

# Interventions for behavioral health comorbidities in the hospice setting: a scoping review

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**Background:** Behavioral health (BH) comorbidities in hospice patients are widespread and impact important outcomes, including symptom burden, quality of life, and caregiver wellbeing. However, evidence-based BH interventions tailored for the hospice setting remain understudied.

**Methods:** We conducted a scoping review with the objective of mapping studies of interventions for BH comorbidities in the hospice setting. We included empirical studies among hospice patients of interventions with BH outcomes. We abstracted data on study design, intervention type, and patient characteristics.

**Results:** Our search generated 7,672 unique results, of which 37 were ultimately included in our analysis. Studies represented 16 regions, with the United Kingdom (n=13) most represented. The most frequent intervention type was complementary and alternative interventions (n=13), followed by psychotherapeutic interventions (n=12). Most of the studies were either pilot or feasibility investigations. Fifteen studies employed a randomized controlled trial design. The most frequently utilized measurement tools for BH outcomes included the Hospital Anxiety and Depression Scale and the Edmonton Symptom Assessment Scale. Seventeen studies demonstrated statistically significant results in a BH outcome measure. BH conditions prevalent among hospice patients that were the focus of intervention efforts included depression symptoms, anxiety symptoms, and general psychological distress. No study focused on trauma-related disorders or substance use disorders.

**Conclusions:** This scoping review reveals a concerning gap in research regarding evidence-based BH interventions in hospice settings, especially in the U.S. Despite extensive utilization of hospice care services and the high prevalence of BH conditions among hospice patients, randomized controlled trials focused on improving BH outcomes remain scant. The current BH practices, like the widespread use of benzodiazepines and antipsychotics, may not be rooted in robust evidence, underscoring an urgent need for investment in hospice research infrastructure and tailored clinical trials to test behavioral approaches to mitigate mental health outcomes at the end of life.

**Keywords:** Hospice; behavioral health (BH); mental health; psychiatry; end-of-life

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## Introduction

### Background

Palliative care and hospice aim to deliver holistic care focused on improving the quality of life for individuals with serious illnesses. To support this goal, hospice and palliative medicine services seek to provide care across multiple domains, including physical, spiritual, psychological, and social (1). While palliative care is delivered across serious illness trajectories, hospice is a specific model of palliative care focused on end-of-life care. In the United States (U.S.), hospice utilizes a capitated care model to provide comprehensive person-focused care in the last six months of life (2). Hospice is a highly significant model of palliative care delivery from a public health perspective; in the U.S., approximately half of all Medicare decedents receive hospice services (3). Despite its significance and reach, hospice may be underrepresented in clinical serious illness care research because of challenges conducting research in hospice settings (4).

Patients living with serious illness have significant behavioral health (BH) burdens [defined as mental health conditions and substance use disorders (5)]. A large minority (~40%) of individuals in palliative care settings (including hospice) experience mood and anxiety symptoms, and more than half of all individuals in end-of-life care settings

experience delirium (6-12). Over the past several years, there has been increasing recognition that palliative care fails to fully address the significant psychological burden imposed by serious illness (13-15). In response to this recognition, a growing body of scholarship has addressed the epidemiology (7,8), impact (16), assessment (17-19), and management (20,21) of BH conditions in the palliative care setting.

### Rationale and knowledge gap

Recent scholarship on optimizing BH components of palliative care has largely been situated in ambulatory and inpatient palliative care settings. However, there are key differences between hospice and other palliative care settings. From a patient perspective, hospice patients must have a prognosis of six months or less for eligibility, while general palliative care includes patients living with serious illnesses but not approaching end-of-life (22). Structurally, many palliative care programs operate in a consultative role in a medical system with access to specialist clinicians, including mental health referral resources. In contrast, hospice provides comprehensive care. Furthermore, hospice utilizes a unique delivery system and interdisciplinary team structure (which in the U.S. must include physicians, chaplains, social workers, and nurses). In the U.S., hospice is often oriented around delivering care in the home or nursing home setting. As such, interventions targeting BH conditions in U.S. hospice care generally must be deployable in the home setting. In other regions such as the United Kingdom (UK), hospice may be delivered in specialized medical settings such as residential hospices, which may also have unique BH workforce limitations relative to general medical settings (23). In the U.S., because of the capitated payment model, increasing the hospice workforce to include BH experts may not be financially feasible; therefore, ideal interventions should be deliverable by the core hospice interdisciplinary team. Finally, because the median length of hospice utilization is often short [48 days in the UK (24), 18 days in the U.S. (3), and 20 days in international models of home-based palliative care (25)], interventions must be feasibly delivered over a relatively brief period, which may be incongruent with many commonly utilized mental health treatments (e.g., psychotherapy, serotonergic antidepressants).

While existing literature reviews synthesize epidemiologic and intervention data on BH research in general palliative care settings (14-16,21), few studies

### Highlight box

#### Key findings

- There is a dearth of research into interventions targeting behavioral health conditions for hospice patients. This may reflect unique challenges of studying and delivering behavioral health in the hospice setting.

#### What is known and what is new?

- Patients on hospice experience high rates of behavioral health comorbidities including depression, anxiety, and delirium. Such comorbidities impact key end-of-life care outcomes including quality of life and symptom burden.
- Only a small number of interventions specifically for behavioral health have been adapted for, studied among, or implemented in hospice settings. This study demonstrates gaps in behavioral health research in hospice.

#### What is the implication, and what should change now?

- A greater emphasis must be placed on building infrastructure to successfully conduct research on behavioral health comorbidities in hospice settings, with a focus on generating implementation-ready, scalable interventions appropriate for patients at the end-of-life.

specifically focused on the hospice setting. Given the significance of hospice as a widely disseminated, highly utilized model of palliative care delivery with distinct structural and clinical delivery features, this represents a substantial gap in the literature.

### **Objective**

We sought to review BH intervention studies in the hospice setting. We define BH interventions as interventions specifically targeting mental health and substance use disorders or psychiatric symptoms (e.g., depression, anxiety) as their primary therapeutic target. Our decision to conduct a scoping rather than a systematic review was driven by our primary objective: to map existing literature and to characterize the state of BH intervention research in the hospice setting rather than to delineate clinical guidelines or recommendations. In doing so, we sought to identify gaps and opportunities to develop research and clinical paradigms to address the BH needs of patients receiving hospice care. We present this article in accordance with the PRISMA-ScR reporting checklist (26) (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-508/rc>).

### **Methods**

We conducted a modified scoping review utilizing Arksey and O'Malley's scoping review framework (27) with enhancements to leverage team-based science, including the use of expert consultants (authors M.C.R. and V.P.) and representation of both clinical and research perspectives (28). Arksey and O'Malley outline a six-step process by which to conduct scoping reviews. Step 1: the research question was identified by the senior author (a clinician-investigator with expertise in BH and hospice and palliative medicine) in collaboration with the study team and research librarian (see the Objective subsection in the Introduction). Step 2: a research librarian (co-author D.W.) refined the search strategy based on the research question (see the Literature search subsection in the Methods and Appendix 1). Step 3: study selection occurred based on study protocol (see the Inclusion and exclusion criteria subsection and the Study selection and data extraction subsection, both in the Methods). Step 4: data were extracted and charted (see the Study selection and data extraction subsection in the Methods). Step 5: data were synthesized and presented (see the Study selection and data extraction subsection and the Results section). Step 6: we also utilized the optional expert

consultation step noted above. In addition to emphasizing team-based science, we modified the typical scoping review methodology by conducting this study as a "nested" review; our initial search and screening processes were for general BH studies in hospice. At the full-text review stage, we delineated content areas (intervention versus epidemiology/outcomes/assessment) to generate two interrelated reviews from our initial search and screening. We conducted a scoping rather than a systematic review because scoping reviews are preferred when the foci entail identifying knowledge gaps and characterizing existing evidence in a field (26). We did not register a review protocol a priori.

### **Literature search**

A comprehensive search of four databases (PubMed/Medline, Embase, Cochrane, and Scopus) was performed by a research librarian (co-author D.W.) with the strategy developed in collaboration with senior author D.S. (see Appendix 1). The search strategy included relevant vocabulary for concepts including hospice care and mental/BH (see Appendix 1). To be as expansive as possible and limit selection bias, our initial search was performed without limiting articles by publication date, language, or article type. The initial search was conducted on 11/9/2021 and then updated on 5/25/2023.

