Technical Brief
Number 30

Assessment Tools for Palliative Care

Agency for Healthcare Research and Quality

Effective Health Care Program

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None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

The information in this report is intended to help health care decisionmakers—patients and clinicians, health system leaders, and policymakers, among others—make well-informed decisions and thereby improve the quality of health care services. This report is not intended to be a substitute for the application of clinical judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical reference and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances presented by individual patients.

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses, when appropriate, prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy, or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers, as well as the health care system as a whole, by providing important information to help improve health care quality.

If you have comments on this Technical Brief, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857, or by email to epc@ahrq.hhs.gov.

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Key Informants

In designing the study questions, we consulted a panel of Key Informants that represented subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the technical brief. Key Informants are not involved in the analysis of the evidence nor the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than $10,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. We worked with the Task Order Officer to balance, manage, or mitigate any conflicts of interest.

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Peer Reviewers

Prior to publication of the final evidence report, we sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report do not necessarily represent the views of individual reviewers.

Peer Reviewers must disclose any financial conflicts of interest greater than $10,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential nonfinancial conflicts may be retained. We worked with the Task Order Officer to balance, manage, or mitigate any potential nonfinancial conflicts of interest identified.

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Assessment Tools for Palliative Care

Structured Abstract

Objectives. To (1) provide an overview of palliative care assessment tools designed to be completed by or with patients or caregivers, including which tools have been applied to clinical care, as quality indicators, or in evaluations of interventions, and (2) identify needs for future palliative care assessment tool development and evaluation.

Methods. First, we engaged Key Informants representing both patient/caregiver and provider/researcher perspectives to help guide the project. We then sought systematic reviews of palliative care assessment tools and applications of tools through searches of PubMed, CINAHL, Cochrane, PsycINFO and PsycTESTS from January 1, 2007 to August 29, 2016. We conducted supplemental searches of information on palliative care tools, including comprehensive reviews published prior to our date limitation, Web sites, and a targeted search for primary articles to identify tools where no recent high-quality systematic review was identified. We organized tools by the eight domains (subdomains) from the National Consensus Project Clinical Practice Guidelines for Palliative Care: structure and process, physical, psychological and psychiatric, social (caregiver), spiritual and religious, cultural, care at the end of life (bereavement), ethical and legal; as well as a ninth domain for multidimensional tools (quality of life and patient experience).

Results: We included 10 systematic reviews of palliative care assessment tools (7 addressing different domains and 3 addressing applications of tools). We identified 152 tools (97 from systematic reviews and 55 from supplemental sources). Key gaps included: no identified systematic review for the subdomain of pain and a paucity of tools to assess structure and process, cultural, ethical and legal domains, and patient-reported experience. Information on internal consistency, reliability, construct validity, and usability was available for many tools, but few studies evaluated responsiveness (sensitivity to change). Only six studies evaluated the use of assessment tools in clinical practice, and we identified only one quality indicator with a specified assessment tool. Twenty-three different palliative care assessment tools were used in 43 intervention studies.

Conclusions: We identified more than 150 assessment tools addressing most domains of palliative care, but few tools addressed the spiritual, structure and process, ethical and legal, or cultural domains, or the patient-reported experience subdomain. While some data on the psychometric properties of tools exist, the responsiveness of different tools to change has largely not been evaluated. Future research should focus on: (1) developing or testing tools in palliative care populations for domains with few or no tools, (2) evaluating responsiveness of tools for all domains, and (3) further studying the use of palliative care tools in clinical care and as quality indicators.

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Introduction

Background

Palliative care is defined as care that provides relief from pain and other symptoms and supports quality of life for patients with serious advanced illness and their families.[1] Over the last decade, a multi-professional group published consensus guidelines that define the domains that palliative care should address (Figure 1).[2] Because palliative care is fundamentally concerned with the patient/caregiver experience, the best way to assess these domains involves patient and/or caregiver reports. Therefore, valid and responsive patient and caregiver assessment tools addressing all domains are essential to measuring the quality and effectiveness of palliative care.

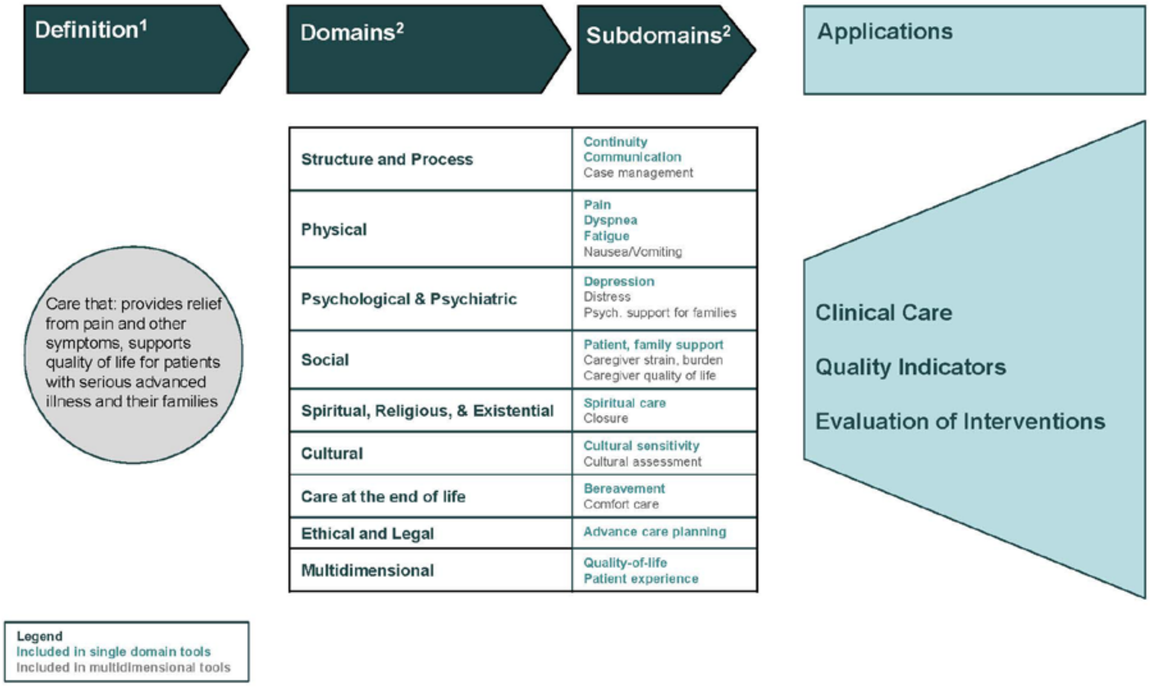
We defined an assessment tool as a data collection instrument (generally a scale, questionnaire or survey) that has been psychometrically evaluated, is completed by or with patients or caregivers, and collects data at the individual patient or caregiver level (see Appendix A for Glossary). Assessment tools may include patient and caregiver reports of physical symptoms (e.g., pain and dyspnea), mental health issues (e.g., depression), caregiver outcomes (e.g., quality of life and burden), and processes of care (e.g., communication and continuity). For conceptual ease, palliative care assessment tools can be categorized by the eight domains defined within the National Consensus Project Guidelines (Figure 1)[2] as well as by a ninth domain for palliative care assessment tools that are innately multidimensional (i.e., tools that assess quality of life or patient experience). The multidimensional domain tools include items that cross multiple domains and often address areas such as physical health and functional status, mental health, social and role function, as well as physical and psychological symptoms (i.e., Edmonton Symptom Assessment Score,[3] Memorial Symptom Assessment Score,[4] etc.). Each of the domains may also have subdomains, such as the subdomains of pain, dyspnea, or fatigue which are within the over-arching physical domain.

Palliative care assessment tools may be used for varying applications within palliative care. Assessment tools may be used by providers in clinical care to directly assess symptoms or other issues with patients or families. Assessment tools may also be used as quality indicators, defined as population-based measures that enable users to quantify the quality of an aspect of care by comparing it to evidence-based criteria.[5] Finally, assessment tools may be used in research studies to evaluate the impact of a specific palliative care intervention(s).

Exploration of assessment tools across three applications – clinical, quality indicators, and intervention - is important because a tool's utility may vary by its application. For example, measuring aspects of care important for research-related, academic inquiry may not be important, or even feasible, in clinical care delivery. Assessment tools to be primarily used in clinical care settings are optimally simple and brief to facilitate ease of completion by a seriously ill patient and/or a frequently-overwhelmed family member. In contrast, assessment tools to be used primarily to evaluate interventions may be lengthier and/or specific to targeted intervention-related domains of palliative care; when optimal, these tools are both highly responsive (sensitive to change) and reliable to facilitate detection of intervention-related outcome variations.

Ultimately, palliative care assessment tools should be reliable, valid, and responsive assessments of aspects of care that are important to patients and caregivers.[6] These tools should also be particularly responsive to palliative care interventions as well as easily administered in palliative care populations and settings.[7] Given these goals, researchers and others seeking to improve the quality of palliative care face two challenges (1) determining whether there are sufficient tools to address all palliative care domains and applications, and (2) determining, for each domain and application, which tools are the most appropriate for use as determined by reliability, validity, and responsiveness.

Figure 1. Conceptualization of domains and applications of palliative care assessment tools



Domains	Subdomains
Structure and Process	Continuity Communication Case management
Physical	Pain Dyspnea Fatigue Nausea/Vomiting
Psychological & Psychiatric	Depression Distress Psych. support for families
Social	Patient, family support Caregiver strain, burden Caregiver quality of life
Spiritual, Religious, & Existential	Spiritual care Closure
Cultural	Cultural sensitivity Cultural assessment
Care at the end of life	Bereavement Comfort care
Ethical and Legal	Advance care planning
Multidimensional	Quality-of-life Patient experience

1. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington DC: National Academy of Sciences; 2015.
2. As adapted from: National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, Third Edition. 2015. http://www.nationalconsensusproject.org. Accessed on December 1, 2015.

Over the past 15 years, various groups have published compilations of palliative care assessment tools to try to address the challenges of measurement. In the mid-1990s, Teno et al. published a Toolkit of Instruments to Measure End-of-Life Care (TIME).8 (See Appendix B for a list of acronyms.) In 2004, for the National Institutes of Health State of the Science Conference on Improving End-of-Life Care,9 the End of Life Care and Outcomes systematic review10 updated the TIME review and summarized the psychometric properties of 99 additional, relevant assessment tools and their use in assessing palliative care interventions.11, 12 The PEACE Palliative Care Quality Measures project then updated the End of Life Care and Outcomes review through February 2007 and reported on a select number of tools.13

Since the PEACE project in 2007, no reviews have addressed the use of assessment tools across palliative care domains, although additional tools have been developed and applied in these domains. Subsequent systematic reviews have addressed a few individual domains and some multidimensional domains (e.g., quality of life); however, these reviews have not been synthesized into a comprehensive overview of the field. Given that these tools are frequently used together or overlap in measured concepts, and given the growth of the field of palliative care in clinical scope and research over the past ten years, an integrated overview of assessment tools is valuable. This overview would also: identify domains that lack sufficient assessment tools; highlight areas for future research; and provide a resource for individuals choosing tools for use in clinical care, quality indicators, or intervention settings.

Objectives of This Technical Brief

Our objectives are to provide a comprehensive overview of palliative care assessment tools that could be used by stakeholders interested in the use of palliative care assessment tools for application in clinical care, as quality indicators, or for evaluation of interventions. We also sought to identify evidence gaps and suggest next steps for future research about palliative care assessment tools.

Guiding Questions

Our work was guided by the following questions:

Guiding Question 1: In each of the palliative care domains, what palliative care assessment tools exist and have been evaluated in palliative care populations and/or settings?

Guiding Question 2: What is the state of current research on the reliability, validity, responsiveness, and usability of these assessment tools?

Guiding Question 3: What data exist regarding the application of these tools specifically in clinical care, as quality indicators, or for evaluation of interventions?

Guiding Question 4: What are the key gaps in tool development and evaluation and what are the opportunities for future research?

Methods

Engagement with Key Informants

We recruited Key Informants to give a balanced perspective on different domains, and applications of palliative care tools in providing guidance for our work. Key Informants included clinicians providing palliative care, leading palliative care assessment tool researchers, and caregivers for patients who had received palliative care. We conducted telephone meetings with the Key Informants to explore their perspectives related to assessment tools, particularly their beliefs regarding the efficacy and applicability of existing tools. We conducted two one and one-half hour-long meetings with the Key Informants: one call for caregivers, and one for clinicians/researchers. (See Appendix C for Key Informant questions.) Two team members reviewed the recordings and notes from the calls to identify themes.

Systematic Review Search

We searched for English-language systematic reviews using Cochrane, PubMed, CINAHL, PsycINFO, and PsycTESTS. (Detailed search strategies are available in Appendix D.) The search was conducted through August 29, 2016. We also screened the Palliative Care Research Cooperative Group (PCRC) list of reviews.[14] In our searches, we included all age groups, populations, and settings, but selected tools relevant to care in the U.S. We searched for reviews published within the last 10 years, because the PEACE systematic review was completed in 2007. We followed Evidence-based Practice Center (EPC) Program guidelines for the use of existing systematic reviews[15] and assessed the quality of relevant systematic reviews using the Risk of Bias in Systematic Reviews (ROBIS) tool.[16] Paired team members independently screened search results to select (1) systematic reviews describing palliative care assessment tools and their properties, and (2) systematic reviews on the use of palliative care assessment tools for the three applications of clinical practice, quality indicators, and evaluation of interventions. For each domain or subdomain and application, we chose one systematic review using these criteria: relevance, dual ROBIS quality assessment (Appendix E), the date of publication, and the availability of evidence tables.

Supplemental Search

We conducted supplemental searches for domains or subdomains that either (a) did not have a systematic review published within the last ten years or (b) had a systematic review with a search completed greater than three years ago. (See Appendix F for search flow of systematic review and supplemental searches.) Our supplemental search included:

1. Three comprehensive reviews of tools:
    a. The TIME Toolkit of Instruments to Measure End-of-Life Care[6]
    b. The systematic review for the National Institutes of Health State of the Science Conference on Improving End-of-Life Care [9-10]
    c. The PEACE Palliative Care Quality Measures project[11,17]
2. Web sites of compiled lists and databases of published palliative care tools:
    a. University of Washington End-of-Life Care Research Program Instruments[18]
    b. City of Hope Pain & Palliative Care Resource Center[19]
    c. National Palliative Care Research Center Measurement and Evaluation Tools[20]
    d. Center for Research on End-of-Life Care[22]

3. If we identified no tools through the above approaches, we conducted a targeted search in PubMed to identify primary literature on palliative care assessment tools addressing the specific domain or subdomain (Inclusion criteria used for the search can be found in Appendix G).

Since our supplemental searches did not include peer-reviewed data on tool characteristics, such as validity or reliability, we did not abstract those characteristics. Tools identified in the supplemental searches are summarized in the Appendices (Appendix J, Evidence Table 1).

Data Organization

We used the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care domains along with a ninth domain of “multidimensional tools” as a conceptual framework (Figure 1). We abstracted information from selected existing systematic reviews based on key elements from the National Quality Forum criteria for Patient Reported Outcomes in Performance Measurement,[17] developed by an expert panel and are based on scientific acceptability (i.e., validity, reliability, and responsiveness) and usability (i.e., verification that the tool has been used, is feasible, and provides useful information for palliative care in the areas of clinical practice, quality indicators, or evaluation of interventions).

Peer Review and Public Commentary

A draft version of this Technical Brief was posted for peer review on August 19, 2016, and we revised the report in response to reviewer comments.

Results

Summary of Engagement with Key Informants

We engaged nine Key Informants: two caregivers and seven clinicians/researchers who are experts in palliative care and assessment tools in areas including oncology, geriatrics, pediatrics, critical care, hospice, tool development, palliative care quality indicators, and evaluation of palliative care interventions.

Caregivers

Both caregivers reported completing numerous written questionnaires with “tons of questions,” which overwhelmed them and became so granular that the caregivers felt they could not provide an accurate depiction of their experience and the issues that mattered most to them. Caregivers also felt that the way the assessments were administered “always felt rushed” in that they did not have time to reflect on the questions and often just indicated “their initial thoughts” or just “bubbled in an answer”. They felt that the information captured in the tools was meaningful to clinicians, but they were not convinced the tools impacted patients or families.

To enhance the efficacy of detailed assessment tools, the advocates suggested that any encounter or survey should start with a question to identify the patient or family member’s unique “biggest concern,” and surveys or questionnaires should ultimately empower the patient or family member to “say what is on his or her mind.” For example, one caregiver supported her mother while she took care of her stepfather. The mother’s biggest concern was learning how she could keep her husband at home until the end of his life; this concern was not otherwise a priority for the physician.

Providers

Discussions with providers were focused on their experiences with the assessment tools. Many felt that these tools were being used appropriately in research but they were not used often enough in clinical care delivery or as quality indicators. Providers agreed that the eight domains and the “cross domains” category (multidimensional area) added by this team were valid, but they noted that more specificity is required in each domain and that the domains still do not address some crucial aspects of palliative care (e.g., overall scale of experience, advance care planning, and informed decision making). They specifically noted that there are few tools that assess the spiritual domain. They noted significant confounding between the care delivered and the experience of that care, as well as difficulty in assessing communication (including disagreement about whether communication is a process or an outcome).

The providers noted several issues related to the successful use of assessment tools. First, owing to their illnesses, patients are often unable to complete complex or lengthy assessment tools. Second, assessment tools as quality indicators are an inherent contradiction, which may result in poor or easily misconstrued measurements: “successful” palliative interventions do not typically lead to an improvement in assessment tool-based scores but, rather, to a slowing in the decline of impairments. Third, many tools include “ceiling effects” with consequent limitations in responsiveness or ability to detect change, particularly in patient experience metrics. Fourth, if used as quality indicators, some assessment tools could unintentionally incentivize actions that are detrimental to patient care, such as treating pain aggressively to bring down pain scores included in the tools, rather than balancing pain management with risks and harms of treatments, such as sedation, that are not included in the tools. Finally, the providers also raised concerns that long, detailed assessments are often not completed and, thus, cannot capture a global assessment of the patient's actual clinical experience.

Systematic Review and Supplemental Searches

For the systematic review search, we identified 354 unique citations, of which 40 systematic reviews were eligible for inclusion. From these, we selected ten recent high-quality systematic reviews: seven addressing domains of palliative care and three addressing applications of palliative care assessment tools. (Note: the systematic review for interventions, published after our search date, was brought to our attention by one of our advisors.)

For three (physical, care at the end of life, and multidimensional) of the nine domains we identified key subdomains (Figure 1). For the physical domain, these key subdomains are pain, dyspnea, and fatigue. For the care at the end of life domain, the key subdomain was bereavement. For the multidimensional domain, we determined the key subdomains to be quality of life and patient experience. Only one domain (social) and one subdomain (bereavement) had systematic reviews with search strategies that were less than three years old such that we did not complete a supplemental search. Two domains (psychological and psychiatric; spiritual, religious, and existential) and three subdomains (dyspnea; quality of life; patient experience) had systematic reviews with search strategies greater than three years old and thus required supplemental searches. Three domains (structure and process; cultural; ethical and legal) and two subdomains (pain; fatigue) lacked any recent systematic review (Table 1). There was only one domain (cultural) for which we identified no tools through either systematic reviews or our supplemental search, including a targeted search of PubMed (Appendix H, Figure H-2).

We identified a total of 152 tools; 97 tools were identified from systematic reviews, and supplemental searches identified an additional 55 tools (Table 1; Appendix H, Figure H-1). A list of all identified tools organized by domain or subdomain is available in Appendix I.

State of the Research on Assessment Tools by Domain and Key Subdomains (Guiding Questions 1 and 2)

Domain 1: Structure and Process

We did not identify a systematic review for this domain. In a supplemental search, we identified two tools (Appendix J, Evidence Table 1).

Domain 2: Physical

Physical symptoms include multiple subdomains such as pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, and constipation. Based on subdomains addressed in previous reviews, we summarized assessment tools for the three key subdomains of: dyspnea, pain, and fatigue.[8, 11-13, 17]

Physical - Subdomain: Dyspnea

We selected one systematic review - Dorman 2007[18] – which identified 26 tools that met our inclusion criteria. Tools addressed severity, descriptions, and functional impact or limitations related to dyspnea. Settings included inpatient and outpatient care and home settings and a wide variety of conditions, including cancer, chronic obstructive pulmonary disease, heart failure, and other lung conditions. The review reported internal consistency reliability for 14 tools, convergent validity for 23 tools, and responsiveness was reported for only eight tools. The review reported usability (i.e., time to complete) for 15 tools (Table 2; Appendix J, Evidence Tables 2a-2e).

Physical – Subdomain: Pain

We did not identify any high-quality, recent systematic review for the subdomain of pain. We identified 25 tools in our supplemental search (Appendix J, Evidence Table 1).

Physical – Subdomain: Fatigue

We did not identify any high-quality, recent systematic review for the subdomain of fatigue. Our supplemental search identified seven tools (Appendix J, Evidence Table 1).

Table 1. Summary of the search for palliative care assessment tools

Domain or Application	Identified in Systematic Review, N	Identified in Supplemental Search, N	Source of Information	Search Dates of the Systematic Reviews
Domains				
1. Structure and Process of Care	0	2	1 Website 1 Supplemental comprehensive review[11]	NA
2. Physical--Dyspnea	26	0	1 Systematic review[18]	Up to September 2005
2. Physical—Pain	0	25	2 Websites	NA
2. Physical—Fatigue	0	7	2 Websites	NA
3. Psychological and Psychiatric	8	18	1 Systematic review[19] 4 Websites 1 Supplemental comprehensive review[11]	1960 to unspecified end date
4. Social Aspects of Care	8	Not done	1 Systematic review[20]	Up to September 2014
5. Spiritual, Religious, and Existential	2	0	1 Systematic review[21] (Supplemental search completed but no new tools identified)	Up to June 2010
6. Cultural	0	0	none	NA
7. Care at the End of Life—Bereavement	17	Not done	1 Systematic review, [22]	Up to August 2014
8. Ethical and Legal	0	2	1 Website	NA
9. Multidimensional Tools—Quality of Life	28	0	1 Systematic review[23]	January 1990 to April 2008
9. Multidimensional Tools—Patient Experience	8	1	1 Systematic review[24] 1 Website	January 1990 to June 2012
Total Number of Tools	97	55		
Applications				
Clinical Care	6	NA	1 Systematic review[25]	1985 to August 2011
Quality Indicators	1	NA	1 Systematic review[26]	Up to October 2011
Interventions	23	NA	1 Systematic review[27]	Up to December 2015

NA=not applicable

.

