Review Article

Narrative Interventions in the Palliative Care Setting: A Scoping Review

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Abstract

Context. This scoping review maps the existing literature on narrative interventions within a palliative care and end-of-life context.

Objectives. A scoping review was performed to address the following research question: What observational or randomized controlled trials have been performed to evaluate narrative interventions in the palliative care setting?

Methods. A search across multiple electronic databases was performed. The search results were screened. Relevant articles were reviewed for the identification of common themes and challenges.

Results. After reviewing 495 citations from electronic searches, and 44 articles from author archives or from manual review of article reference lists, we identified 34 articles for inclusion. Narrative interventions have focused on reflection or communication, and have been studied among providers, students, patients, and caregivers. Only patient/caregiver studies used randomized controlled design. Most studies were small and at the level of evaluating feasibility. Challenges include a high degree of heterogeneity among interventions and heterogeneity among parameters for evaluating those interventions.

Conclusion. Narrative interventions are actively being evaluated with the intention of improving communication and well-being among all parties within the palliative care and end-of-life experience. The field would benefit from selecting a subset of outcomes that are comparable across studies, and a common framework for describing narrative interventions. Scant literature exists regarding narrative interventions to assist providers in communication. J Pain Symptom Manage 2019;58:696–706. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Narrative medicine, storytelling, reflection, communication, palliative care, medical humanism

Background

From its inception, the field of palliative care has acknowledged the vital importance of incorporating spiritual and humanistic dimensions in the care of patients and caregivers facing serious illness.[1] In an era of expanding systemization, evidence-based practice, and concern for cost-effectiveness, the need to define, evaluate, and reliably implement spiritual and humanistic palliative care has become more acute. One promising approach to the research and practice of palliative care is narrative medicine. Initially conceived and articulated by Rita Charon, narrative medicine draws on methods from literary criticism (including narratology, the study of the structure and function of narratives) to help a listener gain proficiency in hearing, interpreting, and responding to stories.[2] As an intervention, narrative medicine may take the form of a writing exercise, journaling, oral storytelling, reflective discussion of a story or poem, or a defined approach to patient communication.[1] A review of medical interventions, across all patient populations, that expressly reference narrative medicine was recently completed by Fioretti et al.[3] and found

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modest evidence of benefit, although synthesis was limited by the small number of studies and the diversity of interventions and outcome measures. Thus, narrative medicine potentially offers palliative care providers theoretically grounded and teachable clinical skills, as well as means to enhance clinician and patient/caregiver well-being.

Broad groups within the palliative care setting for whom narrative medicine may have significance include patients and caregivers, health care providers, and learners. Each group has distinct yet overlapping needs, which may be met by narrative approaches. Palliative care patients face multidimensional pain, including physical, emotional, interpersonal, and spiritual/existential components,[4,5] and thus may especially benefit from non-pharmacologic interventions such as story-telling and narrative exercises.[6] Within the health care provider setting, patients and providers often have mirrored expectations and disappointments: patients expect that providers will care for them as whole people rather than as instances of illness, whereas providers feel uncertainty about their ability to address the emotional experience of patients living with terminal illness.[7,8] Providers also need approaches to help them find joy and resilience in the emotionally demanding work of palliative care at the end of life. Without these tools, providers are at risk of emotional or spiritual exhaustion, often discussed in the context of "burnout," which is highly prevalent in the field of palliative care.[9,10] Medical learners, including physicians, nurses, and physician assistants in training, may also benefit from curricula that incorporate narrative medicine interventions to palliative care. Attention to personal and patient stories through activities such as patient interviews or reflective essays offer concrete and definable approaches to the otherwise abstract educational aims of humanism, self-awareness, professional wellness, and compassion.[11,12]

These needs are complex and challenging to study empirically, let alone fix practically. Narrative approaches fit intuitively with the goals and challenges of palliative care—and work over the last two decades has begun to explore measurable impacts. However, we were unable to find a broad review of what has been accomplished in the study of narrative approaches to palliative care at the end of life. The aim of this scoping review article is to map the concepts, interventions, and measurements that have been used to evaluate narrative approaches to palliative care needs in the literature. The scoping review methodology has been chosen because it allows a flexible and iterative means of representing a relatively young field of investigation, one which clarifies the current state of explorations and approaches, as well as the gaps and challenges to be addressed in future studies.[13−15] Our hope is that these findings will serve as a platform for further investigations.

