

Arts Engagement Facilitated by Artists With Individuals With Life-limiting Illness: An Integrative Review of the Literature

Jennifer Baxley Lee (✉ jlee@arts.ufl.edu)

Ulster University, Institute of Nursing and Health Sciences Research, Northern Ireland, UK University of Florida, Center for Arts in Medicine, College of the Arts, Florida, USA <https://orcid.org/0000-0003-3403-5044>

Sonja McIlpatrick

Ulster University Faculty of Life and Health Sciences

Lisa Fitzpatrick

Ulster University Faculty of Arts Humanities and Social Sciences

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Abstract

Background

Living with life-limiting illness significantly impacts quality of life. A growing body of evidence suggests that arts engagement, facilitated by artists, promotes a sense of well-being and connection with others. However, much of the evidence is drawn from the use of the arts in broad health contexts or from creative arts therapies' literature. This review aimed to systematically identify and synthesize existing evidence in order to reveal key knowledge gaps and to inform future research and practice.

Methods

An integrative review of the literature was conducted using a pre-defined, comprehensive search strategy. Databases searched included: PubMed inclusive of MEDLINE, CINAHL, PsycINFO, Scopus, Web of Science, and Embase. Search terms included variations on *visual arts*, *literary arts*, and *performing arts*; *service users* or *patients*; and *palliative care* or *end-of-life care*. The quality and rigor of articles were scored using Hawker and colleagues' tool designed to systematically appraise disparate studies. Synthesis was conducted using a constant comparison method as outlined in the integrative review framework.

Results

Eight reviewed studies explored literary, performing, and visual arts engagement in residential hospice, day hospice, and hospitals in England, the United States, France, and Canada. Seven of eight studies used qualitative methods and one study engaged in mixed methods. Patient perspectives were most commonly represented followed by health care professionals and family members. Creative writing, music, and visual art were predominant modalities whilst dance and theatre were underrepresented. Themes identified across studies associated arts engagement with 1) a sense of well-being, 2) a newly discovered, or re-framed, sense of self, 3) connection with others, 4) challenges associated with practice.

Conclusion

This review synthesized current evidence and key knowledge gaps regarding artists' facilitation of arts engagement in palliative and end-of-life (EOL) care. It serves as a starting point in the consideration of next steps in standardizing professional practice and preparation for artists working in palliative and EOL care settings specifically. Recommendations for future research include exploring the value of collaboration between artists and palliative care teams when engaging with individuals living with life-limiting illness.

Background

Living with life-limiting illness significantly impacts quality of life.^[1-4] Life-limiting illness disrupts a person's sense of self^[5-7] and requires coping with changes in routine and frequent healthcare visits.^[8] Serious illness is often associated with difficult-to-manage symptoms such as pain, sleep disruption, depression, and anxiety, all of which contribute to reduced quality of life.^[1,2,4,9] Many individuals experience social isolation and stigma after receiving a life-limiting diagnosis, which further impacts their sense of self and well-being as well as their ability to cope with illness.^[6,8] A goal of palliative care is to complement standard treatment, which often offers limited options for these individuals, with a customized range of nonpharmacological modalities to manage symptoms, enhance quality of life, provide social support, and promote active living.^[1-4,9]

An expanding body of evidence demonstrates positive impacts of the arts on health and well-being.^[10,11] The developing field of arts on prescription, also known as social prescribing, is an effort to engage the health benefits of the arts.^[12-13] Participation in music, such as singing or drumming, has been linked with positive psychoneuroimmunological effects.^[10-11,13] Historically and currently, in publications such as the recently released *Intersectoral Action: The Arts, Health and Well-being*^[20] and the *State of the Field* reports in the United States, England, Australia, and Canada,^[15-18] authors describe arts engagement as promoting health and well-being across patient populations, however, the evidence cited is predominantly drawn from literature exploring the creative arts therapies. Studies and review papers rarely distinguish the professional work of artists working with individuals with life-limiting

illness from creative arts therapists¹⁰ or artists working in broader health care contexts such as in hospitals or public health settings.

The documented health benefits of arts engagement with patients across healthcare contexts suggest that the arts have the potential to uniquely complement the goals of palliative care.^[10,14,21-27] Fancourt and Finn's scoping review^[10] identifies that the arts are well-positioned to address complex or difficult conditions for which there are not presently complete solutions. Studies conducted with patients in inpatient palliative care services in hospitals in the United States have suggested that engagement in the arts, including visual, performing, and literary arts activities, impacts quality of life and a sense of well-being.^[19,20] Defining characteristics of palliative care^[3-4,9,21-22] such as interdisciplinarity, a team approach, and life-affirming activities, offer a support system, and promote living as actively as possible until death may be uniquely addressed through arts engagement. Individuals receiving palliative care, their healthcare providers, and their family members and loved ones are invested in safe and effective care that emphasizes meaningful engagement in a patient's life beyond their illness.^[6] Artists provide opportunities to engage in arts activities to achieve these goals.^[5,23-29]

Illustrating a growing recognition of these practices, a 2015 *British Medical Journal* supplemental issue featured arts activities in palliative care settings with topics ranging from visual arts for legacy-making to "dance in health activities" for stroke patients.^[30-31] Given the World Health Organization's (WHO) call to frame palliative care as a public health issue^[21-22] and integrate it across systems of health care delivery, it is worth consideration how artists might collaborate with, and serve as an integral resource to, the palliative care team at this time. Whilst there is growing evidence that supports the value of arts engagement in palliative care, it is important to identify the range and impacts of these practices.^[28,32-38]

Characterizing the range of arts practices in which individuals receiving palliative or EOL care are engaged can be a daunting task in that the concepts of both the *arts* and *palliative care* are broadly applied in the literature and can be difficult to define.^[32-37] A primary challenge is differentiating the roles of artists from those of creative arts therapists, particularly when working within palliative or EOL care contexts.^[32] Ongoing efforts to professionalize and standardize arts practices delivered by artists in palliative and EOL care thus benefit from a synthesis of the growing body of evidence in the field.^[35-37] A second challenge is interdisciplinarity introduces complexity. Therefore, establishing arts in health as a field of practice and profession in its own right requires identifying the skills and proficiencies that artists need when navigating palliative care contexts specifically.^[35-38] Building an evidence base, standardizing practice, and providing professional training and education, then, are vital steps in building the capacity of artists to serve as a workforce with vulnerable populations or in specialized health settings such as in palliative or EOL-care.^[35-38]

Whilst artists are increasingly working in health care settings, and in palliative and EOL care specifically,^[10,27-28] a limited body of evidence exists to examine and advance arts engagement and the potential benefits to patients, families, and healthcare providers. Opportunities for the increased benefit and wider availability for arts engagement are potentially lost due to a lack of standards of practice and limited formal training programs or a clear professional pathway for artists.^[33-38] Further, a risk of harm exists without evidenced standards including agreed theoretical frames, professional competencies, or scope of practice. Existing literature was therefore reviewed and findings presented as one step toward evidencing standards and professionalizing practice of the arts delivered by artists working in palliative or EOL care. The review aimed to identify and synthesize existing evidence to reveal key knowledge gaps to inform future research and practice.

