

Draft Technical Brief

Number XX

Assessment Tools for Palliative Care

Prepared for:

Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

This information is distributed solely for the purposes of predissemination peer review. It has not been formally disseminated by the Agency for Healthcare Research and Quality. The findings are subject to change based on the literature identified in the interim and peer-review/public comments and should not be referenced as definitive. It does not represent and should not be construed to represent an Agency for Healthcare Research and Quality or Department of Health and Human Services (AHRQ) determination or policy.

Contract No. [To be added for final report]

Prepared by: [To be added for final report]

Investigators: [To be added for final report]

AHRQ Publication No. XX-EHCXXX
<Month Year>

This report is based on research conducted by an Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. xxx-xxxx-xxxxx). The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

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.

This report is made available to the public under the terms of a licensing agreement between the author and the Agency for Healthcare Research and Quality. This report may be used and reprinted without permission except those copyrighted materials that are clearly noted in the report. Further reproduction of those copyrighted materials is prohibited without the express permission of copyright holders.

AHRQ or U.S. Department of Health and Human Services endorsement of any derivative products that may be developed from this report, such as clinical practice guidelines, other quality enhancement tools, or reimbursement or coverage policies, may not be stated or implied.

Persons using assistive technology may not be able to fully access information in this report. For assistance, contact EffectiveHealthCare@ahrq.hhs.gov.

Suggested citation: [To be added for final report]

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.

Andrew Bindman, M.D.
Director
Agency for Healthcare Research and Quality

Arlene S. Bierman M.D., M.S.
Director
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

Stephanie Chang M.D., M.P.H.
Director, EPC Program
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

David Niebuhr, M.D., M.P.H., M.Sc.
Task Order Officer
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality

Acknowledgments

. The authors gratefully acknowledge the following individuals for their contributions to this project: **[To be added for final report]**

Key Informants

In designing the study questions, the EPC consulted a panel of Key Informants that represents 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. The Task Order Officer and the EPC work to balance, manage, or mitigate any conflicts of interest.

Assessment Tools for Palliative Care

Structured Abstract

Objectives: To (1) summarize the characteristics of palliative care assessment tools designed to be completed by or with patients or caregivers and describe how these tools have been applied for clinical care, quality indicators, and evaluation of interventions, and (2) identify needs for future palliative care assessment tool development and evaluation.

Data Sources: (1) Interviews with Key Informants representing both patient/caregiver and provider perspectives, (2) systematic reviews of palliative care assessment tools and applications of tools found through search of PubMed, CINAHL, Cochrane, PsycINFO and PsycTESTS from January 1, 2007 to March 2, 2016, (3) supplemental sources of information on palliative care tools, including previous reviews, websites and information from outside experts, and (4) a targeted search for primary articles when no tools in a domain were identified through these approaches.

Review Methods: Paired investigators independently screened literature search results and websites to determine eligibility of systematic reviews or primary articles, where applicable, and assessed risk of bias of systematic reviews. We selected the most relevant, recent, and highest-quality systematic reviews for each domain, multidimensional area, and application, and added data from supplemental sources. One investigator abstracted information, and a second investigator verified the abstracted information. We organized tools by domains from the National Consensus Project Clinical Practice Guidelines for Palliative Care: structure and processes, physical, psychological and psychiatric, social (caregiver), spiritual and religious, care at the end of life (bereavement), ethical and legal, and multidimensional tools (quality of life and patient experience).

Results: We included nine systematic reviews of palliative care assessment tools (7 for different domains and multidimensional tools and 2 for applications of tools). We identified 146 tools (98 from systematic reviews and 48 from websites). Key gaps included the following: no identified systematic review for the subdomain of pain and lack of many tools focusing on structure and process, cultural, ethical or legal domains, or for patient-reported experience (all but 2 patient experience tools were caregiver-reported). Only two tools for the spiritual domain were evaluated in palliative care populations. Among multidimensional tools, none contained items addressing the cultural domain. Information on internal consistency reliability, construct validity, and usability was available for many tools, but few studies evaluated responsiveness (sensitivity to change). For application of tools, only six studies evaluated the use of tools in clinical practice and we identified only one quality indicator with a specified assessment tool. Among 38 palliative care interventions, only 20 palliative care assessment tools were used for evaluation (7 physical domain, 6 psychiatric and psychological, 2 multidimensional-patient experience, and 5 multidimensional-quality of life).

Conclusions: While assessment tools exist for most domains of palliative care, few to no tools address the spiritual, ethical, or cultural domains or patient-reported experience. While there is some data on the psychometric properties of tools, the responsiveness of different tools to change and/or comparisons between tools have not been evaluated. Future research should focus on: (1)

developing or testing tools that address domains for which few to no tools exist, (2) evaluating responsiveness of tools for all domains, (3) improving the use of palliative care tools in clinical care, quality indicators, and evaluation of interventions.

Contents

Introduction	1
Background.....	1
Definition of Terms.....	2
Guiding Questions	3
Methods	4
Discussions with Key Informants	4
Data Collection	4
Systematic Review Search.....	4
Palliative Care Website Search and Search of Supplemental Sources	5
Results	6
Key Informant Summary	6
Caregiver Advocates.....	6
Providers	6
Results of the Literature Search and Supplemental Searches	7
Tools Focusing on Single Domains	8
Domain 1: Structure and Processes of Care.....	8
Domain 2: Physical.....	8
Domain 3: Psychological and Psychiatric	11
Domain 4: Social.....	11
Domain 5: Spiritual, Religious, and Existential.....	11
Domain 6: Cultural	14
Domain 7: Care at the End of Life.....	14
Domain 8: Ethical and Legal	14
Multidimensional Tools	14
Quality of Life.....	17
Patient Experience	17
Use of Assessment Tools for Different Applications	22
Clinical Care	22
Quality Indicators.....	22
Evaluation of Interventions.....	22
Discussion	
Next Steps.....	26
Systematic Reviews	26
Tool Development	26
Tool Evaluation.....	27
Applications for Assessment Tools	27
Conclusions.....	27
References	28
 Tables	
Table 1. National Consensus Guidelines Domains for Quality Palliative Care example subdomains	1
Table 2. Summary of the literature search and website search for tools in domains and multidimensional tools.....	7

Table 3. Summary table for physical domain (dyspnea subdomain) included from the selected review.....	9
Table 4. Summary table for psychological and psychiatric tools included from the selected review.....	12
Table 5. Summary table for social tools included from the selected systematic review.	13
Table 6. Summary table for spiritual, religious, and existential tools included from the selected systematic review.....	13
Table 7. Summary table for care at the end of life (bereavement) included from the selected review.....	15
Table 8. Summary table for quality of life tools included from the selected review.....	18
Table 9. Summary table for patient experience tools included from the selected review	21
Table 10. Summary of tools identified in the reviews and supplemental searches that were used in 38 studies evaluating palliative care interventions	23

Figures

Figure 1. Evidence map of percentage of psychometric properties reported on existing assessment tools, organized by National Consensus Project for Quality Palliative Care domains and multidimensional domains.	25
---	----

Appendixes

Appendix A. List of Acronyms
Appendix B. Glossary of Terms Used to Describe Tools
Appendix C. Key Informant Questions
Appendix D. Detailed Search Strategies
Appendix E. ROBIS Assessment
Appendix F. Systematic Review 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 for Main Comparisons

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 (Table 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 that address all domains are essential to measuring the quality and effectiveness of palliative care.

An assessment tool is defined as a data collection instrument, completed by or with patients or caregivers, that collects data at the individual patient or caregiver level. 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) (Table 1).²

Table 1. National Consensus Guidelines Domains for Quality: Palliative care and example subdomains

1. Structure and Processes (e.g., continuity, communication)
2. Physical (e.g., pain, dyspnea)
3. Psychological and Psychiatric
4. Social Aspects of Care (e.g., caregiving)
5. Spiritual, Religious, and Existential
6. Cultural (e.g., addressing cultural identity and practices)
7. Care at the End of Life (e.g., bereavement)
8. Ethical and Legal (e.g., care planning)

Assessment tools have several applications in palliative care; key applications include clinical care, quality indicators, and evaluation of interventions. 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 a specific aspect of care by comparing it to evidence-based criteria,³ particularly using patient- or caregiver-reported data to evaluate care. And, tools may be used to evaluate the impact of palliative care interventions in research studies. Exploration of assessment tools across applications is important because a tool's utility may vary by its application; for example, measurement of aspects of care important for research-related, academic inquiry may not be important, or even feasible, in clinical care delivery. Measuring the effectiveness of palliative care interventions requires reliable and valid assessment tools that assess aspects of care that matter to patients and families,⁴ evaluate the impact of interventions, and can be administered in palliative care populations and settings.⁵

Not surprisingly, because the field of palliative care has grown substantially during the past decade, the number of assessment tools for palliative care has increased exponentially. This poses two challenges for researchers and policymakers seeking to improve the quality of palliative care: (1) determining whether there are sufficient tools to address all necessary 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.

Over the past fifteen 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).⁶ (See Appendix A for a list of acronyms.) In 2004, for the National Institutes of Health State of the Science Conference on Improving End-of-Life Care,⁷ the End of Life Care and Outcomes systematic review⁸ updated the TIME review and summarized the psychometric properties of 99 additional, relevant assessment tools and their use in assessing palliative care interventions.^{9, 10} 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.¹¹

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 topics that are innately multidimensional (e.g., quality of life); however, these reviews have not been synthesized into a comprehensive analysis of the field. Given that these tools are frequently used together or overlap in measured concepts and given the exponential growth of the field of palliative care in clinical scope and research, an integrated overview of assessment tools is valuable. A review is needed to identify domains that still lack sufficient assessment tools; highlight areas for future research; and provide a resource for individuals choosing tools for use in clinical care, quality measures, or evaluation of interventions.

Our objective was to provide a comprehensive overview of palliative care assessment tools which could be used by stakeholders interested in the use of palliative care assessment tools within clinical care, as quality measures, or for the evaluation of interventions. We used the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care domains (Table 1) as a conceptual framework and also consulted with caregivers, clinicians, and researchers to incorporate their input about palliative care assessment tools. We then reviewed prior comprehensive systematic reviews of assessment tools.^{9, 12, 13} We also reviewed other recent reviews and, when needed, website compendia, PubMed, and additional expert input about current tools for use by and with patients and families in palliative care. In addition to describing the properties of the tools, we also summarized research on the use of palliative care assessment tools for three applications in palliative care: clinical practice, quality indicators, and evaluation of interventions in studies. Finally, we identified next steps for future research.

Definition of Terms

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

Assessment tool: An instrument completed by or with patients or families, and used to collect data at the individual patient level. Examples include tools used to evaluate the following: patient symptoms (e.g., pain); the quality of care (e.g., follow up questions about pain control posed to the patient); or the experience of care (e.g., a caregiver's assessment of how well providers communicated).¹⁴

Domain/subdomain: Domain of the National Consensus Guidelines (e.g., Physical domain) or subdomain included in one of those domains (e.g., pain).

Single domain tool: A tool that addresses a single palliative care domain as defined by the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care.

Multidimensional tool: A tool that, within the same single instrument, assesses multiple palliative domains as defined by the National Consensus Project Clinical Practice Guidelines for

Quality Palliative Care. We considered tools assessing quality of life and patient experience as multidimensional tools.

Application: Use of a tool for clinical practice, quality indicators, or evaluation of interventions in studies.

Quality indicator: A population-based measure that enables users to quantify the quality of a specific aspect of care by comparing it to evidence-based criteria.³ Indicators require the identification of two groups: (1) the numerator—patients whose care meets the indicator criteria (e.g., those who are asked about their pain), and (2) the denominator—those who are eligible for the indicator, or the population of focus (e.g., all patients with a serious illness). When quality indicators include patient- or caregiver-reported data, they require the use of assessment tools.

Additional terms and definitions for the psychometric properties of tools are available in Appendix B.

Guiding Questions

All guiding questions for this topic brief relate to the three applications for palliative care assessment tools: clinical practice, quality indicators, and evaluation of interventions. We organized the results according to the eight domains in the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (Table 1), plus one additional section for multidimensional tools (quality of life, patient experience).

Guiding Question 1: What assessment tools have been developed or used?

- a. For what settings, populations, and intended use were the tools developed?
- b. What are the key features of the tools (domains addressed, types of outcomes, modes of administration)?