Methods

Scoping Review

We chose a scoping methodology because our prestudy familiarity with related studies suggested a relatively small and heterogenous body of work. The scoping review methodology is a well-described method for conducting exploratory review articles in which the primary aims include the following: conceptual mapping of the existing literature, identification of research gaps, assessment of the potential feasibility of a systematic review, and/or communication about the state of a field of research to those outside of the specialist community.[13−15] In contrast to a systematic review, a scoping review does not necessarily evaluate the quality of evidence of the studies identified, and similarly, does not offer recommendations to guide or change clinical practice. The emphasis is on disseminating a representation of the state of current research—what has been done, how it has been conceptualized, what are the gaps in theoretical framework and empirical outcomes—to guide and harmonize further research.

Identifying Research Question

The research question was developed by the research team in collaboration with a medical informationist:

> "What observational or randomized controlled studies have been performed to evaluate narrative interventions in the palliative care setting?"

Identifying Relevant Studies

In collaboration with an expert medical informationist, we identified and searched several electronic databases: PubMed, PsychInfo, CINAHL, Scopus, Web of Science, ATLA religion, and Sociological Abstracts. This review did not have a registered review protocol. Search terms were initially proposed on the basis of the clinical team's expert knowledge. The team worked with the informationist to identify allied Medical Subject Headings (MeSH)/Index terms within relevant databases. After a preliminary search of PubMed, additional search terms and index terms identified from articles that met inclusion criteria were used to expand the set of search terms. When MeSH/Index terms were not available within a database, then the corresponding free-text search term was used. The search results reported here reflect the finalized search terms. The following were the search terms (with minor variation between databases depending on available MeSH/Index terms): Writing, Narration, Narrative Medicine, Expressive Writing, Reflective Writing, Creative Writing, Journaling, Narrative Therapy, Writing Therapy, Biography Therapy, Storytelling connected by AND to Death, Death and Dying, Hospice, Terminally Ill, Terminal Cancer, Palliative Care, End of Life. For example, the PsychINFO search strategy, with no additional parameters, was: *"Reflectiveness" OR "Creative Writing" OR "Bibliotherapy" OR "Narrative" OR "Narrative Therapy" OR "Storytelling" OR "Life Review") AND ("Hospice" OR "Terminally Ill Patients" OR "Terminal Cancer" OR "Palliative Care" OR "Death and Dying."* We also used all relevant articles known to the authors and reviewed the reference lists from identified articles to further expand our search. Searches were completed collaboratively by the medical informationist and a study author (T.L.). Copies of the search terms and results were saved in pdf, html, or text files—depending on the database export formatting.

Study Selection

We searched for English language articles assessing an intervention using story-telling, writing, or narrative/story-based communication in the palliative care context and included any studies with qualitative or quantitative outcomes, including both observational and randomized controlled designs. The outcome could pertain to care provider, trainee, or patient/caregiver experience or performance. We excluded editorials or theoretical position articles, case reports of experiences/interventions/curricula that did not include an assessment of outcomes, and studies that used the qualitative research method of narrative analysis (inductive analysis, grounded theory, etc.) in the absence of a narrative intervention, which we defined as the exposure of the population under study to a narrative process posited by the authors to influence the outcome of interest.

Using the outlined criteria, two reviewers (T.L. and L.S.) independently assessed the titles and abstracts of search results. Articles that potentially met criteria were reviewed in full text. The two reviewers then met with the third review author (D.W.), and any articles not initially included by both reviewers were deliberated on and refereed by the third author as needed, until consensus was reached among all three authors.

Charting Data

We designed a preliminary data extraction chart and tested the design by having two authors (T.L. and L.S.) independently use the chart on the same five articles. The charting results were compared, and iterative adjustments were made. Then a single reviewer (T.L.) completed the data extraction for the remaining articles. Data fields included the following: title, author, year of publication, country of study origin, aim, study population, methodology, study intervention and comparator (if present), theoretical framework or conceptual genealogy (if provided), how outcomes measured, primary outcome result, additional outcome results (if relevant to review question), future design modification (as discussed by study authors), and critiques or limitations, if any. Although we noted some study limitations to identify thematic research challenges and gaps, we did not perform a formal evaluation of evidence quality.