Methods

An integrative review of the literature was conducted inclusive of studies using experimental and nonexperimental designs as well as theoretical and conceptual articles.^[39-48] The literature search used a pre-defined, comprehensive search strategy to ensure both rigour and broad scope. The review question was: "What are the outcomes and limitations in the literature describing artists engaging the arts with individuals with life-limiting illness, and what are the key knowledge gaps?" The following databases were searched for this review: PubMed inclusive of MEDLINE, CINAHL, PsycINFO, Scopus, Web of Science, and EMBASE. Search terms included variations on *visual arts*, *literary arts*, and *performing arts*; *service users* or *patients*; and *palliative care* or *EOL care* (see Table 1). Developing an effective search strategy was challenging, given the complexity of the variables and a lack of Medical

Subject Headings (MeSH) terms and clear keywords to streamline the search. The term *art* was problematic in that *antiretroviral therapy* and *assistive reproductive therapies* use the abbreviation “ART” hence, synonyms were identified (see Table 1).

No restrictions were placed on study design or date of publication. Studies were selected if they focused on visual, performing or literary arts delivered by an artist with individuals living with life-limiting illness (see Table 2). Those focused on arts engagement provided by creative arts therapists including music therapy, dance/movement therapy, art therapy, poetry therapy, bibliotherapy or expressive arts therapy were excluded. The purpose of this exclusion criterion was to isolate arts engagement delivered by artists in palliative care.

As terms such as “life-limiting illness” and “palliative care or EOL care” can include a wide range of contexts and conditions in the broadest use of the terms, studies were included if the following keywords were identified: palliative care, hospice, dying, terminal, metastatic, or EOL (see Table 1) and synonyms. This decision excluded studies on arts engagement with individuals with conditions or illnesses that were not categorized as necessarily life-limiting such as stroke or cancer unless identified as metastatic.

Following preliminary searches, the need for additional exclusion criteria became apparent. Studies were excluded if the arts intervention was provided by a healthcare professional, for example, an occupational therapist, child life specialist, or chaplain. Studies were also excluded if they investigated arts programs in which creative arts therapists and artists worked in collaboration and the practices were reported without distinction between the two. This criterion was necessary to meet the research aim of establishing an evidence base to distinguish arts engagement delivered by artists from the professional practice of creative arts therapists.

After the database search, reference lists of all articles were screened and a hand search of journals was conducted. Reference lists of relevant review papers were scanned for missed articles. One additional article that met inclusion criteria was identified during this process and was added to the review.

The initial search, conducted in December of 2018, yielded 337 studies. After removal of duplicates and studies that did not meet inclusion criteria, 329 studies underwent screening by title, abstract, and keywords. Articles were included in the full-text review if they met the following criteria: described a study examining literary, performing, or visual arts facilitated by an artist with individuals living with life-limiting illness and/or receiving palliative or end of life care and included the key terms *palliative care*, *hospice*, *terminally ill*, or *metastatic*. Of the 28 studies that met these criteria, eight remained eligible after full-text review and are included in this analysis. The search was updated in August 2020 and no additional articles were added at this time. Figure 1 presents the PRISMA diagram of the study selection process.^[49-50]

The first author (J. B. L.) served as a primary reviewer for determination of eligibility and assessment of study quality. A second reviewer (B. C.) independently applied the inclusion and exclusion criteria to confirm eligibility for inclusion and also assessed the quality of each included study. Both reviewers assessed quality of the studies using critical appraisal tools designed by Hawker, Payne, Kerr, and Hardy^[45] for the appraisal of disparate studies, specifically applying Appendices B-D of the tool.^[45] Whilst a range of appraisal tools such as the Mixed Methods Appraisal Tool and the CASP checklists were considered,^[46-47] the wide range of study designs under review presented a challenge. Following critical appraisal of study quality, the first author (J.B.L.) and the independent reviewer (B.C.) extracted data from the eight included studies. Extracted data were then systematically analyzed using constant comparison as outlined in the integrative review framework.^[41] Table 3 summarizes study characteristics and critical appraisal (See Appendix 1).

Results

The eight studies included in the review represented visual, literary, and performing arts engagement facilitated by artists with patients in hospitals, residential hospice, and day hospice settings in England, the United States, France, and Canada.^[19-20,48-53] Design, methods, measures, participants, interventions, and overall quality varied widely among the studies. Table 3 summarizes key study characteristics: 1) participants and settings, 2) interventions and measures, 3) outcomes, and 4) challenges.

Participants and Settings

Studies were conducted in a range of geographical locations, including England ($n = 4$), the United States ($n = 2$), France, and Canada ($n = 1$ for each). Study participants ($N = 191$ total) included a range of individuals living with life-limiting illness and receiving palliative or EOL care. Several studies include adult participants who received inpatient palliative care in hospitals: two include adult cancer patients ($n = 95$)^[20] and ($n = 10$)^[48] and one includes adult patients in inpatient palliative care and their family members ($n = 49$)^[19]. A fourth study, which also focuses on adult cancer patients, includes four women with breast cancer, two of whom have metastatic disease.^[49] This latter study takes place in a theatre school and drama center at a university in partnership with the local cancer center. In the only case study reviewed, participants are adult patients in residential hospice ($n = 2$).^[50] Of the two studies whose participants are patients enrolled in day hospice,^[50-51] only Kennett^[51] reports the number of participants ($n = 10$). The last study includes patients in palliative care and oncology settings in a university hospital and is the only study to include pediatric patients (aged ≥ 13 years, $n = 24$).^[53]