Guiding Question 2: What is the state of current research on these assessment tools?

- a. Is there published information available on reliability, validity, responsiveness, and usability?

Guiding Question 3: In what context have these assessment tools been used?

- a. In what settings and populations have they been used?
- b. How have they been applied?

Guiding Question 4: What are key issues with the use of assessment tools?

- a. What are the key strengths and weaknesses of the overall collection of currently available tools (e.g., standardization, burden on patients and caregivers, unintended consequences)?
- b. What are the key gaps in tool development and evaluation, and what are the opportunities for future research?
- c. How have the identified weaknesses and gaps affected the field of palliative care?

Methods

Discussions with Key Informants

We conducted telephone interviews with Key Informants to get their perspectives related to assessment tools, including the efficacy and issues with existing tools and the location of information about tools. (See Appendix C for Key Informant questions.) Key Informants included caregivers for patients who had received palliative care, clinicians providing palliative care, and leading palliative care researchers and quality experts. We analyzed the information gathered from Key Informants, along with the current research on palliative care assessment tools, to identify gaps and issues for future research.

Data Collection

For each of the domains identified in the National Consensus Project Clinical Practice Guidelines for Palliative Care and for multidimensional tools, we sought and compiled information on palliative care assessment tools from systematic reviews. Since a preliminary assessment of domain-specific systematic reviews found existing high-quality reviews that summarized palliative care assessment tools for all five of the domains where we expected to find more than three tools, we used those systematic reviews to collect information on assessment tools. If we did not identify a systematic review for a particular domain, we sought information about assessment tools from supplemental sources (unpublished compilations or databases of published information on tools). We followed the same methods for data collection for each of the three applications in palliative care: clinical practice, quality indicators, and evaluation of interventions in studies.

Systematic Review Search

We searched for systematic reviews using Cochrane, PubMed, CINAHL, PsycINFO, and PsycTESTS. (Detailed search strategies are available in Appendix D.) We followed Evidence-based Practice Center (EPC) 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 We selected reviews published within the last 10 years, because the PEACE systematic review was completed in 2007. We searched for (1) systematic reviews describing palliative care assessment tools and their properties and (2) systematic reviews on the use of palliative care assessment tools for three applications in palliative care: clinical practice, quality indicators, and evaluation of interventions in studies. For each domain, multidimensional area, and application, we chose a systematic review using these criteria: our ROBIS quality assessment (Appendix E), the relevance and date of publication, and the availability of evidence tables.

For domains and key subdomains (pain, dyspnea) without any systematic review specifically addressing that domain, we first abstracted information from three older, comprehensive reviews of tools: the TIME Toolkit of Instruments to Measure End-of-Life Care, first published in the mid-1990s;⁶ the systematic review for the National Institutes of Health State of the Science Conference on Improving End-of-Life Care;^{9, 10} and the PEACE Palliative Care Quality Measures project.^{11, 17} For domains with systematic reviews older than three years, we also searched websites as described below. If no tools could be identified through these approaches, we conducted a targeted search in PubMed to identify primary literature on the specific domain. (Inclusion criteria used for the systematic review search can be found in Appendix F.)

Palliative Care Website Search and Search of Supplemental Literature

For domains or multidimensional areas without systematic reviews or with a systematic review published more than three years ago, we attempted to identify tools through older reviews and targeted website searches (Appendix G). This method was selected over a search for primary studies of psychometric properties of tools because (1) the literature was already shown to lack comprehensive systematic reviews on this domain, (2) a full systematic review for each of the domains is beyond the scope of a Technical Brief, and (3) detailed, up-to-date websites on this topic exist. We limited our website search to compiled lists and databases of published palliative care tools, including the University of Washington End-of-Life Care Research Program Instruments,¹⁸ the City of Hope Pain & Palliative Care Resource Center,¹⁹ the National Palliative Care Research Center Measurement and Evaluation Tools,²⁰ the Toolkit of Instruments to Measure End-of-Life Care (TIME),²¹ the End of Life Care and Outcomes systematic review,⁹ the PEACE Palliative Care Quality Measures systematic review of assessment tools,¹⁷ and the Center for Research on End-of-Life Care.²²

We did not do additional searching for the applications of tools. Additional information was also provided by an outside expert who identified information about evaluation of interventions where palliative care tools are used.²³

Results

Key Informant Summary

The Key Informants included two caregiver advocates and seven providers who are experts in palliative care and assessment tools in areas including oncology, pediatrics, critical care, health services research, outcomes research, palliative care quality measures, palliative care clinical trials, and assessment tool development.

Caregiver Advocates

Both advocates reported that they had completed numerous written questionnaires with “tons of questions” that “always felt rushed.” They felt that the information captured in the tools was meaningful to clinicians, but they were not convinced that the tools had an impact on 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.”

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, referral timing, culture, and informed decisionmaking). They specifically noted that there are few to no tools that assess the spiritual domain. They also 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, there is an inherent contradiction in the use of assessment tools as quality indicators, 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 measures, some assessment tools could unintentionally incentivize actions that are detrimental to patient care, such as treating pain aggressively to bring down pain scores that are included in the tools, rather than balancing pain management with risks and harms of treatments for other, particular measures, such as alertness, 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.

Results of the Literature Search and Supplemental Searches

For the systematic review search, we identified 354 unique citations, of which 40 systematic reviews were eligible for inclusion. Of the eligible reviews, nine were considered sufficient to include in the Technical Brief, in terms of relevance, date of search, and risk of bias. Seven of these reviews addressed assessment tools: five addressed single domain tools and two addressed multidimensional tools. The other two reviews addressed applications: clinical care and quality indicators (information about evaluation of interventions where palliative care tools are used was provided by an outside expert).²³ Since the same reviews addressed both Guiding Questions 1 and 2, results for these are described together. The systematic reviews identified 98 tools, and the website and other supplemental searches identified an additional 48 tools (Table 2; Appendix H, Figure H-1).

For the culture domain, for which we identified no tools through systematic reviews or the website search, we conducted a targeted search of PubMed. We found no primary articles applicable to this domain (Appendix H, Figure H-2).

A list of all identified tools is available in Appendix I.

Table 2. Summary of the literature search and website search for tools and their applications

Domain or Application	Included in Review(s), N	Included in Supplemental Search, N	Source of Information	Search Dates of the SRs
Tools in Single Domains or Multidimensional				
Structure and Processes	0	2	1 Website 1 Supplemental comprehensive systematic review ⁹	NA
Physical	26	25	1 Systematic review ²⁴ 2 Websites	Up to September 2005
Psychological and Psychiatric	8	18	1 Systematic review ²⁵ 4 Websites 1 Supplemental comprehensive systematic review ⁹	1960 to unspecified end date
Social	8	NA	1 Systematic review ²⁶	Not reported; published in 2016
Spiritual, Religious, and Existential	2	0	1 Systematic review ²⁷ (Websites searched but no new tools identified)	Up to June 2010
Cultural*	0	0	NA (Websites and PubMed searched but no tools identified)	NA
Care at the End of Life	17	NA	1 Systematic review, ²⁸	Up to August 2014
Ethical and Legal	0	2	1 Website	NA
Multidimensional Tools—Quality of Life	29	0	1 Systematic review ²⁹	January 1990 to April 2008
Multidimensional Tools—Patient Experience	8	1	1 Systematic review ³⁰ (Websites searched but no new tools identified)	January 1990 to June 2012
Tools included in rows above that were used in systematic reviews of applications†				
Clinical Care	6	NA	1 Systematic review ³¹	1985 to August 2011
Quality Indicators	1	NA	1 Systematic review ³²	Up to October

				2011
Evaluation of Interventions	20	NA	1 Systematic source identified by outside expert ²³	Up to December 2015

NA: We did not search websites for a domain when the included systematic review was recent and did not require a website search. We assumed that the end date for Michels et al. was recent as it was published in 2016 and included recent publications. Because there was no end date for Ziegler et al. and the review covered only cancer, we conducted a complete website review without date inclusions.

* We searched PubMed for the cultural domain but identified no tools.

†For the applications of quality indicators, clinical care, and evaluation of interventions, the number of tools is matched against tools identified in the systematic reviews and in the websites only.

Tools Focusing on Single Domains

Domain 1: Structure and Processes of Care

As anticipated, since this domain is generally addressed as part of multidimensional tools (patient experience), we did not identify a systematic review for this domain. In the supplemental searches, we identified two tools: the McCusker 4-item instrument on continuity and the Quality of Communication Questionnaire (Appendix J, Evidence Table 1).

Domain 2: Physical

As described in the National Consensus Statement for Quality Palliative Care, physical symptom subdomains include numerous symptoms such as pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, and constipation. Summarizing tools across all physical symptoms was beyond the scope of this brief, so we summarized assessment tools for the two key subdomains: dyspnea and pain (these and other symptoms are also addressed in multidimensional tools for quality of life and patient experience). We identified one systematic review, reporting on 26 tools, for the domain of dyspnea;²⁴ however, we did not identify any systematic reviews for pain, so tools for this subdomain are summarized from website searches (Table 3; Appendix J, Evidence Tables 2a-2e).

Key Subdomain: Dyspnea

The selected systematic review²⁴ identified 29 tools, including 26 tools that met 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. Internal consistency reliability was reported for 14 tools. Convergent validity was reported for 23 tools. Responsiveness was reported for only eight tools. Usability (time to complete) was reported for 15 tools (Table 3; Appendix J, Evidence Tables 2a-2e).

Because the systematic review for the dyspnea subdomain was more than three years old, we completed a supplemental search but identified no additional tools.

Key Subdomain: Pain

We did not identify a systematic review addressing palliative care assessment tools for the subdomain of pain. Thus, we relied on the supplemental search to identify 25 tools (Appendix J, Evidence Table 1).

Table 3. Summary table for physical domain (dyspnea subdomain) included from the selected review

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 Scale³³	Asthma, COPD, ventilated	N	Y	Y	N	Y	1
Numeric Rating Scale or Dyspnea Numeric Scale^{34, 35}	Cancer, COPD	N	Y	Y	N	Y	1
Modified Borg Scale³⁶	COPD, restrictive lung disease, asthma	N	Y	Y	N	Y	1
Global Shortness of Breath Question³⁷	COPD	N	Y	N	Y	N	1
Faces Scale³⁸	Ventilated	N	Y	N	N	N	1
Dyspnea Descriptor Questionnaire (heart failure)³⁹	Heart failure	Y	N	N	N	N	13
Dyspnea Descriptor Questionnaire (COPD)⁴⁰	COPD	Y	N	N	N	N	16
Dyspnea Assessment Questionnaire⁴¹	Cancer	N	Y	N	N	N	43
Amyotrophic Lateral Sclerosis Functional Rating Scale – revised⁴²	MND (Motor Neuron Disease)	Y	Y	N	N	N	3
American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale⁴³	COPD, asthma	Y	Y	N	N	Y	5
Breathlessness, Cough and Sputum Scale⁴⁴	COPD	N	Y	Y	Y	N	1
Chronic Heart Failure Questionnaire – dyspnea subscale⁴⁵	Heart failure	Y	Y	Y	Y	Y	5
Cardiovascular Limitations and Symptoms Profile⁴⁶	Ischemic heart disease	N	Y	N	N	Y	6
Chronic Lung Disease Severity Index⁴⁷	Chronic lung disease	Y	Y	N	N	N	2
Chronic Respiratory Questionnaire – dyspnea subscale⁴⁸	COPD, interstitial lung disease, cystic fibrosis, alpha antitrypsin deficiency, MND	Y	Y	Y	Y	Y	5
Chronic Respiratory Questionnaire – Standardized dyspnea questions⁴⁹	ND	N	N	N	N	N	5

Table 3. Summary table for physical domain (dyspnea subdomain) included from the selected review (continued)

Tool	Population	Internal Consistency Reliability Measured	Convergent Validity Measured	Discriminant or Criterion Validity Measured	Responsive -ness Measured	Time to Complete Measured	Number of Items
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Lung Cancer supplement, breathlessness subscale⁵⁰	Lung cancer	Y	Y	Y	N	N	3
London Chest Activity of Daily Living Scale⁵¹	COPD	Y	Y	Y	N	N	15
Motor Neurone Disease Dyspnea Rating Scale⁵²	MND	Y	Y	N	N	Y	5
Medical Research Council Dyspnea Scale⁵³	COPD, interstitial lung disease, asthma, other	N	Y	Y	N	Y	1
Oxygen Cost Diagram⁵⁴	Respiratory disease, COPD, heart failure	N	Y	N	Y	Y	1
Pulmonary Functional Status and Dyspnea Questionnaire – modified⁵⁵	COPD	Y	Y	Y	N	Y	5
Rand Instrument⁵⁶	Heart failure, respiratory disease	N	Y	N	Y	Y	9
St George’s Respiratory Questionnaire⁵⁷	COPD, asthma, bronchiectasis	Y	Y	Y	Y	Y	16
University of Cincinnati Dyspnea Questionnaire⁵⁸	Asthma, sarcoid, COPD, fibrosis	Y	Y	N	N	Y	30
University of California San Diego Shortness of Breath Questionnaire⁵⁹	COPD, asthma, cystic fibrosis, lung transplant	Y	Y	N	Y	Y	24

* From the Clinical Practice Guidelines for Quality Palliative Care
 COPD=chronic obstructive pulmonary disease; MND=motor neuron disease Y=measured for tool, N=not measured for tool, ND=not described in review

Domain 3: Psychological and Psychiatric

The selected systematic review²⁵ included 48 tools, of which eight were evaluated in palliative care populations and focused on this domain. Settings where the tools were tested included 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 internal consistency reliability, responsiveness, or usability (time to complete); seven tools had data on convergent validity (Table 4; Appendix G, Evidence Tables 3a-3e).