Table 2. Summary table of tools addressing physical domain (dyspnea subdomain) identified from Dorman et al., 2007[18]

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsive -ness Measured	Time to Complete Measured	Number of Items
Visual Analogue Scale[28]	Asthma, COPD, ventilated	NA	Y	Y	N	Y	1
Numeric Rating Scale or Dyspnea Numeric Scale[29, 30]	Cancer, COPD	NA	Y	Y	N	Y	1
Modified Borg Scale[31]	COPD, restrictive lung disease, asthma	NA	Y	Y	N	Y	1
Global Shortness of Breath Question[32]	COPD	NA	Y	N	Y	N	1
Faces Scale[33]	Ventilated	NA	Y	N	N	N	1
Dyspnea Descriptor Questionnaire (heart failure)[34]	Heart failure	Y	N	N	N	N	13
Dyspnea Descriptor Questionnaire (COPD)[35]	COPD	Y	N	N	N	N	16
Dyspnea Assessment Questionnaire[36]	Cancer	N	Y	N	N	N	43
Amyotrophic Lateral Sclerosis Functional Rating Scale – revised[37]	MND (Motor Neuron Disease)	Y	Y	N	N	N	3
American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale[38]	COPD, asthma	Y	Y	N	N	Y	5
Breathlessness, Cough and Sputum Scale[39]	COPD	NA	Y	Y	Y	N	1
Chronic Heart Failure Questionnaire – dyspnea subscale[40]	Heart failure	Y	Y	Y	Y	Y	5
Cardiovascular Limitations and Symptoms Profile[41]	Ischemic heart disease	N	Y	N	N	Y	6
Chronic Lung Disease Severity Index[42]	Chronic lung disease	Y	Y	N	N	N	2
Chronic Respiratory Questionnaire – dyspnea subscale[43]	COPD, interstitial lung disease, cystic fibrosis, alpha antitrypsin deficiency, MND	Y	Y	Y	Y	Y	5

Table 2. Summary table of tools addressing physical domain (dyspnea subdomain) identified from Dorman et al., 2007[18]

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsive-ness Measured	Time to Complete Measured	Number of Items
Chronic Respiratory Questionnaire – Standardized dyspnea questions[44]	ND	N	N	N	N	N	5
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Lung Cancer supplement, breathlessness subscale[45]	Lung cancer	Y	Y	Y	N	N	3
London Chest Activity of Daily Living Scale[46]	COPD	Y	Y	Y	N	N	15
Motor Neuron Disease Dyspnea Rating Scale[47]	MND	Y	Y	N	N	Y	5
Medical Research Council Dyspnea Scale[48]	COPD, interstitial lung disease, asthma, other	N	Y	Y	N	Y	1
Oxygen Cost Diagram[49]	Respiratory disease, COPD, heart failure	NA	Y	N	Y	Y	1
Pulmonary Functional Status and Dyspnea Questionnaire – modified[50]	COPD	Y	Y	Y	N	Y	5
Rand Instrument[51]	Heart failure, respiratory disease	N	Y	N	Y	Y	9
St George's Respiratory Questionnaire[52]	COPD, asthma, bronchiectasis	Y	Y	Y	Y	Y	16
University of Cincinnati Dyspnea Questionnaire[53]	Asthma, sarcoid, COPD, fibrosis	Y	Y	N	N	Y	30
University of California San Diego Shortness of Breath Questionnaire[54]	COPD, asthma, cystic fibrosis, lung transplant	Y	Y	N	Y	Y	24

COPD=chronic obstructive pulmonary disease; MND=motor neuron disease; N=not measured for tool; NA=not applicable; ND=not described in review; Y=measured for tool

Domain 3: Psychological and Psychiatric

The Ziegler 2011 systematic review[19] included eight tools that met our inclusion criteria. Tools were tested in the following settings: inpatient and outpatient care and a palliative care unit, and included cancer patients with advanced disease and cancer patients at the time of first cancer recurrence. The tools addressed depression, anxiety, distress, and psychological response to cancer. No tools had data on responsiveness or usability (time to complete); one tool had data on internal consistency reliability and seven tools had data on convergent validity in the palliative care population (Table 3; Appendix J, Evidence Tables 3a-3e).

Because the search from the systematic review for this domain was greater than three years old and addressed only cancer, we completed a supplemental search that yielded 18 additional tools (Appendix J, Evidence Table 1).

Domain 4: Social Aspects of Care

The Michels 2016 systematic review[20] included eight tools that met our inclusion criteria: caregiver-reported assessment tools that addressed outcomes of informal caregivers (i.e., caregiver burden, strain and quality of life). The review reported information on internal consistency reliability for all tools, convergent validity for seven tools, and responsiveness for three tools. The assessment tools ranged from 13 to 35 items, with only one tool with information on usability (time to complete) (Table 4; Appendix J, Evidence Tables 4a-4e).

As the systematic review was published in 2016, we did not conduct a supplemental search.

Domain 5: Spiritual, Religious, and Existential

The Selman 2011 systematic review[21] identified two tools that met our inclusion criteria. Of note, the review collected and described assessment tools for spirituality as defined by “religious faith as well as existential/humanist positions” and “applicable to all human beings” and no specific target population was pre-identified for the search. The two tools, The Beck Hopelessness Scale and the Ironson-Woods Spirituality/Religiousness Index, specifically address spirituality and are evaluated in an ethnically diverse U.S. palliative care population (i.e., the Beck Hopelessness Scale was validated in populations including AIDS patients and hospice inpatients with cancer; the Ironson-Woods Spirituality/Religiousness Index was validated in an HIV/AIDS population).[55, 56] Both tools had information on internal consistency reliability, convergent validity, criterion or discriminant validity, and responsiveness but no information on usability (time to complete) (Table 5; Appendix J, Evidence Tables 5a-5e).

Because the search from the systematic review was more than three years old, we completed a supplemental search, but did not identify any additional tools.

Table 3. Summary table of tools addressing psychological and psychiatric domain identified from Ziegler et al., 2011[19]

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Criterion or Discriminant Validity Measured	Responsive -ness Measured	Time to Complete Measured	Number of Items
Hospital Anxiety and Depression Scale[57]	Patients receiving palliative care with a prognosis of six months or less	N	Y	ND	N	Y	14
Two Single Items: "Are you depressed?" and "Have you lost interest?"[58]	Palliative care population	N	Y	ND	N	Y	2
Distress Thermometer (via touch screen)[59]	Patients with advanced disease	N	Y	ND	N	Y	1
Brief Symptom Inventory-18 item (via touch screen)[59]	Patients with advanced disease	N	Y	ND	N	Y	18
General Health Questionnaire-12 item[59]	Patients with advanced disease	N	Y	ND	N	Y	12
Brief Edinburgh Depression Scale[60]	Patients receiving palliative care with a prognosis of six months or less	Y	Y	ND	N	Y	6
Beck Depression Inventory-Short Form[57]	Patients with metastatic breast cancer	N	Y	ND	N	Y	13
Mental Adjustment to Cancer[61]	Patients at first recurrence of breast cancer	N	N	ND	N	N	40

Y=measured for tool, N=not measured for tool, ND=not described in review

Table 4. Summary table of tools addressing social domain identified from Michels et al., 2016[20]

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Criterion or Discriminant Validity Measured	Responsive -ness Measured	Time to Complete Measured	Number of Items
Caregiver's Burden Scale in End-of-life Care[62]	Family caregivers of patients with terminal cancer	Y	Y	Y	Y	N	16
Caregiver Impact Scale[63]	Caregivers of patients with advanced cancer	Y	N	N	N	N	14
Caregiver Quality of Life Index – Cancer[64]	Caregivers of patients with cancer	Y	Y	Y	Y	Y	35
Caregiver Reaction Assessment[65]	Caregivers of patients receiving palliative care	Y	Y	N	N	N	24
Caregiver Strain Index[66]	Caregivers for patients with symptomatic advanced cancer	Y	Y	N	N	N	13
Family Appraisal of Caregiving Questionnaire for Palliative Care[67]	Caregivers of patients receiving palliative care	Y	Y	N	N	N	26
Quality of Life in Life-Threatening Illness-Family Carer Version[68]	Caregivers of patients receiving palliative care for cancer	Y	Y	N	Y	N	16
Zarit Burden Inventory[69]	Advanced conditions	Y	Y	N	N	N	22

Y=measured for tool, N=not measured for tool, ND=not described in review

Table 5. Summary table of tools addressing spiritual, religious, and existential domain identified from Selman et al., 2011[21]

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Criterion or Discriminant Validity Measured	Responsive -ness Measured	Time to Complete Measured	Number of Items
Beck Hopelessness Scale[55, 70, 71]	Ethnically diverse U.S. population; validated in palliative care population	Y	Y	Y	Y	N	120
Ironson-Woods Spirituality/Religiousness Index[56]	Ethnically diverse U.S. population	Y	Y	Y	Y	N	22

Y=measured for tool, N=not measured for tool, ND=not described in review

Domain 6: Cultural

The cultural domain refers to whether care is sensitive to a patient's culture, race, or ethnicity. We identified no existing systematic review or eligible tools that focused on the cultural domain. In addition to completing the supplemental search, we also evaluated whether any of the tools addressing the multidimensional domain had items that addressed the cultural domain, and none did.

Domain 7: Care at the End of Life

The care at the end of life domain includes multiple subdomains such as bereavement, quality of death, symptom scores immediately prior to death, or caregiver assessments of the quality of death. Based on subdomains addressed in previous reviews, we selected the key subdomain of bereavement.[8, 11-13, 17]

Subdomain: Bereavement

The Sealey 2015 systematic review[22] identified 17 tools that met our inclusion criteria. The review did not define settings where the tools are tested, and tools are only for bereaved adults and caregivers (not patients). Some tools addressed specific patient populations (e.g., patients with dementia, cancer, trauma, or in hospice) or specific caregiver populations (e.g., spouses or those with prolonged grief disorder). The tools are designed for pre-death bereavement risk, after-death bereavement assessment, or for the assessment of complicated or prolonged bereavement. All tools had information on internal consistency reliability. Three tools had data on convergent validity. None of the tools had data on responsiveness, and only two had data on usability (time to complete). The number of items ranged widely from five to 91 items (Table 6; Appendix J, Evidence Tables 6a-6e).

We did not conduct a supplemental search because the systematic review search strategy was conducted through 2014.

Domain 8: Ethical and Legal

We did not identify any systematic reviews focusing on tools addressing the ethical and legal domain. We completed a supplemental search which identified two eligible tools, the Relatives' Patient Management questionnaire and the Willingness to Accept Life-sustaining Treatment instrument (Appendix J, Evidence Table 1).

Domain 9: Multidimensional

Multidimensional tools can include subdomains such as quality of life, patient experience, or satisfaction with care. Based on subdomains addressed in previous reviews,[8, 11-13, 17] we selected the two key subdomains quality of life (which may include areas such as physical health and functional status, mental health, social and role function, and physical and psychological symptoms) and patient experience.

Table 6. Summary table of tools addressing care at the end of life domain (bereavement subdomain) identified from Sealey et al., 2015[22]

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Criterion or Discriminant Validity Measured	Responsive -ness Measured	Time to Complete Measured	Number of Items
Bereavement Experience Questionnaire–24[72]	Bereaved adults	Y	N	ND	N	N	24
Brief Grief Questionnaire[73-75]	Recipients of crisis counselling following 911 terrorist attacks; bereaved community-dwelling adults	Y	N	ND	N	N	5
Core Bereavement Items[76]	Bereaved adults	Y	Y	ND	N	N	17
Grief Evaluation Measure[77]	Bereaved adults	Y	N	ND	N	Y	91
Grief Experience Questionnaire[78]	Bereaved spouses	Y	N	ND	N	Y	55
Hogan Grief Reaction Checklist[79]	Parentally bereaved people	Y	N	ND	N	N	61
Inventory of Complicated Grief[80]	Bereaved spouses	Y	N	ND	N	N	19
Inventory of Complicated Grief–Revised[81-83]	Bereaved spouses	Y	N	ND	N	N	15
Inventory of Traumatic Grief[84]	Elderly widowed residents; bereaved adults	Y	N	ND	N	N	34
Marwit–Meuser Caregiver Grief Inventory[85-87]	Caregivers of people with dementia, acquired brain injury, cancer	Y	Y	ND	N	N	50
Marwit–Meuser Caregiver Grief Inventory–Short Form[88]	Adult caregivers of people with dementia	Y	Y	ND	N	N	18
Prolonged Grief–12[89, 90]	Caregivers of people with dementia, hospice patients	Y	N	ND	N	N	12
Prolonged Grief–13[91, 92]	Adults; bereaved caregivers with prolonged grief disorder	Y	N	ND	N	N	13

Table 6. Summary table of tools addressing care at the end of life domain (bereavement subdomain) identified from Sealey et al., 2015[22] (continued)

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Criterion or Discriminant Validity Measured	Responsive-ness Measured	Time to Complete Measured	Number of Items
Revised Grief Experience Inventory[93]	Hospice caregivers following the death of a loved one	Y	N	ND	N	N	22
Texas Revised Inventory of Grief[94-97]	Bereaved psychiatric outpatients; bereaved adults	Y	N	ND	N	N	21
Two-Track Bereavement Questionnaire[98]	Bereaved adults	Y	N	ND	N	N	70
Two-Track Bereavement Questionnaire–CG30*[99]	Adults bereaved by traumatic deaths	Y	N	ND	N	N	30

Y=measured for tool, N=not measured for tool, ND=not described in review

* Reference given in the systematic review for the Two-Track Bereavement Questionnaire-CG30 is a conference abstract. We were unable to retrieve the abstract to verify, after exhausting all resources.

Subdomain - Quality of Life

The Albers 2010 systematic review[23] identified 28 tools that met our inclusion criteria. The tools were developed for and evaluated in hospice, home care, outpatient and inpatient settings (including palliative care units), and long term care. Populations included palliative care patients, seriously ill patients, cancer patients, and patients near the end of life. Many tools contained items that addressed most domains, including structure and process (four tools), physical (21 tools), psychological and psychiatric (20 tools), spiritual, religious and existential (11 tools), social (11 tools), ethical and legal (six tools) and care at the end of life (two tools) (Table 7). No tools contained items that addressed the cultural domain. All tools had data on internal consistency reliability, while 27 had data about convergent validity, seven had data on responsiveness, and 14 had data on usability (time to complete) (Appendix J, Evidence Tables 7a-7e).

As the search from the systematic review was greater than three years old, we completed a supplemental search but identified no additional tools.

Subdomain - Patient Experience

The Lendon 2015 systematic review[24] identified eight tools that met our inclusion criteria. Six tools only addressed the caregiver's perception of the patient's quality of end-of-life care, and two addressed the patient's or the caregiver's perception. The tools had a range of 25-74 items and contained items that addressed most domains, including structure and process (six tools), physical (seven tools), psychological and psychiatric (seven tools), spiritual, religious and existential (seven tools), social (five tools), and are at the end of life (five tools); we could not determine from the review whether ethical and legal and cultural domains were addressed (Table 8). Six tools had information on internal consistency reliability. Four had information on convergent validity. None had data on responsiveness or usability (time to complete) (Appendix J, Evidence Tables 8a-8e).

Because the search from the systematic review was more than three years old, we completed a supplemental search which identified one additional tool, the Caregiver Evaluation of Quality of End-of-Life Care (Appendix J, Evidence Table 1).

Table 7. Summary table of tools addressing multidimensional domain (quality of life subdomain) identified from Albers et al., 2010[23]

Tool	Domains Included	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsive-ness Measured	Time to Complete Measured	Number of Items
Brief Hospice Inventory[100]	Physical, Psychological and Psychiatric	Patients in hospice	Y	N	ND	N	Y	17
Cambridge Palliative Audit Schedule[101]	Physical, Psychological and Psychiatric	Patients receiving palliative care	Y	Y	ND	Y	N	2x10
Demoralization Scale[102]	Psychological and Psychiatric	Patients with cancer	Y	Y	ND	N	N	24
Edmonton Functional Assessment Tool[103, 104]	Physical	Patients with cancer	Y	Y	ND	N	N	11
Emanuel and Emanuel Medical Directive[105]	Ethical/Legal	Patients who are severely ill	Y	Y	ND	Y	Y	48
European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal Cancer Module[106]	Physical	Patients with esophageal cancer	Y	Y	ND	Y	Y	18
European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric Cancer Module[107]	Physical, Psychological and Psychiatric	Patients with adenoma carcinoma of the stomach	Y	Y	ND	Y	Y	22
Edmonton Symptom Assessment Scale[108]	Physical, Psychological and Psychiatric	Patients receiving palliative care	Y	Y	ND	N	Y	10

Table 7. Summary table of tools addressing multidimensional domain (quality of life subdomain) identified from Albers et al., 2010[23] (continued)

Tool	Domains Included	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsive-ness Measured	Time to Complete Measured	Number of Items
FACIT-Pal Functional Assessment of Chronic Illness Therapy-Palliative Subscale[109]	Physical, Psychological and Psychiatric, Social, Ethical/Legal	Patients with life limiting illness	Y	Y	ND	N	N	19
Hospice Quality of Life Index[110, 111]	Physical, Psychological and Psychiatric, Social, Spiritual	Patients in hospice	Y	Y	ND	N	Y	28
Life Closure Scale[112]	Psychological and Psychiatric	Patients who are terminally ill	Y	Y	ND	N	N	20
Life Evaluation Questionnaire[113]	Psychological and Psychiatric, Social	People with incurable cancer	Y	Y	ND	N	N	44
McMaster Quality of Life Scale[114]	Physical, Psychological and Psychiatric, Social	Patients receiving palliative care	Y	Y	ND	Y	Y	32
McGill Quality of Life Questionnaire[115, 116]	Physical, Psychological and Psychiatric, Social, Spiritual	People with life threatening illness	Y	Y	ND	Y	Y	16
McGill Quality of Life Questionnaire-Cardiff Short Form[117]	Physical, Psychological and Psychiatric, Spiritual	Patients who are terminally ill	Y	Y	ND	N	Y	8
McCanse Readiness for Death Instrument[118]	Physical, Psychological and Psychiatric, Social, Spiritual	Patients who are terminally ill	Y	Y	ND	N	N	28
Memorial Symptom Assessment Scale[119, 120]	Physical, Psychological and Psychiatric	Patients with cancer	Y	Y	ND	N	Y	32
Condensed Memorial Symptom Assessment Scale[121]	Physical, Psychological and Psychiatric	Patients with cancer	Y	Y	ND	N	Y	14

Table 7. Summary table of tools addressing multidimensional domain (quality of life subdomain) identified from Albers et al., 2010[23] (continued)

Tool	Domains Included	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsive-ness Measured	Time to Complete Measured	Number of Items
Memorial Symptom Assessment Scale-Global Distress Index[122]	Physical, Psychological and Psychiatric	Patients with cancer	Y	N	ND	N	N	11
Missoula-VITAS Quality of Life Index[123, 124]	Physical, Social, Spiritual	Patients who are terminally ill	Y	Y	ND	Y	N	25
Needs Assessment for Advanced Cancer Patients[125]	Structure and Process, Physical, Social, Spiritual	Patients with advanced cancer	Y	N	ND	N	Y	132
Patient Autonomy Questionnaire[126]	Ethical/Legal	Patients receiving palliative care for cancer	Y	Y	ND	N	N	4/9
Patient Dignity Inventory[127]	Physical, Social, Spiritual	Patients nearing the end of life	Y	Y	ND	N	Y	25
Problems and Needs in Palliative Care Questionnaire[128]	Structure and Process, Physical, Psychological and Psychiatric, Social Spiritual, Ethical/Legal	Patients receiving palliative care	Y	Y	ND	N	N	138
Problems and Needs in Palliative Care Questionnaire-Short Version[129]	Structure and Process, Physical, Psychological and Psychiatric, Social Spiritual, Ethical/Legal	Patients receiving palliative care	Y	Y	ND	N	N	33
Palliative care Outcome Scale[130]	Physical, Psychological and Psychiatric, Spiritual	Patients with advanced cancer	Y	Y	ND	Y	Y	10
Quality of Life at the End of Life[131]	Structure and Process, Psychological and Psychiatric, Ethical/Legal, End of Life	Patients who are seriously ill	Y	Y	ND	N	N	26
Spiritual Needs Inventory[132]	Spiritual	Patients near the end of life	Y	Y	ND	N	N	17

Y=measured for tool, N=not measured for tool, ND=not described in review

Table 8. Summary table of tools addressing multidimensional domain (patient experience subdomain) identified from Lendon et al., 2015[24]*

Tool	Domains included	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsive -ness Measured	Time to Complete Measured	Number of Items
After Death Bereaved Family Member Interview[133-140]	Structure and Process, Physical, Spiritual, Psychological and Psychiatric, Social, End of Life	Close relatives, Surrogates, Caregivers	Y	Y	Y	N	N	74
End of Life in Dementia-Satisfaction with Care & Comfort Assessment in Dying[136, 141, 142]	Structure and Process, Physical, Spiritual, Psychological and Psychiatric	Patients or health care proxies, Caregivers	Y	N	N	N	N	41
Family Assessment of Treatment of End-of-Life Survey[143-147]	Structure and Process, Physical, Social, Psychological and Psychiatric, Spiritual, End of Life	Family members	Y	N	Y	N	N	58
Family Evaluation of Hospice Care[148-155]	Structure and Process, Physical, Spiritual, Psychological and Psychiatric, Social, End of Life	Family members	N	N	N	N	N	56
Family Satisfaction in the ICU[156-158]	Structure and Process, Physical, Spiritual, Social, End of Life	Family members	Y	Y	N	N	N	25
Family Satisfaction with Advanced Cancer Care[159-166]	Psychological and Psychiatric, Physical, Social	Caregivers, Family members	N	N	N	N	N	30
Quality of Dying and Death[158, 167-171]	Physical, Psychological and Psychiatric, Spiritual, End of Life	Family members	Y	Y	Y	N	N	31
Quality of End-of-Life Care and Satisfaction with Treatment[172-174]	Structure and Process, Spiritual, Psychological and Psychiatric	Patients, Family members	Y	Y	Y	N	N	47

Y=measured for tool, N=not measured for tool, ND=not described in review

*Note that ethical and legal, and cultural domains could not be determined from the review.

Applications of Assessment Tools (Guiding Question 3)

Clinical Care

The Antunes 2014 systematic review[25] evaluated the use of patient-reported outcome measures in clinical care in adults in palliative care settings and found 31 studies evaluating implementation issues. Six studies are conducted in the U.S. and reported on the use of specific assessment tools. The six tools used in these studies included multidimensional tools (quality of life tools, three studies), physical (numerical rating or visual analog scales for pain, two studies), and psychological or psychiatric (one study). We identified four of these tools in systematic reviews (The Edmonton Symptom Assessment Scale, Missoula-VITAS Quality of Life Index, Memorial Symptom Assessment Scale, and Functional Assessment of Chronic Illness Therapy-Lung) and two in our supplemental searches (Numeric Rating Scale for Pain, and Visual Analogue Scale for Pain). Settings included hospices, cancer centers, nursing homes, emergency care, and home. Most clinical care was of cancer patients (Appendix J, Evidence Tables 9a-9b).

Quality Indicators

The De Roo 2013 systematic review[26] evaluated quality indicators developed specifically for palliative care. This review identified ten U.S. indicator sets. However, only one indicator specified a palliative care assessment tool (most are indicators abstracted from the medical record, rather than reported by or with patients or caregivers). The one palliative care assessment tool, Family Evaluation of Hospice Care,[175] was a multidimensional tool assessing patient experience, which we identified from the patient experience systematic review (Lendon, 2015) (Appendix J, Evidence Tables 10a-10b).

Evaluation of Interventions

The Kavalieratos 2016 systematic review[27] evaluated assessment tools used in randomized controlled trials of palliative care interventions in adults with terminal or life-limiting illness.[27] In the 43 included studies evaluating palliative care interventions, the authors found 23 palliative care assessment tools that are used to evaluate the interventions related to the physical domain (seven tools), psychological and psychiatric domain (six tools), patient experience (two tools), or quality of life (six tools). The most commonly used physical domain palliative care assessment tool was the Numeric Rating Scale for Pain, but this was used in only four of the studies. The most commonly used palliative care assessment tool for the psychological and psychiatric domain was the Hospital Anxiety and Depression Scale, which was used in only six of 27 studies evaluating this domain. For multidimensional tools, the most commonly used palliative care assessment tool for quality of life was the Edmonton Symptom Assessment Scale, which was used in only five studies. Two studies used two different multidimensional patient experience palliative care assessment tools (Table 9; Appendix J, Evidence Tables 1 and 11).

