

Assessment Tools for Palliative Care

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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 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.

Contents

Introduction.....	1
Background.....	1
Objectives of This Technical Brief.....	3
Guiding Questions	3
Methods.....	4
Engagement with Key Informants	4
Systematic Review Search.....	4
Supplemental Search.....	4
Data Organization	5
Peer Review and Public Commentary	5
Results.....	6
Summary of Engagement with Key Informants	6
Caregivers	6
Providers	6
Systematic Review and Supplemental Searches.....	7
State of the Research on Assessment Tools by Domain and Key Subdomains (Guiding Questions 1 and 2)	7
Domain 1: Structure and Process.....	7
Domain 2: Physical.....	7
Domain 3: Psychological and Psychiatric.....	12
Domain 4: Social Aspects of Care	12
Domain 5: Spiritual, Religious, and Existential.....	12
Domain 6: Cultural	15
Domain 7: Care at the End of Life.....	15
Subdomain: Bereavement	15
Domain 8: Ethical and Legal	15
Domain 9: Multidimensional	15
Applications of Assessment Tools (Guiding Question 3).....	24
Clinical Care	24
Quality Indicators.....	24
Evaluation of Interventions.....	24
Discussion (Guiding Question 4).....	26
Next Steps	27
Tool Development	27
Tool Evaluation.....	27
Systematic Reviews	30
Applications of Assessment Tools.....	30
Limitations	30
Conclusions.....	31
Tables	
Table 1. Summary of the search for palliative care assessment tools.....	9
Table 2. Summary table of tools addressing physical domain (dyspnea subdomain) identified from Dorman et al., 2007 ¹⁸	10

Table 2. Summary table of tools addressing physical domain (dyspnea subdomain) identified from Dorman et al., 2007 ¹⁸	11
Table 4. Summary table of tools addressing social domain identified from Michels et al., 2016 ²⁰ 14	14
Table 5. Summary table of tools addressing spiritual, religious, and existential domain identified from Selman et al., 2011 ²¹	14
Table 6. Summary table of tools addressing care at the end of life domain (bereavement subdomain) identified from Sealey et al., 2015 ²²	16
Table 6. Summary table of tools addressing care at the end of life domain (bereavement subdomain) identified from Sealey et al., 2015 ²² (continued)	17
Table 7. Summary table of tools addressing multidimensional domain (quality of life subdomain) identified from Albers et al., 2010 ²³	19
Table 7. Summary table of tools addressing multidimensional domain (quality of life subdomain) identified from Albers et al., 2010 ²³ (continued)	20
Table 7. Summary table of tools addressing multidimensional domain (quality of life subdomain) identified from Albers et al., 2010 ²³ (continued)	21
Table 8. Summary table of tools addressing multidimensional domain (patient experience subdomain) identified from Lendon et al., 2015 ^{24*}	22
Table 9. Summary of palliative care assessment tools that are used in 23 studies evaluating palliative care interventions and how often they were used.....	25

Figures

Figure 1. Conceptualization of domains and applications of palliative care assessment tools.....	2
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	29

Appendixes

Appendix A. Glossary
Appendix B. List of Acronyms
Appendix C. Key Informant Questions
Appendix D. Detailed Search Strategy
Appendix E. ROBIS Assessment
Appendix F. Systematic Review and Supplemental Search Flow
Appendix G. Inclusion Criteria for the Systematic Review
Appendix H. Results of the Literature Search
Appendix I. Palliative Care Tools Master List
Appendix J. Evidence Tables

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.