Interventions and Measures

Type of arts engagement, method of delivery, and outcome measures varied widely across studies. In three of the studies, arts engagement took place one-to-one or in small groups centered on the patient and any visitors who were present.^[19-20,48] In five studies, arts engagement occurred in a small group of patients sometimes referenced as a workshop.^[49-53]

The literary arts predominated, with five studies (63%) incorporating creative writing.^[20,49,51,52,53] Live music played for patients who participated through song selection was the primary intervention in two studies and included as one of several modalities in a third study.^[19,20,48] Interventions in three studies involved a range of visual arts activities including painting, mixed media, pottery, sculpture, knitting, and textile arts.^[20,50,51] Only one study featured playwriting and theatre performance.^[49] Finally, dance/movement was mentioned briefly in a study of a multidisciplinary program designed to “integrate the arts as standard of care” by offering performing arts activities such as live music and movement alongside visual arts and literary arts engagement.^[20]

Researchers predominantly collected and reported the observations and accounts of patients regarding the effects of the arts engagement programs. In the one study that included pediatric patients,^[53] the investigator included the perspectives of cancer patients and staff members in their analyses. Artists’, referenced as arts facilitators’ in one instance, observations and accounts are included in two studies: first, in an analysis of artists’ clinical documentation on arts engagement with palliative care patients, artists reported meaningful interactions in which they observed patients as relaxed, energized, grateful, and feeling an overall sense of well-being, with patient self-report confirming these observations.^[20] Secondly, Kennett explored arts facilitators’ awareness of group process and asked them to explicitly describe their facilitation processes, particularly regarding how much they chose to direct the participants versus allowing broader freedom of expression.^[51]

Outcomes

Researchers in seven of the studies collected qualitative data, whilst one study had a mixed-methods design and included both qualitative findings and health outcomes measures. Primary themes reported across studies included: a sense of well-being, a newly discovered – or re-framed – sense of self, and a sense of connection.

Well-being

The theme of a sense of wellbeing was described as “enjoyment,” “invigoration,” or “enthusiasm”. Peng and colleagues reported the following themes: “spirituality, comfort, relaxation, escape, and reflection.”^[19] Anderson and colleagues reported that patients experienced “relaxation, gratitude, invigoration, and accessing spirituality” associated with art-making. Meaning-making and spirituality were noted as themes in four studies.^[19-20,50,53] Pommeret et al.’s study contributed a balance of weighing positive emotions such as “joy and well-being” experienced by patients with difficulties described such as “fatigue”, “effort” and reflection on dying or on how illness has altered their lives and sense of autonomy.^[48]

Peng et al. was the only study to also include quantitative health outcome measures: namely, the Edmonton Symptom Assessment Scale (ESAS) and the measurement of opioid usage before and after the intervention.^[19] Following a live music intervention,

patients reported decreases in symptoms such as pain, nausea, shortness of breath, anxiety, and feelings of depression. The authors also documented a decrease in opioid usage and an increase in a reported sense of well-being.

Discovering, or re-framing, sense of self

A second theme was a newly discovered sense of one's self as evidenced by themes such as "discovery," "agency," or "self-esteem" through "reflection", "expression", and "archiving stories and memories". The case studies that Sánchez-Camus reported featured themes such as patients' sense of discovery, agency, and accomplishment.^[50] This study highlighted the unique ability of the arts to create an opportunity for reflection and meaning-making and to archive stories and memories for patients and their loved ones. Live music, in Pommeret and co-authors work, introduced a "pause" for reflection that can have both positive and difficult impacts is notable, and it is this study that observes how live music transforms its audience members "from patient to person".^[48] Bolton also noted themes of discovery, a sense of accomplishment, and a "byproduct" of enhanced self-esteem.^[53]

Connection

Anderson et al. described "establishing trust and bonds" between artists and patients.^[20] Artists in this study reported a sense of "professional fulfillment", "kinship", and capacity to contribute to "highly personalized care" through enhanced communication with family and staff correlated with arts engagement. As mentioned above, these themes were threaded throughout the articles included in this review. Bolton found that creative writing allowed reflection, expression, and connection.^[53]

McLoughlin reported that patients experienced enjoyment, agency, and connection through literature and writing, adding that there is value in a "time out from illness" pointing to the value of arts engagement to re-frame a patient's identity beyond their illness.^[52] The author further reported that consistency and reliability of the facilitator and group members were key to participants' opening up to one another and expressing emotion in the group. Bolton also noted this effect.^[53]

Challenges

Authors in several of the reviewed studies reported challenges in designing and delivering arts engagement interventions. Sinding and colleagues described a study exploring the effects of an intervention involving playwriting and a theatre performance with two women with metastatic breast cancer and two women with nonmetastatic breast cancer.^[49] Whilst many themes that emerged reinforced the findings of the other articles, such as meaning-making, connection, and "moments of comfort", the authors also reported an asymmetry in experiences between actors living with metastatic breast cancer and those who were not. The purpose of the study was to "create a drama, working from a focus group study conducted the previous year about the information needs of women with metastatic breast cancer and from a series of interviews with oncologists" and "to explore what it means to have metastatic disease and what it means to provide oncological care to women with this diagnosis". This study explicitly reported that feelings of vulnerability, stigma, and the alienation of living with life-limiting illness were activated or highlighted by the intervention. Pommeret and colleagues reported similar findings as music introduced a "pause" in care and, therefore, time for patients to reflect.^[48] Pommeret et al. explored live music played for patients in both 1:1 and small-group settings. Whilst the study reports a wide range of positive aspects aligning with the thematic findings of a sense of well-being and social connection, the authors also noted limitations and challenges hesitation, anxiety, effort, and fatigue on the part of the patients. Practitioner difficulties also arose including song choice.

The arts interventions in Sinding et al.^[49] and Kennett^[51] both included public-facing artwork through a theatre performance and visual art exhibit, respectively. Sinding and colleagues described the experience of rehearsing as invaluable to women living with breast cancer and asserted that whilst "participatory models challenge traditional ethical frameworks," they present an opportunity to "rethink assumptions about harm" in research. Kennett reported that participants described feelings of well-being overall that are consistent with the themes mentioned above, such as enjoyment, excitement, pride, purpose, agency, and connection. The public-facing aspect of the work in Kennett's study, however, introduced anxiety-producing elements of art making, a sense of competition between group members, and anticlimax when the exhibit was over. Participants also reported finding value in making something tangible and permanent, having an incentive to reach a goal, and a sense of satisfaction at having produced a high quality of work. The abovementioned study characteristics were synthesized to reveal key knowledge gaps and to explore broader implications of the review which will now be discussed.