Table 9. Summary of palliative care assessment tools that are used in 23 studies evaluating palliative care interventions and how often they were used

Domain, N Tools	Tool (Number of studies in which tool was used)
Physical, 7 tools	Numerical Rating Scale for Pain (4)† Chronic Respiratory Disease Questionnaire (1) University of California, San Diego Shortness of Breath Questionnaire (1) Brief Pain Inventory (2)† Pain as Assessed in the Medical Outcomes Study (1)† Visual Analog Scale for Pain (1)† Memorial Pain Assessment Card (1)†
Psychological and Psychiatric, 6 tools	Center for Epidemiologic Studies Depression Scale (5)† Cornell Scale for Depression in Dementia (1)† General Health Questionnaire-12 Item (1) Hospital Anxiety and Depression Scale (6) Impact of Event Scale (1)† Patient Health Questionnaire-9 (4)† Profile of Mood States (4)†
Multidimensional - Patient Experience, 2 tools	Family Satisfaction with Advanced Cancer Care (16 item version) (1) McCusker Scale (1)†
Multidimensional - Quality of Life, 5 tools	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-30 Item (2) Edmonton Symptom Assessment Scale (5) Functional Assessment of Chronic Illness Therapy-Palliative Sub Scale (3) Memorial Symptom Assessment Scale (2) McGill Quality of Life Scale (1) Quality of Life at the End of Life (3)

† Indicates tool that was found during supplemental search

Discussion (Guiding Question 4)

We identified 152 different palliative care assessment tools with varying psychometric properties reported across eight of the nine domains of palliative care (Figure 2). While some domains and subdomains (dyspnea; psychological and psychiatric; social; bereavement) had many assessment tools, other domains had few (spiritual, religious, and existential; ethical and legal) or no (cultural) tools. Few tools addressed usability (time to complete). Moreover, the burden associated with tools, as evaluated by the number of items in each tool, varied significantly by domain; for example, the mean number of items per tool identified in the systematic review was 24, but domain means varied between: seven items (Dyspnea), 13 items (psychological and psychiatric), 21 items (social), 22 items (spiritual, religious, and existential), 33 items (bereavement), 30 items (quality of life), and 47 items (patient experience). The key gaps by domain are:

- For the structure and process domain, we identified only two tools through our supplemental search, one on continuity and one on communication. Since our Key Informants identified communication as a key aspect of palliative care, this lack of tools suggests that this is an important area for future tool development.
- For the physical domain, we focused on the subdomains of dyspnea, pain, and fatigue. For dyspnea, only eight of the 26 tools had testing of responsiveness (sensitivity to change), which is needed to evaluate the impact of clinical or other interventions. We identified no systematic review that specifically compiled and compared pain assessment tools in palliative care populations. We identified a number of pain assessment tools in our supplemental search, but given the critical importance of this subdomain for palliative care, a detailed systematic review of the evaluation of the use of these tools in palliative care populations and their psychometric testing is needed. We identified seven tools assessing fatigue but no high quality recent systematic review.
- For the psychological and psychiatric domain, we identified eight tools in palliative care populations, but the scope of the review we found for this domain was limited to patients with cancer. We identified additional tools in our supplemental search that may be relevant. A systematic review to synthesize the properties and relevance of these tools would be useful.
- In the social domain, few of the eight tools were specifically developed for patients receiving palliative care and many potentially relevant tools described in the systematic review had not been tested in palliative care populations. Insufficient or incomplete information was available about the psychometric properties of these tools. Future research comparing these tools and exploring their responsiveness in palliative care populations is needed.
- The lack of tools assessing the spiritual, religious and existential domain is also a key gap, as noted by the Key Informants and confirmed by our search: we identified only two tools that focused on spirituality evaluated in palliative care populations. Further development of spirituality tools for palliative care and testing of existing tools in this population would be valuable.
- We found no assessment tools focusing on the cultural domain, and multidimensional tools also did not address this domain. This domain should be considered for future tool

development. Future research is also needed to determine how this domain could be included in multidimensional tools.
- In the care at end of life - bereavement subdomain, many of the tools were developed in palliative care populations but the information on validity and responsiveness was sparse. Most tools were also long, with one tool having 91 component items. As emphasized by our Key Informants, short, easy-to-complete tools are important, especially for the bereaved informal caregivers who complete these tools; few simple, low-burden, yet meaningful assessment tools exist.
- For the ethical and legal domain, we identified only three tools in our supplemental search and there were only six multidimensional assessment tools that had items addressing this domain. Future research is needed to both conceptualize and develop specific tools; this could also involve the evaluation of pre-existing items in multidimensional tools.
- The Key Informants emphasized the importance of patient-reported experience (multidimensional domain); however, we found only two tools assessing patient-reported experience (the rest were for caregiver-reported experience).
- Across domains, we identified no high-quality systematic review that addressed palliative care assessment tools for use in pediatric populations.

In assessing the applications for which palliative care assessment tools are used, the systematic review evaluating use of assessment tools in clinical care found only six studies.[25] We did identify one assessment tool being used as a quality indicator[26] in the United States, although this assessment tool from the National Hospice and Palliative Care Organization is no longer in use and has been replaced by the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey.[176] (Of note, this technical brief predates the new CMS Hospice Item Set (HIS) of quality indicators, which is being revised at the time of this report.[177]) We identified 23 palliative care assessment tools that were used to evaluate interventions[27]; however, none of these tools was used in more than six of the 43 palliative care intervention studies summarized in the systematic review. This lack of standardization may limit the ability to compare and synthesize evidence across studies of palliative care interventions.

Next Steps

Tool Development

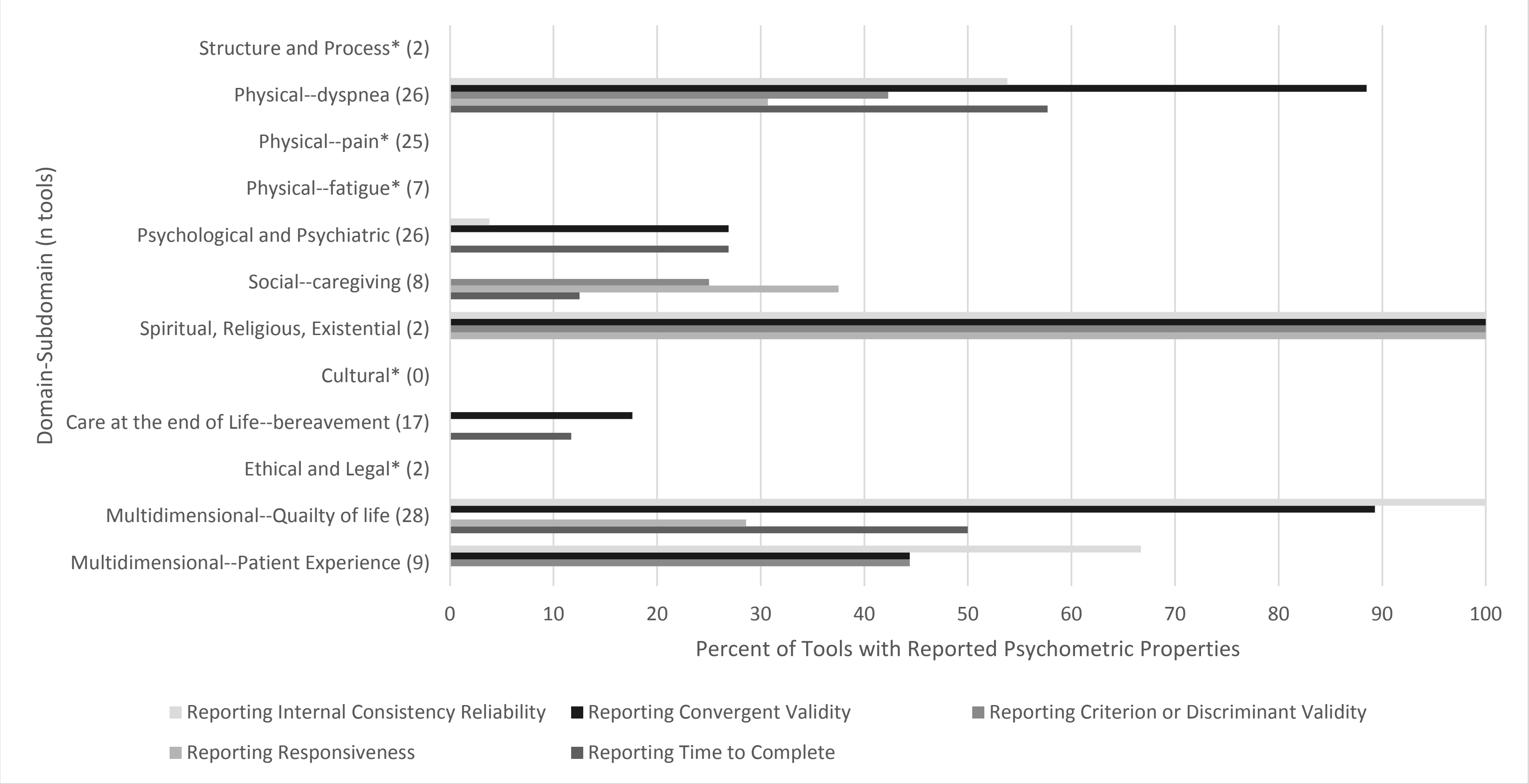
- Research is needed to conceptualize, develop, validate, and test assessment tools that specifically address the following domains and subdomains in palliative care populations: structure and Process; fatigue; cultural; spiritual, religious and existential; ethical and legal; and patient experience as reported by patients rather than caregivers.

Tool Evaluation

- Some domains and subdomains had multiple tools that were neither tested in palliative care populations nor evaluated for responsiveness. For the spiritual, religious and existential, and social domains, few tools had been developed for or evaluated in palliative care populations. For bereavement subdomain, patient experience, and quality of life, many tools were not only long and thus likely burdensome, but also had not been evaluated for responsiveness.

- Across all domains and subdomains, the following would be helpful: additional evaluation of existing tools in other populations, including pediatric populations (with modifications as needed for palliative care and for non-cancer populations); updates and modifications, as needed (many tools may be out of date and have not been updated or recently tested); and additional testing for validity and responsiveness.
- Further research should also address use of assessment tools longitudinally and across settings and populations.

Figure 2. Evidence map of percent of tools with psychometric properties reported in existing systematic reviews of palliative care assessment tools, organized by National Consensus Project for Quality Palliative Care domains and multidimensional domains



*No systematic reviews were identified for this domain or subdomain.

Systematic Reviews

- For the physical domain, a systematic review of assessment tools addressing pain and fatigue in palliative care populations is needed, and an updated review is needed for dyspnea tools.
- For the psychological and psychiatric domain, a systematic review is needed to evaluate tools for conditions other than cancer and to evaluate psychometric properties of tools more broadly.
- For multidimensional – patient experience, a systematic review is needed to evaluate psychometric properties of the tools.
- For all domains, systematic reviews of psychometric properties following guidance of COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) would be useful.[178]
- A high-quality systematic review focusing on the use of tools in pediatrics would also be useful.

Applications of Assessment Tools

- More research is needed on the use of assessment tools in clinical care across all domains. This research should include evaluation of the effectiveness of the tools in measuring changes in outcomes, feasibility, and usability in clinical care. It should also include broad input from patient and caregiver perspectives.
- Research is needed on the use of patient-reported assessment tools as quality indicators, including indicators of patient and caregiver experience outside the hospice setting.
- Additional analysis of the appropriateness of tools, particularly across diseases and populations, would help determine which patient and caregiver assessment tools are most useful in the evaluation of different types of palliative care interventions. This analysis could be a large study evaluating many different tools, or could be included as part of the pilot testing for future evaluations of palliative care interventions. This sort of analysis could help to standardize which tools are used and how they are implemented.
- Other organizations may use the survey of tools in this report to provide more specific recommendations for tools; consensus work to recommend tools would be helpful for researchers in palliative care. Such consensus recommendations should include broader input from patient and caregiver perspectives. Further research should also facilitate or clarify consensus about the use of specific assessment tools across settings and populations.

Limitations

By using the National Consensus Project Guidelines as a framework for the domains and limiting our Technical Brief to tools evaluated in palliative care populations, we possibly excluded tools that may be relevant in some applications in palliative care populations. We also recognize that other definitions of palliative care exist, and the tools covered in this report do not cover the full scope of potentially relevant populations. The systematic reviews we selected may not have summarized some potentially eligible tools or studies evaluating some properties of these tools.

As we excluded tools that were not specifically studied in palliative care populations, multiple tools assessing the spiritual, religious and existential domain - including the Spiritual Well-Being (FACIT-Sp) tool, the Spiritual Well-Being Scale, and the Koenig Religious Coping Index - were not included in this report, but may be useful in palliative care research. Similarly, many tools assessing social-caregiver domain have not been evaluated in palliative care populations. This report also focused on caregiver areas of burden, strain and quality of life, and did not include other subdomains relevant to caregivers that might be useful for palliative care.

Another limitation is our reliance on existing systematic reviews. While these systematic reviews were the best ones available, many had incomplete information regarding tool psychometric properties with some information on usability, reliability, and validity but minimal information on responsiveness. Although we did not find much information on responsiveness, a more detailed literature search for each tool would be needed to determine evidence for responsiveness.

Finally, some tools included in this review also have multiple versions that were not always noted in our sources. Future users of these tools should search for and consider different versions that might be more appropriate.

Conclusions

While we identified more than 150 assessment tools for palliative care, few tools focused on the spiritual, structure and process, or the ethical and legal domains, or the patient-reported experience subdomain of palliative care, and we found no tool addressing the cultural domain. Moreover, we found few studies assessing the use of tools in clinical practice or as quality indicators. Few studies of palliative care interventions used the same palliative care assessment tools. Future research should focus on further development of tools; evaluating tools in palliative care populations; and evaluating the responsiveness of tools.

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Appendix A. Glossary

Adapted from: National Quality Forum. Patient Reported Outcomes (PROs) in Performance Measurement, 2013 and Guidance for Measure Testing and Evaluating Scientific Acceptability of Measure Properties, 2011. Qualityforum.org.

Table A-1. Glossary of terms.

Term	Definition/examples
1. Reliability	The degree to which an instrument is free from random error
1a. Internal consistency reliability (multi-item scales)	Correlations between items on the same test
1b. Test-retest reliability (reproducibility or stability over time)	Test-retest estimation at different times
1c. Inter-rater reliability	Degree of agreement among raters (e.g., patient vs proxy)
2. Validity (Focus on construct validity – associations with different measures)	The degree to which an instrument reflects what it is supposed to measure
2a. Convergent validity	Documentation of empirical findings that support predefined hypotheses on the expected associations among measures similar to the measured patient reported measure
2b. Discriminant validity	Documentation that measures that are **not** supposed to be related are, in fact, unrelated
2c. Criterion validity	Extent to which a measure is related to an outcome. Can be concurrent (at the same time) or predictive (at a future time)
3. Sensitivity to change/ responsiveness	Empirical evidence of changes in scores consistent with predefined hypotheses regarding changes in the target population
4. Burden	Time, effort, and other demands on the respondent and administrator
4a. Number of items	Number of items; long and short form
4b. Modes of administration	Paper, web-based, interview
4c. Completion time (usability)	Time for the respondent

Appendix B. List of Acronyms

Table B-1: List of acronyms.

Acronym	Definition
AHRQ	Agency for Healthcare Research and Quality
AIDS	Acquired Immune Deficiency Syndrome
ALSFRS-R	Amyotrophic lateral sclerosis functional rating scale
ATS-DLD-78	American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale
BCOS	Bakas Caregiving Outcomes Scale
BCSS	Breathlessness, Cough and Sputum Scale
BDI	Beck Depression Inventory
BEQ-24	Bereavement Experience Questionnaire–24
BGQ	Brief Grief Questionnaire
BHI	Brief Hospice Inventory
BHS	Beck Hopelessness Scale
BIC	Burden Index of Caregivers
CAMPAS-R	Cambridge Palliative Audit Schedule
CARES-MIS	Cancer Rehabilitation Evaluation System Medical Interaction Subscale
CBI	Core Bereavement Items
CBS-EOLC	Caregiver's Burden Scale in end-of-life care
CES-D	Center for Epidemiologic Studies Depression scale
CHF	Congestive Heart Failure
CHQ	Chronic Heart Failure Questionnaire
CHQ-D	Chronic Heart Failure Questionnaire – Dyspnea Subscale
CI	Confidence Interval
CIS	Caregiver Impact Scale
CLASP	Cardiovascular Limitations and Symptoms Profile
CLD	Chronic Lung Disease Severity Index
CMSAS	Condensed Memorial Symptom Assessment Scale
COPD	Chronic obstructive pulmonary disease
CQOLI	Caregiver Quality of Life Index
CQOLI-C	Caregiver Quality of Life Index – Cancer
CQOLI-R	Caregiver Quality of Life Index – Revised
CRA	Caregiver Reaction Assessment
CRQ	Chronic Respiratory Questionnaire
CRQ-D	Chronic Respiratory Questionnaire – Dyspnea Subscale
CSDD	Cornell Scale for Depression in Dementia
CSI	Caregiver Strain Index
DAQ	Dyspnea Assessment Questionnaire
DDQ	Dyspnea Descriptor Questionnaire
DS	Demoralization Scale
EFAT and EFAT-2	Edmonton Functional Assessment Tool
EOLD	End of Life Dementia
EORTC QLQ-ST022	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module
EORTC-QLQ	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire
EPC	Evidence-based Practice Center
EQ-5D	EuroQOL
ESAS	Edmonton Symptom Assessment Scale
Faces	Faces scale
FACIT	Functional Assessment of Chronic Illness Therapy
FACIT-Pal	Functional Assessment of Chronic Illness Therapy-Palliative sub scale
FACIT-L	Functional Assessment of Chronic Illness Therapy-Lung

Table B-1: List of acronyms. (continued)

Acronym	Definition
FACQ-PC	Family Appraisal of Caregiving Questionnaire for Palliative Care
FAMCARE	Family Satisfaction with Advanced Cancer Care
GEM	Grief Evaluation Measure
GEQ	Grief Experience Questionnaire
GHQ-12	General Health Questionnaire-12 item
Global SOB	Global shortness of breath question
HADS	Hospital Anxiety and Depression Scale
HGRC	Hogan Grief Reaction Checklist
HIV	Human Immunodeficiency Virus
HQLI	Hospice Quality of Life Index
ICG	Inventory of Complicated Grief
ICG-R	Inventory of Complicated Grief–Revised
ICU	Intensive Care Unit
IES	Impact of Event Scale
IPC	Sat-Fam
ITG	Inventory of Traumatic Grief
ITU	Intensive Therapy Unit
I-W SR Index Short Form	Ironson-Woods Spirituality/Religiousness Index
KI	Key Informant
KQ	Key Question
LASA	Linear Analogue Scale Assessment
LC13	Lung Cancer supplement, breathlessness scale
LCADL	London Chest Activity of Daily Living Scale
LCS	Life Closure Scale
LEQ	Life Evaluation Questionnaire
MBCBS	Montgomery Borgatta Caregiver Burden Scale
mBORG	Modified Borg Scale
MCOHPQ	Modified City of Hope Patient Questionnaire
MDRS-D	Motor Neurone Disease Dyspnea Rating Scale
MMCGI	Marwit–Meuser Caregiver Grief Inventory
MND	Motor neuron disease
MOS	Medical Outcomes Study
MOS-HIV	Medical Outcomes Study HIV Health Survey
MPAC	Memorial Pain Assessment Card
MQLS	McMaster Quality of Life Scale
MQOL	McGill Quality of Life Questionnaire
MQOL-CSF	McGill Quality of Life Questionnaire-Cardiff Short Form
MRC	Medical Research Council Dyspnea Scale
MRDI	McCanse Readiness for Death Instrument
MSAS	Memorial Symptom Assessment Scale
MSAS-GDI	Memorial Symptom Assessment Scale-Global Distress Index
MVQOLI-R	Missoula-VITAS Quality of Life Index
N	Not present in the primary article
NA-ACP	Needs Assessment for Advanced Cancer Patients
NCP	National Consensus Project for Quality Palliative Care Clinical Practice
ND	No data available (review did not abstract)
NRS	Numeric rating scale
NS	Not Significant
OCD	Oxygen cost diagram
PAINAID	Pain in Advanced Dementia
PASS	Pain Anxiety Symptoms Scale
PAQ	Patient Autonomy Questionnaire
PDI	Patient Dignity Inventory

Table B-1: List of acronyms. (continued)

Acronym	Definition
PEACE	"Prepare, Embrace, Attend, Communicate, Empower" project
PFSDQ-M	Pulmonary Functional Status and Dyspnea Questionnaire-modified
PG-12	Prolonged Grief–12
PG-13	Prolonged Grief–13
PHQ-9	Patient Health Questionnaire-9
PNPC	Problems and Needs in Palliative Care questionnaire
PNPCsv	Problems and Needs in Palliative Care questionnaire short version
POMS	Profile of Mood States
POS	Palliative care Outcome Scale
PRIME-MD	Primary Care Evaluation of Mental Disorders
PSE	Present State Examination
QODD	Quality of Dying and Death questionnaire
QOLLTI-F	Quality of Life in Life-Threatening Illness-Family Career Version
QUAL-E	Quality of Life at the end of life
RAND	Rand Instrument: Shortness of Breath Batter from the Medical History Questionnaire
RDCQ	Reactions to the Diagnosis of Cancer Questionnaire
R-GEI	Revised Grief Experience Inventory
ROBIS	Risk of Bias in Systematic Reviews
RSCD	Regional Study of Care for the Dying
SF-12	Short Form 12 Health Survey
SF-36	Short Form 36 Health Survey
SGRO	St George’s Respiratory Questionnaire (activity subscale)
SMD	Standardized Mean Difference
SNI	Spiritual Needs Inventory
SQ	The Symptom Questionnaire
SS-SOBS	Symptom Scale (shortness of breath subscale)
STAI	State-Trait Anxiety Inventory
TIME	Toolkit of Instruments to Measure End-of-Life Care
TOI	Trial Outcome Index
TOO	Task Order Officer
TRIG	Texas Revised Inventory of Grief
TTBQ	Two-Track Bereavement Questionnaire
TTBQ2-CG30	Two-Track Bereavement Questionnaire
TQPM	Cancer Total Quality Pain Management Patient Assessment Tool
UCDQ	University of Cincinnati Dyspnea Questionnaire
UCSD SOBQ	University of California San Diego Shortness of Breath Questionnaire
VAS	Visual analogue scale
WALT	Willingness to Accept Life-Sustaining Treatment Instrument
WHO	World Health Organization
WONCA	World Organization of National Colleges, Academies and Academic Association of General Practitioners
Y	Present in the primary article
ZBI	Zarit Burden Inventory

Appendix C. Key Informant Questions

Questions for Patient Advocates:

1. What are key elements of high quality palliative care from your perspective?
2. Have you ever as a caregiver (or has the person you were caring for) been asked to fill out or asked questions from an assessment tool or survey, such as ratings of symptoms or a questionnaire about your experience with palliative care?

   If yes:
   - Were the questions meaningful?
   - Did the questions lead to a better experience?

   If no:

   Why?
3. Based on your experiences, what do doctors and palliative care staff need to know from the patient or caregiver that can be captured in a questionnaire or similar tool?
4. Are there key things missing from the domains below that patients/ caregivers should be asked about?
5. Based on your experiences, do you have any other thoughts about how these tools or surveys should or should not be used in palliative care?