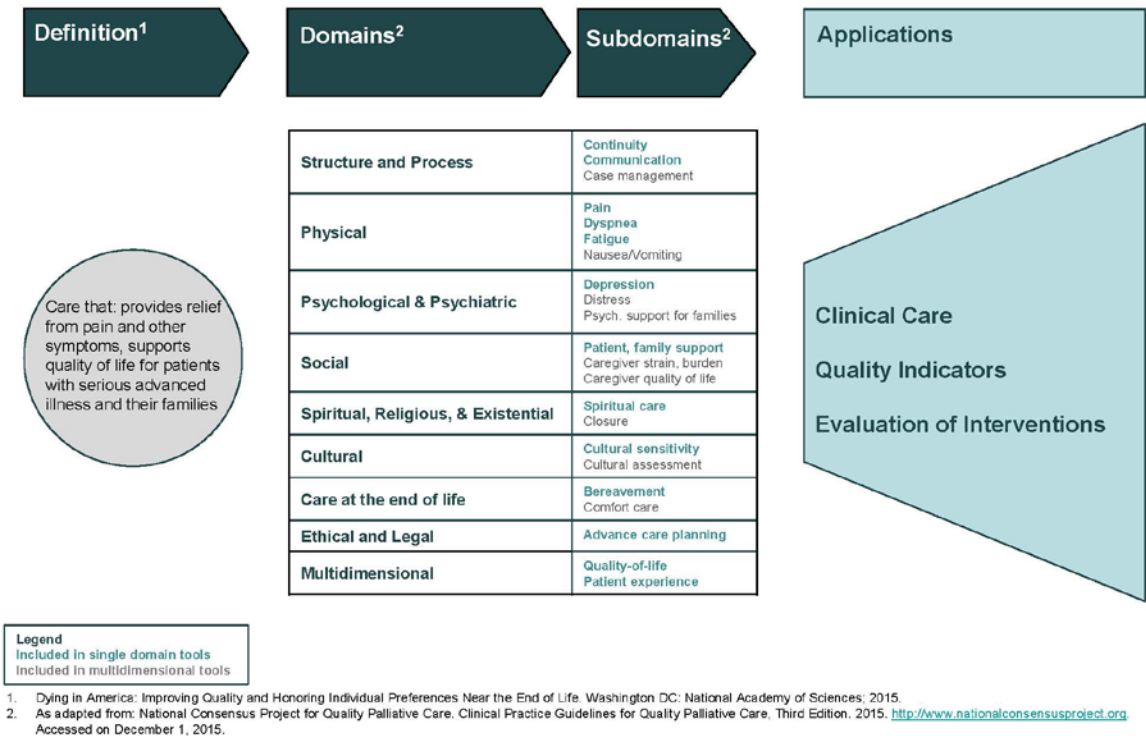
Palliative care assessment tools may be used for varying applications within palliative care. Assessment tools may be used by providers in clinical care to directly assess symptoms or other issues with patients or families. Assessment tools may also be used as quality indicators, defined as population-based 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



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 reviews¹⁵ 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 Care⁶
 - b. The systematic review for the National Institutes of Health State of the Science Conference on Improving End-of-Life Care⁹⁻¹⁰
 - 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 Instruments¹⁸
 - b. City of Hope Pain & Palliative Care Resource Center¹⁹
 - c. National Palliative Care Research Center Measurement and Evaluation Tools²⁰
 - d. Center for Research on End-of-Life Care²²

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 2007¹⁸ – 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., 2007¹⁸

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 Scale²⁸	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 Scale³¹	COPD, restrictive lung disease, asthma	NA	Y	Y	N	Y	1
Global Shortness of Breath Question³²	COPD	NA	Y	N	Y	N	1
Faces Scale³³	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 Questionnaire³⁶	Cancer	N	Y	N	N	N	43
Amyotrophic Lateral Sclerosis Functional Rating Scale – revised³⁷	MND (Motor Neuron Disease)	Y	Y	N	N	N	3
American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale³⁸	COPD, asthma	Y	Y	N	N	Y	5
Breathlessness, Cough and Sputum Scale³⁹	COPD	NA	Y	Y	Y	N	1
Chronic Heart Failure Questionnaire – dyspnea subscale⁴⁰	Heart failure	Y	Y	Y	Y	Y	5
Cardiovascular Limitations and Symptoms Profile⁴¹	Ischemic heart disease	N	Y	N	N	Y	6
Chronic Lung Disease Severity Index⁴²	Chronic lung disease	Y	Y	N	N	N	2
Chronic Respiratory Questionnaire – dyspnea subscale⁴³	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., 2007¹⁸

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 questions⁴⁴	ND	N	N	N	N	N	5
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Lung Cancer supplement, breathlessness subscale⁴⁵	Lung cancer	Y	Y	Y	N	N	3
London Chest Activity of Daily Living Scale⁴⁶	COPD	Y	Y	Y	N	N	15
Motor Neuron Disease Dyspnea Rating Scale⁴⁷	MND	Y	Y	N	N	Y	5
Medical Research Council Dyspnea Scale⁴⁸	COPD, interstitial lung disease, asthma, other	N	Y	Y	N	Y	1
Oxygen Cost Diagram⁴⁹	Respiratory disease, COPD, heart failure	NA	Y	N	Y	Y	1
Pulmonary Functional Status and Dyspnea Questionnaire – modified⁵⁰	COPD	Y	Y	Y	N	Y	5
Rand Instrument⁵¹	Heart failure, respiratory disease	N	Y	N	Y	Y	9
St George’s Respiratory Questionnaire⁵²	COPD, asthma, bronchiectasis	Y	Y	Y	Y	Y	16
University of Cincinnati Dyspnea Questionnaire⁵³	Asthma, sarcoid, COPD, fibrosis	Y	Y	N	N	Y	30
University of California San Diego Shortness of Breath Questionnaire⁵⁴	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 review¹⁹ 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 review²⁰ 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 review²¹ 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., 2011¹⁹

