

Appendix A: List of Acronyms

Table A-1: List of acronyms.

Acronym	Definition
AHRQ	Agency for Healthcare Research and Quality
AIDS	Acquired Immune Deficiency Syndrome
ALSFRS-R	Amyotrophic lateral sclerosis functional rating scale
ATS-DLD-78	American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale
BCOS	Bakas Caregiving Outcomes Scale
BCSS	Breathlessness, Cough and Sputum Scale
BDI	Beck Depression Inventory
BEQ-24	Bereavement Experience Questionnaire–24
BGQ	Brief Grief Questionnaire
BHI	Brief Hospice Inventory
BHS	Beck Hopelessness Scale
BIC	Burden Index of Caregivers
CAMPAS-R	Cambridge Palliative Audit Schedule
CBI	Core Bereavement Items
CBS-EOLC	Caregiver's Burden Scale in end-of-life care
CES-D	Center for Epidemiologic Studies Depression scale
CHQ	Chronic Heart Failure Questionnaire
CI	Confidence Interval
CIS	Caregiver Impact Scale
CLASP	Cardiovascular Limitations and Symptoms Profile
CLD	Chronic Lung Disease Severity Index
CMSAS	Condensed Memorial Symptom Assessment Scale
COPD	Chronic obstructive pulmonary disease
CQOLI	Caregiver Quality of Life Index
CQOLI-C	Caregiver Quality of Life Index – Cancer
CQOLI-R	Caregiver Quality of Life Index – Revised
CRA	Caregiver Reaction Assessment
CRQ	Chronic Respiratory Questionnaire
CSI	Caregiver Strain Index
DAQ	Dyspnea Assessment Questionnaire
DDQ	Dyspnea Descriptor Questionnaire
DS	Demoralization Scale
EFAT and EFAT-2	Edmonton Functional Assessment Tool
EORTC QLQ-ST022	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module
EORTC-QLQ	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire
EPC	Evidence-based Practice Center
ESAS	Edmonton Symptom Assessment Scale
Faces	Faces scale
FACIT	Functional Assessment of Chronic Illness Therapy
FACIT-Pal	Functional Assessment of Chronic Illness Therapy-Palliative sub scale
FACIT-L	Functional Assessment of Chronic Illness Therapy-Lung
FACQ-PC	Family Appraisal of Caregiving Questionnaire for Palliative Care
FAMCARE	Family Satisfaction with Advanced Cancer Care
GEM	Grief Evaluation Measure
GEQ	Grief Experience Questionnaire
GHQ-12	General Health Questionnaire-12 item
Global SOB	Global shortness of breath question
HADS	Hospital Anxiety and Depression Scale
HGRC	Hogan Grief Reaction Checklist
HIV	Human Immunodeficiency Virus

HQLI	Hospice Quality of Life Index
ICG	Inventory of Complicated Grief
ICG-R	Inventory of Complicated Grief-Revised
IES	Impact of Event Scale
IPC	Sat-Fam
ITG	Inventory of Traumatic Grief
I-W SR Index Short Form	Ironson-Woods Spirituality/Religiousness Index
KI	Key Informant
KQ	Key Question
LCADL	London Chest Activity of Daily Living Scale
LCS	Life Closure Scale
LEQ	Life Evaluation Questionnaire
MBCBS	Montgomery Borgatta Caregiver Burden Scale
mBORG	Modified Borg Scale
MDRS-D	Motor Neurone Disease Dyspnea Rating Scale
MMCGI	Marwit-Meuser Caregiver Grief Inventory
MND	Motor neuron disease
MPAC	Memorial Pain Assessment Card
MQLS	McMaster Quality of Life Scale
MQOL	McGill Quality of Life Questionnaire
MQOL-CSF	McGill Quality of Life Questionnaire-Cardiff Short Form
MRC	Medical Research Council Dyspnea Scale
MRDI	McCanse Readiness for Death Instrument
MSAS	Memorial Symptom Assessment Scale
MSAS-GDI	Memorial Symptom Assessment Scale-Global Distress Index
MVQOLI-R	Missoula-VITAS Quality of Life Index
NA	Not applicable
NA-ACP	Needs Assessment for Advanced Cancer Patients
NCP	National Consensus Project for Quality Palliative Care Clinical Practice
ND	Not described in the systematic review
NRS	Numeric rating scale
NS	Not Significant
OCD	Oxygen cost diagram
PASS	Pain Anxiety Symptoms Scale
PAQ	Patient Autonomy Questionnaire
PDI	Patient Dignity Inventory
PEACE	"Prepare, Embrace, Attend, Communicate, Empower" project
PFSDQ-M	Pulmonary Functional Status and Dyspnea Questionnaire-modified
PG-12	Prolonged Grief-12
PG-13	Prolonged Grief-13
PNPC	Problems and Needs in Palliative Care questionnaire
PNPCsv	Problems and Needs in Palliative Care short version
POS	Palliative care Outcome Scale
PSE	Present State Examination
QODD	Quality of Dying and Death questionnaire
QOLLTI-F	Quality of Life in Life-Threatening Illness-Family Carer Version
QUAL-E	Quality of Life at the end of life
RDCQ	Reactions to the Diagnosis of Cancer Questionnaire
R-GEI	Revised Grief Experience Inventory
ROBIS	Risk of Bias in Systematic Reviews
RSCD	Regional Study of Care for the Dying
SGRO	St George's Respiratory Questionnaire (activity subscale)
SMD	Standardized Mean Difference
SNI	Spiritual Needs Inventory
SQ	The Symptom Questionnaire
SS-SOBS	Symptom Scale (shortness of breath subscale)
STAI	State-Trait Anxiety Inventory
TIME	Toolkit of Instruments to Measure End-of-Life Care

TOO	Task Order Officer
TRIG	Texas Revised Inventory of Grief
TTBQ	Two-Track Bereavement Questionnaire
TTBQ2-CG30	Two-Track Bereavement Questionnaire
TQPM	Cancer Total Quality Pain Management Patient Assessment Tool
UCDQ	University of Cincinnati Dyspnea Questionnaire
UCSD SOBQ	University of California San Diego Shortness of Breath Questionnaire
VAS	Visual analogue scale
WHO	World Health Organization
ZBI	Zarit Burden Inventory

Appendix B. Glossary of Terms Used to Describe Tools

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

Table B-1. Glossary of terms.

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

Appendix C: Key Informant Questions

Questions for Patient Advocates:

1. What are key elements of high quality palliative care from your perspective?
2. Have you ever as a caregiver (or has the person you were caring for) been asked to fill out or asked questions from an assessment tool or survey, such as ratings of symptoms or a questionnaire about your experience with palliative care?
 - If yes:
 - Were the questions meaningful?
 - Did the questions lead to a better experience?
 - If no:
 - Why?
3. Based on your experiences, what do doctors and palliative care staff need to know from the patient or caregiver that can be captured in a questionnaire or similar tool?
4. Are there key things missing from the domains below that patients/ caregivers should be asked about?
5. Based on your experiences, do you have any other thoughts about how these tools or surveys should or should not be used in palliative care?

These are the domains:

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

Questions for Providers:

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

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

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

Appendix D: Detailed Search Strategy

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

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

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

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

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

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

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

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

Appendix E: ROBIS Assessment

Table E-1: Summary of ROBIS assessments.

	Author, year	Domain 1: Study eligibility criteria	Domain 2: Identification and selection of studies	Domain 3: Data collection and study appraisal	Domain 4: Synthesis and findings	Risk of Bias in the Review
Physical (N=5)						
	Allsop, 2015 ¹	Low	Unclear	Unclear	Unclear	Unclear
	Ben-Aharon, 2008 ²	Low	Low	High	Unclear	Unclear
	Dorman, 2007* ³	Low	Low	Unclear	Low	Low
	Gilbertson-White, 2011 ⁴	High	High	High	High.	High
	Hjermstad, 2008 ⁵	Low	High	High	Unclear	High
Psychosocial and Psychiatric (N=10)						
	Hosie, 2013 ⁶	High	Unclear	Unclear	Unclear	Unclear
	Kayser, 2012 ⁷	Low	Low	Unclear	Unclear	Unclear
	Leonard, 2014 ⁸	High	High	Unclear	Unclear	High
	Lockett, 2010 ⁹	Low	Unclear	Unclear	Low	Unclear
	Mitchell, 2010 ¹⁰	Low	Unclear	Unclear	Low	Unclear
	Mitchell, 2012 ¹¹	Low	Low	Unclear	Unclear	Unclear
	Thekkumpurath, 2008 ¹²	Low	Unclear	High	Low	High
	Vodermaier, 2009 ¹³	Low	Low	High	Low	High
	Wakefield, 2015 ¹⁴	Low	Low	Low	Low	Low
	Ziegler, 2011* ¹⁵	Low	Low	Low	Low	Low
Social (N=2)						
	Hudson, 2010 ¹⁶	Low	Low	Unclear	Unclear	Low
	Michels, 2016* ¹⁷	Low	Low	Low	Unclear	Low
Spiritual, Religious, and Existential (N=7)						
	Best, 2015 ¹⁸	Low	Low	Unclear	Low	Low
	Brandstatter, 2012 ¹⁹	High	Unclear	Unclear	Unclear	High
	Gijsberts, 2011 ²⁰	High	Unclear	Unclear	Unclear	Unclear
	Harding, 2012 ²¹	Unclear	Unclear	Unclear	Unclear	Unclear
	Krikorian, 2013 ²²	Low	Low	Unclear	Low	Low
	Selman, 2011* ²³	Low	Low	Low	Low	Low
	Selman, 2011 ²⁴	Low	Low	Low	Low	Low
Care of the Patient at the End-of-Life (N=1)						
	Sealey, 2015* ²⁵ 37	Unclear	Low	Low	Low	Low

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

	Author, year	Domain 1: Study eligibility criteria	Domain 2: Identification and selection of studies	Domain 3: Data collection and study appraisal	Domain 4: Synthesis and findings	Risk of Bias in the Review
Multidimensional (N=11)						
	Albers, 2010 ^{*26}	Low	Low	Low	Unclear	Low
	Bausewein, 2011 ²⁷	Low	Low	High	Unclear	Unclear
	Chiu, 2014 ²⁸	Unclear	High	High	Unclear	High
	Hermans, 2014 ²⁹	Low	Low	Low	Unclear	Unclear
	Jordhoy, 2007 ³⁰	Unclear	Unclear	Unclear	Unclear	High
	Lendon, 2015 ^{*31}	Low	Low	Unclear	Low	Low
	Mularski, 2007 ³²	Low	Low	High	Unclear	Unclear
	Paiva, 2014 ³³	Low	Low	Low	Unclear	Unclear
	Parker, 2011 ³⁴	Unclear	Low	Unclear	Unclear	Unclear
	Pearson, 2007 ³⁵	Low	High	High	High	High
	Stiel, 2012 ³⁶	Low	Unclear	Unclear	Unclear	Unclear
Reviews of Clinical Care Tools (N=2)						
	Antunes, 2014 ^{*37}	Low	Low	Unclear	Low	Low
	Wasteson, 2009 ³⁸	Low	High	Unclear	Unclear	Unclear
Reviews of Quality Indicators (N=3)						
	Bausewein, 2011 ²⁷	Low	Low	High	Unclear	Unclear
	De Roo, 2013 ^{*39}	Low	Low	Unclear	Unclear	Low
	Pasman, 2009 ⁴⁰	Low	Low	Unclear	Unclear	Unclear

* Systematic review included in the report.