These are the domains:

1. Structure/Process of care (e.g., continuity, communication)
2. Physical Aspects of Care (e.g., pain, dyspnea)
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care (including caregiving)
5. Spiritual, Religious and Existential Aspects of Care
6. Cultural Aspects of Care (including cultural competence)
7. Care of the Patient at the End of Life
8. Ethical and Legal Aspects of Care (care planning)
9. Tools that cross domains (patient experience/satisfaction, comprehensive assessment)

Questions for Providers:

We are organizing assessment tools by domains from the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, which are:

1. Structure/Process of care (e.g., continuity, communication)
2. Physical Aspects of Care (e.g., pain, dyspnea)
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care (including caregiving)
5. Spiritual, Religious and Existential Aspects of Care
6. Cultural Aspects of Care (including cultural competence)
7. Care of the Patient at the End of Life
8. Ethical and Legal Aspects of Care (care planning)
9. Tools that cross domains (patient experience/satisfaction, comprehensive assessment)

1. Are these categories still valid, or do they need to be changed?
2. Based on your experiences and perceptions:
   a. What are key general issues with use of assessment tools in palliative care? (We are not looking for comments on specific tools, but rather on overall issues such as standardization, burden, unintended consequences, etc.).
   b. What are your experiences and perceptions about palliative care assessment tools that are used for:
   - clinical care delivery?
   - quality indicators?
   - evaluating the effectiveness of interventions?
3. How do you think tools should be evaluated? For example: validity, reliability, responsiveness and what should be the standard to consider a tool "good"?
4. How have the drawbacks of existing tools or lack of available tools affected the field of
   - palliative care for:
   - clinical care delivery?
   - quality indicators?
   - evaluating the effectiveness of interventions?
5. In addition to the list attached, are there any other databases or sources that we should search for studies about palliative care assessment tools?
6. Are there any specific issues you would like to bring up about assessment tools specifically for any of the domains (as above, <u>not for specific tools</u> but for the domain as a whole)?
   - structures and processes of care (e.g., continuity, communication):
   - physical aspects of care (e.g., pain, dyspnea, fatigue, nausea, anorexia, diarrhea, constipation):
   - the domain of psychological and psychiatric care:
   - social aspects of care, including caregiving:
   - spiritual, religious, and existential aspects of care (e.g., spiritual distress):
   - cultural aspects of care, including cultural competence:
   - end-of-life care:
   - ethical and legal aspects of care (e.g., care planning):
   - tools that cross multiple domains (e.g.., satisfaction, comprehensive assessment)
7. Are there key research gaps regarding palliative care assessment tools?

Appendix D. Detailed Search Strategy

Table D-1: PubMed search limited to systematic reviews and meta-analyses and published in 2007 or later.

Database	Search
PubMed	(("palliative care"[mh] OR "palliative care"[tiab] OR "end of life"[tiab] OR "hospice care"[mh] OR "terminally ill"[tiab] OR "terminal care"[tiab] OR “terminal illness”[tiab] OR Hospice[tiab]) AND (“assessment tool”[tiab] OR “assessment tools”[tiab] OR "Surveys and questionnaires"[Mesh] OR "Questionnaires"[tiab] OR "Questionnaire"[tiab] OR "self report"[tiab] OR instrument[tiab] OR instruments[tiab] OR scale[tiab] OR scales[tiab] OR instrumentation[tiab] OR "Psychometrics"[Mesh] OR "Psychometrics"[tiab] OR "Psychometric"[tiab]))

Table D-2: The Cochrane Library search strategy limited to systematic reviews and meta-analyses and published in 2007 or later.

Cochrane	#1	MeSH descriptor: [Palliative Care] explode all trees
	#2	MeSH descriptor: [Hospice Care] explode all trees
	#3	"palliative care":ti,ab,kw (Word variations have been searched)
	#4	"terminally ill":ti,ab,kw (Word variations have been searched)
	#5	"terminal care":ti,ab,kw (Word variations have been searched)
	#6	"terminal illness":ti,ab,kw (Word variations have been searched)
	#8	hospice:ti,ab,kw (Word variations have been searched)
	#9	MeSH descriptor: [Terminal Care] explode all trees
	#10	#1 or #2 or #3 or #4 or #5 or #6 or #8or #9
	#11	MeSH descriptor: [Surveys and Questionnaires] explode all trees
	#12	MeSH descriptor: [Psychometrics] explode all trees
	#13	"assessment tool":ti,ab,kw (Word variations have been searched)
	#14	"assessment tools":ti,ab,kw (Word variations have been searched)
	#15	Questionnaires:ti,ab,kw (Word variations have been searched)
	#16	Questionnaire:ti,ab,kw (Word variations have been searched)
	#17	"self report":ti,ab,kw (Word variations have been searched)
	#18	instrument:ti,ab,kw (Word variations have been searched)
	#19	instruments:ti,ab,kw (Word variations have been searched)
	#20	scale:ti,ab,kw (Word variations have been searched)
	#21	scales:ti,ab,kw (Word variations have been searched)
	#22	instrumentation:ti,ab,kw (Word variations have been searched)
	#23	Psychometrics:ti,ab,kw (Word variations have been searched)
	#24	Psychometric:ti,ab,kw (Word variations have been searched)
	#25	#10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24
		#10 and #25

Table D-3: CINAHL search strategy limited to systematic reviews and meta-analyses and published in 2007 or later.

CINAHL/ PsycINFO/ PsycTESTS		S16 AND S44	
		S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43	
		AB "psychometrics"	
		TI "psychometrics"	
		AB "psychometric"	
		TI "psychometric"	
		AB "scales"	
		TI "scales"	
		AB "scale"	
		TI "scale"	
		AB "instrumentation"	
		TI "instrumentation"	
		AB "instruments"	
		TI "instruments"	
		AB "instrument"	
		TI "instrument"	
		AB "self report"	
		TI "self report"	
		AB "questionnaires"	
		TI "questionnaires"	
		AB "questionnaire"	
		TI "questionnaire"	
		AB "assessment tools"	
		TI "assessment tools"	
		AB "assessment tool"	
		TI "assessment tool"	
		MH "psychometrics"	
		MH "self report"	
		MH Questionnaires	
		S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15	
		AB "terminal care"	
		TI "terminal care"	
		AB "terminal illness"	
		TI "terminal illness"	
		AB "terminally ill"	
		TI "terminally ill"	
		AB "hospice"	
		TI "hospice"	
		AB "end of life"	
		TI "end of life"	
		AB "palliative care"	
		TI "palliative care"	
		MH "terminal care"	
		MH "hospice care"	
		MH "palliative care"	

Table D-4: PubMed search limited to primary studies addressing culture and published in 2007 or later.

#	Search
1	"palliative care"[mh] OR "palliative care"[tiab] OR "end of life"[tiab] OR "hospice care"[mh] OR "terminally ill"[tiab] OR "terminal care"[tiab] OR “terminal illness”[tiab] OR Hospice[tiab])
2	(“assessment tool”[tiab] OR “assessment tools”[tiab] OR "Surveys and questionnaires"[Mesh] OR "Questionnaires"[tiab] OR "Questionnaire"[tiab] OR "self report"[tiab] OR instrument[tiab] OR instruments[tiab] OR scale[tiab] OR scales[tiab] OR instrumentation[tiab] OR "Psychometrics"[Mesh] OR "Psychometrics"[tiab] OR "Psychometric"[tiab])
3	ulture[mh] OR Culture[tiab] OR Cultural[tiab] OR Linguistics[mh] OR Linguistics[tiab] OR Linguistic[tiab] OR Language[mh] OR Language[tiab] OR Languages[tiab] OR “Family communication”[tiab] OR Customs[tiab] OR Custom[tiab] OR Beliefs[tiab] OR Values[tiab] OR Race[tiab] OR Ethnicity[tiab] OR “Social groups”[tiab] OR Truth telling[tiab])
	1 AND 2 AND 3

Appendix E. ROBIS Assessment

Table E-1: Summary of ROBIS assessments.

	Author, year	**Domain 1: Study eligibility criteria**	**Domain 2: Identification and selection of studies**	**Domain 3: Data collection and study appraisal**	**Domain 4: Synthesis and findings**	**Risk of Bias in the Review**
Physical (N=8)						
	Allsop, 2015[1]	Low	Unclear	Unclear	Unclear	Unclear
	Ben-Aharon, 2008[2]	Low	Low	High	Unclear	Unclear
	Dorman, 2007*[3]	Low	Low	Unclear	Low	Low
	Gilbertson-White, 2011[4]	High	High	High	High.	High
	Hjermstad, 2008[5]	Low	High	High	Unclear	High
	Minton, 2009[6]	Low	Low	High	Unclear	Unclear
	Seyidova-Khoshknabi, 2011[7]	Low	Unclear	High	Unclear	Unclear
	Tomlinson, 2013[8]	Low	Unclear	High	Unclear	Unclear
Psychosocial and Psychiatric (N=10)						
	Hosie, 2013[9]	High	Unclear	Unclear	Unclear	Unclear
	Kayser, 2012[10]	Low	Low	Unclear	Unclear	Unclear
	Leonard, 2014[11]	High	High	Unclear	Unclear	High
	Luckett, 2010[12]	Low	Unclear	Unclear	Low	Unclear
	Mitchell, 2010[13]	Low	Unclear	Unclear	Low	Unclear
	Mitchell, 2012[14]	Low	Low	Unclear	Unclear	Unclear
	Thekkumpurath, 2008[15]	Low	Unclear	High	Low	High
	Vodermaier, 2009[16]	Low	Low	High	Low	High
	Wakefield, 2015[17]	Low	Low	Low	Low	Low
	Ziegler, 2011*[18]	Low	Low	Low	Low	Low
Social (N=2)						
	Hudson, 2010[19]	Low	Low	Unclear	Unclear	Low
	Michels, 2016*[20]	Low	Low	Low	Unclear	Low
Spiritual, Religious, and Existential (N= 7)						
	Best, 2015[21]	Low	Low	Unclear	Low	Low
	Brandstatter, 2012[22]	High	Unclear	Unclear	Unclear	High
	Gijsberts, 2011[23]	High	Unclear	Unclear	Unclear	Unclear
	Harding, 2012[24]	Unclear	Unclear	Unclear	Unclear	Unclear
	Krikorian, 2013[25]	Low	Low	Unclear	Low	Low
	Selman, 2011*[26]	Low	Low	Low	Low	Low
	Selman, 2011[27]	Low	Low	Low	Low	Low

Table E-1: Summary of ROBIS assessments (continued).

	Author, year	**Domain 1: Study eligibility criteria**	**Domain 2: Identification and selection of studies**	**Domain 3: Data collection and study appraisal**	**Domain 4: Synthesis and findings**	**Risk of Bias in the Review**
Care of the Patient at the End of Life (Bereavement) (N=1)						
	Sealey, 2015*[28]	Unclear	Low	Low	Low	Low
Multidimensional (Quality of life and Patient Experience) ((N=11)						
(Quality of life)	Albers, 2010*[29]	Low	Low	Low	Unclear	Low
	Bausewein, 2011[30]	Low	Low	High	Unclear	Unclear
	Coombes, 2016 31 2106	Low	Unclear	Unclear	Unclear	Unclear
	Chiu, 2014[32]	Unclear	High	High	Unclear	High
	Hermans, 2014[33]	Low	Low	Low	Unclear	Unclear
	Jordhoy, 2007[34]	Unclear	Unclear	Unclear	Unclear	High
(Patient experience)	Lendon, 2015*[35]	Low	Low	Unclear	Low	Low
(Quality of life)	Paiva, 2014[36]	Low	Low	Low	Unclear	Unclear
	Parker, 2011[37]	Unclear	Low	Unclear	Unclear	Unclear
	Pearson, 2007[38]	Low	High	High	High	High
	Stiel, 2012[39]	Low	Unclear	Unclear	Unclear	Unclear
Prior comprehensive systematic reviews (N=1)						
	Mularski, 2007*[40]	Low	Low	Unclear	Unclear	Unclear
Reviews of Clinical Care Tools (N=2)						
	Antunes, 2014*[41]	Low	Low	Unclear	Low	Low
	Wasteson, 2009[42]	Low	High	Unclear	Unclear	Unclear
Reviews of Quality Indicators (N=3)						
	Bausewein, 2011[30]	Low	Low	High	Unclear	Unclear
	De Roo, 2013*[43]	Low	Low	Unclear	Unclear	Low
	Pasman, 2009[44]	Low	Low	Unclear	Unclear	Unclear
Reviews of Interventions (N=1)						
	Kavalieratos, 2016*†[45]	Low	Low	Low	Unclear	Low

N=sample size

* Systematic review included in the report.

† Unpublished article—ROBIS was conducted on the PROSPERO publically available protocol.

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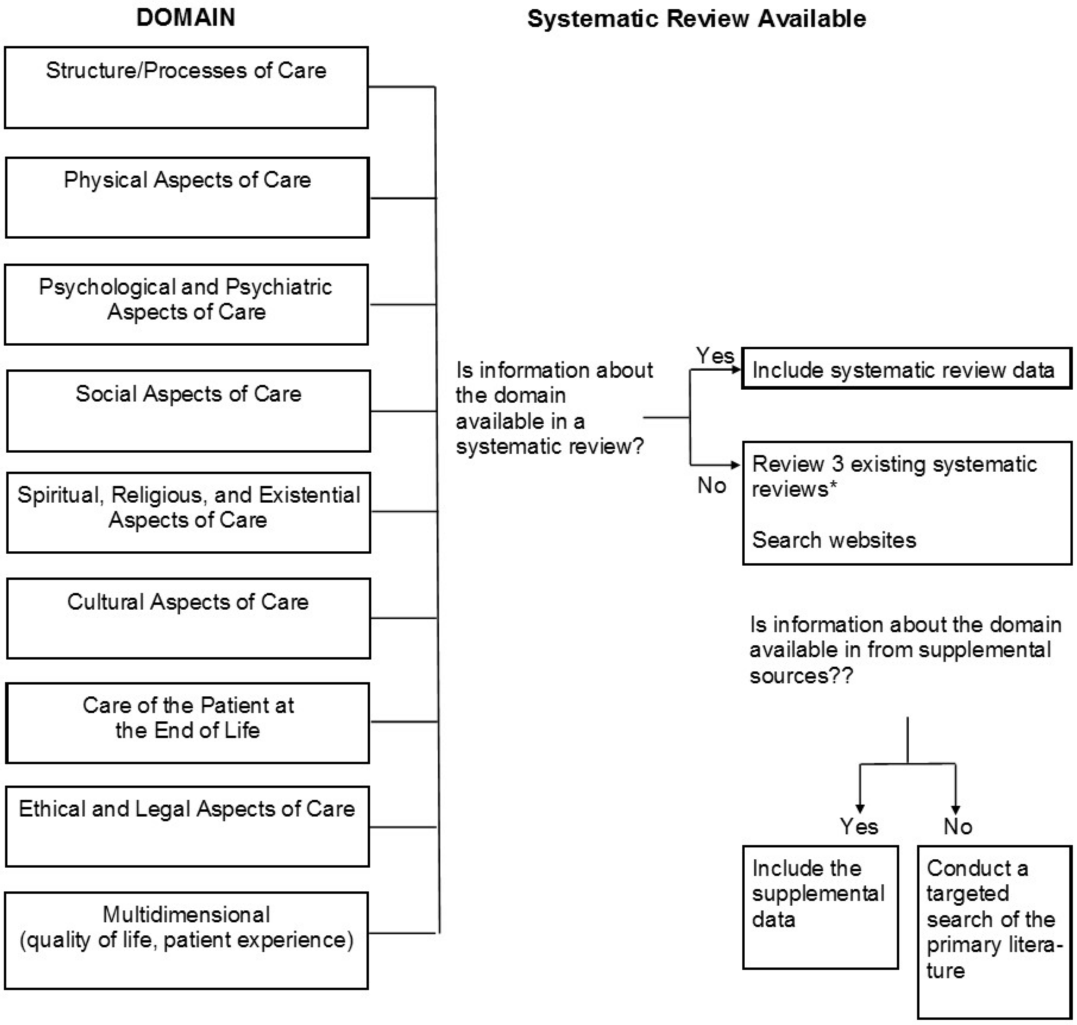
Appendix F. Systematic Review and Supplemental Search Flow



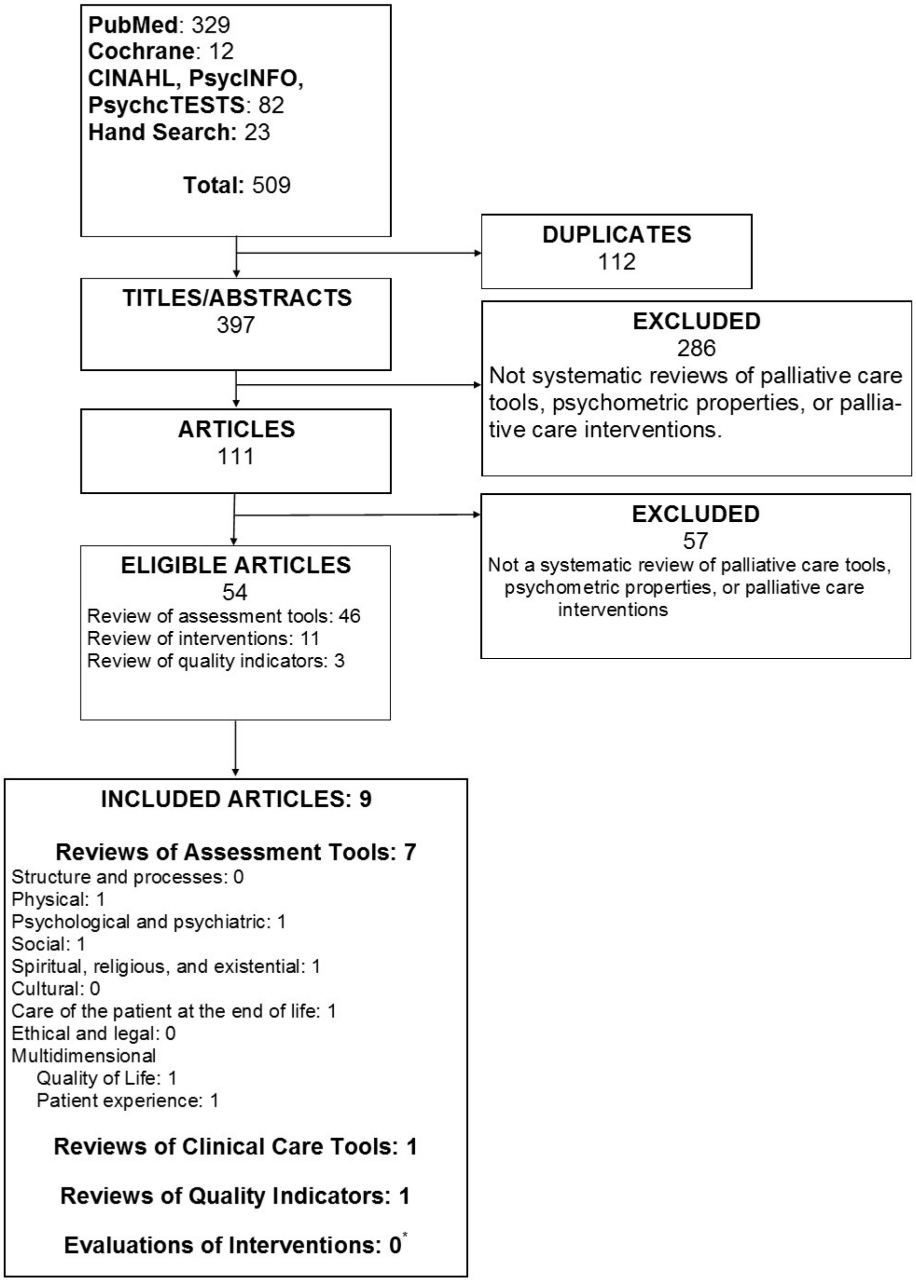
* TIME Toolkit of Instruments to Measure End-of-Life Care; National Institutes of Health State of the Science Conference on Improving End-of-Life Care; PEACE Palliative Care Quality Measures project

Appendix G. Inclusion Criteria for the Systematic Review

	Criteria
Content	Evaluates palliative care assessment tools used in palliative care in the areas of (1) clinical practice, (2) quality indicators, (3) evaluation of interventions
Population	Tools developed, evaluated, or implemented in populations defined as palliative care or meeting the definition of palliative care (care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families[1]) All diseases, age groups, and settings
Study Design	Systematic reviews For interventions, include systematic reviews of prospective controlled trials
Language/ Country	English (for reviews)/United States (for tools)– since palliative care and use of assessment tools varies widely among countries, we focused on assessment tools used in US populations
Admissible Evidence	From published original studies: reliability, validity, and responsiveness (as summarized in reviews or websites)

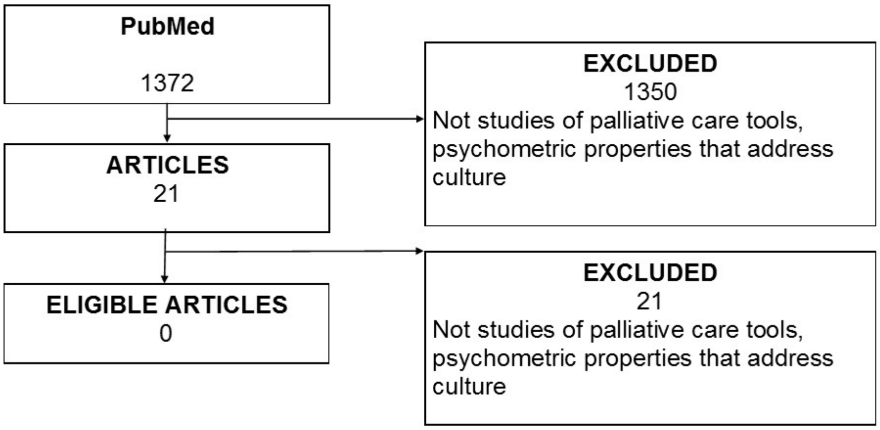
Appendix H. Results of the Literature Search

Figure H-1. Results of the main literature search to identify relevant systematic reviews



*Information for this domain obtained from an unpublished systematic review.