Because the systematic review for the psychological and psychiatric domain was greater than three years old and addressed only cancer, we completed a supplemental search which yielded 17 additional tools (Appendix J, Evidence Table 1).

Domain 4: Social

The selected systematic review²⁶ included 36 assessment tools, with eight that met the inclusion criteria for this domain. The eight were caregiver-reported assessment tools that addressed informal caregiver outcomes (e.g., burden, caregiver strain). There was 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 5; Appendix J, Evidence Tables 4a-4e).

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

Domain 5: Spiritual, Religious, and Existential

The selected systematic review²⁷ identified nine assessment tools, including two that met inclusion criteria for this domain. 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. Only two tools met our inclusion criteria. The two tools, The Beck Hopelessness Scale and the Ironson-Woods Spirituality/Religiousness Index, specifically address spirituality and were developed for and/or validated 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).^{60, 61} Both tools had information on internal consistency reliability, convergent validity, criterion or discriminant validity, validity, and responsiveness but no information on usability (time to complete) (Table 6; Appendix J, Evidence Tables 5a-5e).

Because the systematic review for the spiritual, religious, and existential domain was more than three years old, we conducted a supplemental search but identified no additional tools.

Table 4. Summary table for psychological and psychiatric tools included from the selected review

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 Scale⁶²	Patients receiving palliative care with a prognosis of six months or less	ND	Y	ND	ND	Y	14
Two Single Items: “Are you depressed?” and “Have you lost interest?”⁶³	Palliative care population	ND	Y	ND	ND	Y	2
Distress Thermometer (via touch screen)⁶⁴	Patients with advanced disease	ND	Y	ND	ND	Y	1
Brief Symptom Inventory-18 item (via touch screen)⁶⁴	Patients with advanced disease	ND	Y	ND	ND	Y	18
General Health Questionnaire-12 item⁶⁴	Patients with advanced disease	ND	Y	ND	ND	Y	12
Brief Edinburgh Depression Scale⁶²	Patients receiving palliative care with a prognosis of six months or less	ND	Y	ND	ND	Y	6
Beck Depression Inventory-Short Form⁶⁵	Patients with metastatic breast cancer	ND	Y	ND	ND	Y	13
Mental Adjustment to Cancer⁶⁶	Patients at first recurrence of breast cancer	ND	N	ND	ND	N	40

* from the Clinical Practice Guidelines for Quality Palliative Care
Y=measured for tool, N=not measured for tool, ND=not described in review

Table 5. Summary table for social tools included from the selected systematic review

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 Care⁶⁷	Family caregivers of patients with terminal cancer	Y	Y	Y	Y	N	16
Caregiver Impact Scale⁶⁸	Caregivers of patients with advanced cancer	Y	N	N	N	N	14
Caregiver Quality of Life Index – Cancer⁶⁹	Caregivers of patients with cancer	Y	Y	Y	Y	Y	35
Caregiver Reaction Assessment⁷⁰	Caregivers of patients receiving palliative care	Y	Y	N	N	N	24
Caregiver Strain Index⁷¹	Caregivers for patients with symptomatic advanced cancer	Y	Y	N	N	N	13
Family Appraisal of Caregiving Questionnaire for Palliative Care⁷²	Caregivers of patients receiving palliative care	Y	Y	N	N	N	26
Quality of Life in Life-Threatening Illness-Family Carer Version⁷³	Caregivers of patients receiving palliative care for cancer	Y	Y	N	Y	N	16
Zarit Burden Inventory⁷⁴	Advanced conditions	Y	Y	N	N	N	22

* From the Clinical Practice Guidelines for Quality Palliative Care
Y=measured for tool, N=not measured for tool, ND=not described in review

Table 6. Summary table for spiritual, religious, and existential tools included from the selected systematic review

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^{60, 75, 76}	Ethnically diverse U.S. population; validated in palliative care population	Y	Y	Y	Y	N	120
Ironson-Woods Spirituality/Religiousness Index⁶¹	Ethnically diverse U.S. population	Y	Y	Y	Y	N	22

* From the Clinical Practice Guidelines for Quality Palliative Care
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. As anticipated, we identified no eligible tools that focused on the cultural domain. We conducted a supplemental search as well as a PubMed search for primary literature on the cultural domain and found no additional tools. We evaluated whether multidimensional tools addressed the cultural domain and report on our findings in the section about multidimensional tools.

Domain 7: Care at the End of Life

The selected review²⁸ identified 70 “grief measures” and reported on 19 assessment tools, of which 17 (family self-reported bereavement risk assessment tools) met our inclusion criteria. The review did not define settings where the tools were tested, and tools were 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 were designed for pre-death bereavement risk, after-death bereavement assessment, or for the assessment of complicated or prolonged bereavement. Internal consistency reliability was reported for all tools. Three tools had data on convergent validity. None of the following were reported: criterion or discriminant validity, responsiveness or usability (time to complete). The number of items was reported and ranged widely, from 5 to 91 items (Table 7; Appendix J, Evidence Tables 6a-6e).

Because the systematic review was conducted through 2014, we did not conduct a supplemental search.

Domain 8: Ethical and Legal

As anticipated, we did not identify a systematic review focusing on 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).

We evaluated whether multidimensional tools addressed the ethical and legal domain and reported on our findings in the section about multidimensional tools.

Multidimensional Tools

Some tools address concepts (i.e., quality of life, patient experience) that are both beyond the eight National Consensus Project Quality Domains and innately multidimensional. Moreover, our Key Informants identified multidimensional tools as a key area to review. Consequently, we included a category of multidimensional tools and identified two systematic reviews that addressed quality of life²³ (which may include areas such as physical health and functional status, mental health, social and role function, and physical and psychological symptoms) or patient experience^{29, 30} (Appendix J, Evidence Tables 7a-7e, and 8a-8e).

Table 7. Summary table for care at the end of life (bereavement) included from the selected review

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 ⁷⁷	Bereaved adults	Y	N	ND	ND	ND	24
Brief Grief Questionnaire ⁷⁸⁻⁸⁰	Recipients of crisis counselling following 911 terrorist attacks; bereaved community-dwelling adults	Y	N	ND	ND	ND	5
Core Bereavement Items ⁸¹	Bereaved adults	Y	Y	ND	ND	ND	17
Grief Evaluation Measure ⁸²	Bereaved adults	Y	N	ND	ND	ND	91
Grief Experience Questionnaire ⁸³	Conjugally bereaved adults to suicide, natural causes, or accidental death	Y	N	ND	ND	ND	55
Hogan Grief Reaction Checklist ⁸⁴	Parentally bereaved people	Y	N	ND	ND	ND	61
Inventory of Complicated Grief ⁸⁵	Conjugally bereaved elders	Y	N	ND	ND	ND	19
Inventory of Complicated Grief–Revised ⁸⁶⁻⁸⁸	Conjugally bereaved elders	Y	N	ND	ND	ND	15
Inventory of Traumatic Grief ⁸⁹	Elderly widowed residents; bereaved adults	Y	N	ND	ND	ND	34
Marwit–Meuser Caregiver Grief Inventory ⁹⁰⁻⁹²	Caregivers of people with dementia, acquired brain injury, cancer	Y	Y	ND	ND	ND	50
Marwit–Meuser Caregiver Grief Inventory–Short Form ⁹³	Adult caregivers of people with dementia	Y	Y	ND	ND	ND	18
Prolonged Grief–12 ^{94, 95}	Caregivers of people with dementia, hospice patients	Y	N	ND	ND	ND	12
Prolonged Grief–13 ^{96, 97}	Adults; bereaved caregivers with prolonged grief disorder	Y	N	ND	ND	ND	13

Table 7. Summary table for care at the end of life (bereavement) included from the selected review (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 ⁹⁸	Hospice caregivers following the death of a loved one	Y	N	ND	ND	ND	22
Texas Revised Inventory of Grief ⁹⁹⁻¹⁰²	Bereaved psychiatric outpatients; bereaved adults	Y	N	ND	ND	ND	21
Two-Track Bereavement Questionnaire ¹⁰³	Bereaved adults	Y	N	ND	ND	ND	70
Two-Track Bereavement Questionnaire–CG30 ¹⁰⁴	Adults bereaved by traumatic deaths	Y	N	ND	ND	ND	30

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

Quality of Life

The selected systematic review²⁹ reported on 29 quality of life assessment tools evaluated in 36 studies. 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. Multiple tools addressed almost all the domains, including structure and processes (4 tools), physical (21 tools), psychological and psychiatric (20 tools), spiritual (11 tools), social (11 tools), ethical/legal (6 tools) and end of life (2 tools) (Table 8). None appeared to address the cultural domain. All tools had information on internal consistency reliability. In total, 27 tools had information about construct validity. Seven tools had data on responsiveness. Fourteen tools had data on usability (time to complete) (Appendix J, Evidence Tables 7a-7e).

As the systematic review for quality of life assessment tools was greater than three years old, we completed a supplemental search which identified no additional tools.

Patient Experience

The included systematic review³⁰ identified 51 tools, of which eight met 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 perception. The tools had a range of 25-74 items and addressed most domains, including structure and processes (6 tools), physical (7 tools), psychological and psychiatric (7 tools), spiritual (7 tools), social (5 tools), and end of life (5 tools); whether ethical/legal and cultural domains were addressed could not be determined from the review (Table 9). None of the following were reported: setting, population where the tools were tested, reliability, validity, responsiveness, nor usability (Appendix H, Evidence Tables 8a-8e).