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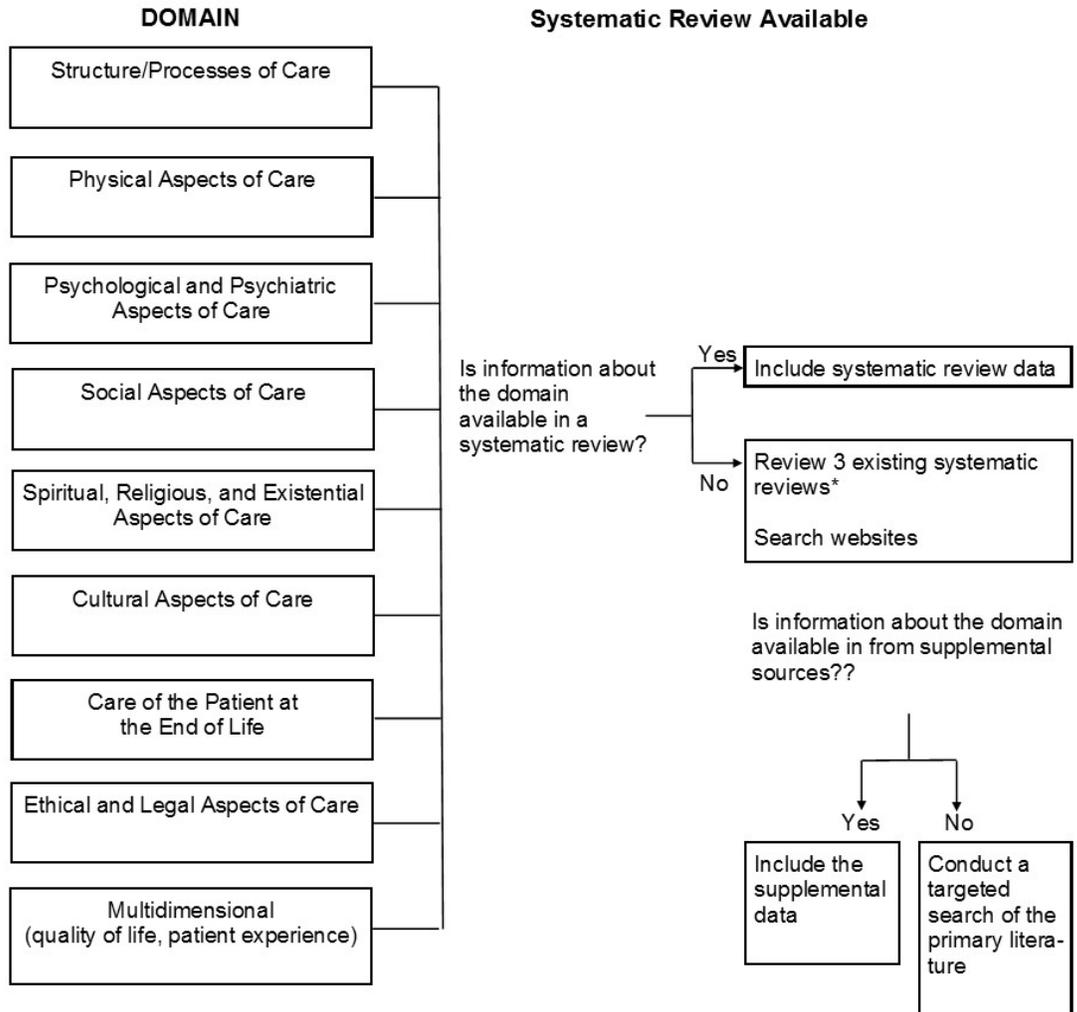
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Appendix F: Inclusion Criteria for the Systematic Review

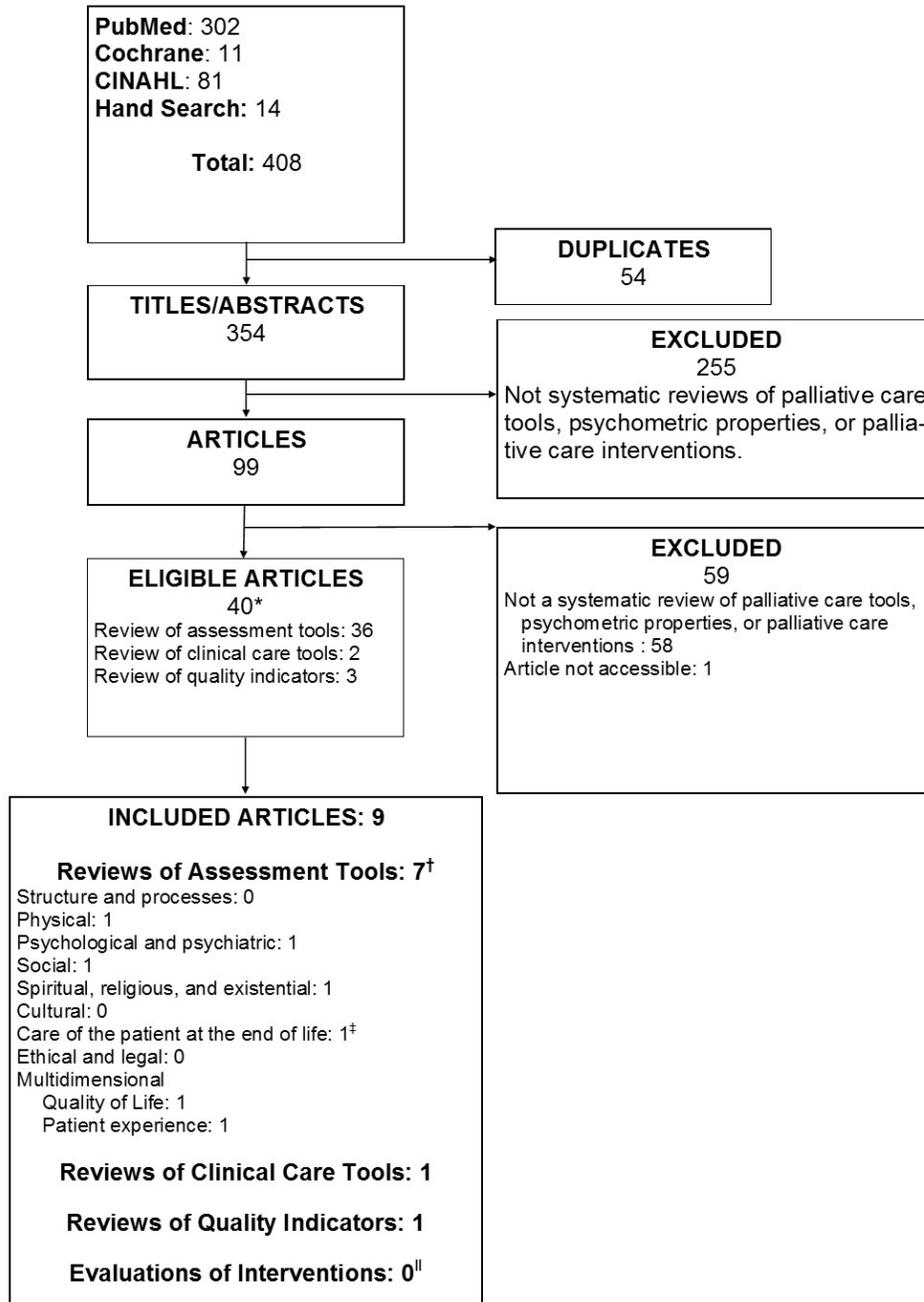
	Criteria
Content	Evaluates palliative care assessment tools used in palliative care in the areas of (1) clinical practice, (2) quality indicators, (3) evaluation of interventions
Population	Tools developed, evaluated, or implemented in populations defined as palliative care or meeting the definition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

Appendix G: Systematic Review Search Flow



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

Appendix H: Results of the Literature Search



* Sum of the articles exceeds 40 because some reviews could be categorized in more than one way.
 † Sum of included articles exceeds 7 because some reviews could be categorized in more than one way.
 ‡ The review of the literature identified a scoping review on the domain: Care of the patient at the end of life.
 † Information for this domain obtained from an outside expert.

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

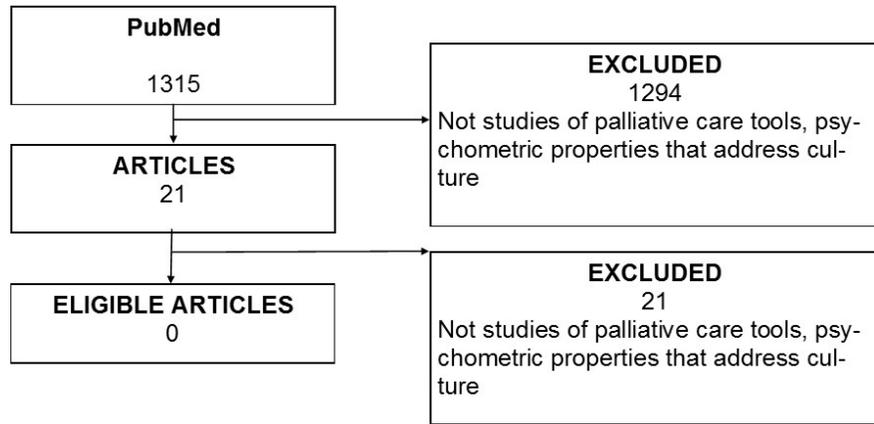


Figure H-2: Results of the additional literature search to identify primary article addressing culture.

Appendix I: Palliative Care Tools Master List

List of Palliative Care Tools Used Arranged by Domain:

Domain 1: Structure and Processes

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

Domain 2: Physical

3. MD Anderson Symptom Inventory
4. Family Pain Questionnaire
5. Patient Pain Interview
6. Patient Pain Questionnaire
7. Psychosocial Pain Assessment Form
8. The Breakthrough Pain Questionnaire
9. Brief Pain Inventory
10. City of Hope Mayday Pain Resource Center Pain Audit Tools
11. City of Hope Mayday Pain Resource Center Patient Pain Questionnaire
12. Descriptor Differential Scale
13. Integrated Pain Score
14. McGill Pain Questionnaire
15. Memorial Pain Assessment Card (MPAC)
16. Numerical Rating Scale for pain (NRS)
17. Pain as assessed in the Medical Outcomes Study
18. Pain Disability Index
19. Pain Management Index
20. Pain Perception Profile
21. Patient Outcome Questionnaire
22. Cancer Total Quality Pain Management Patient Assessment Tool (TQPM)
23. Unmet Analgesic Needs Questionnaire
24. Verbal Rating Scale for Pain
25. Visual Analogue Scale for Pain
26. West Haven-Yale Multidimensional Pain Inventory
27. Wisconsin Brief Pain Questionnaire
28. Visual analogue scale for dyspnea (HVAS/ VVAS)
29. Numeric Rating Scale (NRS) for dyspnea or dyspnea numeric scale
30. Modified Borg Scale (mBORG)
31. Global shortness of breath question (Global SOB)
32. Faces scale (Faces)
33. Dyspnea Descriptor Questionnaire (heart failure); DDQ (heart failure)
34. Dyspnea Assessment Questionnaire (DAQ)
35. Amyotrophic lateral sclerosis functional rating scale – revised, respiratory subscale (ALSFRRS-R)
36. American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale (ATS-DLD-78)
37. Breathlessness, Cough and Sputum Scale (BCSS)
38. Chronic Heart Failure Questionnaire – dyspnea subscale (CHQ-D)
39. Cardiovascular Limitations and Symptoms Profile (CLASP)
40. Chronic Lung Disease Severity Index (CLD)
41. Chronic Respiratory Questionnaire – dyspnea subscale (CRQ-D, CRQ-SAI-D)
42. CRQ Standardized dyspnea questions (CRQ-SAS-D, CRQ-IAS-D)
43. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Lung Cancer supplement, breathlessness subscale (EORTC-QLQ; LC13 breathlessness)
44. London Chest Activity of Daily Living Scale (LCADL)
45. Motor Neurone Disease Dyspnea Rating Scale (MDRS-D)
46. Medical Research Council Dyspnea Scale (MRC)
47. Oxygen cost diagram (OCD)
48. Pulmonary Functional Status and Dyspnea Questionnaire-modified (PFSDQ-M)
49. Rand Instrument: shortness of breath battery from the Medical History Questionnaire (Rand)

50. St George's Respiratory Questionnaire (activity subscale) (SGRO)
51. University of Cincinnati Dyspnea Questionnaire (UCDQ)
52. University of California San Diego Shortness of Breath Questionnaire (UCSD SOBQ)

Domain 3: Psychosocial and Psychiatric

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

Domain 4: Social

79. Caregiver's Burden Scale in end-of-life care (CBS-EOLC)
80. Caregiver Impact Scale (CIS)
81. Caregiver Quality of Life Index – Cancer (CQOLI-C)
82. Caregiver Reaction Assessment (CRA)
83. Caregiver Strain Index (CSI)
84. Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC)
85. Quality of Life in Life-Threatening Illness-Family Carer Version (QOLLTI-F)
86. Zarit Burden Inventory (ZBI)

