



Information Gathering Report

Hospice Quality Reporting Program – Option Year 2



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Table of Acronyms

AAHPM	American Academy of Hospice and Palliative Medicine
ACC	Associate Certified Chaplain
AH	Avoidable Hospitalization
APBCC	Advanced Practice Board Certified Chaplain
BCC	Board Certified Chaplain
BCCI	Board of Chaplaincy Certification Inc.
BMI	Body Mass Index
CAHPS	Hospice Consumer Assessment of Healthcare Providers and Systems
CAPC	Center to Advance Palliative Care
CC	Chaplain Credentialing
CMOS	Comfort Measures Order Set
CMS	Centers for Medicare & Medicaid Services
COP	Conditions of Participation
COPD	Chronic Obstructive Pulmonary Disease
CPST	Continuous Palliative Sedation Therapy
DNR	Do Not Resuscitate
EORTC-QLQ-C30	European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire-C30
ESAS	Edmonton Symptom Assessment Scale
HIS	Hospice Item Set
HIV	Human Immunodeficiency Virus
HOPE	Hospice Outcomes & Patient Evaluation
HPNA	Hospice and Palliative Nurses Association
HQRP	Hospice Quality Reporting Program
ICSI	Institute for Clinical Systems Improvement
IDG	Interdisciplinary Group
IPOS	Integrated Palliative Care Outcomes Scale
MWM Project	Measuring What Matters Project
NASW	National Association of Social Workers
NCHPC	National Coalition for Hospice and Palliative Care
NCP	National Consensus Project
NHATS	National Health and Aging Trends Survey
NHPCO	National Hospice and Palliative Care Organization
NQF	National Quality Forum
PASI	Patient Preferences About Serious Illness Instrument

PCG	Pharmacy-Based Cost Group
PCHPC SOP	Professional Chaplains in Hospice and Palliative Care's Standards of Practice
PHQ9	Patient Health Questionnaire 9
POLST	Physician Orders for Life-Sustaining Treatment
POS	Palliative Care Outcomes Scale
PSI	Problem Solving Intervention
QSC	Quality of Spiritual Care
RESPECT	Risk Evaluation for Support: Predictions for Elder-life in the Community Tool
SDAT	Spiritual Distress Assessment Tool
SDOH	Social Determinants of Health
SHR	Standardized Hospitalization Ratio
SME	Subject Matter Expert
SWAN	Social Worker Assessment Notes
SWAT	Social Worker Assessment Tool
TEP	Technical Expert Panel
WHO	World Health Organization

Executive Summary

Background

Many Americans rely on hospice care for end-of-life support. In 2019, more than 1.6 million Americans received hospice care, with Centers for Medicare & Medicaid Services (CMS) spending \$20.9 billion on hospice services (MedPAC, 2021). High quality hospice services are critical to terminally ill patients. CMS anticipates expanding the Hospice Quality Reporting Program (HQRP) over the next several years to include additional meaningful quality measures to help consumers make informed decisions when selecting a hospice for end-of-life-support. This expansion includes introducing the Hospice Outcomes & Patient Evaluation (HOPE), a patient assessment instrument that will incorporate the remaining Hospice Item Set (HIS) and developing outcome and other quality measures to assess the quality of care provided to hospice patients throughout the hospice stay.

The Hospice Information Gathering Reports support these efforts by reviewing available resources to inform HOPE development and related quality measures. Since CMS released the last Information Gathering Report, a second annual technical expert panel (TEP) meeting was held. The TEP deliberations, in addition to discussions with the HOPE development team, the hospice quality measurement development team, and federal stakeholders, identified areas where additional information could support the HQRP expansion.

This 2021 Information Gathering Report focuses on:

Treatment of moderate to severe pain. As in prior years, the TEP sought additional information to aid in developing a pain measure, including information on:

- The prevalence of moderate to severe pain,
- The length of time needed to see a reduction in moderate to severe pain,
- Whether patients experiencing pain that is difficult to control are equally distributed across hospice providers,
- Whether pain is over- or undertreated in the hospice setting.

To complement the detailed neuropathic pain discussion in last year's report, here we provide information on:

- Current approaches to risk-adjusting for neuropathic pain,
- Potential disparities in neuropathic pain that may be exacerbated by risk-adjustment.

This information addresses TEP discussions on the appropriateness of a measure focused on higher levels of pain and the associated reassessment timeframe, whether such a measure would disproportionately impact certain hospices, and whether a pain reduction measure risks overtreatment of pain.

Patient Preferences. The TEP continued to stress the importance of integrating patient preferences in hospice care. For example, participating clinicians noted the importance of customized care planning which, ideally, should be informed by patient's preferences for pain management and their individual preference for the acceptable threshold of pain. To support the development of valid and reliable spiritual and psychosocial care items, the instrument development team requested supporting evidence for assessment item(s) measuring patient preferences. To support these stakeholders, and better understand how patient preferences can be integrated into a quality measure we needed to learn:

- How patient preferences are used in quality measurement and improvement activities,

- Evidence for assessment item measurement of patient preferences for symptom management,
- Whether goal achievement is consistent with patient preferences,
- The concordance between patient/proxy report and medical/determinations that symptom management goals were achieved,
- The concordance between patient and proxy preferences for symptom management.

Spiritual and Psychosocial Assessment and Care: A primary goal for HOPE is to promote patient-centered-care—in the hospice setting spiritual and psychosocial care are key components of patient-centered care. To support the development of valid and reliable spiritual and psychosocial care items, the instrument development team requested scientific evidence and clinical guidelines related to spiritual assessment and care and psychosocial assessment and care, as conducted by spiritual care counselors and social workers, respectively. To support these stakeholders we needed to learn:

- Standards of practice for assessment and interventions for spiritual and psychosocial care, including existing assessment items and tools,
- Evidence or guidelines for spiritual and psychosocial assessment and care as conducted by a spiritual counselor or social worker,
- Spiritual and psychosocial care outcomes for palliative care patients,
- Requirements for permission to use the Spiritual Distress Assessment Tool (SDAT).

Medication Management: The TEP supported a medication management measure. As such, preliminary information gathering activities will inform the quality measurement team as they consider further development of this concept. Specifically, we sought to understand the aspects of medication management that would be most relevant to quality of care in the hospice setting.

General Hospice Activities: To better inform HQRP measurement and reporting activities, we gathered information on recent quality measurement and reporting activities in the hospice setting.

Treatment of Moderate to Severe Pain

Recent studies specific to moderate or severe pain in a hospice or palliative care setting, report prevalence estimates ranging from 22% to 65%, and suggest that such pain can be reduced in two to three days. Few studies address the distribution of hospice patients who experience moderate to severe pain, however a few studies suggested that certain types of patients may be more likely to experience moderate or severe pain, or less to likely to respond to treatments for such pain. Collectively, these studies suggest differences in the experience of pain and its management by specific patient populations, diagnoses, and hospice profit status, among others. At least some of the differences can reflect quality of care provided by a given hospice, such as consistently performing comprehensive pain assessments. However, the studies currently available do not provide sufficient evidence to determine why factors such as profit status or length of stay influence a patient’s experience of pain and its management, though they suggest that these discrepancies can be addressed by care improvements. In addition, pain management differences within subpopulations, we further reviewed the literature for whether pain was generally over- or undertreated. Most studies indicated that patients receiving hospice or palliative care are more likely to receive pain treatment than those in other settings, though studies do not suggest pain is overtreated in these settings. However, some literature shows that pain is likely to be undertreated.

Though we provided an in-depth review of the neuropathic pain literature in the 2020 Information Gathering Report, the TEP remained concerned about how neuropathic pain may affect a quality measure related to treating moderate or severe pain. Specifically, the TEP discussed whether a measure should risk adjust for neuropathic pain. Given the limited information specific to the hospice setting, we identified risk-adjustment methodologies used in other settings. We found two US examples: Medicare’s standardized hospitalization ratio (SHR) for dialysis facilities, and Maryland’s newly developed Pre-Avoidable Hospitalization (AH) Model. In both models, neuropathic pain is considered an independent risk factor for hospital admission and therefore risk adjusted. The SHR used a structured TEP review of co-morbidities to determine how likely they were to be result of facility care. Co-morbidities that were scored as “unlikely” or “very unlikely” to be the result of facility care were considered appropriate risk-adjusters (University of Michigan Kidney Epidemiology and Cost Center, 2016). Maryland’s model, which estimates a patient’s risk of experiencing an avoidable hospital event, identified its risk factors through a comprehensive literature review (Henderson et al., 2020). One study was specifically focused on risk-adjusters for end-of-life care and found that proper treatment of neuropathic pain prior to death is a key indicator of whether patients received appropriate end-of-life care (Smets, 2020). Additionally, a majority of HQRP TEP members (6 of 10) favored including neuropathic pain in a moderate to severe pain measure without risk adjusting.

We further searched for potential disparities in who experiences neuropathic pain to ensure any disparities would not be exacerbated by risk adjustment. The SHR model mentioned earlier does not include race, ethnicity, or socioeconomic status, but sensitivity analyses of model data suggested no clear disparities in outcomes based on these factors. Several other studies, though not specific to the hospice setting, suggest factors such as race, socioeconomic status, co-morbidities, and environmental factors do influence who experiences neuropathic pain and how they experience it.

In sum, while neuropathic pain appears to be an independent risk factor for hospital admission in dialysis and primary care patients, it is unclear if or how this applies to hospice patients. Similarly, while there appear to be many factors that contribute to potential disparities in neuropathic pain screening, and how neuropathic is experienced and managed, it is not clear which of these would persist in the hospice setting rather than an outpatient setting.

Patient Preferences

Few studies addressed capturing patient preferences in a standardized way, with some studies specifically noting a lack a standard definition of patient preferences or suggesting that even when providers and patients discuss preferences the results are not documented. Further, most literature on patient preferences was specific to end-of-life care, with more limited findings on preferences related to symptom management. With respect to end-of-life care, many patients are skeptical of or unwilling to complete formal advance directives, opting instead for informal discussion with practitioners (Cain et al., 2018). Even when providers do engage patients in discussion about end-of-life preferences, the results may go undocumented. One study found discrepancies in the occurrence of goals-of-care discussion—which can be used to elicit and respond to patient preferences—as reported by patients, clinicians, and medical records, suggesting variable understandings of what constitutes a goals-of-care discussion (Modes et al., 2019). In implementing the HQRP in 2016, CMS recognized the importance of incorporating end-of life preferences, with HIS including items specific to preferences on cardiopulmonary resuscitation, life-sustaining treatments, and hospitalization.

Symptom management preferences involve decisions that are related to, but ultimately separate from, HIS items about cardiopulmonary resuscitation, life-sustaining treatments, and hospitalization, and there is currently no standardized assessment approach for patient preferences about symptom management. One instrument used by some hospices to elicit symptom management preferences is the Patient Preferences About Serious Illness Instrument (PASI), a resource intended to be used in conjunction with existing

advanced care planning directives, such as the Physician Orders for Life-Sustaining Treatment (POLST), which documents patient’s treatment preferences as actionable medical orders. However, a recent multi-setting study suggests that providers found implementing PASI at the point of care challenging. They cited challenges such as time constraints and knowing at what stage of disease progression to introduce the tool.

A current HQRP process measure (NQF# 3235) includes the extent to which hospice providers discussed — or attempted to discuss — at least one of three preference items with documentation in clinical records (CMS, 2021¹). Research studies suggest that population-level adherence to this measure is high, but that individual experiences with the HQRP treatment preferences measure have been more variable (Zheng et al., 2018 & Hunt et al., 2021). The Measuring What Matters (MWM) project selected “Care Consistency with Documented Care Preferences” (MWM #9) as one of ten indicators for quality measurement in U.S. healthcare settings, and evidence indicated this measure also has a high adherence rate (Unroe et al., 2016 & Kamal et al., 2016). However, despite consensus among interdisciplinary experts that goal-concordant care should be the primary outcome construct of end-of-life care, there is still no standardized or reliable method of measurement (Sudore et al., 2018; Johnson et al., 2018). Recognizing these conceptual gaps, a 2021 targeted literature review defined four methods used to measure goal-concordant care in palliative care research — patient report, bereaved caregiver report, longitudinal data, and population level indicators — and discussed strengths and weaknesses of each method (Ernecoff et al., 2021).

Most studies on goal-concordant care focus on the distinction between life-sustaining treatment and comfort care, and more research is needed regarding goal-concordant care in the realm of symptom management, particularly in the hospice setting. The few studies identified suggest that proxies do not consider patient preferences to have been adequately met, but these perceptions do not impact their assessment of overall quality of care. Further research is also needed regarding concordance between patient/proxy report and medical clinical determinations that symptom management goals were achieved.

Spiritual Care

Practice guidelines describe spiritual care as an integral part of hospice and palliative care, and spiritual assessments are essential to providing spiritual care. The guidelines reviewed indicated that hospices should:

- Routinely assess spiritual needs
- Provide counseling to meet spiritual needs
- Include a spiritual counselor in the interdisciplinary group
- Facilitate visits by spiritual counselors who can address spiritual needs
- Respect spiritual beliefs and practices

In general, guidelines we reviewed did not prescribe particular spiritual care interventions; however, some practice guidelines (World Health Organization, 2018; Ahluwalia, 2018) identified interventions for spiritual care: life review/dignity therapy, meaning-oriented therapy, legacy-building, guided-visualization, mindfulness meditation, yoga and other mind-body interventions, art therapy, and

¹ The preference items were initially endorsed as [NQF #1614](#). As of August 2021, this measure is no longer reported as a single measure but remains a component of NQF #3235.

journaling. Practice guidelines varied in their directives regarding the role of spiritual counselors and the staff responsible for spiritual care. Those describing standards of practice for hospice focused on spiritual counselors as the sole providers of spiritual care.

Trained spiritual counselors can provide effective spiritual care in the hospice and palliative care setting. Nurses, doctors, and social workers can also effectively provide spiritual care when they are properly trained to do so. However, multiple studies suggest current training on spiritual care among nurses and other healthcare providers is often inadequate. Providers considered these conversations difficult, with providers who personally hold religious beliefs being more comfortable having spiritual care discussions with patients. However, providers who received training on spiritual care more easily recognized spiritual distress and found fewer barriers to addressing a patient's spiritual care needs.

Despite the evidence for the importance of well-trained spiritual care providers, there is currently no clearly articulated consensus regarding credentials needed to provide spiritual care. The Hospice Conditions of Participation have no statements regarding qualifications or credentials for spiritual care and/or pastoral counseling (e.g., education, courses, certifications, trainings) (42 C.F.R § 418). There is no licensure for spiritual care providers, though several organizations offer certifications with varying requirements.

The literature on outcomes of spiritual care as in intervention for hospice and palliative care patients fell into two categories; studies either examined 1) designated spiritual care interventions or 2) broader interventions that included spiritual care. [Dignity Therapy](#) was the most common spiritual intervention examined in recent empirical work. Studies of Dignity Therapy or a variation of Dignity Therapy (Abbreviated Dignity Therapy, Dignity Talk, dignity therapy/life plan intervention) generally found positive impacts such as improved well-being. Other interventions had a spiritual care component but were broader than spiritual care alone. As a result, we could not determine the degree to which spiritual care influenced patient outcomes in these studies. These interventions did show positive results such as improved quality of life, though most were disease specific. The HealthCare Chaplaincy Network asserts that although patients and their caregivers want spiritual care, and spiritual care is associated with improved outcomes, there are few reliable and valid quality indicators. They recommend some structural, process, and outcome quality indicators of spiritual care, and have suggested tools for measuring each (see **Table 1** in the Spiritual Care section of this report).

One tool for measuring spiritual care needs is the Spiritual Distress Assessment Tool (SDAT). This tool was one example reviewed by the instrument development team and technical expert panel. The SDAT in its entirety (items and scoring) is an open access article distributed under the terms of the [Creative Commons CC BY license](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Psychosocial Assessment

Hospice Conditions of Participation (42 CFR. § 418.64(c)) specify that in the hospice setting, medical social services must be provided by a qualified social worker under the direction of a physician and services must be based upon a psychosocial assessment as well as the patient and family needs (42 CFR § 418.64(c)). The regulation further defines a social worker as someone with either a Master of Social Work (MSW), a baccalaureate degree in social work, or a baccalaureate degree in psychology, sociology or a related field provided they are supervised by an MSW. In addition to the educational requirements, social workers must also have at least one year of social work experience in a healthcare setting. (42 CFR §418.114(b)(3)).

The limited regulatory definition of psychosocial care provides opportunity for national associations to suggest added guidance on psychosocial assessment and care. The National Coalition for Hospice and

Palliative Care (NCHPC), the National Hospice and Palliative Care Organization (NHPCO), and the National Association of Social Workers (NASW) each supply their own recommendations for what type of information should be collected during a psychosocial assessment. Such information includes an evaluation of emotional distress and identification of patient coping skills, spiritual needs, emotional history, support systems, and cultural values and beliefs.

Two tools developed and used by hospice social worker were identified: The Social Worker Assessment Tool (SWAT) and the Social Worker Assessment Notes (SWAN). SWAT and SWAN are similar assessments that screen patients for psychosocial issues such as depression, anxiety, safety, and grief. Additional psychosocial tools were not both approved by hospice organizations and developed by social workers. While SWAT and SWAN meet these criteria and capture various aspects of a patient's psychosocial experience in hospice, future development and testing is needed to confirm that the tools effectively measure psychosocial treatment.

There is limited evidence on outcomes of psychosocial interventions and treatment in the hospice setting. With respect to physical symptoms, one study suggests social decline can worsen physical symptoms in hospice patients (Seow et al., 2021) while another found the psychosocial interventions had no effect on fatigue for cancer patients (Poort et al., 2017). For mental health symptoms, in some cases interventions that include a social worker can improve outcomes such as anxiety and depression (Rogers et al., 2017). In sum, there is limited evidence to help us understand the outcomes related to psychosocial care in the hospice setting, but existing evidence suggests benefits for improved mental health rather than improvement in physical symptoms.

Medication Management

We conducted a preliminary literature review to further consideration of a medication management measure concept. Our results include two broad categories—the reasonable use of medications at the end of life, and the role of patients, families, and caregivers in managing medication at the end-of-life.

Recent studies suggest that patients remain on unnecessary medication at the end-of-life, such as cholesterol or blood-pressure reducing medications, and providers need education and guidelines to support more reasonable use of medications at the end of life. The studies further reflect a lack of guidelines and education to support medication use at the end of life. A small quality improvement study found success in using clinical pharmacy specialists to discontinue medications no longer needed, and the Center to Advance Palliative Care's (CAPC) clinical training recommendations indicate adjusting medications as a component of medication management for patients with serious illness.

Nurses and other caregiver perceptions of medication management reflect challenges in provider and patient/caregiver communication and in providing adequate education to caregivers. Nurses acknowledge that patients and caregivers often have inadequate knowledge of their medications, but few providers probe into the patient or caregivers experience of taking or providing medication, or probe for the underlying cause of medication management issues. This is particularly present for pain medications, with one hospice-based study finding that nurses and caregivers both believed that the caregivers did not have sufficient knowledge to manage pain medication. The caregivers were unable to communicate their concerns (e.g., unsure what to say), and nurses were not aware that caregivers felt unable to communicate their concerns (Mayahara et al., 2017)

A number of these studies also include recommendations for improving medication management challenges, with most recommending developing guidelines and educational tools to support providers, patients, and family caregivers. Currently, there is a lack of consensus on clinical guidelines defining hospice's role in supporting medication management by family caregivers (Tjia, 2019). Both the Joint Commission and a recent US quality improvement study (Hay et al., 2019) provide examples of how to address these challenges, The Joint Commission's new CMS requirements for hospices include

the interdisciplinary team determining the patient's and family's ability to administer medications safely and competently. A recent quality improvement study in a US inpatient hospice and palliative care facility tested an evidence-based staff protocol for educating patients and families about pain medication side effects. The study found both improvements in staff knowledge and staff confidence in their ability to effectively communicate with patients and families about pain medication side effects.

Other Recent Hospice Literature

To identify any emerging trends outside of our specific research questions, we conducted an environmental scan to identify literature related to general quality of care in the hospice setting published in the last one to two years. Our results fell into three main categories: quality measurement, the experience of patients in hospice compared to other settings, and emerging practices in hospice care.

With respect to quality measurement, two articles used CMS Hospice Compare data². The first compared themes in Yelp reviews of California hospice providers with themes captured by Hospice Compare's care-giver survey items, assuming that the user-generated content of Yelp reflects what families or caregivers consider useful to others when considering a hospice provider. While there was significant overlap between Hospice Compare and Yelp, the Yelp reviews addressed a wider range of themes, such as whether staff was compassionate and caring, whether the patient or family was grateful to the hospice, comprehensiveness of services, agency management, staff professionalism, and whether staff was knowledgeable or skilled (Rahman et al., 2021). Also using data from Hospice Compare, the Joint Commission released a dashboard report for hospices that supports measures related to opioids, pain, dyspnea, and spiritual concerns (Elliot & DeMarzo, 2019). Another set of studies focused on the setting of care and suggest that home hospice offers a better experience of care than residential care settings like nursing homes. For example, home hospice patients were more likely to be treated with respect than patients who receive care in a residential care setting (Xu et al., 2020).

Recent literature with respect to hospice care explored the value of physical activity for hospice patients and ensuring that hospice is received timely. In both the home and inpatient hospice settings physiotherapy improved activities of daily living and the patients' ability to manage their conditions (Ćwirlej-Sozańska et al., 2020; Burke, 2020). In terms of identifying when a patient might be appropriate for hospice, a recent Canadian study found that functional ability measures better capture patient decline than individual chronic diseases, and that the Risk Evaluation for Support: Predictions for Elder-life in the Community Tool (RESPECT), a risk-evaluation tool intended to predict death in six months, better identified patients with limited life expectancy than current practices. The authors suggested using RESPECT to supplement home healthcare assessments to help decide when a patient may need comprehensive palliative or hospice care assessments (Hsu et al., 2021).

Conclusion

To support the HQRP in developing quality measures and an assessment instrument, we have identified current information on treating moderate to severe pain, patient preferences for symptom management, spiritual care, psychosocial care, medication management, and general hospice activities—all with information specific to the hospice setting whenever possible.

In some cases, such as treating moderate to severe pain, evidence supports the current HQRP measures under development, including the time required to reduce moderate to severe pain. In other areas, like risk adjustment for neuropathic pain, patient and proxy concordance of patient symptom management preferences, and psychosocial outcomes, we found limited evidence for the hospice setting. In those cases, we provided information from other settings to support HQRP activities. Where applicable, such as

² Hospice Care is known as Care Compare as of December 2020. Results may not be replicable in Care Compare.

understanding standards of practice for spiritual and psychosocial care, we reviewed regulations and the websites of provider associations to understand the current information available to hospice agencies.

We also explored evidence for future potential areas of measure development, such as medication management, finding gaps concerning the reasonable use of medications at the end of life and the engagement of patients and caregivers. Additionally, we broadly searched for information that pertained to quality measurement in hospice. We found an examination of the usefulness of Hospice Compare items, potential functional improvements from providing physiotherapy to hospice patients, and alternatives to predicting when a patient may be ready to enter hospice.

This report will inform the HQR TEP, the quality measure development team, the instrument development team, and other hospice stakeholders to advance, in collaboration with CMS, including additional meaningful quality measures in the HQR.

Background and Significance

Many Americans rely on hospice care for end-of-life support. In 2019, more than 1.6 million Americans received hospice care, with Centers for Medicare & Medicaid Services (CMS) spending \$20.9 billion on hospice services (MedPAC, 2021). These services are critical to terminally patients. CMS continually strives to improve hospice quality and the experience of care for beneficiaries within the context of the [Meaningful Measures Framework](#), which prioritizes high-impact quality measure areas that are meaningful to patients, their families and caregivers.

CMS anticipates expanding the Hospice Quality Reporting Program (HQRP) over the next several years to include additional meaningful quality measures. The Abt team, under contract to CMS, supports this work. Currently, we are developing a patient assessment instrument, the Hospice Outcomes & Patient Evaluation tool (HOPE), and quality measures to assess the quality of care provided to hospice patients. HOPE is expected to incorporate the remaining Hospice Item Set (HIS) data collection tool items. The primary goals for HOPE are to reflect the care needs of patients and their families and caregivers through the dying process, prioritize the safety and comfort of individuals enrolled in hospice nationwide, and promote person-centered care.

The Hospice Information Gathering Reports support these efforts by reviewing available resources to inform HOPE development and related quality measures. The [2019 Information Gathering Report](#) used stakeholder input, environmental scans, literature reviews, and focus groups to establish a candidate list of domains for HOPE inclusion. The [2020 Information Gathering Report](#) used similar methods to explore specific areas where additional information was needed to support quality measure development. Specifically, it addressed potential adaptation of the Integrated Palliative Outcome Scale (IPOS) for HOPE, the most current signs and symptoms of a patient who is actively dying, and additional information on pain and dyspnea management to support related quality measures.

Since CMS released the last Information Gathering Report, the [second annual technical expert panel \(TEP\) meeting was held](#). The meeting focused on candidate outcome measures assessing pain and symptom management and identifying priorities for future measure development. These discussions, in addition to discussions with the HOPE development team, the hospice quality measurement development team, and federal stakeholders, highlighted areas where more information could support the expansion of the HQRP. To that end, this 2021 Information Gathering Report focuses on:

- **Treatment of moderate to severe pain.** As in prior years, the TEP wanted more information to support developing a pain measure, including information on
 - The prevalence of moderate to severe pain,
 - The length of time needed to see a reduction in moderate to severe pain,
 - Whether patients experiencing pain that is difficult to control are equally distributed across hospice providers,
 - Whether pain is over- or undertreated in the hospice setting.

To compliment the detailed pain discussion in the 2020 report, here we provide information on

- Current approaches to risk-adjusting for neuropathic pain,
- Potential disparities in neuropathic pain that may be exacerbated by risk adjustment.

This information addresses TEP discussions on the appropriateness of a measure focused on higher levels of pain and the associated reassessment timeframe, whether such a measure would disproportionately impact certain hospices, and whether a pain reduction measure risks overtreatment of pain.

- **Patient Preferences.** The TEP continued to stress the importance of integrating patient preferences in hospice care. For example, participating clinicians noted the importance of customized care planning which, ideally, should be informed by patient’s preferences for pain management and their individual preference for the acceptable threshold of pain. To support the development of valid and reliable spiritual and psychosocial care items, the instrument development team requested supporting evidence for assessment items(s) measuring patient preferences. To support these stakeholders, and better understand how patient preferences can be integrated into a quality measure we needed to learn:
 - How patient preferences are used in quality measurement and improvement activities,
 - Evidence for assessment item measurement of patient preferences for symptom management,
 - Whether goal achievement is consistent with patient preferences,
 - The concordance between patient/proxy report and medical/determinations that symptom management goals were achieved,
 - The concordance between patient and proxy preferences for symptom management.

- **Spiritual and Psychosocial Assessment and Care:** A primary goal for HOPE is to promote patient-centered-care—in the hospice setting spiritual and psychosocial care are key components of patient-centered care. To support the development of valid and reliable spiritual and psychosocial care items, the instrument development team requested scientific evidence and clinical guidelines related to spiritual assessment and care, and psychosocial assessment and care, as conducted by spiritual care counselors and social workers, respectively. To support these stakeholders, we needed to learn:
 - Standards of practice for assessment and interventions for spiritual and psychosocial care, including existing assessment items and tools,
 - Evidence or guidelines for spiritual and psychosocial assessment and care as conducted a by spiritual counselor or social worker,
 - Spiritual and psychosocial care outcomes for palliative care patients,
 - Requirements for permission to use the Spiritual Distress Assessment Tool (SDAT).

- **Medication Management:** The TEP supported a medication management measure. As such, preliminary information gathering activities will help as the quality measurement team considers further development of this concept. Specifically, we sought to understand the aspects of medication management that would be most relevant to quality of care in the hospice setting.

- **General Hospice Activities:** To better inform HQRP measurement and reporting activities we gathered information on recent quality measurement and reporting activities in the hospice setting.

Methods

To address this year's information gathering topics, we searched for and reviewed both peer-reviewed and grey literature. We also asked for information directly from the TEP and other stakeholders, who supplied us literature they felt was relevant to our topics. For some topic areas, such as understanding standards for practice, we conducted a review of the applicable rules and regulations. We additionally sent a brief informal survey to the TEP to capture their thoughts on risk-adjustment for neuropathic pain.

For our literature reviews, we used MEDLINE/PubMed® database, supplemented with searches in Google Scholar, using pre-developed search terms (e.g., MeSH) specific to the topic. For grey literature, we established a list of well-known resources and applied key words from our topics to find relevant information. We also asked TEP members if they were aware of any recent and relevant articles that we should consider. We limited our results to articles published within the past five years, except for the general hospice activities topic, where we used a shorter period of one to two years. For rules and regulations, we searched for the topic in Google using keywords and reviewed results from websites with a .gov domain name.

In some cases, we found insufficient information specific to the hospice setting. In those cases, we considered information that reflects care provided in other settings, such as palliative care and home health. In cases where results are specific to a hospice subpopulation (e.g., cancer patients) or sub-setting (e.g., general inpatient, skilled nursing facility, home), we have stated so in our results.

Throughout the process we consulted key stakeholders to clarify the purpose or intent of the research questions and confirm expected sources of information, as needed. For more details on our methods refer to **Appendix I**. We present a summary of search results for each section in **Appendix II**, and complete literature review tables for each section in **Appendix III**.

Treating Moderate to Severe Pain

As the HQRP continues to evaluate the feasibility of a pain outcome measure, we conducted literature reviews to determine the prevalence of moderate to severe pain, the length of time needed to achieve a reduction in moderate to severe pain, and whether pain that is difficult to control is evenly distributed across hospice providers. We also looked for whether the most current literature suggests pain is over- or undertreated in the hospice setting and information related to risk-adjustment for neuropathic pain.

Prevalence of moderate to severe pain

We found five recent studies specific to the prevalence of moderate or severe pain in a hospice or palliative care setting, with prevalence estimates ranging from 22% to 65%. Two of these studies suggest that hospice patients or more seriously ill patients are more likely to experience pain than less seriously ill patients. One study of cancer patients in US nursing homes during their the last 90 days of life estimated that 21.7% of those receiving hospice were experiencing moderate to severe pain, compared to 18% of non-hospice users. (Hunnicutt et al., 2017). Presumably, patients experiencing higher levels of pain are more likely to be referred to hospice. A Canadian study of patients receiving home-based palliative care found that 65% of seriously ill patients reported daily or severe pain, compared to 54% of not seriously ill patients at initial assessment. At reassessment, an average of 46.6% of patients continued to report daily pain that was severe or excruciating (Harman et al., 2019).

Additional studies assessed the prevalence of moderate to severe pain within specific diagnoses, with cancer exhibiting the highest prevalence at 46%. A Brazilian study of patients in a private post-acute care facility providing hospice care found 25% of dementia patients and 46% of cancer patients experience moderate to severe pain (Soares et al., 2018). A Spanish study of nursing home residents receiving palliative of care found that, on average, patients without dementia reported moderate pain while patient with dementia reported less intense pain (Puente-Fernandez et al., 2020). Finally, a US study of community-dwelling hospice patients in Florida found that 40% of patients reported neuropathic pain symptoms (numbness and tingling in the hands or feet), and that patients who experience those symptoms reported higher pain severity and distress than patients without these symptoms (1.5 vs. 1.8 out of a 4-point scale) (Toftagen et al., 2019).

Length of time needed to reduce moderate to severe pain

Most of the identified studies (three of five) reflected a reduction in moderate to severe pain in two or three days. The remaining studies did not reassess pain until seven days. Only two studies were not specific to cancer patients. One was a Norwegian study of nursing home patients in their last days of life that found that the proportion of patients experiencing moderate pain (i.e., an Edmonton Symptom Assessment Scale [ESAS] score of 3-6) decreased about 0.06 percent between assessments (34.6% to 32.5%). However, for patients experiencing severe pain (i.e., an ESAS score of 7-10) the rate decreased 48% between assessments (25.6% to 13.3%). The median time between reassessments was 3 days (Sandvik, 2016). The other, a US study of home hospice patients saw the percentage of patients with moderate to severe pain decrease almost 82% at the 48-hour assessment (32.5% to 6.0%) (Campbell et al., 2017).

The remaining studies were specific to cancer patients in European countries. Two were of patients with cancer in an inpatient hospice setting, one in Italy and one in Croatia, with both typically re-assessing pain after one week. The Italian study found decreases in ESAS scores between admission and discharge (5.26 to 2.5), with an average hospital stay of seven days. A follow-on study looking at specific sub-populations found ESAS score decreases for patients with anxiety (6.2 to 3.5) and depression (5.6 to 3.6) (Mercadante, 2016, 2019). The smaller Croatian study, which also reassessed pain at one week, is the only study that did not find a statistically significant reduction in patient-reported pain levels. (Golčić, 2018). The third study focused on cancer patients was a UK case study of a breast-cancer patient admitted to an inpatient hospice unit presenting with opioid-induced hyperalgesia (extreme pain response). At three

days treatment for breakthrough pain was reduced, and at four days the patient reported improvements in pain and hyper-sensitivity (Wall & Chauhan, 2018).

Distribution of pain that is difficult to control across hospice providers

Few studies address the distribution of hospice patients who experience moderate to severe pain, however a few studies suggested that certain types of patients may be more likely to experience moderate or severe pain or be less likely to respond to treatments for such pain. A 2020 study of different-sized hospices compared cancer pain and treatment among African American and Caucasian American patients. They found no significant difference in pain intensity (though most pain reported was mild) or in Cancer Pain Practice Index scores (an indicator of receipt of evidence-based practices). However, African American patients were less likely to receive a comprehensive pain assessment upon admission (Booker et al., 2020). A 2016 analysis of the National Home Health and Home Care survey determined the non-Hispanic black patients were also less likely to have a first pain assessment than non-Hispanic white patients. Hispanic patients are both less likely to use opioid analgesics, and more likely to report pain at their final assessment than non-Hispanic whites (Cea et al., 2016). However, the same study found that patients who did use opioid analgesics were more likely to report pain at their final assessment and less likely to report improvement in pain or effective pain management than patients who did not use opioids. This may be because patients who receive opioids are experiencing more severe pain. The Cea study looked at additional factors associated with pain reduction. Patients with longer lengths of stay (8 – 21 days), with do not resuscitate (DNR) directives, or receiving services from non-profit providers were more likely to report improvements in pain and effective management of their pain between the first and last assessments than those with shorter lengths of stay, no DNR directives, or for-profit providers. Patients with cancer, and those receiving services from for-profit hospices were more likely to report having pain at their last assessment than those without cancer or those receiving services from a non-profit hospice (Cea et al., 2016).