Because the systematic review for patient and caregiver-reported experiences 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 8. Summary table for multidimensional - quality of life tools included from the selected review

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 Inventory¹⁰⁵	Physical, Psychological and Psychiatric	Patients in hospice	Y	N	ND	N	Y	17
Cambridge Palliative Audit Schedule¹⁰⁶	Physical, Psychological and Psychiatric	Patients receiving palliative care	Y	Y	ND	Y	N	2x10
Demoralization Scale¹⁰⁷	Psychological and Psychiatric	Patients with cancer	Y	Y	ND	N	N	24
Edmonton Functional Assessment Tool^{108, 109}	Physical	Patients with cancer	Y	Y	ND	N	N	11
Emanuel and Emanuel Medical Directive¹¹⁰	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 Module¹¹¹	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 Module¹¹²	Physical, Psychological and Psychiatric	Patients with adenoma carcinoma of the stomach	Y	Y	ND	Y	Y	22
Edmonton Symptom Assessment Scale¹¹³	Physical, Psychological and Psychiatric	Patients receiving palliative care	Y	Y	ND	N	Y	10
FACIT-Pal Functional Assessment of Chronic Illness Therapy-Palliative Subscale¹¹⁴	Physical, Psychological and Psychiatric, Social, Ethical/Legal	Patients with life limiting illness	Y	Y	ND	N	N	19

Table 8. Summary table for multidimensional - quality of life tools included from the selected review (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
Hospice Quality of Life Index ^{115, 116}	Physical, Psychological and Psychiatric, Social, Spiritual	Patients in hospice	Y	Y	ND	N	Y	28
Life Closure Scale ¹¹⁷	Psychological and Psychiatric	Patients who are terminally ill	Y	Y	ND	N	N	20
Life Evaluation Questionnaire ¹¹⁸	Psychological and Psychiatric, Social	People with incurable cancer	Y	Y	ND	N	N	44
McMaster Quality of Life Scale ¹¹⁹	Physical, Psychological and Psychiatric, Social	Patients receiving palliative care	Y	Y	ND	Y	Y	32
McGill Quality of Life Questionnaire ^{120, 121}	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 ¹²²	Physical, Psychological and Psychiatric, Spiritual	Patients who are terminally ill	Y	Y	ND	N	Y	8
McCanse Readiness for Death Instrument ¹²³	Physical, Psychological and Psychiatric, Social, Spiritual	Patients who are terminally ill	Y	Y	ND	N	N	28
Memorial Symptom Assessment Scale ^{124, 125}	Physical, Psychological and Psychiatric	Patients with cancer	Y	Y	ND	N	Y	32
Condensed Memorial Symptom Assessment Scale ¹²⁶	Physical, Psychological and Psychiatric	Patients with cancer	Y	Y	ND	N	Y	14
Memorial Symptom Assessment Scale-Global Distress Index ¹²⁷	Physical, Psychological and Psychiatric	Patients with cancer	Y	N	ND	N	N	11
Missoula-VITAS Quality of Life Index ^{128, 129}	Physical, Social, Spiritual	Patients who are terminally ill	Y	Y	ND	Y	N	25
Needs Assessment for Advanced Cancer Patients ¹³⁰	Structure and Process, Physical, Social, Spiritual	Patients with advanced cancer	Y	N	ND	N	Y	132
Patient Autonomy Questionnaire ¹³¹	Ethical/Legal	Patients receiving palliative care for cancer	Y	Y	ND	N	N	4/9
Patient Dignity Inventory ¹³²	Physical, Social, Spiritual	Patients nearing the end of life	Y	Y	ND	N	Y	25

Table 8. Summary table for multidimensional - quality of life tools included from the selected review (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
Problems and Needs in Palliative Care Questionnaire ¹³³	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 ¹³⁴	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 ¹³⁵	Physical, Psychological and Psychiatric, Spiritual	Patients with advanced cancer	Y	Y	ND	Y	Y	10
Quality of Dying and Death Questionnaire ¹³⁶	Physical, Psychological and Psychiatric, Spiritual, End of Life	Family members of patients who are terminally ill	Y	Y	ND	N	N	31
Quality of Life at the End of Life ¹³⁷	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 ¹³⁸	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 9. Summary table for multidimensional - patient experience tools included from the selected review

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 ¹³⁹⁻¹⁴⁶	Structure and Processes, Physical, Spiritual, Psychosocial, Social, End of Life	Close relatives, Surrogates, Caregivers	ND	ND	ND	ND	ND	74
End of Life in Dementia-Satisfaction with Care & Comfort Assessment in Dying ^{142, 147, 148}	Structure and Processes, Physical, Spiritual, Psychosocial	Patients or health care proxies, Caregivers	ND	ND	ND	ND	ND	41
Family Assessment of Treatment of End-of-Life Survey ¹⁴⁹⁻¹⁵³	Structure and Processes, Physical, Social, Psychosocial, Spiritual, End of Life	Family members	ND	ND	ND	ND	ND	58
Family Evaluation of Hospice Care ¹⁵⁴⁻¹⁶¹	Structure and Processes, Physical, Spiritual, Psychosocial, Social, End of Life	Family members	ND	ND	ND	ND	ND	56
Family Satisfaction in the ICU ¹⁶²⁻¹⁶⁴	Structure and Processes, Physical, Spiritual, Social, End of Life	Family members	ND	ND	ND	ND	ND	25
Family Satisfaction with Advanced Cancer Care ¹⁶⁵⁻¹⁷²	Psychosocial, Physical, Social	Caregivers, Family members	ND	ND	ND	ND	ND	30
Quality of Dying and Death ^{164, 173-177}	Physical, Psychosocial, Spiritual, End of Life	Family members	ND	ND	ND	ND	ND	48
Quality of End-of-Life Care and Satisfaction with Treatment ¹⁷⁸⁻¹⁸⁰	Structure and Processes, Spiritual, Psychosocial	Patients, Family members	ND	ND	ND	ND	ND	47

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

Note that Ethical/Legal and Cultural domains could not be determined from the review.

Use of Assessment Tools for Different Applications

Palliative care assessment tools can be used for three key applications: clinical care, quality indicators, and evaluation of palliative care interventions in studies.

Clinical Care

The included systematic review³¹ 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 were conducted in the U.S. and reported on the use of specific assessment tools. The tools used in these six studies included multidimensional tools (quality of life tools, 3 studies), physical (numerical rating or visual analog scales for pain, 2 studies), and psychological or psychiatric (1 study). Four of these were reported in the palliative care assessment tool reviews described above, and two (for pain, where there was no systematic review) were listed on websites. Settings included hospices, cancer centers, nursing homes, emergency care, and home. Most settings were treating cancer patients. The palliative care assessment tools used in the U.S. studies included The Edmonton Symptom Assessment Scale, Missoula-VITAS Quality of Life Index, Memorial Symptom Assessment Scale, Functional Assessment of Chronic Illness Therapy-Lung (all included in quality of life), Numeric Rating Scale for Pain, and Visual Analogue Scale for Pain (Appendix J, Evidence Tables 9a-9b).

Quality Indicators

The selected systematic review³² evaluated quality indicators developed specifically for palliative care. This review identified 10 U.S. indicator sets. However, only one indicator specified a palliative care assessment tool (most were indicators abstracted from the medical record, rather than reported by or with patients or caregivers). The one palliative care assessment tool was a multidimensional tool for patient experience, identified in the patient experience systematic review (Appendix J, Evidence Tables 10a-10b).

Evaluation of Interventions

The selected systematic review, Kavalieratos et al.,²³ evaluated assessment tools used in randomized controlled trials of palliative care interventions in adults with terminal or life-limiting illness.²³ In the 38 included studies evaluating palliative care interventions, the authors found 44 instances of palliative care assessment tools that were used to evaluate the interventions related to the physical domain (7 tools), psychological and psychiatric domain (6 tools), patient experience (2 tools), or quality of life (5 tools). In this report, only seven palliative care assessment tools in the physical domain, six in psychological and psychiatric, two in patient experience, and five in quality of life were used to evaluate these interventions, with 45 instances of all of these tools being used. The most commonly used physical domain palliative care assessment tool was the Numeric Rating Scale for Pain, which was used in only three of the studies. The most commonly used palliative care assessment tool for the psychosocial and psychiatric domain was the Center for Epidemiologic Studies Depression Scale, which was used in only five 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 four studies. Two studies used multidimensional

patient experience palliative care assessment tools, both of which were different tools (Table 10; Appendix J, Evidence Tables 1 and 11).

Table 10. Summary of palliative care assessment tools that were used in 38 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 (3) [†] Chronic Respiratory Disease Questionnaire (1) University of California, San Diego Shortness of Breath Questionnaire (1) Brief Pain Inventory (1) [†] Pain as Assessed in the Medical Outcomes Study (1) [†] Visual Analog Scale for Pain (1) [†] Memorial Pain Assessment Card (1) [†]
Psychosocial 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 (4) 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 (4) Functional Assessment of Chronic Illness Therapy-Palliative Sub Scale (3) Memorial Symptom Assessment Scale (2) Quality of Life at the End of Life (3)

[†]Indicates tool that was found during supplemental search

Discussion

Our overview demonstrates the strength of relevant tool development and evaluation, with 146 different assessment tools related to palliative care (Figure 1). However, while some domains (e.g., Physical, Psychological and Psychiatric, Social, and Care at the End of Life) had many assessment tools, other domains (Spiritual, Religious, and Existential; Cultural; and Ethical and Legal) had few to no tools, and there were many weaknesses and research gaps even in domains with many tools. Few tools addressed usability (time to complete). The burden associated with tools, as evaluated by the number of items in each tool, varied significantly by domain. The mean number of items per tool identified in the systematic review was 24, but domain means varied with: 7 items (physical domain), 13 items (psychological domain), 21 items (social domain), 22 items (spiritual domain), 33 items (end-of-life care), 30 items (quality of life), and 47 items (patient experience).

For the structure and processes domain, we identified only two tools from ancillary website searches, one on continuity and one on communication. In contrast, our Key Informants identified communication as a key aspect of palliative care, so this is an important area for future tool development.

For the physical domain, our review focused on the subdomains of dyspnea and pain. For dyspnea, a particular gap is that only 8 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 compiles and compares pain assessment tools in palliative care populations. We identified a number of pain assessment tools from our ancillary 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.

For the psychosocial and psychiatric domain, we identified eight tools in palliative care populations, but the scope of this review was limited to patients with cancer. We identified a number of additional tools identified in ancillary website reviews that may be relevant. A systematic review to synthesis the properties and the 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 review had not been tested in palliative care populations. There was also insufficient or incomplete information about the psychometric properties of most tools. Future research comparing these tools and exploring their responsiveness in palliative care populations is needed.

The spiritual domain is also a key gap, as noted by the Key Informants and confirmed by our search: there were only two included tools that focused on spirituality and were evaluated in palliative care populations and no published palliative care interventions used tools assessing spirituality. The lack of tools to assess this specific domain is a potential reason that this domain remains under-explored in existing studies of palliative care interventions.

Although the cultural domain is one of the eight key domains of palliative care, we found no assessment tools focusing on this topic in any of the searches, 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 domain of care at the end of life, our search identified 17 tools to assess bereavement. While many of these tools were developed in palliative care populations, the information on

validity and responsiveness was sparse and the majority of tools were long, with one tool having 91 component items. Short, easy-to-complete tools are important and there is a lack of simple, low-burden, yet meaningful assessment tools.