Domain 5: Spiritual, Religious, and Existential

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

Domain 6: Cultural

—No tools were found for this domain.—

Domain 7: Care at the End of Life

89. Bereavement Experience Questionnaire–24 (BEQ-24)
90. Brief Grief Questionnaire (BGQ)
91. Core Bereavement Items (CBI)
92. Grief Evaluation Measure (GEM)
93. Grief Experience Questionnaire (GEQ)
94. Hogan Grief Reaction Checklist (HGRC)
95. Inventory of Complicated Grief (ICG)
96. Inventory of Complicated Grief–Revised (ICG-R)
97. Inventory of Traumatic Grief (ITG)
98. Marwit–Meuser Caregiver Grief Inventory (MMCGI)
99. Marwit–Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF)
100. Prolonged Grief–12 (PG-12)
101. Prolonged Grief–13 (PG-13)

- 102.Revised Grief Experience Inventory (R-GEI)
- 103.Texas Revised Inventory of Grief (TRIG)
- 104.Two-Track Bereavement Questionnaire (TTBQ)
- 105.Two-Track Bereavement Questionnaire (TTBQ2-CG30)

Domain 8: Ethical and Legal

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

Multidimensional Tools

Quality of Life

- 108.Brief Hospice Inventory (BHI)
- 109.Cambridge Palliative Audit Schedule (CAMPAS-R)
- 110.Demoralization Scale (DS)
- 111.Edmonton Functional Assessment Tool (EFAT and EFAT-2)
- 112.Emanuel and Emanuel Medical Directive
- 113.European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module (EORTC QLQ-OES18)
- 114.European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module (EORTC QLQ-ST022)
- 115.Edmonton Symptom Assessment Scale (ESAS)
- 116.Functional Assessment of Chronic Illness Therapy-Palliative sub scale (FACIT-Pal)
- 117.Hospice Quality of Life Index (HQLI)
- 118.Life Closure Scale (LCS)
- 119.Life Evaluation Questionnaire (LEQ)
- 120.McMaster Quality of Life Scale (MQLS)
- 121.McGill Quality of Life Questionnaire (MQOL)
- 122.McGill Quality of Life Questionnaire-Cardiff Short Form (MQOL-CSF)
- 123.McCanse Readiness for Death Instrument (MRDI)
- 124.Memorial Symptom Assessment Scale (MSAS)
- 125.Condensed Memorial Symptom Assessment Scale (CMSAS)
- 126.Memorial Symptom Assessment Scale-Global Distress Index (MSAS-GDI)
- 127.Missoula-VITAS Quality of Life Index (MVQOLI-R)
- 128.Needs Assessment for Advanced Cancer Patients (NA-ACP)
- 129.Patient Autonomy Questionnaire (PAQ)
- 130.Patient Dignity Inventory (PDI)
- 131.Problems and Needs in Palliative Care questionnaire (PNPC)
- 132.Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv)
- 133.Palliative care Outcome Scale (POS)
- 134.Quality of Dying and Death questionnaire (QODD)
- 135.Quality of life at the end of life (QUAL-E)
- 136.Spiritual Needs Inventory (SNI)

Patient Experience

- 137.After Death Bereaved Family Member Interview
- 138.End of Life in Dementia- Satisfaction with Care & Comfort Assessment in Dying
- 139.Family Assessment of Treatment of End-of-Life survey
- 140.Family Evaluation of Hospice Care
- 141.Family Satisfaction in the ICU
- 142.Family Satisfaction with Advanced Cancer Care (FAMCARE)
- 143.Quality of Dying and Death
- 144.Quality of End-of-Life Care and Satisfaction with Treatment
- 145.EOLD- Satisfaction with Care & Comfort Assessment in Dying
- 146.Caregiver Evaluation of Quality of End-of-Life Care

Appendix J. Evidence Tables

Evidence Table 1. Tools identified in the supplemental searches.

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

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

Domain	Website/Review	URL	Tools
Psychological and psychiatric	The City of Hope Pain & Palliative Care Resource Center	http://prc.coh.org/res_inst.asp	World Health Organization (WHO) (Five) Well-Being Index
	The National Palliative Care Research Center Measurement and Evaluation Tools	http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx	Geriatric Depression Scale (long and short form)
			Hamilton Depression Scale
			Scales of Psychological Well-Being
	Toolkit of Instruments to Measure End-of-Life Care (TIME)	https://nts122.chcr.brown.edu/pcoc/BIBLIOGRAPHIES.HTM	Center for Epidemiologic Studies Depression Scale (CES-D)
			Impact of Event Scale (IES)
			Mental Health Inventory
PASS Pain Anxiety Symptoms Scale			
Profile of Mood States			
Present State Examination (PSE)			
Reactions to the Diagnosis of Cancer Questionnaire (RDCQ)			
Self-rating Depression Scale			
The Symptom Questionnaire (SQ)			
State-Trait Anxiety Inventory (STAI)			
Starck Scale			
Symptom Anxiety and Depression Scale			
End of Life Care and Outcomes Systematic Review	http://onlinelibrary.wiley.com/doi/10.1111/j.1475-6773.2007.00721.x/abstract	Cornell Scale for Depression in Dementia	
PEACE Palliative Care Quality Measures project	http://www.med.unc.edu/pcare/files/assessment-instruments-for-end-of-life-care	PRIME-MD / PHQ-9	
Ethical and legal aspects of care	End of Life Care and Outcomes Systematic Review	http://onlinelibrary.wiley.com/doi/10.1111/j.1475-6773.2007.00721.x/abstract	Relatives' patient management questionnaire
			Willingness to Accept Life-sustaining Treatment instrument (WALT)
Patient experience	Center for Research on End-of-Life Care	http://endoflife.weill.cornell.edu/research/assessments_and_tools	Caregiver Evaluation of Quality of End-of-Life Care

Evidence Table 2a. Characteristics of the selected review, Dorman, 2007¹ addressing the physical domain (subdomain, dyspnea).

Author, year of systematic review/website	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools included (number of studies)	Years of search (range)
Dorman, 2007 ¹	Breathlessness, physical aspects of care	Patient-based scales for either clinical or research purposes and evaluation of at least two psychometric properties	29(30 studies), 26 included in this report	Up to 2005

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 2b. Population and setting of tools included in the selected review, Dorman, 2007¹ addressing the physical domain (subdomain, dyspnea).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Gift, 1989 ²	Visual analogue scale (HVAS and VVAS)	Asthma, COPD, ventilated	ED, outpatient, inpatient, ITU, Pulmonary rehab, coronary care unit
Gift, 1998 ³ Tanaka, 2002 ⁴	Numeric rating scale (NRS) or Dyspnea Numeric Scale	Cancer, COPD	Outpatient, home
Borg, 1982 ⁵ Borg, 1970 ⁶	Modified Borg Scale (mBORG)	COPD, restrictive lung disease, asthma	Outpatient
Simon, 1990 ⁷	Global shortness of breath question (Global SOB)	COPD	Outpatient, randomized controlled trial
Powers, 1999 ⁸	Faces scale (Faces)	Ventilated	Coronary care unit, intensive therapy unit
Parshall, 2001 ⁹	Dyspnea Descriptor Questionnaire (heart failure); DDQ (heart failure)	Heart failure	ED
Parshall, 2002 ¹⁰	Dyspnea Descriptor Questionnaire (COPD); DDQ (COPD)	COPD	ED
Heyse-Moore, 1993 ¹¹	Dyspnea Assessment Questionnaire (DAQ)	Cancer	Hospice
Cedarbaum, 1999 ¹²	Amyotrophic lateral sclerosis functional rating scale – revised, respiratory subscale (ALSFRRS-R)	MND (Motor Neuron Disease)	Trial
Ferris, 1978 ¹³	American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale (ATS-DLD-78)	COPD, asthma	Outpatient
Leidy, 2003 ¹⁴	Breathlessness, Cough and Sputum Scale, breathlessness subscale (BCSS)	COPD	RCT
Guyatt, 1989 ¹⁵	Chronic Heart Failure Questionnaire – dyspnea subscale (CHQ-D)	Heart failure	Outpatient, RCT
Lewin, 2002 ¹⁶	Cardiovascular Limitations and Symptoms Profile (CLASP)	Ischemic heart disease	Outpatient
Selim, 1997 ¹⁷	Chronic Lung Disease Severity Index (CLD)	Chronic lung disease	Outpatient
Guyatt, 1987 ¹⁸	Chronic Respiratory Questionnaire – dyspnea subscale (CRQ-D, CRQ-SAI-D)	COPD, interstitial lung disease, cystic fibrosis, alpha antitrypsin deficiency, MND	Outpatient, inpatient, pulmonary rehabilitation, RCT
Schunemann, 2003 ¹⁹	CRQ Standardized dyspnea questions (CRQ-SAS-D, CRQ-IAS-D)	N	N

Evidence Table 2b. Population and setting of tools included in the selected review, Dorman, 2007¹ addressing the physical domain (subdomain, dyspnea) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Bergman, 1994 ²⁰	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Lung Cancer supplement, breathlessness subscale (EORTC-QLQ; LC13 breathlessness)	Lung cancer	RCT
Garrod, 2000 ²¹	London Chest Activity of Daily Living Scale (LCADL)	COPD	Outpatient, home
Dougan, 2000 ²²	Motor Neurone Disease Dyspnea Rating Scale, dyspnea subscale (MDRS-D)	MND	Outpatient
Fairburn, 1959 ²³	Medical Research Council Dyspnea Scale (MRC)	COPD, interstitial lung disease, asthma, other	Outpatient
McGavin, 1978 ²⁴	Oxygen cost diagram (OCD)	Respiratory disease, COPD, heart failure	Outpatient
Lareau, 1994 ²⁵	Pulmonary Functional Status and Dyspnea Questionnaire-modified (PFSDQ-M)	COPD	Pulmonary rehabilitation
Rosenthal, 1981 ²⁶	Rand Instrument: shortness of breath battery from the Medical History Questionnaire (Rand)	Heart failure, respiratory disease	Outpatient
Jones, 1992 ²⁷	St George's Respiratory Questionnaire (activity subscale) (SGRO)	COPD, asthma, bronchiectasis	Outpatient, pulmonary rehabilitation
Lee, 1998 ²⁸	University of Cincinnati Dyspnea Questionnaire (UCDQ)	Asthma, sarcoid, COPD, fibrosis	Outpatient, exercise lab
Eakin, 1998 ²⁹	University of California San Diego Shortness of Breath Questionnaire (UCSD SOBQ)	COPD, asthma, cystic fibrosis, lung transplant	Pulmonary rehabilitation, outpatient

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

Evidence Table 2c. Domain characteristics of tools included in the selected review, Dorman, 2007¹ addressing the physical domain (subdomain, dyspnea).