Discussion

Findings of the studies in this review suggest that arts engagement can elicit a highly individualized, substantive, and positive experience among patients living with life-limiting illness. Findings also suggest that there are challenges that arise in practice requiring further attention to skills and proficiencies requisite of navigating palliative care needs to facilitate safe, effective, and meaningful arts engagement. Among the eight studies reviewed, study subjects were predominantly adult patients, though family members, health professionals, and staff, or artists or facilitators were included in two studies each.^[19,51] It was notable that only one study included pediatric patients in the sample.^[53] Nuances of arts engagement with pediatric patients as compared to adults certainly will benefit from further study. The literary arts were the most prevalent discipline represented in the interventions, followed by visual arts and music. Dance, playwriting, and theatre performance were underrepresented, having been included in only one study each.^[49]

Primary themes reported in these studies reinforce existing evidence in the field of arts in health. Themes such as arts engagement promoting a sense of well-being, an enhanced sense of self, and connection with others to uniquely facilitate meaning-making, discovery, reflection, and expression are well documented in the broader literature.^[10,14-18] Hence, it could be argued that arts engagement addresses primary aims of palliative care such as to offer opportunities for patients to review and embody the question “what gives your life meaning?” and to provide social support for patients and family members.^[23-26]

In keeping with the ethos of palliative care, patients and artists alike benefit from artists’ inclusion on the interdisciplinary team. Several of the reviewed studies highlighted the necessity of artist collaboration with the healthcare team.^[19,20,48,51,53] Health professionals’ interactions with artists included referring patients to an arts program, informing artists’ of relevant patient health status, and assisting the patient with coming and going from an art workshop. Artists are noted, by a staff member in one study, to have provided “enriching and enormously positive” experiences for patients, which “enhanced communication”.^[53] The “confidence” and “non-threatening” approach exuded by the artist is also noted. This observation raises the question of how the arts could become more integrated into the delivery of palliative care services, perhaps in a manner that improves quality of care and provides respite and support for the team.^[54] In light of the World Health Organization’s call to consider palliative care as a public health issue and for earlier integration across health care systems, further discussion is warranted as to how expertise within the arts might be engaged in collaboration with the palliative care team.^[21-22]

In the only mixed-methods study included in this review,^[19] arts engagement was incorporated into palliative care as a means of nonpharmacological symptom management. Researchers reported significant physiological impacts of live music such as decreases in pain, anxiety, nausea, shortness of breath, and feelings of depression along with a significant increase in feelings of well-being. Investigators also noted that opioid use decreased in experimental participants in the period following the music intervention as compared to the control among participants who did not elect to participate in music. A mixed-methods approach bears further exploration, given the emphasis in palliative care on providing nonpharmacological treatments for symptom management. This same study introduced that it was a challenge to isolate variables, for example, determining the benefits of live music versus the presence of a musician.

Findings of the reviewed studies also highlighted specific challenges and opportunities related to facilitating the arts in palliative care. In order to safely and effectively navigate alongside patients who are experiencing difficult-to-manage physical symptoms, social stigma, and social isolation, as introduced in these studies, artists require working knowledge of the health care context.^[45,48,49,54] Given the impacts of the current pandemic, the implications of social isolation whilst living with a life-limiting illness are even more pronounced than in the past.^[55-57] The pandemic has introduced a new layer of stress and a role for artists who can safely facilitate virtual arts engagement bears consideration^[58-59]. Artists working in health care and public health are innovating in facilitating the arts through remote delivery and this work may have significant implications for palliative and EOL care.

Sinding and co-authors’ description of creating a theatre performance with women with breast cancer^[49] alongside Kennett’s description of a collaborative art exhibition^[51] both revealed that specific considerations are critical to implementing public-facing work in safe and effective ways and that these programs may also offer unique benefits when implemented within scope. Pommeret and colleagues also presented patient- and practice-related difficulties^[48] encountered during and following live music with patients. Patient difficulties included fatigue, a loss of sense of autonomy, and references to death or dying following the live

music intervention. Authors also identified professional practice-related challenges such as song selection that are worth exploring further. These findings present a critical opportunity to shape future recommendations regarding preparation for practice and to guide a research agenda.

A strength of this review was the use of an integrative design, which allowed for a thorough and systematic search through a broad body of literature, including experimental and nonexperimental studies to synthesize a wide array of evidence. Thus, few high-quality, well-defined studies exist from which to draw meaningful comparisons or reliable conclusions about the benefits and risks of arts engagement. Peer-reviewed articles were sparse regarding artists' professional work engaging the arts with patients in palliative and EOL care. Standards and formalization of such context-specific practice were not identified. Whilst common themes emerged across the articles included in this review, one finding is a need for well-designed studies with fastidious and consistent reporting of protocols, samples, and interventions that can be compared across studies and replicated. From such studies, evidence-based practices can be established and professional standards created to meet the unique needs of patients in palliative care. Steps can then be taken at a policy-level to adopt and implement these standards to benefit patients, artists, and the health care organizations within which they serve.

Recommendations for Future Research and Practice

Based on the present review of the eight studies that met inclusion criteria, the following recommendations are made to further efforts to understand how to maximize the benefits, minimize the risks and address the challenges of these practices. The present review reveals a lack of consistency in reporting among extant studies on arts engagement. Consistency in reporting advances reproducibility and generalizability allowing for a more robust synthesis of findings. Future studies on arts engagement in palliative care would therefore benefit from the consistent use of outcome measures, reporting guidelines, and terminology for search terms and keywords, for example. An outcomes measure included in this review was the Edmonton Symptom Assessment Scale (ESAS) however the Warwick-Edinburgh Mental Well-being Scale (WEMWS), the General Self-Efficacy Scale, or the Health-Related Quality of Life (HRQoL) are also frequently used in arts in health research.^[10,13,29] Reporting of protocols should transparently describe the roles, scope, and responsibilities of each team member, especially those implementing the intervention. Reporting should include theoretical or conceptual framework, role descriptions, training and orientation to palliative or other health care context, artist compensation, team structures, and intervention descriptors. Transparency in reporting will further efforts to advance understanding of arts engagement with patients in palliative care. In an effort to index future studies, the corresponding author has proposed the umbrella term "arts in health" with sub-terms "music in health", "dance in health", "visual art in health", and "literary arts in health" as MeSH terms in the National Library of Medicine.