Collectively, these studies suggest differences in the experience of pain and its management by specific patient populations, diagnoses, and hospice agency profit status, among others. At least some of the differences can reflect quality of care provided by a given hospice, such as consistently conducting comprehensive pain assessments. However, the studies currently available do not provide sufficient evidence to determine why factors such as profit status or length of stay influence a patient's experience of pain and its management, though they suggest that these discrepancies can be addressed by care improvements.

Over- or undertreatment of pain

As discussed in the prior section, there are some differences within subpopulations with respect to pain management, however, we further reviewed the literature for whether pain was generally over- or undertreated. None of the identified articles suggested that pain is over-treated, while most indicated that patients receiving hospice or palliative care are more likely to receive pain treatment than those in other settings. However, some literature shows that pain is likely to be undertreated.

Three recent studies found that hospice provides patients more pain treatment than other healthcare settings. A US study of nursing home residents with cancer in the last 90 days of life found patients receiving hospice were more likely to receive pharmacologic pain management, a scheduled pain regimen, as-needed medication, and non-pharmacologic pain management than non-hospice patients. These findings were consistent for both patient and staff reported assessments. (Hunnicuttt et al., 2017). A UK study, also of patients with cancer found that, compared to patients who died in the hospital setting, patients who died in hospice were more likely to receive a strong opioid and less likely to get a late prescription for a strong opioid prescription. Patients who died in hospice were equally as likely to receive an opioid as patients who died at home or in a care home, but patients at home or in a care home received their first opioid prescription later and, in most cases (75%), it was for diamorphine, a drug used

in the last days of life (Ziegler et al., 2016). A Canadian study of patients receiving continuous palliative sedation therapy (CPST) found that hospice patients were more likely to have the order for CPST administered to them than patients in a palliative care unit or an inpatient setting (85% vs 82% and 75%, respectively). Additionally, the mean duration of CPST was longer for hospice patients than patients in an inpatient setting or palliative care unit (61.6 hours vs. 24.1 and 20.5 hours, respectively) (Abdul-Razzak et al., 2019).

Though studies suggests that hospice provides more pain management than other settings, there are still concerns about undertreatment of pain in the seriously ill. A small Australian review of opioid errors in an inpatient palliative care unit found that more than half patients received a lower dose of opioids than ordered (Heneka et al., 2019). The Center to Advanced Palliative Care (CAPC) recently highlighted a workshop led by the National Academy of Science, Engineering, and Medicine that discussed the fear of prescribers and pharmacists of legal culpability when supplying opioids, which maintains systemic barriers to opioid prescribing for the seriously ill (Meier, 2019). Though one UK study found that, for terminally ill patients who had been hospitalized, use of a proxy can lead to overestimation, and therefore overtreatment of symptoms, they did not find this to be the case for pain (Dawber et al., 2019).

CAPC has opined on how best to balance providing proper access to care for those with a serious illness, and efforts to curb inappropriate opioid prescribing and use. They suggest improving provider education, improving patient self-management strategies, evaluating the risks and benefits of opioids, and providing patients and families with educational tools, as approaches to mitigate the under treatment of pain (Meier, 2019).

Neuropathic pain risk adjustment and disparities

Though we provided an in-depth of review of neuropathic pain literature in the 2020 Information Gathering Report, the TEP remained concerned about how it may affect a quality measure related to moderate or severe pain. Specifically, the TEP discussed whether a measure should risk adjust for neuropathic pain. We conducted an environmental scan to identify whether neuropathic pain is used in any current risk-adjustment methodologies, and to identify whether any disparities with respect to neuropathic pain exist that could be exacerbated by risk-adjustment. Given the limited information specific to the hospice setting, here were present findings from other settings

We found two US examples of risk-adjustment for neuropathic pain: Medicare's standardized hospitalization ratio (SHR) for dialysis facilities, and Maryland's newly developed Pre-Avoidable Hospitalization (AH) Model. Both models consider neuropathic pain an independent risk factor for hospital admission and therefore risk adjusted. The SHR relied on their TEP to determine appropriate risk factors. Specifically, they evaluated co-morbidities that had a prevalence of at least 0.1% in the population and had a statistically significant relationship with mortality or hospitalization. Then they scored each co-morbidity on how likely it was to be the result of facility care. Co-morbidities that were scored as "unlikely" or "very unlikely" to be the result of facility care were considered appropriate risk-adjusters. Six neuropathic pain diagnoses met these criteria (University of Michigan Kidney Epidemiology and Cost Center, 2016). Maryland's model, which estimates a patient's risk of experiencing an avoidable hospital event, identified its risk factors through a comprehensive literature review focused on risk factors for potentially avoidable readmissions (Henderson et al., 2020). We additionally found a Czech Republic model that determines how funds will be distributed to insurers by determining pharmacy-based cost groups (PCGs). PCGs are based on drug consumption and demographic risk factors. The PCG for neuropathic pain has a risk index of 2.2671, indicating these are higher cost patients (Škodová, 2020).

One study was specifically focused on risk-adjusters for end-of-life care, unlike our earlier examples. This Belgian study found that age, household type, type of cancer, and living in a rural or urban environment are important risk adjusters for various quality indicators assessing different aspects of end-of-life

care. However, it found appropriate treatment of neuropathic pain prior to death a key indicator of whether patients received appropriate end-of-life care (Smets, 2020). Additionally, in March of 2021 we sent a targeted survey to the current HQRP TEP members to confirm their neuropathic pain preferences. A majority of TEP members (6 of 10) favored including neuropathic pain in a moderate to severe pain measure. Three members favored risk-adjusting such a measure for neuropathic pain, and one member favored excluding neuropathic pain from such a measure.

In addition to literature on risk-adjustment methodology, we further searched for potential disparities in who experiences neuropathic pain to ensure any disparities would not be exacerbated by risk adjustment. The SHR model mentioned earlier does not include race, ethnicity, or socioeconomic status, but they conducted sensitivity analysis that suggested no clear disparities in outcomes based on these factors. (University of Michigan Kidney Epidemiology and Cost Center, 2016). Several other studies suggest factors such as race, socioeconomic status, co-morbidities, and environmental factors do influence who experiences neuropathic pain and how they experience it.

Though not specific to the hospice population, three studies indicate racial differences in neuropathic pain—one in its prevalence and severity, one in screening, and one in medication adherence. A US study of breast cancer patients with chemotherapy induced peripheral neuropathy found the prevalence and severity of the neuropathy was higher in Black or African American women than in white women. These differences were both statistically and clinically significant, and persisted when controlling for other characteristics like age, BMI, and diabetes (Simon et al., 2017). A UK study of adults with Type II diabetes found primary care practices less likely to screen women and Asian patients for neuropathy than men and white patients, respectively (Whyte et al., 2019). Another study, of privately insured US patients, found that minority populations had lower neuropathy medication adherence than white patients (Reynolds et al., 2020).

Environmental and socio-economic factors also exhibit disparities in the experience of neuropathic pain. A study on the genetics of neuropathic pain confirmed the environment plays an important role in the clinical pathways of neuropathic pain, and understanding these factors is crucial both to diagnose and treat neuropathic pain. (Calvo et al., 2019). One US study of an impoverished community proximal to coal ash discharge, an [environmental justice community](#), had a high prevalence of neuropathic pain—and residents believed this resulted from their exposure to coal ash. (Amiri & Zhao, 2019). Socio-economic factors also contribute to the experience of neuropathic pain, with a US study finding that increasing out-of-pocket medication costs for neuropathy patients decreased adherence (Reynolds et al., 2020). Another study of patients living with HIV found that there were not racial ethnic differences in how frequently they reported neuropathy as a symptom, but patients with the lowest incomes were more likely to report more burdensome symptoms. (Schnall et al., 2018). The previously mentioned UK study of patients with Type II diabetes also compared the highest and lowest quintiles for the Index of Multiple Deprivations and found economically deprived patients were less likely to receive neuropathy screening than their less deprived counterparts (Whyte et al., 2019).

In sum, while neuropathic pain appears to be an independent risk factor for hospital admission in dialysis and primary care patients, it is unclear if or how this applies to hospice patients. Similarly, while there appear to be many factors that contribute to potential disparities in neuropathic pain screening and how neuropathic pain is experienced and managed, it is not clear which of these would persist in the hospice setting rather than an outpatient setting.

Patient Preferences

Given the person-centered mission of hospice care, honoring patient preferences is crucial for ensuring a quality end-of-life experience. However, in both research and clinical practice, “preferences” are often used interchangeably with “choices,” “values,” and “goals,” making it difficult to generalize findings across settings (Unroe et al., 2016). Furthermore, research suggests that treatment preferences among hospice patients and their family caregivers do not necessarily correlate with their previously stated values, highlighting the difficulties in using terms like “preferences” and “values” interchangeably (Heyland et al., 2017). These variable definitions make it difficult for there to be a centralized and consistent approach to eliciting, capturing, and fulfilling patient preferences across all hospices — despite consensus among clinicians, researchers, and policymakers about the importance of doing so.

Evidence of assessment item measurement of symptom management preferences

Few studies addressed capturing patient preferences in a standardized way, with some specifically noting a lack of standardization or suggesting that even when providers and patients discuss preferences the results are not documented. A recent literature review found “significant variation in the source of patient preferences and the medical interventions for which preferences were reported”, noting assessment approaches ranged from patient interviews and questionnaires to post-mortem chart review to standardized data collection tools (Johnson et al., 2018). Ultimately, hospices use a range of approaches to elicit, capture, and document patient preferences.

End-of-life preferences

Many patients are skeptical of or unwilling to complete formal advance directives, opting instead for informal discussion with practitioners (Cain et al., 2018). Discrete choice experiments (DCE), in which clinicians ask patients to choose between hypothetical but realistic scenarios, show promise for eliciting preferences in home-based palliative care settings (Gomes et al., 2017). Another study of palliative care patients expected to live two to three years employed lay healthcare workers who used motivational interviewing strategies with patients. These healthcare workers documented the patient’s self-defined end-of-life goals on a medical record flow sheet (Schellinger et al., 2018).

Yet even when providers engage patients in discussion about end-of-life preferences, the results may go undocumented. A recent study of US critical care patients suggest that patient preferences are often unavailable or unreliably recorded in most routine claims data or electronic health records (Walkey et al., 2017). Another study of outpatients in the last two years of life found no documentation of goals-of-care discussions for nearly 40% of the visits for which clinicians reported the discussion occurred in an after-visit questionnaire (Modes et al., 2019). This study also found discrepancies in the occurrence of goals-of-care discussions as reported by patients, clinicians, and medical records—suggesting variable understandings regarding what constitutes a goals-of-care discussion.

In implementing the HQRP in 2016, the CMS recognized the importance of incorporating patient preferences into standardized national quality measurement. Specifically, the HIS includes the following items: “The patient and/or responsible party were asked about preferences regarding the use of cardiopulmonary resuscitation” (F2000); “The patient and/or responsible party were asked about preferences regarding life-sustaining treatments other than CPR” (F2100); and “The patient and/or responsible party were asked about preference regarding hospitalization” (F2200) (Centers for Medicare and Medicaid Services, 2021).

Symptom management preferences

There is currently no standardized assessment approach for patient preferences about symptom management — decisions that are related to, but ultimately separate from, HIS items of cardiopulmonary

resuscitation, life-sustaining treatments, and hospitalization. However, one instrument used by some hospices to elicit symptom management preferences is the Patient Preferences About Serious Illness Instrument (PASI), a resource intended to be used in conjunction with existing advanced care planning directives, such as the Physician Orders for Life-Sustaining Treatment (POLST), which documents patient’s treatment preferences as actionable medical orders (Whitehead & Carter, 2017). While the PASI does not measure the extent to which hospices incorporate patient preferences, clinicians may use the instrument to start a dialogue with patients. In the symptom management domain, questions include “How important is it to you to have your symptoms under control?” “Which of these symptoms (pain, anxiety, breathing problems, sleeping problems, poor appetite, constipation, diarrhea, nausea/vomiting, depression, fatigue/weakness) are your top 3 concerns?” and “Are your symptoms being addressed/managed?”.

While the PASI “encourages patients to express their concerns more freely,” a 2016 mixed-methods multi-setting study found that nurse practitioners caring for the seriously ill experienced challenges “integrating the PASI into their busy practices,” as well as deciding whether to “start [end-of-life] conversations with their chronically ill patients early” rather than only using the instrument with terminally ill patients (Whitehead et al., 2016). Given concerns about time constraints, some nurse practitioners expressed their desire for patients to fill out the PASI themselves, even though that would “not allow for the intended guided dialogue.”

Use of patient preferences in quality measurement and improvement

A current HQRP process measure ([NQF# 3235](#)) includes the extent to which hospice providers discussed—or attempted to discuss — at least one of the three HIS preference items in the seven days prior to or five days after hospice admission, with documentation in clinical records (CMS, 2021)³. In a 2018 nationwide study of HIS admission data, researchers found that most hospices discuss treatment preferences with patients at admission (Zheng et al., 2018). Specifically, the percentage of hospice patient stays with chart documentation that the hospice discussed, or attempted to discuss, preferences for life-sustaining treatments was 98%. Nevertheless, only 53.5% of hospices reported discussing treatment preferences for *all* their patients — indicating room for improvement for almost half of the country’s hospices.

While population-level adherence to NQF#1641 is high, clinicians’ individual experiences with the HQRP treatment preferences measure have been more variable. For instance, in a 2021 qualitative study with providers from four geographically diverse hospices in the U.S., participants predominately viewed NQF #1641 as a “check-the-box” task (Hunt et al., 2021). Meanwhile, a smaller number of participants appreciated the measure’s promotion of “consistency of documentation early in the admission process,” regardless of whether it addressed the “subtleties of patient preferences.” Ultimately, many interviewees, recommended shifting from “limited, objective, process measures such as HIS toward comprehensive, subjective, outcome-based measures that capture the essence of care provided in hospice.” For example, as part of a 2016 multisite observational cohort study of inpatient palliative care, researchers tested a measure for seriously ill patients to report how well they “feel heard and understood” in the hospital environment — a more “global assessment of healthcare quality” (Gramling et al., 2016).

To achieve quality hospice care, patient preferences must be both elicited and honored. For this reason, the Measuring What Matters (MWM) project of the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA) selected “Care Consistency with Documented Care Preferences” (MWM #9) as one of ten indicators for quality measurement in U.S. healthcare settings, reflecting the “importance of assessing care preferences, and then following through

³The preference items were initially endorsed as [NQF #1614](#). As of August 2021, this measure is no longer reported as a single measure but remains a component of NQF #3235.

on stated patient choices for treatments” (Unroe, et al., 2016). A 2016 study of patients consulted for specialty palliative care found MWM Measure #9 to have an adherence rate of more than 90% across care settings, including 91% at home (Kamal et al., 2016).

While there is significant adherence to MWM Measure #9 in various palliative care settings, challenges remain. Despite consensus among interdisciplinary experts that goal-concordant care should be the primary outcome construct of end-of-life care, there is still no standardized or reliable method of measurement (Sudore et al., 2018; Johnson et al., 2018). Recognizing these conceptual gaps, a 2021 targeted literature review defined four methods used to measure goal-concordant care in palliative care research — patient report, bereaved caregiver report, longitudinal data, and population level indicators — and discussed strengths and weaknesses of each method (Ernecoff et al., 2021).

Concordance Between Patient Preferences and Patient Care and Goals

Research on the concordance between patient preferences and patient goals in the hospice setting is limited, perhaps due to the measurement challenges previously discussed. Studies from other settings suggest concordance rates of 72% to 98%, though there does seem to be variation based on whether the patient preferred comfort care or interventional care. A US medical center compared documented preferences to end-of-life care events for inpatients and found that 72% experienced end-of-life care that was fully concordant with their preferences (Turley et al., 2016). Another study, which used the US National Health and Aging Trends Survey (NHATS) and includes validated measures of perceptions of quality of care in the last months of life, found that seven in eight bereaved family members (87.5%) reported that care in the last month of life (including symptom management) was consistent with the decedent’s wishes. Of the 12.6% of family members who reported the patient did not receive care consistent with their goals, they cited unmet needs for addressing sadness and anxiety, pain, and dyspnea (Khandelwal, 2017). A cluster randomized clinical trial of Boston nursing home facilities found significantly lower rates of goal concordance (as reported by proxies) when patients with advanced dementia received comfort care as opposed to intensive care — which was deemed “not surprising” given the documentation required to “avoid multiple burdensome interventions” (Cohen et al., 2019). Highlighting a similar discrepancy, a US study of seriously ill patients in an outpatient setting with a life-expectancy of two years found that 85% of patients who prioritized extending life reported goal-concordant care, whereas only half of patients who prioritized relief of pain and discomfort—typical goals of hospice care—reported goal-concordant care (Modes et al., 2020). Conversely, a 2018 multi-setting retrospective cohort study that included inpatient hospices in Singapore found that 98% of individuals who wished for comfort measures met their preferences, while significantly fewer decedents who preferred intensive treatment experienced goal-concordant care (Tan et al., 2018).

Concordance Between Patient and Proxy Preferences and Clinical Determinations of Symptom Management

Because most studies of goal-concordant care focus on the distinction between life-sustaining treatment and comfort care, more research is needed regarding goal-concordant care in the realm of symptom management. For example, while advance care planning interventions show promise for increasing concordance between patient and proxy preferences, there is a dearth of literature focusing specifically on dyadic (e.g., patient and caregiver) preferences for symptom management (Chan et al., 2018; Jung & Matthews, 2021). As for whether patient and proxy preferences align with clinical determinations, a proxy’s assessment of whether their loved one’s symptoms were adequately managed does not appear to affect their perceptions of care quality. A 2017 trial found that a decision aid intervention improved end-of-life communication for nursing home patients with advanced dementia but showed no effect on the families’ ratings of symptom management, quality of care, or whether treatment was consistent with preferences (Hanson et al., 2017). Similarly, a secondary analysis of NHATS focused on home care found no statistically significant relationship between how a proxy rated overall end-of-life care, and their perceptions of how the patient’s symptoms were managed (Kricke et al., 2019). This suggests that proxies

may be tolerant of unmet symptom managements needs because they consider pain symptoms like pain and difficulty breathing to be part of the dying process.

Spiritual Care

Standards of practice for spiritual care interventions and assessments, including existing assessment items and tools

Practice guidelines describe spiritual care as an integral part of hospice and palliative care, and spiritual assessments are essential to providing spiritual care. Notes that spiritual care is distinct from religion and can be of value to hospice patients regardless of whether they hold religious beliefs. The guidelines reviewed indicated that hospices should:

- Routinely assess spiritual needs,
- Provide counseling to meet spiritual needs,
- Include a spiritual counselor in the interdisciplinary group,
- Facilitate visits by spiritual counselors who can address spiritual needs,
- Respect spiritual beliefs and practices.

In general, guidelines did not prescribe particular spiritual care interventions; however, the World Health Organization (WHO) guidelines identified the following: life review/dignity therapy, meaning-oriented therapy, legacy-building, guided-visualization, mindfulness meditation, yoga and other mind-body interventions, art therapy and journaling.

Below we summarize standards of practice for spiritual care as described in different practice guidelines, followed by a table of existing items and tools for spiritual screening, spiritual history, and spiritual assessment.

- Medicare's Hospice Conditions of Participation (COPs) specify that hospices should: 1) complete comprehensive assessments that include a patient's spiritual status, 2) include a pastoral counselor in the interdisciplinary group (IDG) 3) have the IDG work to address spiritual needs, 4) provide spiritual counseling that includes an assessment of and counseling to meet spiritual needs, and 5) facilitate visits by local clergy or other spiritual counselors who can address spiritual needs. (42 CFR § 418)
- The WHO states that patients should receive spiritual screening, assessment, support, and referral to a spiritual care provider, when needed, to address spiritual needs and concerns. Any spiritual distress or pain should be treated with the same level of intensity as physical distress or pain. They named life review/dignity therapy, meaning-oriented therapy, legacy-building, guided visualization, mindful meditation, yoga, and other mind-body interventions, are therapy, and journaling as spiritual care intervention. (World Health Organization, 2016; Ahluwalia, 2018)
- The National Consensus Projects' (NCPs) Clinical Guidelines for Quality Palliative Care (NCP Guidelines) advise that spiritual assessments include: 1) a spiritual screening as part of each clinical assessment to identify whether the patient has spiritual needs that require a chaplain or other spiritual case worker, 2) a spiritual history at the initial clinical evaluation to identify patient preferences and values that may affect medical decision-making, and 3) if needed based on the screening and history, a full spiritual assessment by a chaplain or case worker to evaluate spiritual needs or concerns and inform the plan of care. Each component should be conducted with standardized tools, and the IDG should reassess spiritual needs when prognosis or other significant transitions occur. (National Consensus Project, 2018)

- The Institute for Clinical Systems Improvement (ICSI) developed consensus recommendations for spiritual aspects care as part of their palliative care guidelines. They recommend use of validated assessment tools to assess palliative care needs in the spiritual domain (Institute for Clinical Systems Improvement, 2020).
- The Standards of Practice for Professional Chaplains in Hospice and Palliative Care (PCHPC SOPs) states that a spiritual care assessment is appropriate even when a patient or their family does not identify with or express interest in religion, and that a comprehensive assessment: 1) includes information about spiritual or religious needs, emotional and social needs, and the hopes and resources of the patient or the situation 2) identifies potential obstacles to or risk factors for effective spiritual, religious or existential care, and 3) keeps in mind the difference between spirituality and religion. The assessment may employ a standardized instrument. (Standards of Practice for Professional Chaplains in Hospice and Palliative Care)
- Guidelines from the Mayo Clinic on providing end-of-life care for cultural and religious minorities emphasize the importance of addressing patients' cultural and religious/spiritual (RS) values. Rather than taking a categorical approach, physicians should use a framework to inquire about cultural and RS beliefs (including validated tools to assess spiritual care needs), support patients where they are able, and engage in an interdisciplinary team approach that includes chaplain services and community RS leaders to provide necessary cross-cultural care (Partain et al., 2017).

A complete listing of existing spiritual care items and tools the project team identified is provided in **Appendix IV**. The HOPE instrument development team has worked with practicing spiritual care counselors, industry experts and the Technical Expert Panel to develop HOPE spiritual care items. Refer to the HOPE Alpha Test Report for additional information.

SDAT permissions

Monod and colleagues developed the Spiritual Distress Assessment Tool (SDAT), including items and scoring (Monod et al., 2010). This is an open access article distributed under the terms of the [Creative Commons CC BY license](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. Thus, the SDAT items may be used if the appropriate conditions are met. Questions about other uses should be directed to the journal: Journalpermissions@springernature.com.

Evidence or guidelines for spiritual counselors providing spiritual assessments or spiritual care

Practice guidelines varied in their directives on the role of spiritual counselors and the staff responsible for spiritual care. Those describing standards of practice for hospice focused on spiritual counselors as the sole providers of spiritual care.

- Medicare's COPs specify that hospices should include a pastoral counselor in the IDG and facilitate visits by local clergy or other spiritual counselors who can address spiritual needs (42 CFR § 418).
- The PCHPC SOPs state that the chaplain 1) gathers and evaluates patient data pertinent to the patients' situation or biological, psychosocial, spiritual, or religious health, 2) develops and implements a plan of care, 2) involves the patient and the patient's family and team members in articulating desired outcomes, interventions, and a personalized care plan when possible and appropriate, 3) acknowledges and respect the patient's and family's beliefs, cultures, and values and uses appropriate resources to effectively communicate and intervene, and 4) modifies

outcomes and interventions based on changes in the status or wishes of the patient or his/her family (Association of Professional Chaplains, 2014).

Guidelines pertaining to palliative care more broadly recognized the importance of spiritual counselors, while also suggesting that all palliative care staff be prepared to support patients' spiritual care needs.

- NCP Guidelines specify that palliative care professionals acknowledge their own spirituality as part of their professional role and be provided with education and support to address each patient's and family's spirituality. They further state that professional chaplains conduct spiritual assessments as the spiritual care specialist, in collaboration with the faith community, based on the patient's wishes. (National Consensus Project, 2018)
- ICSI guidelines recommend that the IDG include clinically trained spiritual counselors. Clinicians should screen for spiritual resources and concerns and refer accordingly to spiritual care providers. These guidelines also include suggested approaches for clinicians attending to a patient's spiritual care (e.g., offering compassionate presence) (Institute for Clinical Systems Improvement, 2020).
- The WHO recommends that medical doctors, non-physician clinicians, nurses, and community health workers be able to provide counseling and spiritual support at the end of life, and that patients should be referred to a spiritual care provider when needed to support their spiritual needs or concerns (World Health Organization, 2016).

According to the literature, spiritual counselors are valuable components of palliative and hospice care, but it is important that they be trained in hospice or palliative care settings. In interviews with all professions in the hospice core interdisciplinary team, spiritual care providers focused the most on the strength of their specific professional knowledge, including their training in different religions and traditions, spiritual values, and compassion (Kobayashi & MacAllister, 2016). Chaplains in palliative care reported their primary activities as relationship building, care at the time of death, and helping patients with existential or spiritual issues (Jeuland et al., 2017). Indeed, chaplain involvement provides more comprehensive support to palliative care patients. Christian clergy in England reported no formal training in palliative care and little experience working with palliative care providers, and a study of clergy in the US found that patient end-of-life conversations (e.g., about considering hospice, stopping treatment, and forgoing future treatment) were less likely when clergy held religious beliefs about prolonging life and less medical knowledge (Goodhead et al., 2016; Balboni et al., 2017). Educating clergy about end-of-life care may improve end-of-life care.

Multiple studies illustrate the need for spiritual care training among nurses and other healthcare providers. One study of nursing students found that most did not receive any palliative care education, and as a result their knowledge of psychological and spiritual care was low (Khraisat et al., 2017). In another study of oncology care nurses, the nurses reported receiving little or no training on communication about spirituality, and patients were more likely to initiate such conversations than nurses (Wittenberg et al., 2017). One study reported that, in addition to nurses, social workers and other healthcare providers in palliative or end-of-life care had difficulty having conversations about spiritual care, either with the patient or the family members (Wittenberg et al., 2016). As for physicians, a US survey found that, overall, physicians endorsed a limited role in the provision of spiritual care, but opinions varied based on the physicians' own religious characteristics. Specifically, more religious physicians were more likely to feel it appropriate to always encourage patients to talk to a chaplain (Smyre et al. 2018). Physicians also face barriers in addressing spiritual care, including an inability to identify existential suffering, a lack of training for how to address it, and time constraints (Amonoo et al., 2020).

Echoing palliative care practice guidelines, evidence suggests that other clinical staff can effectively provide spiritual care if they have adequate training. Nurses and healthcare providers who received spiritual care training were better equipped to recognize when patients might be spiritually distressed, and thus were prepared to assess and explore patients' spiritual needs (O'Brien et al., 2019). Physicians who received training in end-of-life spiritual care during residency reported fewer barriers to addressing patients' spiritual needs, compared to those who did not receive the training and reported positive effects of the training even after 8 years. (Anandarajah et al., 2016). A trial of a spiritual care training program for palliative care doctors and nurses in Singapore found that patients whose clinicians received the training reported improved quality of life, but there was no difference in patient spiritual well-being between the groups. (Yang et al., 2017). Two studies found positive outcomes of chaplain-implemented spiritual care training for clinical staff in palliative care. In one study, palliative care team members had increased attention to patients' spiritual and existential needs following the training, but there was no impact on patients' spiritual distress (van de Geer et al., 2017). In the other study, following the training, physicians and nurses were more attuned to spiritual suffering, demonstrated skills designed to address spiritual concerns, and had increased confidence in discussing spiritual needs with their patients (English & Picchi, 2019).

Despite the evidence for the importance of well-trained spiritual care providers, there is currently no clearly articulated consensus regarding credentials required to provide spiritual care. The Hospice Conditions of Participation have no statements regarding qualifications or credentials for spiritual care and/or pastoral counseling (e.g., education, courses, certifications, trainings) (42 C.F.R § 418). Spiritual care providers are described as pastoral or other counselors taking part in the IDG, whose members are individuals qualified and competent to practice in the professional roles as listed.

There is no licensure for spiritual care providers, though there are options for certification, which have arisen out of a body of knowledge commonly referred to as Clinical Pastoral Education. Several organizations offer certifications, though the requirements vary.

- Association of Professional Chaplains offers [BCCI \(Board of Chaplaincy Certification Inc\) Certification](#). Chaplains are certified as board certified chaplains (BCC) or associate certified chaplains (ACC).
- Spiritual Care Association offers three types of certification for chaplains: [Chaplain Credentialing \(CC\)](#), [Board Certified Chaplain \(BCC\)](#), [Advanced Practice Board Certified Chaplain \(APBCC\)](#).
- National Association of Catholic Chaplains certifies chaplains.
- [Neshama: Association of Jewish Chaplains](#) certifies chaplains.

Spiritual care outcomes for hospice and palliative care patients

The literature on outcomes of spiritual care as an intervention for hospice and palliative care patients fell into two categories. Studies examined either designated spiritual care interventions or broader interventions that included spiritual care.

Designated spiritual care interventions

[Dignity Therapy](#) was the most common spiritual intervention examined in recent empirical work. Studies of Dignity Therapy or a variation of Dignity Therapy (Abbreviated Dignity Therapy, Dignity Talk, dignity therapy/life plan intervention) generally found positive impacts. For example, Dignity Therapy improved wellbeing, and decreased demoralization and desire for death in terminally ill patients (Brožek et al., 2019; Julião et al., 2017). For patients with advanced cancer, abbreviated dignity therapy increased feelings of (1) self-expression, (2) connection with loved ones, (3) sense of purpose, and (4) continuity of

self (Beck et al., 2019). In addition to patients, one study focused on the inpatient palliative care setting found that family members and health providers felt that a Dignity Talk intervention facilitated end-of-conversations, enhanced family connections, and enhanced patient sense of value and dignity. (Guo et al., 2018). Three studies specifically involve home-based hospice or home-based palliative care. One found higher Dignity Impact scores for home-based hospice patients who received Dignity Therapy than those in usual care (Scarton et al., 2018). Another, a Spanish study that compared Dignity Therapy to regular counseling, found that though overall well-being improved, Dignity Therapy patients had worse outcomes related to depression, resilience, and anxiety. (Rudilla et al., 2016). This suggests that counseling may be an effective, or even preferred, alternative to Dignity Therapy. Lastly, an Australian study compared Dignity Therapy both to [Life Review](#) and a control group. Dignity therapy did increase generativity and ego-integrity but there were no changes in dignity-related distress or physical, social, emotional, and functional well-being (Vuksanovic et al., 2017).

Several studies assessed outcomes of different spiritual care interventions among hospice and palliative care patients. Most found positive outcomes, or no difference. Four were specific to cancer patients, two in an inpatient setting and two in an outpatient setting. A US study of outpatient advanced cancer patients who received individual meaning-centered psychotherapy reported improved quality of life, sense of meaning, and spiritual well-being, and less anxiety and desire for hastened death (Breitbart et al., 2018). Similarly, a second US study of cancer outpatients with limited life expectancy found that patients reported increased spiritual well-being and increased ability to cope with their cancer after receiving spiritual care delivered by a chaplain using the Spiritual Assessment and Intervention Model ([Spiritual AIM](#)) (Kestenbaum et al., 2017). Studies of cancer patients in an inpatient setting echoed these findings. One, in Japan, found that patients who received spiritual care using SpiPas (Spiritual Pain Assessment Sheet) maintained their spiritual well-being over time while those not receiving the intervention had lower spiritual well-being. This study also associated spiritual care with less hospital anxiety (Ichihara et al., 2019). Another, in the US, found the majority of inpatient palliative care patients with advanced cancer who completed the [Go Wish card game](#) did not increase their anxiety, and agreed it was beneficial to talk about end-of-life priorities (Delgado-Guay et al., 2016). The two remaining articles were specific to home-based care. US home hospice patients who received an educational intervention explaining hospice chaplain services and the benefits of spiritual support were more likely to accept spiritual support (Soroka et al., 2019). In Belgium, structured spiritual history taking for home-based palliative care patients with a life-limiting illness was not associated with any change in well-being, quality of life, pain, or patient-provider trust (Vermandere et al., 2016).

Interventions including spiritual care

Several studies examined interventions that had a spiritual care component but were broader than spiritual care alone. As a result, it is not possible to determine the degree to which spiritual care influenced patient outcomes in these studies. However, studies of these interventions showed positive results though most are disease specific. One found that for outpatients with heart failure, receiving an early palliative care intervention that included spirituality (Educate, Nurture, Advise, Before Life Ends Comprehensive Heartcare for Patients and Caregivers [ENABLE CHF-PC]) improved perceived health status and functional status but had no effect on mood or quality of life (Bakitas et al., 2020). Two additional US studies focused on outpatient cancer patients. One found that lung cancer patients who received an interdisciplinary palliative care intervention that included a focus on spiritual well-being reported improved spiritual well-being (Sun et al., 2016). The other found that patients who received a palliative care intervention that included spiritual issues had improved physical, emotional, and functional well-being, though the intervention did not affect social and spiritual well-being, or general distress (Nguyen et al., 2018). A Canadian study of inpatients who were imminently dying and referred to palliative care

tested use of a comfort measures order set (CMOS). CMOS are a standardized framework for assessing imminently dying patients’ symptoms and needs. Patients who received CMOS had increased spiritual care involvement, but the CMOS did not make a difference in patient distress at the time of death (Lau et al., 2018). A Spanish study focused on patients with advanced chronic disease receiving home-based palliative care studied support teams (including some chaplains) trained to deliver psychosocial care. Patients of these teams had decreased anxiety and emotional distress and reported increased mood and meaning in life (Gómez-Batiste et al., 2017). Lastly, one small UK study of hospice patients found that, though not a specific aim of the intervention, acupuncture improved the spiritual well-being of one-third to more than one-half of participants, depending on how broadly spirituality was defined (McPhail et al., 2018).