Author, year, of individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Gift, 1989 ²	VAS	Physical	Dyspnea	N
Gift, 1998 ³ Tanaka, 2002 ⁴	NRS or dyspnea numeric scale	Physical	Dyspnea	N
Borg, 1982 ⁶	mBORG	Physical	Dyspnea	N
Simon, 1990 ⁷	Global SOB	Physical	Dyspnea	N
Powers, 1999 ⁸	Faces	Physical	Dyspnea	N
Parshall, 2001 ⁹	DDQ heart failure	Physical	Dyspnea	N
Parshall, 2002 ¹⁰	DDQ COPD	Physical	Dyspnea	N
Heyse-Moore, 1993 ¹¹	DAQ	Physical	Dyspnea	N
Cedarbaum, 1999 ¹²	ALSFRS-R	Physical	Dyspnea	Respiratory subscale
Ferris, 1978 ¹³	ATS-DLD-78	Physical	Dyspnea	N
Leidy, 2003 ¹⁴	BCSS	Physical	Dyspnea	Breathlessness subscale
Guyatt, 1989 ¹⁵	CHQ-D	Physical	Dyspnea	Dyspnea subscale
Lewin, 2002 ¹⁶	CLASP	Physical	Dyspnea	N
Selim, 1997 ¹⁷	CLD	Physical	Dyspnea	N
Guyatt, 1987 ¹⁸	CRQ-D, CRQ-SAI-D	Physical	Dyspnea	Dyspnea subscale
Schunemann, 2003 ¹⁹	CRQ-SAS-D, CRQ-IAS-D	Physical	Dyspnea	N
Bergman, 1994 ²⁰	EORTC-QLQ; LC13 breathlessness	Physical	Dyspnea	Breathlessness subscale
Garrod, 2000 ²¹	LCADL	Physical	Dyspnea	N
Dougan, 2000 ²²	MDRS-D	Physical	Dyspnea	Dyspnea subscale
Fairburn, 1959 ²³	MRC	Physical	Dyspnea	N
McGavin, 1978 ²⁴	OCD	Physical	Dyspnea	N
Lareau, 1994 ²⁵	PFSDQ-M	Physical	Dyspnea	N
Rosenthal, 1981 ²⁶	MHQ, Rand subscale	Physical	Dyspnea	N
Jones, 1992 ²⁷	SGRO	Physical	Dyspnea	Activity subscale
Lee, 1998 ²⁸	UCDQ	Physical	Dyspnea	N
Eakin, 1998 ²⁹	UCSD SOBQ	Physical	Dyspnea	N

ALSFRS-R =Amyotrophic lateral sclerosis functional rating scale – revised ; ATS-DLD-78=American Thoracic Society Division of Lung Diseases 1978 Dyspnea Scale; BCSS =Breathlessness, Cough and Sputum Scale; CHQ-D =Chronic Heart Failure Questionnaire – dyspnea subscale; CLASP =Cardiovascular Limitations and Symptoms Profile ; CLD =Chronic Lung Disease Severity Index; CRQ-D, CRQ-SAI-D =Chronic Respiratory Questionnaire – dyspnea subscale; CRQ-SAS-D, CRQ-IAS-D =CRQ Standardized dyspnea questions; DAQ =Dyspnea Assessment Questionnaire; DDQ (COPD)=Dyspnea Descriptor Questionnaire (COPD); DDQ =Dyspnea Descriptor Questionnaire (heart failure); EORTC-QLQ =European Organization for Research and Treatment of Cancer Quality of Life Questionnaire ; Faces =Faces scale ; Global SOB =Global shortness of breath question ; LC13 breathlessness=Lung Cancer supplement, breathlessness subscale; LCADL =London Chest Activity of Daily Living Scale; mBORG =Modified Borg Scale; MDRS-D =Motor Neurone Disease Dyspnea Rating Scale; MRC =Medical Research Council Dyspnea Scale ; N=no data was in the article but

review attempted abstraction; ; ND=no data available and review did not attempt abstraction;; NR=not reported in th systematic review or on the website; NRS=Numeric rating scale ; OCD =Oxygen cost diagram; PFSDQ-M =Pulmonary Functional Status and Dyspnea Questionnaire-modified; Rand =Rand Instrument: shortness of breath battery from the Medical History Questionnaire ; SGRO =St George's Respiratory Questionnaire (activity subscale) ; UCDQ =University of Cincinnati Dyspnea Questionnaire; UCSD SOBQ =University of California San Diego Shortness of Breath Questionnaire ; VAS=Visual analogue scale ; Y=data available

Evidence Table 2d. Measurement characteristics of tools included in the selected review, Dorman, 2007¹ addressing the physical domain (subdomain, dyspnea).

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

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

Evidence Table 2e. Psychometric properties of tools included in the selected review, Dorman, 2007¹ addressing the physical domain (subdomain, dyspnea).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Gift, 1989 ²	Visual analogue scale	N	Y	ND	Y	Y	N
Gift, 1998 ³ Tanaka, 2002 ⁴	Numeric rating scale or dyspnea numeric scale	N	Y	ND	Y	Y	N
Borg, 1982 ⁶	Modified Borg Scale	N	Y	ND	Y	Y	N
Simon, 1990 ⁷	Global shortness of breath question	N	N	ND	Y	N	Y
Powers, 1999 ⁸	Faces scale	N	Y	ND	Y	N	N
Parshall, 2001 ⁹	DDQ (heart failure)	Y	Y	ND	N	N	N
Parshall, 2002 ¹⁰	DDQ (COPD)	Y	Y	ND	N	N	N
Heyse-Moore, 1993 ¹¹	DAQ	N	N	ND	Y	N	N
Cedarbaum, 1999 ¹²	ALSFRS-R	Y	N	ND	Y	N	N
Ferris, 1978 ¹³	ATS-DLD-78	Y	Y	ND	Y	N	N
Leidy, 2003 ¹⁴	BCSS	N	Y	ND	Y	Y	Y
Guyatt, 1989 ¹⁵	CHQ-D	Y	Y	ND	Y	Y	Y
Lewin, 2002 ¹⁶	(CLASP)	N	Y	ND	Y	N	N
Selim, 1997 ¹⁷	(CLD)	Y	N	ND	Y	N	N
Guyatt, 1987 ¹⁸	(CRQ-D, CRQ-SAI-D)	Y	Y	ND	Y	Y	Y

Evidence Table 2e. Psychometric properties of tools included in the selected review, Dorman, 2007¹ addressing the physical domain (subdomain, dyspnea) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency	Test-retest reliability (also for TOTAL SCORE only, not subscales)	Inter-rater reliability	Construct validity	Other validity results (discriminant, criterion)	Sensitivity to change/ responsiveness
Schunemann, 2003 ¹⁹	(CRQ-SAS-D, CRQ-IAS-D)	ND	ND	ND	ND	ND	ND
Bergman, 1994 ²⁰	(EORTC-QLQ; LC13 breathlessness)	Y	Y	ND	Y	Y	N
Garrod, 2000 ²¹	(LCADL)	Y	Y	ND	Y	Y	N
Dougan, 2000 ²²	(MDRS-D)	Y	N	ND	Y	N	N
Fairburn, 1959 ²³	Scale (MRC)	N	N	ND	Y	Y	N
McGavin, 1978 ²⁴	OCD	N	Y	ND	Y	N	Y
Lareau, 1994 ²⁵	PFSDQ-M	Y	Y	ND	Y	Y	N
Rosenthal, 1981 ²⁶	MHQ, Rand subscale	N	Y	ND	Y	N	Y
Jones, 1992 ²⁷	SGRO	Y	Y	ND	Y	Y	Y
Lee, 1998 ²⁸	UCDQ	Y	Y	ND	Y	N	N
Eakin, 1998 ²⁹	UCSD SOBQ	Y	Y	ND	Y	N	Y

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

Evidence Table 3a. Characteristics of the selected review, Ziegler, 2011³⁰ addressing psychosocial and psychiatric care domain.

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
Ziegler, 2011 ³⁰	Psychosocial, Self-report measures of psychological distress, Cancer patients, Hospitals/hospices/primary care	Exploring the validation of a self-report measure alongside a structured clinical interview for psychiatric disorder	48 tools (85 studies) – 8 tools (6 studies) focusing on psychosocial domain in palliative care populations	1960 to unspecified end date

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 3b. Population and setting of tools included in the selected review, Ziegler, 2011³⁰ addressing psychosocial and psychiatric care domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)- if review reports testing in multiple populations, broadest is listed (English and US relevant only)	Setting where testing results are reported from
Lloyd-Williams, 2007 ³¹	Hospital Anxiety and Depression Scale (HADS)	Palliative care patients with a prognosis of six months or less	N
Akechi, 2004 ³²	Two single items: Are you depressed? and Have you lost interest?	Palliative care population	Palliative care unit
Thekkumpurath, 2009 ³³	Distress Thermometer (via touch screen)	patients with advanced disease	inpatient or outpatient care
Thekkumpurath, 2009 ³³	Brief Symptom Inventory-18	patients with advanced disease	inpatient or outpatient care
Thekkumpurath, 2009 ³³	General Health Questionnaire-12 item (GHQ-12)	patients with advanced disease	inpatient or outpatient care
Lloyd-Williams, 2007 ³¹	Brief Edinburgh Depression Scale	Palliative care patients with a prognosis of six months or less	N
Love, 2004 ³⁴	Beck Depression Inventory-Short Form	Metastatic breast cancer patients with recurrence	N
Okamura, 2005 ³⁵	Mental Adjustment to Cancer	Patients at first recurrence of breast cancer	N

GHQ-12 =General Health Questionnaire-12 item ; HADS =Hospital Anxiety and Depression Scale ; N=no data was in the article but review attempted abstraction

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

Evidence Table 3c. Domain characteristics of tools included in the selected review, Ziegler, 2011³⁰ addressing psychosocial and psychiatric care domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Subscales
Lloyd-Williams, 2007 ³¹	Hospital Anxiety and Depression Scale (HADS)	Psychosocial	Anxiety, depression	2 subscales
Akechi, 2004 ³²	Two single items: Are you depressed? and Have you lost interest?	Psychosocial	Depression	N
Thekkumpurath, 2009 ³³	Distress Thermometer (via touch screen)	Psychosocial	Distress	N
Thekkumpurath, 2009 ³³	Brief Symptom Inventory-18 (via touch screen)	Psychosocial	Depression, anxiety, somatoform	3 subscales
Thekkumpurath, 2009 ³³	General Health Questionnaire-12 item (GHQ-12)	Psychosocial	Distress	N
Lloyd-Williams, 2007 ³¹	Brief Edinburgh Depression Scale	Psychosocial	Depression	N
Love, 2004 ³⁴	Beck Depression Inventory-Short Form	Psychosocial	Depression	N
Okamura, 2005 ³⁵	Mental Adjustment to Cancer	Psychosocial	Psychological response to having cancer	5 subscales

GHQ-12 =General Health Questionnaire-12 item ; HADS =Hospital Anxiety and Depression Scale ; N=no data was in the article but review attempted abstraction

Evidence Table 3d. Measurement characteristics of tools included in the selected review, Ziegler, 2011³⁰ addressing psychosocial and psychiatric care domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Tool completed by	Mode of administration	Number of items	Completion time (usability)
Lloyd-Williams, 2007 ³¹	Hospital Anxiety and Depression Scale (HADS)	Patient	Paper	14	5 minutes
Akechi, 2004 ³²	Two single items: Are you depressed? and Have you lost interest?	Patient	Paper	2	Approx 1-2 minutes
Thekkumpurath, 2009 ³³	Distress Thermometer	Patient	Touch screen	1	Approx 1 minute
Thekkumpurath, 2009 ³³	Brief Symptom Inventory-18	Patient	Touch screen	18	Approx 10 minutes
Thekkumpurath, 2009 ³³	General Health Questionnaire-12 item (GHQ-12)	Patient	Touch screen	12	5 minutes
Lloyd-Williams, 2007 ³¹	Brief Edinburgh Depression Scale	Patient	N	6	Approximately 3 minutes
Love, 2004 ³⁴	Beck Depression Inventory-Short Form	Patient	N	13	Approximately 5-10 minutes
Okamura, 2005 ³⁵	Mental Adjustment to Cancer	Patient	N	40	N

GHQ-12 =General Health Questionnaire-12 item ; HADS =Hospital Anxiety and Depression Scale ; N=no data was in the article but review attempted abstraction

Evidence Table 3e. Psychometric properties of tools included in the selected review, Ziegler, 2011³⁰ addressing psychosocial and psychiatric care domain.

Author, year, of individual study(s) within the review for each tool	Instrument	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Convergent validity (Type of construct validity)	Specific additional construct validity types: discriminant, criterion	Sensitivity to change/ responsiveness
Lloyd-Williams, 2007 ³¹	Hospital Anxiety and Depression Scale (HADS)	ND	ND	ND	Y	ND	ND
Akechi, 2004 ³²	Two single items: Are you depressed? and Have you lost interest?	ND	ND	ND	Y	ND	ND
Thekkumpurath, 2009 ³³	Distress Thermometer	ND	ND	ND	Y	ND	ND
Thekkumpurath, 2009 ³³	Brief Symptom Inventory-18	ND	ND	ND	Y	ND	ND
Thekkumpurath, 2009 ³³	General Health Questionnaire-12 item (GHQ-12)	ND	ND	ND	Y	ND	ND
Lloyd-Williams, 2007 ³¹	Brief Edinburgh Depression Scale	ND	ND	ND	Y	ND	ND
Love, 2004 ³⁴	Beck Depression Inventory-Short Form	ND	ND	ND	Y	ND	ND
Okamura, 2005 ³⁵	Mental Adjustment to Cancer	ND	ND	ND	N	ND	ND

GHQ-12 =General Health Questionnaire-12 item ; HADS =Hospital Anxiety and Depression Scale ; N=no data was in the article but review attempted abstraction; ND=no data available and review did not attempt abstraction; Y=data available

Evidence Table 4a. Characteristics of the selected review, Michels, 2016³⁶ addressing the social domain.