Notably, the review findings include patients' perceptions of engagement with artists as a primary measure. It is clear in this limited sample that there is perceived value of the arts to enhance quality of life and to complement the social and existential aims of palliative care. It would be constructive to include family members and clinician perspectives,^[54] as they are included in only one study.^[19] Whilst clinicians focus broadly on physical care and comfort, the arts amplify holistic aspects of care and therefore, align with and fulfill the broader aims of palliative care.

Further research is also needed to understand benefits, risks, and challenges unique to each of the art forms, and especially dance and drama, in palliative care, which are underrepresented in the literature to date. Consistency in the use and reporting of protocols, outcome measures, and terminologies across studies exploring each art form will again be helpful in this effort. In addition, future research efforts should aim to expand understanding of arts engagement with pediatric patients in palliative care.^[4,26] Such studies would benefit from collaboration with interprofessional health team members such as Child Life specialists and creative arts therapists.

Whilst the goal of the present review was to maintain a narrow focus on artists' delivery of the arts with individuals with life-limiting illness, it bears consideration that a range of clinicians including creative arts therapists have expertise and investment in arts engagement as clinical care. Interdisciplinary collaboration, therefore, is key. A future literature review synthesizing studies that shed light on arts engagement delivered by clinicians as part of clinical care would thus offer useful insights. One study, for example, introduced an arts program in hospice featuring artists and creative arts therapists working cooperatively. An interdisciplinary and collaborative model such as this is worth exploring further.^[60]

Some studies explored arts engagement provided by allied health professionals, the use of the arts in nursing or medical education, or to enhance the clinical care environment. Each of these topics is worth examining in its own right. Examples included the work of chaplains or occupational therapists (OTs) with patients in palliative care settings.^[61-66] Activities that incorporate creative elements such as “legacy projects”, “life reviews”, and “illness narratives” notably share some common elements with the review topic. For example, arts engagement complements an occupational therapy aim such as “creative occupation” or a chaplaincy aim of “meaning construction”.^[62,65-66] Studies authored by allied health professionals using arts engagement in their work with patients in palliative care should be aggregated and reviewed to reveal knowledge and proficiencies that might complement existing services in palliative care. Studies examining the role of the arts to enhance nursing or medical education,^[67-68] to prevent health care provider burnout,^[69-70] or to enhance the design in the environment of care^[71] were not included in this review as they do not feature arts engagement with patients, yet such activities bear exploration in an effort to map the range and reach of the arts in palliative and EOL care.

Additional consideration is recommended for patient populations with specialized needs.

It is recognized that by excluding clusters of conditions such as dementia, studies describing artists’ work in dementia care were not outlined.^[72] However, due to the nuanced aspects of dementia care, the authors of the present review recommend that this area is explored separately to account for the practical considerations specific to changes in cognitive functioning.^[73-75] Similarly, dance programs for Parkinson’s disease require highly nuanced practice and are well-structured and mapped in the literature.^[76-80] Therefore, it is recommended that a research agenda is mapped for arts engagement for each patient population identified as having specialized needs to identify outcome measures best suited to assess benefits and risks.

Finally, in a few studies not included in the present review, researchers engaged expressive writing (EW) with women with metastatic breast cancer. These studies introduced feasibility issues with intervention delivery, adherence, and follow up, which are instructive for the present review topic.^[81-83] While ease of recruitment indicated patient interest in an arts-based intervention, adherence was low^[81] and patients reported distress immediately following the intervention. In one instance, patients had a significant increase in the use of mental health services following the intervention.^[82] EW in these studies was introduced and facilitated by a research nurse or assistant, and the reported feasibility issues may demonstrate the value of an artists’ expertise in facilitation. Given the vulnerability of patients with life-limiting diagnoses and challenging symptoms, researchers in future studies should carefully consider design, methods, and protocols for safe and effective delivery of arts interventions.

Limitations And Strengths

The small body of literature identified by the search is a limitation as well as the disparate and heterogeneous set of study designs and methodologies. On this note, as just eight studies were identified, there is a lack of geographical representation as well as diversity of study subjects with consideration for key variables such as age, race, or gender, for example. A key component of the design of this review was to focus on artists at the expense of excluding creative arts therapies’ literature. This can be viewed as both a strength and a limitation. Whilst the study aimed to describe the professional practice of artists and to glean insight from a gap in the literature, creative arts therapies’ literature offers notable insight into the delivery of the arts in palliative and EOL care settings.

Conclusion

This integrative review synthesizes current evidence including outcomes and key knowledge gaps on delivery of the arts by artists in palliative and EOL care. The literature demonstrates that individuals living with life-limiting or chronic illness with limited treatment options benefit from a range of non-pharmacological measures to manage symptoms and enhance quality of life. Findings in this review suggest that arts engagement in palliative and EOL care contributes to quality of life including a sense of well-being and connection with others among those living with life-limiting illness. Overall, positive associations with arts engagement are identified, largely by patient- and staff-report. Evidence suggests arts engagement impacts a sense of well-being, selfhood, and connection. Further research will expand the evidence base in support of standardized practice and implementation of arts practice in palliative and EOL care settings.

Further study is needed to determine the active factors associated with arts engagement with patients in palliative and EOL care. Recommendations for future research include targeted exploration of palliative care team members', family members', and artists' perceptions, underrepresented populations such as pediatric palliative care patients and underrepresented art forms, such as dance and drama. Additional recommendations include those subjects, beyond the scope of this review, that may directly bear on the review topic. Overall, findings moderately substantiate the benefits of arts engagement as a means of enhancing the quality of life, and potentially the quality of care, among patients receiving palliative and EOL care. They also offer guidance as to the limits of practice and key knowledge gaps, therein substantiating a need for further research to guide policy and practice.

Whilst there are developments toward professionalizing practice in arts in health, a gap remains in the standardization of practice, hence synthesis of the evidence is positioned for wider impact. Given what is known about the vulnerability of individuals living with life-limiting illness, amplified during a time of pandemic, and the value of safe, effective, and meaningful arts engagement, it is critical to systematically examine available evidence. This review is one step toward aggregating existing evidence to further efforts to make the arts more widely available to individuals living with life-limiting illness.