Summarizing/Collating

Based on the initial search results, we grouped the studies into the following three categories: those that focused on patient/family reflection, provider/trainee reflection, and provider/trainee communication. We synthesized the studies within each group by quantitative analysis, as well as qualitative analysis initiated by a single reviewer (T.L.)—who compared extracted variables to identify themes—and confirmed by author consensus. We reported the results through graphical and narrative methods.

Results

The initial searches were performed in October 2017. Searches as described in the Methods section of this article yielded a total of 495 results. Forty-four articles from the review team's archives or review of article reference lists were also identified for possible inclusion. After individual review by two independent reviewers and resolution of discrepancies, 34 articles were identified for inclusion (Fig. 1).

Study Characteristics

Studies ranged in publication date from 1984 to 2017; all but one were published after 2000. Studies involved seven countries (Australia, Canada, Columbia, Japan, New Zealand, U.K., and U.S.), with 19 of 34 articles published by a group restricted to the U.S. Studies were published in 21 distinct journals. Seventeen of 31 studies used a controlled design, with 16 of these described as randomized. This scoping review revealed the following three major thematic categories in which studies fell: seven of 34 studies focused on provider or trainee reflection, three of 34 studies focused on provider/trainee communication with patient/family or between providers, and 24 of 34 studies focused on patient/family reflection (Table 1).

Provider/Trainee Reflection

All seven of the articles that focused on provider and/or trainee use of narrative practices for personal reflection were observational, and included sample

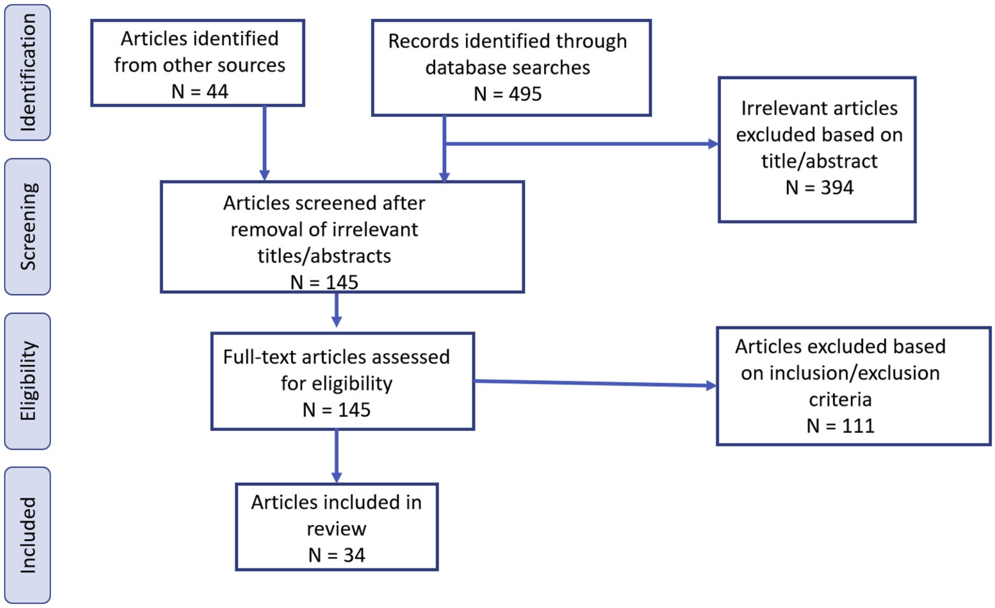

Fig. 1. Flow chart of search results.

sizes ranging from $n = 6$ to $n = 522$.[16,17] Study locations were Canada, the U.K., the U.S., and New Zealand; three of seven studies were U.S.-based. The majority (four of seven articles) studied the benefit of narrative interventions for medical trainees (medical students and physician assistant students). All studies pertaining to medical students were in the narrative reflection category (as opposed to communication). One study (one of seven studies) addressed a narrative reflection exercise focused on post-graduate providers (residents); this was the sole study in any category to specifically study the post-graduate provider population (one of 31 studies). Two of seven studies focused on medical providers with a scope not limited to trainees: one studied interdisciplinary palliative care teams—including participants such as physicians, residents, chaplains, and social workers—and the other, nurses from a pediatric oncology unit.[16,18]

Provider Reflection

The two of seven studies that investigated practicing providers emphasized the potential role of narrative interventions for self-care, stress reduction, and avoidance of burn-out and did not use a dedicated patient encounter.[16,18] In MacPherson, the intervention involved pairs of nurses who recounted and heard each other's stories of grief and loss associated with their work in pediatric oncology (two sessions each averaging 15 minutes). In O'Neil et al., the intervention was a thought of the day exercise accompanied by a brief group discussion among an interdisciplinary team (sessions lasted about 20 minutes daily over a three-month survey period).