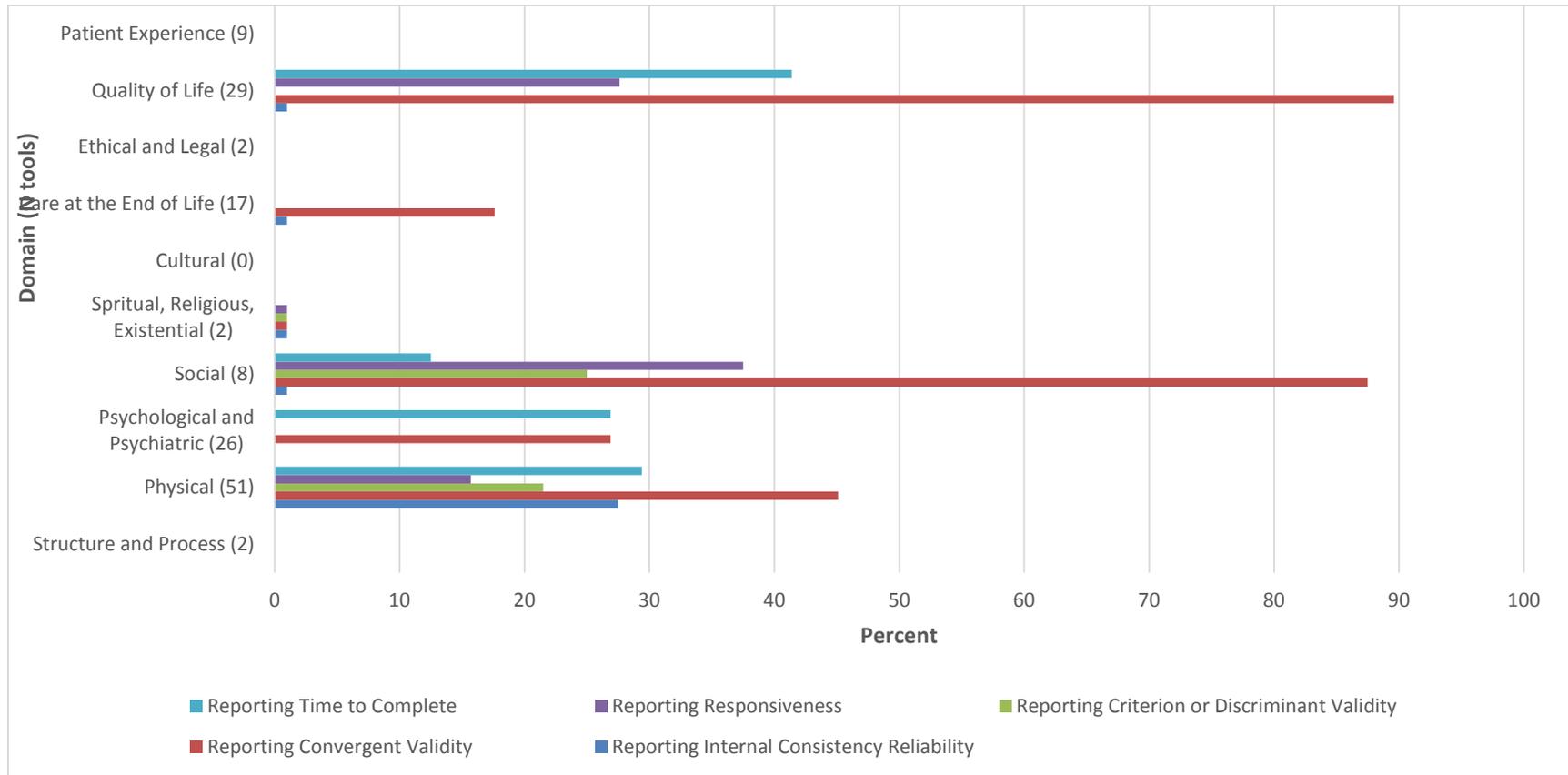


Figure 1. Evidence map of percentage of psychometric properties reported on existing assessment tools, organized by National Consensus Project for Quality Palliative Care domains and multidimensional domains

Regarding the ethical and legal domain, we identified only three tools in ancillary website searches focusing on this domain, 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, which could also involve the evaluation of pre-existing items in multidimensional tools.

The domain of patient experience was identified as important by Key Informants; however, we found only two tools assessing patient-reported experience in our literature search (most were for caregiver-reported experience).

In assessing the applications for which palliative care assessment tools are used, the systematic review evaluating assessment tools in clinical care found only six studies.³¹ We did identify one assessment tool being used as a quality indicator³² 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 (<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/index.html>). 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 (<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Hospice-Item-Set-HIS.html>).

The palliative care assessment tools that we identified were overwhelmingly developed for, and being used in, the application of evaluation of interventions. In the information provided by the outside expert on use of tools for evaluation of interventions, studies used palliative care assessment tools assessing the physical domain, psychological and psychiatric domain, and multidimensional – quality of life, but few used assessments of multidimensional - patient experience. Of those that did assess patient experience, only two were identified in this report, with no assessment tool for patient experience being used by more than one study.²³ No palliative care assessment tool that we identified was used in more than five of the 38 studies.

Next Steps

Systematic Reviews

- For the physical domain, a systematic review of assessment tools for pain in palliative care populations is needed, and an updated review is needed for dyspnea tools.
- For the psychiatric and psychological domain, a systematic review is needed to evaluate tools for conditions other than cancer and to evaluate psychometrics of tools more broadly.
- For multidimensional – patient experience, a systematic review is needed to evaluate psychometrics of the tools.
- For all domains, a formal systematic review of psychometric properties following guidance and using tools of Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) would be useful.¹⁸¹

Tool Development

- Research is needed to conceptualize, develop, validate, and test assessment tools that specifically address the following domains in palliative care populations: structure and processes; spiritual, religious and existential; ethical and legal; and, particularly, cultural and multidimensional – patient experience tools that are reported by patients, rather than caregivers.
- For multidimensional tools, further development of tools for patient experience and quality of life should address the cultural domain in particular.

Tool Evaluation

- Some domains had multiple tools, but often these were not tested in palliative care populations and not evaluated for responsiveness. For the spiritual domain, few tools had been tested in palliative care populations. For care at the end of life (bereavement), patient experience, and quality of life, in particular, many tools were not only long and likely burdensome, but also had not been evaluated for responsiveness. Across all domains, the following would be helpful: additional evaluation of existing tools in other populations (with modifications, as needed, especially 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 validity testing.

Applications of Assessment Tools

- More research is needed on the use of assessment tools in clinical care across all domains, but particularly in domains related to the spiritual, social, cultural, and ethical domains. This research should include evaluation of the effectiveness of the tools in improving outcomes, feasibility, and usability in clinical care. It should also include 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, in-depth analysis of multidimensional tools, particularly across component domains and with additional expert consensus, would help determine which patient and caregiver assessment tools are most useful in the evaluation of palliative care interventions. This analysis, with endorsement by organizations involved in palliative care research, could help to better standardize which tools are used and how they are implemented.

Conclusions

While many assessment tools for palliative care exist and address key domains, few to no tools focus on the structure and process, ethical and cultural domains, or patient-reported experience. Also, few spirituality tools were tested in palliative care populations. Moreover, few studies assess existing tools in clinical practice or quality measurement, and evaluations of palliative care interventions used few palliative care assessment tools. Future research should focus on further development of multidimensional tools, particularly for the cultural domain; evaluating tools in palliative care populations in domains where this has not been done, particularly the spiritual domain; and evaluating the responsiveness of tools, both single and multidimensional, in all domains.

References

1. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington DC: 2015 by the National Academy of Sciences; 2015. life care and its outcomes. *Health Serv Res.* 2007 Oct;42(5):1848-70. doi: 10.1111/j.1475-6773.2007.00721.x. PMID: 17850523.
2. 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.
3. Agency for Healthcare Research and Quality. National Quality Measures Clearinghouse. <http://www.qualitymeasures.ahrq.gov/tutorials/varieties.aspx>. Accessed on February 16 2015.
4. Aslakson RA, Bridges JF. Assessing the impact of palliative care in the intensive care unit through the lens of patient-centered outcomes research. *Curr Opin Crit Care.* 2013 Oct;19(5):504-10. doi: 10.1097/MCC.0b013e328364d50f. PMID: 23995120.
5. Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med.* 2013 Nov;16(11):1329-34. doi: 10.1089/jpm.2013.9468. PMID: 24073685.
6. Teno J. Toolkit of Instruments to Measure End of Life Care (TIME) Center for Gerontology and Health Care Research. Brown Medical School. 2001.
7. . NIH State-of-the-Science Conference Statement on improving end-of-life care. NIH Consens State Sci Statements. 2004 Dec 6-8;21(3):1-26. PMID: 17308546.
8. Lorenz K, Lynn J, Morton S, et al. End-of-Life Care and Outcomes. Evidence Report/Technology Assessment No. 110. AHRQ Publication No. 05-E004-2 Agency for Healthcare Research and Quality. Rockville, MD: 2004.
9. Mularski RA, Dy SM, Shugarman LR, et al. A systematic review of measures of end-of-life care and its outcomes. *Health Serv Res.* 2007 Oct;42(5):1848-70. doi: 10.1111/j.1475-6773.2007.00721.x. PMID: 17850523.
10. Dy SM, Shugarman LR, Lorenz KA, et al. A systematic review of satisfaction with care at the end of life. *J Am Geriatr Soc.* 2008 Jan;56(1):124-9. doi: 10.1111/j.1532-5415.2007.01507.x. PMID: 18031485.
11. Hanson LC, Scheunemann LP, Zimmerman S, et al. The PEACE project review of clinical instruments for hospice and palliative care. *J Palliat Med.* 2010 Oct;13(10):1253-60. doi: 10.1089/jpm.2010.0194. PMID: 20874234.
12. Singer A, Goebel J, Kim Y, et al. Populations and Interventions for Palliative and End-of-Life Care: A Systematic Review. *J Palliat Med.* In Press.
13. Dy SM, Aslakson R, Wilson RF, et al. Closing the quality gap: revisiting the state of the science (vol. 8: improving health care and palliative care for advanced and serious illness). *Evid Rep Technol Assess (Full Rep).* 2012 Oct(208.8):1-249. PMID: 24423021.
14. Seow H, SM D. Quality indicators for pain management. In: Moore R, ed *Handbook of Pain and Palliative Care: Biobehavioral Approaches across the Life Course.* Springer; 2012.
15. Robinson KA, Chou R, Berkman ND, et al. Twelve recommendations for integrating existing systematic reviews into new reviews: EPC guidance. *J Clin Epidemiol.* 2016 Feb;70:38-44. doi: 10.1016/j.jclinepi.2015.05.035. PMID: 26261004.
16. Whiting P, Savovic J, Higgins JP, et al. ROBIS: A new tool to assess risk of bias in systematic reviews was developed. *J Clin Epidemiol.* 2016 Jan;69:225-34. doi: 10.1016/j.jclinepi.2015.06.005. PMID: 26092286.

17. PEACE Hospice and Palliative Care Quality Measures. UNC School of Medicine; 2015. <https://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures>. Accessed on December 1, 2015.
18. End-of-Life Care Research Program: Instruments. University of Washington School of Medicine; 2015. <http://depts.washington.edu/eolcare/products/instruments/>. Accessed on December 1, 2015.
19. Categories of Materials. City of Hope Pain and Palliative Care Resource Center; 2015. http://prc.coh.org/res_inst.asp. Accessed on December 1, 2015.
20. Measurement and Evaluation Tools. National Palliative Care Research Center; 2013. <http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx>. Accessed on December 1, 2015.
21. Teno J. Toolkit of Instruments to Measure End-of-Life Care. Center for Gerontology and Health Care Research, Brown Medical School; 2004. <https://nts122.chcr.brown.edu/pcoc/indextools.htm>. Accessed on May 2, 2016.
22. Center for Research on End-Of-Life Care: Assessments And Tools. Weill Cornell Medical College. http://endoflife.weill.cornell.edu/research/assessments_and_tools. Accessed on August, 5 2016.
23. Kavalieratos D, Corbelli J, Ernecoff N, et al. Effectiveness of palliative and supportive care: a systematic review. PROSPERO; 2014. http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42014013696. Accessed on May 4, 2016.
24. Dorman S, Byrne A, Edwards A. Which measurement scales should we use to measure breathlessness in palliative care? A systematic review. *Palliat Med.* 2007 Apr;21(3):177-91. doi: 10.1177/0269216307076398. PMID: 17363394.
25. Ziegler L, Hill K, Neilly L, et al. Identifying psychological distress at key stages of the cancer illness trajectory: a systematic review of validated self-report measures. *J Pain Symptom Manage.* 2011 Mar;41(3):619-36. doi: 10.1016/j.jpainsymman.2010.06.024. PMID: 21310585.
26. Michels CT, Boulton M, Adams A, et al. Psychometric properties of carer-reported outcome measures in palliative care: A systematic review. *Palliat Med.* 2016 Jan;30(1):23-44. doi: 10.1177/0269216315601930. PMID: 26407683.
27. Selman L, Siegert R, Harding R, et al. A psychometric evaluation of measures of spirituality validated in culturally diverse palliative care populations. *J Pain Symptom Manage.* 2011 Oct;42(4):604-22. doi: 10.1016/j.jpainsymman.2011.01.015. PMID: 21640549.
28. Sealey M, Breen LJ, O'Connor M, et al. A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliat Med.* 2015 Jul;29(7):577-89. doi: 10.1177/0269216315576262. PMID: 25805738.
29. Albers G, Echteld MA, de Vet HC, et al. Evaluation of quality-of-life measures for use in palliative care: a systematic review. *Palliat Med.* 2010 Jan;24(1):17-37. doi: 10.1177/0269216309346593. PMID: 19843620.
30. Lendon JP, Ahluwalia SC, Walling AM, et al. Measuring Experience With End-of-Life Care: A Systematic Literature Review. *J Pain Symptom Manage.* 2015 May;49(5):904-15 e1-3. doi: 10.1016/j.jpainsymman.2014.10.018. PMID: 25543110.
31. Antunes B, Harding R, Higginson IJ. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med.* 2014 Feb;28(2):158-75. doi: 10.1177/0269216313491619. PMID: 23801463.