### **Inclusion and exclusion criteria**

We used the following eligibility criteria for included studies:

- ❖ Study design: we included clinical trials (including both controlled and uncontrolled clinical trials) as well as observational and pseudo-experimental studies of interventions.
- ❖ Population: we included studies of adult hospice patients either exclusively or as at least 33% of the study population. For studies conducted outside the U.S., we also included studies in which at least 33% of patients received care at a hospice-equivalent end-of-life care paradigm (e.g., a care setting providing care focused on quality of life to patients with a prognosis of six months or less). We set this threshold based on our goal that an intervention had been substantially evaluated in hospice patients and our concern that some studies may have theoretically included hospice patients but not successfully recruited a substantial portion of such

patients relative to patients in other settings.

- ❖ **Intervention:** we included studies of BH interventions (psychotherapy or other behavioral interventions, psychopharmacology) and studies of complementary and alternative interventions if a BH outcome was measured as a primary or secondary outcome. We used the National Center for Complementary and Integrative Health classification recommendations to define complementary and alternative interventions (29).
- ❖ **Outcomes:** we included studies that included a primary or secondary BH outcome (e.g., depression symptoms, anxiety symptoms, psychological distress, agitation/confusion). We excluded studies focused solely on caregiver outcomes.
- ❖ **Publication status and language:** we included English-language conference abstracts and full-text articles published in peer-reviewed journals.

### *Study selection and data extraction*

Retrieved studies were screened for inclusion using Covidence (30), a web-based literature review platform. Two independent reviewers reviewed the titles and abstracts against the initial inclusion/exclusion criteria. Conflicts were resolved by D.S., the senior investigator, and a physician trained in both psychiatry and palliative medicine. All empirical studies involving BH in the hospice setting were eligible for inclusion at this stage. Studies screened for full-text review were initially designated as intervention or non-intervention studies. Given that this study included only patient-focused interventions, studies focused on caregivers were excluded from the present review. Two independent study team members evaluated full-text intervention studies with discrepancies resolved by senior author D.S..

### **Data extraction**

Data extraction was conducted using a templated tool integrated into the Covidence platform (see [Appendix 2](#)). Primary author L.B. extracted data from each article and subsequently verified by senior author D.S. Extracted data included: year(s) of data collection, study location, study design, analytical sample size, sample characteristics (including percent of study population in hospice and percent of study population with oncologic disease), hospice setting (e.g., inpatient or home), intervention details (type of intervention, description, length, interventionist), category of outcome (BH, quality of life, other), outcome

measures used, and study results.

### **Critical appraisal**

We elected not to appraise the quality of the literature, given our primary objective of mapping the literature rather than synthesizing evidence about specific interventions.

### **Data synthesis**

We synthesized evidence along two domains. In mapping the literature, we collected data on both study characteristics (*Tables 1-3*) and the nature of BH interventions and results (*Table 4*). We present study design elements in aggregate and categorize BH interventions across the studies as behavioral, pharmacologic, complementary/alternative, or other.

While analyzing data, we recognized that heterogeneity in the use of the term hospice between health systems presented an unexpected challenge. While some health systems (e.g., those of the U.S. and the UK) distinguish the hospice model of care from other palliative care services, this distinction is not universally recognized. Furthermore, the definition of hospice varies across health systems. To avoid excluding potentially relevant studies but also to highlight research in hospice as a unique care delivery model, we present data for all identified articles and also present subgroup analyses of studies conducted in the UK and Ireland (68-70), Australia (71), New Zealand (72), the U.S. (73), Canada (74), Ireland, and Poland (75). These regions were included because they utilize hospice models consisting of distinct structures of care, at least some of which are delivered in the community/home setting and targeted towards individuals at the end of life. However, even among these systems, there is significant variability in how care is delivered at home versus facilities, regulations regarding concurrent disease-modifying treatments, distinct hospice providers, and payment models. We subsequently refer to these as *the hospice model subgroup*.

We excluded other regions from the subgroup analysis if the model of hospice appeared to consist predominantly of inpatient palliative care wards/units [e.g., China (76), Japan (77,78)], if there seemed to be no distinction between hospice and palliative care services [e.g., India (79), Bosnia (80)], or if we were unable to clarify the model of care within a given health system.

## **Results**

### *Data extraction*

The initial result yielded 12,062 results at the screening stage (*Figure 1*). Upon removing duplicates, we conducted

**Table 1** Overview of included studies

Authors	Title	Region	Hospice model subgroup	Sample size	Type of intervention	Randomized controlled trial?
Anderson <i>et al.</i> , 2008 (31)	The use of cognitive behavioural therapy techniques for anxiety and depression in hospice patients: a feasibility study	Ireland	Yes	11 patients	Psychotherapy	No
Cheng <i>et al.</i> , 2010 (32)	A pilot study on the effectiveness of anticipatory grief therapy for elderly facing the end of life	Hong Kong	No	26 patients	Psychotherapy	No
Chochinov <i>et al.</i> , 2011 (33)	Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial	Canada	Yes	326 patients	Psychotherapy	Yes
De Vincenzo <i>et al.</i> , 2023 (34)	Spiritual well-being, dignity-related distress and demoralisation at the end of life-effects of dignity therapy: a randomised controlled trial	Italy	No	67 patients	Psychotherapy	Yes
Fang & Li, 2017 (35)	Existential cognitive therapy for terminal cancer patients with depression or demoralization: A randomized controlled trial	Taiwan	No	43 patients	Psychotherapy	Yes
Galfin <i>et al.</i> , 2012 (36)	A brief guided self-help intervention for psychological distress in palliative care patients: a randomised controlled trial	UK	Yes	34 patients	Psychotherapy	Yes
Gallagher <i>et al.</i> , 2017 (37)	Perceptions of family members of palliative medicine and hospice patients who experienced music therapy	U.S.	Yes	50 family member-patient dyads	Complementary and alternative medicine	No
Havyer <i>et al.</i> , 2022 (38)	Impact of Massage Therapy on the Quality of Life of Hospice Patients and Their Caregivers: A Pilot Study	U.S.	Yes	25 patient-caregiver dyads	Complementary and alternative medicine	No
Henderson <i>et al.</i> , 2006 (39)	The use of benzodiazepines in palliative care	UK	Yes	93 patients	Pharmacology	No
Horne-Thompson & Grock, 2008 (40)	The effect of music therapy on anxiety in patients who are terminally ill	Australia	Yes	25 patients	Complementary and alternative medicine	Yes
Hudson <i>et al.</i> , 2013 (41)	Space to breathe: A new hospice based palliative care, respiratory and psychology programme for patients with severe COPD and their carers	UK	Yes	Unspecified	Psychotherapy	No
Hulbert-Williams <i>et al.</i> , 2021 (42)	Brief Engagement and Acceptance Coaching for Hospice Settings (the BEACHeS study): results from a Phase I study of acceptability and initial effectiveness in people with non-curative cancer	UK	Yes	10 patients	Psychotherapy	No
Husić & Mešić, 2010 (43)	Daily hospice: Depression and anxiety after mastectomy for breast cancer	Bosnia	No	70 patients	Psychotherapy and complementary and alternative medicine	No

Table 1 (continued)



Table 1 (continued)