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
Michels, 2016 ³⁶	Social support, caregivers	Used a self-reported multidimensional measure that assessed caregiver outcomes; measures were directed at unpaid informal carers; patients were diagnosed with an advanced progressive illness or were receiving palliative care; both carers and patients were ≥18years old; the study was reported in English.	38 tools (112 studies); only 8 tools were included (8 studies abstracted) that are specifically related to palliative care in the US.	Not explicitly reported

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 4b. Population and setting of tools included in the selected review, Michels, 2016³⁶ addressing the social domain.

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Dumont, 2008 ³⁷	Caregiver's Burden Scale in end-of-life care (CBS-EOLC)	Family caregivers of terminal cancer patients	ND
Cameron, 2002 ³⁸	Caregiver Impact Scale (CIS)	Caregivers of advanced cancer patients	ND
Weitzner, 1999 ³⁹	Caregiver Quality of Life Index – Cancer (CQOLI-C)*	Caregivers of cancer	ND
Hudson, 2006 ⁴⁰	Caregiver Reaction Assessment (CRA)	Caregivers of patients receiving palliative care	ND
Hwang, 2003 ⁴¹	Caregiver Strain Index (CSI)	Caregivers for symptomatic advanced cancer patients	ND
Cooper, 2006 ⁴²	Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC)	Caregivers of palliative care patients	ND
Cohen, 2006 ⁴³	Quality of Life in Life-Threatening Illness-Family Carer Version (QOLLTI-F)	Caregivers of palliative cancer patients	ND
Higginson, 2010 ⁴⁴	Zarit Burden Inventory (ZBI)	Advanced conditions	ND

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

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

Evidence Table 4c. Domain characteristics of tools included in the selected review, Michels, 2016³⁶ addressing the social domain.

Author, year, of individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed	Sub-scales
Dumont, 2008 ³⁷	CBS-EOLC	Social	ND	ND
Cameron, 2002 ³⁸	CIS	Social	ND	ND
Weitzner, 1999 ³⁹	CQOLI-C	Social	ND	ND
Hudson, 2006 ⁴⁰	CRA	Social	ND	ND
Hwang, 2003 ⁴¹	CSI	Social	ND	ND
Cooper, 2006 ⁴²	FACQ-PC	Social	ND	ND
Cohen, 2006 ⁴³	QOLLTI-F	Social	ND	ND
Higginson, 2010 ⁴⁴	ZBI	Social	ND	ND

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

Evidence Table 4d. Measurement characteristics of tools included in the selected review, Michels, 2016³⁶ addressing the social domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Dumont, 2008 ³⁷	CBS-EOLC	ND	ND	16	N
Cameron, 2002 ³⁸	CIS	ND	ND	14	N
Weitzner, 1999 ³⁹	CQOLI-C	ND	ND	35	10 minutes
Hudson, 2006 ⁴⁰	CRA	ND	ND	24	N
Hwang, 2003 ⁴¹	CSI	ND	ND	13	N
Cooper, 2006 ⁴²	FACQ-PC	ND	ND	26	N
Cohen, 2006 ⁴³	QOLLI-F	ND	ND	16	N
Higginson, 2010 ⁴⁴	ZBI	ND	ND	22	N

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

Evidence Table 4e. Psychometric properties of tools included in the selected review, Michels, 2016³⁶ addressing the social domain.

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Dumont, 2008 ³⁷	CBS-EOLC	$\alpha=0.95$	N	ND	Y	Y	Y
Cameron, 2002 ³⁸	CIS	$\alpha=0.87$	N	ND	N	N	N
Weitzner, 1999 ³⁹	CQOLI-C	$\alpha=0.91$	Y	ND	Y	Y	Y
Hudson, 2006 ⁴⁰	CRA	$\alpha=0.76-0.83$	N	ND	Y	N	N
Hwang, 2003 ⁴¹	CSI	$\alpha=0.84$	NR	ND	Y	N	N
Cooper, 2006 ⁴²	FACQ-PC	$\alpha=0.73-0.86$	Y	ND	Y	N	N
Cohen, 2006 ⁴³	QOLLTI-F	$\alpha=0.86$	Y	ND	Y	N	Y
Higginson, 2010 ⁴⁴	ZBI	$\alpha=0.69-0.93$	N	ND	Y	N	N

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

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

Evidence Table 5a. Characteristics of the selected review, Selman, 2011⁴⁵ addressing the spiritual, religious, and existential domain.

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools in the review and number included (number of studies)	Years of search (range)
Selman, 2011 ⁴⁵	Spirituality	Measures related to “palliative care” and “spirituality” and “outcome measure”; original research or validating measures; must be in English.	9 in review, 2 patient/family assessments included here.	Through June 10, 2010: No restriction on start date of searches

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 5b. Population and setting of tools included in the selected review, Selman, 2011⁴⁵ addressing the spiritual, religious, and existential domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)-	Setting where testing results are reported from
Rosenfeld, 2004 ⁴⁶ Nissim, 2010 ⁴⁷ Abbey, 2006 ⁴⁸	Beck Hopelessness Scale (BHS)	Ethnically diverse U.S. population; made for a general population but has been validated in palliative care population.	Inpatient
Ironson, 2002 ⁴⁹	Ironson-Woods Spirituality/Religiousness Index (I-W SR Index Short Form)	Ethnically diverse US population	ND

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

Evidence Table 5c. Domain characteristics of tools included in the selected review, Selman, 2011⁴⁵ addressing the spiritual, religious, and existential domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Rosenfeld, 2004 ⁴⁶ Nissim, 2010 ⁴⁷ Abbey, 2006 ⁴⁸	BHS	Spirituality	Hopelessness	ND
Ironson, 2002 ⁴⁹	I-W SR Index Short Form	Spirituality	ND	ND

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

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

Evidence Table 5d. Measurement characteristics of tools included in the selected review, Selman, 2011⁴⁵ addressing the spiritual, religious, and existential domain.

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Rosenfeld, 2004 ⁴⁶ Nissim, 2010 ⁴⁷ Abbey, 2006 ⁴⁸	BHS	ND	ND	20	N
Ironson, 2002 ⁴⁹	I-W SR Index Short Form	ND	ND	22	N

BHS =Beck Hopelessness Scale ; I-W SR Index Short Form =Ironson-Woods Spirituality/Religiousness Index; N=no data was in the article but review attempted abstraction; ND=no data available and review did not attempt abstraction

Evidence Table 5e. Psychometric properties of tools included in the selected review, Selman, 2011⁴⁵ addressing the spiritual, religious, and existential domain.

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant , criterion)	Sensitivity to change/ responsiveness
Rosenfeld, 2004 ⁴⁶ Nissim, 2010 ⁴⁷ Abbey, 2006 ⁴⁸	BHS	Y	N	N	Y	Y	Y
Ironson, 2002 ⁴⁹	I-W SR Index Short Form	Y	Y	N	Y	Y	Y

BHS =Beck Hopelessness Scale ; I-W SR Index Short Form =Ironson-Woods Spirituality/Religiousness Index; N=no data was in the article but review attempted abstraction; Y=data available

Evidence Table 6a. Characteristics of the selected review, Sealey, 2015⁵⁰ addressing care of the patient at end of life.

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools included (number of studies)	Years of search (range)
Sealey, 2015 ⁵⁰	End-of-life: bereavement*	Bereavement risk assessment measures appropriate for different points in the caring and bereavement trajectories	19 in review, 17 patient/family assessments included here	1980 through August 2014

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

* Scoping review

Evidence Table 6b. Population and setting of tools in the selected review, Sealey, 2015⁵⁰ addressing care of the patient at end of life.

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Guarnaccia, 1998 ⁵¹	Bereavement Experience Questionnaire–24 (BEQ-24)	Bereaved adults	N
Shear, 2006 ⁵² Ito, 2012 ⁵³ Fujisawa, 2010 ⁵⁴	Brief Grief Questionnaire (BGQ)	Recipients of crisis counselling following 911 terrorist attacks; bereaved community dwelling adults	Outpatient
Burnett, 1997 ⁵⁵	Core Bereavement Items (CBI)	Bereaved adults	N
Jordan, 2005 ⁵⁶	Grief Evaluation Measure (GEM)	Bereaved adults:	N
Barrett, 1989 ⁵⁷	Grief Experience Questionnaire (GEQ)	Conjugally bereaved adults to suicide, natural causes or accidental death	N
Hogan, 2001 ⁵⁸	Hogan Grief Reaction Checklist (HGRC)	Parentally bereaved people	N
Prigerson, 1995 ⁵⁹	Inventory of Complicated Grief (ICG)	Conjugally bereaved elders	N
Prigerson, 2009 ⁶⁰ O'Connor, 2010 ⁶¹ Guldin, 2011 ⁶²	Inventory of Complicated Grief–Revised (ICG-R)	Conjugally bereaved elders	N
Prigerson, 2001 ⁶³	Inventory of Traumatic Grief (ITG)	Elderly widowed residents; bereaved adults	N
Marwit, 2002 ⁶⁴ Marwit, 2006 ⁶⁵ Marwit, 2008 ⁶⁶	Marwit–Meuser Caregiver Grief Inventory (MMCGI) (and short form)	Caregivers of people with dementia, acquired brain injury, cancer	N
Marwit, 2005 ⁶⁷	Marwit–Meuser Caregiver Grief Inventory–Short Form (MM-CGI-SF)	Adult caregivers of people with dementia	N
Kiely, 2008 ⁶⁸ Lai, 2014 ⁶⁹	Prolonged Grief–12 (PG-12)	Caregivers of people with dementia, hospice patients	Residential aged care (person who died)
Lichtenthal, 2011 ⁷⁰ Papa, 2014 ⁷¹	Prolonged Grief–13 (PG-13)	Adults; bereaved caregivers with prolonged grief disorder	N
Lev, 1993 ⁷²	Revised Grief Experience Inventory (R-GEI)	Hospice caregivers following the death of a loved one	N
Faschingbauer, 1987 ⁷³ Zisook, 1982 ⁷⁴ Faschingbauer, 1977 ⁷⁵ Futterman, 2010 ⁷⁶	Texas Revised Inventory of Grief (TRIG)	Bereaved psychiatric outpatients; bereaved adults	Outpatient
Rubin, 2009 ⁷⁷	Two-Track Bereavement Questionnaire (TTBQ)	Bereaved adults	N
Bar Nadav, 2014 ⁷⁸	Two-Track Bereavement Questionnaire (TTBQ2-CG30)	Adults bereaved by traumatic deaths	N

BEQ-24=Bereavement Experience Questionnaire–24; BGQ =Brief Grief Questionnaire ; CBI =Core Bereavement Items; GEM =Grief Evaluation Measure ; GEQ =Grief Experience Questionnaire ; HGRC =Hogan Grief Reaction Checklist; ICG =Inventory of Complicated Grief ; ICG-R =Inventory of Complicated Grief–Revised ; ITG =Inventory of Traumatic Grief ; MMCGI =Marwit–Meuser Caregiver Grief Inventory and short form; MM-CGI-SF =Marwit–Meuser Caregiver Grief Inventory–Short Form ; PG-12=Prolonged Grief–12; PG-13=Prolonged Grief–13; N=no data was in the article

but review attempted abstraction; R-GEI =Revised Grief Experience Inventory; TRIG =Texas Revised Inventory of Grief ; TTbQ =Two-Track Bereavement Questionnaire ; TTbQ2-CG30=Two-Track Bereavement Questionnaire

Evidence Table 6c. Domain characteristics of tools in the selected review, Sealey, 2015⁵⁰ addressing care of the patient at end of life.