Table 1
Articles Categorized by Population and Study Design

Population	Total Articles	Design
Provider/Trainee Reflection-focused	7	Observational: 7
Provider/Trainee Communication-focused	3	Observational: 3
Patient/Family Reflection-focused	24	Observational: 7 Controlled: 17

MacPherson and O'Neil et al. selected outcome measures related to tolerability and impact on provider well-being. MacPherson, in addition to using study-specific assessment tools, also included two standardized instruments—the Hogan Grief Reaction Checklist and the Inventory of Social Support. Participants also recorded their story-telling sessions, and the researcher performed applied inductive content analysis on these recordings. O'Neil et al. used study-specific quantitative (Likert) and qualitative (short answer) components to understand team member perceptions of thought of the day exercises.

Together, these two studies showed good tolerability of the interventions among providers. In MacPherson, the intervention was reported by participants to have a greater impact on making sense of past events and less impact on reducing grief. The study ended before the planned number of sessions because of feasibility issues with scheduling (two sessions were completed rather than the planned four). In O'Neil et al., participants primarily valued team building and dedicated time for reflection, while identifying time constraints on the inpatient palliative service as the major barrier.

Trainee Reflection

Studies assessing outcomes in students/post-graduate physicians identified intervention goals related to cultivating humanism and professionalism, including self-care through patient connection and meaning making. Kim et al.[19] in particular used a patient interview activity explicitly as part of a wider student self-care intervention. The single study focusing on post-graduate physicians/residents oriented toward preparing residents to practice the skill of being able to appreciate the emotional, existential, and spiritual aspects of caring for people who are at the end of life.[20] The duration of time required of participants to transcribe interviews, compose essays, and engage in reflective discussions, was not specifically reported in these studies. In the one study of medical trainees that did not involve a patient encounter, the total curriculum lasted 8.5 hours initially, and this was reduced to 6.5 hours in subsequent years.[17]

Almost all studies of medical trainees (four of five) centered on an interview with a patient in palliative/hospice care, which served as the subject for subsequent reflection. In the three relevant medical student interventions, the format of interview is not clearly specified in the published articles, suggesting varied degrees of guidance to students on how to elicit important thoughts and experiences from patients at the end of life. Each reflective exercise had a distinct process: in Borgstrom et al.,[21] students wrote a reflective essay; in McBain et al.,[22] students produced a work of expressive art (poetry, photography, etc.) companied by a written commentary; in Kim et al.,[19] students transcribed their interviews, completed a reflective questionnaire, and participated in a group discussion. The study with a post-graduate physician population used an interview format based on a dignity therapy intervention that led to the production of a life review document, as well as reflection taking place in the context of the semi-structured interview used to measure outcomes.[20]

The one medical trainee study that did not center on a patient interview, by Rosenbaum et al.[17] used a mandatory curriculum on death and dying for facilitated small groups with these components: 1) visualization exercise in which students imagined the circumstances of one's own death under ideal circumstances, a version of the so-called "good death"; 2) writing a personal history of one's experiences with death; 3) writing a reflective essay on one's reaction to the course; and 4) group discussion.

Studies reported on a small range of outcomes. Kim et al.[19] solely evaluated the student feedback on curriculum with Likert scales and open-responses. Borgstrom et al.,[21] McBain et al.,[22] and Rosenbaum et al.[17] each reported both student feedback on curriculum and content analysis of themes from student essays. Tait et al.[20] used qualitative interviews with participants as part of the evaluation. In general, participants rated interventions as tolerable and valuable—although a subgroup of students in multiple studies questioned the value of time dedicated to reflective essays or transcribing interview notes. Tait et al. notably elicited participant discussion of ways in which mentors implicitly or explicitly modeled negative views of palliative care and death with dignity, an example of "hidden curriculum."

