included covariates. Associations with sociodemographic, socioeconomic and physical health factors mirrored those in the wider literature, where evidence is mixed.[29] Associations found in this review with poorer mental health, and to some extent social circumstances, are consistent with risk factors identified for the general and older population[29,30] and among those with advanced terminal illness.[34] Surprisingly, no studies assessed living arrangements, such as living alone and future research could include these important variables in analyses.

Limitations of the studies included in the review

Although included studies were diverse, some settings were noticeably absent, including care homes. Currently almost a quarter of deaths occur in care homes in England[73] and care homes are projected to be the most common place of death in England and Wales by 2040.[74] Pooled prevalence of loneliness among care home residents has been estimated at up to 61% for moderate loneliness.[39] Only two studies, using data from a randomised controlled trial, compared loneliness across people with differing or multiple diagnoses, limiting our understanding of how loneliness may differ by condition at end of life. Methodologies and loneliness measurements differed across studies, there was wide variation in sample size and for the studies assessing correlates, there was inconsistent adjustment for covariates. Further, no study included a loneliness measure incorporating aspects of existential loneliness, of particular relevance to end of life populations.[22]

Strengths and limitations of the review

Strengths of the review include the structured narrative approach, guided by accepted standards, and use of a broad definition of end of life, to capture the diversity of settings, conditions and uncertainty of timing.[16] Nevertheless, the broad definition may mean some studies were either missed or incorrectly included. Further, where studies retrospectively identified their sample by date of death, estimates of loneliness included individuals whose deaths were accidental and unrelated to terminal illness. Finally, we conducted a narrative review due to heterogeneity among studies. This resulted in reporting ranges of prevalence, considered preferable to producing a point estimate from studies with few similarities.

Implications for further research, policy and practice

Estimates of loneliness prevalence across a wider range of country contexts, care settings and conditions warrant further exploration. The 10 year health plan for England sets out an ambition for three radical shifts in how health care is delivered, including moving care into the community, rather than hospital settings.[75] This type of health system reform is occurring in other contexts globally.[76] It will be important to extend understanding of loneliness to all those dying at home, not only those receiving state-funded home care, and to institutional settings including care homes.[77] Exploration of how loneliness prevalence differs by condition and better understanding potential population risk factors is also important. With these priorities in mind, future research might investigate possibilities to modify a standardised loneliness measurement tool to incorporate existential loneliness, adapting the tool to better measure loneliness at end of life. This could include applicability across cultures, settings and with different patient groups. This review focussed on loneliness among people at the end of life, however, reviewing the literature specifically for carers at end of life would be beneficial.

For policy and practice, the review highlighted loneliness as an important consideration for the care and support of people at end of life. Loneliness is increasingly recognised as a societal issue in need of coordinated action[78] and the needs of people with advanced illness should be acknowledged in new policies and strategies. An integrative review of loneliness at end of life identified potentially modifiable factors to reduce or mitigate loneliness at end of life, operating at different levels.[27] At the individual level, these include interventions such as befriending services; at the meso level, opportunities to make care homes, hospitals and hospices more home-like environments; and at the macro level, compassionate communities to better support lonely individuals.[27] Tailored interventions need to be developed for diverse groups.[28] Underpinning evidence of loneliness prevalence and at-risk end of life population groups is critical to making the case for developing and funding these approaches and raising awareness among health and social care providers in community settings where palliative care may be less common. Evidence indicates integrated approaches are important, necessitating support at multiple levels, from staff training to recognise the signs of loneliness to mobilisation of community resources through compassionate communities.[79,80]

Conclusions

Evidence indicates a significant minority of adults at the end of life experience moderate or high loneliness. There is emerging evidence of higher loneliness among individuals with non-cancer compared to cancer conditions and multiple morbidity, though there are currently only two comparative studies. Correlates of loneliness at the end of life may include poorer mental health and some social and physical health factors. However, there was significant heterogeneity in study quality, loneliness measurement, country, care settings and conditions investigated, which limits interpretations across studies. Further research is needed in more countries and settings, and to assess the effectiveness of supportive interventions, better informing evidence-based approaches to recognising and mitigating loneliness at the end of life.

Acknowledgements

We would like to acknowledge Irena Cenzer and Ashwin Kotwal for agreeing to provide subsample data from their original study, and Kate Maitland for providing advice on diagnoses indicating terminal illness.

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Ethical considerations

This research reviewed published literature and did not require ethics approval.

Consent to participate

This research reviewed published literature and did not require participant consent.

Author contributions

EM and BH designed the study. EM, CG, TM and BH developed the search strategy, EM conducted the searches, EM and BH screened the records and extracted the data. EM assessed the risk of bias, carried out the narrative synthesis and prepared the manuscript. All authors provided critical input to the analysis and manuscript drafts. All the authors have read and approved the final version of the manuscript.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. EM and BH's roles are funded by Marie Curie.

Declaration of conflicting interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Clare Gardiner is a member of the editorial advisory board for Palliative Medicine.

Data availability statement

Data collated for this review are available from the authors on request.

Supplemental material

Supplemental material for this article is available online.

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