32. De Roo ML, Leemans K, Claessen SJ, et al. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage*. 2013 Oct;46(4):556-72. doi: 10.1016/j.jpainsymman.2012.09.013. PMID: 23809769.
33. Gift AG. Validation of a vertical visual analogue scale as a measure of clinical dyspnea. *Rehabil Nurs*. 1989 Nov-Dec;14(6):323-5. PMID: 2813949.
34. Gift AG, Narsavage G. Validity of the numeric rating scale as a measure of dyspnea. *Am J Crit Care*. 1998 May;7(3):200-4. PMID: 9579246.
35. Tanaka K, Akechi T, Okuyama T, et al. Prevalence and screening of dyspnea interfering with daily life activities in ambulatory patients with advanced lung cancer. *J Pain Symptom Manage*. 2002 Jun;23(6):484-9. PMID: 12067772.
36. Borg G. Perceived exertion as an indicator of somatic stress. *Scand J Rehabil Med*. 1970;2(2):92-8. PMID: 5523831.
37. Simon PM, Schwartzstein RM, Weiss JW, et al. Distinguishable types of dyspnea in patients with shortness of breath. *Am Rev Respir Dis*. 1990 Nov;142(5):1009-14. doi: 10.1164/ajrccm/142.5.1009. PMID: 2240820.
38. Powers J, Bennett SJ. Measurement of dyspnea in patients treated with mechanical ventilation. *Am J Crit Care*. 1999 Jul;8(4):254-61. PMID: 10392226.
39. Parshall MB, Welsh JD, Brockopp DY, et al. Reliability and validity of dyspnea sensory quality descriptors in heart failure patients treated in an emergency department. *Heart Lung*. 2001 Jan-Feb;30(1):57-65. doi: 10.1067/mhl.2001.112499. PMID: 11174368.
40. Parshall MB. Psychometric characteristics of dyspnea descriptor ratings in emergency department patients with exacerbated chronic obstructive pulmonary disease. *Res Nurs Health*. 2002 Oct;25(5):331-44. doi: 10.1002/nur.10051. PMID: 12221688.
41. Heyse-Moore L. On dysonoea in advanced cancer. South Hampton University; 1993.
42. Cedarbaum JM, Stambler N, Malta E, et al. The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function. BDNF ALS Study Group (Phase III). *J Neurol Sci*. 1999 Oct 31;169(1-2):13-21. PMID: 10540002.
43. Ferris B. Recommended respiratory disease questionnaire for use with adults and children in epidemiological research. *American Review of Respiratory Disease*. 1978;118:7-53.
44. Leidy NK, Schmier JK, Jones MK, et al. Evaluating symptoms in chronic obstructive pulmonary disease: validation of the Breathlessness, Cough and Sputum Scale. *Respir Med*. 2003 Jan;97 Suppl A:S59-70. PMID: 12564612.
45. Guyatt GH, Nogradi S, Halcrow S, et al. Development and testing of a new measure of health status for clinical trials in heart failure. *J Gen Intern Med*. 1989 Mar-Apr;4(2):101-7. PMID: 2709167.
46. Lewin RJ, Thompson DR, Martin CR, et al. Validation of the Cardiovascular Limitations and Symptoms Profile (CLASP) in chronic stable angina. *J Cardiopulm Rehabil*. 2002 May-Jun;22(3):184-91. PMID: 12042687.
47. Selim AJ, Ren XS, Fincke G, et al. A symptom-based measure of the severity of chronic lung disease: results from the Veterans Health Study. *Chest*. 1997 Jun;111(6):1607-14. PMID: 9187183.
48. Schunemann HJ, Griffith L, Jaeschke R, et al. A comparison of the original chronic respiratory questionnaire with a standardized version. *Chest*. 2003 Oct;124(4):1421-9. PMID: 14555575.
49. Guyatt GH, Berman LB, Townsend M, et al. A measure of quality of life for clinical trials in chronic lung disease. *Thorax*. 1987 Oct;42(10):773-8. PMID: 3321537.

50. Bergman B, Aaronson NK, Ahmedzai S, et al. The EORTC QLQ-LC13: a modular supplement to the EORTC Core Quality of Life Questionnaire (QLQ-C30) for use in lung cancer clinical trials. EORTC Study Group on Quality of Life. *Eur J Cancer*. 1994;30A(5):635-42. PMID: 8080679.
51. Garrod R, Bestall JC, Paul EA, et al. Development and validation of a standardized measure of activity of daily living in patients with severe COPD: the London Chest Activity of Daily Living scale (LCADL). *Respir Med*. 2000 Jun;94(6):589-96. doi: 10.1053/rmed.2000.0786. PMID: 10921765.
52. Dougan CF, Connell CO, Thornton E, et al. Development of a patient-specific dyspnoea questionnaire in motor neurone disease (MND): the MND dyspnoea rating scale (MDRS). *J Neurol Sci*. 2000 Nov 1;180(1-2):86-93. PMID: 11090871.
53. Fairbairn AS, Wood CH, Fletcher CM. Variability in answers to a questionnaire on respiratory symptoms. *Br J Prev Soc Med*. 1959 Oct;13:175-93. PMID: 13821340.
54. McGavin CR, Artvinli M, Naoe H, et al. Dyspnoea, disability, and distance walked: comparison of estimates of exercise performance in respiratory disease. *Br Med J*. 1978 Jul 22;2(6132):241-3. PMID: 678885.
55. Lareau SC, Carrieri-Kohlman V, Janson-Bjerklie S, et al. Development and testing of the Pulmonary Functional Status and Dyspnea Questionnaire (PFSDQ). *Heart Lung*. 1994 May-Jun;23(3):242-50. PMID: 8039994.
56. Rosenthal M, Lohr KN, Rubenstein RS, et al. Congestive heart failure. Santa Monica, CA: Rand Corporation; 1981.
57. Jones PW, Quirk FH, Baveystock CM, et al. A self-complete measure of health status for chronic airflow limitation. The St. George's Respiratory Questionnaire. *Am Rev Respir Dis*. 1992 Jun;145(6):1321-7. doi: 10.1164/ajrccm/145.6.1321. PMID: 1595997.
58. Lee L, Friesen M, Lambert IR, et al. Evaluation of dyspnea during physical and speech activities in patients with pulmonary diseases. *Chest*. 1998 Mar;113(3):625-32. PMID: 9515835.
59. Eakin EG, Resnikoff PM, Prewitt LM, et al. Validation of a new dyspnea measure: the UCSD Shortness of Breath Questionnaire. University of California, San Diego. *Chest*. 1998 Mar;113(3):619-24. PMID: 9515834.
60. Abbey JG, Rosenfeld B, Pessin H, et al. Hopelessness at the end of life: the utility of the hopelessness scale with terminally ill cancer patients. *Br J Health Psychol*. 2006 May;11(Pt 2):173-83. doi: 10.1348/135910705x36749. PMID: 16643692.
61. Ironson G, Solomon GF, Balbin EG, et al. The Ironson-woods Spirituality/Religiousness Index is associated with long survival, health behaviors, less distress, and low cortisol in people with HIV/AIDS. *Ann Behav Med*. 2002 Winter;24(1):34-48. PMID: 12008793.
62. Lloyd-Williams M, Shiels C, Dowrick C. The development of the Brief Edinburgh Depression Scale (BEDS) to screen for depression in patients with advanced cancer. *J Affect Disord*. 2007 Apr;99(1-3):259-64. doi: 10.1016/j.jad.2006.09.015. PMID: 17055588.
63. Akechi T, Okuyama T, Sugawara Y, et al. Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol*. 2004 May 15;22(10):1957-65. doi: 10.1200/jco.2004.08.149. PMID: 15143090.
64. Thekkumpurath P, Venkateswaran C, Kumar M, et al. Screening for psychological distress in palliative care: performance of touch screen questionnaires compared with semistructured psychiatric interview. *J Pain Symptom Manage*. 2009 Oct;38(4):597-605. doi: 10.1016/j.jpainsymman.2009.01.004. PMID: 19692204.

65. Love AW, Grabsch B, Clarke DM, et al. Screening for depression in women with metastatic breast cancer: a comparison of the Beck Depression Inventory Short Form and the Hospital Anxiety and Depression Scale. *Aust N Z J Psychiatry*. 2004 Jul;38(7):526-31. doi: 10.1111/j.1440-1614.2004.01385.x. PMID: 15255825.
66. Okamura M, Yamawaki S, Akechi T, et al. Psychiatric disorders following first breast cancer recurrence: prevalence, associated factors and relationship to quality of life. *Jpn J Clin Oncol*. 2005 Jun;35(6):302-9. doi: 10.1093/jjco/hyi097. PMID: 15961434.
67. Dumont S, Fillion L, Gagnon P, et al. A new tool to assess family caregivers' burden during end-of-life care. *J Palliat Care*. 2008 Autumn;24(3):151-61. PMID: 18942565.
68. Cameron JI, Franche RL, Cheung AM, et al. Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*. 2002 Jan 15;94(2):521-7. doi: 10.1002/cncr.10212. PMID: 11900237.
69. Weitzner MA, McMillan SC, Jacobsen PB. Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage*. 1999 Jun;17(6):418-28. PMID: 10388247.
70. Hudson PL, Hayman-White K. Measuring the psychosocial characteristics of family caregivers of palliative care patients: psychometric properties of nine self-report instruments. *J Pain Symptom Manage*. 2006 Mar;31(3):215-28. doi: 10.1016/j.jpainsymman.2005.07.010. PMID: 16563316.
71. Hwang SS, Chang VT, Alejandro Y, et al. Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliat Support Care*. 2003 Dec;1(4):319-29. PMID: 16594221.
72. Cooper B, Kinsella GJ, Picton C. Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psychooncology*. 2006 Jul;15(7):613-22. doi: 10.1002/pon.1001. PMID: 16287207.
73. Cohen R, Leis AM, Kuhl D, et al. QOLLTI-F: measuring family carer quality of life. *Palliat Med*. 2006 Dec;20(8):755-67. doi: 10.1177/0269216306072764. PMID: 17148530.
74. Higginson IJ, Gao W, Jackson D, et al. Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *J Clin Epidemiol*. 2010 May;63(5):535-42. doi: 10.1016/j.jclinepi.2009.06.014. PMID: 19836205.
75. Rosenfeld B, Gibson C, Kramer M, et al. Hopelessness and terminal illness: the construct of hopelessness in patients with advanced AIDS. *Palliat Support Care*. 2004 Mar;2(1):43-53. PMID: 16594234.
76. Nissim R, Flora DB, Cribbie RA, et al. Factor structure of the Beck Hopelessness Scale in individuals with advanced cancer. *Psychooncology*. 2010 Mar;19(3):255-63. doi: 10.1002/pon.1540. PMID: 19274620.
77. Guarnaccia CA, B H. Factor structure of the bereavement experience questionnaire: the BEQ-24, a revised short-form. *Omega*. 1998;37:303-16.
78. Shear KM, Jackson CT, Essock SM, et al. Screening for complicated grief among Project Liberty service recipients 18 months after September 11, 2001. *Psychiatr Serv*. 2006 Sep;57(9):1291-7. doi: 10.1176/appi.ps.57.9.1291. PMID: 16968758.
79. Ito M, Nakajima S, Fujisawa D, et al. Brief measure for screening complicated grief: reliability and discriminant validity. *PLoS One*. 2012;7(2):e31209. doi: 10.1371/journal.pone.0031209. PMID: 22348057.
80. Fujisawa D, Miyashita M, Nakajima S, et al. Prevalence and determinants of complicated grief in general population. *J Affect Disord*. 2010 Dec;127(1-3):352-8. doi: 10.1016/j.jad.2010.06.008. PMID: 20580096.