Provider/Trainee Communication

Three of 31 articles addressed narrative techniques as they apply to directly enhancing communication—whether with patients or other providers. Two of the three studies used the framework, developed by a research team including Wittenberg-Lyles et al.,[23,24] abbreviated as COMFORT (C, communication; O, orientation and opportunity; M, mindful presence; F, family; O, openings; R, relating; and T, team), with the aim of helping providers feel increased "comfort" communicating with patients and families about aspects of palliative care. The remaining study, by Campion-Smith et al.,[25] used narratives by providers as a way to reinforce other learning activities pertaining to end-of-life care. All three studies were observational. The studies by Wittenberg-Lyles et al. were based in the U.S., whereas that by Campion-Smith was based in the U.K. Target populations ranged from 28 to 177 participants, and included either multidisciplinary providers or trainees.

Provider Communication

Wittenberg-Lyles et al. 2014[23] examined 177 participants who completed at least one online COMFORT module—105 nurses, 25 physicians, and a category of "other" disciplines totaling 47 (which included pharmacists, respiratory therapists, and nursing aides). Campion-Smith et al. 2011[25] assessed 16 doctors, five nurses, two social workers, and one ambulance emergency care practitioner, and was the more extensive intervention both in terms of time commitment (six sessions of two hours each) and duration (the follow-up survey was completed at five months after completion of the course).

Both research teams reported high completion rates and data regarding participant opinions. In both articles, participants identified conversations relating to end-of-life prognosis and care as a major source of anxiety. In addition, several providers in the Campion-Smith article expressed thematically that storytelling helped to facilitate interprofessional communication. This study was notable for its use of the Kirkpatrick learning scale to categorize the subjective responses of participants in interview and survey. The Kirkpatrick learning scale categorizes learning along a spectrum from internal changes (personal change in attitudes) to gradually more external effects (e.g., changes to organizational structure or to one's actions in specific situations). Several participants reported effects toward the outward end of the Kirkpatrick scale, including changes to the specific language used when talking to families and caregivers about death. Of note, chaplains and social workers, for whom the intervention might have strong relevance, were underrepresented in both studies, and neither study attempted to measure objective outcomes related to clinical behavior or patient care.

Trainee Communication

Nursing students were the subjects of the remaining observational study.[24] The three-hour COMFORT intervention included a combination of lectures, case studies, small group discussions, and exercises, and trained learners in narrative clinical practice, person-centered messages, task and relational components in all interactions, and practice of skills in three encounters. Pre- and post-intervention surveys assessed participant attitudes and perceived confidence in performing patient communication. Outcomes were measured using several quantitative participant response tests: the Communication Skills Attitude Scale, the Perceived Importance of Medical Communication Scale, and the Caring Self-Efficacy Scale. To assess the perceived quality of the intervention, 10 items with five-point Likert-type scale from the Course Experience Questionnaire were also included. The study demonstrated statistically significant improvement in attitudes and self-efficacy. Limitations include a lack of control group and results based on self-report only.

Patient/Caregiver Reflection

Most studies identified for this scoping review focused on interventions for patients and caregivers (24 of 34). The articles we identified for this section span the widest time range, from 1984 to 2017, and include randomized and controlled designs as well as observational studies. Fourteen of 24 studies were based solely in the U.S. The remaining studies were based in the U.K., Australia, Canada, and Japan as well as three with multinational settings: one, a collaboration between the U.S. and Colombia, by Cepeda et al.,[26] and two studies from Chochinov et al.[27,28] that included Australia, Canada, and the U.S.

We noted significant heterogeneity in research aims and methods. Of the studies that had looked directly at an intervention, 17 of 23 studies involved an intervention versus control model—all involving some form of randomization, with the exception of Imrie and Troop 2012.[29] Of the six of 23 studies that evaluated an intervention using an observation rather than randomized, controlled design, five of six were published by research groups that also published a randomized, controlled design; the exception was Tuck et al.[27,30–32] Among the studies with an intervention introduced by the study authors, 15 of 23 had a primary outcome related to the effect of the study intervention (reduction of stress, grief, and pain), whereas all other interventional studies (eight of 20) primarily assessed intervention feasibility with patient outcome as exploratory/secondary outcomes. Of the studies that assessed patient outcomes, two of 15 were very small and had solely qualitative outcomes, in this sense being "pre-feasibility."[29,33]

There was significant variability in outcome measures, which partly reflects the variety of aims and study populations (most notably pediatric and adult). The quantitative assessment tools used in at least two studies by separate research groups were Likert pain scales, Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp), Hospital Anxiety and Depression Scale (HADS), Perceived Stress Scale, Edmonton Symptom Assessment Scale, State-Trait Anxiety Inventory, Patient Dignity Index, Profile of mood states components, Pittsburgh Sleep Quality Index, and Impact of Event Scale. The Perceived Stress Scale, Edmonton Symptom Assessment Scale, HADS, and components from FACIT-Sp were used by three different research groups.