Authors	Title	Region	Hospice model subgroup	Sample size	Type of intervention	Randomized controlled trial?
Iglewicz <i>et al.</i> , 2015 (44)	Ketamine for the treatment of depression in patients receiving hospice care: a retrospective medical record review of thirty-one cases	U.S.	Yes	31 patients	Pharmacology	No
Imrie & Troop, 2012 (45)	A pilot study on the effects and feasibility of compassion-focused expressive writing in Day Hospice patients	UK	Yes	13 patients	Other	No
Johnston <i>et al.</i> , 2022 (46)	'Playlist for Life' at the end of life: a mixed-methods feasibility study of a personalised music listening intervention in the hospice setting	UK	Yes	5 patients, 5 family, 5 staff	Complementary and alternative medicine	No
Kieszkowska-Grudny <i>et al.</i> , 2016 (47)	The place and role of Skype consultancies among palliative patients and the impact of this type of care on a quality of life, pain, anxiety and depression symptoms assessment in home hospice care patient	Poland	Yes	252 patients	Psychotherapy	No
Kutner <i>et al.</i> , 2008 (48)	Massage therapy versus simple touch to improve pain and mood in patients with advanced cancer: A randomized trial	U.S.	Yes	298 patients	Complementary and alternative medicine	Yes
Lloyd-Williams <i>et al.</i> , 2013a (49)	Antidepressant medication in patients with advanced cancer: an observational study	UK	Yes	629 patients	Pharmacology	No
Lloyd-Williams <i>et al.</i> , 2013b (50)	A pilot randomised controlled trial to reduce suffering and emotional distress in patients with advanced cancer	UK	Yes	100 patients	Psychotherapy	Yes
Lloyd-Williams <i>et al.</i> , 2018 (51)	Pilot randomised controlled trial of focused narrative intervention for moderate to severe depression in palliative care patients: DISCERN trial	UK	Yes	57 patients	Psychotherapy	Yes
Louis & Kowalski, 2002 (52)	Use of aromatherapy with hospice patients to decrease pain, anxiety and depression and to promote an increased sense of well-being	U.S.	Yes	17 patients	Complementary and alternative medicine	No
Macleod, 1998 (53)	Methylphenidate in terminal depression	New Zealand	Yes	26 patients	Pharmacology	No
Moon <i>et al.</i> , 2022 (54)	Effect of Laughter Therapy on Mood Disturbances, Pain, and Burnout in Terminally Ill Cancer Patients and Family Caregivers	South Korea	No	23 patient-caregiver dyads	Other	No
Moorey <i>et al.</i> , 2009 (55)	A cluster randomized controlled trial of cognitive behaviour therapy for common mental disorders in patients with advanced cancer	UK	Yes	80 patients	Psychotherapy	Yes

Table 1 (continued)

Table 1 (continued)

Authors	Title	Region	Hospice model subgroup	Sample size	Type of intervention	Randomized controlled trial?
Morrison <i>et al.</i> , 2013 (56)	A retrospective chart review of the efficacy of ketamine for depression in patients receiving hospice care	U.S.	Yes	31 patients	Pharmacology	No
Myrcik <i>et al.</i> , 2021 (57)	Influence of Physical Activity on Pain, Depression and Quality of Life of Patients in Palliative Care: A Proof-of-Concept Study	Poland	Yes	92 patients	Other	No
Nakayama <i>et al.</i> , 2009 (58)	A pilot study on effectiveness of music therapy in hospice in Japan	Japan	No	10 patients	Complementary and alternative medicine	No
Pedersen & Bjorkhem-Bergman, 2018 (59)	Tactile massage reduces rescue doses for pain and anxiety: an observational study	Sweden	No	41 patients	Complementary and alternative medicine	No
Pilgrem 2023 (60)	Social and therapeutic horticulture as a palliative care intervention	UK	Yes	218 patients	Complementary and alternative medicine	No
Plaskota <i>et al.</i> , 2012 (61)	A hypnotherapy intervention for the treatment of anxiety in patients with cancer receiving palliative care	UK	Yes	21 patients	Complementary and alternative medicine	No
Ramanathan <i>et al.</i> , 2017 (62)	Effect of a 12-week yoga therapy program on mental health status in elderly women inmates of a hospice	India	No	40 patients	Complementary and alternative medicine	Yes
Romeo <i>et al.</i> , 2015 (63)	Acupuncture to Treat the Symptoms of Patients in a Palliative Care Setting	U.S.	Yes	26 patients	Complementary and alternative medicine	No
Shea <i>et al.</i> , 2018 (64)	Improving end-of-life quality through the implementation and testing of a ketamine protocol for reduction of depression and pain	U.S.	Yes	10 patients	Pharmacology	No
Soden <i>et al.</i> , 2004 (65)	A randomized controlled trial of aromatherapy massage in a hospice setting	UK	Yes	42 patients	Complementary and alternative medicine	Yes
Sullivan <i>et al.</i> , 2017 (66)	Randomized, double-blind, placebo-controlled study of methylphenidate for the treatment of depression in SSRI-treated cancer patients receiving palliative care	U.S.	Yes	32 patients	Pharmacology	Yes
Sun <i>et al.</i> , 2021 (67)	Impact of spiritual care on the spiritual and mental health and quality of life of patients with advanced cancer	China	No	100 patients	Other	Yes

COPD, chronic obstructive pulmonary disease; DISCERN trial, focused narrative intervention; SSRI, selective serotonin reuptake inhibitors.

title and abstract screening on 7,672 citations. Three hundred eighty-two studies were selected for full-text review. On categorization, 92 full texts were identified as intervention studies and evaluated for inclusion in this study. Following full-text review, 37 studies were included

and underwent data extraction (Table 1).

### Study characteristics

Studies included were from populations globally, most

**Table 2** Study characteristics

Variable	Value, n [%]
Article type	
Full text	32 [86]
Abstract only	5 [14]
Study design	
Randomized controlled trials	13 [35]
Other clinical trials	16 [43]
Other study types	8 [22]
Hospice setting	
Inpatient	13 [35]
Home	5 [14]
Other	6 [16]
Multiple settings	9 [24]
Unspecified	4 [11]
Blinding	
Unblinded	28 [76]
Single-blinded	5 [14]
Unspecified	4 [11]
Cancer patient Inclusion	
Below 33%	1 [3]
Between 33 and 66%	1 [3]
Above 66%	26 [70]
Unspecified	9 [24]
Study location	
U.S.	9 [24]
UK	13 [35]
Other	15 [41]
Interventionist*	
Researcher	6 [16]
Mental health clinician	5 [14]
Nurse	4 [11]
Physician	4 [11]
Massage therapist	4 [11]
Music therapist	3 [8]
Interdisciplinary team	2 [5]
Not described	1 [3]
Other	9 [24]
Not relevant	4 [11]

\*, some studies had more than one interventionist.

commonly the UK (29.7%) (36,39,41,42,45,46,49-51,55,60,61,65) and the U.S. (24.3%) (37,38,44,48,52,56,63,64,66). Twenty-eight studies were from hospice model subgroup regions (U.S., UK, Canada, Australia, New Zealand, Ireland, and Poland). Most studies were conducted in inpatient hospices (35%) or multiple hospice types (24%), and over two-thirds of studies enrolled primarily cancer patients (*Table 2*). Among hospice model subgroup studies, fewer (25%) of studies were predominantly inpatient. In contrast, most studies conducted in health systems that deliver only inpatient hospice or do not distinguish between palliative care and hospice (67%) were conducted in inpatient settings. Sample sizes ranged from 11 to 629 participants (mean 82.9, standard deviation 122.9). This was similar among the hospice model subgroup studies (mean 97.7; standard deviation 136.4).

Fewer than half of all studies (35% total; 32% in the hospice model subgroup) were randomized controlled trials (33-36,40,48,50,51,55,62,65,66). Other study designs included were observational/retrospective cohort designs used to estimate treatment effects or feasibility and uncontrolled clinical trials. Among 19 studies with control groups, thirteen employed usual care or standard palliative care arm (33-36,43,47,50,51,54,55,63,65,67).

Studies' follow-up periods varied considerably from three days to six months, with an average of 6.8 weeks. Twelve studies did not provide information on the duration of their follow-up period.

Study participants (*Table 3*) were largely older adults. Of 31 studies that gave participant age information, only three studies had mean or median participant age under 60 years (and only one in the hospice model subgroup) (43,46,67). Most studies recruited more women than men; of 29 studies that gave gender breakdowns, 23 had a higher proportion of female participants. Only ten studies reported the racial and ethnic demographics of their participants. Among those studies providing this information in which white, British white or non-Hispanic white was an option, these were invariably the most highly represented groups in the study.