81. Burnett P, Middleton W, Raphael B, et al. Measuring core bereavement phenomena. *Psychol Med*. 1997 Jan;27(1):49-57. PMID: 9122308.
82. Jordan JR, Baker J, Matteis M, et al. The grief evaluation measure (GEM): an initial validation study. *Death Stud*. 2005 May;29(4):301-32. doi: 10.1080/07481180590923706. PMID: 15849881.
83. Barrett TW, Scott TB. Development of the Grief Experience Questionnaire. *Suicide Life Threat Behav*. 1989 Summer;19(2):201-15. PMID: 2749862.
84. Hogan NS, Greenfield DB, Schmidt LA. Development and validation of the Hogan Grief Reaction Checklist. *Death Stud*. 2001 Jan-Feb;25(1):1-32. doi: 10.1080/07481180125831. PMID: 11503760.
85. Prigerson HG, Maciejewski PK, Reynolds CF, 3rd, et al. Inventory of Complicated Grief: a scale to measure maladaptive symptoms of loss. *Psychiatry Res*. 1995 Nov 29;59(1-2):65-79. PMID: 8771222.
86. Prigerson HG, Horowitz MJ, Jacobs SC, et al. Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Med*. 2009 Aug;6(8):e1000121. doi: 10.1371/journal.pmed.1000121. PMID: 19652695.
87. O'Connor M, Lasgaard M, Shevlin M, et al. A confirmatory factor analysis of combined models of the Harvard Trauma Questionnaire and the Inventory of Complicated Grief-Revised: are we measuring complicated grief or posttraumatic stress? *J Anxiety Disord*. 2010 Oct;24(7):672-9. doi: 10.1016/j.janxdis.2010.04.009. PMID: 20510576.
88. Guldin MB, O'Connor M, Sokolowski I, et al. Identifying bereaved subjects at risk of complicated grief: Predictive value of questionnaire items in a cohort study. *BMC Palliat Care*. 2011;10:9. doi: 10.1186/1472-684x-10-9. PMID: 21575239.
89. Prigerson HG, SC J. Traumatic grief as a distinct disorder: a rationale, consensus criteria, and a preliminary empirical test. In: Stroebe MS, Hansson RO, Stroebe W, et al. (eds) *Handbook of bereavement research: consequences, coping, and care*. Washington, DC: American Psychological Association; 2001.
90. Marwit SJ, Meuser TM. Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. *Gerontologist*. 2002 Dec;42(6):751-65. PMID: 12451156.
91. Marwit SJ, Kaye PN. Measuring grief in caregivers of persons with acquired brain injury. *Brain Inj*. 2006 Dec;20(13-14):1419-29. PMID: 17378234.
92. Marwit SJ, Chibnall JT, Dougherty R, et al. Assessing pre-death grief in cancer caregivers using the Marwit-Meuser Caregiver Grief Inventory (MM-CGI). *Psychooncology*. 2008 Mar;17(3):300-3. doi: 10.1002/pon.1218. PMID: 17518412.
93. Marwit SJ, Meuser TM. Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Stud*. 2005 Apr;29(3):191-205. doi: 10.1080/07481180590916335. PMID: 15816111.
94. Kiely DK, Prigerson H, Mitchell SL. Health care proxy grief symptoms before the death of nursing home residents with advanced dementia. *Am J Geriatr Psychiatry*. 2008 Aug;16(8):664-73. doi: 10.1097/JGP.0b013e3181784143. PMID: 18669945.
95. Lai C, Luciani M, Morelli E, et al. Predictive role of different dimensions of burden for risk of complicated grief in caregivers of terminally ill patients. *Am J Hosp Palliat Care*. 2014 Mar;31(2):189-93. doi: 10.1177/1049909113490227. PMID: 23689368.
96. Lichtenthal WG, Nilsson M, Kissane DW, et al. Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatr Serv*. 2011

- Oct;62(10):1225-9. doi: 10.1176/appi.ps.62.10.1225
10.1176/ps.62.10.pss6210_1225. PMID: 21969652.
97. Papa A, Lancaster NG, Kahler J. Commonalities in grief responding across bereavement and non-bereavement losses. *J Affect Disord.* 2014 Jun;161:136-43. doi: 10.1016/j.jad.2014.03.018. PMID: 24751321.
98. Lev E, Munro BH, McCorkle R. A shortened version of an instrument measuring bereavement. *Int J Nurs Stud.* 1993 Jun;30(3):213-26. PMID: 8335431.
99. Faschingbauer T, DeVaul RA, S Z. The Texas Revised Inventory of Grief. In: Zisook S (ed.) *Biopsychosocial aspects of bereavement.* Washington, DC: American Psychiatric Press, Inc.; 1987.
100. Zisook S, Devaul RA, Click MA, Jr. Measuring symptoms of grief and bereavement. *Am J Psychiatry.* 1982 Dec;139(12):1590-3. doi: 10.1176/ajp.139.12.1590. PMID: 7149059.
101. Faschingbauer TR, Devaul RA, Zisook S. Development of the Texas Inventory of Grief. *Am J Psychiatry.* 1977 Jun;134(6):696-8. doi: 10.1176/ajp.134.6.696. PMID: 869041.
102. Futterman A, Holland JM, Brown PJ, et al. Factorial validity of the Texas Revised Inventory of Grief-Present scale among bereaved older adults. *Psychol Assess.* 2010 Sep;22(3):675-87. doi: 10.1037/a0019914. PMID: 20822280.
103. Rubin SS, Nadav OB, Malkinson R, et al. The two-track model of bereavement questionnaire (TTBQ): development and validation of a relational measure. *Death Stud.* 2009 Apr;33(4):305-33. doi: 10.1080/07481180802705668. PMID: 19368062.
104. Bar Nadav O, SS R. Assessing complicated grief using the Two-Track Bereavement Questionnaire (TTBQ). The 10th international conference on Grief and Bereavement in Contemporary Society: East meets West expanding frontiers and diversity; 2014 Hong Kong. p. 54.
105. Guo H, Fine PG, Mendoza TR, et al. A preliminary study of the utility of the brief hospice inventory. *J Pain Symptom Manage.* 2001 Aug;22(2):637-48. PMID: 11495710.
106. Ewing G, Todd C, Rogers M, et al. Validation of a symptom measure suitable for use among palliative care patients in the community: CAMPAS-R. *J Pain Symptom Manage.* 2004 Apr;27(4):287-99. doi: 10.1016/j.jpainsymman.2003.12.012. PMID: 15050656.
107. Kissane DW, Wein S, Love A, et al. The Demoralization Scale: a report of its development and preliminary validation. *J Palliat Care.* 2004 Winter;20(4):269-76. PMID: 15690829.
108. Kaasa T, Loomis J, Gillis K, et al. The Edmonton Functional Assessment Tool: preliminary development and evaluation for use in palliative care. *J Pain Symptom Manage.* 1997 Jan;13(1):10-9. PMID: 9029857.
109. Kaasa T, Wessel J. The Edmonton Functional Assessment Tool: further development and validation for use in palliative care. *J Palliat Care.* 2001 Spring;17(1):5-11. PMID: 11324186.
110. Schwartz CE, Merriman MP, Reed GW, et al. Measuring patient treatment preferences in end-of-life care research: applications for advance care planning interventions and response shift research. *J Palliat Med.* 2004 Apr;7(2):233-45. doi: 10.1089/109662104773709350. PMID: 15130201.
111. Blazeby JM, Conroy T, Hammerlid E, et al. Clinical and psychometric validation of an EORTC questionnaire module, the EORTC QLQ-OES18, to assess quality of life in patients with oesophageal cancer. *Eur J Cancer.* 2003 Jul;39(10):1384-94. PMID: 12826041.
112. Blazeby JM, Conroy T, Bottomley A, et al. Clinical and psychometric validation of a questionnaire module, the EORTC QLQ-

- STO 22, to assess quality of life in patients with gastric cancer. *Eur J Cancer*. 2004 Oct;40(15):2260-8. doi: 10.1016/j.ejca.2004.05.023. PMID: 15454251.
113. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. *Cancer*. 2000 May 1;88(9):2164-71. PMID: 10813730.
114. Lyons KD, Bakitas M, Hegel MT, et al. Reliability and validity of the Functional Assessment of Chronic Illness Therapy-Palliative care (FACIT-Pal) scale. *J Pain Symptom Manage*. 2009 Jan;37(1):23-32. doi: 10.1016/j.jpainsymman.2007.12.015. PMID: 18504093.
115. McMillan SC, Weitzner M. Quality of life in cancer patients: use of a revised Hospice Index. *Cancer Pract*. 1998 Sep-Oct;6(5):282-8. PMID: 9767348.
116. McMillan SC, Dunbar SB, W. Z. Validation of the Hospice Quality-of-Life Index and the Constipation Assessment Scale in end-stage cardiac disease patients in hospice care. *J Hosp Palliat Nurs*. 2008;10:106-17.
117. Dobratz MC. The life closure scale: additional psychometric testing of a tool to measure psychological adaptation in death and dying. *Res Nurs Health*. 2004 Feb;27(1):52-62. doi: 10.1002/nur.20003. PMID: 14745856.
118. Salmon P, Manzi F, Valori RM. Measuring the meaning of life for patients with incurable cancer: the life evaluation questionnaire (LEQ). *Eur J Cancer*. 1996 May;32A(5):755-60. PMID: 9081350.
119. Sterkenburg CA, King B, Woodward CA. A reliability and validity study of the McMaster Quality of Life Scale (MQLS) for a palliative population. *J Palliat Care*. 1996 Spring;12(1):18-25. PMID: 8857243.
120. Cohen SR, Mount BM, Bruera E, et al. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. *Palliat Med*. 1997 Jan;11(1):3-20. PMID: 9068681.
121. Cohen SR, Mount BM. Living with cancer: "good" days and "bad" days--what produces them? Can the McGill quality of life questionnaire distinguish between them? *Cancer*. 2000 Oct 15;89(8):1854-65. PMID: 11042583.
122. Lua PL, Salek S, Finlay I, et al. The feasibility, reliability and validity of the McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF) in palliative care population. *Qual Life Res*. 2005 Sep;14(7):1669-81. PMID: 16119179.
123. McCause RP. The McCause Readiness for Death Instrument (MRDI): a reliable and valid measure for hospice care. *Hosp J*. 1995;10(1):15-26. PMID: 7789938.
124. Sherman DW, Ye XY, Beyer McSherry C, et al. Symptom assessment of patients with advanced cancer and AIDS and their family caregivers: the results of a quality-of-life pilot study. *Am J Hosp Palliat Care*. 2007 Oct-Nov;24(5):350-65. doi: 10.1177/1049909106299063. PMID: 17998406.
125. Lobchuk MM. The memorial symptom assessment scale: modified for use in understanding family caregivers' perceptions of cancer patients' symptom experiences. *J Pain Symptom Manage*. 2003 Jul;26(1):644-54. PMID: 12850647.
126. Chang VT, Hwang SS, Kasimis B, et al. Shorter symptom assessment instruments: the Condensed Memorial Symptom Assessment Scale (CMSAS). *Cancer Invest*. 2004;22(4):526-36. PMID: 15565810.
127. Hickman SE, Tilden VP, Tolle SW. Family reports of dying patients' distress: the adaptation of a research tool to assess global symptom distress in the last week of life. *J Pain Symptom Manage*. 2001 Jul;22(1):565-74. PMID: 11516598.
128. Byock IR, Merriman MP. Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index.