Caregiver Reflection

Of the 24 articles, four focused on narrative interventions solely for friends/caregivers of patients with life-threatening or critical illness, or at the end of life—generally these were bereaved persons.[31,34–36] Two of four articles reported on randomized controlled trials, whereas the remaining two were observation studies.

The four studies had fairly similar aims, relating to the feasibility or efficacy of writing or storytelling interventions to reduce distress among those grieving. Of note, all studies focused on interventions for family or caregivers after a patient death had occurred. Study sizes ranged from six to 69.

Lattanzi and Hall[34] completed a purely descriptive study based on responses to a survey mailed to family members of patients who had received care at a single hospice center. The three of four remaining studies investigated a study-specific storytelling intervention. Two of four studies were from a single research group and reported on the tolerability and feasibility of a storytelling intervention to reduce distress in patient surrogates who had been involved in decisions to limit life support in intensive care unit patients.[31,36] Another article, by O'Connor et al.,[35] focused on participants who were recently bereaved, and was the only study in the family/caregiver group that sought to measure the impact of a narrative intervention on participant levels of distress in the context of bereavement. The latter intervention was a day-long program of narrative exercises and completion of study questionnaires, whereas the narrative interventions studied by Barnato et al. and Schenker et al. lasted one to two hours and were completed either in person or by telephone.[31,35,36]

Outcome measures where heterogenous between research groups and included the General Health Questionnaire—30, the Core Bereavement Items, the Self-Care Index, the Brief Resilience Scale, Impact of Event Scale, HADS, and Primary Care Evaluation of Mental Disorders Patient Health Questionnaire, and decision regret using the Decision Regret Scale. Schenker et al. and Barnato et al. also used the subjective units of distress scale before and after their narrative intervention to assess the immediate impact of their interventions on the distress level of surrogates reporting narratives.

O'Connor et al.[35] did not find a significant impact of the studied intervention on participant grief or well-being. Barnato et al.[36] and Schenker et al.[31] reported good adherence to the intervention, with high tolerability in the primary outcomes, and the storytelling intervention was not found to increase the distress of participants as measured by subjective units of distress scale.

Patient and Caregiver Reflection

Two of 21 articles studied palliative patient-caregiver dyads—with emphasis on patient outcomes. The research group of Allen et al.[37,38] conducted the studies, both randomized controlled trials of a creative activity intervention in which about 40 patient-caregiver dyads completed a creative activity relating to the patient's legacy over three weekly sessions. The primary difference was that the 2008 intervention was administered by a trained study interventionist and the 2014 intervention was administered by senior volunteers. The 2008 study reported excellent completion rates among the group of participants who completed the baseline assessment (30 of 32 dyads completed all three legacy activities). In the 2014 study, completion rates were lower (28 of 45 dyads completed post-intervention phase), with the loss of participants attributed primarily to decline in health or death.

Patient Reflection

The remaining 18 of 24 studies focused on narrative interventions for palliative care patients, whether in the context of life-threatening illness or end of life. Of these studies, four studied pediatric participants, all in the context of cancer diagnoses.[33,39–41] Sample sizes ranged from six to 441; the median size was 36 patients. Recruitment approaches varied, including referrals from providers, contact through support groups, or soliciting participants from clinical sites (physician waiting room, intensive care unit, and hospice facility).

Seven articles included some form of content analysis of patient narratives.[26,29,32,42–45] One of these studies was a qualitative analysis of materials from a separately published quantitative study—both by Vuksanovic et al.[44,46] Most commonly, the qualitative analysis was performed using a named research method (such as grounded theory or inductive content analysis). In one article,[26] a Likert scale was used to assess the perceived emotionality of participants' writing. Two studies[29,43] used a computerized content analysis program, previously developed by emotional disclosure researchers, to assess the psychological processes associated with the written content. One study used a text analysis program, Word Miner 1.0, to look for themes that distinguished the narratives of those who experienced improvement in the primary outcome after intervention compared with those who did not.[45]

Several common themes emerged from comparing study designs across publications, as follows: 1) how many episodes of a narrative intervention would be feasible (because of the population of patients at end of life, multiple sessions saw significant loss of participants), 2) modality to use for the intervention (writing vs. oral storytelling and associated issues regarding inclusion or exclusion of participants based on literacy or cognitive impairment), and 3) site of the intervention—group setting, individual, supervised or independent/home based, and whether to have intervention in person or remotely (telephone or online).