### *Interventions and interventionists*

The most common types of interventions involved the use of complementary alternative medicine, such as massage, acupuncture, music therapy, and yoga (35% of total studies; 36% of hospice model subgroup studies) rather than conventional BH interventions (psychotherapy



Table 3 Participant characteristics

Authors	Age* (years)	Age range (years)	Gender (N, %)	Race/ethnicity (N, %)	Education	Mortality during study	Other patient characteristics
Anderson <i>et al.</i> , 2008 (31)	65	28–64	Female (8, 72.7%), male (3, 27.3%)	Unspecified	Unspecified	1 death	–
Cheng <i>et al.</i> , 2010 (32)	81.8	66–97	Female (18, 69.2%), male (8, 30.8%)	Unspecified	Below primary school level (12, 46.2%)	1 death	Widowed (17, 65.4%), participants had an average of 5 comorbidities, 24% had pre-existing diagnosis of clinical depression
Chochinov <i>et al.</i> , 2011 (33)	65.1 (14.4)	22–102	Female (165, 50.6%) male (161, 49.4%)	White (291, 89.8%), other (33, 10.2%)	Less than high school education (30, 9.2%), completed high school (107, 32.8%), college or post-graduate training (188, 57.7%), could not answer (1, 0.3%)	28 deaths	Living alone (86, 26.3%), living with spouse (138, 42.3%), living with others (52, 15.9%), combination (50, 15.3%)
De Vincenzo <i>et al.</i> , 2023 (34)	73.2 (11.4)	Unspecified	Female (46, 68.7%), male (21, 31.3%)	Unspecified	No title (5, 7.5%), primary school (14, 20.9%), middle school level (11, 16.4%), high school level (27, 40.3%), master's degree (10, 14.9%)	36 deaths (11 before baseline, 25 during follow up)	Unmarried/widowed/separated (41, 61.2%), married (26, 38.8%)
Fang & Li, 2017 (35)	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	–
Galfin <i>et al.</i> , 2012 (36)	Treatment: 67.3 (11.60); Ctrl: 62.67 (11.86)	Treatment: 49–87; Ctrl: 49–86	Female (19, 55.9%), male (15, 44.1%)	Unspecified	No higher education (18, 52.9%)	2 deaths	Living alone (7, 20.6%), living with another person (27, 79.4%)
Gallagher <i>et al.</i> , 2017 (37)	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	None	–
Havyer <i>et al.</i> , 2022 (38)	77	Patients: 44–102	Female (10, 37.0%), male (17, 63.0%)	White (27, 100%)	Unspecified	6 deaths	–
Henderson <i>et al.</i> , 2006 (39)	73	62–84	Female (57, 62%), male (36, 38%)	Unspecified	Unspecified	Unspecified	Past psychiatric history (19, 20%)
Horne-Thompson & Grock, 2008 (40)	73.9 (13.32)	18–90	Female (14, 56%), male (11, 44%)	Unspecified	Unspecified	Unspecified	–
Hudson <i>et al.</i> , 2013 (41)	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	–
Hulbert-Williams <i>et al.</i> , 2021 (42)	65.7 (10.9)	46–81	Female (4, 40%), male (6, 60%)	Unspecified	Unspecified	3 deaths	Married/partnered (5, 50%)
Husić & Mešić, 2010 (43)	59.31 (9.67)	49.6–68.9	Female (70, 100%)	Unspecified	Unspecified	Unspecified	Living alone, (14, 20%), living with family (56, 80%) Low economic status (56, 80%), middle economic status, (26, 37.1%), high economic status (5, 7.1%)

Table 3 (continued)

Table 3 (continued)

Authors	Age* (years)	Age range (years)	Gender (N, %)	Race/ethnicity (N, %)	Education	Mortality during study	Other patient characteristics
Iglewicz <i>et al.</i> , 2015 (44)	68	44–89	Female (20, 64.5%), male (11, 35.5%)	Unspecified	Unspecified	Unspecified	Married (11, 35%)
Imrie & Troop, 2012 (45)	67.5 (14.9)	38–86	Female (8, 61.5%), male (5, 38.5%)	Unspecified	Unspecified	None	–
Johnston <i>et al.</i> , 2022 (46)	59	34–82	Female (10, 66.6%), male (5, 33.3%)	Unspecified	Unspecified	None	–
Kieszkowska-Grudny <i>et al.</i> , 2016 (47)	Stage 1: 68.9 (13.5)	Stage 1: 18–100	Stage 1: female (90.1, 63%), male (52.9, 37%)	Unspecified	Unspecified	None	–
	Stage 2: 69.4 (11.6)	Stage 2: 38–95	Stage 2: female (80.1, 56%), male (34, 44%)				
Kutner <i>et al.</i> , 2008 (48)	Massage therapy: 65.2 (14.4); Ctrl: 64.2 (14.4)	Unspecified	Female (232, 61.1%), male (148, 38.9%)	Non-Hispanic White (325, 85.5%), other (55, 14.5%)	College or higher (151, 39.2%)	17 deaths	Married/partnered (170, 44.7%), single (210, 55.3%)
Lloyd-Williams <i>et al.</i> , 2013a (49)	66 (12.87)	21–93	Female (422, 67%), male (207, 33%)	White British (613, 97%), other (16, 3%)	Unspecified	235 deaths	Married (323, 51%), single (living with family/friend) (58, 9%), single (living alone) (217, 35%), other (30, 5%)
Lloyd-Williams <i>et al.</i> , 2013b (50)	66	31–89	Female (68, 68%), male (32, 32%)	White/White British (96.9, 96.9%), other (3.1, 3.1%)	Unspecified	25 deaths	Married/cohabitating (55, 55%), not married/cohabitating (45, 45%)
Lloyd-Williams <i>et al.</i> , 2018 (51)	65.1	36–88	Female (39, 71%), male (16, 29%)	Unspecified	Unspecified	16 deaths	Living in one of 20% most deprived LSOAs in England (11.6, 20.4%)
Louis & Kowalski, 2002 (52)	61.8	42–79	Female (8, 47.1%), male (9, 52.9%)	White (15, 88.2%), other (2, 11.8%)	Unspecified	None	–
Macleod, 1998 (53)	63.8	42–79	Female (10, 38.5%), male (16, 61.5%)	Unspecified	Unspecified	None	–
Moon <i>et al.</i> , 2022 (54)	Intervention: 61.0 (12.61); Ctrl: 60.8 (10.63)	Unspecified	Female (13, 26.5%), male (36, 73.5%)	Unspecified	Unspecified	None	–
Moorey <i>et al.</i> , 2009 (55)	64 (12.6)	Unspecified	Unspecified	White British (62, 78%), other White (7, 8.8%), mixed race (2, 2.5%), Asian (2, 2.5%), Black Caribbean (3, 3.8%), Black African (1, 1.3%), other (3, 3.8%)	Unspecified	23 deaths, 16 too ill/possible deaths	Married or cohabitating (48, 60%), widowed (15, 18.8%), divorced or separated (11, 13.8%), single (6, 7.5%)  Social class 1 or 2 (25, 31.3%), social class 3 (34, 42.5%), social class 4 or 5 (21, 26.3%)

Table 3 (continued)

Table 3 (continued)

Authors	Age* (years)	Age range (years)	Gender (N, %)	Race/ethnicity (N, %)	Education	Mortality during study	Other patient characteristics
Morrison <i>et al.</i> , 2013 (56)	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	–
Myrcik <i>et al.</i> , 2021 (57)	66.5 (9.6)	41–90	Female (57, 62%), male (35, 38%)	Unspecified	Unspecified	None	–
Nakayama <i>et al.</i> , 2009 (58)	73.1 (9.7)	Unspecified	Female (7, 70%), male (3, 30%)	Japanese (10, 100%)	Unspecified	None	–
Pedersen & Bjorkhem-Bergman, 2018 (59)	71	38–95	Female (24, 58.5%), male (17, 41.5%)	Unspecified	Unspecified	Unspecified	–
Pilgrem 2023 (60)	75.6 (13.5)	30–99	Female (133, 61%), males (85, 39%)	Unspecified	Unspecified	Unspecified	–
Plaskota <i>et al.</i> , 2012 (61)	60	46–80	Female (8, 72.7%), male (3, 27.3%)	Unspecified	Unspecified	2 deaths	–
Ramanathan <i>et al.</i> , 2017 (62)	Experimental group: 68.9 (7.55); wait-listed ctrl: 68.2 (8.8)	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	–
Romeo <i>et al.</i> , 2015 (63)	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	–
Shea <i>et al.</i> , 2018 (64)	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	Unspecified	–
Soden <i>et al.</i> , 2004 (65)	73	44–85	Female (32, 76%), male (10, 24%)	Unspecified	Unspecified	3 deaths	–
Sullivan <i>et al.</i> , 2017 (66)	64	Unspecified	Female (7, 21.9%), male (25, 78.1%)	White (31, 96.9%), Black (1, 3.1%)	Treatment: 13.5 years (SD =2.0), Ctrl: 11.9 years (SD =3.3)	2 deaths	Married/partnered (12, 37.5%)
Sun <i>et al.</i> , 2021 (67)	Treatment: 50.1 (12.4); Ctrl: 54.9 (13.8)	27–83	Female (62, 72.9%), male (23, 27.1%)	Han (76, 89.4%), Manchu (7, 8.2%), Hui (1, 1.2%), Mongolian (1, 1.2%)	Primary school (15, 17.6%), junior high school (28, 43.1%), high school (22, 25.9%), university (18, 21.2%), postgraduate and above (2, 2.4%)	None	Married (71, 83.5%); monthly household income (in CNY) ≤1,000 (20, 23.5%), 1,000–2,999 (32, 37.6%), 3,000–4,999 (21, 24.7%), 5,000–6,999 (5, 5.9%), ≥7,000 (7, 8.2%)

\* , mean or mean (standard deviation). LSOAs, lower layer super output areas.

or psychopharmacology) (37,38,40,46,48,52,58–63,65). Approximately one-third of the studies involved psychotherapeutic interventions, most frequently cognitive therapy (three studies) (31,35,55) and dignity therapy (two studies) (33,34) (Table 4). Fewer than 20% of interventions

involved pharmacologic treatment, most frequently rapid-acting psychotropics such as ketamine (three studies) (44,56,64) and methylphenidate (two studies) (53,66). Of note, all pharmacotherapy studies were conducted in the hospice model subgroup.