Association between spirituality and outcomes

Studies examining the association between patient spirituality and outcomes show the importance of spiritual care in multiple settings. Two small studies were specific to the hospice setting. The first, an Italian study, found that spirituality was an important predictor of quality of life for cancer patients even when controlling for physical, emotional, and psychosocial wellbeing. They further found that higher faith scores on the [FACIT-Sp](#) scale were more associated with quality of life than higher meaning/peace scores (Bovero et al., 2016). The second, a New Zealand study in the community-based hospice setting, found that even for patients without declared religious faith a spiritual assessment may have a role in managing death and anxiety at the end of life (Byrne & Morgan, 2019). In the outpatient palliative care setting spiritual well-being was associated with feeling more informed and supported during decision-making and lower levels of uncertainty and decisional conflict (Rego et al., 2020), while spiritual pain was associated with lower quality of life (Pérez-Cruz et al., 2019). A study of home- and hospital-based palliative care associated spiritual well-being with lower anxiety and depression (Bernard et al., 2017). Patient spirituality was not related to survival time in the inpatient palliative care setting (Shin et al., 2018). In the hospital setting, whether patients received a chaplain visit predicted patient satisfaction and R/S interventions were associated with five of six patient satisfaction items (Sharma et al., 2016). Another hospital-based study found though spirituality was negatively associated with dyspnea among patients with COPD, it was positively associated with quality of life among patients with lung cancer (Hasegawa et al., 2017). Lastly, in outpatient oncology clinics, spiritual well-being was associated with lower anxiety and depression and higher quality of life (patient functioning and global health status) (Chen et al., 2021), while higher spiritual needs were associated with less satisfaction with care and a lower perception of quality of care (Astrow et al., 2018).

Implications

The HealthCare Chaplaincy Network asserts that although patients and their caregivers want spiritual care, and spiritual care is associated with improved outcomes, there are currently no valid and reliable quality indicators for spiritual care., excepting the [Quality of Spiritual Care \(QSC\) scale](#). They reviewed guideline-based or empirically developed and tested measures, instruments, and tools. The recommendations that resulted from that review, which we present in **Table 1**, include structural, process, and outcome quality indicators of spiritual care and suggested tools for measuring each. (HealthCare Chaplaincy Network, 2021)

Table 1: Spiritual Care Quality Indicators

Quality Indicator	Metric	Suggested Tools
Structural Indicators		
Certified or credentialed spiritual care professional(s) are	Institutional policy recognizes chaplains as official members of the	Policy Review

Table 1: Spiritual Care Quality Indicators

Quality Indicator	Metric	Suggested Tools
provided proportionate to the size and complexity of the unit served and officially recognized as integrated/embedded members of the clinical staff.	clinical team.	
Dedicated sacred space is available for meditation, reflection, and ritual	Yes/No	
Information is provided about the availability of spiritual care services.	Percentage of patients who say they were informed that spiritual care was available	Client Satisfaction Survey
Professional education and development programs in spiritual care are provided for all disciplines on the team to improve their provision of generalist spiritual care.	All clinical staff receive regular spiritual care training appropriate to their scope of practice and to improve their practice.	Lists of programs, number of attendees, and feedback forms
Spiritual care quality measures are reported regularly as part of the organization's overall quality program and are used to improve practice	List of spiritual care quality measures reported	Audit of organizational quality data and improvement initiatives
Process Indicators		
Specialist spiritual care is made available within a time frame appropriate to the nature of the referral	Percentage of staff who made referrals to spiritual care and report the referral was responded to in a timely manner. Percentage of referrals responded to within Chaplaincy Service guidelines	Survey of staff Chaplaincy data reports
All clients are offered the opportunity to have a discussion of religious/spiritual concerns	Percentage of clients who say they were offered a discussion of religious/spiritual concerns	Client Survey
An assessment of religious, spiritual and existential concerns using a structured instrument is developed and documented, and the information obtained from the assessment is integrated into the overall care plan	Percentage of clients assessed using established tools such as FICA, Hope, 7X7, or Outcome Oriented models with a spiritual care plan as part of the overall plan of care	Chart Review
Spiritual, religious, and cultural practices are facilitated for clients, the people important to them, and staff	Referrals for spiritual practices	Referral Logs, including disposition of referrals
Families are offered the opportunity to discuss spiritual issues during goals of care conferences.	Percentage of meeting reports in which it is noted that families are given the opportunity to discuss spiritual issues	Chart Audit

Table 1: Spiritual Care Quality Indicators

Quality Indicator	Metric	Suggested Tools
Spiritual care is provided in a culturally and linguistically appropriate manner. ⁴ Clients' values and beliefs are integrated into plans of care.	Percentage of clients who say that they were provided care in a culturally and linguistically appropriate manner Percentage of documented plans of care that mention client beliefs and values	Client Survey Chart Audit
End-of-Life and Bereavement Care is provided as appropriate to the population served	Care plans for clients approaching end-of-life include document attention to end-of-life care A documented plan for bereavement care after all deaths	Chart Audit
Outcomes		
Clients' spiritual needs are met	Client-reported spiritual needs documented before and after spiritual care	Spiritual Needs Assessment Inventory for Patients (SNAP) Spiritual Needs Questionnaire (SpNQ)
Spiritual care increases client satisfaction	Client-reported satisfaction documented before and after spiritual care	HCAHPS #21 QSC
Spiritual care reduces spiritual distress	Client-reported spiritual distress documented before and after spiritual care	"Are you experiencing spiritual pain right now?"
Spiritual interventions increase clients' sense of peace	Client-reported peace measure documented before and after spiritual care	Facit-SP-Peace Subscale "Are you at peace?"
Spiritual care facilitates meaning-making for clients and family members	Client-reported measure of meaning documented before and after spiritual care	Facit-SP- Meaning Subscale RCOPE
Spiritual care increases spiritual well-being	Client-reported spiritual well-being documented before and after spiritual care	Facit-SP

SOURCE: HealthCare Chaplaincy Network (2021). What is Quality Spiritual Care in Health Care and How Do You Measure It? https://healthcarechaplaincy.org/wp-content/uploads/2021/06/quality_indicators_document_1_7_2021.pdf

Psychosocial Care

Standards of practice for assessment and intervention in psychosocial care

The Hospice Conditions of Participation include psychosocial care, which they refer to as medical social services. (42 CFR § 418). In hospice, medical social services must be provided by a qualified social worker under the direction of a physician and services must be based upon a psychosocial assessment as well as the patient and family needs (42 CFR § 418.64 C). As defined by the regulation, a social worker must have either a Master of Social Work (MSW), a baccalaureate degree in social work, or a baccalaureate degree in psychology, sociology or a related field provided they are supervised by an MSW. Social work degrees must be conferred by schools accredited by the Council on Social Work Education. In addition to the educational requirements, social workers must also have at least one year of social work experience in a healthcare setting. (42 CFR § 418.114.b.3).

The limited regulatory definition of psychosocial care provides opportunity for national associations to offer added guidance on psychosocial assessment and care. The NCHPC, the NHPCO, and the NASW each supply their own recommendations for what type of information should be collected during a psychosocial assessment. We summarize these recommendations in **Table 2**.

Table 2. Common Guideline for Psychosocial Assessments

Guideline	Description	Sources
Evaluate for emotional distress	Assess patient for signs of depression, anxiety, dementia, delirium	NCHPC, NHPCO, NASW
Identify coping skills	Determine how the patient copes with mental distress currently and in the past	NCHPC, NHPCO, NASW
Spiritual assessment	Identify patient/family spiritual needs and history	NCHPC, NHPCO, NASW
Cultural considerations	Identify the patient's cultural values and beliefs	NCHPC, NHPCO, NASW
Identify emotional history	Screen for past depression, suicidal ideation, and other mental health issues	NCHPC, NHPCO, NASW
Identify support systems	Assess patient's support systems (family, etc.) and take note of resources or interventions needed	NHPCO, NASW

Evidence or guidelines for social workers providing psychosocial assessments/care

In assessing existing psychosocial tools and items used by social workers, we found little evidence of a hospices widely using standardize assessments. An assessment of US hospices found that 72% of administered psychosocial assessments were unique to the hospice setting and did not draw upon existing assessments (Cagle et al., 2016). The “unique” assessments screened for much of the same information: coping, bereavement, depression, and anxiety. A 2018 study interviewed a national US sample of hospice social workers about whether they used a standard assessment tool. The results found that not only do most social workers not use a standardized tool, but the tools they are given are usually developed by a non-social worker (Reese & Csikai, 2018). Ideal psychosocial assessments are not only approved by hospice organizations but also developed by social workers.

We found two tools developed and used by hospice social workers: The Social Worker Assessment Tool (SWAT) and the Social Worker Assessment Notes (SWAN). The Social Work Outcomes Task Force within NHPCO developed SWAT, which is designed to be an initial assessment that screens patients for psychosocial issues. It has 11 questions, scored from 1 (not well at all) to 5 (extremely well), that evaluate a patient on a range of psychosocial issues, including depression, anxiety, safety, and grief (Reese et al.,

2006). In testing, researchers found that patients improved their SWAT scores by the second social work visit. SWAN is a similar assessment developed by social workers at Hospice Austin, a Texas-based hospice agency, in collaboration with social workers from the University of Texas. Instead of scoring patients, the social worker identifies whether work needs to be done in several psychosocial categories and links notes to a plan of care (Hansen et al., 2015). Both assessment tools categorize psychosocial needs similarly, as illustrated in **Table 3**.

Table 3: Psychosocial Categories included in SWAT and SWAN

Psychosocial Category	Included in SWAT?	Included in SWAN?
Care Needs	x	x
Safety Concerns	x	x
Financial Needs	x	x
Understanding of Prognosis		x
Sense of well-being		x
Interpersonal Issues/Social Support	x	x
Anticipatory Grief and Coping	x	x
Suicidal Ideation	x	x
Cultural Values	x	x
Advance Planning		x
Anxiety	x	

We identified additional psychosocial tools that were not both approved by hospice organizations and developed by social workers. These tools include:

- Dignity Impact Scale
- Palliative Care Needs Assessment Tool
- Suncoast Solutions
- Patient Health Questionnaire 9 (PHQ9)
- Bereavement Risk Assessment Tool
- Suffering Scale

While SWAT and SWAN are both social worker-developed tools which can capture various aspects of a patient’s psychosocial experience in hospice, future development and testing is required to confirm that the tools effectively measure psychosocial treatment. The HOPE instrument development team has worked with practicing social workers, industry experts and the Technical Expert Panel to develop HOPE psychosocial care items. Refer to the HOPE Alpha Test Report for additional information.

Potential psychosocial care outcomes

There is limited evidence that psychosocial interventions and treatment provide improved health outcomes in the hospice setting. Illustrating the need for psychosocial interventions, a study focused on the psychosocial symptoms of cancer patients receiving home-based palliative care found that up to 75% of them experienced severe social decline as their illness developed. They further found that psychosocial symptoms worsen as death approaches, and these worsening symptoms are associated with a decline in physical conditions as well (Seow et al., 2021). A 2017 study of inpatient palliative care patients with heart failure found that an interdisciplinary intervention (including a social worker) showed “consistently

greater benefits in quality of life, anxiety, depression, and spiritual well-being compared to [usual care]” (Rogers et al., 2017). However, a systematic review focused on fatigue in cancer patients found no statistically meaningful evidence that psychosocial treatment reduced fatigue. (Poort et al., 2017). In sum, there is limited evidence to help us understand the outcomes related to psychosocial care in the hospice setting, but existing evidence suggests that benefits for improved mental health rather than for improved physical symptoms.

Medication Management

The TEP supported the concept of a medication management measure. We conducted a preliminary literature review to support the quality measure development team as they consider further development of the measure concept. Specifically, we sought to understand the aspects of medication management that would be most relevant to quality of care in the hospice setting. Our results represent two broad categories related to medication management: the reasonable medication use at the end of life, and the role of patients, families, and caregivers in managing medication at the end of life.

Reasonable use of medications at the end of life

Four recent studies address reasonable use of medications at the end of life, suggesting patients remain on unnecessary medication, or medications that are preventive (e.g., cholesterol or blood-pressure reducing medications) rather than those needed to control symptoms, at the end of life. Two are Dutch studies, with the first finding that patients in inpatient palliative care facilities, on average, see a decrease in the number of prescribed drugs between admission and their date of death but that patients still die with medication not used for symptom control (Van Nordennen et al., 2016). The second looked at patients who died in the hospital, in hospice, or at home. They found that patients who die an expected death received an average of nine medications in the week before death, and six medications on the day of death (Arevalo et al., 2018). As reported in a Danish study, healthcare professionals consider reasonable use of medications an essential aspect of good care for older people with limited life expectancy, and providers play a crucial role in reasonable use of medications. They further believed that collaboration between different providers should be improved to facilitate reasonable use of medications at the end of life (Lundby, 2020). The Van Nordennen study supports this, acknowledging that providing medications not needed for symptom control represents an increased pill burden, and that physicians need to develop guidelines and educational programs for decreasing medication at the end of life (Van Nordennen et al., 2016). A small US quality improvement study in an inpatient Veteran's Affairs hospice, used clinical pharmacy specialists to optimize pharmacotherapy and found that the specialists also played a significant role in discontinuing drugs no longer indicated (Basri et al., 2018). To support reasonable medication use at the end of life, CAPC's clinical training recommendations for physicians caring for patients with serious illness includes consideration of deprescribing as a component of medication management (CAPC, 2021).

Engagement of patients, families, and caregivers

Six studies solicited the perceptions of nurses and other caregivers with respect to medication management and reflect challenges in provider and patient/caregiver communication and in providing adequate caregiver education. A UK study found that healthcare professionals tended to focus on prescribing issues towards the end of life, rather than express awareness or curiosity about the patient's perspective and experience of taking medication. Some professionals seemed resigned to deliberate or inadvertent failure on the part of patients to take medication as prescribed, with few providers investigating the underlying causes of patient issues with medication. Nurses making home visits recognized that several issues with medications stemmed from patients not fully understanding what their medications were, what they were for, and how they should be taken. The study further reported that despite the involvement of multiple health professionals few took responsibility for overarching management of medications (Wilson et al., 2020). A US study of New England hospice nurses found that the educational support provided to family caregivers of patients with advanced cancer focuses more on symptom management and less on understanding medication administration or organizational skills (Tjia, 2019).

Three additional studies, all US-based, focused on provider perceptions of managing pain medication specifically and highlight the challenges of communication between nurses and caregivers. One analyzed statements about pain management between home hospice nurses and family caregivers of cancer patients. Named challenges related to communication and teamwork, as well as a caregivers medication

skills and knowledge. They further found nurses responded to caregiver challenges mostly by validating the challenge, rather than addressing it. In 42% of cases the nurse provided information to the caregiver, and in 14% of cases nurses did not address the caregiver statements of pain management challenges (Han et al., 2018). Another study of home hospice caregivers in Washington state confirmed that caregiver-centric and patient-centric issues can affect effective pain management, and that the most frequent issues family caregivers raised were caregiver's functional issues, caregiver's beliefs, pain assessment issues, caregiver-healthcare system communication, and the patients' inability to verbalize pain (Chi et al., 2018). A third study recruited advisory groups from a community-based hospice agency and found that caregivers felt stressed about administration of analgesics and that they did not know enough to manage them. Yet caregivers did not communicate their concerns to nurses, reporting that they were unsure what to ask and did not want to bother nurses. Nurses agreed that caregivers often lacked adequate knowledge but were not aware that caregivers struggled to communicate their concerns (Mayahara et al., 2017).

Practice recommendations

A number of these studies also include recommendations for improving medication management challenges. A Dutch study that interviewed patients, caregivers, nurses, and physicians found that nurses can and should play an important role in medication management at the end of life by informing, supporting, representing, and involving all relevant parties, and that nurses should be reinforced by education and training to take up this role (Huisman et al., 2020). A prior UK study supported this, finding that patients at the end of life and their relatives, nurses, and doctors agree that nurses play an important role as an intermediary between patients and caregivers and their physicians. They further recommended developing of a guideline that considers the "frailty, needs, wishes, and expectations" of patients with limited life expectancy, and that it should support a "interdisciplinary setting-transcendent" approach to medication management that reflects patient preferences and that facilitates appropriate medication use (Dees et al., 2018). The previously mentioned Chi and Tjia studies agree, with one expressing the need to develop guidelines or educational tools to support family caregivers, ensuring that family caregivers can manage patients' pain effectively at home, and another reflecting the need for a standardized approach to conducting patient-centered medication review. (Chi et al., 2018; Tjia, 2019). Tjia also discusses the lack of consensus on clinical guidelines defining hospice's role in supporting medication management by family caregivers, and the lack of standardized tools and education in end-of-life care for health-care professionals. Tjia further acknowledged that because conversations about medication management, especially deprescribing, can be stressful for patients and caregivers, they should be implemented as part of trusting relationship that is built upon strong communication and listening skills (Tjia, 2019). Similarly, the previously mentioned Han study concluded that pain management can cause anxiety and burden for caregivers, and nurses should address caregivers' pain management challenges during home visits. He further acknowledged that communication and educational tools designed to reduce caregiver barriers to pain management would likely improve clinical practice, as well as patient and caregiver related outcomes (Han et al., 2018). Underscoring the importance of supporting families and caregivers in medication management, a recent Los Angeles Times article described a patient in extreme pain for two days before he died as a direct result of a hospice nurse failing to show that patient's family how to safely give the morphine (Christenson & Poston, 2020).

Both the Joint Commission and a recent US quality improvement study provide examples of how to address these challenges. The Joint Commission's new CMS requirements for hospices include the interdisciplinary team determining the patient's and family's ability to administer medications safely and competently. Further, the hospice, based on the patient's condition and assessed need, is required to provide training and education on 1) the safe and effective use of medication, and 2) the identification, handling, and safe disposal of hazardous medications and infectious waste (Joint Commission, 2021). A recent quality improvement study in a US inpatient hospice and palliative care facility tested an evidence-based staff protocol for educating patients and families about pain medication side effects. Specifically,

they looked at whether implementing the protocol improved the CAHPS® Hospice Survey indicator for whether patients and caregivers understood a medication's side effects. They found both improvements in staff knowledge and staff confidence in their ability to effectively communicate with patients and families regarding pain medication side effects. They also saw 6.6% increase in the CAHPS survey indicator within 6 months (Hay et al., 2019).

Other Recent Hospice Literature

To identify any emerging trends outside of our research questions, we conducted an environmental scan to identify literature related quality of care in the hospice setting published in the last two years. Our results fell into three main categories: quality measurement, the experience of patients in hospice relative to other settings, and emerging practices in hospice care.

Quality Measurement

Two articles used CMS Hospice Compare data⁴, with one positing additional content themes for the caregiver survey items that may be useful to the public when selecting a hospice, and the other supporting quality improvement within hospice agencies. The first compared themes in Yelp reviews of California hospice providers with themes captured by Hospice Compare's care-giver survey items, assuming that the user-generated content of Yelp reflects what families or caregivers consider useful to others considering a hospice provider. While there was significant overlap between Hospice Compare and Yelp, the Yelp reviews addressed a wider range of themes. Specifically, Yelp reviews included whether staff was compassionate and caring, whether the patient or family was grateful to the hospice, the quality of patient care, medication management, provision of grief or bereavement counseling or support, comprehensiveness of services, agency management, staff professionalism, whether staff was knowledgeable or skilled, safety, and medical equipment and supplies. Two themes included in the Hospice Compare survey questions were not identified in Yelp reviews: family training and provision of emotional and spiritual support (Rahman et al., 2021). Also using data from Hospice Compare, the Joint Commission released a dashboard report for hospices. The dashboard supports the following measures: patients on opioids offered/prescribed a bowel regimen, screening for pain during initial nursing assessment, comprehensive assessment of pain within one day of a positive pain screen, treatment for dyspnea within one day of a positive dyspnea screen, and documentation of discussion regarding spiritual/religious concerns (Elliot & DeMarzo, 2019).

Setting of Care

Another set of studies focused on the setting of care suggest that home hospice offers a better experience of care than residential care settings like nursing homes. Based on CAHPS Hospice Survey data, caregivers of patients who received hospice in a nursing home or assisted living facility reported worse experiences than those who cared for patients receiving hospice at home. The differences were particularly large with respect to hospice team communication and getting help for symptoms (Quigley et al., 2020). An NHATS study confirms this, with patients receiving hospice in their home having the highest overall scores, which represent 13 indicators across five major domains for end-of-life care. Specifically, patients with home hospice were more likely to be treated with respect than patients receiving hospice in a residential care setting, though they were also more likely to experience pain. Both patients receiving hospice at home and in a residential care setting were more likely to have discussed religion than patients who were not receiving hospice (Xu et al., 2020).

Emerging Practices

Recent literature with respect to hospice care explored the value of physical activity and ensuring that hospice is received timely. A small Polish study found that a physiotherapy intervention for patients receiving hospice at home significantly improved scores in activities of daily living, such as taking medications and dressing, and significantly improved assessments of mobility and balance, depression, and quality of life (Ćwirlej-Sozańska et al., 2020). Another small study in the UK complements these findings. The authors found that patients and providers in hospice facilities perceived benefit to physical activity, including the ability to manage physical, functional, and psychological conditions. However,

⁴ Hospice Care is known as Care Compare as of December 2020. Results may not be replicable in Care Compare.

participants did express concerns such as risk of injury (Burke et al., 2020). In terms of identifying when a patient might be appropriate for hospice, a recent Canadian study evaluated the ability of its Risk Evaluation for Support: Predictions for Elder-life in the Community Tool (RESPECT) to predict death within six months. It found that measures of functional ability better capture patient decline than individual chronic diseases, and that the RESPECT better identified patients with limited life expectancy than current practices. The authors suggested using RESPECT to supplement home healthcare assessments to help decide when comprehensive palliative or hospice care assessments may be needed (Hsu et al., 2021).

Conclusion

High-quality hospice care honors patient, family, and caregiver needs by addressing physical, psychosocial, emotional, and spiritual well-being throughout the dying experience. It follows that measuring high-quality hospice care must be based on the principles of addressing physical, psychosocial, emotional, and spiritual well-being for patients, their families and caregivers. To support this work, the HQRP is developing quality measures and an assessment instrument to collect data to support those measures. To support this work, we have identified current information on the treating moderate to severe pain; patient preferences for symptom management; spiritual care; psychosocial care; medication management—specific to the hospice setting whenever possible. We further identified other recent hospice literature to identify trend outside of our research questions.

In some cases, such as treating moderate and severe pain, evidence supports current approaches. In others, like risk adjustment for neuropathic pain, patient and proxy concordance of patient symptom management preferences, and psychosocial outcomes, evidence in the hospice setting was limited. In those cases, we provided information from other settings to support HQRP activities. Where applicable, such as for spiritual and psychosocial care, we reviewed regulations and provider associations websites to understand the current information available to hospice agencies.

We also explored evidence for future potential areas of measure development, such as medication management, finding gaps in reasonable use of medications at the end of life and engaging patients and caregivers. Additionally, we broadly searched for information on hospice quality measurement, identifying an examination of the usefulness of Hospice Compare (now Care Compare) items, potential functional improvements from providing physiotherapy to hospice patients, and alternatives to predicting when a patient may be ready to enter hospice.

As in prior years, this report will inform the HQRP TEP, the quality measure development team, the instrument development team, and other hospice stakeholders to advance, in collaboration with CMS, inclusion of additional meaningful quality measures in the HQRP.

Appendix I: Methods

The Information Gathering Team used a stepwise process to identify information relevant to our research questions. Those steps are outlined here.

Determine search terms. We determined a specific set of search terms to both identify the hospice setting and to identify work relevant to each specific research question using the following steps:

- Determine MeSH terms using [MeSH on Demand](#),
- Determine additional non-MeSH terms,
- Discuss identified search terms as a group and solicit expert review where needed,
- Finalize search terms.

The following search terms to identify the hospice setting were consistent across all searches:

- MeSH terms included: Hospices, Hospice Care, Hospice and Palliative Care Nursing, Terminal Care.
- Non-MeSH terms included: end-of-life care.

Determine search parameters and identify articles. We conducted our literature searches in PubMed, which include MEDLINE indexed journals, journal and manuscripts deposited in PubMed Central, and the National Center for Biotechnology Information Bookshelf. We used the following steps to conduct the search and ensure the most relevant results.

1. Determine Boolean phrase using predetermined search terms (i.e., how terms will connect using and/or)
2. Set results filters to adult, human, and English language results in the past 5 years.
3. Use the Advanced Search option to search in the Title and Abstract fields

If this yielded fewer than ten results, we updated the parameters to search in all Text Word fields. If this still yielded fewer than ten results than we searched in All Fields and reviewed the search terms with subject matter expert to see if the terms should be revised. If a search yielded greater than 500 results, we revised our search terms to narrow the results and consulted with a subject matter expert. We exported results to an EndNote library.

Review identified articles. To facilitate review, we designated folders within each EndNote Library for relevant articles, somewhat relevant articles, and insufficiently relevant articles that we rejected from our results. We further sorted rejected articles based on how detailed our review was. Some were rejected based on the relevance of their title or abstract. Remaining articles were either kept or rejected based on a review of the full text. Potential reasons for rejection include incorrect setting, incorrect population, or lack of specificity to target questions. If less than five articles remained after the review process, we consulted with a subject matter expert and conducted a supplementary Google Scholar search.

Supplement results using Google Scholar. For searches with fewer than five relevant articles remaining after review, we conducted a search in Google Scholar using the same search terms and review criteria outlined for our PubMed searches.

Identify and review rules and regulations. For research questions that included reviewing standards of practice or practice guidelines, we reviewed applicable rules and regulations using the following process:

- Identify rules and regulations that govern the topic using Google searches and choose documents that end in .gov. If we only identified state regulations, we searched for other states' versions of the regulation to identify key differences.
- Search the rule or regulation using the previously identified search terms. We were careful to include complete language when reviewing rules and regulations so as not to misconstrue their content.

Identify and review grey literature. The Information Gathering task lead identified relevant grey literature by using the hospice search terms identified above at the [Harvard Kennedy School Think Tank](#) as well as the following individual sites with a focus on healthcare or hospice:

- Center to Advance Palliative Care
- Institute for Healthcare Improvement
- Joint Commission
- Robert Wood Johnson Foundation
- The Commonwealth Fund
- Kaiser Family Foundation
- National Academy of Medicine
- NCHPC
- Hospice and Palliative Care Nurses Association
- American Academy of Hospice and Palliative Care
- NHPCO (membership required)
- Visiting Nurse Associations of America

The task lead reviewed the search results within each site and compiled links relevant to hospice or our topics. The larger Information Gathering team searched these compiled links using the previously determined search terms for each of their research questions. For the Center to Advance Palliative Care site, staff searched the overall site with their research question specific search terms. Where warranted, staff searched additional websites specific to their research question (e.g., the National Association of Social Workers for the psychosocial care questions).

Six of the sites did not yield any recent, accessible, and relevant content: Institute for Healthcare Improvement, NCHPC, Hospice and Palliative Nurses Association, American Academy of Hospice and Palliative Care, Robert Wood Johnson Foundation, and Hospital Foundation of America

Review additional supplemental information. We compiled information provided by the TEP, subject matter experts, and other stakeholders over the course of the year. Information Gathering staff reviewed these materials and incorporated findings relevant into their research questions.

Appendix II: Search Results

Treating Moderate to Severe Pain

Prevalence of moderate to severe pain	
Search Terms	<ul style="list-style-type: none"> • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain” AND (“moderate” OR “severe” OR “perception” OR “manage*” OR “severity”)) AND “prevalence” • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“moderate pain” OR “severe pain” OR “pain perception” OR “perception of pain” OR “pain manage*” OR “pain severity”) AND (“prevalence”) • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“moderate pain” OR “severe pain” OR “pain severity”) AND (“prevalence”)
Search Date	March 10, 2021
Total Peer-Reviewed Articles	13
Total Google Scholar Results	N/A
Total Grey Literature Articles	0
Title/Abstract Rejection	1
Article Rejections	7
Final Articles	5
Length of time needed to reduce moderate to severe pain	
Search Terms	<ul style="list-style-type: none"> • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain” AND (“moderate” OR “severe” OR “severity”)) AND (“time to treat” OR “reduction” OR “improvement” OR “management” OR “perception” OR “days”) • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“moderate pain” OR “severe pain” OR “pain severity”) AND (“time to treat” OR “pain reduction” OR “pain improvement” OR “pain management” OR “pain perception” OR “perception of pain” OR “days”)
Search Date	March 11, 2021
Total Peer-Reviewed Articles	28 ⁵
Total Google Scholar Results	N/A
Total Grey Literature Articles	0
Title/Abstract Rejection	7
Article Rejections	15
Final Articles	6
Distribution of pain that is difficult to control across hospice providers	
Search Terms	((“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain” AND (“moderate” OR “severe” OR “perception” OR “manage*” OR “severity”)) AND (“disparities” OR “health equity” OR “equity” OR “distrib*))
Search Date	May 20, 2021
Total Peer-Reviewed Articles	14
Total Google Scholar Results	N/A
Total Grey Literature Articles	0

⁵ One identified article was a secondary analysis of an identified article. The original analysis was within the past five years and was manually added to the EndNote file for inclusion

Title/Abstract Rejection	7
Article Rejections	5
Final Articles	2
Over- or undertreatment of pain	
Search Terms	<ul style="list-style-type: none"> • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain”) AND (“under*” OR “over*”) • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain”) AND (“undertreat*” OR “overtreat*”) • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain” OR “opioid”) AND (“undertreat*” OR “overtreat*” OR “overuse” OR “underuse”) • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain” OR “opioid”) AND (“undertreat*” OR “overtreat*” OR “overuse” OR “underuse” OR “overprescribe” OR “underprescribe”) • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“pain” OR “opioid” OR “analgesic”) AND (“undertreat*” OR “overtreat*” OR “overuse” OR “underuse” OR “overprescribe” OR “underprescribe”)
Search Date	May 21, 2021
Total Peer-Reviewed Articles	36 ⁶
Total Google Scholar Results	N/A
Total Grey Literature Articles	2
Title/Abstract Rejection	17
Article Rejections	11
Final Articles	9
Neuropathic pain risk adjustment	
Search Terms	<ul style="list-style-type: none"> • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“neuropathic pain” OR “neuropathy” OR “nerve pain” OR “neuralgia”) AND “risk adjustment”) • (“neuropathic pain” OR “neuropathy” OR “nerve pain” OR “neuralgia”) AND “risk adjustment”) [PubMed Search—no results when hospice string was used] • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“neuropathic pain” OR “neuropathy” OR “nerve pain” OR “neuralgia”) AND “risk adjustment”) [Google Scholar search]
Search Date	May 18, 2021
Total Peer-Reviewed Articles	3
Total Google Scholar Results	44
Total Grey Literature Articles	0
Title/Abstract Rejection	41
Article Rejections	2
Final Articles	4
Neuropathic pain disparities	
Search Terms	<ul style="list-style-type: none"> • (“hospice” OR “hospice care” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“neuropathic pain” OR “neuropathy” OR “nerve pain” OR “neuralgia”) AND (“disparities” OR “health equity” OR “equity”)

⁶ We were unable to access one article.