Abbreviations

BC = breast cancer; CINAHL: Cumulative Index of Nursing and Allied Health Literature; EMBASE: Excerpta Medica dataBASE; ESAS: Edmonton Symptom Assessment Scale; EOL: end-of-life; EW: expressive writing; HRQoL: Health-Related Quality of Life; MBC: metastatic breast cancer; MEDLINE: Medical Literature Analysis and Retrieval System Online; MeSH: Medical Subject Headings; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; WEMWS: the Warwick-Edinburgh Mental Well-being Scale

Declarations

- Ethics approval and consent to participate
- Consent for publication
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements

Ethics approval and consent to participate

Not applicable

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Authors' contributions

All authors, J.B.L, S.M., and L.F. made substantial intellectual contributions from conception and design through to the manuscript at each step of development. J.B.L. conducted the search, primary and secondary screening, critical appraisal, analysis, and manuscript preparation. S.M. and L.F. contributed to conception and design as well as intellectual contribution within each section of the manuscript, and critical appraisal of the manuscript. All authors have critically revised and given the final approval of the manuscript to be submitted for publication.

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Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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Tables

Table 1. Search Terms

Arts Engagement		Palliative Care		Patients		Exclusion Criteria
"arts intervention" OR "arts in medicine" OR "arts and health" OR "arts in health" OR "arts in healthcare" OR "arts for health" OR "creative arts" OR "creative expression" OR "expressive arts" OR "visual arts" OR "art making" OR art-making OR "painting" OR "drawing" OR "watercolor" OR "collage" OR "dance" OR "theat*" OR "drama" OR "music" OR "singing" OR "chor*" OR "performing art*" OR "literary art*" OR "poetry" OR "haiku" OR "oral history" OR "creative writing" OR "expressive writing" OR "storytelling" OR "mural*" OR "puppetry"	AND	"Palliative Care" [Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Palliative Medicine" [Mesh] OR "Hospice Care"[Mesh] OR "Hospices"[Mesh] OR "Terminal Care" [Mesh] OR palliati* [Text Word] OR hospice[Text Word] OR "end of life"[Text Word] OR EOL[Text Word] OR dying[Text Word] OR "terminally ill"[Text Word] OR "supportive care" [Text Word]	AND	("Patients" [Mesh] OR patient[Text Word] OR patients[Text Word] OR "service users" [Text Word] OR "healthcare users"[Text Word] OR participants[Text Word] OR clients[Text Word] OR consumers[Text Word])	NOT	"art therapy"[All Fields] OR "music therapy"[All Fields] OR "dance therapy"[All Fields] OR "dance/movement therapy" [All Fields] OR "drama therapy"[All Fields] OR "psychodrama"[All Fields] OR "poetry therapy"[All Fields] OR "creative arts therapy"[All Fields] OR "creative arts therapies"[All Fields] OR "Creative Arts Therapies"[Mesh] OR "Art Therapy" [Mesh] OR "Music Therapy" [Mesh] NOT "in theat*" OR antiretroviral OR assisted reproductive therapy

Table 2. Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
<ol style="list-style-type: none"> 1. Empirical studies including both quantitative and qualitative studies 2. Grey literature, including published reports or program evaluation 3. Literary, performing, visual, or multidisciplinary arts engagement provided by artists with individuals living with life-limiting illness and/or interfacing with palliative or end of life care. 	<ul style="list-style-type: none"> o Creative arts therapies interventions such as music therapy, art therapy, or dance/movement therapy o Studies with participants with a serious or chronic illness that is not life-limiting, such as stroke, cancer survivorship, dementia o Arts engagement provided <i>for or by</i> health professionals, trained volunteers, family members, or patients themselves

Table 3. Study characteristics and critical appraisal^[45] (N=8)

Author (Year) Country	Design/ methods	Participants	Setting	Intervention	Results	Quality ^[45]
Pommeret et al. (2019) France ^[48]	Qualitative/semi- structured interviews	Hospitalized patients receiving palliative treatment for cancer; 5 of whom were receiving EOL care (n=10)	Inpatient hospital palliative care dept.	Live music including singing and playing a musical instrument (such as guitar, piano or percussion) both 1:1 and in small groups such as with family members or staff or in the hallway	Positive emotions including joy and well-being Music as envelopment and immersion; a "cocoon"; humor Attention and comfort; social connection; memories Reflections on altered state of health and loss of autonomy, dying A sense of effort required and fatigue "patient as person" "travel back and forth between the past, the present and the future."	35
Peng et al. (2018) US ^[19]	Mixed methods	Palliative care patients and their family members at time of consult (n=46)	Inpatient hospital	Live music to address pain, anxiety, and stress associated with EOL	Significant decreases in pain, anxiety, nausea, shortness of breath, and feelings of depression Significant increase in feelings of well- being; Opioid use decreased in periods after the music intervention Themes: spirituality, comfort, relaxation, escape, and reflection	35
Anderson et al.	Qualitative/	Patients in	Inpatient	Music (e.g. cello,	1) Patient-	34

(2017) US [20]	Thematic analysis of artist reports and patient observations	palliative care inpatient service (n=95)	hospital	flute, violin, harp, singing), fabric art, knitting, and guided imagery	<p>centered themes relaxation, animation, spirituality, and gratitude</p> <p>2) Artist-centered themes: professional fulfillment, kinship, and empathy with patient suffering.</p> <p>3) Patient-artist: bonds and establishing trust.</p> <p>“slow time” and “slow listening”;</p> <p>Allows for highly personalized care</p>
Sanchez-Camus (2011) England [50]	Qualitative/Case study	Hospice patients (n=2)	Hospice	Painting in visual arts workshops	<p>Themes: Discovery, Agency, Reassessment of their lives</p> <p>24</p> <p>“enables the patient to become an active member in the management of their death process.</p> <p>“a collaborative endeavour”</p> <p>“engages patients”</p> <p>“a sense of control, accomplishment and appreciation”</p> <p>“endless possibilities to learn and explore even while dying”</p> <p>Rich and varied stories and</p>

					memories; "Art as archive"	
Bolton (2007) England [53]	Qualitative	Cancer patients receiving palliative care (n=24)	Hospital	Therapeutic creative writing including fiction, poetry, autobiographical writing in a range of settings from one-to-one to groups and inpatient, hospice, home, and community	Process of writing, talking about and reflecting on writing "Discovered talent"; "Discovered what they thought, felt, and remembered" "Essential reflection at a significant stage of their lives." "Coping" "Expressed issues needing attention" Self-confidence, self-esteem; "tackled difficult issues" "Private nature of personal narrative"	30
Sinding et al. (2002) CA [49]	Qualitative/ research-based theatre	Women with MBC (n=2) Women with BC (n=2)	Theatre rehearsal and performance space	Theatre performance	Rehearsing "uncovering - making public"; making tangible Congruence – "what I say with what I viscerally know"; "Inner/outer" "Meaning of illness"	25

temporarily
changed”

“Moments of
comfort and
solace”

“caring and
supportive
feelings
[ensemble]”

Asymmetry of
disclosure
(those with BC
and those with
MBC)

“story hard to
tell”

Vulnerability:
“unsupported”
“unpleasant”
“intensely
difficult at
times”

Fulfilling:

“I’m glad I hung
in there” “virtue
of hanging in, of
getting and
staying involved,
of “acting” in
relation to
illness.”