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Guarnaccia, 1998 ⁵¹	BEQ-24	End of life	Bereavement (following a patient's death)	N
Shear, 2006 ⁵² Ito, 2012 ⁵³ Fujisawa, 2010 ⁵⁴	BGQ	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	N
Burnett, 1997 ⁵⁵	CBI	End of life	Bereavement (following a patient's death)	Images and thoughts, acute separation and grief
Jordan, 2005 ⁵⁶	GEM	End of life	Bereavement (following a patient's death)	Seven sections
Barrett, 1989 ⁵⁷	GEQ	End of life	Bereavement (following a patient's death)	Somatic and general grief reactions, meaning making, social support, stigmatization, guilt, responsibility for the death, shame, rejection, self-destructive behavior and reactions exclusive to suicide survivors
Hogan, 2001 ⁵⁸	HGRC	End of life	Bereavement (following a patient's death)	Six factors
Prigerson, 1995 ⁵⁹	ICG	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	N
Prigerson, 2009 ⁶⁰ O'Connor, 2010 ⁶¹ Guldin, 2011 ⁶²	ICG-R	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	Two factors
Prigerson, 2001 ⁶³	ITG	End of life	Bereavement (following a patient's death)	Two factors
Marwit, 2002 ⁶⁴ Marwit, 2006 ⁶⁵ Marwit, 2008 ⁶⁶	MMCGI	End of life	Bereavement (pre-death risk)	Personal sacrifice burden, heartfelt sadness and longing and worry and felt isolation

Evidence Table 6c. Domain characteristics of tools in the selected review, Sealey, 2015⁵⁰ addressing care of the patient at end of life (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Marwit, 2005 ⁶⁷	MM-CGI-SF	End of life	Bereavement (pre-death risk)	Personal sacrifice burden, heartfelt sadness and longing and worry and felt isolation
Kiely, 2008 ⁶⁸ Lai, 2014 ⁶⁹	PG-12	End of life	Bereavement (pre-death risk)	N
Lichtenthal, 2011 ⁷⁰ Papa, 2014 ⁷¹	PG-13	End of life	Bereavement (complicated or prolonged bereavement following a patient's death)	N
Lev, 1993 ⁷²	R-GEI	End of life	Bereavement (following a patient's death)	Existential concerns, depression, feelings of tension and guilt and physical distress
Faschingbauer, 1987 ⁷³ Zisook, 1982 ⁷⁴ Faschingbauer, 1977 ⁷⁵ Futterman, 2010 ⁷⁶	TRIG	End of life	Bereavement (following a patient's death)	Past behavior and present feelings
Rubin, 2009 ⁷⁷	TTBQ	End of life	Bereavement (following a patient's death)	Five factors
Bar Nadav, 2014 ⁷⁸	TTBQ2-CG30	End of life	Bereavement (following a patient's death)	Four factors

BEQ-24=Bereavement Experience Questionnaire-24; BGQ =Brief Grief Questionnaire ; CBI =Core Bereavement Items; GEM =Grief Evaluation Measure ; GEQ =Grief Experience Questionnaire ; HGRC =Hogan Grief Reaction Checklist; ICG =Inventory of Complicated Grief ; ICG-R =Inventory of Complicated Grief-Revised ; ITG =Inventory of Traumatic Grief ; MMCGI =Marwit-Meuser Caregiver Grief Inventory and short form; MM-CGI-SF =Marwit-Meuser Caregiver Grief Inventory-Short Form ; PG-12=Prolonged Grief-12; PG-13=Prolonged Grief-13; N=no data was in the article but review attempted abstraction; R-GEI =Revised Grief Experience Inventory; TRIG =Texas Revised Inventory of Grief ; TTBQ =Two-Track Bereavement Questionnaire ; TTBQ2-CG30=Two-Track Bereavement Questionnaire

Evidence Table 6d. Measurement characteristics of tools in the selected review, Sealey, 2015⁵⁰ addressing care of the patient at end of life.

Author, year, #refID of individual study(s)	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Guarnaccia, 1998 ⁵¹	BEQ-24	Caregiver	ND	24	ND
Shear, 2006 ⁵² Ito, 2012 ⁵³ Fujiwara, 2010 ⁵⁴	BGQ	Caregiver	ND	5	ND
Burnett, 1997 ⁵⁵	CBI	Caregiver	ND	17	ND
Jordan, 2005 ⁵⁶	GEM	Caregiver	ND	91	ND
Barrett, 1989 ⁵⁷	GEQ	Caregiver	ND	55	ND
Hogan, 2001 ⁵⁸	HGRC	Caregiver	ND	61	ND
Prigerson, 1995 ⁵⁹	ICG	Caregiver	ND	19	ND
Prigerson, 2009 ⁶⁰ O'Connor, 2010 ⁶¹ Guldin, 2011 ⁶²	ICG-R	Caregiver	ND	15	ND
Prigerson, 2001 ⁶³	ITG	Caregiver	ND	34	ND
Marwit, 2002 ⁶⁴ Marwit, 2006 ⁶⁵ Marwit, 2008 ⁶⁶	MMCGI	Caregiver	ND	50	ND
Marwit, 2005 ⁶⁷	MM-CGI-SF	Caregiver	ND	18	ND
Kiely, 2008 ⁶⁸ Lai, 2014 ⁶⁹	PG-12	Caregiver	ND	12	ND
Lichtenthal, 2011 ⁷⁰ Papa, 2014 ⁷¹	PG-13	Caregiver	ND	13	ND
Lev, 1993 ⁷²	R-GEI	Caregiver	ND	22	ND
Faschingbauer, 1987 ⁷³ Zisook, 1982 ⁷⁴ Faschingbauer, 1977 ⁷⁵ Futterman, 2010 ⁷⁶	TRIG	Caregiver	ND	21	ND
Rubin, 2009 ⁷⁷	TTBQ	Caregiver	ND	70	ND
Bar Nadav, 2014 ⁷⁸	TTBQ2-CG30	Caregiver	ND	30	ND

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

Evidence Table 6e. Psychometric properties of tools in the selected review, Sealey, 2015⁵⁰ addressing care of the patient at end of life.

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Guarnaccia, 1998 ⁵¹	BEQ-24	Cronbach's alpha 0.70 - 0.84	N	ND	N	ND	ND
Shear, 2006 ⁵² Ito, 2012 ⁵³ Fujisawa, 2010 ⁵⁴	BGQ	Cronbach's alpha 0.75- 0.82	N	ND	N	ND	ND
Burnett, 1997 ⁵⁵	CBI	Cronbach's alpha 0.91	N	ND	Y	ND	ND
Jordan, 2005 ⁵⁶	GEM	Cronbach's alpha 0.91- 0.97	Y	ND	N	ND	ND
Barrett, 1989 ⁵⁷	GEQ	Cronbach's alpha 0.97	N	ND	N	ND	ND
Hogan, 2001 ⁵⁸	HGRC	Cronbach's alpha 0.90	Y	ND	N	ND	ND
Prigerson, 1995 ⁵⁹	ICG	Cronbach's alpha 0.94	Y	ND	N	ND	ND
Prigerson, 2009 ⁶⁰ O'Connor, 2010 ⁶¹ Guldin, 2011 ⁶²	ICG-R	Cronbach's alpha 0.90 -0.94	N	ND	N	ND	ND
Prigerson, 2001 ⁶³ .	ITG	Cronbach's alpha 0.94-0.95	Y	ND	N	ND	ND
Marwit, 2002 ⁶⁴ Marwit, 2006 ⁶⁵ Marwit, 2008 ⁶⁶	MM-CGI	Cronbach's alpha 0.86-0.96	N	ND	Y	ND	ND
Marwit, 2005 ⁶⁷	MM-CGI-SF	Cronbach's alpha 0.80-0.83	N	ND	Y	ND	ND
Kiely, 2008 ⁶⁸ Lai, 2014 ⁶⁹	PG-12	Cronbach's alpha 0.81	N	ND	N	ND	ND
Lichtenthal, 2011 ⁷⁰ Papa, 2014 ⁷¹	PG-13	Cronbach's alpha total 0.82-0.94	N	ND	N	ND	ND
Lev, 1993 ⁷²	R-GEI	Cronbach's alpha 0.93	N	ND	N	ND	ND
Faschingbauer, 1987 ⁷³ Zisook, 1982 ⁷⁴ Faschingbauer, 1977 ⁷⁵ Futterman, 2010 ⁷⁶	TRIG	Cronbach's alpha 0.86;	N	ND	N	ND	ND

Evidence Table 6e. Psychometric properties of tools in the selected review, Sealey, 2015⁵⁰ addressing care of the patient at end of life (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Rubin, 2009 ⁷⁷	TTBQ	Cronbach's alpha 0.94	N	ND	N	ND	ND
Bar Nadav, 2014 ⁷⁸	TTBQ2-CG30	Cronbach's alpha 0.91	N	ND	N	ND	ND

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

Evidence Table 7a. Characteristics of the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life).

Author, year	Review focus – NCP domain, tool (and definition if relevant), population, setting	Inclusion criteria	Number of tools included (number of studies)	Years of search (range)
Albers, 2010 ⁷⁹	Feasibility and clinimetric quality of QOL measurement instruments suitable for use in palliative care	(1) the study should describe the development or validation of a measurement tool; (2) the measurement instrument should measure (at least one domain of) quality of life in a population of patients for whom there are no further curative treatment options; (3) the study should have investigated at least one measurement property of the instrument; (4) the measurement instrument should have been validated in an English or a Dutch population.	29 (36 studies)	January 1990 to April 2008

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

Evidence Table 7b. Population and setting of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Guo, 2001 ⁸⁰	Brief Hospice Inventory BHI	Hospice patients	Hospice
Ewing, 2004 ⁸¹	Cambridge Palliative Audit Schedule CAMPAS-R	Palliative care patients	Home care
Kissane, 2004 ⁸²	Demoralization Scale DS	Cancer patients	Inpatients
Kaasa, 1997 ⁸³ Kaasa, 2001 ⁸⁴	Edmonton Functional Assessment Tool EFAT and EFAT-2	Cancer patients	Palliative care unit
Schwartz, 2004 ⁸⁵	Emanuel and Emanuel Medical Directive	Severely ill patients	Inpatients, dialysis clinics, rehabilitation hospitals, long-term facilities
Blazeby, 2003 ⁸⁶	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module EORTC QLQ-OES18	Esophageal cancer patients	N
Blazeby, 2004 ⁸⁷	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module EORTC QLQ-ST022	Patients with adenoma carcinoma of the stomach	N
Chang, 2000 ⁸⁸	Edmonton Symptom Assessment Scale ESAS	Palliative care patients	In- and outpatients
Lyons, 2009 ⁸⁹	Functional Assessment of Chronic Illness Therapy-Palliative Subscale FACIT-Pal	Patients with life limiting illness	N
Mcmillan, 1998 ⁹⁰ McMillan, 2008 ⁹¹	Hospice Quality of Life Index HQLI	Hospice patients	Hospice home care
Dobratz, 2004 ⁹²	Life Closure Scale LCS	Terminally ill patients	Hospice
Salmon, 1996 ⁹³	Life Evaluation Questionnaire LEQ	People with incurable cancer	Outpatient, inpatient
Sterkenberg, 1996 ⁹⁴	McMaster Quality of Life Scale MQLS	Palliative care patients	In and outpatient, and community-based
Cohen, 1997 ⁹⁵ Cohen, 2000 ⁹⁶	McGill Quality of Life Questionnaire MQOL	People with life threatening illness	Palliative care inpatient units, outpatient, home care
Lua, 2005 ⁹⁷	McGill Quality of Life Questionnaire-Cardiff Short Form MQOL-CSF	Terminally ill patients	Hospice center, inpatient
McCanse, 1995 ⁹⁸	McCanse Readiness for Death Instrument MRDI	Terminally ill patients	Hospice
Sherman, 2007 ⁹⁹ Lobchuk, 2003 ¹⁰⁰	Memorial Symptom Assessment Scale MSAS	Cancer patients	N