**Table 4** Interventions and outcomes

Authors	Intervention description	Control condition	BH outcomes measured	Measures	Results of note	Significant
Anderson <i>et al.</i> , 2008 (31)	Brief cognitive behavioral therapy	None	Anxiety, depression, levels of happiness	HADS; VAS	Decreases in anxiety (mean HADS-A 10 to 6.6; $P=0.03$ ) and depression (mean HADS-D 9.9 to 7.2; $P=0.04$ ) pre- and post-test were statistically significant	Depression, anxiety
Cheng <i>et al.</i> , 2010 (32)	Anticipatory grief therapy	None	Depression	GDS-15 (Chinese version)	There was significant improvement in average depression immediately after intervention (mean GDS-15 from 7.57 to 6.13, $P<0.05$ )	Depression
Chochinov <i>et al.</i> , 2011 (33)	Dignity therapy	Standard palliative or client-centered care	Anxiety, depression, desire for death, suffering, hopelessness, suicidal ideation	HADS; SISC	No significant differences on HADS. Participants in intervention arm less likely to report depression/sadness on post-study survey than participants in control arms ( $P<0.01$ )	N/A
De Vincenzo <i>et al.</i> , 2023 (34)	Dignity therapy	Standard palliative care	Psychological distress	PDI	Decrease in psychological distress from baseline to follow-up in intervention group (mean 18.9 to 17.6 on PDI psychology subscale; $P=0.02$ ), but not control	Distress
Fang & Li, 2017 (35)	Existential cognitive therapy	Usual care	Depression	PHQ-9	No differences between groups; both intervention and control groups trended better in depression as time progressed	N/A
Galfin <i>et al.</i> , 2012 (36)	Guided self-help training	Usual care	Anxiety, depression	BDI and GAD-7	Those in the intervention group had significantly decreased anxiety compared to those in the control group (mean 13.5 to 6.07 on GAD-7; $P<0.001$ )	Anxiety
Gallagher <i>et al.</i> , 2017 (37)	Music therapy	None	Anxiety, depression	0–10 points numeric rating scale	Significant reductions in depression after intervention period (2.4 to 0.9 on 10-point scale; $P=0.01$ )	Depression
Havyer <i>et al.</i> , 2022 (38)	Massage therapy	None	Anxiety, depression	ESAS	40.9% of patients experienced improvement in depression and 54.5% experienced improvements in anxiety	N/A
Henderson <i>et al.</i> , 2006 (39)	Benzodiazepines	None	Indication for being prescribed benzodiazepines and progress	Medical records	70% of patients appeared clinically improved with benzodiazepines	N/A
Horne-Thompson & Grock, 2008 (40)	Music therapy	Volunteer engagement	Anxiety, depression	ESAS	8/13 intervention group and 1/11 control group participants experienced reduction in ESAS anxiety score ( $P<0.005$ )	Anxiety
Hudson <i>et al.</i> , 2013 (41)	Palliative care, respiratory, and psychology program	None	Anxiety, depression	HADS	No changes in HADS scores	N/A
Hulbert-Williams <i>et al.</i> , 2021 (42)	Brief engagement and acceptance coaching	None	Psychological distress	Distress thermometer	Intervention perceived as feasible and efficacious	N/A
Husić & Mešić, 2010 (43)	Daily hospice care	Usual care	Anxiety, depression	Zung's self-rating scales	Reduction in depression score (59.85 to 55.65 on Zung's self-rating scale; $P<0.0001$ ) and anxiety score (54.97 to 43.43; $P<0.0001$ ). Control group worsening depression scores over time ( $P<0.0001$ ) but also improved anxiety ( $P=0.002$ )	Depression, anxiety

Table 4 (continued)

Table 4 (continued)

Authors	Intervention description	Control condition	BH outcomes measured	Measures	Results of note	Significant
Iglewicz <i>et al.</i> , 2015 (44)	Ketamine	None	Therapeutic effect on depression, global improvement of depression	CGI	Participants demonstrated positive therapeutic effects up until one week post-dose. Most participants (80%) had positive global improvement at some point post-dosing	N/A
Imrie & Troop, 2012 (45)	Self-compassion-focused expressive writing	Stress-focused writing task	Depression, self-esteem	SISE; SDHS	Pilot study; no generalizable impact on mood and self-esteem	N/A
Johnston <i>et al.</i> , 2022 (46)	Playlist for life music intervention	None	Anxiety, depression	HADS	Pilot study; no generalizable impact on HADS	N/A
Kieszkowska-Grudny <i>et al.</i> , 2016 (47)	Skype consultancy	Standard palliative care	Anxiety, depression	HADS <sup>2</sup>	Intervention group had higher depression scores than control group after intervention period (no magnitude given; $P < 0.05$ )	N/A
Kutner <i>et al.</i> , 2008 (48)	Massage therapy	Simple touch	Mood	MPAC	Statistically significant improved mood (mean change of 1.58 on MPAC)	Mood
Lloyd-Williams <i>et al.</i> , 2013a (49)	Anti-depressant medication	None	Depression	PHQ and BEDS	No differences in depression scores between or within groups over time	N/A
Lloyd-Williams <i>et al.</i> , 2013b (50)	Focused narrative interviews	Usual care	Anxiety, depression, spiritual well-being	BEDS, ESAS, FACIT	No significant results; improvements in depression and anxiety based on trends	N/A
Lloyd-Williams <i>et al.</i> , 2018 (51)	Focused narrative intervention	Usual care	Depression	PHQ-9	No significant impact on depression identified	N/A
Louis & Kowalski, 2002 (52)	Humidified water and essential lavender oil treatments	Within subjects design - control session	Anxiety, depression, well-being	Verbal 11-point scales	No significant differences in anxiety and depression scores by treatment group or pre/post intervention status	N/A
Macleod, 1998 (53)	Methylphenidate	None	Depression	CGI	26.8% of participants had "moderate" or "marked" therapeutic responses to methylphenidate	N/A
Moon <i>et al.</i> , 2022 (54)	Laughter therapy	Usual care	Mood	Mood disturbance LASA scale	Mood disturbance decreased significantly in intervention group (mean difference $-1.91$ ; $P < 0.001$ ) from pre- to post-test and increased significantly in control group (mean difference $1.59$ ; $P < 0.001$ )	Mood
Moorey <i>et al.</i> , 2009 (55)	Cognitive behavioral therapy	Usual care	Anxiety, depression	HADS	Participants in the CBT group had significantly lower anxiety over time compared with the control group ( $P = 0.01$ )	Anxiety
Morrison <i>et al.</i> , 2013 (56)	Ketamine	None	Depression	CGI	Patients who received ketamine were more likely than not to have a clinical response (magnitude not provided; $P < 0.011$ )	Clinical response
Myrcik <i>et al.</i> , 2021 (57)	Physical activity education program	None	Depression	BDI	Mean depression decreased between baseline and last post-test (mean $18.48$ to $15.65$ on BDI; significance not reported)	N/A
Nakayama <i>et al.</i> , 2009 (58)	Music therapy	None	Mood	Mood inventory form	Mean depression and anxiety trended down after music therapy, though results were not significant	N/A

Table 4 (continued)

Table 4 (continued)