Participatory
models
challenge
traditional
ethical
frameworks;
Rethink
assumptions
about harm

Stigma of
cancer:
alienating,
dangerous,
disruptive,
unmanageable

					Insight into patients' lived experience can educate providers	
Kennett (2000) England [51]	Qualitative/ Phenomenological/ In-depth semi-structured interviews	Terminally ill patients in day hospice (n=10); Staff/tutors (n=11) (N=21)	Day hospice	Visual and literary arts	<p>Patient themes:</p> <ul style="list-style-type: none"> • enjoyment, enthusiasm, excitement • pride accompanied by a desire to produce the best work possible; • surprise at the quality of work; • achievement and acquisition of new skills; • sense of purpose, incentive to achieve a goal; • competition; • valuing mutual support and sharing skills with others; • some anxiety that the work may not be good enough; • satisfaction in the permanence of the work; • hope. <p>A subgroup of above-identified themes: expressions of self-esteem, autonomy, social integration, and hope</p> <p>Anticlimax when the exhibit was over</p>	32
McLoughlin(2000) England [52]	Qualitative	Patients in day hospice (n=NA)	Day hospice	Creative writing in small group	Writing group provides time out from illness; enjoyment in literature; patients as individuals;	20

Group provides a place to reduce isolation and spontaneity, surprise, play, control, reverie and

concentration

Consistency is key

Expressed emotion over time

Note. BC = breast cancer; EOL = EOL; MBC = metastatic breast cancer; NR = not reported

Table 4. Key findings and study limitations (N=8)

Author (Year) Country	Key findings	Limitations
Pommeret et al., 2019, France	Brought joy and well-being to the palliative care unit. Patients also encountered difficulties during the intervention: reference to an altered general state, to loss of autonomy; a sense of the effort required, of fatigue; an adaptation period; reference to the end of life, to death; a difficulty in choosing songs.	Small number of participants Investigator was the unit psychologist, potentially increasing “desirability bias”
Peng et al., 2019 United States	Music as non-pharmacological symptom management in palliative care Decrease in opioid use Decrease in reported pain, anxiety, nausea, shortness of breath, feelings of depression Significant increase in wellbeing Themes: spirituality, comfort, relaxation, escape, and reflection	Small cohort due to low patient census No control group Challenges isolating variables, for example, benefits of live music versus the presence of a musician
Anderson et al. (2017) United States [20]	Patient themes: Artists observed physical, emotional, and spiritual responses in patients including relaxation, invigoration, and accessing spirituality, unique to artist-patient interaction. Artist themes: professional fulfillment, kinship, and empathy with patient suffering. Artist-patient bond and trust with patients	Patient observations by artists who facilitate the interaction observed may present bias Difficult to compare across artistic disciplines No direct input from patients or health professionals
Sanchez- Camus (2011) England [50]	Themes: Creative process assists dying person in dealing with complexities of transitional phase Art-making allows objectivity and critical thinking, placemaking through memory, legacy, new narration of life when faced with death	Two case studies in very different contexts Highly conceptual and lacking concrete detail about practice
Bolton, (2007) England	Engaging in writing, as well as talking about writing, provided essential reflection at a significant stage in patients’ lives Facilitated patients’ ability and opportunity to discover what they thought, felt, and remembered Enhanced awareness of, and ability to, express issues to which focused attention needed to be paid Offered satisfaction and fulfillment of creative expression and exploration and the production of writing which to them and close others were vital	Lack of clarity around role and scope of practice of the author noted as “researcher therapist writer” Use of the term “therapeutic”
Sinding et al. (2002) CA [49]	Theatre as rehearsing behavior Making tangible Congruence of inner and outer – “what I say with what I viscerally know” Meaning-making Moments of comfort and solace Social cohesion: “caring and supportive feelings from [ensemble]”	Painful disclosure Vulnerability Precarious position of the understudy – “unsupported” and “unpleasant” “intensely difficult at times”

	<p>I'm glad I hung in there" - fulfilling</p> <p>Rethink assumptions about harm;</p> <p>Insight into patients' lived experience educates providers</p>	<p>Participatory models challenge traditional ethical frameworks</p> <p>Stigma is alienating</p>
<p>Kennett (2000)</p> <p>England ^[51]</p>	<p>Raw Themes: enjoyment, enthusiasm, excitement, pride, achievement, satisfaction, sense of purpose, mutual support, permanence (legacy)</p> <p>Distilled Themes: positive expressions of self-esteem, autonomy, social integration, and hope.</p> <p>Hope as the essence of the phenomenon, important in palliative care where continuation of active medical intervention has been equated with the provision of hope.</p>	<p>Small sample</p> <p>A wide range of disciplines represented but not clearly linked to specific themes or findings</p> <p>Art therapy mentioned but not distinguished</p>
<p>McLoughlin (2000)</p> <p>England ^[52]</p>	<p>Benefits of poetry include: enjoyment, sustenance, therapeutic (contains anxiety), inspirational, giving form/containing, joy, comfort, welcoming, self-exploration, spontaneity, play, surprise, control, reverie, and concentration</p> <p>Transition and transitional space is common to hospice and poetry both</p> <p>Poetry helps patients negotiate changes brought about by illness</p> <p>Prizes patients as individuals and reduces isolation</p>	<p>Lacking rigour as study design, method and analysis not discussed</p>