Evidence Table 7b. Population and setting of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument (s) (Full name and abbreviation)	Population (s)	Setting where testing results are reported from
Chang, 2004 ¹⁰¹	Condensed Memorial Symptom Assessment Scale CMSAS	Cancer patients	In- and outpatients
Hickman, 2001 ¹⁰²	Memorial Symptom Assessment Scale-Global Distress Index MSAS-GDI	Cancer patients	Inpatients
Byock, 1998 ¹⁰³ Schwartz, 2005 ¹⁰⁴	Missoula-VITAS Quality of Life Index MVQOLI-R	Terminally ill patients	Hospice, dialysis clinics; hospices; long-term care facilities
Rainbird, 2005 ¹⁰⁵	Needs Assessment for Advanced Cancer Patients NA-ACP	Advanced cancer patients	N
Vernooij-Dassen, 2005 ¹⁰⁶	Patient Autonomy Questionnaire PAQ	Palliative cancer patients	N
Chochinov, 2008 ¹⁰⁷	Patient Dignity Inventory PDI	Patients nearing the end of life	Inpatients
Osse, 2004 ¹⁰⁸	Problems and Needs in Palliative Care questionnaire PNPC	Palliative care patients	Home
Osse, 2007 ¹⁰⁹	Problems and Needs in Palliative Care questionnaire-short version PNPC-sv	Palliative care patients	Home
Hearn, 1999 ¹¹⁰	Palliative care Outcome Scale POS	Advanced cancer patients	Centers providing palliative care, including inpatient, outpatient, day, home and primary care
Curtis, 2002 ¹¹¹	Quality of Dying and Death questionnaire QODD	Family members of terminally ill patients	N
Steinhauser, 2004 ¹¹²	Quality of life at the end of life QUAL-E	Seriously ill patients	N
Hermann, 2006 ¹¹³	Spiritual Needs Inventory SNI	Patients near the end of life	Outpatient and inpatient hospice

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool ; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OES18=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCanse Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=no data was in the article but review attempted abstraction; PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory

Evidence Table 7c. Domain and subscale characteristics of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Guo, 2001 ⁸⁰	BHI	Physical, Psychological and Psychiatric	ND	N
Ewing, 2004 ⁸¹	CAMPAS-R	Physical, Psychological and Psychiatric	ND	Subscale
Kissane, 2004 ⁸²	DS	Psychological and Psychiatric	ND	Subscale and total
Kaasa, 1997 ⁸³ Kaasa, 2001 ⁸⁴	EFAT	Physical	ND	Total
Schwartz, 2004 ⁸⁵	Emanuel and Emanuel Medical Directive	Ethical/legal	ND	N
Blazeby, 2003 ⁸⁶	EORTC QLQ-OES18	Physical	ND	Subscale
Blazeby, 2004 ⁸⁷	EORTC QLQ-ST022	Physical, Psychological and Psychiatric	ND	Subscale
Chang, 2000 ⁸⁸	ESAS	Physical, Psychological and Psychiatric	ND	Total
Lyons, 2009 ⁸⁹	FACIT-Pal	Physical, Psychological and Psychiatric, Social, Ethical/Legal	ND	Total
McMillan, 1998 ⁹⁰ McMillan, 2008 ⁹¹	HQLI	Physical, Psychological and Psychiatric, Social, Spiritual	ND	Subscale and total
Dobratz, 2004 ⁹²	LCS	Psychological and Psychiatric	ND	Subscale and total
Salmon, 1996 ⁹³	LEQ	Psychological and Psychiatric, Social	ND	Subscale
Sterkenberg, 1996 ⁹⁴	MQLS	Physical, Psychological and Psychiatric, Social	ND	N
Cohen, 1997 ⁹⁵ Cohen, 2000 ⁹⁶	MQOL	Physical, Psychological and Psychiatric, Social, Spiritual	ND	Subscale and total
Lua, 2005 ⁹⁷	MQOL-CSF	Physical, Psychological and Psychiatric, Spiritual	ND	Subscale and total
McCanse, 1995 ⁹⁸	MRDI	Physical, Psychological and Psychiatric, Social, Spiritual	ND	Total
Sherman, 2007 ⁹⁹ Lobchuk, 2003 ¹⁰⁰	MSAS	Physical, Psychological and Psychiatric	ND	Subscale and total
Chang, 2004 ¹⁰¹	CMSAS	Physical, Psychological and Psychiatric	ND	Subscale and total
Hickman, 2001 ¹⁰²	MSAS-GDI	Physical, Psychological and Psychiatric	ND	Total
Byock, 1998 ¹⁰³ Schwartz, 2005 ¹⁰⁴	MVQOLI-R	Physical, Social, Spiritual	ND	Subscale and total

Evidence Table 7c. Domain and subscale characteristics of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life) (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument	Domain (from NCP national guidelines)	Subdomains of NCP domain addressed (eg, pain, dyspnea)	Sub-scales
Rainbird, 2005 ¹⁰⁵	NA-ACP	Structure and Process, Physical, Social, Spiritual	ND	Subscale
Vernooij-Dassen, 2005 ¹⁰⁶	PAQ	Ethical/legal	ND	Total
Chochinov, 2008 ¹⁰⁷	PDI	Physical, Social, Spiritual	ND	N
Osse, 2004 ¹⁰⁸	PNPC	Structure and Process, Physical, Psychological and Psychiatric, Social Spiritual, Ethical/Legal	ND	Subscale
Osse, 2007 ¹⁰⁹	PNPC-sv	Structure and Process, Physical, Psychological and Psychiatric, Social Spiritual, Ethical/Legal	ND	Subscale
Hearn, 1999 ¹¹⁰	POS	Physical, Psychological and Psychiatric, Spiritual	ND	N
Curtis, 2002 ¹¹¹	QODD	Physical, Psychological and Psychiatric, Spiritual, End of Life	ND	Total
Steinhauser, 2004 ¹¹²	QUAL-E	Structure and Process, Psychological and Psychiatric, Ethical/Legal, End of Life	ND	Subscale and total
Hermann, 2006 ¹¹³	SNI	Spiritual	ND	Subscale and total

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool ; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OES18=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCance Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=no data was in the article but review attempted abstraction; ND=no data available and review did not attempt abstraction; PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory

Evidence Table 7d. Measurement characteristics of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life).

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Guo, 2001 ⁸⁰	BHI	Patient	N	17	9 minutes
Ewing, 2004 ⁸¹	CAMPAS-R	Patient	N	2x10	N
Kissane, 2004 ⁸²	DS	Patient	N	24	N
Kaasa, 1997 ⁸³ Kaasa, 2001 ⁸⁴	EFAT	Proxy	N	11	N
Schwartz, 2004 ⁸⁵	Emanuel and Emanuel Medical Directive	Patient	interview	48	2-3 hours
Blazeby, 2003 ⁸⁶	EORTC QLQ-OES18	Patient	N	18	15 minutes (including completion of EORTC QLQ-C30)
Blazeby, 2004 ⁸⁷	EORTC QLQ-ST022	Patient	N	22	15 min. (including completion of EORTC QLQ-C30)
Chang, 2000 ⁸⁸	ESAS	Patient	N	10	5 minutes
Lyons, 2009 ⁸⁹	FACIT-Pal	Patient	N	19	N
McMillan, 1998 ⁹⁰ McMillan, 2008 ⁹¹	HQLI	Patient	N	28	10-15 minutes
Dobratz, 2004 ⁹²	LCS	Patient	N	20	N
Salmon, 1996 ⁹³	LEQ	Patient	N	44	N
Sterkenberg, 1996 ⁹⁴	MQLS	Patient	N	32	3-30 minutes
Cohen, 1997 ⁹⁵ Cohen, 2000 ⁹⁶	MQOL	Patient	N	16	10-30 minutes
Lua, 2005 ⁹⁷	MQOL-CSF	Patient	N	8	3.26 minutes
McCanse, 1995 ⁹⁸	MRDI	Patient	interview	28	N
Sherman, 2007 ⁹⁹ Lobchuk, 2003 ¹⁰⁰	MSAS	Patient/proxy	N	32	20-60 minutes
Chang, 2004 ¹⁰¹	CMSAS	Patient	N	14	2-4 minutes
Hickman, 2001 ¹⁰²	MSAS-GDI	Proxy	N	11	N
Byock, 1998 ¹⁰³ Schwartz, 2005 ¹⁰⁴	MVQOLI-R	Patient	N	25	N
Rainbird, 2005 ¹⁰⁵	NA-ACP	Patient	N	132	76 minutes
Vernooij-Dassen, 2005 ¹⁰⁶	PAQ	Patient	N	4/9	N
Chochinov, 2008 ¹⁰⁷	PDI	Patient	N	25	2 minutes (max: 10-15)
Osse, 2004 ¹⁰⁸	PNPC	Patient	N	138	N

Evidence Table 7d. Measurement characteristics of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life) (continued).

Author, year, of relevant individual study(s) within the review for each tool	Instrument (abbreviation)	Form completed by	Mode of administration	Number of items	Completion time (usability)
Osse, 2007 ¹⁰⁹	PNPC-sv	Patient	N	33	N
Hearn, 1999 ¹¹⁰	POS	Patient/proxy	N	10	6.9 minutes
Curtis, 2002 ¹¹¹	QODD	Proxy	interview	31	N
Steinhauser, 2004 ¹¹²	QUAL-E	Patient	interview	26	N
Hermann, 2006 ¹¹³	SNI	Patient	N	17	N

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool ; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OES18=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCanse Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=no data was in the article but review attempted abstraction; ND=no data available and review did not attempt abstraction; PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory

Evidence Table 7e. Psychometric properties of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Guo, 2001 ⁸⁰	BHI	Cronbach's α of the 2 subscales: 0.88; 0.94	Y	ND	N	ND	N
Ewing, 2004 ⁸¹	CAMPAS-R	Cronbach's α severity: 0.77; Cronbach's α interference: 0.80	N	ND	Y	ND	Y
Kissane, 2004 ⁸²	DS	Cronbach's α : 0.70–0.89	N	ND	Y	ND	N
Kaasa, 1997 ⁸³ Kaasa, 2001 ⁸⁴	EFAT EFAT-2	EFAT-2 Cronbach's α : 0.86	N	ND	Y	ND	N
Schwartz, 2004 ⁸⁵	Emanuel and Emanuel Medical Directive	Cronbach's α across treatments by scenario: 0.80–0.85; Cronbach's α across scenarios by treatment: 0.86–0.90	Y	ND	Y	ND	Y
Blazeby, 2003 ⁸⁶	EORTC QLQ-OES18	Cronbach's α : 0.61–0.75	N	ND	Y	ND	Y
Blazeby, 2004 ⁸⁷	EORTC QLQ-ST022	Cronbach's α : 0.72–0.80	N	ND	Y	ND	Y
Chang, 2000 ⁸⁸	ESAS	Cronbach's α of the overall ESAS: 0.79	Y	ND	Y	ND	N
Lyons, 2009 ⁸⁹	FACIT-Pal	Cronbach's α : 0.75–0.85	N	ND	Y	ND	N
McMillan, 1998 ⁹⁰ McMillan, 2008 ⁹¹	HQLI	Cronbach's α : 0.78–0.85	N	ND	Y	ND	N
Dobratz, 2004 ⁹²	LCS	Cronbach's α for 2 subscales: 0.80; 0.82	N	ND	Y	ND	N
Salmon, 1996 ⁹³	LEQ	Cronbach's α : 0.70–0.85	Y	ND	Y	ND	N

Evidence Table 7e. Psychometric properties of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Sterkenberg, 1996 ⁹⁴	MQLS	Cronbach's α for patients: overall scale: 0.8; Cronbach's α for family: overall scale: 0.87	Y	ND	Y	ND	y
Cohen, 1997 ⁹⁵ Cohen, 2000 ⁹⁶	MQOL	Cronbach's α : >0.70 except physical subscale (0.62)	Y	ND	Y	ND	Y
Lua, 2005 ⁹⁷	MQOL-CSF	Cronbach's α : 0.64–0.81, except existential domain (0.46)	Y	ND	Y	ND	N
McCanse, 1995 ⁹⁸	MRDI	Cronbach's α of the overall MRDI: 0.59	Y	ND	Y	ND	N
Sherman, 2007 ⁹⁹ Lobchuk, 2003 ¹⁰⁰	MSAS, MSAS (FC)	Cronbach's α AIDS patients; caregivers: 0.78–0.87; 0.86–0.91 Cronbach's α cancer patients; caregivers: 0.78–0.83; 0.81–0.86	N	ND	Y	ND	N
Chang, 2004 ¹⁰¹	CMSAS	Cronbach's α : 0.72–0.85	N	ND	Y	ND	N
Hickman, 2001 ¹⁰²	MSAS-GDI	Cronbach's α of the overall MSAS-GDI: 0.82	N	ND	N	ND	N
Byock, 1998 ¹⁰³ Schwartz, 2005 ¹⁰⁴	MVQOLI, MVQOLI-R	Cronbach's α of the overall MVQOLI: 0.77	N	ND	Y	ND	Y
Rainbird, 2005 ¹⁰⁵	NA-ACP	Cronbach's α : 0.79–0.98	Y	ND	N	ND	N
	PAQ	Cronbach's α of the 9-item version: 0.86 Cronbach's α of the 4-item version: 0.71	N	ND	Y	ND	N

Evidence Table 7e. Psychometric properties of tools included in the selected review, Albers, 2010⁷⁹ addressing multidimensional tools (quality of life) (continued).