Figure H-2. Results of the additional literature search to identify primary articles assessing palliative care tools in the cultural domain



Appendix I. Palliative Care Tools Master List

List of Palliative Care Tools Used Arranged by Domain:

Domain 1: Structure and Processes

1. McCusker 4-item instrument for continuity
2. Quality of communication questionnaire

Domain 2: Physical

Pain

3. MD Anderson Symptom Inventory
4. Family Pain Questionnaire
5. Patient Pain Interview
6. Patient Pain Questionnaire
7. Psychosocial Pain Assessment Form
8. The Breakthrough Pain Questionnaire
9. Brief Pain Inventory
10. City of Hope Mayday Pain Resource Center Pain Audit Tools
11. City of Hope Mayday Pain Resource Center Patient Pain Questionnaire
12. Descriptor Differential Scale
13. Integrated Pain Score
14. McGill Pain Questionnaire
15. Memorial Pain Assessment Card (MPAC)
16. Numerical Rating Scale for pain (NRS)
17. Pain as assessed in the Medical Outcomes Study
18. Pain Disability Index
19. Pain Management Index
20. Pain Perception Profile
21. Patient Outcome Questionnaire
22. Cancer Total Quality Pain Management Patient Assessment Tool (TQPM)
23. Unmet Analgesic Needs Questionnaire
24. Verbal Rating Scale for Pain
25. Visual Analogue Scale for Pain
26. West Haven-Yale Multidimensional Pain Inventory
27. Wisconsin Brief Pain Questionnaire

Dyspnea

28. Visual analogue scale for dyspnea (HVAS/ VVAS)
29. Numeric Rating Scale (NRS) for dyspnea or dyspnea numeric scale
30. Modified Borg Scale (mBORG)
31. Global shortness of breath question (Global SOB)
32. Faces scale (Faces)
33. Dyspnea Descriptor Questionnaire (heart failure); DDQ (heart failure)
34. Dyspnea Descriptor Questionnaire (COPD)
35. Dyspnea Assessment Questionnaire (DAQ)
36. Amyotrophic lateral sclerosis functional rating scale – revised, respiratory subscale (ALSFRS-R)
37. American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale (ATS-DLD-78)
38. Breathlessness, Cough and Sputum Scale (BCSS)
39. Chronic Heart Failure Questionnaire – dyspnea subscale (CHQ-D)
40. Cardiovascular Limitations and Symptoms Profile (CLASP)
41. Chronic Lung Disease Severity Index (CLD)
42. Chronic Respiratory Questionnaire – dyspnea subscale (CRQ-D, CRQ-SAI-D)
43. Chronic Respiratory Questionnaire Standardized dyspnea questions (CRQ-SAS-D, CRQ-IAS-D)
44. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Lung Cancer supplement, breathlessness subscale (EORTC-QLQ; LC13 breathlessness)
45. London Chest Activity of Daily Living Scale (LCADL)
46. Motor Neurone Disease Dyspnea Rating Scale (MDRS-D)

47. Medical Research Council Dyspnea Scale (MRC)
48. Oxygen cost diagram (OCD)
49. Pulmonary Functional Status and Dyspnea Questionnaire-modified (PFSDQ-M)
50. Rand Instrument: shortness of breath battery from the Medical History Questionnaire (Rand)
51. St George's Respiratory Questionnaire (activity subscale) (SGRO)
52. University of Cincinnati Dyspnea Questionnaire (UCDQ)
53. University of California San Diego Shortness of Breath Questionnaire (UCSD SOBQ)

Fatigue

54. Epworth Sleepiness Scale (ESS)
55. Fatigue Questionnaire (FQ)
56. Fatigue Symptom Inventory (FSI)
57. Fatigue Severity Scale (FSS)
58. Multidimensional Fatigue Symptoms Inventory (MFSI)
59. Piper Fatigue Scale
60. Brief Fatigue Inventory

Domain 3: Psychosocial and Psychiatric

61. WHO (Five) Well-Being Index
62. Geriatric Depression Scale (long and short form)
63. Hamilton Depression Scale
64. Scales of Psychological Well-Being
65. Center for Epidemiologic Studies Depression Scale (CES-D)
66. Impact of Event Scale (IES)
67. Mental Health Inventory
68. Pain Anxiety Symptoms Scale (PASS)
69. Profile of Mood States
70. Present State Examination (PSE)
71. Reactions to the Diagnosis of Cancer Questionnaire (RDCQ)
72. Self-rating Depression Scale
73. The Symptom Questionnaire (SQ)
74. State-Trait Anxiety Inventory (STAI)
75. Starck Scale
76. Symptom Anxiety and Depression Scale
77. Cornell Scale for Depression in Dementia
78. PRIME-MD / PHQ-9
79. Hospital Anxiety and Depression Scale (HADS)
80. Two single items: Are you depressed? and Have you lost interest?
81. Distress Thermometer
82. Brief Symptom Inventory-18
83. General Health Questionnaire-12 item (GHQ-12)
84. Brief Edinburgh Depression Scale
85. Beck Depression Inventory-Short Form
86. Mental Adjustment to Cancer

Domain 4: Social (Caregiving)

87. Caregiver's Burden Scale in end-of-life care (CBS-EOLC)
88. Caregiver Impact Scale (CIS)
89. Caregiver Quality of Life Index – Cancer (CQOLI-C)
90. Caregiver Reaction Assessment (CRA)
91. Caregiver Strain Index (CSI)
92. Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC)
93. Quality of Life in Life-Threatening Illness-Family Career Version (QOLLTI-F)
94. Zarit Burden Inventory (ZBI)

Domain 5: Spiritual, Religious, and Existential

95. Beck Hopelessness Scale (BHS)
96. Ironson-Woods Spirituality/Religiousness Index (I-W SR Index Short Form)

Domain 6: Cultural

—No tools were found for this domain.—

Domain 7: Care at the End of Life (Bereavement)

97. Bereavement Experience Questionnaire–24 (BEQ-24)
98. Brief Grief Questionnaire (BGQ)
99. Core Bereavement Items (CBI)
100. Grief Evaluation Measure (GEM)
101. Grief Experience Questionnaire (GEQ)
102. Hogan Grief Reaction Checklist (HGRC)
103. Inventory of Complicated Grief (ICG)
104. Inventory of Complicated Grief–Revised (ICG-R)
105. Inventory of Traumatic Grief (ITG)
106. Marwit–Meuser Caregiver Grief Inventory (MMCGI)
107. Marwit–Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF)
108. Prolonged Grief–12 (PG-12)
109. Prolonged Grief–13 (PG-13)
110. Revised Grief Experience Inventory (R-GEI)
111. Texas Revised Inventory of Grief (TRIG)
112. Two-Track Bereavement Questionnaire (TTBQ)
113. Two-Track Bereavement Questionnaire (TTBQ2-CG30)

Domain 8: Ethical and Legal

114. Relatives' patient management questionnaire
115. Willingness to Accept Life- sustaining Treatment instrument (WALT)

Multidimensional Tools

Quality of Life

116. Brief Hospice Inventory (BHI)
117. Cambridge Palliative Audit Schedule (CAMPAS-R)
118. Demoralization Scale (DS)
119. Edmonton Functional Assessment Tool (EFAT and EFAT-2)
120. Emanuel and Emanuel Medical Directive
121. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module (EORTC QLQ-OESI8)
122. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module (EORTC QLQ-ST022)
123. Edmonton Symptom Assessment Scale (ESAS)
124. Functional Assessment of Chronic Illness Therapy-Palliative sub scale (FACIT-Pal)
125. Hospice Quality of Life Index (HQLI)
126. Life Closure Scale (LCS)
127. Life Evaluation Questionnaire (LEQ)
128. McMaster Quality of Life Scale (MQLS)
129. McGill Quality of Life Questionnaire (MQOL)
130. McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF)
131. McCanse Readiness for Death Instrument (MRDI)
132. Memorial Symptom Assessment Scale (MSAS)
133. Condensed Memorial Symptom Assessment Scale (CMSAS)
134. Memorial Symptom Assessment Scale-Global Distress Index (MSAS-GDI)
135. Missoula-VITAS Quality of Life Index (MVQOLI-R)
136. Needs Assessment for Advanced Cancer Patients (NA-ACP)
137. Patient Autonomy Questionnaire (PAQ)
138. Patient Dignity Inventory (PDI)
139. Problems and Needs in Palliative Care questionnaire (PNPC)
140. Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv)
141. Palliative care Outcome Scale (POS)
142. Quality of life at the end of life (QUAL-E)
143. Spiritual Needs Inventory (SNI)

Patient Experience

144. After Death Bereaved Family Member Interview
145. End of Life in Dementia- Satisfaction with Care & Comfort Assessment in Dying
146. Family Assessment of Treatment of End-of-Life survey
147. Family Evaluation of Hospice Care
148. Family Satisfaction in the ICU
149. Family Satisfaction with Advanced Cancer Care (FAMCARE)
150. Quality of Dying and Death
151. Quality of End-of-Life Care and Satisfaction with Treatment
152. Caregiver Evaluation of Quality of End-of-Life Care

Appendix J. Evidence Tables

Evidence Table 1. Tools identified in the supplemental searches.

Domain	Website/Review	URL	Tools
Structure and process of care	Toolkit of Instruments to Measure End-of-Life Care (TIME)	https://nts122.chcr.brown.edu/pcoc/BIBLIOGRAPHIES.HTM	McCusker 4-item instrument for continuity
	End of Life Care and Outcomes Systematic Review	http://onlinelibrary.wiley.com/doi/10.1111/j.1475-6773.2007.00721.x/abstract	Quality of communication questionnaire
Physical Pain	The City of Hope Pain & Palliative Care Resource Center	http://prc.coh.org/res_inst.asp and subsite search: http://prc.coh.org/pain_assessment.asp (Tools only address pain and dyspnea)	MD Anderson Symptom Inventory
			Family Pain Questionnaire
			Patient Pain Interview
			Patient Pain Questionnaire
			Psychosocial Pain Assessment Form
	Toolkit of Instruments to Measure End-of-Life Care (TIME)	https://nts122.chcr.brown.edu/pcoc/BIBLIOGRAPHIES.HTM	The Breakthrough Pain Questionnaire
			Brief Pain Inventory
			City of Hope Mayday Pain Resource Center Pain Audit Tools
			City of Hope Mayday Pain Resource Center Patient Pain Questionnaire
			Descriptor Differential Scale
			Integrated Pain Score
			McGill Pain Questionnaire
			Memorial Pain Assessment Card
			Numerical Rating Scale for Pain
			Pain as assessed in the Medical Outcomes Study
			Pain Disability Index
			Pain Management Index
			Pain Perception Profile
			Patient Outcome Questionnaire
			Cancer Total Quality Pain Management Patient Assessment Tool (TQPM)
			Unmet Analgesic Needs Questionnaire
			Verbal Rating Scale for Pain
			Visual Analogue Scale for Pain
			West Haven-Yale Multidimensional Pain Inventory
			Wisconsin Brief Pain Questionnaire

Evidence Table 1. Tools identified in the supplemental searches (continued).

Domain	Website/Review	URL	Tools
Physical Fatigue	Toolkit of Instruments to Measure End-of-Life Care (TIME)	https://nts122.chcr.brown.edu/pcoc/BIBLIOGRAPHIES.HTM	Epworth Sleepiness Scale (ESS)
			Fatigue Questionnaire (FQ)
			Fatigue Symptom Inventory (FSI)
			Fatigue Severity Scale (FSS)
			Multidimensional Fatigue Symptoms Inventory (MFSI)
			Piper Fatigue Scale
	The National Palliative Care Research Center Measurement and Evaluation Tools	http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx	Brief Fatigue Inventory
Psychological and psychiatric	The City of Hope Pain & Palliative Care Resource Center	http://prc.coh.org/res_inst.asp	World Health Organization (WHO) (Five) Well-Being Index
	The National Palliative Care Research Center Measurement and Evaluation Tools	http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx	Geriatric Depression Scale (long and short form)
			Hamilton Depression Scale
			Scales of Psychological Well-Being
	Toolkit of Instruments to Measure End-of-Life Care (TIME)	https://nts122.chcr.brown.edu/pcoc/BIBLIOGRAPHIES.HTM	Center for Epidemiologic Studies Depression Scale (CES-D)
			Impact of Event Scale (IES)
			Mental Health Inventory
			PASS Pain Anxiety Symptoms Scale
			Profile of Mood States
			Present State Examination (PSE)
			Reactions to the Diagnosis of Cancer Questionnaire (RDCQ)
			Self-rating Depression Scale
			The Symptom Questionnaire (SQ)
			State-Trait Anxiety Inventory (STAI)
			Starck Scale
			Symptom Anxiety and Depression Scale
	End of Life Care and Outcomes Systematic Review	http://onlinelibrary.wiley.com/doi/10.1111/j.1475-6773.2007.00721.x/abstract	Cornell Scale for Depression in Dementia
	PEACE Palliative Care Quality Measures project	http://www.med.unc.edu/pcare/files/assessment-instruments-for-end-of-life-care	PRIME-MD / PHQ-9

Evidence Table 1. Tools identified in the supplemental searches (continued).

Domain	Website/Review	URL	Tools
Ethical and legal aspects of care	End of Life Care and Outcomes Systematic Review	http://onlinelibrary.wiley.com/doi/10.1111/j.1475-6773.2007.00721.x/abstract	Relatives' patient management questionnaire
			Willingness to Accept Life-sustaining Treatment instrument (WALT)

CES-D=Center for Epidemiologic Studies Depression Scale; PHQ-9= Patient Health Queationnaire-9; PRIME-MD=Primary Care Evaluation of Mental Disorders; PSE=Present State Examination; RDCQ=Reactions to the Diagnosis of Cancer Questionnaire; SQ=The Symptom Questionnaire; STAI=State-Trait Anxiety Inventory; TIME=Toolkit of Instruments to Measure End-of-Life Care; TQPM=Cancer Total Quality Pain Management Patient Assessment Tool; WALT=Willingness to Accept Life-Sustaining Treatment Instrument; WHO=World Health Organization

Evidence Table 2a. Characteristics of the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea).

Author, year of systematic review/website	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools included (number of studies)	Years of search (range)
Dorman, 2007[2]	Breathlessness, physical aspects of care	Patient-based scales for either clinical or research purposes and evaluation of at least two psychometric properties	29 (30 studies), 26 included in this report	Up to 2005

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 2b. Population and setting of tools included in the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Gift, 1989[3]	Visual analogue scale (HVAS and VVAS)	Asthma, COPD, ventilated	ED, outpatient, inpatient, ITU, Pulmonary rehab, coronary care unit
Gift, 1998[4] Tanaka, 2002[5]	Numeric rating scale (NRS) or Dyspnea Numeric Scale	Cancer, COPD	Outpatient, home
Borg, 1982[6] Borg, 1970[7]	Modified Borg Scale (mBORG)	COPD, restrictive lung disease, asthma	Outpatient
Simon,1990[8]	Global shortness of breath question (Global SOB)	COPD	Outpatient, randomized controlled trial
Powers, 1999[9]	Faces scale (Faces)	Ventilated	Coronary care unit, intensive therapy unit
Parshall, 2001[10]	Dyspnea Descriptor Questionnaire (heart failure); DDQ (heart failure)	Heart failure	ED
Parshall, 2002[11]	Dyspnea Descriptor Questionnaire (COPD); DDQ (COPD)	COPD	ED
Heyse-Moore, 1993[12]	Dyspnea Assessment Questionnaire (DAQ)	Cancer	Hospice
Cedarbaum, 1999[13]	Amyotrophic lateral sclerosis functional rating scale – revised, respiratory subscale (ALSFRS-R)	MND (Motor Neuron Disease)	Trial
Ferris, 1978[14]	American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale (ATS-DLD-78)	COPD, asthma	Outpatient
Leidy, 2003[15]	Breathlessness, Cough and Sputum Scale, breathlessness subscale (BCSS)	COPD	RCT
Guyatt, 1989[16]	Chronic Heart Failure Questionnaire – dyspnea subscale (CHQ-D)	Heart failure	Outpatient, RCT
Lewin, 2002[17]	Cardiovascular Limitations and Symptoms Profile (CLASP)	Ischemic heart disease	Outpatient
Selim, 1997[18]	Chronic Lung Disease Severity Index (CLD)	Chronic lung disease	Outpatient
Guyatt, 1987[19]	Chronic Respiratory Questionnaire – dyspnea subscale (CRQ-D, CRQ-SAI-D)	COPD, interstitial lung disease, cystic fibrosis, alpha antitrypsin deficiency, MND	Outpatient, inpatient, pulmonary rehabilitation, RCT
Schunemann, 2003[20]	CRQ Standardized dyspnea questions (CRQ-SAS-D, CRQ-IAS-D)	N	N

Evidence Table 2b. Population and setting of tools included in the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Bergman, 1994[21]	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Lung Cancer supplement, breathlessness subscale (EORTC-QLQ; LC13 breathlessness)	Lung cancer	RCT
Garrod, 2000[22]	London Chest Activity of Daily Living Scale (LCADL)	COPD	Outpatient, home
Dougan, 2000[23]	Motor Neurone Disease Dyspnea Rating Scale, dyspnea subscale (MDRS-D)	MND	Outpatient
Fairburn, 1959[24]	Medical Research Council Dyspnea Scale (MRC)	COPD, interstitial lung disease, asthma, other	Outpatient
McGavin, 1978[25]	Oxygen cost diagram (OCD)	Respiratory disease, COPD, heart failure	Outpatient
Lareau, 1994[26]	Pulmonary Functional Status and Dyspnea Questionnaire-modified (PFSDQ-M)	COPD	Pulmonary rehabilitation
Rosenthal, 1981[27]	Rand Instrument: shortness of breath battery from the Medical History Questionnaire (Rand)	Heart failure, respiratory disease	Outpatient
Jones, 1992[28]	St George's Respiratory Questionnaire (activity subscale) (SGRO)	COPD, asthma, bronchiectasis	Outpatient, pulmonary rehabilitation
Lee, 1998[29]	University of Cincinnati Dyspnea Questionnaire (UCDQ)	Asthma, sarcoid, COPD, fibrosis	Outpatient, exercise lab
Eakin, 1998[30]	University of California San Diego Shortness of Breath Questionnaire (UCSD SOBQ)	COPD, asthma, cystic fibrosis, lung transplant	Pulmonary rehabilitation, outpatient

ALSFRS-R =Amyotrophic lateral sclerosis functional rating scale – revised; ATS-DLD-78=American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale; BCSS =Breathlessness, Cough and Sputum Scale; CHQ-D =Chronic Heart Failure Questionnaire – dyspnea subscale; CLASP =Cardiovascular Limitations and Symptoms Profile; CLD =Chronic Lung Disease Severity Index; COPD=chronic obstructive pulmonary disease; CRQ-D, CRQ-SAI-D =Chronic Respiratory Questionnaire – dyspnea subscale; CRQ-SAS-D, CRQ-IAS-D =CRQ Standardized dyspnea questions; DAQ =Dyspnea Assessment Questionnaire; DDQ (COPD)=Dyspnea Descriptor Questionnaire (COPD); DDQ =Dyspnea Descriptor Questionnaire (heart failure); ED=emergency department; EORTC-QLQ =European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Faces =Faces scale; Global SOB =Global shortness of breath question; ITU=intensive therapy unit; LC13 breathlessness=Lung Cancer supplement, breathlessness subscale; LCADL =London Chest Activity of Daily Living Scale; mBORG =Modified Borg Scale; MDRS-D =Motor Neurone Disease Dyspnea Rating Scale; MND=motor neurone disease; MRC =Medical Research Council Dyspnea Scale; N=not present in the primary article; NR=not reported in the systematic review or on the website; NRS=Numeric rating scale; OCD =Oxygen cost diagram; PFSDQ-M =Pulmonary Functional Status and Dyspnea Questionnaire-modified; Rand =Rand Instrument: shortness of breath battery from the Medical History Questionnaire; RCT=randomized controlled trial; SGRO =St George's Respiratory Questionnaire (activity subscale); UCDQ =University of Cincinnati Dyspnea Questionnaire; UCSD SOBQ =University of California San Diego Shortness of Breath Questionnaire; VAS=Visual analogue scale

Evidence Table 2c. Domain characteristics of tools included in the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea).

Author, year, of individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Gift, 1989[3]	VAS	Physical	Dyspnea	N
Gift, 1998[4] Tanaka, 2002[5]	NRS or dyspnea numeric scale	Physical	Dyspnea	N
Borg, 1982[7]	mBORG	Physical	Dyspnea	N
Simon,1990[8]	Global SOB	Physical	Dyspnea	N
Powers, 1999[9]	Faces	Physical	Dyspnea	N
Parshall, 2001[10]	DDQ heart failure	Physical	Dyspnea	N
Parshall, 2002[11]	DDQ COPD	Physical	Dyspnea	N
Heyse-Moore, 1993[12]	DAQ	Physical	Dyspnea	N
Cedarbaum, 1999[13]	ALSFRS-R	Physical	Dyspnea	Respiratory subscale
Ferris, 1978[14]	ATS-DLD-78	Physical	Dyspnea	N
Leidy, 2003[15]	BCSS	Physical	Dyspnea	Breathlessness subscale
Guyatt, 1989[16]	CHQ-D	Physical	Dyspnea	Dyspnea subscale
Lewin, 2002[17]	CLASP	Physical	Dyspnea	N
Selim, 1997[18]	CLD	Physical	Dyspnea	N
Guyatt, 1987[19]	CRQ-D, CRQ-SAI-D	Physical	Dyspnea	Dyspnea subscale
Schunemann, 2003[20]	CRQ-SAS-D, CRQ-IAS-D	Physical	Dyspnea	N
Bergman, 1994[21]	EORTC-QLQ; LC13 breathlessness	Physical	Dyspnea	Breathlessness subscale
Garrod, 2000[22]	LCADL	Physical	Dyspnea	N
Dougan, 2000[23]	MDRS-D	Physical	Dyspnea	Dyspnea subscale
Fairburn, 1959[24]	MRC	Physical	Dyspnea	N
McGavin, 1978[25]	OCD	Physical	Dyspnea	N
Lareau, 1994[26]	PFSDQ-M	Physical	Dyspnea	N
Rosenthal, 1981[27]	MHQ, Rand subscale	Physical	Dyspnea	N
Jones, 1992[28]	SGRO	Physical	Dyspnea	Activity subscale
Lee, 1998[29]	UCDQ	Physical	Dyspnea	N
Eakin, 1998[30]	UCSD SOBQ	Physical	Dyspnea	N

Evidence Table 2c. Domain characteristics of tools included in the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea). (continued)

ALSFRS-R =Amyotrophic lateral sclerosis functional rating scale – revised; ATS-DLD-78=American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale; BCSS =Breathlessness, Cough and Sputum Scale; CHQ-D =Chronic Heart Failure Questionnaire – dyspnea subscale; CLASP =Cardiovascular Limitations and Symptoms Profile; CLD =Chronic Lung Disease Severity Index; CRQ-D, CRQ-SAI-D =Chronic Respiratory Questionnaire – dyspnea subscale; CRQ-SAS-D, CRQ-IAS-D =CRQ Standardized dyspnea questions; DAQ =Dyspnea Assessment Questionnaire; DDQ (COPD)=Dyspnea Descriptor Questionnaire (COPD); DDQ =Dyspnea Descriptor Questionnaire (heart failure); EORTC-QLQ =European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Faces =Faces scale; Global SOB =Global shortness of breath question; LC13 breathlessness=Lung Cancer supplement, breathlessness subscale; LCADL =London Chest Activity of Daily Living Scale; mBORG =Modified Borg Scale; MDRS-D =Motor Neurone Disease Dyspnea Rating Scale; MRC =Medical Research Council Dyspnea Scale; N=not present in the primary article; ND=no data available (review did not abstract);**;** NR=not reported in the systematic review or on the website; NRS=Numeric rating scale; OCD =Oxygen cost diagram; PFSDQ-M =Pulmonary Functional Status and Dyspnea Questionnaire-modified; Rand =Rand Instrument: shortness of breath battery from the Medical History Questionnaire; SGRO =St George's Respiratory Questionnaire (activity subscale); UCDQ =University of Cincinnati Dyspnea Questionnaire; UCSD SOBQ =University of California San Diego Shortness of Breath Questionnaire; VAS=Visual analogue scale; Y=present in the primary article

Evidence Table 2d. Measurement characteristics of tools included in the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea).