The studies that did look for patient outcomes beyond tolerability and feasibility were either preliminary, underpowered, or did not detect a benefit in the primary outcome, with the notable exception being the three studies by Ando et al.[26,28,29,33,41,43–49] Cepeda et al. focused on the single outcome of pain and found no difference in this primary outcome between interventions. Studies by the group of Ando et al.[45,48,49] selected a single quantitative metric of spiritual well-being at the primary outcome (initially the Skalen zur Erfassung von Lebens qualitat bei Tumorkranken-Modified Version, in 2006 study, and later, FACIT-Sp components when this instrument became available in Japanese) and demonstrated statistically significant improvement across several papers. Other studies often measured many parameters—consistent with the exploratory aims of these studies—and therefore even numerically positive outcomes were generally not statistically significant when researchers accounted for use of multiple comparisons. An additional thematic challenge across

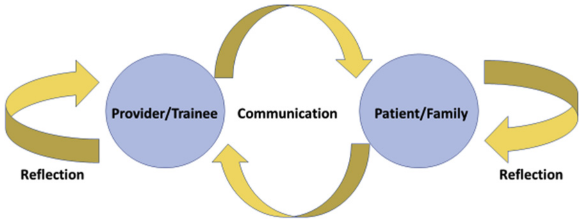

Fig. 2. Three interrelated foci for narrative interventions.

studies was the selection of meaningful outcome measures.

Discussion

We identified 34 papers that met our criteria for evaluation of a narrative intervention in the palliative care context. This area of research, which has expanded over recent years, demonstrated a diversity of concerns and approaches and target populations. We found it useful to group the studies according to target population and function; the broad categories—and their interconnections—correspond to our own conceptualization of the potential uses of narrative medicine in the field of palliative care (Fig. 2).

All studies involving provider/trainee reflection were descriptive in nature. Participants generally reported good tolerability of the intervention, but we noted significant heterogeneity in aims, interventions, and outcome measures. Outcomes were mostly subjective, and the quantitative tools were primarily author-designed or borrowed from other research domains and therefore not previously validated in the study population. Narrative interventions to reduce palliative care provider burnout represents an area of great opportunity, in which validated metrics and institutionally meaningful outcomes are becoming better established. Long-term assessment of provider attitudes and especially behaviors would also provide valuable insight.

Among patient and caregiver articles, many focused on demonstrating feasibility. Where the primary outcome was some measure of a clinical effect, most notably Chochinov et al. 2011[28] and Wise et al. 2017,[47] an intervention effect was often not observed or of small size although significant statistically. The notable exception was the work by Ando et al.[45,48,49]—the 2008 and 2010 studies by this group are comparable with the studies Chochinov et al. 2011 and Wise et al. 2017, as Chochinov used the complete FACIT-Sp and the Wise and Ando studies used subcomponents of FACIT-Sp. Chochinov did not find a significant change in this parameter—although it should be noted that their study included the faith, as well as meaning/well-being, components of the scale, whereas Wise et al. noted a small but statistically significant improvement, and Ando et al. noted a larger and statistically significant effect. Although multiple secondary outcomes were reported as positively associated with interventions, these results must be viewed in light of the risk for Type I error in the setting of multiple hypothesis testing. Of note, most researches involved *the production* of narratives by patients and/or caregivers (24 of 34). Interventions which make use of the appreciation and interpretation of a narrative (e.g., poem, film clip, short story) fall as much within the purview of narrative medicine as does production. Among patients/caregivers, the feasibility of patient story-telling interventions was frequently limited by functional decline and demands on time—discussion of narrative pieces could have clinical benefit while being less physically and cognitively demanding.