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 Scale⁵⁷	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 item⁵⁹	Patients with advanced disease	N	Y	ND	N	Y	12
Brief Edinburgh Depression Scale⁶⁰	Patients receiving palliative care with a prognosis of six months or less	Y	Y	ND	N	Y	6
Beck Depression Inventory-Short Form⁵⁷	Patients with metastatic breast cancer	N	Y	ND	N	Y	13
Mental Adjustment to Cancer⁶¹	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., 2016²⁰

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 Care⁶²	Family caregivers of patients with terminal cancer	Y	Y	Y	Y	N	16
Caregiver Impact Scale⁶³	Caregivers of patients with advanced cancer	Y	N	N	N	N	14
Caregiver Quality of Life Index – Cancer⁶⁴	Caregivers of patients with cancer	Y	Y	Y	Y	Y	35
Caregiver Reaction Assessment⁶⁵	Caregivers of patients receiving palliative care	Y	Y	N	N	N	24
Caregiver Strain Index⁶⁶	Caregivers for patients with symptomatic advanced cancer	Y	Y	N	N	N	13
Family Appraisal of Caregiving Questionnaire for Palliative Care⁶⁷	Caregivers of patients receiving palliative care	Y	Y	N	N	N	26
Quality of Life in Life-Threatening Illness-Family Carer Version⁶⁸	Caregivers of patients receiving palliative care for cancer	Y	Y	N	Y	N	16
Zarit Burden Inventory⁶⁹	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., 2011²¹

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 Index⁵⁶	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 review²² 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., 2015²²

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–24⁷²	Bereaved adults	Y	N	ND	N	N	24
Brief Grief Questionnaire⁷³⁻⁷⁵	Recipients of crisis counselling following 911 terrorist attacks; bereaved community-dwelling adults	Y	N	ND	N	N	5
Core Bereavement Items⁷⁶	Bereaved adults	Y	Y	ND	N	N	17
Grief Evaluation Measure⁷⁷	Bereaved adults	Y	N	ND	N	Y	91
Grief Experience Questionnaire⁷⁸	Bereaved spouses	Y	N	ND	N	Y	55
Hogan Grief Reaction Checklist⁷⁹	Parentally bereaved people	Y	N	ND	N	N	61
Inventory of Complicated Grief⁸⁰	Bereaved spouses	Y	N	ND	N	N	19
Inventory of Complicated Grief–Revised⁸¹⁻⁸³	Bereaved spouses	Y	N	ND	N	N	15
Inventory of Traumatic Grief⁸⁴	Elderly widowed residents; bereaved adults	Y	N	ND	N	N	34
Marwit–Meuser Caregiver Grief Inventory⁸⁵⁻⁸⁷	Caregivers of people with dementia, acquired brain injury, cancer	Y	Y	ND	N	N	50
Marwit–Meuser Caregiver Grief Inventory–Short Form⁸⁸	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., 2015²² (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 review²³ 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 review²⁴ 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 care 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., 2010²³

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 Inventory¹⁰⁰	Physical, Psychological and Psychiatric	Patients in hospice	Y	N	ND	N	Y	17
Cambridge Palliative Audit Schedule¹⁰¹	Physical, Psychological and Psychiatric	Patients receiving palliative care	Y	Y	ND	Y	N	2x10
Demoralization Scale¹⁰²	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 Directive¹⁰⁵	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 Module¹⁰⁶	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 Module¹⁰⁷	Physical, Psychological and Psychiatric	Patients with adenoma carcinoma of the stomach	Y	Y	ND	Y	Y	22
Edmonton Symptom Assessment Scale¹⁰⁸	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., 2010²³ (continued)

Tool	Domains Included	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsiveness Measured	Time to Complete Measured	Number of Items
FACIT-Pal Functional Assessment of Chronic Illness Therapy-Palliative Subscale¹⁰⁹	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 Scale¹¹²	Psychological and Psychiatric	Patients who are terminally ill	Y	Y	ND	N	N	20
Life Evaluation Questionnaire¹¹³	Psychological and Psychiatric, Social	People with incurable cancer	Y	Y	ND	N	N	44
McMaster Quality of Life Scale¹¹⁴	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 Form¹¹⁷	Physical, Psychological and Psychiatric, Spiritual	Patients who are terminally ill	Y	Y	ND	N	Y	8
McCanse Readiness for Death Instrument¹¹⁸	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 Scale¹²¹	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., 2010²³ (continued)