Author, year, of individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Gift, 1989[3]	Visual analogue scale	N	ND	1	Y*
Gift, 1998[4] Tanaka, 2002[5]	Numeric rating scale or dyspnea numeric scale	N	ND	1	Y*
Borg, 1982[7]	Modified Borg Scale	N	ND	1	Y*
Simon,1990[8]	Global shortness of breath question	N	ND	1	N
Powers, 1999[9]	Faces scale	Patient	ND	1	N
Parshall, 2001[10]	DDQ (heart failure)	N	ND	13	N
Parshall, 2002[11]	DDQ (COPD)	N	ND	16 (reduced to 7)	N
Heyse-Moore, 1993[12]	(DAQ)	Patient	ND	43	N
Cedarbaum, 1999[13]	(ALSFRS-R)	N	ND	3	N
Ferris, 1978[14]	(ATS-DLD-78)	N	ND	5	Y*
Leidy, 2003[15]	(BCSS)	N	ND	1	N
Guyatt, 1989[16]	(CHQ-D)	Patient	ND	5	Y*
Lewin, 2002[17]	(CLASP)	N	ND	6	Y*
Selim, 1997[18]	(CLD)	N	ND	2	N
Guyatt, 1987[19]	(CRQ-D, CRQ-SAI-D)	Patient	ND	5 (out of 25)	Y*
Schunemann, 2003[20]	(CRQ-SAS-D, CRQ-IAS-D)	Patient	ND	5	N
Bergman, 1994[21]	(EORTC-QLQ; LC13 breathlessness)	N	ND	3	N
Garrod, 2000[22]	(LCADL)	N	ND	15	N
Dougan, 2000[23]	(MDRS-D)	Patient	ND	5 (out of 13)	Y*
Fairburn, 1959[24]	(MRC)	N	ND	1	Y*
McGavin, 1978[25]	(OCD)	Patient	ND	1	Y*
Lareau, 1994[26]	(PFSDQ-M)	N	ND	5	Y*
Rosenthal, 1981[27]	(MHQ, Rand subscale)	N	ND	9	Y*
Jones, 1992[28]	(SGRO)	N	ND	16	Y*
Lee, 1998[29]	(UCDQ)	N	ND	30	Y*
Eakin, 1998[30]	(UCSD SOBQ)	N	ND	24	Y*

ALSFRS-R =Amyotrophic lateral sclerosis functional rating scale – revised; ATS-DLD-78=American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale; BCSS =Breathlessness, Cough and Sputum Scale; CHQ-D =Chronic Heart Failure Questionnaire – dyspnea subscale; CLASP =Cardiovascular Limitations and Symptoms Profile; CLD =Chronic Lung Disease Severity Index; CRQ-D, CRQ-SAI-D =Chronic Respiratory Questionnaire – dyspnea subscale; CRQ-SAS-D, CRQ-IAS-D =CRQ Standardized dyspnea questions; DAQ =Dyspnea Assessment Questionnaire; DDQ (COPD)=Dyspnea Descriptor Questionnaire (COPD); DDQ =Dyspnea Descriptor Questionnaire (heart failure); EORTC-QLQ =European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Faces =Faces scale; Global SOB =Global shortness of breath question; LC13 breathlessness=Lung Cancer supplement, breathlessness subscale; LCADL =London Chest Activity of Daily Living Scale; mBORG =Modified Borg Scale; MDRS-D =Motor Neurone Disease Dyspnea Rating Scale; MRC =Medical Research Council Dyspnea Scale; N=not present in the primary article;; ND=no data available (review did not abstract);**;** NR=not reported in the systematic review or on the website; NRS=Numeric rating scale; OCD =Oxygen cost diagram; PFSDQ-M =Pulmonary Functional Status and Dyspnea Questionnaire-modified; Rand =Rand Instrument: shortness of breath battery from the Medical History Questionnaire; SGRO =St George's Respiratory Questionnaire (activity subscale); UCDQ =University of Cincinnati Dyspnea Questionnaire; UCSD SOBQ =University of California San Diego Shortness of Breath Questionnaire; VAS=Visual analogue scale; Y=present in the primary article

* The review noted completion time (usability) was available for the tool, but did not state what that completion time is.

Evidence Table 2e. Psychometric properties of tools included in the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Gift, 1989[3]	Visual analogue scale	ND	Y	ND	Y	Y	N
Gift, 1998[4] Tanaka, 2002[5]	Numeric rating scale or dyspnea numeric scale	ND	Y	ND	Y	Y	N
Borg, 1982[7]	Modified Borg Scale	ND	Y	ND	Y	Y	N
Simon,1990[8]	Global shortness of breath question	ND	N	ND	Y	N	Y
Powers, 1999[9]	Faces scale	ND	Y	ND	Y	N	N
Parshall, 2001[10]	DDQ (heart failure)	Y	Y	ND	N	N	N
Parshall, 2002[11]	DDQ (COPD)	Y	Y	ND	N	N	N
Heyse-Moore, 1993[12]	DAQ	N	N	ND	Y	N	N
Cedarbaum, 1999[13]	ALSFRS-R	Y	N	ND	Y	N	N
Ferris, 1978[14]	ATS-DLD-78	Y	Y	ND	Y	N	N
Leidy, 2003[15]	BCSS	ND	Y	ND	Y	Y	Y
Guyatt, 1989[16]	CHQ-D	Y	Y	ND	Y	Y	Y
Lewin, 2002[17]	(CLASP)	N	Y	ND	Y	N	N
Selim, 1997[18]	(CLD)	Y	N	ND	Y	N	N
Guyatt, 1987[19]	(CRQ-D, CRQ-SAI-D)	Y	Y	ND	Y	Y	Y

Evidence Table 2e. Psychometric properties of tools included in the selected review, Dorman, 2007[2] addressing the physical domain (subdomain, dyspnea) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency	Test-retest reliability (also for TOTAL SCORE only, not subscales)	Inter-rater reliability	Construct validity	Other validity results (discriminant, criterion)	Sensitivity to change/ responsiveness
Schunemann, 2003[20]	(CRQ-SAS-D, CRQ-IAS-D)	ND	ND	ND	ND	ND	ND
Bergman, 1994[21]	(EORTC-QLQ; LC13 breathlessness)	Y	Y	ND	Y	Y	N
Garrod, 2000[22]	(LCADL)	Y	Y	ND	Y	Y	N
Dougan, 2000[23]	(MDRS-D)	Y	N	ND	Y	N	N
Fairburn, 1959[24]	Scale (MRC)	N	N	ND	Y	Y	N
McGavin, 1978[25]	OCD	ND	Y	ND	Y	N	Y
Lareau, 1994[26]	PFSDQ-M	Y	Y	ND	Y	Y	N
Rosenthal, 1981[27]	MHQ, Rand subscale	N	Y	ND	Y	N	Y
Jones, 1992[28]	SGRO	Y	Y	ND	Y	Y	Y
Lee, 1998[29]	UCDQ	Y	Y	ND	Y	N	N
Eakin, 1998[30]	UCSD SOBQ	Y	Y	ND	Y	N	Y

ALSFRS-R =Amyotrophic lateral sclerosis functional rating scale – revised; ATS-DLD-78=American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale; BCSS =Breathlessness, Cough and Sputum Scale; CHQ-D =Chronic Heart Failure Questionnaire – dyspnea subscale; CLASP =Cardiovascular Limitations and Symptoms Profile; CLD =Chronic Lung Disease Severity Index; CRQ-D, CRQ-SAI-D =Chronic Respiratory Questionnaire – dyspnea subscale; CRQ-SAS-D, CRQ-IAS-D =CRQ Standardized dyspnea questions; DAQ =Dyspnea Assessment Questionnaire; DDQ (COPD)=Dyspnea Descriptor Questionnaire (COPD); DDQ =Dyspnea Descriptor Questionnaire (heart failure); EORTC-QLQ =European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Faces =Faces scale; Global SOB =Global shortness of breath question; LC13 breathlessness=Lung Cancer supplement, breathlessness subscale; LCADL =London Chest Activity of Daily Living Scale; mBORG =Modified Borg Scale; MDRS-D =Motor Neurone Disease Dyspnea Rating Scale; MRC =Medical Research Council Dyspnea Scale; N=not present in the primary article;; ND=no data available (review did not abstract); NRS=Numeric rating scale; OCD =Oxygen cost diagram; PFSDQ-M =Pulmonary Functional Status and Dyspnea Questionnaire-modified; Rand =Rand Instrument: shortness of breath battery from the Medical History Questionnaire; SGRO =St George's Respiratory Questionnaire (activity subscale); UCDQ =University of Cincinnati Dyspnea Questionnaire; UCSD SOBQ =University of California San Diego Shortness of Breath Questionnaire; VAS=Visual analogue scale; Y=present in the primary article

Evidence Table 3a. Characteristics of the selected review, Ziegler, 2011[31] addressing psychosocial and psychiatric care domain.

Author, year of systematic review/website	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
Ziegler, 2011[31]	Psychosocial, Self-report measures of psychological distress, Cancer patients, Hospitals/hospices/primary care	Exploring the validation of a self-report measure alongside a structured clinical interview for psychiatric disorder	48 tools (85 studies) – 8 tools (6 studies) focusing on psychosocial domain in palliative care populations	1960 to unspecified end date

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 3b. Population and setting of tools included in the selected review, Ziegler, 2011[31] addressing psychosocial and psychiatric care domain.

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Love, 2004[32]	Hospital Anxiety and Depression Scale (HADS)	Metastatic breast cancer patients with recurrence	N
Akechi, 2004[33]	Two single items: Are you depressed? and Have you lost interest?	Palliative care population	Palliative care unit
Thekkumpurath, 2009[34]	Distress Thermometer (via touch screen)	Patients with advanced disease	inpatient or outpatient care
Thekkumpurath, 2009[34]	Brief Symptom Inventory-18	Patients with advanced disease	inpatient or outpatient care
Thekkumpurath, 2009[34]	General Health Questionnaire-12 item (GHQ-12)	Patients with advanced disease	inpatient or outpatient care
Lloyd-Williams, 2007[35]	Brief Edinburgh Depression Scale	Palliative care patients with a prognosis of six months or less	N
Love, 2004[32]	Beck Depression Inventory-Short Form	Metastatic breast cancer patients with recurrence	N
Okamura, 2005[36]	Mental Adjustment to Cancer	Patients at first recurrence of breast cancer	N

GHQ-12 =General Health Questionnaire-12 item; HADS =Hospital Anxiety and Depression Scale; N=not present in the primary article

(Note that some studies were listed more than once; in that case, the study validating in the broadest population and that had psychometrics was abstracted. All results were similar)

Evidence Table 3c. Domain characteristics of tools included in the selected review, Ziegler, 2011[31] addressing psychosocial and psychiatric care domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Subscales
Love, 2004[32]	Hospital Anxiety and Depression Scale (HADS)	Psychosocial	Anxiety, depression	2 subscales
Akechi, 2004[33]	Two single items: Are you depressed? and Have you lost interest?	Psychosocial	Depression	N
Thekkumpurath, 2009[34]	Distress Thermometer (via touch screen)	Psychosocial	Distress	N
Thekkumpurath, 2009[34]	Brief Symptom Inventory-18 (via touch screen)	Psychosocial	Depression, anxiety, somatoform	3 subscales
Thekkumpurath, 2009[34]	General Health Questionnaire-12 item (GHQ-12)	Psychosocial	Distress	N
Lloyd-Williams, 2007[35]	Brief Edinburgh Depression Scale	Psychosocial	Depression	N
Love, 2004[32]	Beck Depression Inventory-Short Form	Psychosocial	Depression	N
Okamura, 2005[36]	Mental Adjustment to Cancer	Psychosocial	Psychological response to having cancer	5 subscales

GHQ-12 =General Health Questionnaire-12 item; HADS =Hospital Anxiety and Depression Scale; N=not present in the primary article

Evidence Table 3d. Measurement characteristics of tools included in the selected review, Ziegler, 2011[31] addressing psychosocial and psychiatric care domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Love, 2004[32]	Hospital Anxiety and Depression Scale (HADS)	Patient	Paper	14	5 minutes
Akechi, 2004[33]	Two single items: Are you depressed? and Have you lost interest?	Patient	Paper	2	Approximately 1-2 minutes
Thekkumpurath, 2009[34]	Distress Thermometer	Patient	Touch screen	1	Approximately 1 minute
Thekkumpurath, 2009[34]	Brief Symptom Inventory-18	Patient	Touch screen	18	Approximately 10 minutes
Thekkumpurath, 2009[34]	General Health Questionnaire-12 item (GHQ-12)	Patient	Touch screen	12	5 minutes
Lloyd-Williams, 2007[35]	Brief Edinburgh Depression Scale	Patient	N	6	Approximately 3 minutes
Love, 2004[32]	Beck Depression Inventory-Short Form	Patient	N	13	Approximately 5-10 minutes
Okamura, 2005[36]	Mental Adjustment to Cancer	Patient	N	40	N

GHQ-12 =General Health Questionnaire-12 item; HADS =Hospital Anxiety and Depression Scale; N=not present in the primary article

Evidence Table 3e. Psychometric properties of tools included in the selected review, Ziegler, 2011[31] addressing psychosocial and psychiatric care domain.

Author, year, of individual study(s) within the review for each tool	Instrument	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Convergent validity (Type of construct validity)	Specific additional construct validity types: discriminant, criterion	Sensitivity to change/ responsiveness
Love, 2004[32]	Hospital Anxiety and Depression Scale (HADS)	N	ND	ND	Y	ND	N
Akechi, 2004[33]	Two single items: Are you depressed? and Have you lost interest?	N	ND	ND	Y	ND	N
Thekkumpurath, 2009[34]	Distress Thermometer	N	ND	ND	Y	ND	N
Thekkumpurath, 2009[34]	Brief Symptom Inventory-18	N	ND	ND	Y	ND	N
Thekkumpurath, 2009[34]	General Health Questionnaire-12 item (GHQ-12)	N	ND	ND	Y	ND	N
Lloyd-Williams, 2007[35]	Brief Edinburgh Depression Scale	Y	ND	ND	Y	ND	N
Love, 2004[32]	Beck Depression Inventory-Short Form	N	ND	ND	Y	ND	N
Okamura, 2005[36]	Mental Adjustment to Cancer	N	ND	ND	N	ND	N

GHQ-12 =General Health Questionnaire-12 item; HADS =Hospital Anxiety and Depression Scale; N=not present in the primary article; ND=no data available (review did not abstract); Y=present in the primary article

Evidence Table 4a. Characteristics of the selected review, Michels, 2016[37] addressing the social domain.

Author, year of systematic review/website	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
Michels, 2016[37]	Social support, caregivers	Used a self-reported multidimensional measure that assessed caregiver outcomes; measures were directed at unpaid informal carers; patients were diagnosed with an advanced progressive illness or were receiving palliative care; both carers and patients were ⩾18years old; the study was reported in English.	38 tools (112 studies); only 8 tools were included (8 studies abstracted) that are specifically related to palliative care in the US.	Not explicitly reported

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 4b. Population and setting of tools included in the selected review, Michels, 2016[37] addressing the social domain.

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Dumont, 2008[38]	Caregiver's Burden Scale in end-of-life care (CBS-EOLC)	Family caregivers of terminal cancer patients	ND
Cameron, 2002[39]	Caregiver Impact Scale (CIS)	Caregivers of advanced cancer patients	ND
Weitzner, 1999[40]	Caregiver Quality of Life Index – Cancer (CQOLI-C)*	Caregivers of cancer	ND
Hudson, 2006[41]	Caregiver Reaction Assessment (CRA)	Caregivers of patients receiving palliative care	ND
Hwang, 2003[42]	Caregiver Strain Index (CSI)	Caregivers for symptomatic advanced cancer patients	ND
Cooper, 2006[43]	Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC)	Caregivers of palliative care patients	ND
Cohen, 2006[44]	Quality of Life in Life-Threatening Illness-Family Carer Version (QOLLTI-F)	Caregivers of palliative cancer patients	ND
Higginson, 2010[45]	Zarit Burden Inventory (ZBI)	Advanced conditions	ND

CBS-EOLC =Caregiver's Burden Scale in end-of-life care; CIS =Caregiver Impact Scale; CQOLI-C =Caregiver Quality of Life Index – Cancer; CRA =Caregiver Reaction Assessment; CSI=Caregiver Strain Index; FACQ-PC =Family Appraisal of Caregiving Questionnaire for Palliative Care; ND=no data available (review did not abstract); QOLLTI-F =Quality of Life in Life-Threatening Illness-Family Carer Version; ZBI =Zarit Burden Inventory

*Note that a CQOLI-R version for hospice patients is also available with data

Evidence Table 4c. Domain characteristics of tools included in the selected review, Michels, 2016[37] addressing the social domain.

Author, year, of individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Dumont, 2008[38]	CBS-EOLC	Social	ND	ND
Cameron, 2002[39]	CIS	Social	ND	ND
Weitzner, 1999[40]	CQOLI-C	Social	ND	ND
Hudson, 2006[41]	CRA	Social	ND	ND
Hwang, 2003[42]	CSI	Social	ND	ND
Cooper, 2006[43]	FACQ-PC	Social	ND	ND
Cohen, 2006[44]	QOLLTI-F	Social	ND	ND
Higginson, 2010[45]	ZBI	Social	ND	ND

CBS-EOLC =Caregiver's Burden Scale in end-of-life care; CIS =Caregiver Impact Scale; CQOLI-C =Caregiver Quality of Life Index – Cancer; CRA =Caregiver Reaction Assessment; CSI=Caregiver Strain Index; FACQ-PC =Family Appraisal of Caregiving Questionnaire for Palliative Care; ND=no data available (review did not abstract); QOLLTI-F =Quality of Life in Life-Threatening Illness-Family Carer Version; ZBI =Zarit Burden Inventory

Evidence Table 4d. Measurement characteristics of tools included in the selected review, Michels, 2016[37] addressing the social domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Dumont, 2008[38]	CBS-EOLC	ND	ND	16	N
Cameron, 2002[39]	CIS	ND	ND	14	N
Weitzner, 1999[40]	CQOLI-C	ND	ND	35	10 minutes
Hudson, 2006[41]	CRA	ND	ND	24	N
Hwang, 2003[42]	CSI	ND	ND	13	N
Cooper, 2006[43]	FACQ-PC	ND	ND	26	N
Cohen, 2006[44]	QOLLTI-F	ND	ND	16	N
Higginson, 2010[45]	ZBI	ND	ND	22	N

CBS-EOLC =Caregiver’s Burden Scale in end-of-life care; CIS =Caregiver Impact Scale; CQOLI-C =Caregiver Quality of Life Index – Cancer; CRA =Caregiver Reaction Assessment; CSI=Caregiver Strain Index; FACQ-PC =Family Appraisal of Caregiving Questionnaire for Palliative Care; N=not present in the primary article; ND=no data available (review did not abstract); QOLLTI-F =Quality of Life in Life-Threatening Illness-Family Carer Version; ZBI =Zarit Burden Inventory

Evidence Table 4e. Psychometric properties of tools included in the selected review, Michels, 2016[37] addressing the social domain.

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Convergent validity (Type of construct validity)	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Dumont, 2008[38]	CBS-EOLC	α=0.95	N	ND	Y	Y	Y
Cameron, 2002[39]	CIS	α=0.87	N	ND	N	N	N
Weitzner, 1999[40]	CQOLI-C	α=0.91	Y	ND	Y	Y	Y
Hudson, 2006[41]	CRA	α=0.76–0.83	N	ND	Y	N	N
Hwang, 2003[42]	CSI	α=0.84	NR	ND	Y	N	N
Cooper, 2006[43]	FACQ-PC	α=0.73–0.86	Y	ND	Y	N	N
Cohen, 2006[44]	QOLLTI-F	α=0.86	Y	ND	Y	N	Y
Higginson, 2010[45]	ZBI	α=0.69–0.93	N	ND	Y	N	N

CBS-EOLC =Caregiver’s Burden Scale in end-of-life care; CIS =Caregiver Impact Scale; CQOLI-C =Caregiver Quality of Life Index – Cancer; CRA =Caregiver Reaction Assessment; CSI=Caregiver Strain Index; FACQ-PC =Family Appraisal of Caregiving Questionnaire for Palliative Care ; N=not present in the primary article; ND=no data available (review did not abstract); QOLLTI-F =Quality of Life in Life-Threatening Illness-Family Carer Version; Y=present in the primary article; ZBI =Zarit Burden Inventory

(Note that for this review’s, definition of construct validity was not same as we had defined and sometimes factor analysis is reported here; we coded this as Y)

Evidence Table 5a. Characteristics of the selected review, Selman, 2011[46] addressing the spiritual, religious, and existential domain.

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
Selman, 2011[46]	Spirituality	Measures related to "palliative care" and "spirituality" and "outcome measure"; original research or validating measures; must be in English.	9 in review, 2 patient/ family assessments included here.	Through June 10, 2010: No restriction on start date of searches

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 5b. Population and setting of tools included in the selected review, Selman, 2011[46] addressing the spiritual, religious, and existential domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)-	Setting where testing results are reported from
Rosenfeld, 2004[47] Nissim, 2010[48] Abbey, 2006[49]	Beck Hopelessness Scale (BHS)	Ethnically diverse U.S. population; made for a general population but has been validated in palliative care population.	Inpatient
Ironson, 2002[50]	Ironson-Woods Spirituality/Religiousness Index (I-W SR Index Short Form)	Ethnically diverse US population	ND

BHS =Beck Hopelessness Scale; I-W SR Index Short Form =Ironson-Woods Spirituality/Religiousness Index; ND=no data available (review did not abstract)

Evidence Table 5c. Domain characteristics of tools included in the selected review, Selman, 2011[46] addressing the spiritual, religious, and existential domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Rosenfeld, 2004[47] Nissim, 2010[48] Abbey, 2006[49]	BHS	Spirituality	Hopelessness	ND
Ironson, 2002[50]	I-W SR Index Short Form	Spirituality	ND	ND

BHS =Beck Hopelessness Scale; I-W SR Index Short Form =Ironson-Woods Spirituality/Religiousness Index; ND=no data available (review did not abstract)

*Was defined in review as the "Spiritual Constructs Measured (as stated in validation article)"

Evidence Table 5d. Measurement characteristics of tools included in the selected review, Selman, 2011[46] addressing the spiritual, religious, and existential domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Rosenfeld, 2004[47] Nissim, 2010[48] Abbey, 2006[49]	BHS	ND	ND	20	N
Ironson, 2002[50]	I-W SR Index Short Form	ND	ND	22	N

BHS =Beck Hopelessness Scale; I-W SR Index Short Form =Ironson-Woods Spirituality/Religiousness Index; N=not present in the primary article; ND=no data available (review did not abstract)

Evidence Table 5e. Psychometric properties of tools included in the selected review, Selman, 2011[46] addressing the spiritual, religious, and existential domain.

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Rosenfeld, 2004[47] Nissim, 2010[48] Abbey, 2006[49]	BHS	Y	N	N	Y	Y	Y
Ironson, 2002[50]	I-W SR Index Short Form	Y	Y	N	Y	Y	Y

BHS =Beck Hopelessness Scale; I-W SR Index Short Form =Ironson-Woods Spirituality/Religiousness Index; N=not present in the primary article; Y=present in the primary article

Evidence Table 6a. Characteristics of the selected review, Sealey, 2015[51] addressing care of the patient at end of life (bereavement).