	• ((“neuropathic pain” OR “neuropathy” OR “nerve pain” OR “neuralgia”) AND (“disparities” OR “health equity” OR “equity”))
Search Date	May 20, 2021
Total Peer-Reviewed Articles	52
Total Google Scholar Results	N/A
Total Grey Literature Articles	0
Title/Abstract Rejection	36
Article Rejections	9
Final Articles	7

Patient Preferences

Evidence of assessment item measurement of symptom management preferences	
Search Terms	((“hospice” OR “hospices” OR “hospice care” OR “palliative care” OR “palliative medicine” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“patient” AND “prefer*”) AND (“quality” AND “measure*”) AND (“assessment” OR “assessment item” OR “survey” OR “questionnaire”) AND (“symptom” AND manage*))
Search Date	May 27, 2021
Total Peer-Reviewed Articles	13
Total Google Scholar Results	35
Total Grey Literature Articles	3
Title/Abstract Rejection	20
Article Rejections	28
Final Articles	3
Patient preferences used in quality measurement and improvement activities	
Search Terms	((“hospice” OR “hospices” OR “hospice care” OR “palliative care” OR “palliative medicine” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“patient” AND “prefer*”) AND (“quality” AND “measure*”))
Search Date	March 29, 2021
Total Peer-Reviewed Articles	114
Total Google Scholar Results	42
Total Grey Literature Articles	5
Title/Abstract Rejection	71
Article Rejections	80
Final Articles	10
Concordance between patient preferences and patient goals	
Search Terms	((“hospice” OR “hospices” OR “hospice care” OR “palliative care” OR “palliative medicine” OR “end-of-life care” OR “terminal care” OR “hospice and palliative care nursing”) AND (“patient” AND “prefer*”) AND (“goal” OR “goals”) AND (“concordan*” OR “consistent” OR “consistency” OR “achieve*))
Search Date	April 24, 2021
Total Peer-Reviewed Articles	12
Total Google Scholar Results	57
Total Grey Literature Articles	2
Title/Abstract Rejection	27
Article Rejections	34
Final Articles	10

Concordance between patient/proxy and medical/clinical determinations of symptom management	
Search Terms	((("hospice" OR "hospices" OR "hospice care" OR "palliative care" OR "palliative medicine" OR "end-of-life care" OR "terminal care" OR "hospice and palliative care nursing") AND (("patient" OR "proxy" OR "caregiver" OR "family" OR "relative") AND ("prefer*")) AND ("goal" OR "goals") AND ("concordan*" OR "consistent" OR "consistency" OR "achieve*")) AND ("symptom" AND manage*))
Search Date	April 10, 2021
Total Peer-Reviewed Articles	27
Total Google Scholar Results	18
Total Grey Literature Articles	0
Title/Abstract Rejection	17
Article Rejections	26
Final Articles	2
Concordance between patient and proxy preferences for symptom management	
Search Terms	((("hospice" OR "hospices" OR "hospice care" OR "palliative care" OR "palliative medicine" OR "end-of-life care" OR "terminal care" OR "hospice and palliative care nursing") AND (("patient" OR "proxy" OR "caregiver" OR "family" OR "relative") AND ("prefer*")) AND ("concordan*" OR "consistent" OR "consistency") AND ("symptom" AND manage*))
Search Date	May 2, 2021
Total Peer-Reviewed Articles	4
Total Google Scholar Results	12
Total Grey Literature Articles	2
Title/Abstract Rejection	7
Article Rejections	8
Final Articles	3

Spiritual Care

Standards of practice for assessment and interventions for spiritual care	
<ul style="list-style-type: none"> • Reviewed relevant practice guidelines, identified by subject matter experts • Reviewed previous work on qualifications, credentials, licensure, and certification for spiritual care providers (<i>Reviewed CoPs, Interpretive Guidelines, Medicare Benefit Manual - Hospice - Chapter 9, several websites and articles relevant to "consensus, standards, scope of practice, professional organizations, Clinical Pastoral Education, certification."</i>) 	
Evidence or guidelines for spiritual assessment and care as conducted by a spiritual counselor	
Search Terms	((("hospice)" OR "(hospices)" OR "(hospice care)" OR "(palliative care)" OR "(palliative medicine)" OR "(hospice and palliative care nursing)" OR "(terminal care)") AND ("(spiritual assessment)" OR "(spiritual care)" OR "(spirituality)" OR "(spiritualism)" OR "(religious)" OR "(existential)") AND ("(spiritual caseworker)" OR "(chaplain)" OR "(clergy)") AND ("(social work)" OR "(social workers)" OR "(nurse)"))
Search Date	March 3, 2021
Total Peer-Reviewed Articles	24
Total Google Scholar Results	N/A
Total Grey Literature Articles	0
Title/Abstract Rejection	4
Article Rejections	6
Final Articles	14

Spiritual outcomes for hospice and palliative care patients	
Search Terms	<ul style="list-style-type: none"> • ("hospice") OR "(hospices)" OR "(hospice care)" OR "(palliative care)" OR "(palliative medicine)" OR "(hospice and palliative care nursing)" OR "(terminal care)" AND ("(spiritual intervention)" OR "(religious intervention)" OR "(life review)" OR "(dignity therapy)" OR "(meaning-centered intervention)" OR "(spiritual care)") AND "(patients)" AND ("(outcomes)" OR "(wellbeing)" OR "(pain)" OR "(distress)") • ("hospice") OR "(hospices)" OR "(hospice care)" OR "(palliative care)" OR "(palliative medicine)" OR "(hospice and palliative care nursing)" OR "(terminal care)" AND "(patients)" AND ("(spiritual assessment)" OR "(spiritual care)" OR "(spirituality)" OR "(spiritualism)") AND ("(outcomes)" OR "(pain)" OR "(distress)")
Search Date	March 1, 2021, and March 4, 2021
Total Peer-Reviewed Articles	180
Total Google Scholar Results	N/A
Total Grey Literature Articles	2
Title/Abstract Rejection	115
Article Rejections	37
Final Articles	30

Psychosocial Assessment and Care

Standards of practice for assessment and interventions for psychosocial care	
Search Terms	((("hospice" OR "hospice care" OR "hospice and palliative care nursing") AND ("psychosocial assessment)" OR "(assessment)") AND "(social work))
Search Date	March 18, 2021
Total Peer-Reviewed Articles	17
Total Google Scholar Results	N/A
Total Grey Literature Articles	4
Title/Abstract Rejection	10
Article Rejections	3
Final Articles	8
Psychosocial care outcomes for palliative care patients	
Search Terms	((("hospice" OR "hospice care" OR "end of life care" OR "terminal care" OR "hospice and palliative care nursing") AND ("psychosocial care" OR "psychosocial" OR "psychosocial assessment") AND "outcome")
Search Date	March 18, 2021
Total Peer-Reviewed Articles	20
Total Google Scholar Results	N/A
Total Grey Literature Articles	0
Title/Abstract Rejection	0
Article Rejections	17
Final Articles	3

Medication Management

Medication Management	
Search Terms	("hospice" OR "hospice care" OR "end-of-life care" OR "terminal care" OR "hospice and palliative care nursing") AND ("medication" AND "management")
Search Date	May 24, 2021
Total Peer-Reviewed Articles	67

Total Google Scholar Results	N/A
Total Grey Literature Articles	2
Title/Abstract Rejection	49
Article Rejections	4
Final Articles	14

Other Recent Hospice Literature

Other Recent Hospice Literature	
Search Terms	("hospice") AND ("quality")
Search Date	June 22, 2021
Total Peer-Reviewed Articles	77
Total Google Scholar Results	N/A
Total Grey Literature Articles	1
Title/Abstract Rejection	65
Article Rejections	7
Final Articles	7

Appendix III-A: Treating Moderate to Severe Pain Literature Review Tables

Prevalence of Moderate to Severe Pain

Prevalence of moderate to severe pain: Literature review table				
Citation	Setting	Population	Design	Main Findings
Harman, L. E., Guthrie, D. M., Cohen, J., Declercq, A., Fisher, K., Goodridge, D., Hirdes, J. P., & Seow, H. (2019, Jan 9). Potential quality indicators for seriously ill home care clients: a cross-sectional analysis using Resident Assessment Instrument for Home Care (RAI-HC) data for Ontario. <i>BMC Palliative Care</i> , 18(1), 3. https://doi.org/10.1186/s12904-018-0389-y	Canada, home-based palliative care	14,312 patients Ontario patients receiving home-based palliative care considered seriously ill, as defined by a prognosis of less than 6 months to live or presence of severe health instability	Secondary analysis of Resident Assessment Instrument for Home Care data completed between 2006 and 2013 was used to develop quality indicators relevant to the needs of older seriously ill clients.	54% of not-seriously ill patients and 65% of seriously ill patients had daily/severe pain. A mean of 46.6% patients had daily pain that was severe or excruciating on reassessment (their "prevalence of disruptive or intense daily pain" quality indicator).
Hunnicutt, J. N., Tjia, J., & Lapane, K. L. (2017, Mar). Hospice Use and Pain Management in Elderly Nursing Home Residents with Cancer. <i>Journal of Pain and Symptom Management</i> , 53(3), 561-570. https://doi.org/10.1016/j.jpainsymman.2016.10.369	US, nursing home with and without hospice	78,160 Medicare beneficiaries with cancer who were nursing home residents in the last 90 days of life in 2011- 2012.	Residents in pain in hospice were matched with like residents without hospice by facility, type of pain assessment, and weeks until death. Conditional logistic regression models were used to estimate the association between hospice use and pain management	Pain prevalence was higher in residents using hospice (59.9%; 95% CI = 59.3 - 60.5) than those without hospice (50.0%; 95% CI 49.4 - 50.6). 21.7% (95% CI 21.2 - 22.2) of hospice users reported moderate of severe pain (18.4% [95% CI = 21.1-22.2] in non-hospice users).
Puente-Fernández, D., Campos-Calderón, C. P., Burgos, A. A. E., Hueso-Montoro, C., Roldán-López, C. B., & Montoya-Juárez, R. (2020, Feb 25). Palliative Care Symptoms, Outcomes, and Interventions for Chronic Advanced Patients in Spanish Nursing Homes with and without Dementia. <i>Int J Environ Res Public Health</i> , 17(5). https://doi.org/10.3390/ijerph17051465	Spain, nursing home palliative care	107 nursing home residents receiving palliative care from six nursing homes in the Metropolitan Health District of Grenada	A cross-sectional study using a convenience sample of nursing homes with staff interested in participating. Assessment used the ESAS and outcomes were measures using the POS.	On average patients, without dementia reported moderate pain (6 on the ESAS; IQR of 4-7). Patients with dementia reported less intense pain (means of 3.5; IQR 2-6).

Prevalence of moderate to severe pain: Literature review table				
Citation	Setting	Population	Design	Main Findings
Soares, L. G. L., Japiassu, A. M., Gomes, L. C., Pereira, R., Peçanha, C., & Goldgaber, T. (2018, Oct). Prevalence and intensity of dyspnea, pain, and agitation among people dying with late stage dementia compared with people dying with advanced cancer: a single-center preliminary study in Brazil. <i>Ann Palliat Med</i> , 7(4), 437-443. https://doi.org/10.21037/apm.2018.05.06	Brazil, private post-acute facility hospice	57 patients who died with dementia and 54 patients who dies with cancer.	Retrospective cohort analysis that reviewed electronic charts for ESAS scores from death backwards 3 days.	25% of dementia patients and 46% of cancer patients experience moderate to severe pain (dementia: n=14, 25%; cancer: n=25, 46%).
Toftagen, C., Visovsky, C., Dominic, S., & McMillan, S. (2019, Sep). Neuropathic symptoms, physical and emotional well-being, and quality of life at the end of life. <i>Supportive Care in Cancer</i> , 27(9), 3357-3364. https://doi.org/10.1007/s00520-018-4627-x	US, home hospice	717 cancer patients with an identified family caregiver receiving hospice from two community non-profit private hospices in Central Florida	Cross-sectional descriptive study conducting a secondary analysis of hospice data from two Florida hospices. Instruments used were the Memorial Symptom Assessment Scale, Hospice Quality of Life Index, Palliative Performance Status, and Katz Activities of Daily Living Index	Patients with numbness/tingling had higher pain severity (1.5 v 1.8 mean out of a 4-point scale; p = 0.001) and pain distress than those without numbness/tingling (1.5 v 1.8 out of a 4-point scale; p = 0.001).

Length of time needed to reduce moderate to severe pain

Length of time needed to reduce moderate to severe pain: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Campbell, C. L., Kelly, M., & Rovnyak, V. (2017, Sep). Pain management in home hospice patients: A retrospective descriptive study. <i>Nursing & Health Sciences</i> , 19(3), 381-387. https://doi.org/10.1111/nhs.12359	US Home-based hospice	40 cancer and non-cancer patients receiving hospice care at home in an Eastern US hospice.	A retrospective descriptive approach used a convenience sample of patients whose data was extracted from an electronic medical record. Pain scores were self-reported using a scale of 1-10.	The percentage of patients with moderate to severe pain decreased from 32.5% at admission to 6% at the 48-hour reassessment
Golčić, M., Dobrila-Dintinjana, R., Golčić, G., Pavlović-Ružić, I., & Gović-Golčić, L. (2018, Dec). Do Physicians Underestimate Pain in Terminal Cancer Patients? A Prospective Study in a Hospice Setting. <i>The Clinical Journal of Pain</i> ,	Croatia, inpatient hospice	135 inpatient hospice patients admitted with cancer and expected to live less than 3 months.	Prospective study that evaluated patients every 7 days for pain for a total of 4 assessments. Physicians used a numeric rating scale to evaluation pain, and patients used a numeric rating scale, and completed the Quality-of-Life Questionnaire	There were non-statistically significant reductions in patient-reported pain levels after the first week.

Length of time needed to reduce moderate to severe pain: Literature review tables				
Citation	Setting	Population	Design	Main Findings
34(12), 1159-1163. https://doi.org/10.1097/ajp.0000000000000641			Core 15 Pal and the Edmonton Symptom Assessment.	
Mercadante, S., Adile, C., Caruselli, A., Ferrera, P., Costanzi, A., Marchetti, P., & Casuccio, A. (2016). The Palliative-Supportive Care Unit in a Comprehensive Cancer Center as Crossroad for Patients' Oncological Pathway. <i>PLoS One</i> , 11(6), e0157300. https://doi.org/10.1371/journal.pone.0157300	Italy, inpatient hospice	341 inpatient hospice patients with advanced cancer	A consecutive sample of patents was assessed for 10 months. Physical and psychological symptoms were evaluated using the Edmonton Symptom Assessment Scale at admission and time of discharge.	Patients with advanced cancer had a statistically significant decreases in ESAS scores from admission (5.26; SD 2.83) to discharge (2.59; SD 1.98) (p = 0.001). The mean hospital stay was 7 days
Mercadante, S., Adile, C., Ferrera, P., Cortegiani, A., & Casuccio, A. (2019, Aug). Symptom hyper-expression in advanced cancer patients with anxiety and depression admitted to an acute supportive/palliative care unit. <i>Supportive Care in Cancer</i> , 27(8), 3081-3088. https://doi.org/10.1007/s00520-018-4624-0	Italy, inpatient hospice	341 inpatient hospice patients with advanced cancer	A consecutive sample of patents was assessed for 10 months. Physical and psychological symptoms were evaluated using the Edmonton Symptom Assessment Scale at admission and time of discharge.	Pain decreased between admission and discharge for patients with anxiety (6.2 to 3.5; SD 2.5 and 2.2) and depression (5.6 to 3.6; SD 2.8 and 2.3). The mean hospital stay was 7 days.
Sandvik, R. K., Selbaek, G., Bergh, S., Aarsland, D., & Husebo, B. S. (2016, Sep 1). Signs of Imminent Dying and Change in Symptom Intensity During Pharmacological Treatment in Dying Nursing Home Patients: A Prospective Trajectory Study. <i>Journal of the American Medical Directors Association</i> , 17(9), 821-827. https://doi.org/10.1016/j.jamda.2016.05.006	Norway, nursing home	691 patients from 47 nursing homes in their last days of life	Prospective longitudinal trajectory trial that measured the time between the day of imminent date and the actual date of death. Symptom severity was measured using the Edmonton Symptom Assessment Scale	the proportion of patients experiencing moderate pain (ESAS score 3-6) decreased from 34.6% to 32.5% between assessments. The proportion of patients experiencing severe pain (ESAS score of 7-10) decreased from 25.6% to 13.3% between assessments. The median range between assessments was 3 days.
Wall, J., & Chauhan, A. (2018, Jun-Sep). A Case of Opioid-Induced	UK, inpatient hospice	A breast-cancer patient admitted to inpatient hospice unit and	Case report of a 76-year-old lady with metastatic breast cancer, who	Breakthrough pain treatment was reduced on the third day and the

Length of time needed to reduce moderate to severe pain: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Hyperalgesia. <i>Journal of pain & palliative care pharmacotherapy</i> , 32(2-3), 158-160. https://doi.org/10.1080/15360288.2018.1546256		presenting with opioid-induced hyperalgesia	presented to a hospice in severe distress from uncontrolled pain despite an increase in her opioid dose, alongside generalised hypersensitivity and delirium.	patient self-reported improvements in pain and hyper-sensitivity by the fourth day

Distribution of pain that is difficult to control across hospice providers

Length of time needed to reduce moderate to severe pain: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Booker, S. Q., Herr, K. A., & Wilson Garvan, C. (2020, Mar 1). Racial Differences in Pain Management for Patients Receiving Hospice Care. <i>Oncology Nursing Forum</i> , 47(2), 228-240. https://doi.org/10.1188/20.Onf.228-240	US, hospice	32 African American and 32 Caucasian Americans 65 years or with cancer received hospice care in the midwestern US.	Matched cohort secondary analysis of post intervention data is a cluster randomized controlled trial study comparing cancer pain and treatment among African American and Caucasian American patients.	They found no significant difference in pain intensity (though most pain reported was mild) or in Cancer Pain Practice Index scores (an indicator of receipt of evidence-based practices). African American patients were significantly more likely to be in Urban hospices and were less likely to receive a comprehensive pain assessment on admission (mean CPPI score of 0.59 vs 0.74, p =0.04).

<p>Cea, M. E., Reid, M. C., Inturrisi, C., Witkin, L. R., Prigerson, H. G., & Bao, Y. (2016, Nov). Pain Assessment, Management, and Control Among Patients 65 Years or Older Receiving Hospice Care in the U.S. <i>Journal of Pain and Symptom Management</i>, 52(5), 663-672. https://doi.org/10.1016/j.jpainsymman.2016.05.020</p>	<p>US, hospice</p>	<p>Hospice discharges of patients 65 or older in the 2007 National Home Health and Hospice Care Survey</p>	<p>Multivariate logistic regressions were used to identify discharge and agency characteristics predicting guideline concordant care. Adjusted odds ratios and a 95% confidence level associated hospice discharge and agency characteristics with pain assessment.</p>	<p>Non-Hispanic black patients were less likely to have a first pain assessment conducted than non-Hispanic whites (2.96; 0.11 – 0.65). Hispanics are less likely to use opioid analgesics than non-Hispanic whites (0.62; 0.40 – 0.97). Hispanic patients were less likely to report no pain at final assessment than non-Hispanic whites (0.65; 0.42 – 0.99). Patients with a longer length of stay (8 to 21 days) were more likely than patients with a shorter length of stay (0 to 7 days) to report pain improvement of management of effective pain control between the first and last assessments (1.54; 1.09-2.17) Patients with cancer as a primary diagnosis of cancer were less likely than those without a primary care cancer diagnosis to report no pain at final assessment (0.71; 0.58 – 0.86) or improvement or maintenance of effective pain control between the first and assessments (0.63; 0.48 – 0.82). Patients with a DNR directive were more likely to report pain improvement or maintenance of effective pain control than patients with such a directive (1.39; 1.04-1.84) Patients at for-profit hospices were less likely than not-for profit-hospices to report no pain at last assessment (0.76; 0.58-1.00) or pain improvement or maintenance of effective pain control between the first and last assessments (0.67; 0.48-0.95). Patients using opioid analgesics were less likely than patients no</p>
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				using opioid analgesics to report no pain at final assessment (0.65; 0.49-0.85) and to report pain improvement or maintenance of effective pain control between the first and last assessment (0.54; 0.38 – 0.77).
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Over- or undertreatment of pain

Over or undertreatment of pain: Literature review tables				
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Cea, M. E., Reid, M. C., Inturrisi, C., Witkin, L. R., Prigerson, H. G., & Bao, Y. (2016, Nov). Pain Assessment, Management, and Control Among Patients 65 Years or Older Receiving Hospice Care in the U.S. <i>Journal of Pain and Symptom Management</i> , 52(5), 663-672. https://doi.org/10.1016/j.jpainsymman.2016.05.020	US, hospice	Hospice discharges of patients 65 or older in the 2007 National Home Health and Hospice Care Survey	Multivariate logistic regressions were used to identify discharge and agency characteristics predicting guideline concordant care. Adjusted odds ratios and a 95% confidence level associated hospice discharge and agency characteristics with pain assessment.	Non-Hispanic black patients were less likely to have a first pain assessment conducted than non-Hispanic whites (2.96; 0.11 – 0.65). Hispanics are less likely to use opioid analgesics than non-Hispanic whites (0.62; 0.40 – 0.97). Hispanic patients were less likely to report no pain at final assessment than non-Hispanic whites (0.65; 0.42 – 0.99). Patients with a longer length of stay (8 to 21 days) were more likely than patients with a shorter length of stay (0 to 7 days) to report pain improvement of management of effective pain control between the first and last assessments (1.54; 1.09-2.17)

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Over or undertreatment of pain: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Dawber, R., Armour, K., Ferry, P., Mukherjee, B., Carter, C., & Meystre, C. (2019, Jun). Comparison of informal caregiver and named nurse assessment of symptoms in elderly patients dying in hospital using the palliative outcome scale. <i>BMJ Supportive & Palliative Care</i> , 9(2), 175-182. https://doi.org/10.1136/bmjspcare-2015-000850	UK, hospital	50 Terminally ill patients who had been hospitalized, their informal caregivers, and their named nurse at the hospital.	Prospective study of symptom assessments made by a healthcare professional and an informal caregiver as compared to the patients. All used the Palliative Outcome Scale to assess symptoms. Differences in response were tested using Wilcoxon signed-rank test, and weighted kappa statistic was used to test for agreement.	Use of caregiver or healthcare professional proxy can overestimate symptoms and lead to overtreatment, but with respect to pain there was no significant difference between patient and proxy-report agreement for pain (p=0.622 for patient and caregiver; p = 0.497 for patient and healthcare professional).
Heneka, N., Shaw, T., Rowett, D., Lapkin, S., & Phillips, J. L. (2018, Jun). Opioid errors in inpatient palliative care services: a retrospective review. <i>BMJ Supportive & Palliative Care</i> , 8(2), 175-179. https://doi.org/10.1136/bmjspcare-2017-001417	Australia, inpatient palliative care	Three inpatient palliative care services in one Australian state representing 60 beds and 174 medication errors, 55 of which were for opioids.	24-month retrospective review of opioid errors in three inpatient palliative care units. A custom data collection tool captured reported opioid errors, including "near misses".	Over half of patients (57%; n=26) received a lower dose of opioids than ordered as a direct consequence of an error. Thirty-nine percent of patients (n=18) received an opioid overdose due to the error.
Hunnicutt, J. N., Tjia, J., & Lapane, K. L. (2017, Mar). Hospice Use and Pain Management in Elderly Nursing Home Residents with Cancer. <i>Journal of Pain and Symptom Management</i> , 53(3), 561-570. https://doi.org/10.1016/j.jpainsymman.2016.10.369	US, nursing home with and without hospice	78,160 Medicare beneficiaries with cancer who were nursing home residents in the last 90 days of life in 2011- 2012.	Residents in pain in hospice were matched with like residents without hospice by facility, type of pain assessment, and weeks until death. Conditional logistic regression models were used to estimate the association between hospice use and pain management	Patients receiving hospice were more likely (0.95 confidence level) to receive any pharmacologic pain management (OR 1.99; 1.69-2.34); a scheduled pain regimen (OR 1.85; 1.74-1.97) PRN medication (OR 1.32; 1.21-1.44), and nonpharmacologic pain management (OR 1.19; 1.12-1.27) than non-hospice patients. These findings were consistent for both patient and staff reported assessments.
Ziegler, L., Mulvey, M., Blenkinsopp, A., Petty, D., & Bennett, M. I. (2016, Nov). Opioid prescribing for patients with cancer in the last year of life: a longitudinal population cohort study. <i>Pain</i> , 157(11), 2445-2451.	UK, multi-setting including hospice	6,080 patients who died of cancer over a 7-year period in a large UK city and were prescribed analgesics in the last year of life.	Linked UK Cancer Registry data with corresponding primary care medical records to pull prescriptions for analgesics in the last year of life. Patients were stratified into three groups: no prescription, at least one prescription for a non-opioid or weak	Patients who died in a hospital setting were 60% less likely to receive a strong opioid in the last year of life than patients who died in hospice (0.4; CI 0.3-0.5) Patients who died in a hospital setting were 40% more likely to

Over or undertreatment of pain: Literature review tables				
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https://doi.org/10.1097/j.pain.0000000000000656			opioid, or at least one prescription for a strong opioid. Data is presented as relative risk ratios with a 95% confidence level.	receive a late prescription for a strong opioid that patients who died in hospice (1.4; 1.1-1.7) Patients who died at home or in a care home were equally likely to receive an opioid as those who died hospice, but the first opioid prescription was issued later than for hospice patients and in 75% of cases was for diamorphine, a drug used in the last days of life.
Abdul-Razzak, A., Lemieux, L., Snyman, M., Perez, G., & Sinnarajah, A. (2019, Sep). Description of Continuous Palliative Sedation Practices in a Large Health Region and Comparison with Clinical Practice Guidelines. <i>Journal of Palliative Medicine</i> 22(9), 1052-1064. https://doi.org/10.1089/jpm.2018.0372	Canada, multi-setting including hospice	602 patients in hospital, community hospice, or tertiary palliative care who received continuous palliative sedation therapy (CPST) at the end of life via midazolam infusion.	Retrospective chart review of patients who received midazolam for infusion therapy at the end of life for deep CPST to determined adherence with local guidelines. Data was obtained from EMRs or paper charts.	85% of hospice patients for whom CPST was ordered had it administered, compared to 82% in a palliative care unit and 75% in the inpatient setting. The mean duration of CPST was significantly longer in hospice (61.6 hours) compared to the inpatient hospital (24.1 hours) and palliative care unit (20.5 hours) settings (p = 0.002; Kruskal-Wallis non-parametric test).
Meier, D. E. (2019, June 21). How Prescriber Education Will Help Reduce Untreated Pain and Substance Use Disorder. https://www.capc.org/blog/palliative-pulse-march-2016-prescriber-education-will-help-reduce-untreated-pain-substance-use-disorder/	US, Palliative care	N/A	Blog post on CAPC's website that discusses how best to balance provided appropriate access to care for those with a serious illness, and efforts to curb inappropriate opioid prescribing and use.	Approaches to mitigate the under treatment of pain include improving provider education, improving patient self-management strategies, evaluating the risks and benefits of opioids, and providing patients and families with educational tools.

Over or undertreatment of pain: Literature review tables				
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Meier, D. E., & Beresford, L. (2019, June 21). Balancing Pain Treatment with Risks of Comorbid Substance Use Disorder for Patients with Serious Illness. https://www.capc.org/blog/palliative-pulse-the-palliative-pulse-december-2018-balancing-pain-treatment-with-risks-of-comorbid-substance-use-disorder-for-patients-with-serious-illness/	US, Palliative care	N/A	CAPC blog post reflecting on a recent National Academy of Sciences, Engineering, and Medicine workshop	There is a fear from prescribers and pharmacists of legal culpability when providing opioids which maintains systemic barriers to opioid prescribing for the seriously ill.

Neuropathic pain risk adjustment

Neuropathic pain risk adjustment: Literature review tables																																				
Citation	Setting	Population	Design	Main Findings																																
University of Michigan Kidney Epidemiology and Cost Center. (2016). End-stage renal diseases evaluation of potential prevalent comorbidity adjustments in the Standardized Hospitalization Ratio for dialysis facilities [Measure Justification Form]. https://dialysisdata.org/sites/default/files/content/ESRD_Measures/nqf/SHR%20MIF.pdf	US, dialysis facilities	Medicare patients receiving care at dialysis facilities participating in the quality reporting program	The specifications for the standardized hospitalization ratio were submitted as part of the measure justification form an include risk adjusters.	<p>6 neuropathic pain conditions were considered appropriate risk-adjusters:</p> <table border="1"> <thead> <tr> <th colspan="4">Prevalent Comorbidity Coefficients, Data Years 2010-2013</th> </tr> <tr> <th>ICD-9 Description</th> <th>ICD-9 Code</th> <th>Coefficient</th> <th>P-Value</th> </tr> </thead> <tbody> <tr> <td>Peripheral autonomic neuropathy in disorders classified elsewhere</td> <td>337.1</td> <td>0.02621</td> <td><.0001</td> </tr> <tr> <td>Polyneuropathy in diabetes</td> <td>357.2</td> <td>0.04133</td> <td><.0001</td> </tr> <tr> <td>Diabetes with neurological manifestations, Type II or unspecified type, not stated as uncontrolled</td> <td>250.60</td> <td>0.05824</td> <td><.0001</td> </tr> <tr> <td>Diabetes with neurological manifestations, Type I, not stated as uncontrolled</td> <td>250.61</td> <td>0.04909</td> <td><.0001</td> </tr> <tr> <td>Diabetes with neurological manifestations, Type II or unspecified type, uncontrolled</td> <td>250.62</td> <td>0.07612</td> <td><.0001</td> </tr> <tr> <td>Diabetes with neurological manifestations, Type I, uncontrolled</td> <td>250.63</td> <td>0.13715</td> <td><.0001</td> </tr> </tbody> </table> <p>To determine appropriate risk-adjusters, a TEP evaluated comorbidities that had a prevalence of at least 0.1% in the population and had a statistically significant relationship with mortality or hospitalization and scored them on how likely they were to be the results of facility care. 210 comorbidities were scored as “unlikely” or “very unlikely the result of facility care”, and therefore considered appropriate risk-adjusters. The comorbidities included as risk-adjusters must also be present in Medicare claims</p>	Prevalent Comorbidity Coefficients, Data Years 2010-2013				ICD-9 Description	ICD-9 Code	Coefficient	P-Value	Peripheral autonomic neuropathy in disorders classified elsewhere	337.1	0.02621	<.0001	Polyneuropathy in diabetes	357.2	0.04133	<.0001	Diabetes with neurological manifestations, Type II or unspecified type, not stated as uncontrolled	250.60	0.05824	<.0001	Diabetes with neurological manifestations, Type I, not stated as uncontrolled	250.61	0.04909	<.0001	Diabetes with neurological manifestations, Type II or unspecified type, uncontrolled	250.62	0.07612	<.0001	Diabetes with neurological manifestations, Type I, uncontrolled	250.63	0.13715	<.0001
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				in the preceding calendar year and be present on at least two outpatient claims or one inpatient claim.
Henderson, M., Han, F., & Stockwell, I. (2020). Maryland Primary Care Program (MDPCP) Pre-AH Risk Score Specifications and Codebook (Version 3). Other Hilltop Institute (UMBC) Works.	US, primary care	Patients attributed to Maryland primary care practices participating in the Maryland Primary Care Program	Specifications and code for Maryland's pre-Avoidable Hospitalization Model estimates a patient's risk of experiencing an avoidable hospital event and will be used to rank patients	Includes neuropathy as a risk factor. Specifically, for each person month, the neuropathy indicator flag is set to 1 if the person had at least one inpatient or two non-inpatient claims with any diagnosis for neuropathy in the past two years. The neuropathy indicator mean is 0.051. The model identified risk factors through a comprehensive literature review focused on risk factors for potentially avoidable readmission.
Škodová, M. (2020). Improvement of risk adjustment for health insurance companies in the Czech Republic-compensation of costs of patients with renal failure.	Czech Republic, prescriptions	Patients who are insured and consume drugs.	Patients are assigned into one of 25 PCGs based on their drug consumption, and PCGs are combined with demographic risk factors to determine a patient's final risk index. The indexes reflect the "expected effect of belonging to a group on healthcare costs", and the calculation uses weighted least squares. The Czech Republic uses PCGs to determine patient risk for purposes of distributing funds to insurers.	The pharmacy-based cost group (PCG) for neuropathic pain has a risk index of 2.2671.
Smets, T. (2020). Population-level evaluation of the appropriateness of end-of-life care in Belgium [Ghent University].	Belgium,	Patients receiving end-of-life care	Population level study to develop quality indicators for end-of-life care that use administrative data. The process involved a literature search, expert interviews, and expert panels, and statistically evaluating performance on the indicators for patients with cancer, COPD, or dementia.	Age, household type, type of cancer, and living in a rural or urban environment are important risk adjusters for various quality indicators assessing different aspects of appropriate or inappropriate end-of-life care. The report additionally identified a measure of patients who received neuropathic medication while receiving morphine prior to death as a key indicator of receipt of appropriate end-of-life care for patients with dementia or cancer

Neuropathic pain disparities

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Amiri, A., & Zhao, S. (2019, Apr). Working with an environmental justice community: Nurse observation, assessment, and intervention. Nurs Forum, 54(2), 270-279. https://doi.org/10.1111/nuf.12327	US, environmental justice community	Focus group participants in Uniontown, AL. Uniontown meets the criteria for an environmental justice community, with high levels of minority residents and poverty, a failed sewer, and a location proximal to coal ash discharge. The community also has limited access to healthcare services. who reported	3-stage community based participatory research project with a mixed methods design investigating pollution and health status in Uniontown, AL	Focus groups participant reported exposure to coal ash resulted in increased prevalence of neuropathy in the community, though this paper did not test that relationship.																																															

Neuropathic pain disparities Literature review tables				
Citation	Setting	Population	Design	Main Findings
Calvo, M., Davies, A. J., Hébert, H. L., Weir, G. A., Chesler, E. J., Finnerup, N. B., Levitt, R. C., Smith, B. H., Neely, G. G., Costigan, M., & Bennett, D. L. (2019, Nov 20). The Genetics of Neuropathic Pain from Model Organisms to Clinical Application. <i>Neuron</i> , 104(4), 637-653. https://doi.org/10.1016/j.neuron.2019.09.018	N/A	N/A	A review of underlying work neural mechanisms resulting in neuropathic pain that discusses the pathophysiology of neuropathic pain and its relationship with co-morbidities and clinical applications of the findings.	the environment plays an important role in the clinical pathways of neuropathic pain, and understanding these factors is crucial both to diagnose and treat neuropathic pain.
Reynolds, E. L., Burke, J. F., Banerjee, M., Kerber, K. A., Skolarus, L. E., Magliocco, B., Esper, G. J., & Callaghan, B. C. (2020, Mar 31). Association of out-of-pocket costs on adherence to common neurologic medications. <i>Neurology</i> , 94(13), e1415-e1426. https://doi.org/10.1212/wnl.0000000000009039	US, outpatient	42,249 privately insured patients with neuropathy on gabapentinoids and 5,246 patients with neuropathy on SNRIs.	Using privately insured claims from 20001 – 2016 to identify patients prescribed medications with similar efficacy but different out of pocket costs and used instrumental variable analysis to estimate the association of out-of-pocket costs and other patient factors on medication adherence.	Increasing out-of-pocket medication costs for neuropathy patients on gabapentinoids decreased adherence (adjusted incidence rate ratio [IRR] 0.91, CI 0.89 – 0.93) and that minority populations had lower adherence with gabapentinoids compared to white patients. Asian adjusted IIR: 0.89, CI 0.87- 0.91, Hispanic adjusted IRR 0.87; CI 0.85 – 0.89
Schnall, R., Siegel, K., Jia, H., Olender, S., & Hirshfield, S. (2018, Jun). Racial and socioeconomic disparities in the symptom reporting of persons living with HIV. <i>AIDS Care</i> , 30(6), 774-783. https://doi.org/10.1080/09540121.2017.1417532	US, outpatient	1.373 people living with HIV AIDS. Respondents were from all 50 states.	Analysis of an anonymous online survey of symptomatic people living with HIV/AIDS who were asked to report the intensity of 28 frequently occurring symptoms in the past 30 days. The relationship between symptom reporting and demographic factors was investigated using the adaptive least absolute shrinkage and selection operator (LASSO) method.	While neuropathy continues to be a frequently reported symptom, there was no difference between racial and ethnic groups. However, patients with the lowest incomes (<\$20,000) were more likely to report more burdensome symptoms (beta = 0.232; CI 0.097 – 0.367)

Neuropathic pain disparities Literature review tables				
Citation	Setting	Population	Design	Main Findings
Simon, N. B., Danso, M. A., Alberico, T. A., Basch, E., & Bennett, A. V. (2017, Oct). The prevalence and pattern of chemotherapy-induced peripheral neuropathy among women with breast cancer receiving care in a large community oncology practice. <i>Qual of Life Research</i> , 26(10), 2763-2772. https://doi.org/10.1007/s11136-017-1635-0	US, outpatient oncology	126 women treated for breast cancer at a community oncology practice in Virginia who had received taxane-based chemotherapy.	Cross-sectional observational study that used patient surveys and medical chart review to characterize the prevalence and pattern of chemotherapy induced peripheral neuropathy (CIPN) and its impact on quality of life. Demographic and clinical information was abstracted from medical records. Quality of life was assessed using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaires (EORTC-QLQ) C30. The EORTC QLQ CIPN 20 was used to assess CIPN. Clinical significance was defined as at least one half a standard deviation difference between groups. Independent t-tests were used to compare white patients with African American patients.	Chemotherapy induced peripheral neuropathy in breast cancer patients was both more prevalent (82.9% vs 67.1% self-reported CIPN) and more severe (28.6% v. 14.4%; $p < 0.002$ for sensory impairments; 25.0% vs. 15.5%, $p < 0.012$ for motor impairments, and 24.3% vs 13.4%; $p < 0.014$ for autonomic impairments) in Black or African American women than white women. Differences were both statistically (at 95%) and clinically significant (10%), with differences persisting when controlling for treatment characteristics such as age, BMI, and diabetes.
Whyte, M. B., Hinton, W., McGovern, A., van Vlymen, J., Ferreira, F., Calderara, S., Mount, J., Munro, N., & de Lusignan, S. (2019, Oct). Disparities in glycaemic control, monitoring, and treatment of type 2 diabetes in England: A retrospective cohort analysis. <i>PLoS Medicine</i> , 16(10), e1002942. https://doi.org/10.1371/journal.pmed.1002942	UK, primary care	49,380 adults with Type II diabetes in primary care practices	Retrospective cohort analysis. Cohort was identified from the Royal College of General Practitioners Research and Surveillance Center dataset, which is a nationally representative sample of 164 primary care practices. Mixed	Males were more likely to be screened for neuropathy than females (OR 1.05; 95%, CI 1.01 – 1.1), Asian patients were less likely to be screened for neuropathy than white patients (OR 0.88; CI 0.80 – 0.97), and economically deprived patients were less likely to receive neuropathy screening than their less deprived counterparts (OR 0.88; CI 0.80 – 0.97 comparing the lowest and highest quintiles of the Index of Multiple Deprivation)

Neuropathic pain disparities Literature review tables				
Citation	Setting	Population	Design	Main Findings
			effects regression analyses determined the relationship between sex, socioeconomic group, and ethnicity and prescribing rates and diabetes monitoring.	