Author, year, of individual study(s) within the review for each tool	Instrument abbreviation	Reliability: Internal consistency (Total score if present)	Test-retest reliability	Inter-rater reliability	Construct validity	Specific construct validity results: discriminant, criterion)	Sensitivity to change/ responsiveness
Vernooij-Dassen, 2005 ¹⁰⁶	PDI	Cronbach's α : 0.63–0.83	Y	ND	Y	ND	N
Chochinov, 2008 ¹⁰⁷	PNPC	Cronbach's α : 0.67–0.89 (problem aspect)	N	ND	Y	ND	N
Osse, 2007 ¹⁰⁹	PNPpC-sv	Cronbach's α : 0.61–0.86 (problem aspect)	N	ND	Y	ND	N
Hearn, 1999 ¹¹⁰	POS	Cronbach's α patient version: 0.65	Y	ND	Y	ND	Y
Curtis, 2002 ¹¹¹	QODD	Cronbach's α for overall QODD 0.89	N	ND	Y	ND	N
Steinhauser, 2004 ¹¹²	QUAL-E	Cronbach's α : 0.68–0.87	Y	ND	Y	ND	N
Hermann, 2006 ¹¹³	SNI	Cronbach's α : 0.62–0.78	N	ND	N	ND	N

BHI=Brief Hospice Inventory; CAMPAS-R=Cambridge Palliative Audit Schedule; CMSAS=Condensed Memorial Symptom Assessment Scale; DS=Demoralization Scale; EFAT=Edmonton Functional Assessment Tool ; EFAT-2=Edmonton Functional Assessment Tool; EORTC QLQ-OES18=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Oesophageal cancer module; EORTC QLQ-ST022=European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Gastric cancer module; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative Subscale; HQLI=Hospice Quality of Life Index; LCS=Life Closure Scale; LEQ=Life Evaluation Questionnaire; MQLS=McMaster Quality of Life Scale; MQOL=McGill Quality of Life Questionnaire; MQOL-CSF=McGill Quality of Life Questionnaire-Cardiff Short Form; MRDI=McCanse Readiness for Death Instrument; MSAS=Memorial Symptom Assessment Scale; MSAS-GDI=Memorial Symptom Assessment Scale-Global Distress Index; MVQOLI-R=Missoula-VITAS Quality of Life Index; NA-ACP=Needs Assessment for Advanced Cancer Patients; N=no data was in the article but review attempted abstraction; ND=no data available and review did not attempt abstraction; PAQ=Patient Autonomy Questionnaire; PDI=Patient Dignity Inventory; PNPC=Problems and Needs in Palliative Care questionnaire; PNPC-sv=Problems and Needs in Palliative Care questionnaire-short version; POS=Palliative care Outcome Scale; QODD=Quality of Dying and Death questionnaire8; QUAL-E=Quality of life at the end of life; SNI=Spiritual Needs Inventory; Y=data available

Evidence Table 8a. Characteristics of the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience).

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

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 8b. Population and setting of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience).

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

Evidence Table 8b. Population and setting of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience) (continued).

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

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

Evidence Table 8c. Domain and subscale characteristics of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience).

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

Evidence Table 8c. Domain and subscale characteristics of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience) (continued).

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

EOLD=End of Life in Dementia; FAMCARE=Family Satisfaction with Advanced Cancer Care; ICU=intensive care unit; ND=no data available and review did not attempt abstraction

Evidence Table 8d. Measurement characteristics of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience).

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

Evidence Table 8d. Measurement characteristics of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience) (continued).

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

EOLD=End of Life in Dementia; FAMCARE=Family Satisfaction with Advanced Cancer Care; ICU=intensive care unit; ND=no data available and review did not attempt abstraction

Evidence Table 8e. Psychometric properties of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience).

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

Evidence Table 8e. Psychometric properties of tools included in the selected review, Lendon, 2015¹¹⁴ addressing multidimensional tools (patient experience) (continued).

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

EOLD=End of Life in Dementia; FAMCARE=Family Satisfaction with Advanced Cancer Care; ICU=intensive care unit; ND=no data available and review did not attempt abstraction

Evidence Table 9a. Characteristics of the selected review, Antunes, 2014¹⁵⁷ addressing tools used in clinical care.

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

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence Table 9b. Instruments used in the selected review, Antunes, 2014¹⁵⁷ addressing tools used in clinical care.

Author, year	Sample	Physical	Psychological	Social	Spiritual	Cultural	Care of the Patient at the End of Life	Ethical and Legal	Cross domains (experience)	Cross domains (QOL)
Schulman-Green, 2010 ¹⁵⁸	hospices	N	N	N	N	N	N	N	N	ESAS
Schwartz, 2005 ¹⁰⁴	Hospice, home and palliative care settings	N	N	N	N	N	N	N	N	MVQOLI-R, MSAS
Escalante, 2008 ¹⁵⁹	Emergency center, cancer	NRS for fatigue and pain	N	N	N	N	N	N	N	N
Kamel, 2001 ¹⁶⁰	Nursing homes	VAS for pain	N	N	N	N	N	N	N	N
Chang, 2002 ¹⁶¹	Oncology clinic	N	N	N	N	N	N	N	N	FACT-L
Clark, 2009 ¹⁶²	Cancer center	N	'How can we help you and your family' screening instrument	N	N	N	N	N	N	N

ESAS=Edmonton Symptom Assessment Scale; FACT-L= Functional Assessment of Cancer Therapy-Lung; MSAS=Memorial Symptom Assessment Scale; MVQOLI-R=Missoula-VITAS Quality of Life Index; N=no data was in the article but review attempted abstraction; NRS= Numeric rating scale; VAS=Visual Analogue Scale

Evidence table 10a. Characteristics of the selected review, De Roo, 2013¹⁶³ addressing tools used as quality indicators.

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

NCP=National Consensus Project for Quality Palliative Care Clinical Practice

Evidence table 10b. Instruments used the selected review, De Roo, 2013¹⁶³ addressing tools used as quality indicators.

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

ND=no data available and review did not attempt abstraction

Evidence table 11. Tools used in included articles for Kavalieratos, 2014¹⁶⁵ evaluating interventions.

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

Evidence table 11. Tools used in included articles for Kavalieratos, 2014¹⁶⁵ evaluating interventions (continued)

Author (Year)	Sample	Physical Aspects of Care	Psychosocial and Psychiatric Aspects of Care	Cross Domains: Patient Experience	Cross domains: Quality of Life
Given, 2002 ¹⁸²	cancer	Symptom Experience Scale*	NM	NM	SF-36*
Grande, 1999 & 2000 ^{183, 184}	mixed	NM	NM	NM	NM
Grudzen, 2016 ¹⁸⁵	cancer	NM	PHQ-9*†	NM	FACT-G*
Hanks, 2002 ¹⁸⁶	cancer	VAS† MPAC†	WONCA*	MacAdam's Assessment of Suffering*	EORTC QLQ-C30
Higginson, 2014 ¹⁸⁷	mixed	NRS† Chronic Respiratory Disease Questionnaire	HADS	NM	EQ-5D*
Hughes, 1992 ¹⁸⁸	mixed	NM	NM	Greer Satisfaction with Care Survey*	NM
Jordhoy, 2000 & 2001 ^{189, 190}	cancer	NM	Impact of Event Scale*	NM	EORTC QLQ-C30
Kane, 1984 & 1985 ^{191, 192}	cancer	California Pain Assessment Profile*	CES-D*† General Wellbeing Measure*	Ware Scale*	NM
Lowther, 2015 ¹⁹³	HIV	African Palliative Outcomes Scale*	GHQ-12	NM	MOS-HIV*
McCorkle, 1989 ¹⁹⁴	cancer	Symptom Distress Scale*	POMS*†	NM	NM
Northouse, 2005 ¹⁹⁵	cancer	NM	NM	NM	FACT-B* SF-36*
Northouse, 2007 ¹⁹⁶	cancer	Omega Screening Questionnaire* Expanded Prostate Cancer Index Composite*	NM	NM	FACIT-Pal SF-12*
Northouse, 2013 ¹⁹⁷	cancer	NM	NM	NM	FACT-G*
Pantilat, 2010 ¹⁹⁸	mixed	NRS†	NRS†	NM	NM

Evidence table 11. Tools used in included articles for Kavalieratos, 2014¹⁶⁵ evaluating interventions (continued)

Author (Year)	Sample	Physical Aspects of Care	Psychosocial and Psychiatric Aspects of Care	Cross Domains: Patient Experience	Cross domains: Quality of Life
Rabow, 2004 ¹⁹⁹	mixed	UCSD Shortness of Breath Questionnaire Brief Pain Inventory [†] MOS ^{*†}	POMS ^{*†} CES-D ^{*†}	Group Health Association of America Consumer Satisfaction Survey*	Multidimensional Quality of Life Scale-Cancer*
Radwany, 2014 ²⁰⁰	mixed	NM	HADS	NM	MSAS QUAL-E
Rummans, 2006 ²⁰¹	cancer	LASA* Symptom Distress Scale*	POMS ^{*†}	NM	Spitzer Uniscale*
Sidebottom, 2015 ²⁰²	CHF	NM	PHQ-9 ^{*†}	NM	ESAS Minnesota Living with Heart Failure Questionnaire*
Temel, 2010 ²⁰³	cancer	NM	HADS PHQ-9 ^{*†}	NM	FACT TOI* FACT-L*
Wallen, 2012 ²⁰⁴	cancer	Gracely Pain Scale* Symptom Distress Scale*	CES-D ^{*†}	NM	NM
Zimmer, 1984 & 1985 ^{205, 206}	mixed	NM	NM	McCusker scale ^{*†}	NM
Zimmermann, 2014 ²⁰⁷	cancer	NM	NM	FAMCARE-P16 CARES-MIS*	ESAS FACIT-Sp* QUAL-E

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

CES-D=Center for Epidemiologic Studies Depression Scale; CSDD= Cornell Scale for Depression in Dementia; EORTC QLQ-C30=European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-30 items; ESAS=Edmonton Symptom Assessment Scale; FACIT-Pal=Functional Assessment of Chronic Illness Therapy-Palliative sub scale; FLACC= Faces Legs Activity Cry Consolability Behavioral Pain Scale; GHQ-12 =General Health Questionnaire-12 item; HADS =Hospital Anxiety and Depression Scale; ICU=intensive care unit; KCCQ= The Kansas City Cardiomyopathy Questionnaire; MCOHPQ= Modified City of Hope Patient Questionnaire; MOS- Medical Outcomes Study; MPAC=Memorial Pain Assessment Card; MS= MS Palliative Outcome Scale-S5; MSAS=Memorial Symptom Assessment Scale; MVQOLI-R=Missoula-VITAS Quality of Life Index; N=no data was in the article but review attempted abstraction; NRS= Numeric rating scale; PAINAD= Pain in Advanced Dementia; PHQ-9=Patient Health Questionnaire-9; POMS=Profile of Mood States; QUAL-E=Quality of life at the end of life; TOI=Trials Outcome Index (sum of selected FACT subscales); UCSD SOBQ =University of California San Diego Shortness of Breath Questionnaire; VAS=Visual Analogue Scale

[†]Indicates tool that was found during website search.

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