- Palliat Med. 1998 Jul;12(4):231-44. PMID: 9743822.
129. Schwartz CE, Merriman MP, Reed G, et al. Evaluation of the Missoula-VITAS Quality of Life Index--revised: research tool or clinical tool? *J Palliat Med.* 2005 Feb;8(1):121-35. doi: 10.1089/jpm.2005.8.121. PMID: 15662181.
130. Rainbird KJ, Perkins JJ, Sanson-Fisher RW. The Needs Assessment for Advanced Cancer Patients (NA-ACP): a measure of the perceived needs of patients with advanced, incurable cancer. a study of validity, reliability and acceptability. *Psychooncology.* 2005 Apr;14(4):297-306. doi: 10.1002/pon.845. PMID: 15386766.
131. Vernooij-Dassen MJ, Osse BH, Schade E, et al. Patient autonomy problems in palliative care: systematic development and evaluation of a questionnaire. *J Pain Symptom Manage.* 2005 Sep;30(3):264-70. doi: 10.1016/j.jpainsymman.2005.03.010. PMID: 16183010.
132. Chochinov HM, Hassard T, McClement S, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *J Pain Symptom Manage.* 2008 Dec;36(6):559-71. doi: 10.1016/j.jpainsymman.2007.12.018. PMID: 18579340.
133. Osse BH, Vernooij MJ, Schade E, et al. Towards a new clinical tool for needs assessment in the palliative care of cancer patients: the PNPC instrument. *J Pain Symptom Manage.* 2004 Oct;28(4):329-41. doi: 10.1016/j.jpainsymman.2004.01.010. PMID: 15471650.
134. Osse BH, Vernooij-Dassen MJ, Schade E, et al. A practical instrument to explore patients' needs in palliative care: the Problems and Needs in Palliative Care questionnaire short version. *Palliat Med.* 2007 Jul;21(5):391-9. doi: 10.1177/0269216307078300. PMID: 17901098.
135. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. *Qual Health Care.* 1999 Dec;8(4):219-27. PMID: 10847883.
136. Curtis JR, Patrick DL, Engelberg RA, et al. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage.* 2002 Jul;24(1):17-31. PMID: 12183092.
137. Steinhauer KE, Clipp EC, Bosworth HB, et al. Measuring quality of life at the end of life: validation of the QUAL-E. *Palliat Support Care.* 2004 Mar;2(1):3-14. PMID: 16594230.
138. Hermann C. Development and testing of the spiritual needs inventory for patients near the end of life. *Oncol Nurs Forum.* 2006 Jul;33(4):737-44. doi: 10.1188/06.onf.737-744. PMID: 16858454.
139. Arcand M, Monette J, Monette M, et al. Educating nursing home staff about the progression of dementia and the comfort care option: impact on family satisfaction with end-of-life care. *J Am Med Dir Assoc.* 2009 Jan;10(1):50-5. doi: 10.1016/j.jamda.2008.07.008. PMID: 19111853.
140. Baker R, Wu AW, Teno JM, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc.* 2000 May;48(5 Suppl):S61-9. PMID: 10809458.
141. Bakitas M, Ahles TA, Skalla K, et al. Proxy perspectives regarding end-of-life care for persons with cancer. *Cancer.* 2008 Apr 15;112(8):1854-61. doi: 10.1002/cncr.23381. PMID: 18306393.
142. Cohen LW, van der Steen JT, Reed D, et al. Family perceptions of end-of-life care for long-term care residents with dementia: differences between the United States and the Netherlands. *J Am Geriatr Soc.* 2012 Feb;60(2):316-22. doi: 10.1111/j.1532-5415.2011.03816.x. PMID: 22288500.
143. Gelfman LP, Meier DE, Morrison RS. Does palliative care improve quality? A survey of bereaved family members. *J Pain Symptom Manage.* 2008 Jul;36(1):22-8. doi:

- 10.1016/j.jpainsymman.2007.09.008. PMID: 18411019.
144. Hallenbeck J, Hickey E, Czarnowski E, et al. Quality of care in a Veterans Affairs' nursing home-based hospice unit. *J Palliat Med.* 2007 Feb;10(1):127-35. doi: 10.1089/jpm.2006.0141. PMID: 17298261.
145. Shega JW, Hougham GW, Stocking CB, et al. Patients dying with dementia: experience at the end of life and impact of hospice care. *J Pain Symptom Manage.* 2008 May;35(5):499-507. doi: 10.1016/j.jpainsymman.2007.06.011. PMID: 18261878.
146. Teno JM, Clarridge B, Casey V, et al. Validation of Toolkit After-Death Bereaved Family Member Interview. *J Pain Symptom Manage.* 2001 Sep;22(3):752-8. PMID: 11532588.
147. Kiely DK, Volicer L, Teno J, et al. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord.* 2006 Jul-Sep;20(3):176-81. PMID: 16917188.
148. van der Steen JT, Gijsberts MJ, Muller MT, et al. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *Int Psychogeriatr.* 2009 Apr;21(2):321-9. doi: 10.1017/s1041610208008399. PMID: 19193253.
149. Alici Y, Smith D, Lu HL, et al. Families' perceptions of veterans' distress due to post-traumatic stress disorder-related symptoms at the end of life. *J Pain Symptom Manage.* 2010 Mar;39(3):507-14. doi: 10.1016/j.jpainsymman.2009.07.011. PMID: 20083372.
150. Casarett D, Shreve S, Luhrs C, et al. Measuring families' perceptions of care across a health care system: preliminary experience with the Family Assessment of Treatment at End of Life Short form (FATE-S). *J Pain Symptom Manage.* 2010 Dec;40(6):801-9. doi: 10.1016/j.jpainsymman.2010.03.019. PMID: 20813493.
151. Finlay E, Shreve S, Casarett D. Nationwide veterans affairs quality measure for cancer: the family assessment of treatment at end of life. *J Clin Oncol.* 2008 Aug 10;26(23):3838-44. doi: 10.1200/jco.2008.16.8534. PMID: 18688050.
152. Lu H, Trancik E, Bailey FA, et al. Families' perceptions of end-of-life care in Veterans Affairs versus non-Veterans Affairs facilities. *J Palliat Med.* 2010 Aug;13(8):991-6. doi: 10.1089/jpm.2010.0044. PMID: 20649437.
153. Smith D, Caragian N, Kazlo E, et al. Can we make reports of end-of-life care quality more consumer-focused? results of a nationwide quality measurement program. *J Palliat Med.* 2011 Mar;14(3):301-7. doi: 10.1089/jpm.2010.0321. PMID: 21288125.
154. Connor SR, Teno J, Spence C, et al. Family evaluation of hospice care: results from voluntary submission of data via website. *J Pain Symptom Manage.* 2005 Jul;30(1):9-17. doi: 10.1016/j.jpainsymman.2005.04.001. PMID: 16043002.
155. Mitchell SL, Kiely DK, Miller SC, et al. Hospice care for patients with dementia. *J Pain Symptom Manage.* 2007 Jul;34(1):7-16. doi: 10.1016/j.jpainsymman.2007.01.003. PMID: 17509813.
156. Rhodes RL, Mitchell SL, Miller SC, et al. Bereaved family members' evaluation of hospice care: what factors influence overall satisfaction with services? *J Pain Symptom Manage.* 2008 Apr;35(4):365-71. doi: 10.1016/j.jpainsymman.2007.12.004. PMID: 18294811.
157. Rhodes RL, Teno JM, Connor SR. African American bereaved family members' perceptions of the quality of hospice care: lessened disparities, but opportunities to improve remain. *J Pain Symptom Manage.* 2007 Nov;34(5):472-9. doi: 10.1016/j.jpainsymman.2007.06.004. PMID: 17900854.

158. Schockett ER, Teno JM, Miller SC, et al. Late referral to hospice and bereaved family member perception of quality of end-of-life care. *J Pain Symptom Manage*. 2005 Nov;30(5):400-7. doi: 10.1016/j.jpainsymman.2005.04.013. PMID: 16310614.
159. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004 Jan 7;291(1):88-93. doi: 10.1001/jama.291.1.88. PMID: 14709580.
160. Teno JM, Shu JE, Casarett D, et al. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage*. 2007 Aug;34(2):120-5. doi: 10.1016/j.jpainsymman.2007.04.014. PMID: 17583469.
161. York GS, Jones JL, Churchman R. Understanding the association between employee satisfaction and family perceptions of the quality of care in hospice service delivery. *J Pain Symptom Manage*. 2009 Nov;38(5):708-16. doi: 10.1016/j.jpainsymman.2009.03.002. PMID: 19699608.
162. Curtis JR, Treece PD, Nielsen EL, et al. Integrating palliative and critical care: evaluation of a quality-improvement intervention. *Am J Respir Crit Care Med*. 2008 Aug 1;178(3):269-75. doi: 10.1164/rccm.200802-272OC. PMID: 18480429.
163. Gries CJ, Curtis JR, Wall RJ, et al. Family member satisfaction with end-of-life decision making in the ICU. *Chest*. 2008 Mar;133(3):704-12. doi: 10.1378/chest.07-1773. PMID: 18198256.
164. Lewis-Newby M, Curtis JR, Martin DP, et al. Measuring family satisfaction with care and quality of dying in the intensive care unit: does patient age matter? *J Palliat Med*. 2011 Dec;14(12):1284-90. doi: 10.1089/jpm.2011.0138. PMID: 22107108.
165. Aoun S, Bird S, Kristjanson LJ, et al. Reliability testing of the FAMCARE-2 scale: measuring family carer satisfaction with palliative care. *Palliat Med*. 2010 Oct;24(7):674-81. doi: 10.1177/0269216310373166. PMID: 20621947.
166. Carter GL, Lewin TJ, Gianacas L, et al. Caregiver satisfaction with out-patient oncology services: utility of the FAMCARE instrument and development of the FAMCARE-6. *Support Care Cancer*. 2011 Apr;19(4):565-72. doi: 10.1007/s00520-010-0858-1. PMID: 20349317.
167. Lo C, Burman D, Hales S, et al. The FAMCARE-Patient scale: measuring satisfaction with care of outpatients with advanced cancer. *Eur J Cancer*. 2009 Dec;45(18):3182-8. doi: 10.1016/j.ejca.2009.09.003. PMID: 19786345.
168. Lo C, Burman D, Rodin G, et al. Measuring patient satisfaction in oncology palliative care: psychometric properties of the FAMCARE-patient scale. *Qual Life Res*. 2009 Aug;18(6):747-52. doi: 10.1007/s11136-009-9494-y. PMID: 19513815.
169. Ringdal GI, Jordhoy MS, Kaasa S. Measuring quality of palliative care: psychometric properties of the FAMCARE Scale. *Qual Life Res*. 2003 Mar;12(2):167-76. PMID: 12639063.
170. Follwell M, Burman D, Le LW, et al. Phase II study of an outpatient palliative care intervention in patients with metastatic cancer. *J Clin Oncol*. 2009 Jan 10;27(2):206-13. doi: 10.1200/jco.2008.17.7568. PMID: 19064979.
171. Kristjanson LJ, Leis A, Koop PM, et al. Family members' care expectations, care perceptions, and satisfaction with advanced cancer care: results of a multi-site pilot study. *J Palliat Care*. 1997 Winter;13(4):5-13. PMID: 9447806.
172. Meyers JL, Gray LN. The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncol Nurs*

- Forum. 2001 Jan-Feb;28(1):73-82. PMID: 11198900.
173. Mularski R, Curtis JR, Osborne M, et al. Agreement among family members in their assessment of the Quality of Dying and Death. *J Pain Symptom Manage*. 2004 Oct;28(4):306-15. doi: 10.1016/j.jpainsymman.2004.01.008. PMID: 15471648.
174. Hales S, Gagliese L, Nissim R, et al. Understanding bereaved caregiver evaluations of the quality of dying and death: an application of cognitive interviewing methodology to the quality of dying and death questionnaire. *J Pain Symptom Manage*. 2012 Feb;43(2):195-204. doi: 10.1016/j.jpainsymman.2011.03.018. PMID: 21802895.
175. Johnson KS, Elbert-Avila K, Kuchibhatla M, et al. Racial differences in next-of-kin participation in an ongoing survey of satisfaction with end-of-life care: a study of a study. *J Palliat Med*. 2006 Oct;9(5):1076-85. doi: 10.1089/jpm.2006.9.1076. PMID: 17040145.
176. Mularski RA, Heine CE, Osborne ML, et al. Quality of dying in the ICU: ratings by family members. *Chest*. 2005 Jul;128(1):280-7. doi: 10.1378/chest.128.1.280. PMID: 16002947.
177. Norris K, Merriman MP, Curtis JR, et al. Next of kin perspectives on the experience of end-of-life care in a community setting. *J Palliat Med*. 2007 Oct;10(5):1101-15. doi: 10.1089/jpm.2006.2546. PMID: 17985967.
178. Astrow AB, Wexler A, Texeira K, et al. Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? *J Clin Oncol*. 2007 Dec 20;25(36):5753-7. doi: 10.1200/jco.2007.12.4362. PMID: 18089871.
179. Sulmasy DP, McIlvane JM. Patients' ratings of quality and satisfaction with care at the end of life. *Arch Intern Med*. 2002 Oct 14;162(18):2098-104. PMID: 12374518.
180. Sulmasy DP, McIlvane JM, Pasley PM, et al. A scale for measuring patient perceptions of the quality of end-of-life care and satisfaction with treatment: the reliability and validity of QUEST. *J Pain Symptom Manage*. 2002 Jun;23(6):458-70. PMID: 12067770.
181. COSMIN: consensus-based standards for the selection of health measurement instruments. Vrije Universiteit Medisch Centrum. <http://www.cosmin.nl/> Accessed on August 19, 2016.