Appendix III-B: Patient Preferences Literature Review Table

Evidence of assessment item measurement of symptom management preferences

Evidence of assessment item measurement of symptom management preferences: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Centers for Medicare and Medicaid Services (2018). HIS Guidance Manual for Completion of the Hospice Item Set (HIS).	US, hospice	The intended audience for this manual is any hospice provider who administers the HIS for the purposes of quality assessment.	The HIS manual contains guidance for completing each item in the HIS, including those related to treatment preferences.	Hospice providers must discuss – or attempt to discuss – at least one of three preference items in the seven days prior to or five days after hospice admission, with documentation in clinical records. The preference items in the Hospice Item Set (HIS) are: F2000A: The patient and/or responsible party were asked about preferences regarding the use of cardiopulmonary resuscitation (CPR); F2100A: The patient and/or responsible party were asked about preferences regarding life-sustaining treatments other than CPR; F2200A: The patient and/or responsible party were asked about preference regarding hospitalization.
Whitehead, P. B., Ramalingam, N., Carter, K. F., Katz, K., & Harden, S. (2016). Nurse Practitioners' Perspectives on the Patient Preferences About Serious Illness Instrument. <i>Journal of Hospice & Palliative Nursing</i> , 18(4), 332-341. https://doi.org/10.1097/njh.0000000000000256	US, multi-setting	47 nurse practitioners participated in an online survey, and 13 nurse practitioners participated in focus groups. Eligibility criteria for the survey included current care of seriously ill adult patients. Participants were recruited from the registration list of Virginia Council of Nurse Practitioners annual conference.	A mixed-method study including two 90-minute focus groups (each with 6 or 7 participants), as well as an online Qualtrics survey. Chi-squared analyses were used to test differences between individual characteristics (that serve as independent variables, such as age, race, ethnicity, specialty, education, and personal health status) and dependent variables of having end-of-life conversations and comfort with conversations.	Each participant was asked to review a copy of the Patient Preferences About Serious Illness Instrument (PASI). Most participants (n = 9) discussed challenges of integrating the PASI into their busy practices and existing workflows. Concerns about time constraints led some to believe that the PASI should be given to patients in the waiting room, although self-administration does not allow for the intended guided dialogue. Some thought it important to start end-of-life conversations with their chronically ill patients early, whereas others thought only their terminally ill patients should complete the PASI.

Evidence of assessment item measurement of symptom management preferences: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Whitehead, P.B & Carter, K. F. (2017). A Model for Meaningful Conversation in Serious Illness and the Patient Preferences About Serious Illness Instrument. <i>Journal of Hospice & Palliative Nursing</i> , 19(1), 49-58. https://doi.org/10.1097/njh.0000000000000307	US, multi-setting	Patients with serious illness nearing the end of life (population unspecified).	A 2017 Feature Article describes the Patient Preferences About Serious Illness Instrument (PASI), a new model of meaningful conversation in serious illness that can be used in conjunction with existing advanced care planning directives such as Physician Orders for Life-Sustaining Treatments and The Five Wishes. The instrument was adapted from the Preferences About Death and Dying instrument and elicits preferences from 6 domains (symptoms, treatment preferences, family, whole person, life preparation, moment of care).	Practitioners use the PASI to elicit a dialogue with patients by reading the questions with the patient. The instrument can be completed in approximately 10 to 15 minutes. In the “symptoms” domain, patients are asked, “How important is it to you to have your symptoms under control?” Symptoms include pain, anxiety, breathing problems, sleeping problems, poor appetite, constipation, diarrhea, nausea/vomiting, depression, fatigue/weakness, and others. These symptoms were collated based on pilot testing from both inpatient and outpatient palliative and oncology patients. Next, the practitioner asks the patient, “Which of these symptoms are your top 3 concerns? (no need to rank)” and “Are your symptoms being addressed/managed?”

Patient preference in quality measurement and improvement

Patient preferences in quality measurement and improvement: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Cain, C. L., Surbone, A., Elk, R., & Kagawa-Singer, M. (2018). Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. <i>Journal of Pain and Symptom Management</i> , 55(5): 1408-1419. https://doi.org/10.1016/j.jpainsymman.2018.01.007	Non-specific country, palliative care	Focus on minority racial and ethnic groups.	An integrative literature review of palliative care literature to illustrate the influence of culture on palliative care: preferences for care, communication patterns, meanings of sufferings, and decision-making processes.	Individuals' preferences for care for serious illness affect both processes and outcomes of care. Processes include the use of analgesics, types of interventions tried, degree of knowledge about condition desired, and level of family involvement in care decisions. Outcomes include goals of treatment; adherence to prescribed protocol for treatment; degree of physical, mental, and emotional compromise the patient and family may be willing to accept;

Patient preferences in quality measurement and improvement: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				consideration of do-not-resuscitate orders; other forms of advance care planning; and ultimately timing, process, and place of death. Preferences for end-of-life care are shaped by a variety of sociocultural factors.
Gomes, B., de Brito, M., Sarmiento, V. P., Yi, D., Soares, D., Fernandes, J., Fonseca, B., Goncalves, E., Ferreira, P. L., & Higginson, I. J. (2017). Valuing Attributes of Home Palliative Care with Service Users: A Pilot Discrete Choice Experiment. <i>Journal of Pain and Symptom Management</i> , 54(6), 973-985. https://doi.org/10.1016/j.jpainsymman.2017.05.005	Portugal, home palliative care	21 patients with advanced illness and their family caregivers (nominated by the patient as the person providing most help with care) from three public home palliative care services in the North region of Portugal (one rural and two urban) from March 2015 to June 2015.	A cross-sectional survey that piloted the discrete choice experiment (DCE) method using cognitive interviewing.	The discrete choice experiment (DCE) is a feasible and acceptable quantitative method for eliciting user preferences when modeling home palliative care services. Participants are asked to consider different dimensions of a service and voice their preferences by choosing between realistic scenarios.
Gramling, R., Stanek, S., Ladwig, S., Gajary-Coots, E., Cimino, J., Anderson, W., Norton, S. A., Group, A. R. C. W., Aslakson, R. A., Ast, K., Elk, R., Garner, K. K., Gramling, R., Grudzen, C., Kamal, A. H., Lamba, S., LeBlanc, T. W., Rhodes, R. L., Roeland, E., Schulman-Green, D., & Unroe, K. T. (2016). Feeling Heard and Understood: A Patient-Reported Quality Measure for the Inpatient Palliative Care Setting. <i>Journal of Pain and Symptom Management</i> , 51(2), 150-154. https://doi.org/10.1016/j.jpainsymman.2015.10.018	US, hospital and inpatient palliative care	160 hospitalized patients with advanced cancer who were referred to palliative care	A subset of the Palliative Care Communication Research Initiative, a multisite observational cohort study of inpatient palliative care. Researchers tested a self-report field measure for seriously ill patients to report how well they feel heard and understood in the hospital environment.	The measure was easy to comprehend and of very low response burden, even for quite ill patients. It was also quick to administer in either written or spoken form. This measure would satisfy the Measuring What Matters (MWM) call for the development of a 10th item to capture patients' global assessment of their healthcare quality.
Hunt, L. J., Garrett, S. B., Dressler, G., Sudore, R., Ritchie, C. S., & Harrison, K. L. (2021). Goals of Care Conversations Don't Fit in a Box: Hospice Staff Experiences and Perceptions of Advance Care	US, community-based hospice	51 hospice providers from various clinical backgrounds and organizational roles, representing 4 geographically diverse non-profit, community-based hospices in the U.S.	Semi-structured in-depth interviews about participants' experiences with and barriers to ACP quality measurement processes in their organization, opinions about the impacts of federally mandated	Participants predominately viewed the HIS treatment preferences measure (NQF #1641) as a check-the-box task that compromised holistic hospice care. They recommended shifting from limited,

Patient preferences in quality measurement and improvement: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Planning Quality Measurement. <i>Journal of Pain and Symptom Management</i> , 61(5), 917-927. https://doi.org/10.1016/j.jpainsymman.2020.09.042			quality measures, and ideas for improvement.	objective, process measures such as HIS toward comprehensive, subjective, outcome-based measures.
Johnson, S. B., Butow, P. N., Kerridge, I., Bell, M. L., & Tattersall, M. H. N. (2018). How Well Do Current Measures Assess the Impact of Advance Care Planning on Concordance Between Patient Preferences for End-of-Life Care and the Care Received: A Methodological Review. <i>Journal of Pain and Symptom Management</i> , 55(2), 480-495. https://doi.org/10.1016/j.jpainsymman.2017.09.008	Multiple	9 eligible studies (out of 2941 initially identified) that assessed ACP interventions, concordance between patient preference and care received at the end of life, and more than one patient outcome to measure concordance.	A 2018 literature search of Medline and CINHALL articles (2000-2016) that including the terms “advance care planning” AND “outcome assessment”, identified methods for assessing concordance between patient preferences and end-of-life care after advance care planning, assessed the methodological quality of these studies, and synthesized the results of studies regarding the proportion of patients who received end-of-life care concordant with their preferences.	Eight studies formally defined “patient preference”; there was a significant variation in the source of patient preferences and the medical interventions for which preferences were reported. Three studies used patient questionnaires to assess patient preferences. Five studies used post-mortem chart review to determine patient preferences. One study reviewed medical charts and conducted in-person interviews with nursing home residents or their designated proxy to determine preferences for care. Of all studies collecting data on patient preferences, four used a standardized data collection tool.
Kamal, A. H., Bull, J., Ritchie, C. S., Kutner, J. S., Hanson, L. C., Friedman, F., Taylor, D. H., Jr., & Group, A. R. C. W. (2016). Adherence to Measuring What Matters Measures Using Point-of-Care Data Collection Across Diverse Clinical Settings. <i>Journal of Pain and Symptom Management</i> , 51(3), 497-503. https://doi.org/10.1016/j.jpainsymman.2015.12.313	US, multiple palliative care settings	2242 patients were enrolled into the PCRC QDACT quality registry. The population was mostly white, female, and with moderate performance status.	A cross-sectional descriptive study of quality measure implementation across various palliative care settings. The researchers included data entered prospectively into the Quality Data Collection Tool (QDACT) from January 2014 to September 2015. This study was conducted within the PCRC, a multisite research infrastructure to support and coordinate clinical research in palliative care. Data was collected from four academic sites and one community-based site.	MWM Measure #9 (Care Consistency with Documented Care Preferences) had an adherence rate of 100% in the emergency department, 96% on the hospital general floor; 98% in hospital intensive care, 91% at home, 98% in long-term care, 88% in outpatient settings, 96% in all acute care, and 95% in all nonacute care.
Modes, M. E., Engelberg, R. A., Downey, L., Nielsen, E. L., Curtis, J. R., & Kross, E. K. (2019). Did a	US, outpatient clinic	494 patients (with median survival of approximately 2 years) and 124 clinicians	A secondary analysis of a multicenter	52% percent of patients reported the occurrence of a goals-of-care discussion, whereas clinicians

Patient preferences in quality measurement and improvement: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Goals-of-Care Discussion Happen? Differences in the Occurrence of Goals-of-Care Discussions as Reported by Patients, Clinicians, and in the Electronic Health Record. <i>Journal of Pain and Symptom Management</i> , 57(2), 251-259. https://doi.org/10.1016/j.jpainsymman.2018.10.507		caring for them. Participants were selected from two large health systems in the Pacific Northwest.	cluster-randomized trial of a patient-specific pre-conversation communication-priming intervention (Jumpstart Tips). Self-reported surveys collected from patients and clinicians two weeks after a clinic visit assessed occurrence of a goals-of-care discussion. Documentation of a goals-of-care discussion was abstracted from the EHR. Patient-reported receipt of goal-concordant care was assessed by survey two weeks after the visit.	reported the discussions at 66% of the visits, and the EHR documented these discussions at 42% of the visits. Patients who reported occurrence of a goals-of-care discussion were significantly more likely to report receipt of goal-concordant care than patients who reported no discussion; however, neither clinician reports nor EHR documentation of goals-of-care discussions was significantly associated with patients' reports of goal-concordant care. This discordance suggests that patient-clinician pairs may not have a shared understanding of what constitutes a goals-of-care discussion.
Schellinger, S. E., Anderson, E. W., Frazer, M. S., & Cain, C. L. (2018). Patient Self-Defined Goals: Essentials of Person-Centered Care for Serious Illness. <i>American Journal of Hospice and Palliative Medicine</i> , 35(1), 159-165. https://doi.org/10.1177/1049909117699600	US, home-based palliative care	160 patients with advanced heart failure, cancer, and dementia expected to die in 2 to 3 years, in a large Midwestern metropolitan healthcare system who enrolled in the study between November 2012 and March 2014.	A 2018 descriptive qualitative analysis, in which care guides explored what was most important to patients (using motivational interviewing techniques) and documented their self-defined goals on a medical record flow sheet.	Forty percent of goals were coded into the medical domain; 40% were coded to nonmedical domains—social (9%), ethical (7%), family (6%), financial/legal (5%), psychological (5%), housing (3%), legacy/bereavement (3%), spiritual (1%), and end-of-life care (1%). Sixteen percent of the goals were complex and reflected a mix of medical and nonmedical domains, "multiple" goals.
Walkey, A. J., Barnato, A. E., Wiener, R. S., & Nallamothu, B. K. (2017). Accounting for Patient Preferences Regarding Life-Sustaining Treatment in Evaluations of Medical Effectiveness and Quality. <i>American Journal of Respiratory and Critical Care Medicine</i> , 196(8), 958-963.	US, critical care	Patients undergoing or considering life-sustaining treatment.	A 2017 perspective piece that uses a collection of case studies to explore the effect of unmeasured patient resuscitation preferences, while proposing strategies to more consistently elicit, record, and harmonize documentation of patient preferences.	Variation in consistency and quality of processes to elicit and to map patient values onto categories of treatment limitation represents a key challenge to the use of patient resuscitation preferences in the evaluation of healthcare quality. CMS represents a logical site for further centralization of a repository of patient preferences for life-sustaining treatments. Working with

Patient preferences in quality measurement and improvement: Literature review tables				
Citation	Setting	Population	Design	Main Findings
https://doi.org/10.1164/rccm.201701-0165CP				systems such as Patient Orders for Life Sustaining Treatments, CMS could standardize documentation of patient preferences and provide a resource for patients, clinicians, and researchers alike. Nationally standardized processes for the documentation of patient preferences would thus potentially allow for improved individual patient autonomy, increased validity of effectiveness research, and development of preference-sensitive measures of the quality of healthcare delivery.
Zheng, N. T., Li, Q., Hanson, L. C., Wessell, K. L., Chong, N., Sherif, N., Broyles, I. H., Frank, J., Kirk, M. A., Schwartz, C. R., Levitt, A. F., & Rokoske, F. (2018). Nationwide Quality of Hospice Care: Findings from the Centers for Medicare & Medicaid Services Hospice Quality Reporting Program. <i>Journal of Pain and Symptom Management</i> , 55(2), 427-432.e421. https://doi.org/10.1016/j.jpainsymman.2017.09.016	US, hospice	1,218,786 patients discharged from October 1, 2014, to September 30, 2015, from 3922 hospices certified by Medicare on or before September 30, 2015.	A 2018 nationwide study of HIS-admission record data to analyze the distribution of these hospice-level measures, focusing on the mean and median scores and the spread of scores across hospices, to examine the quality of hospice care nationwide and variability in quality across hospices.	Most hospices conduct critical assessments and discuss treatment preferences with patients at admission, although few hospices have perfect scores. The national mean of NQF #1641 (the percentage of hospice patient stays with chart documentation that the hospice discussed or attempted to discuss preferences for life-sustaining treatments) was 98%. More than half of the hospices (53.5%) reported discussing treatment preferences for all (100%) their patient stays.

Concordance between patient preferences and patient goals

Concordance between patient preferences and patient goals: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Cohen, S. M., Volandes, A. E., Shaffer, M. L., Hanson, L. C., Habtemariam, D., & Mitchell, S. L. (2019). Concordance Between Proxy Level of Care Preference and	US, Nursing home	64 Boston-area nursing home facilities. Residents were eligible if they were aged 65 years, had dementia (any type), scored 7 on	A secondary analysis of data from Educational Video to Improve Nursing home Care in End-stage dementia (EVINCE), a cluster	When proxies stated intensive care was preferred, 57.7% of residents' charts were deemed to be concordant with that preference

Concordance between patient preferences and patient goals: Literature review tables				
Citation	Setting	Population	Design	Main Findings
<p>Advance Directives Among Nursing Home Residents with Advanced Dementia: A Cluster Randomized Clinical Trial. <i>Journal of Pain and Symptom Management</i>, 57(1), 37-46.e31. https://doi.org/10.1016/j.jpainsymman.2018.09.018</p>		<p>the Global Deterioration Scale (GDS; range 1–7; higher scores indicate worse dementia), had resided in the NH >90 days, and had an English-speaking proxy who was available for an in-person interview within two weeks.</p>	<p>randomized clinical trial conducted between 2013-2017.</p>	<p>(i.e., no advance directives), and 36.5% were categorized as possibly concordant (i.e., directives for DNR and/or no tube-feeding). When a preference for basic care was indicated, 49.3% of assessments were felt to be concordant with that preference, while 50.7% were determined not to be concordant. Finally, when comfort care was preferred, only 7.0% of charts were deemed to be concordant with that preference, and 6.6% were felt to be possibly concordant.</p>
<p>Ernecoff, N. C., Wessell, K. L., Bennett, A. V., & Hanson, L. C. (2021). Measuring Goal-Concordant Care in Palliative Care Research. <i>Journal of Pain and Symptom Management</i>. https://doi.org/10.1016/j.jpainsymman.2021.02.030</p>	<p>Multiple, palliative care</p>	<p>36 eligible articles (out of 54 initially identified) that included an operational definition for measuring goal-concordant care.</p>	<p>A 2021 targeted literature review (a search of PubMed and Scopus using the search terms “goal-concordant care,” “concordance,” and “care consistency”) defined four methods used to measure goal-concordant care in palliative care research and discussed strengths and weaknesses of each method.</p>	<p>1) Patient-/ Family Caregiver-Reported: allows for nuanced input about preferences directly from patients or caregivers but must account for changes in preferences over time. 2) Family Caregiver-Reported After Death: provides a full retrospective picture of preferences, but particularly prone to recall bias. 3) Longitudinal Data: provides a completer and more detailed picture of treatments received, but prone to systematic bias regarding goal-concordant care. 4) Population-Level Indicators: not generally limited by response rate or reporter bias but lacks granularity and individual patient goals.</p>
<p>Heyland, D. K., Heyland, R., Dodek, P., You, J. J., Sinuff, T., Hiebert, T., Jiang, X., Day, A. G., Team, A. S., & the Canadian Researchers at the End of Life, N. (2017). Discordance between patients' stated values and treatment preferences for end-of-life care: results of a multicentre survey.</p>	<p>Canada, acute care</p>	<p>513 patients at the end of life and 366 family members representing 12 acute care teaching hospitals.</p>	<p>A multicenter prospective audit of communication, planning, and documentation at the end of life in a convenience sample. Questionnaires were administered to 513 elderly patients and 366 family members about their values</p>	<p>Participants' most important stated values were to be comfortable and suffer as little as possible, to have more time with family, to avoid being attached to machines and tubes and that death not be prolonged. The least important stated value was that life be preserved. With few</p>

Concordance between patient preferences and patient goals: Literature review tables				
Citation	Setting	Population	Design	Main Findings
<i>BMJ Supportive & Palliative Care</i> , 7(3), 292-299. https://doi.org/10.1136/bmjspcare-2015-001056			related to end-of-life care, treatment preferences, and decisional conflict.	exceptions, participants' expressed values were not associated with expected corresponding treatment preferences. Of the 109 (40%) patients and 95 (42%) family members who had made decisions about use of life-supports, 68 (56%) patients and 60 (59%) family members had decisional conflict.
Johnson, S. B., Butow, P. N., Kerridge, I., Bell, M. L., & Tattersall, M. H. N. (2018). How Well Do Current Measures Assess the Impact of Advance Care Planning on Concordance Between Patient Preferences for End-of-Life Care and the Care Received: A Methodological Review. <i>Journal of Pain and Symptom Management</i> , 55(2), 480-495. https://doi.org/10.1016/j.jpainsymman.2017.09.008	US, Multiple	9 eligible studies (out of 2941 initially identified) that assessed ACP interventions, concordance between patient preference and care received at the end of life, and more than one patient outcome to measure concordance.	A 2018 literature review (A search of Medline and CINAHL articles (2000-2016) that including the terms "advance care planning" AND "outcome assessment") identified methods for assessing concordance between patient preferences and end-of-life care after advance care planning, assessed the methodological quality of these studies, and synthesized the results of studies regarding the proportion of patients who received end-of-life care concordant with their preferences.	Proportions of patients who received concordant care varied from 14% to 98%. There are three main problems in measuring the effect of ACP on concordance between patient preferences for end-of-life care and the care received, including 1) a lack of reliability and validity of existing measures, 2) a lack of theoretical and conceptual clarity regarding "concordance", and 3) a lack of adequate attention to statistical methods and transparency of reporting. These include difficulties with response shift (i.e., the fact that people's values and choices change over time); a lack of specificity and consistency of documentation (documentation may be incoherent and contain incompatible requests) and the fact that chart reviews are unreliable and prone to bias and error.
Khandelwal, N., Curtis, J. R., Freedman, V. A., Kasper, J. D., Gozalo, P., Engelberg, R. A., & Teno, J. M. (2017). How Often Is End-of-Life Care in the United States Inconsistent with Patients'	US, multiple	1212 family members were interviewed, representing (when weighted) 4.8 million decedents. About 44% of decedents were male and 21% were more than the age of 85 years. Most decedents were	Retrospective secondary analysis of data from the National Health and Aging Trends Study (NHATS), a prospective nationally representative survey of Medicare beneficiaries in the United States	One in eight bereaved family members report that care in the last month of life was not consistent with the decedent's wishes. (To determine whether care was consistent with patients' wishes in

Concordance between patient preferences and patient goals: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Goals of Care? <i>Journal of Palliative Medicine</i> , 20(12), 1400-1404. https://doi.org/10.1089/jpm.2017.0065		white (80%), and 53% of proxy informants were a child of the decedent.	aged 65 and older that began in 2011. NHATS last month of life interview, which includes validated measures of perceptions of quality of care in terms of symptom management, emotional support, communication and decision making, and overall ratings of care.	the last month of life, informants were asked whether any decisions were made about treatments that the patient would not have wanted.) Death at home was more prevalent among decedents receiving goal-concordant care (38.1% vs. 27.9%), whereas death in the hospital was more prevalent among decedents receiving inconsistent care (30.3% vs. 21.6%). Similarly, death in a nursing home was more prevalent among decedents receiving inconsistent care (22.9% vs. 17.8%; $p = 0.052$). Patients with care inconsistent with their preferences were more likely to die in the hospital setting.
Modes, M. E., Heckbert, S. R., Engelberg, R. A., Nielsen, E. L., Curtis, J. R., & Kross, E. K. (2020). Patient-Reported Receipt of Goal-Concordant Care Among Seriously Ill Outpatients-Prevalence and Associated Factors. <i>Journal of Pain and Symptom Management</i> , 60(4), 765-773. https://doi.org/10.1016/j.jpainsymman.2020.04.026	US, outpatient	405 patients from two large health systems in the Pacific Northwest with a median age of 76 years, half of whom were women. Most patients were non-Hispanic and white (78%). Eligible patients had a median estimated survival of approximately two years.	Secondary analysis of enrollment surveys from a multicenter cluster-randomized trial of outpatients with serious illness. Patients reported their prioritized healthcare goal and the focus of their current medical care; these items were matched to define receipt of goal-concordant care.	Although 85% of patients who prioritized extending life reported goal-concordant care, only half of patients who prioritized relief of pain and discomfort reported goal-concordant care. *Limitations: Patients in this study were seriously, but not terminally, ill, as only 40 patients died during the six-month follow-up of the randomized trial. It is possible that goals of care and receipt of goal-concordant care for terminally ill patients may be different than for seriously ill patients.
Sudore, R. L., Heyland, D. K., Lum, H. D., Rietjens, J. A. C., Korff, I. J., Ritchie, C. S., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Lorenz, K., Howard, M., Green, M. J.,	Multiple, non-specific setting	52 multidisciplinary, international ACP experts including clinicians, researchers, and policy leaders from four countries.	Through five rounds of a Delphi panel, conducted between February 2015 and April 2017 panelists were asked to rate patient-centered outcomes on a 7-point "not-at-all" to	Although care consistent with goals was rated as the number one outcome construct, several panelists cautioned that there were difficulties in defining and measuring it. There

Concordance between patient preferences and patient goals: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Simon, J. E., Feuz, M. A., & You, J. J. (2018). Outcomes That Define Successful Advance Care Planning: A Delphi Panel Consensus. <i>Journal of Pain and Symptom Management</i> , 55(2), 245-255 e248. https://doi.org/10.1016/j.jpainsymman.2017.08.025			"extremely important" scale to create an organizing framework of advance care planning outcome constructs.	is still no standardized, valid, or reliable method to measure this outcome, especially across serious illness populations when preferences may vary over time.
Tan, W. S., Bajpai, R., Low, C. K., Ho, A. H. Y., & Car, J. (2018). Using Routinely Collected Data to Ascertain Concordance with Advance Care Planning Preferences. <i>Journal of Pain and Symptom Management</i> , 56(5), 659-666 e652. https://doi.org/10.1016/j.jpainsymman.2018.07.017	Singapore, multi-setting	1731 decedents (aged 21 years and above) with life-limiting or advanced illness who completed their advance care planning documentation and who died between 2011 and 2015.	Retrospective cohort study to illustrate the feasibility of using routinely collected healthcare data (e.g., hospital procedural codes, diagnosis-related codes, health services utilization, and death registry data) to ascertain concordance between care received and patients' stated goals.	98% of individuals who wished for comfort measures met their preferences. 65% percent of individuals who wished to be cared for at home received care at home. Nearly 40% of all individuals who opted to die at home achieved their wishes, whereas 76% of those who opted for home or hospital and home or hospice had their preferences fulfilled.
Turley, M., Wang, S., Meng, D., Kanter, M. H., & Garrido, T. (2016). An information model for automated assessment of concordance between advance care preferences and care delivered near the end of life. <i>Journal of the American Medical Informatics Association</i> , 23(e1), e118-124. https://doi.org/10.1093/jamia/ocv149	US, inpatient	388 patients aged 65 years or older from a Southern California medical center, who passed away during or after an inpatient event between January 1st and September 30th, 2013.	A 2016 population-based assessment of concordance between documented patient preferences (captured through advance care directive forms, POLSTs, code status orders, and powers of attorney) and end-of-life care events (captured by procedure or medication codes in the EHR).	All patient-level preference and care event data were used to create binary matching values for care events and the 15 preference domains. Each event was automatically evaluated in relation to the patient's most recently documented care preference. When events and the most recently documented preference matched, care was coded as concordant. An information model successfully assessed concordance between patient preferences and the end-of-life care received. Among 388 patients, 72% (278) of patients experienced only preference-concordant care events, 13% (50) experienced at least one preference-discordant care event,

Concordance between patient preferences and patient goals: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				and 15% (60) experienced no preference-related care events.
Unroe, K. T., Hickman, S. E., & Torke, A. M. (2016). Care Consistency with Documented Care Preferences: Methodologic Considerations for Implementing the "Measuring What Matters" Quality Indicator. <i>Journal of Pain and Symptom Management</i> , 52(4), 453-458. https://doi.org/10.1016/j.jpainsymman.2016.04.015	US, non-specific	Non-specific end-of-life patients.	Brief methodologic report describing how care consistency with documented care preferences has been measured in research on patients near the end of life. This article outlines challenges and provides recommendations regarding the measurement of "care consistency with documented care preferences," a quality indicator in the Measuring What Matters (MWM) project of the American Academy of Hospice and Palliative Medicine (AAHPM) and Hospice and Palliative Nurses Association (HPNA).	Effective concordance measurement requires documentation of specific treatment preferences in the medical record (in a consistent format and location), regular review to reflect current preferences as clinical conditions change over time, and a consistent measurement approach to comparing within and among providers.

Concordance between patient/proxy report and medical/clinical determinations of symptom management

Concordance between patient/proxy and medical/clinical determinations of symptom management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Hanson, L. C., Zimmerman, S., Song, M. K., Lin, F. C., Rosemond, C., Carey, T. S., & Mitchell, S. L. (2017). Effect of the Goals of Care Intervention for Advanced Dementia: A Randomized Clinical Trial. <i>JAMA Internal Medicine</i> , 177(1), 24-31. https://doi.org/10.1001/jamainternmed.2016.7031	US, nursing home	302 dyads of persons within 60-minutes of Chapel Hill, NC with advanced dementia and family decision makers, enrolled between April 2012 and September 2014.	A single-blind cluster randomized trial, comparing a Goals of Care (GOC) intervention (consisting of a video decision aid and structured care plan meeting for family decision makers for persons with advanced dementia) to a control.	The GOC decision aid intervention was effective to improve end-of-life communication for nursing home residents with advanced dementia. However, family ratings of treatment consistent with preferences, symptom management, and quality of care did not differ between the control and intervention group — suggesting that improved communication does not necessarily change goal concordance or clinical experiences.