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools included (number of studies)	Years of search (range)
Sealey, 2015[51]	End-of-life: bereavement*	Bereavement risk assessment measures appropriate for different points in the caring and bereavement trajectories	19 in review, 17 patient/family assessments included here	1980 through August 2014

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

* Scoping review

Evidence Table 6b. Population and setting of tools in the selected review, Sealey, 2015[51] addressing care of the patient at end of life (bereavement).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Guarnaccia, 1998[52]	Bereavement Experience Questionnaire–24 (BEQ-24)	Bereaved adults	N
Shear, 2006[53] Ito, 2012[54] Fujisawa, 2010[55]	Brief Grief Questionnaire (BGQ)	Recipients of crisis counselling following 911 terrorist attacks; bereaved community dwelling adults	Outpatient
Burnett, 1997[56]	Core Bereavement Items (CBI)	Bereaved adults	N
Jordan, 2005[57]	Grief Evaluation Measure (GEM)	Bereaved adults:	N
Barrett, 1989[58]	Grief Experience Questionnaire (GEQ)	Conjugally bereaved adults to suicide, natural causes or accidental death	N
Hogan, 2001[59]	Hogan Grief Reaction Checklist (HGRC)	Parentally bereaved people	N
Prigerson, 1995[60]	Inventory of Complicated Grief (ICG)	Conjugally bereaved elders	N
Prigerson, 2009[61] O'Connot, 2010[62] Guldin, 2011[63]	Inventory of Complicated Grief–Revised (ICG-R)	Conjugally bereaved elders	N
Prigerson, 2001[64].	Inventory of Traumatic Grief (ITG)	Elderly widowed residents; bereaved adults	N
Marwit, 2002[65] Marwit, 2006[66] Marwit, 2008[67]	Marwit–Meuser Caregiver Grief Inventory (MMCGI) (and short form)	Caregivers of people with dementia, acquired brain injury, cancer	N
Marwit, 2005[68]	Marwit–Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF)	Adult caregivers of people with dementia	N
Kiely, 2008[69] Lai, 2014[70]	Prolonged Grief–12 (PG-12)	Caregivers of people with dementia, hospice patients	Residential aged care (person who died)
Lichtenthal, 2011[71] Papa, 2014[72]	Prolonged Grief–13 (PG-13)	Adults; bereaved caregivers with prolonged grief disorder	N
Lev, 1993[73]	Revised Grief Experience Inventory (R-GEI)	Hospice caregivers following the death of a loved one	N
Faschingbauer, 1987[74] Zisook, 1982[75] Faschingbauer, 1977[76] Futterman, 2010[77]	Texas Revised Inventory of Grief (TRIG)	Bereaved psychiatric outpatients; bereaved adults	Outpatient
Rubin, 2009[78]	Two-Track Bereavement Questionnaire (TTBQ)	Bereaved adults	N
Bar Nadav, 2014[79]	Two-Track Bereavement Questionnaire (TTBQ2-CG30)	Adults bereaved by traumatic deaths	N

BEQ-24=Bereavement Experience Questionnaire–24; BGQ =Brief Grief Questionnaire; CBI =Core Bereavement Items; GEM =Grief Evaluation Measure; GEQ =Grief Experience Questionnaire; HGRC =Hogan Grief Reaction Checklist; ICG =Inventory of Complicated Grief; ICG-R =Inventory of Complicated Grief–Revised; ITG =Inventory of Traumatic Grief; MMCGI =Marwit–Meuser Caregiver Grief Inventory and short form; MM-CGI-SF =Marwit–Meuser Caregiver Grief Inventory–Short Form; PG-12=Prolonged Grief–12; PG-13=Prolonged Grief–13; N=not present in the primary article; R-GEI =Revised Grief Experience Inventory; TRIG =Texas Revised Inventory of Grief; TTBQ =Two-Track Bereavement Questionnaire; TTBQ2-CG30=Two-Track Bereavement Questionnaire

Evidence Table 6c. Domain characteristics of tools in the selected review, Sealey, 2015[51] addressing care of the patient at end of life (bereavement).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Guarnaccia, 1998[52]	BEQ-24	End of life	Bereavement (following a patient's death)	N
Shear, 2006[53] Ito, 2012[54] Fujisawa, 2010[55]	BGQ	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	N
Burnett, 1997[56]	CBI	End of life	Bereavement (following a patient's death)	Images and thoughts, acute separation and grief
Jordan, 2005[57]	GEM	End of life	Bereavement (following a patient's death)	Seven sections
Barrett, 1989[58]	GEQ	End of life	Bereavement (following a patient's death)	Somatic and general grief reactions, meaning making, social support, stigmatization, guilt, responsibility for the death, shame, rejection, self-destructive behavior and reactions exclusive to suicide survivors
Hogan, 2001[59]	HGRC	End of life	Bereavement (following a patient's death)	Six factors
Prigerson, 1995[60]	ICG	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	N
Prigerson, 2009[61] O'Connot, 2010[62] Guldin, 2011[63]	ICG-R	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	Two factors
Prigerson, 2001[64].	ITG	End of life	Bereavement (following a patient's death)	Two factors
Marwit, 2002[65] Marwit, 2006[66] Marwit, 2008[67]	MMCGI	End of life	Bereavement (pre-death risk)	Personal sacrifice burden, heartfelt sadness and longing and worry and felt isolation

Evidence Table 6c. Domain characteristics of tools in the selected review, Sealey, 2015[51] addressing care of the patient at end of life (bereavement) (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Marwit, 2005[68]	MM-CGI-SF	End of life	Bereavement (pre-death risk)	Personal sacrifice burden, heartfelt sadness and longing and worry and felt isolation
Kiely, 2008[69] Lai, 2014[70]	PG-12	End of life	Bereavement (pre-death risk)	N
Lichtenthal, 2011[71] Papa, 2014[72]	PG-13	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	N
Lev, 1993[73]	R-GEI	End of life	Bereavement (following a patient's death)	Existential concerns, depression, feelings of tension and guilt and physical distress
Faschingbauer, 1987[74] Zisook, 1982[75] Faschingbauer, 1977[76] Futterman, 2010[77]	TRIG	End of life	Bereavement (following a patient's death)	Past behavior and present feelings
Rubin, 2009[78]	TTBQ	End of life	Bereavement (following a patient's death)	Five factors
Bar Nadav, 2014[79]	TTBQ2-CG30	End of life	Bereavement (following a patient's death)	Four factors

BEQ-24=Bereavement Experience Questionnaire–24; BGQ =Brief Grief Questionnaire; CBI =Core Bereavement Items; GEM =Grief Evaluation Measure; GEQ =Grief Experience Questionnaire; HGRC =Hogan Grief Reaction Checklist; ICG =Inventory of Complicated Grief; ICG-R =Inventory of Complicated Grief–Revised; ITG =Inventory of Traumatic Grief; MMCGI =Marwit–Meuser Caregiver Grief Inventory and short form; MM-CGI-SF =Marwit–Meuser Caregiver Grief Inventory–Short Form; PG-12=Prolonged Grief–12; PG-13=Prolonged Grief–13; N=not present in the primary article; R-GEI =Revised Grief Experience Inventory; TRIG =Texas Revised Inventory of Grief; TTBQ =Two-Track Bereavement Questionnaire; TTBQ2-CG30=Two-Track Bereavement Questionnaire

Evidence Table 6d. Measurement characteristics of tools in the selected review, Sealey, 2015[51] addressing care of the patient at end of life (bereavement).

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Guarnaccia, 1998[52]	BEQ-24	Caregiver	ND	24	N
Shear, 2006[53] Ito, 2012[54] Fujisawa, 2010[55]	BGQ	Caregiver	ND	5	N
Burnett, 1997[56]	CBI	Caregiver	ND	17	N
Jordan, 2005[57]	GEM	Caregiver	ND	91	30-35 minutes
Barrett, 1989[58]	GEQ	Caregiver	ND	55	< 20 minutes
Hogan, 2001[59]	HGRC	Caregiver	ND	61	N
Prigerson, 1995[60]	ICG	Caregiver	ND	19	N
Prigerson, 2009[61] O'Connot, 2010[62] Guldin, 2011[63]	ICG-R	Caregiver	ND	15	N
Prigerson, 2001[64].	ITG	Caregiver	ND	34	N
Marwit, 2002[65] Marwit, 2006[66] Marwit, 2008[67]	MMCGI	Caregiver	ND	50	N
Marwit, 2005[68]	MM-CGI-SF	Caregiver	ND	18	N
Kiely, 2008[69] Lai, 2014[70]	PG-12	Caregiver	ND	12	N
Lichtenthal, 2011[71] Papa, 2014[72]	PG-13 n	Caregiver	ND	13	N
Lev, 1993[73]	R-GEI	Caregiver	ND	22	N
Faschingbauer, 1987[74] Zisook, 1982[75] Faschingbauer, 1977[76] Futterman, 2010[77]	TRIG	Caregiver	ND	21	N
Rubin, 2009[78]	TTBQ	Caregiver	ND	70	N
Bar Nadav, 2014[79]	TTBQ2-CG30	Caregiver	ND	30	ND

BEQ-24=Bereavement Experience Questionnaire–24; BGQ =Brief Grief Questionnaire; CBI =Core Bereavement Items; GEM =Grief Evaluation Measure; GEQ =Grief Experience Questionnaire; HGRC =Hogan Grief Reaction Checklist; ICG =Inventory of Complicated Grief; ICG-R =Inventory of Complicated Grief–Revised; ITG =Inventory of Traumatic Grief; MMCGI =Marwit–Meuser Caregiver Grief Inventory and short form; MM-CGI-SF =Marwit–Meuser Caregiver Grief Inventory–Short Form; PG-12=Prolonged Grief–12; PG-13=Prolonged Grief–13; N=not present in the primary article; ND=no data available (review did not abstract); R-GEI =Revised Grief Experience Inventory; TRIG =Texas Revised Inventory of Grief; TTBQ =Two-Track Bereavement Questionnaire; TTBQ2-CG30=Two-Track Bereavement Questionnaire

Evidence Table 6e. Psychometric properties of tools in the selected review, Sealey, 2015[51] addressing care of the patient at end of life (bereavement).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Guarnaccia, 1998[52]	BEQ-24	Cronbach's alpha 0.70 - 0.84	N	ND	N	ND	N
Shear, 2006[53] Ito, 2012[54] Fujisawa, 2010[55]	BGQ	Cronbach's alpha 0.75- 0.82	N	ND	N	ND	N
Burnett, 1997[56]	CBI	Cronbach's alpha 0.91	N	ND	Y	ND	N
Jordan, 2005[57]	GEM	Cronbach's alpha 0.91- 0.97	Y	ND	N	ND	N
Barrett, 1989[58]	GEQ	Cronbach's alpha 0.97	N	ND	N	ND	N
Hogan, 2001[59]	HGRC	Cronbach's alpha 0.90	Y	ND	N	ND	N
Prigerson, 1995[60]	ICG	Cronbach's alpha 0.94	Y	ND	N	ND	N
Prigerson, 2009[61] O'Connot, 2010[62] Guldin, 2011[63]	ICG-R	Cronbach's alpha 0.90 -0.94	N	ND	N	ND	N
Prigerson, 2001[64].	ITG	Cronbach's alpha 0.94-0.95	Y	ND	N	ND	N
Marwit, 2002[65] Marwit, 2006[66] Marwit, 2008[67]	MM-CGI	Cronbach's alpha 0.86-0.96	N	ND	Y	ND	N
Marwit, 2005[68]	MM-CGI-SF	Cronbach's alpha 0.80-0.83	N	ND	Y	ND	N
Kiely, 2008[69] Lai, 2014[70]	PG-12	Cronbach's alpha 0.81	N	ND	N	ND	N
Lichtenthal, 2011[71] Papa, 2014[72]	PG-13	Cronbach's alpha total 0.82-0.94	N	ND	N	ND	N
Lev, 1993[73]	R-GEI	Cronbach's alpha 0.93	N	ND	N	ND	N
Faschingbauer, 1987[74] Zisook, 1982[75] Faschingbauer, 1977[76] Futterman, 2010[77]	TRIG	Cronbach's alpha 0.86;	N	ND	N	ND	N

Evidence Table 6e. Psychometric properties of tools in the selected review, Sealey, 2015[51] addressing care of the patient at end of life (bereavement) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Rubin, 2009[78]	TTBQ	Cronbach's alpha 0.94	N	ND	N	ND	N
Bar Nadav, 2014*[79]	TTBQ2-CG30	Cronbach's alpha 0.91	N	ND	N	ND	ND

BEQ-24=Bereavement Experience Questionnaire–24; BGQ =Brief Grief Questionnaire; CBI =Core Bereavement Items; GEM =Grief Evaluation Measure; GEQ =Grief Experience Questionnaire; HGRC =Hogan Grief Reaction Checklist; ICG =Inventory of Complicated Grief; ICG-R =Inventory of Complicated Grief–Revised; ITG =Inventory of Traumatic Grief; MMCGI =Marwit–Meuser Caregiver Grief Inventory and short form; MM-CGI-SF =Marwit–Meuser Caregiver Grief Inventory–Short Form; PG-12=Prolonged Grief–12; PG-13=Prolonged Grief–13; N=not present in the primary article; ND=no data available (review did not abstract); R-GEI =Revised Grief Experience Inventory; TRIG =Texas Revised Inventory of Grief; TTBQ =Two-Track Bereavement Questionnaire; TTBQ2-CG30=Two-Track Bereavement Questionnaire; Y=present in the primary article

*Reference for Bar Nadav, 2014 is a conference abstract. Unable to retrieve full text article to verify TTBQ2-CG30, after exhausting all resources.

Evidence Table 7a. Characteristics of the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life).

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools included (number of studies)	Years of search (range)
Albers, 2010[80]	Feasibility and clinimetric quality of QOL measurement instruments suitable for use in palliative care	(1) the study should describe the development or validation of a measurement tool; (2) the measurement instrument should measure (at least one domain of) quality of life in a population of patients for whom there are no further curative treatment options; (3) the study should have investigated at least one measurement property of the instrument; (4) the measurement instrument should have been validated in an English or a Dutch population.	29 (36 studies)	January 1990 to April 2008

NCP=National Consensus Project for Quality Palliative Care Clinical Practice; QOL=Quality of Life

Evidence Table 7b. Population and setting of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Guo, 2001[81]	Brief Hospice Inventory（BHI)	Hospice patients	Hospice
Ewing, 2004[82]	Cambridge Palliative Audit Schedule (CAMPAS-R)	Palliative care patients	Home care
Kissane, 2004[83]	Demoralization Scale (DS)	Cancer patients	Inpatients
Kaasa, 1997[84] Kaasa, 2001[85]	Edmonton Functional Assessment Tool (EFAT and EFAT-2)	Cancer patients	Palliative care unit
Schwartz, 2004[86]	Emanuel and Emanuel Medical Directive	Severely ill patients	Inpatients, dialysis clinics, rehabilitation hospitals, long-term facilities
Blazeby, 2003[87]	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module (EORTC QLQ-OESI8)	Esophageal cancer patients	N
Blazeby, 2004[88]	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module (EORTC QLQ-ST022)	Patients with adenoma carcinoma of the stomach	N
Chang, 2000[89]	Edmonton Symptom Assessment Scale（ESAS)	Palliative care patients	In- and outpatients
Lyons, 2009[90]	Functional Assessment of Chronic Illness Therapy-Palliative Subscale (FACIT-Pal)	Patients with life limiting illness	N
Mcmillan, 1998[91] McMillan, 2008[92]	Hospice Quality of Life Index (HQLI)	Hospice patients	Hospice home care
Dobratz, 2004[93]	Life Closure Scale (LCS)	Terminally ill patients	Hospice
Salmon, 1996[94]	Life Evaluation Questionnaire（LEQ)	People with incurable cancer	Outpatient, inpatient
Sterkenberg, 1996[95]	McMaster Quality of Life Scale (MQLS)	Palliative care patients	In and outpatient, and community-based
Cohen, 1997[96] Cohen, 2000[97]	McGill Quality of Life Questionnaire (MQOL)	People with life threatening illness	Palliative care inpatient units, outpatient, home care
Lua, 2005[98]	McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF)	Terminally ill patients	Hospice center, inpatient
McCanse, 1995 [99]	McCanse Readiness for Death Instrument (MRDI)	Terminally ill patients	Hospice
Sherman, 2007[100] Lobchuk, 2003[101]	Memorial Symptom Assessment Scale (MSAS)	Cancer patients	N

Evidence Table 7b. Population and setting of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Chang, 2004[102]	Condensed Memorial Symptom Assessment Scale（CMSAS)	Cancer patients	In- and outpatients
Hickman, 2001[103]	Memorial Symptom Assessment Scale-Global Distress Index (MSAS-GDI)	Cancer patients	Inpatients
Byock, 1998[104] Schwartz, 2005[105]	Missoula-VITAS Quality of Life Index (MVQOLI-R)	Terminally ill patients	Hospice, dialysis clinics; hospices; long-term care facilities
Rainbird, 2005[106]	Needs Assessment for Advanced Cancer Patients (NA-ACP)	Advanced cancer patients	N
Vernooij-Dassen, 2005[107]	Patient Autonomy Questionnaire (PAQ)	Palliative cancer patients	N
Chochinov, 2008[108]	Patient Dignity Inventory (PDI)	Patients nearing the end of life	Inpatients
Osse, 2004[109]	Problems and Needs in Palliative Care questionnaire（PNPC)	Palliative care patients	Home
Osse, 2007[110]	Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv)	Palliative care patients	Home
Hearn, 1999[111]	Palliative care Outcome Scale（POS)	Advanced cancer patients	Centers providing palliative care, including inpatient, outpatient, day, home and primary care
Steinhauser, 2004[112]	Quality of life at the end of life (QUAL-E)	Seriously ill patients	N
Hermann, 2006[113]	Spiritual Needs Inventory (SNI)	Patients near the end of life	Outpatient and inpatient hospice

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool ; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OESI8=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCanse Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; N=not present in the primary article; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=not present in the primary article; PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory

Evidence Table 7c. Domain and subscale characteristics of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Guo, 2001[81]	BHI	Physical, Psychological and Psychiatric	ND	N
Ewing, 2004[82]	CAMPAS-R	Physical, Psychological and Psychiatric	ND	Subscale
Kissane, 2004[83]	DS	Psychological and Psychiatric	ND	Subscale and total
Kaasa, 1997[84] Kaasa, 2001[85]	EFAT	Physical	ND	Total
Schwartz, 2004[86]	Emanuel and Emanuel Medical Directive	Ethical/legal	ND	N
Blazeby, 2003[87]	EORTC QLQ-OESI8	Physical	ND	Subscale
Blazeby, 2004[88]	EORTC QLQ-ST022	Physical, Psychological and Psychiatric	ND	Subscale
Chang, 2000[89]	ESAS	Physical, Psychological and Psychiatric	ND	Total
Lyons, 2009[90]	FACIT-Pal	Physical, Psychological and Psychiatric, Social, Ethical/Legal	ND	Total
Mcmillan, 1998[91] McMillan, 2008[92]	HQLI	Physical, Psychological and Psychiatric, Social, Spiritual	ND	Subscale and total
Dobratz, 2004[93]	LCS	Psychological and Psychiatric	ND	Subscale and total
Salmon, 1996[94]	LEQ	Psychological and Psychiatric, Social	ND	Subscale
Sterkenberg, 1996[95]	MQLS	Physical, Psychological and Psychiatric, Social	ND	N
Cohen, 1997[96] Cohen, 2000[97]	MQOL	Physical, Psychological and Psychiatric, Social, Spiritual	ND	Subscale and total
Lua, 2005[98]	MQOL-CSF	Physical, Psychological and Psychiatric, Spiritual	ND	Subscale and total
McCanse, 1995 [99]	MRDI	Physical, Psychological and Psychiatric, Social, Spiritual	ND	Total
Sherman, 2007[100] Lobchuk, 2003[101]	MSAS	Physical, Psychological and Psychiatric	ND	Subscale and total
Chang, 2004[102]	CMSAS	Physical, Psychological and Psychiatric	ND	Subscale and total
Hickman, 2001[103]	MSAS-GDI	Physical, Psychological and Psychiatric	ND	Total
Byock, 1998[104] Schwartz, 2005[105]	MVQOLI-R	Physical, Social, Spiritual	ND	Subscale and total

Evidence Table 7c. Domain and subscale characteristics of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life) (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Rainbird, 2005[106]	NA-ACP	Structure and Process, Physical, Social, Spiritual	ND	Subscale
Vernooij-Dassen, 2005[107]	PAQ	Ethical/legal	ND	Total
Chochinov, 2008[108]	PDI	Physical, Social, Spiritual	ND	N
Osse, 2004[109]	PNPC	Structure and Process, Physical, Psychological and Psychiatric, Social Spiritual, Ethical/Legal	ND	Subscale
Osse, 2007[110]	PNPC-sv	Structure and Process, Physical, Psychological and Psychiatric, Social Spiritual, Ethical/Legal	ND	Subscale
Hearn, 1999[111]	POS	Physical, Psychological and Psychiatric, Spiritual	ND	N
Steinhauser, 2004[112]	QUAL-E	Structure and Process, Psychological and Psychiatric, Ethical/Legal, End of Life	ND	Subscale and total
Hermann, 2006[113]	SNI	Spiritual	ND	Subscale and total

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool ; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OESI8=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCanse Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=not present in the primary article; ND=no data available (review did not abstract); PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory

Evidence Table 7d. Measurement characteristics of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life).

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Guo, 2001[81]	BHI	Patient	N	17	9 minutes
Ewing, 2004[82]	CAMPAS-R	Patient	N	2x10	N
Kissane, 2004[83]	DS	Patient	N	24	N
Kaasa, 1997[84] Kaasa, 2001[85]	EFAT	Proxy	N	11	N
Schwartz, 2004[86]	Emanuel and Emanuel Medical Directive	Patient	interview	48	2-3 hours
Blazeby, 2003[87]	EORTC QLQ-OESI8	Patient	N	18	15 minutes (including completion of EORTC QLQ-C30)
Blazeby, 2004[88]	EORTC QLQ-ST022	Patient	N	22	15 min. (including completion of EORTC QLQ-C30)
Chang, 2000[89]	ESAS	Patient	N	10	5 minutes
Lyons, 2009[90]	FACIT-Pal	Patient	N	19	N
Mcmillan, 1998[91] McMillan, 2008[92]	HQLI	Patient	N	28	10-15 minutes
Dobratz, 2004[93]	LCS	Patient	N	20	N
Salmon, 1996[94]	LEQ	Patient	N	44	N
Sterkenberg, 1996[95]	MQLS	Patient	N	32	3-30 minutes
Cohen, 1997[96] Cohen, 2000[97]	MQOL	Patient	N	16	10-30 minutes
Lua, 2005[98]	MQOL-CSF	Patient	N	8	3.26 minutes
McCanse, 1995 [99]	MRDI	Patient	interview	28	N
Sherman, 2007[100] Lobchuk, 2003[101]	MSAS	Patient/proxy	N	32	20-60 minutes
Chang, 2004[102]	CMSAS	Patient	N	14	2-4 minutes
Hickman, 2001[103]	MSAS-GDI	Proxy	N	11	N
Byock, 1998[104] Schwartz, 2005[105]	MVQOLI-R	Patient	N	25	N
Rainbird, 2005[106]	NA-ACP	Patient	N	132	76 minutes
Vernooij-Dassen, 2005[107]	PAQ	Patient	N	4/9	N
Chochinov, 2008[108]	PDI	Patient	N	25	2 minutes (max: 10-15)
Osse, 2004[109]	PNPC	Patient	N	138	N

Evidence Table 7d. Measurement characteristics of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life) (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Osse, 2007[110]	PNPC-sv	Patient	N	33	N
Hearn, 1999[111]	POS	Patient/proxy	N	10	6.9 minutes
Steinhauser, 2004[112]	QUAL-E	Patient	interview	26	N
Hermann, 2006[113]	SNI	Patient	N	17	N

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool ; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OESI8=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCanse Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=not present in the primary article; ND=no data available (review did not abstract); PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory

Evidence Table 7e. Psychometric properties of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Guo, 2001[81]	BHI	Cronbach's α of the 2 subscales: 0.88; 0.94	Y	ND	N	ND	N
Ewing, 2004[82]	CAMPAS-R	Cronbach's α severity: 0.77; Cronbach's α interference: 0.80	N	ND	Y	ND	Y
Kissane, 2004[83]	DS	Cronbach's α: 0.70–0.89	N	ND	Y	ND	N
Kaasa, 1997[84] Kaasa, 2001[85]	EFAT EFAT-2	EFAT-2 Cronbach's α: 0.86	N	ND	Y	ND	N
Schwartz, 2004[86]	Emanuel and Emanuel Medical Directive	Cronbach's α across treatments by scenario: 0.80–0.85; Cronbach's α across scenarios by treatment: 0.86–0.90	Y	ND	Y	ND	Y
Blazeby, 2003[87]	EORTC QLQ-OESI8	Cronbach's α: 0.61–0.75	N	ND	Y	ND	Y
Blazeby, 2004[88]	EORTC QLQ-ST022	Cronbach's α: 0.72–0.80	N	ND	Y	ND	Y
Chang, 2000[89]	ESAS	Cronbach's α of the overall ESAS: 0.79	Y	ND	Y	ND	N
Lyons, 2009[90]	FACIT-Pal	Cronbach's α: 0.75–0.85	N	ND	Y	ND	N
Mcmillan, 1998[91] McMillan, 2008[92]	HQLI	Cronbach's α: 0.78–0.85	N	ND	Y	ND	N
Dobratz, 2004[93]	LCS	Cronbach's α for 2 subscales: 0.80; 0.82	N	ND	Y	ND	N
Salmon, 1996[94]	LEQ	Cronbach's α: 0.70–0.85	Y	ND	Y	ND	N

Evidence Table 7e. Psychometric properties of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Sterkenberg, 1996[95]	MQLS	Cronbach's α for patients: overall scale: 0.8; Cronbach's α for family: overall scale: 0.87	Y	ND	Y	ND	Y
Cohen, 1997[96] Cohen, 2000[97]	MQOL	Cronbach's α: >0.70 except physical subscale (0.62)	Y	ND	Y	ND	Y
Lua, 2005[98]	MQOL-CSF	Cronbach's α: 0.64–0.81, except existential domain (0.46)	Y	ND	Y	ND	N
McCanse, 1995 [99]	MRDI	Cronbach's α of the overall MRDI: 0.59	Y	ND	Y	ND	N
Sherman, 2007[100] Lobchuk, 2003[101]	MSAS, MSAS (FC)	Cronbach's α AIDS patients; caregivers: 0.78– 0.87; 0.86–0.91 Cronbach's α cancer patients; caregivers: 0.78– 0.83; 0.81–0.86	N	ND	Y	ND	N
Chang, 2004[102]	CMSAS	Cronbach's α: 0.72–0.85	N	ND	Y	ND	N
Hickman, 2001[103]	MSAS-GDI	Cronbach's α of the overall MSAS-GDI: 0.82	N	ND	N	ND	N
Byock, 1998[104] Schwartz, 2005[105]	MVQOLI, MVQOLI-R	Cronbach's α of the overall MVQOLI: 0.77	N	ND	Y	ND	Y
Rainbird, 2005[106]	NA-ACP	Cronbach's α: 0.79–0.98	Y	ND	N	ND	N
Vernooij-Dassen, 2005[107]	PAQ	Cronbach's α of the 9-item version: 0.86 Cronbach's α of the 4-item version: 0.71	N	ND	Y	ND	N

Evidence Table 7e. Psychometric properties of tools included in the selected review, Albers, 2010[80] addressing multidimensional tools (quality of life) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Vernooij-Dassen, 2005[107]	PDI	Cronbach's α: 0.63–0.83	Y	ND	Y	ND	N
Chochinov, 2008[108]	PNPC	Cronbach's α: 0.67–0.89 (problem aspect)	N	ND	Y	ND	N
Osse, 2007[110]	PNPpC-sv	Cronbach's α: 0.61–0.86 (problem aspect	N	ND	Y	ND	N
Hearn, 1999[111]	POS	Cronbach's α patient version: 0.65	Y	ND	Y	ND	Y
Steinhauser, 2004[112]	QUAL-E	Cronbach's α: 0.68–0.87	Y	ND	Y	ND	N
Hermann, 2006[113]	SNI	Cronbach's α: 0.62–0.78	N	ND	N	ND	N

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OESI8=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCanse Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=not present in the primary article; ND=no data available (review did not abstract); PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory; Y=present in the primary article

Evidence Table 8a. Characteristics of the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience).