Authors	Intervention description	Control condition	BH outcomes measured	Measures	Results of note	Significant
Pedersen & Bjorkhem-Bergman, 2018 (59)	Massage therapy	None	Anxiety	ESAS	Improvement in anxiety after intervention (2.3 points on ESAS; $P < 0.001$ ). Reduction in anxiety rescue doses	Anxiety
Pilgrim 2023 (60)	Therapeutic horticulture	None	Distress	Distress thermometer	Distress scores showed statistically significant mean reduction of 54–60% after each session	Distress
Plaskota <i>et al.</i> , 2012 (61)	Hypnotherapy	None	Anxiety, depression	HADS; ESAS	After four intervention sessions, there were significant decreases in both anxiety (−4.73 on HADS-A; $P < 0.01$ ) and depression (−2.82 on HADS-D; $P < 0.05$ )	Depression, anxiety
Ramanathan <i>et al.</i> , 2017 (62)	Yoga	Waitlist	Anxiety, depression	Hamilton Anxiety Rating Scale; Hamilton Depression Rating Scale	Anxiety and depression were statistically significantly reduced between intervention and control groups as well as over time within the intervention group	Depression, anxiety
Romeo <i>et al.</i> , 2015 (63)	Acupuncture	Usual care	Anxiety, depression	ESAS	Depression (3.9 to 2.9; $P < 0.001$ ) and anxiety (3.7 to 2.2; $P < 0.001$ ) were significantly reduced after the intervention	Depression, anxiety
Shea <i>et al.</i> , 2018 (64)	Ketamine	None	Depression	Unspecified	Ketamine was safe and effective for depression. Statistical analyses were not outlined	N/A
Soden <i>et al.</i> , 2004 (65)	Massage with or without aromatherapy	Usual care	Anxiety, depression, psychological symptom distress	HADS	No differences between groups over time	N/A
Sullivan <i>et al.</i> , 2017 (66)	Methylphenidate plus SSRI	Placebo plus SSRI	Depression	Montgomery-Asberg Depression Rating Scale	Both groups had improvements in depression across time (HADS decrease of 3.6 in the methylphenidate group and 2.3 in the control), but there was not a difference in the control and intervention groups	N/A
Sun <i>et al.</i> , 2021(67)	Spiritual care plan	Usual care	Anxiety, depression, spiritual health	HADS; The European Organization for Cancer Research and Treatment Quality of Life Questionnaire-Spiritual Well-Being	Statistically significantly higher proportion of anxiety- and depression-free patients in the intervention (anxiety-free: 95.45%, depression-free: 97.73%) than in the control group (anxiety-free: 60.98%, depression-free: 85.37%)	Depression, anxiety

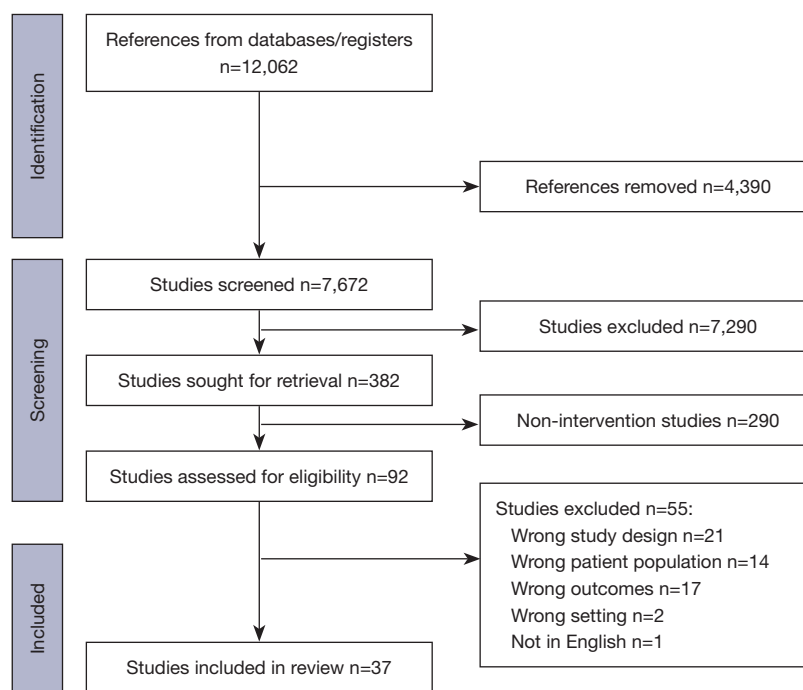
BH, behavioral health; HADS, Hospital Anxiety and Depression scale (variations of this scale exist e.g., HADS-B, HADS-D); VAS, Visual Analogue Scale; GDS-15, Geriatric Depression Scale; SISC, Structured Interview for Symptoms and Concerns; N/A, not applicable; PDI, Patient Dignity Inventory; PHQ, Patient Health Questionnaire (variations of this scale exist e.g. PHQ-9); BDI, Beck Depression Inventory; GAD-7, Generalized Anxiety Disorder Assessment; ESAS, Edmonton Symptom Assessment; CGI, Clinical Global Impression Scale; SISE, Single Item Self-Esteem Scale; SDHS, Short Depression-Happiness Scale; MPAC, Memorial Pain Assessment Card; BEDS, Brief Edinburgh Depression Scale; FACIT, Functional Assessment of Chronic Illness Therapy; LASA, Linear Analog Self-Assessment; CBT, cognitive behavioral therapy; SSRI, selective serotonin reuptake inhibitor.

While studies often used more than one interventionist, interventions were most often undertaken by research interventionists (16%) (Table 2). Only a minority of studies involved interventions delivered by non-physician mental health clinicians (psychologists, social workers). Other interventionists included nurses (10.8%), physicians (psychiatrists, psycho-oncologists) (10.8%), massage therapists (10.8%), music therapists (8.1%), or

interdisciplinary teams (5.4%).

Studies employing session-based interventions ranged in the number of sessions and duration of intervention sessions. Studies ranged in duration from single-session interventions (34,37,40,50-52,56,58) to 28 sessions (in a study of a daily guided self-help intervention) (36). Intervention duration ranged from 20 minutes to 1.5 hours. Ten studies did not provide information about the duration,





**Figure 1** PRISMA-ScR diagram.

timing, and frequency of intervention sessions.

*Table 3* presents the analyzed studies' BH outcomes. Studies universally measured symptoms rather than diagnoses (e.g., depressive symptoms rather than major depressive disorder). The most commonly employed measures used to assess treatment effect included the Hospital Anxiety and Depression Scale (HADS) (in 24% of all studies and 32% of hospice model subgroup studies) (81), the Edmonton Symptom Assessment System-Revised (ESAS) (16% total; 14% of hospice model subgroup studies) (82), the Clinical Global Impression Scale (CGI) (8%) (83), and the Patient Health Questionnaire (PHQ) (8%) (84). Depressive symptoms (81% of all studies; 79% of hospice model subgroup studies) and anxiety symptoms (59% of all studies; 57% of hospice model subgroup studies) were the most frequent BH outcomes. Other constructs measured included distress (n=5), mood (n=3), and well-being (n=4). As a note, we distinguished mood from depression scales because the three studies that used mood as an outcome utilized subjective mood scales that asked about a respondent's overall mood rather than about depression explicitly (e.g., the Memorial Pain Assessment Card asks respondents to rate themselves from "worst mood" to "best mood") (85). A minority of studies (11%, both hospice model subgroup) employed unvalidated scales or were not

specific in their measurement approach. No studies focused on substance use disorders, post-traumatic stress disorder, or serious mental illnesses like psychotic disorders.

### Study results

Notable study outcomes are described in *Table 3*. Slightly fewer than half (17 studies; 46%) of studies demonstrated statistically significant findings related to a BH outcome (i.e., reduction in depression/anxiety symptoms over time between groups) (31,32,34,36,37,40,43,48,54-56,59-63,67). Among the 27 studies in the hospice model subgroup, 9 (33%) had statistically significant results.