Concordance between patient/proxy and medical/clinical determinations of symptom management: Literature review tables

<p>Khandelwal, N., Curtis, J. R., Freedman, V. A., Kasper, J. D., Gozalo, P., Engelberg, R. A., & Teno, J. M. (2017). How Often Is End-of-Life Care in the United States Inconsistent with Patients' Goals of Care? <i>Journal of Palliative Medicine</i>, 20(12), 1400-1404. https://doi.org/10.1089/jpm.2017.0065</p>	<p>US, multiple</p>	<p>1212 family members were interviewed, representing (when weighted) 4.8 million decedents.</p>	<p>Retrospective secondary analysis of data from the National Health and Aging Trends Study (NHATS), a prospective nationally representative survey of Medicare beneficiaries in the United States aged 65 and older that began in 2011. NHATS last month of life interview, which includes validated measures of perceptions of quality of care in terms of symptom management, emotional support, communication and decision making, and overall ratings of care. For perceptions of symptom management, respondents were asked whether the decedent had pain, dyspnea, anxiety, or feelings of sadness. If present, they were asked how much help the decedent received with the symptom. A dichotomized variable for unmet needs for each symptom was created and defined as either having unmet needs or not.</p>	<p>Of the 12.6% of family members who reported that their decedent received care inconsistent with their goals, 56.5% reported unmet need for addressing sadness/anxiety among those reporting symptoms; 30.5% reported unmet need for pain management among those reporting pain; and 27.5% reported unmet need for dyspnea management among those reporting dyspnea.</p> <p>*This study relies solely on anecdotal report and does not include clinical determinations that symptom management goals were achieved.</p>
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Concordance between patient and proxy preferences for symptom management

Concordance between patient and proxy preferences for symptom management: Literature review tables

Citation	Setting	Population	Design	Main Findings
<p>Chan HY, et al. (2018). "Effects of a nurse-led post-discharge advance care planning program for community dwelling patients nearing the end of life and their family members: a randomized controlled trial." <i>Int J Nurs Stud</i>. Nov;87:26-33.</p>	<p>Setting unspecified.</p>	<p>A total of 230 dyads comprising community-dwelling patients screened by the Gold Standards Framework Prognostic Indicator Guidance and their designated family members.</p>	<p>A two-arm parallel-group randomized controlled trial.</p>	<p>After six months, the experimental group exhibited a greater increase in dyadic congruence regarding various end-of-life care preferences than the control group. This study showed that a nurse-led structured advance care planning program could effectively improve dyadic congruence regarding end-of-life care preferences.</p>
<p>Jung, M. Y., & Matthews, A. K. (2021). A Systematic Review of Clinical Interventions Facilitating</p>	<p>Multiple</p>	<p>N/A</p>	<p>A systematic review (A search of MEDLINE via PubMed, CINAHL, Scopus, Embase, and PsycINFO as</p>	<p>Provider-led communication interventions show promise for improving dyadic end-of-life care</p>

Concordance between patient and proxy preferences for symptom management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
<p>End-of-Life Communication Between Patients and Family Caregivers. <i>American Journal of Hospice and Palliative Medicine</i>, 38(2), 180-190. https://doi.org/10.1177/1049909120929323</p>			<p>well as a manual search for additional articles on Google Scholar without date restrictions.) based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines that assessed congruence between patients' end-of-life care preferences and those identified by the nominated family caregivers. Various instruments were used to measure communication outcomes including the patient-specific Statement of Treatment Preferences, Goals of Care documents, and Life-Support Preferences Questionnaires. Of 2955 articles retrieved, 8 met the eligibility criteria. They summarize evidence of the benefit of psychoeducational interventions on increasing the congruence of end-of-life care preferences between patients and family caregivers.</p>	<p>preference congruence (determined by the number of scenarios for which the dyads selected the same response option for hypothetical scenarios).</p>
<p>Kricke, G., Woods, D., Arbaje, A., & Jordan, N. (2019). Nonsymptomatic Factors More Strongly Associated with High-Quality End-of-Life Care than Symptomatic Factors for Community-Dwelling Older Adults with Multiple Chronic Conditions. <i>Journal of Palliative Medicine</i>, 22(5), 522-531. https://doi.org/10.1089/jpm.2018.0389</p>	<p>US, un-specified home care</p>	<p>477 designated proxies of deceased Medicare beneficiaries who had multiple chronic conditions at the end of life.</p>	<p>Retrospective cross-sectional cohort analysis of secondary data derived from the National Health and Aging Trends Study (NHATS), Last Month of Life Interview.</p> <p>Weighted bivariate analyses determined unadjusted relationships between overall care and end-of-life quality. Weighted unadjusted and adjusted multiple logistic regression tested the association of ratings of overall care quality with the perception of quality.</p>	<p>Symptom management was unrelated to the overall quality rating. There was no statistical relationship between proxies' perception of decedents' symptom management and their overall end-of-life care quality rating. A possible explanation is that proxies may expect pain and breathing troubles to be part of the dying experience and may therefore be more tolerant of unmet symptom management needs when rating overall care quality.</p> <p>*This study analyzed proxies' perceptions of symptom</p>

Concordance between patient and proxy preferences for symptom management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				management but did not compare that to decedents' preferences when determining concordance.

Appendix III-C: Spiritual Care Literature Review Tables

Evidence or guidelines for spiritual assessment and care as conducted a spiritual counselor

Evidence or guidelines for spiritual assessment and care as conducted by a spiritual counselor: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Jeuland, J., Fitchett, G., Schulman-Green, D., & Kapo, J. (2017). Chaplains Working in Palliative Care: Who They Are and What They Do. <i>Journal of Palliative Medicine</i> , 20(5), 502-508. https://doi.org/10.1089/jpm.2016.0308	US, hospital-based palliative care	382 full-time hospital-based chaplains from four national professional chaplain organizations who spent 15% or more of their working hours with palliative care teams	National online survey to describe integration of chaplains into palliative care teams.	Half of chaplains surveyed frequently participated in palliative care rounds. Primary chaplain activities were relationship building (76%), care at the time of death (69%), and helping patients with existential issues or spiritual distress (49%).
Khraisat, O. M., Hamdan, M., & Ghazzawwi, M. (2017). Palliative Care Issues and Challenges in Saudi Arabia: Knowledge Assessment Among Nursing Students. <i>Journal of Palliative Care</i> , 32(3-4), 121-126. https://doi.org/10.1177/0825859717743229	Saudi Arabia, non-specific setting	154 Nursing students enrolled in a Riyadh nursing college.	Descriptive survey to assess nursing students' knowledge about palliative care	The mean score on psychological and spiritual care (3 items) was low: 1.74 (SD: 0.84) of 3 (maximum score). 77% of students reported they did not receive palliative care education.
Kobayashi, R., & McAllister, C. A. (2016). Hospice Core Professions' Views on Interdisciplinary Teams: A Qualitative Investigation. <i>Journal of Social Work in the End of Life and Palliative Care</i> , 12(3), 214-230. https://doi.org/10.1080/15524256.2016.1201565	US, Hospice	13 physicians, 19 nurses, 16 social workers, and 15 spiritual care providers from the 2008 Michigan Hospice and Palliative Care Directory	Exploratory qualitative approach using semi structured interviews to understand perspectives of hospice team members and their professional role within the team.	Of all the professions, spiritual care providers focused the most on their specific knowledge (including their training in different religions and traditions, spiritual values, compassion) as a strength useful to patients, families, other team members and teams as a whole.
O'Brien, M. R., Kinloch, K., Groves, K. E., & Jack, B. A. (2019). Meeting patients' spiritual needs during end-of-life care: A qualitative study of nurses' and healthcare professionals' perceptions of spiritual care training. <i>Journal of</i>	England, multi-setting	21 generalist and specialist nursing and healthcare professionals from north and southwest England who had spiritual care training.	Qualitative semi-structured interviews to explore nurses and healthcare professionals' perceptions of spiritual care training on their clinical roles.	Nurses and healthcare providers who received spiritual care training were better equipped to recognize when patients might be spiritually distressed, and thus better prepared to assess and explore patients' spiritual needs.

Evidence or guidelines for spiritual assessment and care as conducted by a spiritual counselor: Literature review tables				
Citation	Setting	Population	Design	Main Findings
<i>Clinical Nursing</i> , 28(1-2), 182-189. https://doi.org/10.1111/jocn.14648				
Wittenberg, E., Ragan S.L., & Ferrell B. (2017). Exploring Nurse Communication About Spirituality. <i>American Journal of Hospice and Palliative Medicine</i> , 36(6), 566-571. https://doi.org/10.1177/1049909116641630	US, multi-setting oncology	57 oncology nurses who attended a Communication, Orientation, & Options, Mindful Communication, Family caregivers, Openings, Relating and Team [COMFORT] training.	Qualitative survey to explore the spiritual care experience of oncology nurses.	Oncology nurses reported having received little or no training on communication about spirituality and relied on their own spiritual knowledge to respond to patients' needs. In most cases, the patient rather than the nurse-initiated conversations about spirituality.
Goodhead, A., Speck, P., & Selman, L. (2016). 'I think you just learnt as you went along' - community clergy's experiences of and attitudes towards caring for dying people: A pilot study. <i>Palliative Medicine</i> , 30(7), 674-683. https://doi.org/10.1177/0269216315625860	England, non-setting specific	14 community-based clergy in two south east London boroughs from 6 Christian denominations	Qualitative interviews semi-structured and a self-completed Death Anxiety Questionnaire	Clergy lacked any formal training in palliative care and had little experience of working with or relating to palliative care providers.
Wittenberg, E., Ferrell, B., Goldsmith, J., & Buller, H. (2016). Provider Difficulties with Spiritual and Forgiveness Communication at the End of Life. <i>American Journal of Hospice and Palliative Medicine</i> , 33(9), 843-848. https://doi.org/10.1177/1049909115591811	US, multi-setting	124 healthcare providers (76% nurses, 14% social workers, 10% other) who attended educational courses.	Cross-sectional survey measuring the frequency and initiation of communication about spirituality and forgiveness with patients/families, the perceived difficulty in communication across topics, and preparation and resources for these discussions.	Healthcare providers reported difficulty with spiritual communication when talking with family after the death of a patient and in conducting a spiritual history with a patient.
Amonoo, H. L., Harris, J. H., Murphy, W. S., Abrahm, J. L., & Peteet, J. R. (2020). The Physician's Role in Responding to Existential Suffering: What Does It Mean to Comfort Always? <i>Journal of Palliative Care</i> , 35(1), 8-12. https://doi.org/10.1177/0825859719839332	US, Inpatient	70-year-old cancer patient with metastatic cancer recurrence and pneumonia	Case study focused on how palliative care clinicians can explore themes of existential suffering	The psychiatry team's identification of and response to a patient's existential distress at the end of life highlighted the barriers that palliative care clinicians face in helping such patients, such as the inability to identify existential suffering, lack of training in how to address it, and time constraints.

Evidence or guidelines for spiritual assessment and care as conducted by a spiritual counselor: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Anandarajah, G., Roseman, J., Lee, D., & Dhandhanian, N. (2016). A 10-Year Longitudinal Study of Effects of a Multifaceted Residency Spiritual Care Curriculum: Clinical Ability, Professional Formation, End of Life, and Culture. <i>Journal of Pain and Symptom Management</i> , 52(6), 859-872.e851. https://doi.org/10.1016/j.jpainsymman.2016.06.006	US, non-setting specific	49 physicians from a family medicine residency in New England	Longitudinal qualitative study (interviews) to examine effects of a required residency curriculum that emphasized inclusive, patient centered, spiritual care.	Physicians who received training in end-of-life spiritual care during residency reported fewer barriers to addressing patients' spiritual needs compared to those who did not receive the training and reported positive effects of the training even after 8 years.
Balboni, M. J., Sullivan, A., Enzinger, A. C., Smith, P. T., Mitchell, C., Peteet, J. R., Tulskey, J. A., VanderWeele, T., & Balboni, T. A. (2017). U.S. Clergy Religious Values and Relationships to End-of-Life Discussions and Care. <i>Journal of Pain and Symptom Management</i> , 53(6), 999-1009. https://doi.org/10.1016/j.jpainsymman.2016.12.346	US, non-setting specific	1,055 clergy randomly sampled from a third-party business file to include all houses of worship in the US	Nationally representative mailed survey on clergy beliefs and practices	Life-prolonging religious values and lower medical knowledge were associated with fewer clergy-congregant end-of-life conversations (e.g., about considering hospice, stopping treatment, and forgoing future treatment). The absence of a clergy-congregant hospice discussion was associated with less hospice and more ICU care in the final week of life.
Yang, G., Tan, Y., Cheung, Y., Lye, W., Lim, S., Ng, W., . . . Neo, P. (2017). Effect of a spiritual care training program for staff on patient outcomes. <i>Palliative and Supportive Care</i> , 15(4), 434-443. doi:10.1017/S1478951516000894	Singapore, hospital-based and home-based palliative care	253 patients newly referred to either inpatient or home-based palliative care with less than 5 visits from a palliative care professional and an estimate survival or more than one month.	Cluster-controlled trial of a spiritual care training program for palliative care doctors and nurses.	Patients whose clinicians received spiritual care training reported improved quality of life, but there was no difference in patient spiritual well-being between the groups.
Smyre, C. L., Tak, H. J., Dang, A. P., Curlin, F. A., & Yoon, J. D. (2018). Physicians' Opinions on Engaging Patients' Religious and Spiritual Concerns: A National Survey. <i>Journal of Pain and Symptom Management</i> , 55(3), 897-905. https://doi.org/10.1016/j.jpainsymman.2017.10.015	US, non-setting specific	1,156 physicians from a stratified random sample generated from the American Medical Association Physician Masterfile representing varied specialties. 05% were geriatrics/hospice and palliative care	Survey exploring what physicians believe about the relative importance of addressing patient's spiritual concerns at the end of life and the appropriateness of interventions addressing those concerns.	Most physicians believed it was good practice to address patients' spiritual concerns at the end of life. More religious physicians were more likely to see spiritual care as essential to good medical practice and feel it appropriate to always encourage patients to talk to a chaplain. Overall, physicians endorsed a limited role in the

Evidence or guidelines for spiritual assessment and care as conducted by a spiritual counselor: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				provision of spiritual care, although opinions varied based on physicians' religious characteristics.
Van de Geer, J., Groot, M., Andela, R., Leget, C., Prins, J., Vissers, K., & Zock, H. (2017). Training hospital staff on spiritual care in palliative care influences patient-reported outcomes: Results of a quasi-experimental study. <i>Palliative Medicine</i> , 31(8), 743-753. https://doi.org/10.1177/0269216316676648	Netherlands, hospital	8 multidisciplinary teams in six hospitals on regular wards for 85 both curative and palliative patients	Quasi-experimental (pragmatic controlled trial) to measure the effects of a spiritual care training on patients reports of their perceived care and treatment.	Spiritual care training implemented by healthcare chaplains for multidisciplinary palliative care teams increased healthcare professionals' attention to patients' spiritual and existential needs, but there was no effect on patients' spiritual distress.
English, W. J. & Picchi, T. (2019). Honoring the Spiritual Dimension of Palliative Care: Development of a Practical Model Based on the Goals of Care Consultation. <i>Supportive Care Coalition</i> . Retrieved from: https://static1.squarespace.com/static/59dd966ee45a7c496fd4d1be/t/5b887b2770a6ade504da7e1a/1535671087841/Spirituality+Booklet.pdf	US, multi-setting palliative care	20 palliative care teams from Supportive Care Coalition member organizations.	Evaluation of training to create a practical model for interdisciplinary palliative care team members to address spiritual concerns of patients.	A model for chaplains to cross-train physicians and nurses to address spiritual suffering improved charting and the incorporation of desired behaviors, and the project had a lasting impact on the palliative care teams themselves. By focusing on their presence as caregivers and learning specific skills designed assess spiritual concerns, palliative care teams can be more attuned to spiritual suffering. Clinicians who were initially skeptical or considered themselves to be non-religious came to value their collaboration with chaplains and reported increased confidence in inquiring about spiritual concerns of their patients.

Spiritual care outcomes for hospice and palliative care patients

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Bakitas, M. A., Dionne-Odom, J. N., Ejem, D. B., Wells, R., Azuero, A., Stockdill, M. L., Keebler, K.,	US, outpatient and community	415 patients with heart failure at a large Southeastern US academic	Single blind randomized clinical trial to determine the effect of an early palliative care telehealth intervention	Patients receiving ENABLE CHF-PC (Educate, Nurture, Advise, Before Life Ends Comprehensive Heartcare

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
<p>Sockwell, E., Tims, S., Engler, S., Steinhauser, K., Kvale, E., Durant, R. W., Tucker, R. O., Burgio, K. L., Tallaj, J., Swetz, K. M., & Pamboukian, S. V. (2020). Effect of an Early Palliative Care Telehealth Intervention vs Usual Care on Patients with Heart Failure: The ENABLE CHF-PC Randomized Clinical Trial. <i>JAMA Internal Medicine</i>, 180(9), 1203-1213. https://doi.org/10.1001/jamainternmed.2020.2861</p>		<p>tertiary medical center and a Veterans Affairs medical center</p>		<p>for Patients and Caregivers) had improved Kansas City Cardiomyopathy Questionnaire (KCCQ) scores and improved Functional Assessment of Chronic Illness Therapy–Palliative (FACIT-Pal-14) scores. There was no effect on mood or quality of life.</p>
<p>Brożek, B., Fopka-Kowalczyk, M., Łabuś-Centek, M., Damps-Konstańska, I., Ratajska, A., Jassem, E., Larkin, P., & Krajnik, M. (2019). Dignity Therapy as an aid to coping for COPD patients at their end-of-life stage. <i>Advances in Respiratory Medicine</i>, 87(3), 135-145. https://doi.org/10.5603/ARM.a2019.0021</p>	<p>Poland, hospital and community palliative care</p>	<p>11 patients in the terminal phase of COPD who were hospitalized at a Polish hospital's Department of Pneumology</p>	<p>Post-treatment questionnaire to assess patient satisfaction with dignity therapy intervention.</p>	<p>After receiving Dignity Therapy, 8 of 10 patients reported the therapy improved their mental well-being. Patients valued the method and form of communication.</p>
<p>Beck, A., Cottingham, A. H., Stutz, P. V., Gruber, R., Bernat, J. K., Helft, P. R., Wilhelm, L., Schmidt, K., Stout, M. E., Willard, C., & Johns, S. A. (2019). Abbreviated dignity therapy for adults with advanced-stage cancer and their family caregivers: Qualitative analysis of a pilot study. <i>Palliative and Supportive Care</i>, 17(3), 262-268. https://doi.org/10.1017/s1478951518000482</p>	<p>US, outpatient oncology clinic</p>	<p>16 patients with advanced-stage cancer from the Indiana University Simon Cancer Center</p>	<p>Qualitative analysis of post-intervention interviews evaluating use of abbreviated dignity therapy.</p>	<p>Abbreviated Dignity Therapy promoted (1) self-expression, (2) connection with loved ones, (3) sense of purpose, and (4) continuity of self. Participants observed that leading the development of their legacy projects promoted independent reflection, autonomy, and opportunities for family interaction when reviewing and discussing the projects.</p>
<p>Byrne, C. M., & Morgan, D. D. (2019). Patterns of religiosity, death</p>	<p>Community hospice, New Zealand</p>	<p>22 Waipuna Hospice patients with end stage disease, mainly cancer.</p>	<p>Cross-sectional study with 3 valid questionnaires: The religious</p>	<p>Systematic spiritual assessment for all patients, not just those with a</p>

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
<p>anxiety, and hope in a population of community-dwelling palliative care patients in New Zealand—What gives hope if religion can't? <i>American Journal of Hospice and Palliative Medicine</i>®, 37(5), 377–384. https://doi.org/10.1177/1049909119891148</p>			<p>Commitment Inventory, the Death and Dying Distress Scale, and the Hospice Herth Index. Surveys were completed by patients at home.</p> <p>Explored the factors triggering distress and whether religiosity is protective against death anxiety.</p>	<p>declared religious faith, may have a role in managing death anxiety at the end of life.</p> <p>There was a small negative correlation between death anxiety and hope, and a strong correlation between religiosity and hope (Pearson Correlation Coefficient +0.75).</p> <p>Fear of being a burden, impact of one's death on loved ones, and fear of being in pain were the three highest scoring questions, indicating they were painful for most people to discuss.</p>
<p>Chen, J., You, H., Liu, Y., Kong, Q., Lei, A., & Guo, X. (2021). Association between spiritual well-being, quality of life, anxiety and depression in patients with gynaecological cancer in China. <i>Medicine (Baltimore)</i>, 100(1), e24264. https://doi.org/10.1097/md.00000000000024264</p>	China, hospital oncology clinic	705 patients with gynecological cancer from West China Second Hospital of Sichuan University	Cross-sectional study examining the association between spiritual well-being with quality of life, anxiety, and depression	Spiritual well-being was positively correlated with functioning scales and global health status, and negatively correlated with anxiety and depression.
<p>Guo, Q., Chochinov, H. M., McClement, S., Thompson, G., & Hack, T. (2018). Development and evaluation of the Dignity Talk question framework for palliative patients and their families: A mixed-methods study. <i>Palliative Medicine</i>, 32(1), 195-205. https://doi.org/10.1177/0269216317734696</p>	Canada, inpatient palliative care	20 palliative patients, 20 family members, and 34 healthcare providers from two inpatient palliative care units in Winnipeg	Mixed methods to assess use of Dignity Talk, and a self-administered question list designed to prompt end-of-life conversations, adapted from the Dignity Therapy question framework	Participants felt Dignity Talk (a self-administered question list designed to prompt end-of-life conversations, adapted from the Dignity Therapy question framework) would be valuable in promoting conversations, enhancing family connections and relationships, enhancing patient sense of value and dignity, promoting effective interaction, and attending to unfinished business.

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Hasegawa, T., Kawai, M., Kuzuya, N., Futamura, Y., Horiba, A., Ishiguro, T., Yoshida, T., Sawa, T., & Sugiyama, Y. (2017). Spiritual Well-Being and Correlated Factors in Subjects with Advanced COPD or Lung Cancer. <i>Respiratory Care</i> , 62(5), 544-549. https://doi.org/10.4187/respcare.05282	Japan, hospital	96 patients with COPD or lung cancer	Cross-sectional study to determine the factors associated with spiritual well-being and compare levels of spiritual well-being between patients with COPD and inoperable lung cancer.	Patients with advanced COPD experienced spiritual well-being similar to that of subjects with inoperable lung cancer. Dyspnea score was significantly associated with spiritual well-being in subjects with COPD, and subjects with COPD appeared to have less support than those with lung cancer.
Julião, M., Oliveira, F., Nunes, B., Carneiro, A. V., & Barbosa, A. (2017). Effect of dignity therapy on end-of-life psychological distress in terminally ill Portuguese patients: A randomized controlled trial. <i>Palliative and Supportive Care</i> , 15(6), 628-637. https://doi.org/10.1017/s1478951516001140	Portugal, inpatient palliative care	80 Patients with a life-threatening disease with a prognosis of 6 months or less	Nonblinded randomized controlled trial to determine the influence of dignity therapy on demoralization syndrome, desire for death, and sense of dignity.	Dignity Therapy was associated with significant decreases in demoralization syndrome and in desire for death prevalence compared with standard care.
McPhail, P., Sandhu, H., Dale, J., & Stewart-Brown, S. (2018). Acupuncture in hospice settings: A qualitative exploration of patients' experiences. <i>European Journal of Cancer Care</i> , 27(2). https://doi.org/10.1111/ecc.12802	Hospice United Kingdom	18 hospice patients from 3 hospices who currently receive or recently received hospice-based acupuncture. Mostly cancer patients	Qualitative study using semi-structured interviews to understand the experience of acupuncture in the hospice setting.	One-third (when defining spirituality by mention of the spirit and one of its variants) to more than one half of participants (when more broadly defining spirituality to include words like "enlightenment" "faith" and "miracle"), felt acupuncture positively affected their spiritual well-being.
Rego, F., Gonçalves, F., Moutinho, S., Castro, L., & Nunes, R. (2020). The influence of spirituality on decision-making in palliative care outpatients: a cross-sectional study. <i>BMC Palliative Care</i> , 19(1), 22. https://doi.org/10.1186/s12904-020-0525-3	Portugal, outpatient palliative care	95 cancer patients from two oncology institutes receiving palliative care.	Cross-sectional study using questionnaires and semi-structured interviews to explore the influence of spirituality on the perception of healthcare decision making.	Patients who were able to implement their decision, compared with others, showed higher scores on the Emotional Well-being, General Quality of life, Meaning/Peace, Faith and Spiritual Well-being subscales, as well as on the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT-Sp) total scale. Higher spiritual wellbeing was

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				associated with lower levels of uncertainty, feeling informed and supported, higher satisfaction with the choice made and lower decisional conflict.
Rudilla, D., Galiana, L., Oliver, A., & Barreto, P. (2016). Comparing counseling and dignity therapies in home care patients: A pilot study. <i>Palliative and Supportive Care</i> , 14(4), 321-329. https://doi.org/10.1017/s1478951515001182	Spain, home-care unit palliative care	75 patients admitted to the home-care unit of General Hospital University Valencia for palliative treatment with advanced/terminal illness and an interest in dignity	Pilot randomized controlled trial to examine the effects of DT and counseling.	Both counseling and Dignity Therapy improved well-being overall, but patients who received DT had worse outcomes related to depression, resilience, and anxiety compared to counseling.
Scarton, L., Oh, S., Sylvera, A., Lamonge, R., Yao, Y., Chochinov, H., Fitchett, G., Handzo, G., Emanuel, L., & Wilkie, D. (2018). Dignity Impact as a Primary Outcome Measure for Dignity Therapy. <i>American Journal of Hospice and Palliative Medicine</i> , 35(11), 1417-1420. https://doi.org/10.1177/1049909118777987	US, palliative care (home and hospital based) and home-based hospice care	326 patients with life expectancy of 6 months or less receiving palliative a care in a hospital or community setting as an affiliated recruitment site	Secondary analysis of posttest data from a 3-arm randomized controlled trial to examine the properties of a new measure of dignity impact.	Patients receiving Dignity Therapy had a significantly higher Dignity Impact score than those in usual care. This is consistent with the DT focus on meaning making, preparation for death, and life-completion tasks.
Soroka, J. T., Collins, L. A., Creech, G., Kutcher, G. R., Menne, K. R., & Petzel, B. L. (2019). Spiritual Care at the End of Life: Does Educational Intervention Focused on a Broad Definition of Spirituality Increase Utilization of Chaplain Spiritual Support in Hospice? <i>Journal of Palliative Medicine</i> , 22(8), 939-944. https://doi.org/10.1089/jpm.2018.057	US, home care hospice	200 terminally ill patients admitted to home care hospice that is part of large Midwestern health system and their caregivers	Quasi-experimental quantitative study to better understand what contributes to spiritual support acceptance in hospice care.	Patients who received an educational intervention that explained hospice chaplain services and the evidence-based benefits of spiritual support were more likely to accept spiritual support compared to control patients. The variables associated with acceptance were age, primary diagnosis, and place of residence.
Vuksanovic, D., Green, H., Morrissey, S., & Smith, S. (2017). Dignity Therapy and Life Review for Palliative Care Patients: A	Australia, hospital-based and home-based palliative care	70 patients with life expectancy of less than 12 months	Randomized controlled trial to evaluate the legacy component of DT as compared with life review and waitlist control groups.	Compared to those in the Life Review and Waitlist Control groups, Dignity Therapy patients showed increased generativity and ego-

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Qualitative Study. <i>Journal of Pain and Symptom Management</i> , 54(4), 530-537.e531. https://doi.org/10.1016/j.jpainsymman.2017.07.016				integrity scores at study completion. There were no significant changes for dignity-related distress or physical, social, emotional, and functional well-being among the three groups.
Bernard, M., Strasser, F., Gamondi, C., Braunschweig, G., Forster, M., Kaspers-Elekes, K., Walther Veri, S., & Borasio, G. D. (2017). Relationship Between Spirituality, Meaning in Life, Psychological Distress, Wish for Hastened Death, and Their Influence on Quality of Life in Palliative Care Patients. <i>Journal of Pain and Symptom Management</i> , 54(4), 514-522. https://doi.org/10.1016/j.jpainsymman.2017.07.019	Switzerland, hospital-based and home-based palliative care	206 treated by a specialized palliative care team and with less than 6-month life expectancy	Cross-sectional, with face-to-face interviews exploring the relationship between spirituality, meaning in life, wishes for hastened death and psychological distress and their influence on quality of life.	Both spiritual well-being and meaning in life were negatively associated with anxiety and depression.
A. Bovero, P. Leombruni, M. Miniotti, G. Rocca and R. Torta. (2016). Spirituality, quality of life, psychological adjustment in terminal cancer patients in hospice. <i>Eur J Cancer Care (Engl)</i> .	Italy, inpatient hospice	115 patients with cancer and a life expectancy of 4 months or less	Correlational examination of the association between spirituality and quality of life, pain, anxiety, depression, and psychological adjustment to cancer.	Associations between FACIT-Sp and the subscales of FACT-G (physical, emotional, and social well-being) were not significant. Spirituality dimension was an important predictor of QoL even when other domains of well-being were controlled. The faith dimension was more associated with quality of life than the meaning/peace dimension in multivariate analysis (beta 0.722; <0.001)
Breitbart, W., Pessin, H., Rosenfeld, B., Applebaum, A. J., Lichenthal, W. G., Li, Y., Saracino, R. M., Marziliano, A. M., Masterson, M., Tobias, K., & Fenn, N. (2018). Individual meaning-centered psychotherapy for the treatment of psychological and existential distress: A randomized controlled	US, outpatient oncology	Patients with advanced cancer (Stage IV) being treated at outpatient clinic at Memorial Sloan Kettering	Randomized controlled trial examining the effectiveness of Individual meaning centered psychotherapy compared to supportive psychotherapy and enhanced usual care in improving spiritual well-being, quality of life, and psychological distress.	There were treatment effects for meaning-centered psychotherapy (IMCP) compared to supportive psychotherapy (SP) for quality of life, sense of meaning, spiritual well-being, anxiety, and desire for hastened death. The effect of IMCP was significantly greater than the effect of SP for quality of life and

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
trial in patients with advanced cancer. <i>Cancer</i> , 124(15), 3231-3239. https://doi.org/10.1002/cncr.31539				sense of meaning but not for the remaining study variables.
Delgado-Guay, M. O., Rodriguez-Nunez, A., De la Cruz, V., Frisbee-Hume, S., Williams, J., Wu, J., Liu, D., Fisch, M. J., & Bruera, E. (2016). Advanced cancer patients' reported wishes at the end of life: a randomized controlled trial. <i>Supportive Care in Cancer</i> , 24(10), 4273-4281. https://doi.org/10.1007/s00520-016-3260-9	US, inpatient palliative care	50 patients with advanced cancer treated at the MD Anderson Cancer Center	Randomized controlled trial to determine end-of-life wishes for patients with advanced cancer and compare patient's preference between the Go Wish card game and the list of wishes statement.	Patients completing the Go Wish card game (GWG) and/or the List of wishes/statements (LOS) most commonly wished to be at peace with God, to pray, and to have family present. Of patients exposed to both tests, 86 % felt the GWG instructions were clear, 90 % felt the GWG was easy to understand, 62 % preferred the GWG, 78 % felt the GWG did not increase their anxiety and 62 % agreed that having conversations about end-of-life priorities was beneficial. There was no difference in anxiety after GWG vs. after LOS.
Vermandere, M., Warmenhoven, F., Van Severen, E., De Lepeleire, J., & Aertgeerts, B. (2016). Spiritual history taking in palliative home care: A cluster randomized controlled trial. <i>Palliative Medicine</i> , 30(4), 338-350. https://doi.org/10.1177/0269216315601953	Belgium, home-based palliative care	99 patients with an incurable, life-threatening disease receiving care from one of 18 regional nursing offices expected to live 2 months or more	Cluster randomized controlled trial to investigate the effect of a structured spiritual history taking on spiritual wellbeing.	Patients who received structured spiritual history taking (ars moriendi model) among patients did not differ from control group patients on spiritual well-being, quality of life, pain, or patient-provider trust.
Sun, V., Kim, J. Y., Irish, T. L., Borneman, T., Sidhu, R. K., Klein, L., & Ferrell, B. (2016). Palliative care and spiritual well-being in lung cancer patients and family caregivers. <i>Psycho-oncology</i> , 25(12), 1448-1455. https://doi.org/10.1002/pon.3987	US, outpatient oncology	475 patients with lung cancer (stage I – IV) and 354 family caregivers receiving care from a comprehensive cancer center in Southern California	Two-group, prospective sequential, quasi-experimental trial testing the effectiveness of an interdisciplinary palliative care	Patients receiving an interdisciplinary palliative care intervention (four educational sessions, including one session focused on spiritual well-being) had better scores for the Meaning/Peace subscale of the FACIT-Sp-12 compared to patients who received usual care. Significant differences were also observed in favor of the intervention group for four specific

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				FACIT-Sp-12 items (feeling peace of mind, able to reach deep down for comfort, and sense of harmony within oneself).
Shin, D. W., Suh, S. Y., Kim, S. H., Park, J., Yoon, S. J., Kim, Y. J., Kang, B., Kwon, J. H., Park, Y., Park, K., Hui, D., Kim, H. J., Himchak, S., Lee, S. S., & Ahn, H. Y. (2018). Is spirituality related to survival in advanced cancer inpatients in Korea? <i>Palliative and Supportive Care</i> , 16(6), 669-676. https://doi.org/10.1017/s1478951517001031	South Korea, inpatient palliative care	Patients with advanced cancer admitted to seven palliative care units with estimated survival of less than 3 months.	Prospective multicenter study to determine whether spirituality was related to survival.	Spirituality was not related to survival time.
Pérez-Cruz, P. E., Langer, P., Carrasco, C., Bonati, P., Batic, B., Tupper Satt, L., & Gonzalez Otaiza, M. (2019). Spiritual Pain Is Associated with Decreased Quality of Life in Advanced Cancer Patients in Palliative Care: An Exploratory Study. <i>Journal of Palliative Medicine</i> , 22(6), 663-669. https://doi.org/10.1089/jpm.2018.034	Chile, clinic-based palliative care	208 patients with cancer with a short survival prognosis	Cross-sectional study to assess the association between spiritual pain and quality of life.	Spiritual pain was associated with lower quality of life.
Nguyen, H. Q., Ruel, N., Macias, M., Borneman, T., Alian, M., Becher, M., Lee, K., & Ferrell, B. (2018). Translation and Evaluation of a Lung Cancer, Palliative Care Intervention for Community Practice. <i>Journal of Pain and Symptom Management</i> , 56(5), 709-718. https://doi.org/10.1016/j.jpainsymman.2018.07.018	US, outpatient oncology	202 patients with non-small-cell lung cancer (Stage II – IV) and 122 caregivers of patients with non-small-cell lung cancer (Stage II – IV) that were able to complete a 3-month follow-up from 3 Kaiser Permanente Southern California sites.	Quasi-experimental multi-phase study to determine effects of a nurse-led palliative care intervention for patients with non-small cell lung cancer and the caregivers	Patients receiving a Lung Cancer Palliative Care Intervention had significant improvements in three (physical, emotional, and functional well-being) of the five QOL domains at one month that were sustained through three months compared to usual care. Social and spiritual well-being and general distress were similar between cohorts at baseline with no significant differences over three months.