Author, year	**Review focus – NCP domain, tool (and definition if relevant), population, setting**	**Inclusion criteria**	**Number of tools in the review and number included (number of studies)**	**Years of search (range)**
Lendon, 2015[114]	Multiple domains, Surveys on End of life care, End-of-life care settings	Measured areas of patient, Family member, or informal caregiver satisfaction And experience with end-of-life care and Included survey questions or instruments regarding Patient/caregiver satisfaction or experience with End-of-life care	Out of 51 tools, included 8 US tools with detailed abstraction in the review (31 articles)	1990 to 2012

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 8b. Population and setting of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Arcand et al, 2009[115] Baker et al, 2000[116] Bakitas et al, 2008[117] Cohen et al, 2012[118] Gelfman et al, 2008[119] Hallenbeck et al, 2007[120] Shega et al, 2008[121] Teno et al, 2001[122]	After Death Bereaved Family Member Interview	Close relatives; Surrogates: Caregivers	Nursing home; Hospitals; Medical centers; geriatric clinic; Inpatient and outpatient hospice
Kiely, 2006[123] Cohen et al, 2012[118] van der Steen et al, 2009[124]	End of Life in Dementia-Satisfaction with Care & Comfort Assessment in Dying	Residents or health care proxies (if resident died before followup); Caregivers	Nursing homes
Alici, 2010 [125] Casarett, 2010[126] Finlay, 2008[127] Lu et al, 2010[128] Smith et al, 2011[129]	Family Assessment of Treatment of End-of-Life survey	Family members	Veterans Administration medical center
Connot et al, 2005[130] Mitchell et al, 2007[131] Rhodes et al, 2008[132] Rhodes et al, 2007[133] Schockett et al, 2005[134] Teno et al, 2004[135] Teno et al, 2007[136] York et al, 2009[137]	Family Evaluation of Hospice Care	Family members	Hospice, home, hospitals, long-term care
Curtis et al, 2008[138] Gries et al, 2008[139] Lewis-Newby et al, 2011[140]	Family Satisfaction in the ICU	Family members	Intensive care unit; Medical Center
Aoun, 2010[141] Carter, 2011[142] Lo, 2009[143] Lo, 2009[144] Ringdal, 2003 [145] Follwell et al, 2009[146] Kristjanson et al, 1997[147] Meyers and Gray, 2001[148]	Family Satisfaction with Advanced Cancer Care (FAMCARE)	Caregivers; Family members	Inpatient and home-based palliative services Oncology outpatient clinic Hospital Home care

Evidence Table 8b. Population and setting of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Mularski, 2004[149] Hales et al, 2012[150] Johnson et al, 2006[151] Lewis-Newby et al, 2011[140] Mularski et al, 2005[152] Notris et al, 2007[153]	Quality of Dying and Death	Family members	Medical center, cancer center, intensive care unit
Astrow et al, 2007[154] Sulmasy et al, 2002a[155] Sulmasy et al, 2002b[156]	Quality of End-of-Life Care and Satisfaction with Treatment	Patients; family members	Hospitals, cancer center

FAMCARE=Family Satisfaction with Advanced Cancer Care; ICU=intensive care unit

Evidence Table 8c. Domain and subscale characteristics of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (e.g,, pain, dyspnea)	Sub-scales
Arcand et al, 2009[115] Baker et al, 2000[116] Bakitas et al, 2008[117] Cohen et al, 2012[118] Gelfman et al, 2008[119] Hallenbeck et al, 2007[120] Shega et al, 2008[121] Teno et al, 2001[122]	After Death Bereaved Family Member Interview	Structure and Process; Physical; Spiritual; Psychosocial; Social; End of Life	ND	ND
Kiely, 2006[123] Cohen et al, 2012[118] van der Steen et al, 2009[124]	End of Life in Dementia-Satisfaction with Care & Comfort Assessment in Dying	Structure and Process; Physical; Spiritual; Psychosocial	ND	ND
Alici, 2010 [125] Casarett, 2010[126] Finlay, 2008[127] Lu et al, 2010[128] Smith et al, 2011[129]	Family Assessment of Treatment of End-of-Life survey	Structure and Process; Physical; Social; Psychosocial; Spiritual; End of Life	ND	ND
Connot et al, 2005[130] Mitchell et al, 2007[131] Rhodes et al, 2008[132] Rhodes et al, 2007[133] Schockett et al, 2005[134] Teno et al, 2004[135] Teno et al, 2007[136] York et al, 2009[137]	Family Evaluation of Hospice Care	Structure and Process; Physical; Spiritual; Psychosocial; Social; End of Life	ND	ND
Curtis et al, 2008[138] Gries et al, 2008[139] Lewis-Newby et al,2011[140]	Family Satisfaction in the ICU	Structure and Process; Physical; Spiritual; Social; End of Life	ND	ND

Evidence Table 8c. Domain and subscale characteristics of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience) (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (e.g., pain, dyspnea)	Sub-scales
Aoun, 2010[141] Carter, 2011[142] Lo, 2009[143] Lo, 2009[144] Ringdal, 2003 [145] Follwell et al, 2009[146] Kristjanson et al, 1997[147] Meyers and Gray,2001[148]	Family Satisfaction with Advanced Cancer Care	Psychosocial; Physical; Social	ND	ND
Mularski, 2004[149] Hales et al, 2012[150] Johnson et al, 2006[151] Lewis-Newby et al, 2011[140] Mularski et al, 2005[152] Notris et al, 2007[153]	Quality of Dying and Death	Physical; Psychosocial; Spiritual; End of Life	ND	ND
Astrow et al, 2007[154] Sulmasy et al, 2002a[155] Sulmasy et al, 2002b[156]	Quality of End-of-Life Care and Satisfaction with Treatment	Structures and Processes; Spiritual; Psychosocial;	ND	ND

FAMCARE=Family Satisfaction with Advanced Cancer Care; ICU=intensive care unit; ND=no data available (review did not abstract)

Evidence Table 8d. Measurement characteristics of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience).

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Arcand et al, 2009[115] Baker et al, 2000[116] Bakitas et al, 2008[117] Cohen et al, 2012[118] Gelfman et al, 2008[119] Hallenbeck et al, 2007[120] Shega et al, 2008[121] Teno et al, 2001[122]	After Death Bereaved Family Member Interview	Family	Interview	74	ND
Kiely, 2006[123] Cohen et al, 2012[118] van der Steen et al, 2009[124]	End of Life in Dementia-Satisfaction with Care & Comfort Assessment in Dying	Patients; Family	Interview; Paper	41	ND
Alici, 2010 [125] Casarett, 2010[126] Finlay, 2008[127] Lu et al, 2010[128] Smith et al, 2011[129]	Family Assessment of Treatment of End-of-Life survey	Family	Paper; Interview	58	ND
Connot et al, 2005[130] Mitchell et al, 2007[131] Rhodes et al, 2008[132] Rhodes et al, 2007[133] Schockett et al, 2005[134] Teno et al, 2004[135] Teno et al, 2007[136] York et al, 2009[137]	Family Evaluation of Hospice Care	Family	Paper; Interview	56	ND
Curtis et al, 2008[138] Gries et al, 2008[139] Lewis-Newby et al, 2011[140]	Family Satisfaction in the ICU	Family	Paper; Interview	25	ND

Evidence Table 8d. Measurement characteristics of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience) (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Aoun, 2010[141] Carter, 2011[142] Lo, 2009[143] Lo, 2009[144] Ringdal, 2003 [145] Follwell et al, 2009[146] Kristjanson et al, 1997[147] Meyers and Gray, 2001[148]	Family Satisfaction with Advanced Cancer Care	Family	Paper; Interview; Computer	30	ND
Mularski, 2004[149] Hales et al, 2012[150] Johnson et al, 2006[151] Lewis-Newby et al, 2011[140] Mularski et al, 2005[152] Notris et al, 2007[153]	Quality of Dying and Death	Family	Paper; Interview	48	ND
Astrow et al, 2007[154] Sulmasy et al, 2002a[155] Sulmasy et al, 2002b[156]	Quality of End-of-Life Care and Satisfaction with Treatment	Patients; Family	Interview	47	ND

FAMCARE=Family Satisfaction with Advanced Cancer Care; ICU=intensive care unit; ND=no data available (review did not abstract)

Evidence Table 8e. Psychometric properties of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Arcand et al, 2009[115] Baker et al, 2000[116] Bakitas et al, 2008[117] Cohen et al, 2012[118] Gelfman et al, 2008[119] Hallenbeck et al, 2007[120] Shega et al, 2008[121] Teno et al, 2001[122]	After Death Bereaved Family Member Interview	Cronbach's α: 0.71-0.80	Y	Y	Y	Y	N
Kiely, 2006[123] Cohen et al, 2012[118] van der Steen et al, 2009[124]	End of Life in Dementia-Satisfaction with Care & Comfort Assessment in Dying	Cronbach's α: 0.83	N	N	N	N	N
Alici, 2010 [125] Casarett, 2010[126] Finlay, 2008[127] Lu et al, 2010[128] Smith et al, 2011[129]	Family Assessment of Treatment of End-of-Life survey	Cronbach's α:0.84	N	N	N	Y	N
Connot et al, 2005[130] Mitchell et al, 2007[131] Rhodes et al, 2008[132] Rhodes et al, 2007[133] Schockett et al, 2005[134] Teno et al, 2004[135] Teno et al, 2007[136] York et al, 2009[137]	Family Evaluation of Hospice Care	N	N	N	N	N	N
Curtis et al, 2008[138] Gries et al, 2008[139] Lewis-Newby et al, 2011[140]	Family Satisfaction in the ICU	Cronbach's α: 0.86	ND	Y	Y	N	N

Evidence Table 8e. Psychometric properties of tools included in the selected review, Lendon, 2015[114] addressing multidimensional tools (patient experience) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Aoun, 2010[141] Carter, 2011[142] Lo, 2009[143] Lo, 2009[144] Ringdal, 2003 [145] Follwell et al, 2009[146] Kristjanson et al, 1997[147] Meyers and Gray, 2001[148]	Family Satisfaction with Advanced Cancer Care	N	N	N	N	N	N
Mularski, 2004[149] Hales et al, 2012[150] Johnson et al, 2006[151] Lewis-Newby et al, 2011[140] Mularski et al, 2005[152] Notris et al, 2007[153]	Quality of Dying and Death	Y	N	N	Y	Y	N
Astrow et al, 2007[154] Sulmasy et al, 2002a[155] Sulmasy et al, 2002b[156]	Quality of End-of-Life Care and Satisfaction with Treatment	Cronbach's α: 0.83 – 0.95	Y	Y	Y	Y	N

FAMCARE=Family Satisfaction with Advanced Cancer Care; ICU=intensive care unit; ND=no data available (review did not abstract)
ND=no data available (review did not abstract)

Evidence Table 9a. Characteristics of the selected review, Antunes, 2014[157] addressing tools used in clinical care.

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
Antunes, 2014[157]	Any patient-reported outcome measure in palliative care	Studies using a patient-reported outcome measure (PROM) alongside the clinical care of adult patients with advanced disease in palliative care settings; and reporting barriers and/or facilitators of the implementation of the PROM	26 in 31 articles; only US studies (7 of the total) and reporting actual tools were abstracted	1985 to 2011

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 9b. Instruments used in the selected review, Antunes, 2014[157] addressing tools used in clinical care.

Author, year	Sample	Physical	Psychological	Social	Spiritual	Cultural	Care of the Patient at the End of Life	Ethical and Legal	Cross domains (experience)	Cross domains (QOL)
Schulman-Green, 2010[158]	hospices	N	N	N	N	N	N	N	N	ESAS
Schwartz, 2005[105]	Hospice, home and palliative care settings	N	N	N	N	N	N	N	N	MVQOLI-R, MSAS
Escalante, 2008[159]	Emergency center, cancer	NRS for fatigue and pain	N	N	N	N	N	N	N	N
Kamel, 2001[160]	Nursing homes	VAS for pain	N	N	N	N	N	N	N	N
Chang, 2002[161]	Oncology clinic	N	N	N	N	N	N	N	N	FACT-L
Clark, 2009[162]	Cancer center	N	'How can we help you and your family' screening instrument	N	N	N	N	N	N	N

ESAS=Edmonton Symptom Assessment Scale; FACT-L= Functional Assessment of Cancer Therapy-Lung; MSAS=Memorial Symptom Assessment Scale; MVQOLI-R=Missoula-VITAS Quality of Life Index; N=not present in the primary article; NRS= Numeric rating scale; VAS=Visual Analogue Scale

Evidence table 10a. Characteristics of the selected review, De Roo, 2013[163] addressing tools used as quality indicators.

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
De Roo, 2013[163]	Any quality indicator in palliative care	Describes the development process and/or characteristics of quality indicators developed specifically for palliative care pro- vided by care organizations or professionals. Numerators and denominators are defined for the quality indicators, or the numerators and denominators can be deduced directly from the descriptions of the quality indicators, or performance standards are given.	17 indicator sets included; 1 in the US included here	Database inception - October 2011

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence table 10b. Instruments used the selected review, De Roo, 2013[163] addressing tools used as quality indicators.

Author, Year	Sample	Structure/ Process	Physical	Psychological	Social	Spiritual	Cultural	Care of the Patient at the End of Life	Ethical and Legal	Cross domains (experience)	Cross domains (QOL)
National Quality Forum, 2006[164]	Hospice	ND	ND	ND	ND	ND	ND	ND	ND	Family evaluation of hospice care	ND

ND=no data available (review did not abstract)

Evidence table 11. Tools used in included articles for Kavalieratos, 2016[165] evaluating interventions.

Author (Year)	Population	Physical Aspects of Care	Psychosocial and Psychiatric Aspects of Care	Cross Domains: Patient Experience	Cross domains: Quality of Life
Ahronheim, 2000[166]	dementia	NM	NM	NM	NM
Aiken, 2006[167]	mixed	NM	NM	NM	MSAS
Bakitas, 2009[168]	cancer	NM	CES-D*[†]	NM	ESAS FACIT-Pal
Bakitas, 2015[169]	cancer		CES-D*[†]	NM	QUAL-E FACIT-Pal FACT TOI*
Bekelman, 2015[170]	CHF	NM	PHQ-9*[†]	NM	KCCQ*
Brannstrom, 2014[171]	CHF	NM	NM	NM	ESAS EQ-5D* KCCQ*
Brumley, 2007[172]	mixed	NM	NM	Reid-Gundlach*	NM
Chapman, 2007[173]	dementia	Faces Legs Activity Cry Consolability Behavioral Pain Scale (FLACC)* Pain in Advanced Dementia (PAINAD)*	Cornell Scale for Depression in Dementia (CSDD)*[†]	NM	NM
Cheung, 2010[174]	ICU inpatients	NM	NM	NM	NM
Clark, 2013[175]	cancer	NM	POMS*[†]	NM	FACT-G*
SUPPORT, 1995[176]	mixed	Scale not reported	NM	NM	NM
Dyar, 2012[177]	cancer	NM	NM	NM	FACT-G* LASA*
Edmonds, 2010[178]	MS	MS Palliative Outcome Scale-S5*	NM	NM	NM
Engelhardt, 2006[179]	mixed	NM	NM	NM	NM
Farquhar, 2014[180]	cancer	NRS[†]	HADS	NM	NM
Farquhar, 2016[181]	non-malignant disease and breathlessness	NRS[†]	HADS	NM	NM
Gade, 2008[182]	mixed	NM	NM	NM	Modified City of Hope Patient Questionnaire (MCOHPQ)*

Evidence table 11. Tools used in included articles for Kavalieratos, 2016[165] evaluating interventions (continued)

Author (Year)	Sample	Physical Aspects of Care	Psychosocial and Psychiatric Aspects of Care	Cross Domains: Patient Experience	Cross domains: Quality of Life
Given, 2002[183]	cancer	Symptom Experience Scale*	NM	NM	SF-36*
Grande, 1999 & 2000[184, 185]	mixed	NM	NM	NM	NM
Grudzen, 2016[186]	cancer	NM	PHQ-9*[†]	NM	FACT-G*
Hanks, 2002[187]	cancer	VAS[†] MPAC[†]	WONCA*	MacAdam's Assessment of Suffering*	EORTC QLQ-C30
Higginson, 2014[188]	mixed	NRS[†] Chronic Respiratory Disease Questionnaire	HADS	NM	EQ-5D*
Hopp, 2016[189]	heart failure	NM	NM	NM	NM
Hughes, 1992[190]	mixed	NM	NM	Greer Satisfaction with Care Survey*	NM
Jordhoy, 2000 & 2001[191, 192]	cancer	NM	Impact of Event Scale*	NM	EORTC QLQ-C30
Kane, 1984 & 1985[193, 194]	cancer	California Pain Assessment Profile*	CES-D*[†] General Wellbeing Measure*	Ware Scale*	NM
Lowther, 2015[195]	HIV	African Palliative Outcomes Scale*	GHQ-12	NM	MOS-HIV*
McCorkle, 1989[196]	cancer	Symptom Distress Scale*	POMS*[†]	NM	NM
McCorkle, 2015[197]	cancer	Symptom Distress Scale*	HADS PHQ-9*[†]	NM	FACT-G*
Notthouse, 2005[198]	cancer	NM	NM	NM	FACT-B* SF-36*
Notthouse, 2007[199]	cancer	Omega Screening Questionnaire* Expanded Prostate Cancer Index Composite*	NM	NM	FACIT-Pal SF-12*
Notthouse, 2013[200]	cancer	NM	NM	NM	FACT-G*
Pantilat, 2010[201]	mixed	NRS[†]	NRS[†]	NM	NM

Evidence table 11. Tools used in included articles for Kavalieratos, 2016[165] evaluating interventions (continued)

Author (Year)	Sample	Physical Aspects of Care	Psychosocial and Psychiatric Aspects of Care	Cross Domains: Patient Experience	Cross domains: Quality of Life
Rabow, 2004[202]	mixed	UCSD Shortness of Breath Questionnaire Brief Pain Inventory† MOS*†	POMS*† CES-D*†	Group Health Association of America Consumer Satisfaction Survey*	Multidimensional Quality of Life Scale-Cancer*
Radwany, 2014[203]	mixed	NM	HADS	NM	MSAS QUAL-E
Rummans, 2006[204]	cancer	LASA* Symptom Distress Scale*	POMS*†	NM	Spitzer Uniscale*
Sidebottom, 2015[205]	CHF	NM	PHQ-9*†	NM	ESAS Minnesota Living with Heart Failure Questionnaire*
Steel, 2016[206]	cancer	BPI	CES-D*†	NM	FACT-G* FACT-Fatigue*
Temel, 2010[207]	cancer	NM	HADS PHQ-9*†	NM	FACT TOI* FACT-L*
Wallen, 2012[208]	cancer	Gracely Pain Scale* Symptom Distress Scale*	CES-D*†	NM	NM
Wong, 2016[209]	heart failure	NM	NM	NM	MQOL Chronic HF Questionnaire* ESAS
Zimmer, 1984 & 1985[210, 211]	mixed	NM	NM	McCusker scale*†	NM
Zimmermann, 2014[212]	cancer	NM	NM	FAMCARE-P16 CARES-MIS*	ESAS FACIT-Sp* QUAL-E

Evidence table 11. Tools used in included articles for Kavalieratos, 2016[165] evaluating interventions (continued)

BPI=Brief Pain Inventory;CHF=congestive heart failure; HIV=human immunodeficiency virus; ICU=intensive care unit; MS=multiple sclerosis; CES-D=Center for Epidemiologic Studies Depression Scale; CSDD= Cornell Scale for Depression in Dementia; EORTC QLQ-C30=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-30 items; EQ-5D=EuroQol; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative sub scale; FACT-B= Functional Assessment of Cancer Therapy – Breast Cancer; FACT-G= Functional Assessment of Cancer Therapy - General; FACT-L= Functional Assessment of Cancer Therapy-Lung; FAMCARE-P16= Family Satisfaction with Advanced Cancer Care (16 item version); FLACC= Faces Legs Activity Cry Consolability Behavioral Pain Scale; GHQ-12 =General Health Questionnaire-12 item; HADS =Hospital Anxiety and Depression Scale; ICU=intensive care unit; KCCQ= The Kansas City Cardiomyopathy Questionnaire; LASA=Linear Analogue Scale Assessment; MCOHPQ= Modified City of Hope Patient Questionnaire; MOS-Medical Outcomes Study; MOS-HIV=Medical Outcomes Study HIV Health Survey; MPAC=Memorial Pain Assessment Card; MQOL=McGill Quality of Life Questionnaire; MS= MS Palliative Outcome Scale-S5; MSAS=Memorial Symptom Assessment Scale; MVQOLI-R=Missoula-VITAS Quality of Life Index; NRS= Numeric rating scale; NRS= Numerical Rating Scale; PAINAD= Pain in Advanced Dementia; PHQ-9=Patient Health Queationnaire-9; POMS=Profile of Mood States; QUAL-E=Quality of life at the end of life; SF-12=Short Form 12; SF-36=Short Form 36 Health Survey; TOI=Trial Outcome Index (sum of selected FACT subscales),; UCSD SOBQ =University of California San Diego Shortness of Breath Questionnaire; VAS=Visual Analogue Scale; WONCA=World Organization of National Colleges, Academies and Academic Association of General Practitioners. NM=no measures specific for that domain (note that multidimensional tools of patient experience and quality of life may address these domains).

**Indicates tool that was not identified in the systematic review of assessment tools for this domain.*

†*Indicates tool that was found during supplemental search.*

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