Figures



PRISMA 2009 Flow Diagram

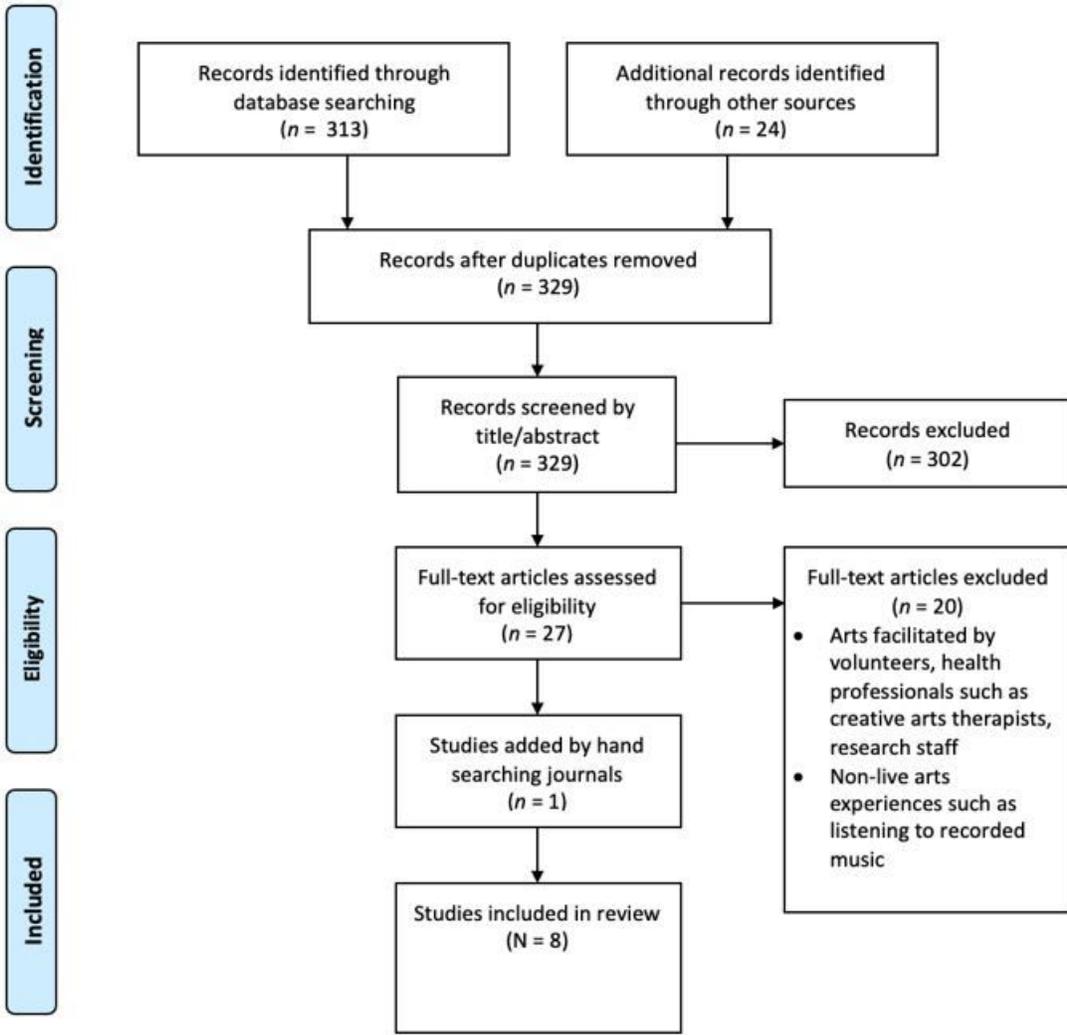


Figure 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram of Screening and Selection Process

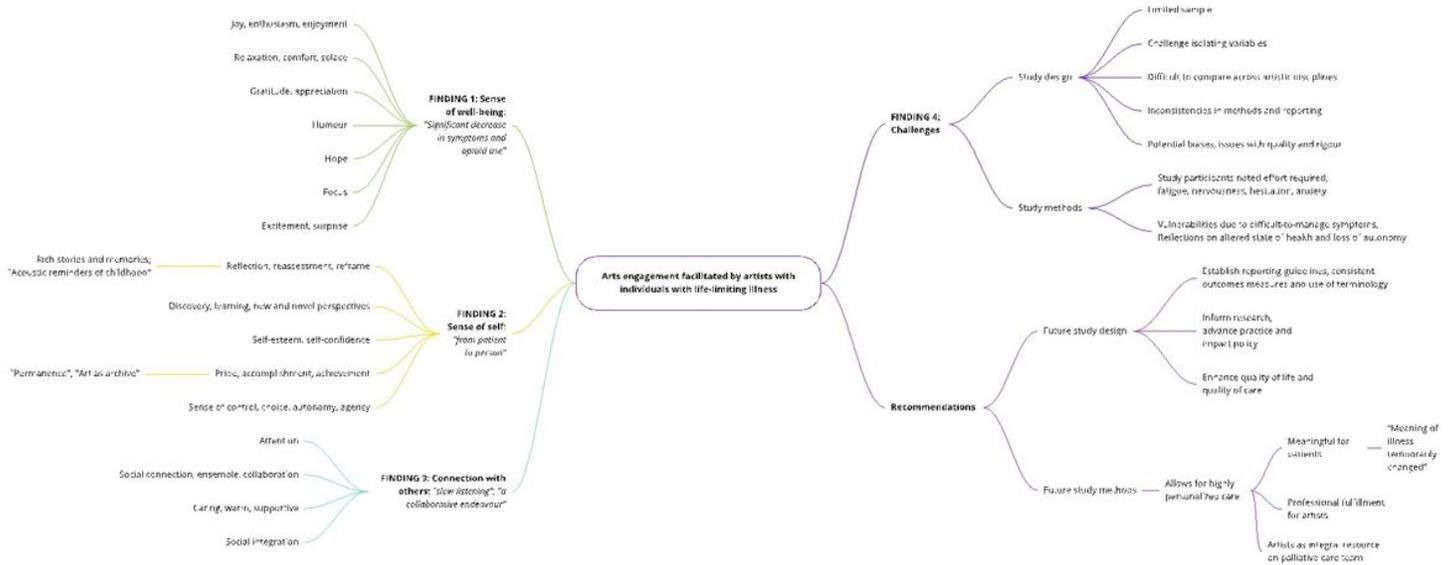


Figure 2

Thematic map of review findings and recommendations

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Appendix.docx](#)