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Gómez-Batiste, X., Mateo-Ortega, D., Lasmariás, C., Novellas, A., Espinosa, J., Beas, E., Ela, S., & Barbero, J. (2017). Enhancing psychosocial and spiritual palliative care: Four-year results of the program of comprehensive care for people with advanced illnesses and their families in Spain. <i>Palliative and Supportive Care</i> , 15(1), 98-109. https://doi.org/10.1017/s1478951516000857	Spain, Palliative care (hospital and home-based)	8,964 patients in palliative care with advanced chronic disease and 11,810 caregivers	Qualitative and quantitative (quasi-experimental, prospective, multicenter, single-group, and pretest/posttest) methods to describe results of the Comprehensive Care for Patients with Advanced Illnesses and their Families program.	Patients of psychosocial support teams (PSTs) comprised of psychologists, social workers, nurses, and other professionals (primarily physicians, but in some cases physiotherapists and chaplains), showed improvements in psychosocial and spiritual dimensions. Patients receiving the intervention had decreased anxiety and emotional distress and reported increased mood and meaning in life.
Ichihara, K., Ouchi, S., Okayama, S., Kinoshita, F., Miyashita, M., Morita, T., & Tamura, K. (2019). Effectiveness of spiritual care using spiritual pain assessment sheet for advanced cancer patients: A pilot non-randomized controlled trial. <i>Palliative and Supportive Care</i> , 17(1), 46-53. https://doi.org/10.1017/s1478951518000901	Japan, inpatient palliative care and inpatient hematology/oncology wards	46 patients with advanced cancer from two hospitals able to complete a three-week follow-up	Nonrandomized controlled trial to obtain preliminary knowledge to design a RCT to clarify the effects of spiritual care using the Spiritual Pain Assessment Sheet.	Patients receiving spiritual care using SpiPas (Spiritual Pain Assessment Sheet) maintained their total FACIT-Sp scores, while those in the control group had worsening scores. Group differences were observed in both peace/meaning and faith subscales. Moreover, the total Hospital Anxiety and Depression Scale (HADS) score was significantly improved in the intervention group compared with the control group. The anxiety subscale also improved significantly. No significant changes were observed in the depression subscale and the total Comprehensive Quality of Life Outcome (CoQoLo) score.
Kestenbaum, A., Shields, M., James, J., Hocker, W., Morgan, S., Karve, S., Rabow, M. W., & Dunn, L. B. (2017). What Impact Do Chaplains Have? A Pilot Study of Spiritual AIM for Advanced Cancer Patients in Outpatient Palliative Care. <i>Journal of Pain and Symptom Management</i> , 54(5), 707-714.	US, outpatient cancer center	31 patients with advanced cancer receiving care at an academic urban comprehensive cancer center and life expectancy of less than 12 months	Pre- post study to evaluate the feasibility and acceptability of chaplain delivered spiritual care using Spiritual AIM	Patients who received chaplain-delivered spiritual care, using the Spiritual Assessment and Intervention Model (Spiritual AIM), showed increases in the Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp-12) Faith subscale, the Mini-Mental Adjustment to Cancer (Mini- MAC)

Spiritual outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
https://doi.org/10.1016/j.jpainsymman.2017.07.027				Fighting Spirit subscale, and Mini-MAC Adaptive Coping factor.
Lau, C., Stilos, K., Nowell, A., Lau, F., Moore, J., & Wynnychuk, L. (2018). The Comfort Measures Order Set at a Tertiary Care Academic Hospital: Is There a Comparable Difference in End-of-Life Care Between Patients Dying in Acute Care When CMOS Is Utilized? <i>American Journal of Hospice and Palliative Medicine</i> , 35(4), 652-663. https://doi.org/10.1177/1049909117734228	Canada, inpatient hospital	Patients receiving oncology or general internal medicine services who were imminently dying and referred to the inpatient palliative care team for end-of-life care at a tertiary academic hospital	Retrospective chart review to assess whether there were differences in care of dying patients when comfort measure order sets were used compared to when they were not.	Patients who received the comfort measures order set (CMOS), a standardized framework for assessing imminently dying patients' symptoms and needs, had increased involvement of spiritual care compared to the those without CMOS. However, initiating CMOS did not result in a significant difference in patient distress around the time of death.
Astrow, A. B., Kwok, G., Sharma, R. K., Fromer, N., Sulmasy, D. P. (2018). Spiritual needs and perception of quality of care and satisfaction with care in hematology/medical oncology patients: A multicultural assessment. <i>Journal of Pain and Symptom Management</i> , 55(1), 56-64. https://doi.org/10.1016/j.jpainsymman.2017.08.009	US, outpatient hematology and oncology	727 patients with cancer that were racially/ethnically and religiously diverse from four hematology/medical oncology clinics in Brooklyn, NY	Observational study to assess spiritual needs in a racially/ethnically and religiously mixed sample of patients and examine the association between spiritual needs and quality of life and care satisfaction.	Most patients (79%) reported at least one spiritual need, and nearly half (48%) were comfortable having their physician inquire about spiritual needs. Patients who considered themselves "spiritual but not religious" reported a higher level of spiritual needs. Higher spiritual needs were associated with less satisfaction with care and lower perception of quality of care.
Center to Advance Palliative Care. (2021). <i>Clinical Training Recommendations for Physicians Caring for Patients with Serious Illness</i> . Retrieved from https://www.capc.org/clinical-training-recommendations-for-all-clinicians-caring-for-patients-with-serious-illness/clinical-training-recommendations-for-physicians-caring-for-patients-with-serious-illness/	US, non-specific	Non-specific	Guidance document (not peer-reviewed)	Recommends structural, process, and quality indicators of spiritual care, including suggested tools for measuring each.

Spiritual outcomes for hospice and palliative care patients: Literature review tables

Citation	Setting	Population	Design	Main Findings
<p>Sharma, V., Marin, D. B., Sosunov, E., Ozbay, F., Goldstein, R., & Handzo, G. F. (2016). The differential effects of chaplain interventions on patient satisfaction. <i>Journal of Health Care Chaplaincy</i>, 22(3), 85–101. https://doi.org/10.1080/08854726.2015.1133203</p>	<p>US, hospital</p>	<p>1,392 adults visited by chaplains, accounting for 1,431 hospitalizations</p>	<p>Prospective study / EHR review to identify skills that may be specific to chaplains, for whom no other healthcare team member has similar training.</p>	<p>Whether or not patients received a chaplain visit was significantly associated with all measures of patient satisfaction. Religious/Spiritual Interventions were significantly associated with 5 of 6 patient satisfaction items, while Psychosocial Interventions were associated with 4 of the 6 patient satisfaction items.</p>

Appendix III-D: Psychosocial Assessment and Care

Standards of practice for assessment and interventions for psychosocial care, including existing assessment items and tools.

Standards of practice for assessment and interventions for psychosocial care: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Cagle, J. G., Osteen, P., Sacco, P., & Jacobson Frey, J. (2016). Psychosocial Assessment by Hospice Social Workers: A Content Review of Instruments from a National Sample. <i>Journal of pain and symptom management</i> , 53(1), 40-48. https://doi.org/https://doi.org/10.1016/j.jpainsymman.2016.08.016	Cluster random sample of hospice agencies from 50 states.	105 hospice locations	Authors interviewed hospice social workers about the type of hospice they work at as well as what type of psychosocial assessment they use.	The researchers found the unique assessments screened for much of the same information: coping, bereavement, depression, and anxiety. There does not appear to be a single psychosocial assessment tool used across the majority of hospices.
Reese, D. J., & Csikai, E. L. (2018). Social Work Assessment and Outcomes Measurement in Hospice and Palliative Care. <i>American Journal of Hospice and Palliative Medicine</i> , 35(12), 1553-1564. https://doi.org/10.1177/1049909118788342	National sample of hospice social workers	203 hospice social workers	Authors interviewed social workers about the type of tool they use for psychosocial assessments.	Most social workers use a form developed by a non-social worker. Few conduct follow-up assessments or document outcomes.
Reese, D. J., Raymer, M., Orloff, S. F., Gerbino, S., Valade, R., Dawson, S., Butler, C., Wise-Wright, M., & Huber, R. (2006). The Social Work Assessment Tool (SWAT). <i>Journal of social work in end-of-life & palliative care</i> , 2(2), 65-95. https://doi.org/10.1300/J457v02n02_0	Hospice and palliative care program	14 hospice locations, 101 patients, 81 primary caregivers, 19 social workers	Authors conducted quantitative analysis on SWAT scores for patients receiving the assessment. Measured comparisons between first and second social worker visits.	Patients significantly improved their SWAT scores by the second visit, indicating that the tool is valid in determining psychosocial needs for patients.
Hansen, A. G., Martin, E., Jones, B., & Pomeroy, E. (2015). Social Work Assessment Notes: A Comprehensive Outcomes-Based Hospice Documentation System. <i>Health and Social Work</i> , 40(3), 191-200. https://doi.org/10.1093/hsw/hlv033	N/A	N/A	Social workers designed an integrated psychosocial patient and caregiver assessment.	SWAN is an additional social worker-developed tool that uses a detailed notes system to assess patients for psychosocial needs and associates the notes to a plan of care.

Citation	Setting	Population	Design	Main Findings
Hospice Care.42 CFR., § 418.114 (2021).	N/A	N/A	N/A	Federal rules surrounding social worker regulation in the hospice setting.
National Coalition for Hospice and Palliative Care (2018). Clinical Practice Guidelines for Quality Palliative Care (4 ed.). https://www.nationalcoalitionhpc.org/ncpl/	N/A	N/A	N/A	Guidelines from NCHPC about psychosocial assessment and care.
National Association of Social Workers (2004). NASW Standards for Palliative & End of Life Care. https://www.socialworkers.org/LinkClick.aspx?fileticket=xBmd58VwEhk%3D&portalid=0	N/A	N/A	N/A	Guidelines from NASW about psychosocial assessment and care.
National Hospice and Palliative Care Organization. (2018). Standards of Practice for Hospice Programs. https://www.nhpco.org/wp-content/uploads/2019/04/Standards_Hospice_2018.pdf	N/A	N/A	N/A	Guidelines from NHPCO about psychosocial assessment and care.

Psychosocial care outcomes for hospice and palliative care patients

Psychosocial care outcomes for hospice and palliative care patients: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Poort, H., Peters, M., Bleijenberg, G., Gielissen, M. F., Goedendorp, M. M., Jacobsen, P., Verhagen, S., & Knoop, H. (2017). Psychosocial interventions for fatigue during cancer treatment with palliative intent. <i>Cochrane Database em Reviews</i> , 7(7), Cd012030. https://doi.org/10.1002/14651858.CD012030.pub2	Systematic literature review in CENTRAL, MEDLINE, Embase, CINAHL, PsycINFO, and clinical trial registries.	535 adults over 18 undergoing cancer treatment with palliative intent	Authors reviewed articles to assess whether psychosocial treatment can reduce fatigue in patients undergoing treatment with palliative intent.	The authors failed to find statistically meaningful evidence to support psychosocial treatment as a tool to reduce fatigue in patients.
Rogers, J. G., Patel, C. B., Mentz, R. J., Granger, B. B., Steinhauer, K. E., Fiuzat, M., Adams, P. A., Speck, A., Johnson, K. S., Krishnamoorthy, A., Yang, H., Anstrom, K. J., Dodson, G. C.,	US, inpatient palliative care facilities	150 patients with heart failure in Kansas	Researchers presented 75 patients with their usual care (UC) and added an interdisciplinary palliative care intervention for the other 75. Used Kansas City Cardiomyopathy Questionnaire and the Functional	Results showed a significantly improved screening for depression and anxiety. Interdisciplinary treatment shows to greatly improve psychosocial symptoms in patients with heart failure.

Psychosocial care outcomes for hospice and palliative care patients: Literature review tables

Citation	Setting	Population	Design	Main Findings
<p>Taylor, D. H., Jr., Kirchner, J. L., Mark, D. B., O'Connor, C. M., & Tulskey, J. A. (2017). Palliative Care in Heart Failure: The PAL-HF Randomized, Controlled Clinical Trial. <i>Journal of the American College of Cardiology</i>, 70(3), 331-341. https://doi.org/10.1016/j.jacc.2017.05.030</p>			<p>Assessment of Chronic Illness Therapy (FACIT-Pal)</p>	
<p>Seow, H., Stevens, T., Barbera, L. C., Burge, F., McGrail, K., Chan, K. K. W., Peacock, S. J., Sutradhar, R., & Guthrie, D. M. (2021). Trajectory of psychosocial symptoms among home care patients with cancer at end-of-life. <i>Psychooncology</i>, 30(1), 103-110. https://doi.org/10.1002/pon.5559</p>	<p>Patients receiving home palliative care</p>	<p>27,295 patients with cancer.</p>	<p>Researchers studied the prevalence of psychosocial symptoms as a patient approaches death.</p>	<p>The study found that social decline, loneliness, and cognitive impairment were all prominent issues among patients.</p>

Appendix II-E: Medication Management Literature Review Table

Medication Management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Lundby, C., Graabæk, T., Ryg, J., Søndergaard, J., Pottegård, A., & Nielsen, D. S. (2020, Apr 2). "... Above All, It's a Matter of This Person's Quality of Life": Health Care Professionals' Perspectives on Deprescribing in Older Patients with Limited Life Expectancy. <i>Gerontologist</i> , 60(3), 439-449. https://doi.org/10.1093/geront/gnz116	Denmark, primary and secondary care settings	32 Healthcare professionals from both primary and secondary care, including family physicians, geriatricians, clinical pharmacologists, clinical pharmacists, nurses, and healthcare assistants.	Six qualitative focus group interviews were conducted using a semi-structured approach	Different groups of HCPs consider deprescribing an essential aspect of good care for older people with limited life expectancy and find that all HCPS play a crucial role on the deprescribing process, with FPs having the primary responsibility. To facilitate deprescribing among this population, however, collaboration between different HCPs should be improved.
Basri, D. S., DiScala, S. L., Brooks, A. T., Vartan, C. M., Silverman, M. A., & Quellhorst, J. (2018, Dec). Analysis of Inpatient Hospice Pharmacist Interventions Within a Veterans Affairs Medical Center. <i>Journal of pain & palliative care pharmacotherapy</i> , 32(4), 240-247. https://doi.org/10.1080/15360288.2019.1615025	US, Inpatient VA hospice	453 interventions during 185 patient care encounters were documented by clinical pharmacy specialist providers between 9/1/16 and 12/31/16.	A quality improvement project to quantify the number and types of pharmacy interventions implemented from the Pharmacists Achieve Results with Medications Documentation tool.	These interventions were documented across 32 unique patients with an average of 14.2 interventions made per patient during this period. CPS providers frequently intervened to optimize pharmacotherapy for the treatment of pain (42.38%), terminal agitation (5.08%), and nausea (3.97%). Additionally, CPS providers played a significant role in deprescribing of medication by discontinuing drugs no longer indicated (18.3%).
van Nordennen, R. T., Lavrijsen, J. C., Heesterbeek, M. J., Bor, H., Vissers, K. C., & Koopmans, R. T. (2016, Jun 1). Changes in Prescribed Drugs Between Admission and the End of Life in Patients Admitted to Palliative Care Facilities. <i>Journal of the American Medical Directors Association</i> , 17(6), 514-518. https://doi.org/10.1016/j.jamda.2016.01.015	Netherlands, inpatient hospice	155 adult patients with an estimated life expectancy of less than 3 months.	An observational multicenter cohort study in 7 inpatient palliative care facilities. The study was conducted from February 1, 2012, to January 1, 2013.	On average, patients were prescribed 6.1 drugs at admission and 4.6 drugs on the day of death. The prescription of analgesics, psycholeptics, and drugs for functional gastrointestinal disorders increased from admission until death. In general, these are drug classes prescribed for symptom control. All other drug classes decreased between admission and the day of death, including different drug classes for the treatment of comorbid disease, such as anticoagulants, beta-blocking

Medication Management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				<p>agents, drugs used in diabetes, and lipid-modifying agents.</p> <p>A reduction in the total amount of medication is seen between admission and death in the palliative care facilities. Although there is an increase in prescribed symptom-specific medication and a reduction in medication prescribed for comorbid disease, there are still patients dying with medication not used for symptom control. This increases pill burden and indicates that physicians need to develop guidelines and educational programs for decreasing medication for comorbidities at the end of life.</p>
<p>Han, C. J., Chi, N. C., Han, S., Demiris, G., Parker-Oliver, D., Washington, K., Clayton, M. F., Reblin, M., & Ellington, L. (2018, May). Communicating Caregivers' Challenges with Cancer Pain Management: An Analysis of Home Hospice Visits. <i>Journal of Pain and Symptom Management</i>, 55(5), 1296-1303. https://doi.org/10.1016/j.jpainsymman.2018.01.004</p>	US, home hospice	Family care givers of cancer patients in 4 geographically diverse US regions.	Using secondary data from audio recordings of hospice nurses' home visits, a deductive content analysis was conducted. We coded caregivers' pain management challenges and immediate nurses' responses to these challenges.	Results showed that the Dignity Therapy group scored higher on the Dignity Impact Scale, which measures a patient's feelings about preparation for death, life completion, and meaning-making.
<p>Mayahara, M., Wilbur, J., O'Mahony, S., & Breitenstein, S. (2017, Apr). E-Pain Reporter: A Digital Pain and Analgesic Diary for Home Hospice Care. <i>Journal of Palliative Care</i>, 32(2), 77-84. https://doi.org/10.1177/0825859717722466</p>	US, not-for profit community-based hospice agency	Caregivers and nurses were recruited from a not-for-profit community-based, hospice agency serving 350 patients daily. Caregivers needed to understand and speak English, be experienced in administering analgesics to hospice patients and 18 years of age or older. Inclusion criteria for the nurse advisory group were:	Using advisory group methods, 2 groups participated in converting a paper-based pain and analgesic diary into digital form and refining it. A caregiver advisory group that includes former lay hospice caregivers and a nurse advisory group that included hospice nurse case managers. Three two-hour advisory group meetings were held with each	Caregivers felt stressed about the administration of analgesics – primarily narcotics- due to lack of knowledge. They felt they did not know enough to manage analgesics but were forced to accept the responsibility. Despite their stress and lack of knowledge they did not communicate their concerns to the nurses. Nurses agreed that

Medication Management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
		individual was a registered nurse we experience in administering pain medication to home hospice patients	group (caregivers and nurses). Meetings were facilitated by a certified hospice and palliative care nurse and a research assistant.	caregivers often lacked adequate knowledge in administering analgesics but were not aware that caregivers struggled to communicate their concerns with the nurses. Caregivers in this study reported a reluctance to communicate with nurses between home visits regarding patient pain because they were not sure what to ask and they did not want to bother nurses.
Wilson, E., Caswell, G., Latif, A., Anderson, C., Faull, C., & Pollock, K. (2020, May 11). An exploration of the experiences of professionals supporting patients approaching the end of life in medicines management at home. A qualitative study. <i>BMC Palliative Care</i> , 19(1), 66. https://doi.org/10.1186/s12904-020-0537-z	UK, outpatient	Participants were a purposive sample of 40 community healthcare professionals (including general practitioners, pharmacists, and specialist palliative and community nurses for across two English counties.	Qualitative interview study with thematic analysis regarding the management of medicines towards the end of life.	<p>Healthcare professionals reported a variety of ways in which they tried to support patients to take medications as prescribed. Standard solutions offered included: rationalising the number of medications; providing different formulations; explaining what medications were for and how best to take them.</p> <p>In general, HCPs/ HCPs tended to focus on prescribing issues, rather than express awareness or curiosity about patient perspectives and experience of medicine taking. Some seemed resigned to deliberate or inadvertent failure on the part of patients to take medication as prescribed.</p> <p>Reviewing and rationalising medications was often seen as the first step to supporting effective medicines management. HCPs, especially nurses making home visits, recognised that several issues with medications stemmed from patients not fully understanding what their medications were, what</p>

Medication Management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				they were for, and how they should be taken. However, they also noted despite the involvement of multiple health professionals few took responsibility for overarching management of medications and many often did not ask the right questions or investigate the underlying causes of patients' issues with medication.
Arevalo, J. J., Geijteman, E. C. T., Huisman, B. A. A., Dees, M. K., Zuurmond, W. W. A., van Zuylen, L., van der Heide, A., & Perez, R. (2018, Feb). Medication Use in the Last Days of Life in Hospital, Hospice, and Home Settings in the Netherlands. <i>Journal of Palliative Medicine</i> , 21(2), 149-155. https://doi.org/10.1089/jpm.2017.0179	Netherlands, hospital, home and hospice.	Patients who died in hospital, hospice, or at home in three regions of the Netherlands.	Retrospective chart review of a convenience sample of patients who died in hospice, in hospital, or home. 180 charts were reviewed. 59 hospice records.	Patients who die an expected death receive many medications in the last week of life. The mean number of medications per patient was nine during the seven-day period before death and six on the day of dying.
Tjia, J., DeSanto-Madeya, S., Mazor, K. M., Han, P., Nguyen, B., Curran, T., Gallagher, J., & Clayton, M. F. (2019, Aug). Nurses' Perspectives on Family Caregiver Medication Management Support and Deprescribing. <i>Journal of Hospice and Palliative Nursing</i> , 21(4), 312-318. https://doi.org/10.1097/njh.0000000000000574	US, home hospice, inpatient hospice, and primary care settings.	Nurse of Advanced cancer patients from three hospice agencies and their referring hospital systems in New England.	Secondary qualitative analysis of 10 nurse interviews exploring views on medication management and deprescribing for advanced cancer patients. We used content analysis to compare reports of existing care practice to the theoretical needs of hospice FCGs based on Lau's framework for hospice caregiver medication management needs.	Regarding intervention content, nurses more commonly discussed providing education than skill building, and within education, nurses mentioned increasing knowledge and providing education for symptom knowledge as part of current clinical practice, more often than they mentioned providing education to increase medication knowledge. When nurses discussed promoting skill building, they primarily focused on symptom management, and less so on medication administration and organization.
Chi, N. C., Demiris, G., Pike, K. C., Washington, K., & Oliver, D. P. (2018, Apr). Pain Management	US, home hospice	15 hospice caregivers for hospice agencies in Washington state. Most were white and female, and a	Theory driven deductive content analysis of secondary data obtained from hospice family caregivers'	The study confirmed Kelley's framework that caregiver-centric and patient-centric issues can affect

Medication Management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Concerns from the Hospice Family Caregivers' Perspective. <i>American Journal of Hospice and Palliative Medicine</i> , 35(4), 601-611. https://doi.org/10.1177/1049909117729477		spouse/partner or adult child living with the patient.	interviews from a randomized clinical trial.	effective pain management. The study provides insights to health-care providers and researchers that family caregivers encounter several challenges, and there is a need to develop guidelines or educational tools to support family caregivers, ensuring that family caregivers can manage patients' pain effectively at home. Issues most frequently raised by the family caregivers in this study were caregiver's functional issues, caregiver's beliefs, pain assessment issues, caregiver-health-care system communication, and patients' inability to verbalize pain.
Dees, M. K., Geijteman, E. C. T., Dekkers, W. J. M., Huisman, B. A. A., Perez, R., van Zuylen, L., van der Heide, A., & van Leeuwen, E. (2018, Oct). Perspectives of patients, close relatives, nurses, and physicians on end-of-life medication management. <i>Palliative and Supportive Care</i> , 16(5), 580-589. https://doi.org/10.1017/s1478951517000761	UK, hospital, hospice, or primary care	Purposive sample of patients with less than 3 months of life expectancy, and for each patient their most involved close relative, a nurse, the medication specialist, and the general practitioner. Patients were recruited from a university hospital, a general hospital, two hospices, and the offices of general practitioners.	Empirical multicenter study with a qualitative approach, including in-depth interviews with patients, relatives, nurses, specialists, and general practitioners. 18 cases/76 interviews.	We found remarkable agreement in participants' perspectives about the roles of professionals in medication management. There was also agreement about the importance of the nurse's role as an intermediary between patients or relatives and physicians Good pharmacotherapeutic care must take into consideration the frailty, needs, wishes, and expectations of these patients. A guideline for providing such care is needed, one that favors a multidisciplinary and interdisciplinary approach that will encourage professionals to initiate timely conversations about the patient's wishes and expectations regarding end-of-life medication and decision-making participation. Such a guideline should support an interdisciplinary setting-transcendent approach to a strategy of medication management that

Medication Management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				reflects the patient's preferences and contributes to more appropriate medication use in palliative care.
Hay, B. B., Marcelin, J. N., & Buck, H. G. (2019, Jun). A Pilot to Improve the Pain Medication Education Experience in Hospice. <i>Journal of Hospice and Palliative Nursing</i> , 21(3), 207-214. https://doi.org/10.1097/njh.0000000000000511	US, 30-bed inpatient hospice and palliative care facility in the southeastern US.	363 patients and direct care staff	Examine whether implementation of an evidence based interprofessional staff protocol for educating hospice patients and families regarding pain medication side effects and management improved CAHPS survey pain indicators by 5% within 6 months. The Model of Improvement served as the framework for this QI project	An interim process evaluation finding of significant improvements in staff knowledge and confidence to effectively communicate with patients and families regarding pain medication side effects and a 6.6% increase in favorable responses to the CAHPS Survey indicator (understanding side effects) within 6 months. Findings suggest that improved communication regarding pain medication side effects and their management by an interdisciplinary team holds potential to improve the patient and family experience of care was an inpatient hospice setting as measures by the CAHPS Hospice Survey.
Huisman, B. A. A., Geijteman, E. C. T., Dees, M. K., Schonewille, N. N., Wieles, M., van Zuylen, L., Szadek, K. M., & van der Heide, A. (2020, May 13). Role of nurses in medication management at the end of life: a qualitative interview study. <i>BMC Palliative Care</i> , 19(1), 68. https://doi.org/10.1186/s12904-020-00574-5	Netherlands, hospital and home.	patients in the last phase of their live-in hospitals, and at home	76 semi-structured interviews were conducted with patients in the last phase of their lives, their informal caregivers, nurses, and physicians. Data was qualitatively analyzed using the constant comparative method. Assessed their perspectives on the role of nurses in medication management in patients in the last phase of their lives.	Nurses can and should play an important role in medication management at the end of life by informing, supporting, representing, and involving all relevant parties. Nurses should be reinforced by education and training to take up this role.
Joint Commission (2021). <i>Revision related to the CMS requirement for hospices</i> . The Joint Commission. Retrieved from https://www.jointcommission.org/-/media/tjc/documents/standards/pre	US, hospice	N/A	CMS requirements for participation	Joint Commission newly requires the interdisciplinary team to 1) determine the patient's and family's ability to safely and competently administer medications, and the hospice to, based on the patient's condition and assessed need,

Medication Management: Literature review tables				
Citation	Setting	Population	Design	Main Findings
publications/hospice_redeeming_pr_epub.pdf				provide training and education to the patient on safe and effective use of medication, and the identification, handling, and safe disposal of hazardous medications and infectious waste.
Christensen, K., & Poston, B. (2020, December 9, 2020). Dying Californians suffer harm and neglect from an industry meant to comfort them, Investigative Report. Los Angeles Times. Retrieved from https://www.latimes.com/california/story/2020-12-09/california-hospice-under-fire-mistreatment-patients	US, Hospice	California hospice patients	Newspaper article series on hospice care in California.	A patient was in extreme pain for two days before he died as a direct result of a hospice nurse failing to show that patient's family how to safely give the morphine
Center to Advance Palliative Care. (2021). <i>Clinical Training Recommendations for Physicians Caring for Patients with Serious Illness</i> . Retrieved July 29, 2021 from https://www.capc.org/clinical-training-recommendations-for-all-clinicians-caring-for-patients-with-serious-illness/clinical-training-recommendations-for-physicians-caring-for-patients-with-serious-illness/	US, non-specific palliative care	Patients with serious illness	Clinical training recommendations	Recommendations for physician caring for patients with serious illness includes consideration of de-prescribing as a component of medication management.

Appendix III-F: Other Recent Hospice Literature Review Table

General Hospice Overview: Literature review tables				
Citation	Setting	Population	Design	Main Findings
Rahman, A., Cardenas, V., Singleton, M., Zhu, Y., Kaur, T., & Enguidanos, S. (2021, Feb). What Consumers Say About Hospices in Online Reviews. <i>Journal of Palliative Medicine</i> , 24(2), 240-247. https://doi.org/10.1089/jpm.2019.0591	California hospice	Hospices identified from 2016 data from the California Office of Statewide Health Planning and Development that were not closed and had more than 3 Yelp reviews (67 hospices and 692 reviews).	Qualitative analysis of Yelp reviews on purposive sample of hospices, analyzed using a grounded theory approach.	<p>They found considerable overlap between the themes captured in Yelp and in Hospice Compare's care-giver survey items.</p> <p>Yelp reviews addressed a wider range of themes than Hospice Compare with "compassionate, caring staff" being the most frequent.</p> <p>Categories and themes</p> <ul style="list-style-type: none"> Patient caregiver relationship Compassionate and caring staff (299) Patient and family grateful to hospice (289) Communication (HC) (151) Respectfulness (HC) (51) Clinical Care Quality of patient care (136) Medication Management (125) Pain and symptom management (HC) (10) Provision of grief of bereavement counseling or support (79) Agency competency Timeliness or responsiveness of staff member (HC) (256) Comprehensiveness of services (63) Agency management (43) Staff professionalism Staff professionalism (124) Knowledgeable, skilled staff (97) Safety (8) Medical supplies and equipment Medical equipment and supplies (104)

General Hospice Overview: Literature review tables				
Citation	Setting	Population	Design	Main Findings
				HC survey items that did not appear in yelp: family training and provision of emotional and spiritual support.
Quigley, D. D., Parast, L., Haas, A., Elliott, M. N., Teno, J. M., & Anhang Price, R. (2020, Jun). Differences in Caregiver Reports of the Quality of Hospice Care Across Settings. <i>Journal of the American Geriatrics Society</i> , 68(6), 1218-1225. https://doi.org/10.1111/jgs.16361	2,636 US hospices	311,365 primary caregivers of patients who died in hospice.	Multilinear regression analysis of 2016 CAHPS Hospice Survey data to examine differences in scores by setting (home, nursing home, hospital, freestanding hospice inpatient unit, and assisted living facility)	Caregivers of decedents who received hospice in a nursing home reportedly significantly worse experiences that caregivers of those in the home for all measures., and ALF scores were also significantly lower than home for all measures. These differences were particularly large for hospice team communication and getting help for symptoms. (p < .001)
Xu, S., Liu, M., Shin, O., Parker, V., & Hernandez, R. (2020, Sep). Differences of Quality in End-of-Life Care across Settings: Results from the U.S. National Health and Aging Trends Study of Medicare Beneficiaries. <i>Journal of Palliative Medicine</i> , 23(9), 1198-1203. https://doi.org/10.1089/jpm.2019.0297	US, Hospice in multiple settings	1,336 proxies of Medicare beneficiaries 65 or older who died between 2013 and 2016.	Compared proxies' overall ratings for 13 indicators across five major domains of end-of-life care by place on residence in the last of decedent's life. Data from the National Health and Aging Trends study, a US based cohort study that collects survey data form a nation. Last month of life interviews were used here.	Hospice recipients in private residences and residential care settings were more likely to experience pain than patients living in private residences without hospice (OR = 2.59; 1.15-3.71 and 1.73; 1:00 – 3:00) Patients receiving hospice in private residence or residential care were both more likely to have discussed religion that patients in a private residence not receiving hospice (0.34; 0.22-0.53 and 0.33; 0.18-0.58) Proxies of participants in private residences with hospice care reported the highest overall rating (beta = 0.20; 0.01-0.39) Hospice residents in private residences were 65% more likely to be treated with respect compared to those in residential care settings.

General Hospice Overview: Literature review tables				
Citation	Setting	Population	Design	Main Findings
<p>Ćwirlej-Sozańska, A., Wójcicka, A., Kluska, E., Stachoń, A., & Żmuda, A. (2020, Jul 9). Assessment of the effects of a multi-component, individualized physiotherapy program in patients receiving hospice services in the home. <i>BMC Palliative Care</i>, 19(1), 101. https://doi.org/10.1186/s12904-020-00600-6</p>	Poland, home hospice	60 home hospice patients in Poland recruited from two participating rehabilitation centers. Patients with better prognoses on survival time and who were not terminal were referred to the physiotherapy program.	A pre- post-test design of one group of an intervention containing a multi-component, individualized physiotherapy program on patients referred for home hospice from March to June 2019.	<p>Physiotherapeutic intervention had a significant impact on improving the performance of ADL as well as the emotional state and quality of life of patients.</p> <p>Average functional level of ADL was 2.9/6 pre and significantly improved to 4.0/6 post.</p> <p>Statistically significant improvements were challenges with bathing and showering (73.3% to 53.3%), functional mobility (61.7% to 30.0%), dressing (55% to 30%), and toilet hygiene (55% - 36.7%), moving further than a walking distance (96.7% to 85%), preparing meals (91.6% to 83.3%), taking prescribed medication (80% to 70%), and managing money (66.7% to 56.7%) (all p < 0.05)</p> <p>Patients exhibited significant improvements in assessments of mobility and balance (Tinetti POMA Scale) (8.2 to 12.3), driven by improvements in gait and balance; Geriatric Depression Scale (16.7 TO 15.7), and World Health Organization Quality of Life scale WHOQOL (46.4 – 52.6) (All p < 0.001 except GDS (0.012)</p>
<p>Burke, S., Utley, A., Belchamber, C., & McDowall, L. (2020, Sep). Physical Activity in Hospice Care: A Social Ecological Perspective to Inform Policy and Practice. <i>Research quarterly for exercise and sport</i>, 91(3), 500-513.</p>	UK, Hospice facility	27 patients and 5 healthcare providers from multiple hospices in the UK	Qualitative analysis using a thematic framework approach that explored factors perceived as important for influencing physical activity participation in hospice care, using a social ecological framework. Used	Physical activity was perceived by patients and health providers as a therapeutic strategy to prevent future health problems and manage existing physical, functional, and psychological conditions.