Among those studies demonstrating significant results, four significantly improved only anxiety symptoms (36,40,55,59). Two of these studies were complementary and alternative medicine (CAM) interventions, and two were psychotherapy interventions. Two studies significantly improved only depression symptoms (32,37): one CAM study and one psychotherapy intervention. Six studies significantly improved both anxiety and depression symptoms (31,43,61-63,67). Interventions that improved both anxiety and depression symptoms were CAM [3], spiritual care/other [1], combined psychotherapy and CAM [1], and psychotherapy [1]. The remaining five studies

improved mood, distress, or overall clinical impression (34,48,54,56,60). These studies consisted of CAM [3], pharmacologic [1], and psychotherapy [1] interventions. Overall, among the 12 studies that significantly improved depression and/or anxiety symptoms, four employed psychotherapy interventions (31,32,36,55), six employed CAM interventions (37,40,59,61-63), one employed combined psychotherapy and complementary and alternative intervention (43), and one employed spiritual care (67).

Among studies that provided a magnitude of change, improvements in depression and anxiety symptoms were relatively modest. For instance, among the two studies utilizing the HADS and demonstrating significant improvements in depression and anxiety symptoms, the magnitude of change on the HADS subscales ranged from 2.7 to 4.7 points (31,61). Of note, these values exceed the proposed minimally important difference of 1.5 points on each component of the HADS (derived from patients with cardiovascular and pulmonary disease) (86,87). Similarly, studies utilizing the ESAS and demonstrating significant improvements in depression and anxiety symptom scores ranged from 1.0 to 2.3 points change on a 10-point scale (59,63). These changes overlap and may exceed the minimally significant difference in individual ESAS symptom measures (88). Most studies measured improvements immediately after the intervention or study, and few demonstrated sustained improvement in symptoms over time following the intervention.

## Discussion

We present the findings of a scoping review of BH interventions employed in the hospice setting. Hospice is arguably the most significant model of end-of-life care from a public health perspective. In 2020, over 5,000 hospices provided care to over 1.7 million Americans. Hospice patients experience high rates of BH symptoms, including depression, anxiety, and agitation (9,12). Unmet BH needs negatively impact patients' quality of life, overall symptom control, and functional status, and diminish caregivers' quality of life and health (16,89-91).

Despite the prevalence and impact of BH conditions in the hospice setting, we found a striking dearth of research on BH interventions targeting hospice patients. Many of the studies that we did identify were small feasibility studies. Furthermore, many included studies focused only partially on BH outcomes or utilized more general CAM

interventions that were not mechanistically focused on BH outcomes (e.g., massage and aromatherapy). We found few randomized controlled trials of psychopharmacologic or psychotherapeutic interventions specifically focused on BH conditions. Furthermore, although most studies looked at depression and/or anxiety symptoms, few focused on delirium/agitation despite its substantial prevalence among hospice patients. Measurement tools were heterogeneous and largely focused on symptom states rather than BH diagnoses. We did not identify any studies on BH interventions for other conditions, such as post-traumatic stress disorder or substance use disorders, despite the burden of these conditions among patients with serious illness (92-94).

The gaps we identified were more pronounced in U.S.-based studies. Among studies conducted in the U.S., we identified only one randomized controlled trial of a psychopharmacologic BH intervention and no study that employed a randomized controlled trial design to test psychotherapy. This is significant because the model of hospice care differs significantly across regions, possibly limiting generalizability. The U.S. model of predominantly home-based care in a capitated payment structure increasingly provided by for-profit private agencies may not translate to other settings (95). For instance, the most represented region in our study was the UK, where a greater proportion of hospice services are provided in inpatient or residential settings (96). Perhaps as a result, included studies underrepresented home-based hospice and over-represented inpatient hospice settings relative to the hospice care landscape in the U.S.

Nearly 40% of included studies involved interventions we categorized as complementary or alternative. Utilization of such interventions may reflect the challenges of deploying traditional BH interventions (psychotherapy and psychopharmacology) in hospice settings, including stigma and prognostic limitations. In addition to being more acceptable to patients and appropriate for the patient population, such interventions may be more feasible in the U.S. hospice care delivery system.

Hospice payment and accountability policies in the U.S. present several barriers to integrating specialist-delivered BH interventions. Hospice care in the U.S. is paid on a capitated basis (that is, hospice organizations are paid per patient per day of care). Payment for the most common form of hospice care, routine home care, hovers between 150–250 U.S. dollars per patient per day, depending on the duration of the patient's hospice enrollment and the

hospice's adherence to quality reporting guidelines (97). Payments delivered to hospice programs must support a range of requisite services provided by an interdisciplinary team, including a physician, a registered nurse, a social worker, and a spiritual care provider (98). In addition to the inherent challenges that the capitated model presents in providing additional BH services, most hospices operating in the U.S. function in a for-profit model that disincentivizes delivery of non-requisite services (95,99). Hospices participating in quality reporting to the Centers for Medicare & Medicaid Services (CMS) are eligible for higher payment rates. However, hospice quality measures and administrative data do not include BH measures. The consumer survey that constitutes the third quality reporting domain contains 2–4 items about anxiety, sadness, and restlessness/agitation (100). In sum, the care delivery structures in the U.S. hospice system and payment, quality, and accountability policies may disincentivize research and care delivery contingent on BH specialists. In contrast, some complementary and alternative interventions studied, such as aromatherapy or therapeutic music listening, can be delivered using the existing hospice workforce.

Our findings generally emphasize the need for and the challenges of conducting psychopharmacology research among hospice patients. In the U.S., most hospice medication kits contain a small number of medications targeting BH symptoms; these include lorazepam and haloperidol, two of the most commonly prescribed hospice medications (101,102). As many as 80% of hospice patients are prescribed benzodiazepines, and as many as 65% are prescribed antipsychotics (103). Furthermore, many hospice patients may be prescribed antidepressants, though treatment is often interrupted towards the end of life (104). In the absence of high-quality psychopharmacologic trials in the hospice setting, the widespread prescribing and/or deprescribing of psychotropics in the hospice setting is either not evidence-based practice, or, at best, reliant on evidence extrapolated from other settings. The extent to which psychopharmacologic agents are utilized in the hospice setting suggests a critical need for evidence-based guidelines leveraging data from hospice settings.

Our findings further reinforce the discordance between the high utilization of hospice and the challenges in conducting research in hospice settings. Because hospice organizations are often distinct from academic medical institutions and may not have built-in research infrastructure, conducting clinical trials in hospice settings poses unique challenges (4). This is reflected in our data;

only one of the seven larger trials ( $\geq 100$  persons) included in the current study was conducted in the U.S., with the rest conducted in regions with more integration between hospice services and other medical services. However, despite these barriers, building a more robust hospice research infrastructure could provide value to various stakeholders, including payors, patients and caregivers, and clinicians.

Our study contributes to the field of hospice research, focusing specifically on hospice care settings rather than all palliative care more broadly. We identify key research gaps with direct implications for current clinical practice. However, our study has several limitations. The *a priori* criteria we established in our protocols introduced significant heterogeneity into our study, and thus, our findings must be couched in a broader process-level challenge. Our goal in conducting this study—to explore the landscape of BH research in the hospice setting—was informed by our context as researchers and clinicians in the U.S. Hospice care in the U.S. is a distinct model of care with specific payment and care delivery structures that distinguish it from other forms of palliative and end-of-life care. As such, we elected to limit our search and inclusion criteria to hospice and not include other palliative and end-of-life care models. We specifically chose to privilege the care setting (hospice) over the population (patients at the end of life) because of the distinct challenges of conducting research and implementing interventions in the (U.S.) hospice setting. In conducting our study, we found that much of the terminology that we used did not translate into other health systems. Many health systems interchangeably use language such as palliative care, hospice, and end-of-life care. Furthermore, among systems that distinguish hospice as a specific model of care, the definition of the model may vary significantly and range from a blanket term for palliative care to a model of predominantly inpatient end-of-life care to largely community-based end-of-life care. Many of the nuances, such as the possibility of receiving hospice care concurrently with disease-oriented treatments (which is generally not allowed in U.S. hospice care for adults), differ between settings. As a result, we may have excluded studies that were conducted in applicable settings, perhaps using different terminology, and we included studies that do not reflect the hospice context in which we were interested. We attempted to mitigate this challenge by specifying those studies conducted in the U.S. and those undertaken in systems with similar hospice care structures (the hospice model subgroup); this presents a

major limitation and an important process-level finding of our study. In attempting to address this weakness in our study, we were surprised to find the overall shortage of descriptions of hospice as a care model across settings. In this sense, a key recommendation emerging from our study is the need for literature describing models of hospice care across health settings to ensure that researchers conducting studies such as ours oriented around a health delivery model can appropriately include studies conducted globally.