We found a striking dearth of publications reporting on the use of narrative interventions for communication, rather than reflection, in the arena of palliative care. The existing articles rely on self-report for outcomes, mostly focusing on provider attitudes. Areas of future research could include: 1) clarifying what narrative methods work best for palliative care communication skills training, including piloting novel methods; and 2) objectively evaluating the impact of clinician narrative training on skills, behavior, and patient/caregiver outcomes. One example of a tractable area of future research that combines these two elements would be the study of narrative approaches to advance care planning. Concurrently assessing the impact of narrative interventions on both patients and providers within a single study could also be of great interest.

Across all studies, one overarching theme we identified was the lack of a common conceptual framework or vocabulary for describing narrative interventions. Of note, we did not restrict our search to studies using a single term, such as “narrative medicine,” which allowed us to identify a wide range of interventions that use narrative practices. As a consequence, we identified multiple research groups operating in a common research area, whereas, at times, using widely divergent terms and concepts. Our present study highlights the opportunity for further consensus building among all relevant stakeholders (including interdisciplinary clinicians, health care systems and cost-effectiveness researchers, specialists in narrative and humanistic interventions, patients, and caregivers) to better establish a common language, including the identification and use of core outcome measures. Validated measures of pain, distress, depression, anxiety, and functional status would be prime candidates for relevant and comparable quantitative outcomes. A measure that consistently showed a statistically significant positive change as a component of a primary outcome in randomized, controlled trials by different research groups was the FACIT-Sp components relating to peace and well-being, although more work needs to be performed to understand the clinical significance of using subcomponents of this instrument.[50] In addition, given the relational aspects of care at the end of life and during critical illness, the measure of caregiver as well as patient outcomes should be encouraged. Finally, given the complexity and specificity of how a patient and caregivers might define a good death, qualitative interviews should likely remain a central component.

Concretely, we believe the most important next step would be to assemble a consortium of relevant stakeholders to define key terms, agree on a taxonomy for interventions, and set core outcome measures for evaluating these interventions. As a starting point, we have used *narrative intervention* as a unifying in term for the diverse practices identified in our study, and have used the terms *reflection* and *communication* to distinguish those interventions undertaken primary for the benefit for the producer of a narrative from those interventions undertaken primarily to enhance understanding between two or more parties. We do not conceptualize reflection and communication as mutually exclusive but rather as descriptive terms for the point of focus for a particular research question.

Our study is the only scoping review of narrative interventions in the palliative care context of which we are aware. Strengths of our research include the use of multiple databases and a systematic approach following standard protocols,[13–15] using independent reviewers and a consensus process. The study did not include a search of the gray literature, nor of non-English language sources. For some databases, such as Scopus, we added parameters to limit the results of searches because of a high volume of non-relevant searches that we did not use for databases with fewer results. With the aim of searching with breadth, we avoided usage of a single search term, such a “narrative” or “writing” by which to define relevant interventions; however, the limitation of this more open approach was increased reliance on reviewers to define what is or is not a narrative intervention. Several studies, such as the music video interventions of Robb et al., provide limited information concerning the details of their intervention within the published article.[33,40,41] Where there was ambiguity without a definite reason to exclude an article, we favored inclusion. We excluded a large volume of studies that included the key term “narrative” in the context only of a qualitative research method rather than a narrative intervention. Generally, this distinction was clear, but in a small subset of cases in which narratives were collected and analyzed to process and understand themes both from a participant and a researcher perspective, the distinction was ambiguous. By having two reviewers separately select studies for inclusion (T.L. and L.S.), with discrepancies refereed by a third reviewer (D.W.), we improved the validity of our selections. As is common with scoping review articles, we did not assess the quality of the evidence based on the accumulated studies and therefore provide no clinical recommendation on narrative interventions. The aim is rather to concisely present the state of the field of inquiry as it currently exists, so that this can be a basis for further research.

Our hope is that this scoping review will serve to highlight commonalities between such allied projects, so that future research can use shared terminology, concepts, and outcomes, anchored jointly by the growing fields of narrative medicine and palliative care.

Conclusion

This review maps out the state of current research in the intersecting areas of narrative medicine and palliative care. Continued dialogue is needed to establish a common language of research (terminology, concepts), as well as establishing core outcomes of interest. Much of the current literature focuses on outcomes of feasibility and self-report of attitudes. More studies measuring the impact on clinical outcomes is important. In particular, research demonstrating the impact of the following interventions is scarce and would be beneficial: narrative communication skills training, the processing (as opposed or in addition to the production) of narratives, and narrative reflection by practicing clinicians.

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