General Hospice Overview: Literature review tables				
Citation	Setting	Population	Design	Main Findings
https://doi.org/10.1080/02701367.2019.1687808			semi-structured interviews and focus groups.	<p>Risk if injury, fear or falls, and concerns related to worsening their existing condition were identified as factors that may potentially deter participation.</p> <p>PA may make patients more aware of their declining condition through negative comparisons of present and past.</p> <p>Group-based PA may foster perceptions of social acceptance and may help counter feelings of alienation.</p>
<p>Hsu, A. T., Manuel, D. G., Pruin, S., Bennett, C., Taljaard, M., Beach, S., Sequeira, Y., Talarico, R., Chalifoux, M., Kobewka, D., Costa, A., Bronskill, S. E., & Tanuseputro, P. (2021, July 5, 2021). Predicting death in home care users: derivation and validation of the Risk Evaluation for Support: Predictions for Elder-Life in the Community Tool (RESPECT). <i>CMAJ</i>(193), E997-1005.</p> <p>https://doi.org/10.1503/cmaj.200022</p>	Canada, Home care	Patients in Ontario, Canada, 50 years of older, with at least one home care assessment (resident assessment instrument for home care) between 2007 and 2013.	Derivation and validation cohort data were used to evaluate the RESPECT's (Risk-evaluation for Support: Predictions for Elder-life in the Community Tool) ability to predict death within 6 months. They used population-based home care data, and the primary outcome of the prediction model was death within 6 months of the assessment. They used a Cox proportional hazard regression. Death was ascertained from the Registered Persons database.	<p>Measure of functional capacity were important factors capturing decline toward death, even more than most individual chronic diseases. A small number of home care users were given a prognosis of less than six months to live, but nearly one-quarter of the study cohort showed health declines correlated with and an elevated six-month mortality, indicating that a sizeable proportion of this population may have end of life care needs that were not identified or met.</p> <p>RESPECT could serve as a trigger for a comprehensive palliative needs assessment after each RAI-HC assessment.</p>
<p>Elliot, T., & DeMarzo, B. (2019, June 3). New Home Health, Hospice Dashboards Spark Quality Conversations. <i>At Home with The Joint Commission</i>.</p> <p>https://www.jointcommission.org/resources/news-and-</p>	Hospice	N/A	Dashboard report	the Joint Commission released a dashboard report for hospices that uses the most recent and available data from CMS Hospice Compare and supports quality improvement efforts. The hospice measures are: patients on opioids

General Hospice Overview: Literature review tables

Citation	Setting	Population	Design	Main Findings
multimedia/blogs/at-home-with-the-joint-commission/2019/07/new-home-health-hospice-dashboards-spark-quality-conversations/				offered/prescribed a bowel regimen, screening for pain during initial nursing assessment, comprehensive assessment of pain within on day of positive pain screen, treatment for dyspnea within one day of positive dyspnea screen, and documentation of discussion regarding spiritual/religious concerns.

Appendix IV: Spiritual Care Existing Assessment Items and Tools

Spiritual Care Existing Items and Tools: Screening

Spiritual Care: Existing Items and Tools: Screening					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Steinhauser, K. E., Voils, C. I., Clipp, E. C., Bosworth, H. B., Christakis, N. A., & Tulskey, J. A. (2006). "Are you at peace?": one item to probe spiritual concerns at the end of life. <i>Archives of Internal Medicine</i> , 166(1), 101-105. https://doi.org/10.1001/archint.e.166.1.101	Single item: "Are you at peace?"	End of life care at VA or university medical center	Patients with advanced serious illness (cancer, congestive heart failure, chronic obstructive pulmonary disease, or end-stage renal disease) United States	Correlational analysis using a cross-sectional sample	Construct validity showed that feeling at peace was strongly correlated with emotional and spiritual well-being. It was equally correlated with faith and purpose subscales, indicating applicability to traditional and nontraditional definitions of spirituality. Asking patients about the extent to which they are at peace offers a brief gateway to assessing spiritual concerns.
Fitchett, G., & Risk, J.L. (2009). Screening for spiritual struggle. <i>Journal of Pastoral Care & Counseling</i> , 63(1-2), 4-12.	Religious Struggle Screening Protocol (aka Rush protocol)	Acute medical rehabilitation unit	Patients admitted for rehabilitation related to amputation, neurological disease, stroke, deconditioning, and orthopedic surgeries, including spine surgery and joint replacements United States	Pilot study of protocol with Patient Care Technicians, medical residents, psychology Interns, and staff psychologists	The protocol identified 7% of the patients as possibly experiencing religious/spiritual struggle. Follow up spiritual assessments by the chaplain confirmed religious/spiritual struggle in all but one of these patients (positive predictive value of 92%) but also identified additional cases of religious/spiritual struggled not identified by the protocol (false negatives).
Pigott C., Pollard A., Thomson K., & Aranda S. (2009). Unmet needs in cancer patients: development of a supportive needs screening tool (SNST). <i>Supportive Care in Cancer</i> , 17(1), 33-45.	Supportive needs screening tool (SNST); includes 2 relevant items	Outpatient oncology	Patients with cancer Australia	Pilot test of tool with senior nurses	Patients and staff reported high acceptability. The SNST has face validity and demonstrated usability in an ambulatory care oncology setting, as first steps in instrument development.

Spiritual Care: Existing Items and Tools: Screening					
Citation	Item or Tool	Setting	Population	Design	Main Findings
https://doi.org/10.1007/s00520-008-0448-7					
Wells-Di Gregorio S., Porensky E.K., Minotti M., Brown S., Snapp J., Taylor R.M., Adolph M.D., Everett S., Lowther K., Callahan K., Strevia D. (2013). The James Supportive Care Screening: integrating science and practice to meet the NCCN guidelines for distress management at a Comprehensive Cancer Center. <i>Psycho-Oncology</i> , 22(9), 2001-8. https://doi.org/10.1002/pon.3256	James Supportive Care Screening (SCS); includes 3 relevant items	Oncology and outpatient palliative care	Patients with cancer United States	Development and validation of tool	Six factors were identified and confirmed including (i) emotional concerns; (ii) physical symptoms; (iii) social/practical problems; (iv) spiritual problems; (v) cognitive concerns; and (vi) healthcare decision making/communication issues. Subscale evaluation reveals good to excellent internal consistency, test-retest reliability, and convergent, divergent, and predictive validity. Results support use of the James SCS to quickly detect the most frequent and distressing symptoms and concerns of cancer patients
Astrow, A.B., Wexler, A., Teixeira, K., He, M. K., & Sulmasy, D. P. (2007). Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? <i>Journal of Clinical Oncology</i> , 25(36), 5753-7. https://doi.org/10.1200/JCO.2007.12.4362	Single item: "Do you feel your spiritual needs are being met?"	Outpatient oncology	Patients with cancer United States	Survey	Most patients had spiritual needs. A slight majority thought it appropriate to be asked about these needs, although fewer thought this compared with reports in other settings. Few had their spiritual needs addressed by the staff. Patients whose spiritual needs were not met reported lower ratings of quality and satisfaction with care.
King, S. D., Fitchett, G., Murphy, P. E., Pargament, K. I., Harrison, D. A., & Loggers, E. T. (2017). Determining best methods to screen for religious/spiritual distress.	R/S distress in cancer patients and survivors; paired item	Cancer center	Cancer survivors United State	Survey	There were no acceptable single item measures for R/S distress. The two-item combination of meaning/joy and self-described R/S

Spiritual Care: Existing Items and Tools: Screening					
Citation	Item or Tool	Setting	Population	Design	Main Findings
<p><i>Supportive Care in Cancer</i>, 25(2), 471-479. https://doi.org/10.1007/s00520-016-3425-6</p>					distress is promising based upon a net sensitivity of 82 % in the full sample and of 87 % in those within 2 years of hematopoietic cell transplantation.
<p>Richards, C. T., Gisondi, M. A., Chang, C. H., Courtney, D. M., Engel, K. G., Emanuel, L., & Quest, T. (2011). Palliative care symptom assessment for patients with cancer in the emergency department: validation of the Screen for Palliative and End-of-life care needs in the Emergency Department instrument. <i>Journal of palliative medicine</i>, 14(6), 757-764. https://doi.org/10.1089/jpm.2010.0456</p>	Screen for Palliative and End-of-Life Care Needs in the Emergency Department (SPEED); single item in spiritual domain: "How much does this illness seem senseless or meaningless?"	Emergency Department & Hospice/Palliative Care/End of life	Emergency department patients with active cancer United States	Development and validation of tool	The SPEED instrument demonstrated reliability and validity for screening for palliative care needs of patients with cancer presenting to the emergency department.
<p>Chochinov, H. M., Hassard, T., McClement, S., Hack, T., Kristjanson, L. J., Harlos, M., Sinclair, S., & Murray, A. (2007). The Patient Dignity Inventory: A novel way of measuring dignity-related distress in palliative care. <i>Journal of Pain and Symptom Management</i>, 36(6), 559-571. https://doi.org/10.1016/j.jpain-symman.2007.12.018</p> <p>Chochinov, H. M., McClement, S. E., Hack, T. F., McKeen, N. A., Rach, A. M., Gagnon, P., Sinclair, S., & Taylor-Brown, J. (2012). The</p>	Patient Dignity Inventory; includes three relevant items	Hospice/Palliative Care/End of life	Palliative care patients near the end of life Canada & Australia	Validation of tool	The PDI is a valid and reliable new instrument, which could assist clinicians to routinely detect end-of-life dignity-related distress. It is worth noting that the Peace of Mind factor, which included an item regarding spiritual concerns, had the lowest Cronbach's coefficient alpha. It is important to acknowledge that the term spirituality lacks definitional specificity.

Spiritual Care: Existing Items and Tools: Screening					
Citation	Item or Tool	Setting	Population	Design	Main Findings
<p>Patient Dignity Inventory: Applications in the oncology setting. <i>Journal of Palliative Medicine</i>, 15(9), 998-1005. http://doi.org/10.1089/jpm.2012.0066</p> <p>Testing & validation of Spanish version: Rullán, M., Carvajal, A., Núñez-Córdoba, J. M., Martínez, M., Carrasco, J. M., García, I., Arantzamendi, M., Belar, A., & Centeno, C. (2015). Spanish Version of the Patient Dignity Inventory: Translation and Validation in Patients with Advanced Cancer. <i>Journal of Pain and Symptom Management</i>, 50(6), 874-881.e871. https://doi.org/10.1016/j.jpain-symman.2015.07.016</p>					
<p>Schofield, P., Gough, K., Ugalde, A., Dolling, L., Aranda, S., & Sanson-Fisher, R. (2012). Validation of the needs assessment for advanced lung cancer patients (NA-ALCP). <i>Psycho-Oncology</i>, 21(4), 451-455. https://doi.org/10.1002/pon.1902</p>	Needs Assessment for Advanced Lung Cancer Patients—Short Form (NA-ALCP); includes one relevant item	Oncology	<p>Patients with advanced lung cancer</p> <p>Australia</p>	Validation of tool	<p>Subscales demonstrated internal reliability consistent with the original scale. Results provided supporting evidence for divergent and convergent validity. This study indicates that the NA-ALCP is psychometrically robust, easily understood and one-quarter the length of the original version.</p>
<p>Tamburini, M., Gangeri, L., Brunelli, C., Beltrami, E., Boeri, P., Borreani, C., Fusco Karmann, C., Greco, M., Miccinesi, G., Murru, L., & Trimigno, P. (2000).</p>	Needs Evaluation Questionnaire (NEQ); includes one relevant item	Hospital	<p>Hospitalized patients with cancer</p> <p>Italy</p>	Design and validation of tool	The validation analysis showed rather good reliability, structure validity and internal consistency of the questionnaire.

Spiritual Care: Existing Items and Tools: Screening					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Assessment of hospitalised cancer patients' needs by the Needs Evaluation Questionnaire. <i>Annals of Oncology</i> , 11(1), 31-37. https://doi.org/10.1023/A:1008396930832					
Emanuel, L. L., Alpert, H. R., & Emanuel, E. E. (2001). Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. <i>Journal of Palliative Medicine</i> , 4(4), 465–474. https://doi.org/10.1089/109662101753381601	Needs at the End-of-Life Screening Tool (NEST 13/NEST 48)	Hospital	Patients with a prognosis of 6 months or less US	Design and validation of tool	Thirteen questions were assigned themes corresponding to each letter of NEST: Needs (social), Existential matters, Symptoms, and Therapeutic matters. In the Existential area it is necessary to “unfold” four dimensions, asking the questions about distress regarding the meaning of the patient’s illness; about spirituality; about whether personal relationships are settled; and about sense of purpose in life. NEST is the first data-driven, comprehensive tool designed from an empirically validated framework and tested survey questions for clinical use in end-of-life care. Evaluation of its performance in another population is needed to complete NEST’s fuller evaluation.
Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., & Pugliese, K. (2009). Improving the quality of	“Are spirituality or religion important in your life?” / “How well are those resources working for you at this time?”	n/a	n/a	Literature review and conference recommendations	Good models of spiritual screening use a few simple questions that can be asked during an overall patient and family screening; example questions provided.

Spiritual Care: Existing Items and Tools: Screening					
Citation	Item or Tool	Setting	Population	Design	Main Findings
spiritual care as a dimension of palliative care: the report of the Consensus Conference. <i>Journal of Palliative Medicine</i> , 12(10), 885-904. http://doi.org/10.1089/jpm.2009.0142					

Spiritual Care Existing Items and Tools: History

Spiritual Care: Existing Items and Tools: History					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Maugans T. A. (1996). The SPIRITual history. <i>Archives of Family Medicine</i> , 5(1), 11–16. https://doi.org/10.1001/archfam.5.1.11	SPIRITual History	Family practice	2 patients from author's family practice United States	Case study	Physicians can comfortably and competently talk with patients about spiritual and religious issues that may impact on healthcare. Use a tool, such as the SPIRIT mnemonic, to aid in history taking and charting of relevant information.
Puchalski, C., & Romer, A. L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. <i>Journal of Palliative Medicine</i> , 3(1), 129–137. https://doi.org/10.1089/jpm.2000.3.129	FICA Spiritual History Tool	Hospice/Palliative Care/End of life	n/a United States	Interview with tool developer	Dr. Puchalski, an internist and geriatrician, designed a tool that physicians or others can integrate into patient interviews. This tool is geared to a time-constrained setting. It was designed for doctors or others to use at the beginning of the examination, something that would not constrain patients from leading the conversation into any area that was important to them. Believed to be applicable cross-culturally because the principles are general; one does not have to use the exact words in the tool.

Spiritual Care: Existing Items and Tools: History					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Koenig H. G. (2002). An 83-year-old woman with chronic illness and strong religious beliefs. <i>JAMA</i> , 288(4), 487–493. https://doi.org/10.1001/jama.288.4.487	Taking a spiritual history	Primary care	83-year-old woman with multiple medical problems and chronic progressive pain United States	Case study	Patient reports that her spirituality lessens the pain and allows her to endure it; her treating physician sought counsel on how to explore the role of spirituality in her life and the risks/benefits of discussing spirituality with a patient. The author discusses previous work showing the connection between religion and better coping with illness. The author also presents questions for taking a spiritual history. Taking a spiritual history or addressing spiritual issues must be done in addition to competently and completely addressing the patient's medical concerns.
Lo, G., Chen, J., Wasser, T., Portenoy, R., & Dhingra, L. (2016). Initial Validation of the Daily Spiritual Experiences Scale in Chinese Immigrants with Cancer Pain. <i>Journal of Pain and Symptom Management</i> , 51(2), 284-291. https://doi.org/10.1016/j.jpainsymman.2015.10.002	Daily Spiritual Experiences Scale - Chinese (DSES-C)	Oncology	Patients with cancer pain United States	Translation and validation of tool	The DSES-C demonstrated high reliability. Construct validity was suggested by a positive association between DSES-C scores and having a religious affiliation. In Chinese Americans with cancer pain, the DSES-C demonstrated acceptable psychometrics.
Frick, E., Riedner, C., Fegg, M. J., Hauf, S., & Borasio, G. D. (2006). A clinical interview assessing cancer patients' spiritual needs and preferences. <i>European journal of cancer care</i> , 15(3), 238–243. https://doi.org/10.1111/j.1365-2354.2005.00646.x	SPIR	Oncology outpatient	Patients with cancer Germany	Design and validation of tool	Patients and interviewing physicians evaluated the SPIR interview as helpful and non-distressing. Following the interview, doctors were able to correctly gauge the importance of spirituality for their patients. In this study, a short clinical assessment of cancer patients' spirituality

Spiritual Care: Existing Items and Tools: History					
Citation	Item or Tool	Setting	Population	Design	Main Findings
					was well received by both patients and physicians.

Spiritual Care Existing Items and Tools: Assessment

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Anandarajah, G., & Hight, E. (2001). Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. <i>American Family Physician</i> , 63(1), 81-89.	HOPE questions	Family practice	Patients seen by family physicians United States	Tool development	Developed as a teaching tool to help medical students, residents and practicing physicians begin the process of incorporating a spiritual assessment into the medical interview. Research has not validated these , but the strength of this approach is that it allows for an open-ended exploration of an individual's general spiritual resources.
Gaudette, H., & Jankowski, K. R. (2013). Spiritual coping and anxiety in palliative care patients: a pilot study. <i>Journal of health care chaplaincy</i> , 19(4), 131–139. https://doi.org/10.1080/08854726.2013.823785	Beliefs and Activities Spirituality Scale (BASS)	Hospice/Palliative Care/End of life	Palliative care patients United States	Pilot cross-sectional study	The reliability of the BASS full scale was reasonably good, with the reliability of the two separate subscales being slightly lower (Beliefs subscale and Activities subscale). White participants tended to report lower scores on the BASS and higher anxiety scores. The findings indicate that spiritual beliefs and activities are components of an overall spirituality that has a beneficial association with anxiety in palliative care patients. The observed beneficial association suggests that spiritual coping may, indeed, help patients to deal with their anxiety.

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Monod, S. M., Rochat, E., Bula, C. J., Jobin, G., Martin, E., & Spencer, B. (2010). The spiritual distress assessment tool: an instrument to assess spiritual distress in hospitalised elderly persons. <i>BMC Geriatrics</i> , 10, 88. https://doi.org/10.1186/1471-2318-10-88	Spiritual Distress Assessment Tool (SDAT)	Hospital geriatric care	Elderly hospitalized persons Switzerland	Development and validation of tool	Four dimensions of spirituality (Meaning, Transcendence, Values, and Psychosocial Identity) and their corresponding needs were defined. A formalised assessment procedure to both identify and subsequently score unmet spiritual needs and spiritual distress was developed. Face validity and acceptability in clinical practice were confirmed by chaplains involved in the focus groups.
Holland, J. C., Kash, K. M., Passik, S., Gronert, M. K., Sison, A., Lederberg, M., Russak, S. M., Baider, L., & Fox, B. (1998). A brief spiritual beliefs inventory for use in quality of life research in life-threatening illness. <i>Psycho-oncology</i> , 7(6), 460–469. <a href="https://doi.org/10.1002/(SICI)1099-1611(199811/12)7:6<460:AID-PON328>3.0.CO;2-R">https://doi.org/10.1002/(SICI)1099-1611(199811/12)7:6<460:AID-PON328>3.0.CO;2-R	Spiritual Belief Inventory (SBI-15)/(SBI-15-R)	Various	Cancer patients (Phase I of measure development), healthy individuals (Phase III) United States	Development and validation of tool	The measure developed encompasses both religious and spiritual aspects of belief systems, in one instrument, as was evidenced by the high correlations with both the intrinsic scale of the ROI and the spiritual measure of belief in a higher or supreme being (Kass et al., 1991). The principal component analyses indicated that a short, 15-item measure can tap both constructs and applies equally to individuals who report themselves as atheists, agnostics, or having no religious affiliation and those with a moderate or strong religious or spiritual orientation.
Hodge, D. R. (2004). Spirituality and people with mental illness: Developing spiritual competency in assessment and intervention.	Initial Spiritual Assessment	n/a	People with mental illness United States	Descriptive	Provides a framework for an initial spiritual assessment that complies with the recent JCAHO (2002) recommendations

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
<p><i>Families in Society</i>, 85(1), 36-44. https://doi.org/10.1606/1044-3894.257</p> <p>Hodge D. R. (2006). A template for spiritual assessment: a review of the JCAHO requirements and guidelines for implementation. <i>Social work</i>, 51(4), 317–326. https://doi.org/10.1093/sw/51.4.317</p>					
<p>Moadel, A. B., Morgan, C., & Dutcher, J. (2007). Psychosocial needs assessment among an underserved, ethnically diverse cancer patient population. <i>Cancer</i>, 109(2 Suppl), 446–454. https://doi.org/10.1002/cncr.22357</p>	<p>Psychosocial Needs Assessment Survey (PNAS); includes spiritual domain</p>	<p>Outpatient oncology</p>	<p>Patients with cancer</p> <p>United States</p>	<p>Development and validation of tool</p>	<p>The survey demonstrated high internal consistency and face validity. The mean percentage of needs endorsed by African Americans, Hispanics, and non-Hispanic whites respectively was 49%, 60%, 31% for Spiritual needs.</p>
<p>McIlmurray, M. B., Thomas, C., Francis, B., Morris, S., Soothill, K., & Al-Hamad, A. (2001). The psychosocial needs of cancer patients: findings from an observational study. <i>European journal of cancer care</i>, 10(4), 261–269. https://doi.org/10.1046/j.1365-2354.2001.00280.x</p>	<p>Psychosocial Needs Inventory (PNI); includes spiritual and emotional section</p>	<p>Hospital</p>	<p>Patients with cancer</p> <p>England</p>	<p>Observational study</p>	<p>'Emotional and spiritual' needs showed significant differences for age with higher levels of need among younger patients except for 'support from a spiritual advisor' (higher among those aged 60 years and above). Women had significantly higher levels of need than men in three items, and in two other items the level of need was significantly higher for breast cancer patients than for those with other tumour types. Lung cancer</p>

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
					patients had a higher level of need than those with other tumour types for 'help in dealing with the feelings of others. 'Support from a spiritual advisor' was a significantly higher level of need for patients at recurrence and at the move to palliative care than for patients at other moments; those at the recurrence stage had a higher level of need for 'help in dealing with the unpredictability of the future'.
Hatch, R. L., Burg, M. A., Naberhaus, D. S., & Hellmich, L. K. (1998). The Spiritual Involvement and Beliefs Scale. Development and testing of a new instrument. <i>The Journal of family practice</i> , 46(6), 476–486.	Spiritual Involvement and Beliefs Scale	Family practice	Patients from a rural family practice and family practice professionals United States	Development and validation of tool	Designed to be widely applicable across religious traditions, to assess actions as well as beliefs, to address key components not assessed in other available measures, and to be easily administered and scored. By several measures, instrument reliability and validity are very good, with high internal consistency; strong test-retest reliability; a clear four-factor structure; and a high correlation with another established measure of spirituality, the Spiritual Well-Being Scale. Compared with other instruments that assess spirituality, the SIBS has several theoretical advantages, including broader scope, use of terms that avoid cultural-religious bias, and assessment of both beliefs and actions. More

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
					testing is underway to further assess its usefulness.
Galek, K., Flannelly, K. J., Vane, A., & Galek, R. M. (2005). Assessing a patient's spiritual needs: a comprehensive instrument. <i>Holistic nursing practice</i> , 19(2), 62–69. https://doi.org/10.1097/00004650-200503000-00006	Patients Spiritual Needs Assessment Scale (PSNAS)	n/a	n/a	Development of tool	Seven major constructs—belonging, meaning, hope, the sacred, morality, beauty, and acceptance of dying—drawn from the literature were embedded within a 29-item survey designed to be inclusive of traditional religion, as well as non-institutional-based spirituality. Article describes item development, but scale not tested, and no information on reliability/validity.
Taylor E. J. (2006). Prevalence and associated factors of spiritual needs among patients with cancer and family caregivers. <i>Oncology nursing forum</i> , 33(4), 729–735. https://doi.org/10.1188/06.ONF.729-735	Spiritual Interests Related to Illness Tool (SPIRIT)	Inpatient and outpatient oncology	Patients with cancer and their family caregivers United States	Descriptive, cross-sectional study	Analysis supported most of the original clustering of items but showed that a few items belonged in a different cluster. Total SpIRIT scores were correlated with frequency of attendance at religious services and number of months since diagnosis. Only the asking “why” and preparing to die subscales were correlated with overall illness-related distress. Women, those who lived with others, and inpatients perceived spiritual needs to be more important.
Büssing, A., Balzat, H. J., & Heusser, P. (2010). Spiritual needs of patients with chronic pain diseases and cancer - validation of the spiritual needs questionnaire. <i>European journal of medical research</i> , 15(6), 266–273.	Spiritual Needs Questionnaire (SpNQ)	Community hospital, cancer support group	Patients with chronic pain conditions, cancer, or other chronic conditions Switzerland & Germany	Cross-sectional study	Intended to measure spiritual, existential, and psychosocial need of patients with chronic diseases. Factor analysis pointed to 4 factors which explain 67% of variance: Religious Needs, Need for Inner Peace, Existentialistic

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
https://doi.org/10.1186/2047-783x-15-6-266 .					Needs (Reflection / Meaning), and Actively Giving. The preliminary results indicate that spiritual needs are conceptually different from life satisfaction and can be interpreted as the patients' longing for spiritual well-being.
Rainbird, K. J., Perkins, J. J., & Sanson-Fisher, R. W. (2005). The Needs Assessment for Advanced Cancer Patients (NA-ACP): a measure of the perceived needs of patients with advanced, incurable cancer. a study of validity, reliability and acceptability. <i>Psycho-oncology</i> , 14(4), 297–306. https://doi.org/10.1002/pon.845	Needs Assessment for Advanced Cancer Patients (NA-ACP); includes spiritual domain	Medical specialists	Patients with advanced, incurable cancer not receiving palliative care Australia	Validation of tool	The principal components analysis revealed seven domains assessing patients' psychological/emotional, medical information/communication, social, symptom, daily living, spiritual and financial needs. The test–retest reliability estimates were within accepted levels, as were all but one of the internal consistency scores. The NA-ACP was highly acceptable for this patient group. The NA-ACP is one of the first multi-dimensional instruments specifically designed to assess the needs of patients with advanced, incurable cancer. The present study provides evidence of the NA-ACP's validity, reliability, and acceptability.
Wu, L. F., Koo, M., Liao, Y. C., Chen, Y. M., & Yeh, D. C. (2016). Development and Validation of the Spiritual Care Needs Inventory for Acute Care Hospital Patients in Taiwan. <i>Clinical nursing research</i> , 25(6), 590–606.	Spiritual Care Needs Inventory (SCNI)	Hospital acute care	Patients with acute disease Taiwan	Development and validation of tool	Principal components analysis of the SCNI revealed two components, (a) meaning and hope and (b) caring and respect, which together accounted for 66.2% of the total variance.

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
https://doi.org/10.1177/1054773815579609					Furthermore, younger age, female sex, Christian religion, and regularly attending religious activities had significantly higher mean total scores in both components. The SCNI was found to be a simple instrument with excellent internal consistency for measuring the spiritual care needs in acute care hospital patients.
Bredle, J. M., Salsman, J. M., Debb, S. M., Arnold, B. J., & Cella, D. (2011). Spiritual well-being as a component of health-related quality of life: The Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp). <i>Religions</i> , 2(1), 77-94. https://doi.org/10.3390/rel2010077	Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp-12)	n/a	n/a	Literature review	FACIT-SP-12 was designed for people with cancer and other chronic illnesses. Cancer patients, psychotherapists, and religious/spiritual experts provided input on the development of the items. It was validated with a large, ethnically diverse sample. It has been successfully used to assess spiritual well-being across a wide range of religious traditions, including those who identify themselves as “spiritual yet not religious.” Part of the larger FACIT measurement system that assesses multidimensional health related quality of life (HRQOL), the FACIT-Sp-12 has been translated and linguistically validated in 15 languages and has been used in dozens of studies examining the relationships among spiritual well-being, health, and adjustment to illness.

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
John E. Fetzer Institute. (1999). Multidimensional Measurement of Religiousness/Spirituality for Use in Health Research. Kalamazoo, MI: John E. Fetzer Institute.	NIA/Fetzer measure	n/a	n/a	National working group report, including literature reviews and recommended instruments	The NIA and the Fetzer Institute convened a panel of scholars with expertise in religiousness/spirituality and health/wellbeing. The working group's primary mission was to develop items for assessing health-relevant domains of religiousness and spirituality as they are broadly understood. The religiousness/spirituality domains included in this document are intended for use in studies that evaluate the relationship between religiousness/spirituality and health. The Brief Multidimensional Measure of Religiousness/Spirituality: 1999 was embedded in the 1997-1998 General Social Survey (GSS), a random national survey of the National Data Program for the Social Sciences. The results to date support the theoretical basis of the measure and indicate it has the appropriate reliability and validity to facilitate further research. Intended for research use.
Fitchett, G., Hisey Pierson, A. L., Hoffmeyer, C., Labuschagne, D., Lee, A., Levine, S., O'Mahony, S., Pugliese, K., & Waite, N. (2020). Development of the PC-7, a Quantifiable Assessment of Spiritual Concerns of Patients Receiving Palliative Care	PC-7	Palliative care	Patients near the end of life United States	Development and validation of tool	The model was developed by a team of chaplains working in palliative care. Phase 1 used literature in the field and the chaplains' clinical practice to identify key concerns in the spiritual care of palliative care patients. Phase 2 focused on developing indicators of those concerns and reliability in the

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Near the End of Life. <i>Journal of Palliative Medicine</i> , 23(2), 248-253. https://doi.org/10.1089/jpm.2019.0188					chaplains' rating of them. Authors demonstrate face validity through: (1) alignment of key model themes with literature on spirituality at end of life, (2) case examples from clinical practice, and (3) support for model from chaplains. Model requires further testing for reliability and validity.
Kenneth Pargament, Donna Burdzy, & Margaret Feuille. (2011). The Brief RCOPE: Current Psychometric Status of a Short Measure of Religious Coping. <i>Religions</i> , 2(1), 51–76. https://doi.org/10.3390/rel2010051	Brief RCOPE	n/a	n/a	Literature review	Two overarching forms of religious coping, positive and negative, were articulated through factor analysis of the full RCOPE. Empirical studies document the internal consistency of the positive and negative subscales of the Brief RCOPE. Moreover, empirical studies provide support for the construct validity, predictive validity, and incremental validity of the subscales. The Negative Religious Coping subscale, in particular, has emerged as a robust predictor of health-related outcomes. Initial evidence suggests that the Brief RCOPE may be useful as an evaluative tool that is sensitive to the effects of psychological interventions. In short, the Brief RCOPE has demonstrated its utility as an instrument for research and practice in the psychology of religion and spirituality.

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Mateo-Ortega, D., Limonero, J. T., Maté-Méndez, J., Beas, E., González-Barboteo, J., Barbero, E., Ela, S., & Gómez-Batiste, X. (2019). Development of a tool to identify and assess psychosocial and spiritual needs in end-of-life patients: The ENP-E scale. <i>Palliative and Supportive Care</i> , 17(4), 441-447. https://doi.org/10.1017/s1478951518000652	Psychosocial and Spiritual Needs Evaluation scale / Instrumento de Evaluación de Necesidades Psicosociales y Espirituales del Enfermo al Final de Vida (ENP-E)	Palliative care	Patients with advanced/terminal cancer Spain	Development and validation of tool	Tool was designed to assess the psychosocial needs of end-of-life (EOL) patients. All respondents evaluated the tool as "excellent." In terms of construct validity, the internal consistency and temporal stability were both adequate. The ENP-E is a novel tool that provides a systematic, holistic assessment of the psychosocial needs of EOL patients. Its routine use would allow clinicians to monitor such needs over time. This would, in turn, permit comprehensive, highly individualized interventions to improve effective PC approach.
Ellison, L. (2006). A review of The Spiritual Well-Being Scale. <i>NewsNotes</i> , 44(1)	Spiritual Well-Being Scale	n/a	n/a	Instrument review	This scale is designed to be a measure of spiritual well-being as defined by religious and existential factors. The publishers of this test recommend its use for clinical and counseling purposes in both individual and group settings. Evidence shows there is sufficiently high reliability and internal consistency, and several authors stated that this test has good face validity. There appears to be sufficient content validity regarding the items in the test. Construct validity appears to be one of the strong points of this instrument. There may be some difficulty in using this instrument in populations

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
					where there is little or no importance placed on a relationship with a personal God. the literature shows that there are still issues regarding the skewness of the data that are collected with this instrument that must be addressed. Because of this result, the high end of the scoring is rendered meaningless. It is only the lack of spiritual well-being that has been found to be statistically viable information.
Balboni, T. A., Prigerson, H. G., Balboni, M. J., Enzinger, A. C., VanderWeele, T. J., & Maciejewski, P. K. (2019). A scale to assess religious beliefs in end-of-life medical care. <i>Cancer</i> , 125(9), 1527-1535. https://doi.org/10.1002/cncr.31946	Religious Beliefs in End-of-Life Medical Care (RBEC)	Oncology	Patients with advanced/terminal cancer (not in hospice or palliative care) United States	Development and validation of tool	The RBEC scale proved to be internally consistent, unidimensional, positively associated with other indicators of patients' religiousness and spirituality (establishing its convergent validity), and inversely associated with patients' terminal illness understanding and acceptance (establishing its criterion validity), suggesting its potential clinical usefulness in promoting informed EOL decision making. The RBEC scale is a reliable and valid tool with which to assess religious beliefs within the context of EOL medical care, beliefs that frequently are endorsed and inversely associated with terminal illness understanding.
O'Reilly, M., Larkin, P., Conroy, M., Twomey, F., Lucey, M., Dunne, C., &	Milford Palliative Care Assessment Tool; includes FICA and Mount Vernon	Palliative care	Patients in palliative care	Mixed methods	Introducing the Milford Palliative Care Assessment Tool was associated with

Spiritual Care: Existing Items and Tools: Assessment					
Citation	Item or Tool	Setting	Population	Design	Main Findings
Meagher, D. J. (2016). The Impact of a Novel Tool for Comprehensive Assessment of Palliative Care (MPCAT) on Assessment Outcome at 6- and 12-Month Follow-Up. <i>Journal of Pain and Symptom Management</i> , 52(1), 107-116. https://doi.org/10.1016/j.jpain-symman.2015.12.343	Cancer Network questioning guidelines		Ireland		significant improvement in assessment of multiple important aspects of patient need. Screening for spiritual distress increased post-intervention (tool), as did the number of referrals made in the first 24 hours after assessment (physiotherapy, occupational therapy, social work, and pastoral care).

Appendix V: References

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