In addition to the systems-level heterogeneity, our study has several other limitations. Our objectives of understanding the research landscape led us to be broad in including studies. As such, some included studies were nebulous regarding whether their design met inclusion criteria and whether they were sufficiently focused on BH outcomes. We also decided not to appraise study quality, which is a limitation in using our work to generate clinical recommendations. However, we felt that study appraisal was inconsistent with our objective of broadly describing existing literature. Finally, as is often the case in hospice and palliative care research, our studies overrepresented cancer patients; 70% of our studies included predominantly or exclusively patients with cancer diagnoses.

Our study represents a clarion call for greater investment in hospice research infrastructure and the use of clinical trials to address the pressing needs of hospice patients. We identified a striking lack of BH intervention research focused on hospice patients compared to specialized serious illness care like oncology or other palliative care models. Addressing this gap requires a multifactorial approach. Investing in research infrastructure and partnerships between private hospices and academic medical institutions could help facilitate research in hospice settings. This is of particular importance given the unique features of the U.S. hospice care model. Further investment in general BH-palliative care integration is also critical. In particular, there is a need to increase the BH workforce and leverage existing BH experts such as hospice and palliative care social workers as investigators and clinicians supported in carrying out BH assessments and interventions (10,105).

## Conclusions

We conducted a scoping review of studies focused on BH interventions in the hospice setting. We identified 37 studies from hospice settings in 16 regions, including complementary and alternative, psychotherapeutic, and psychopharmacologic interventions. Most studies

were small pilot and feasibility studies, while few studies employed adequately powered clinical trials to test for treatment effects. In addition, relatively few studies took place in the U.S., and these studies tended to be smaller, possibly reflecting structural barriers to conducting hospice research in the U.S. Our study highlights two significant gaps in hospice research. First, we identified substantial heterogeneity in terminology around hospice services between health systems, making it difficult to make inferences about research conducted between different health systems. This finding highlights a need for resources to help scholars and health service users across settings understand similarities and differences across models of care in different health systems. Many existing studies we identified were conducted in settings where hospice care was analogous to palliative care more generally, rather than settings with a distinct hospice model of care different from general palliative care services. Second, our study identifies a significant gap in hospice research. Despite the public health importance of the hospice model and the prevalence of impactful BH conditions in patients receiving hospice care, there are few randomized controlled trials of BH interventions for hospice patients. As such, current BH practices in hospice settings, including high utilization of benzodiazepines and antipsychotics, may not be driven by evidence or represent optimal end-of-life BH care.

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## Footnote

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*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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## Appendix 1 Search strategy

Pubmed (11/09/21 and 05/25/23.):

("Hospice Care"[Mesh] OR "Hospices"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR hospice\*[tiab]) AND ("Substance-Related Disorders"[Mesh] OR "Mental Disorders"[Mesh] OR "Behavioral Symptoms"[Mesh] OR anxiety OR depression OR "mental health")

Medline (11/09/21 and 05/25/23.):

1. exp Hospice Care/
2. ((bereav\* or hospice\*) adj2 (care or program\*)).ti,ab.
3. exp Hospices/
4. hospice\*.ti,ab.
5. exp "Hospice and Palliative Care Nursing"/
6. ((hospice\* or palliative) adj2 nurs\*).ti,ab.
7. 1 or 2 or 3 or 4 or 5 or 6
8. exp Substance-Related Disorders/
9. ((substance or drug or chemical) adj2 (abuse\* or dependen\* or disorder\*)).ti,ab.
10. exp Mental Disorders/
11. ((mental or behavior\* or psychiatric) adj1 (disorder\* or illness\* or disease\* or health)).ti,ab.
12. exp Behavioral Symptoms/
13. (behavioral adj2 symptom\*).ti,ab.
14. exp Anxiety/
15. anxiet\*.ti,ab.
16. exp Depression/
17. depressi\*.ti,ab.
18. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. 7 and 18

EMBASE (11/09/21 and 05/25/23.):

1. exp hospice care/
2. ((bereav\* or hospice\*) adj2 (care or program\*)).ti,ab.
3. exp hospice/
4. hospice\*.ti,ab.
5. exp palliative nursing/
6. ((hospice\* or palliative) adj2 nurs\*).ti,ab.
7. 1 or 2 or 3 or 4 or 5 or 6
8. exp drug dependence/
9. ((substance or drug or chemical) adj2 (abuse\* or dependen\* or disorder\*)).ti,ab.
10. exp mental disease/
11. exp anxiety/
12. anxiet\*.ti,ab.
13. exp depression/
14. depressi\*.ti,ab.
15. 8 or 9 or 10 or 11 or 12 or 13 or 14
16. 7 and 15

Cochrane (11/09/21 and 05/25/23.):

- #1 MeSH descriptor: [Hospice Care] explode all trees
- #2 ((bereav\* or hospice\*) NEAR/2 (care or program\*))
- #3 MeSH descriptor: [Hospices] explode all trees
- #4 hospice\*
- #5 MeSH descriptor: [Hospice and Palliative Care Nursing] explode all trees
- #6 ((hospice\* or palliative) NEAR/2 nurs\*)
- #7 #1 or #2 or #3 or #4 or #5 or #6
- #8 MeSH descriptor: [Substance-Related Disorders] explode all trees
- #9 ((substance or drug or chemical) NEAR/2 (abuse\* or dependen\* or disorder\*))
- #10 MeSH descriptor: [Mental Disorders] explode all trees
- #11 ((mental or behavior\* or psychiatric) NEAR/1 (disorder\* or illness\* or disease\* or health))
- #12 MeSH descriptor: [Behavioral Symptoms] explode all trees
- #13 (behavior\* NEAR/2 symptom\*)
- #14 MeSH descriptor: [Anxiety] explode all trees
- #15 anxiet\*
- #16 MeSH descriptor: [Depression] explode all trees
- #17 depressi\*
- #18 #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17
- #19 7 and #18

Scopus (11/09/21 and 05/25/23.):

(TITLE-ABS-KEY (anxiet\* OR depressi\* OR ((drug\* OR substance) W/1 abuse\*)) AND (TITLE-ABS-KEY (hospice\* OR palliative))

## Appendix 2 Data extraction tool

### Preview

#### Basic Information

Authors

Title

Year

Journal

#### Methodology

Study design

1.  RCT
2.  Uncontrolled trial/open pilot
3.  Epidemiology
4.  Retrospective cohort study
5.  Qualitative

6.  Other

Study type

1.  Pilot/feasibility study
2.  Fully powered study

Blinding

1.  Not blinded at all
2.  Single-blinded
3.  Double-blinded
4.  Not applicable

What is the control condition/control intervention (if RCT)?

Length of total study follow-up

Length of post-intervention follow-up

Primary outcomes of interest



BH = behavioral health

QoL = quality of life

non-BH = non-behavioral medical

**Type of outcome (BH, QoL, non-BH) Outcome Description Measurement Tool**

**Outcome 1**

**Outcome 2**

**Outcome 3**

Secondary outcomes of interest

**Type of outcome (BH, QoL, non-BH) Outcome Description Measurement Tool**

**Outcome 1**

**Outcome 2**

**Outcome 3**

## Characteristics of included studies

Country

1.  United States

2.  Other

Sample size

## Population

Types of hospice care received by study participants

1.  Inpatient hospice

2.  Home hospice

3.  Other outpatient hospice

4.  Unspecified

Does the whole sample consist of hospice patients?

1.  Yes

2.  No

If not, what is the % of non-hospice patients?

If applicable, what are the settings of care for the non-hospice patients included in the sample?

1.  Hospital
2.  Nursing home
3.  Ambulatory care
4.  Home care
5.  Other

What % of the sample consists of cancer patients?

1.  Below 33%
2.  Between 33 and 66%
3.  Between 66 and 100%
4.  Unspecified

Main eligibility criteria/main features defining the population studied

## Intervention

Intervention type

1.  Pharmacologic
2.  Psychotherapeutic
3.  Other non-pharmacologic
4.  Model of care

5.  Other

Intervention details

**Name/description of the intervention**

**Duration/length**

**Dose**

**Frequency**

**Interventionist**

## Results

Main findings

**Outcome of interest   Observed effect   Is this result statistically significant?**

**Result 1**

**Result 2**

**Result 3**

**Outcome of interest   Observed effect   Is this result statistically significant?**

**Result 4**

**Result 5**

Additional comments