Tool	Domains Included	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsiveness Measured	Time to Complete Measured	Number of Items
Memorial Symptom Assessment Scale-Global Distress Index¹²²	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 Patients¹²⁵	Structure and Process, Physical, Social, Spiritual	Patients with advanced cancer	Y	N	ND	N	Y	132
Patient Autonomy Questionnaire¹²⁶	Ethical/Legal	Patients receiving palliative care for cancer	Y	Y	ND	N	N	4/9
Patient Dignity Inventory¹²⁷	Physical, Social, Spiritual	Patients nearing the end of life	Y	Y	ND	N	Y	25
Problems and Needs in Palliative Care Questionnaire¹²⁸	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 Version¹²⁹	Structure and Process, Physical, Psychological and Psychiatric, Social Spiritual, Ethical/Legal	Patients receiving palliative care	Y	Y	ND	N	N	33
Palliative care Outcome Scale¹³⁰	Physical, Psychological and Psychiatric, Spiritual	Patients with advanced cancer	Y	Y	ND	Y	Y	10
Quality of Life at the End of Life¹³¹	Structure and Process, Psychological and Psychiatric, Ethical/Legal, End of Life	Patients who are seriously ill	Y	Y	ND	N	N	26
Spiritual Needs Inventory¹³²	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 review²⁵ 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 review²⁶ 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 review²⁷ 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 indicator²⁶ 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 interventions²⁷; 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.

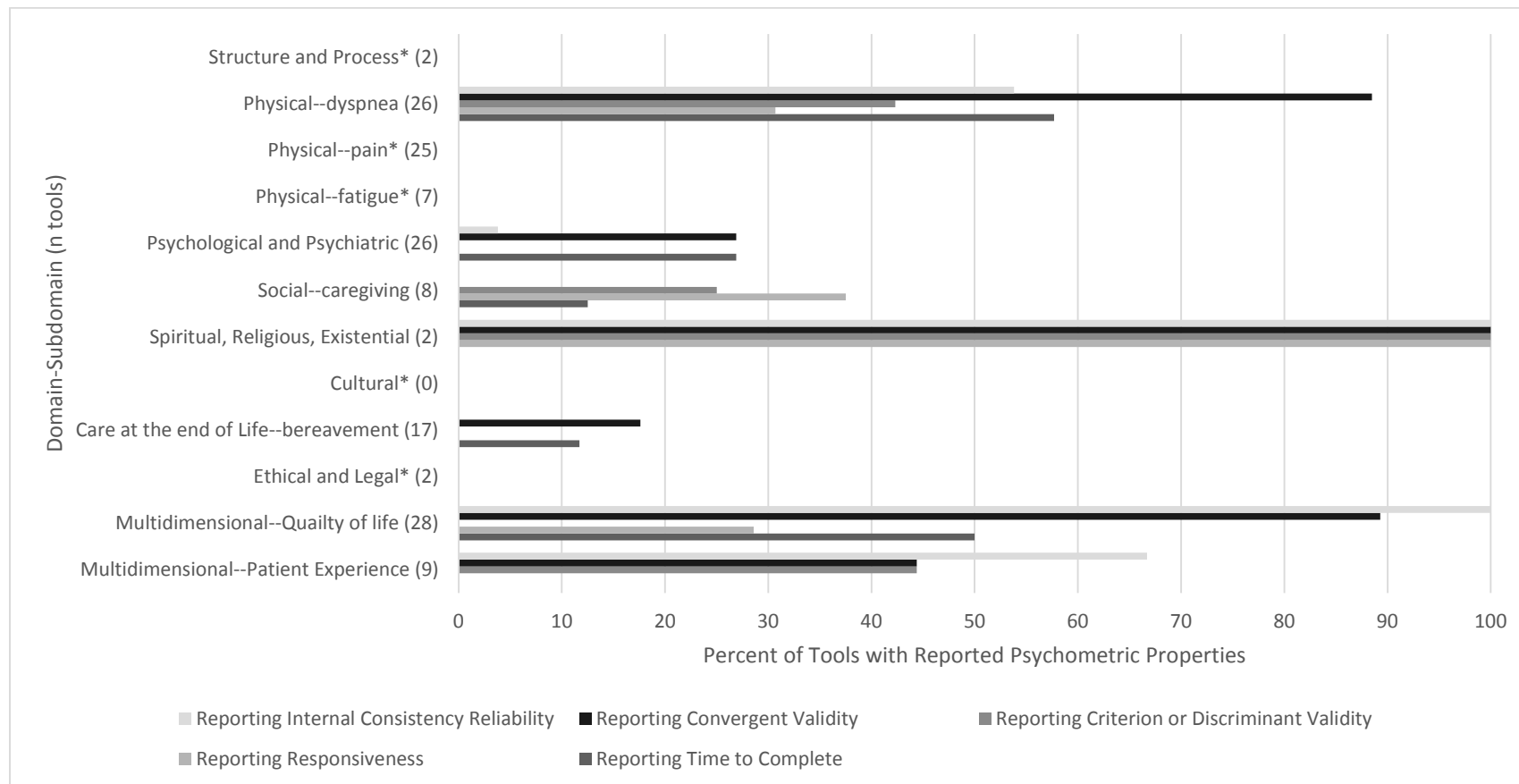
Tool Evaluation

- 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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