



## Assessment Instruments for End of Life Care, by Domain

Instruments by Domain	Abbreviation	First Author (citation)
<b>Physical Symptoms</b>		
Checklist of Non-verbal Pain Indicators	CNPI	Feldt <sup>1</sup>
Discomfort Scale for Dementia of the Alzheimer's Type	DS-DAT	Hurley <sup>2</sup>
Edmonton Symptom Assessment System	ESAS	Bruera <sup>3</sup> Modonesi <sup>4</sup> Tierney <sup>5</sup>
McGill Pain Questionnaire		Melzack <sup>6,7,8</sup>
Pain Assessment in Advanced Dementia	PAIN-AD	Warden <sup>9</sup>
Respiratory Distress Observational Scale	RDOS	Campbell <sup>10</sup>
Symptom Monitor		Hoekstra <sup>11</sup>
Douleur Enfant Gustave Roussy (for children)	DEGR	Gauvain-Piquard <sup>12</sup>
<b>Multiple Domains</b>		
Scales for the Evaluation of EOL Care in Dementia	EOL-D	Kiely <sup>13</sup>
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire	EORTC QLQ-C30	Bjorner <sup>14</sup> Ford <sup>15</sup> Kaasa <sup>16-17</sup> Stromgren <sup>18</sup>
Functional Assessment of Cancer Treatment	FACT	Cella <sup>19</sup> Montoya <sup>20</sup> Thompson <sup>21</sup>
Family Satisfaction with Advanced Cancer Care	FAMCARE	Kristjanson <sup>22-23</sup> Ringdal <sup>24</sup>
McGill Quality of Life (QOL) Questionnaire		Cohen <sup>25,26</sup> Lo <sup>27</sup>
Missoula-VITAS QOL Index		Byock <sup>28</sup> Steele <sup>29</sup> Williams <sup>30</sup>
Palliative Care QOL Instrument		Mystakidou <sup>31</sup>
Quality Care Questionnaire-End of Life	QCQ-EOL	Yun <sup>32</sup>
Quality of Death and Dying	QODD	Curtis <sup>33</sup> Patrick <sup>34</sup>
Quality of End of Life Care and Satisfaction	QUEST	Sulmasy <sup>35</sup>
Structured Interview for Symptoms and Concerns	SISC	Wilson <sup>36</sup>
Toolkit/Family Evaluation of Hospice Care	FEHC	Teno <sup>37</sup> Connor <sup>38-39</sup>
<b>Psychological Symptoms</b>		
Agitation Distress Scale		Morita <sup>40</sup>

<b>Instruments by Domain</b>	<b>Abbreviation</b>	<b>First Author (citation)</b>
Communication Capacity Scale		Morita <sup>47</sup>
Cornell Scale for Depression in Dementia	CSDD	Alexopoulos <sup>41</sup> Kurlowicz <sup>42</sup>
PRIME-MD / PHQ-9		Kroenke <sup>43</sup> Lowe <sup>44</sup> Robinson <sup>45</sup>
<b>Continuity of Care</b>		
McCusker Scale		McCusker <sup>46</sup>
Picker-Commonwealth		Cleary <sup>47</sup>
Care Transitions Measure	CTM	Coleman <sup>48</sup>
<b>Social Aspects of Care</b>		
Bereavement Risk Index	BRI	Beckwith <sup>49</sup> Kristjanson <sup>50</sup> Robinson <sup>51</sup>
Duke-UNC Social Support Scale		Broadhead <sup>52</sup> Herndon <sup>53</sup>
Family Appraisal of Caregiving Questionnaire	FACQ	Cooper <sup>54</sup>
Hogan Grief Reaction Checklist	HGRC	Hogan <sup>55</sup>
<b>Spiritual Aspects of Care</b>		
Meaning in Life Scale		Warner <sup>56</sup>
Brief Spiritual Beliefs Inventory	SBI-15	Holland <sup>57</sup>
<b>Ethical/Legal Aspects of Care</b>		
Decisional Conflict Scale	DCS	O'Connor <sup>58</sup> Song <sup>59</sup>
Quality of Communication	QOC	Engelberg <sup>60</sup>
<b>Function</b>		
Edmonton Functional Assessment Tool	EFAT	Kaasa <sup>23</sup>
Rapid Disability Rating Scale		Linn <sup>61</sup>
<b>Cultural Aspects of Care</b>		
Cultural Competence Scale		Doorenbos <sup>62</sup> Schim <sup>63</sup>
<b>Prognosis</b>		
Palliative Performance Scale	PPS	Anderson <sup>64</sup> Head <sup>65</sup> Olajide <sup>66</sup>

## References

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1. Feldt, K.S., The checklist of nonverbal pain indicators (CNPI). *Pain Manag Nurs*, 2000. 1(1): p. 13-21.
2. Hurley, A.C., et al., Assessment of discomfort in advanced Alzheimer patients. *Res Nurs Health*, 1992. 15(5): p. 369-77.
3. Bruera, E., et al., The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care*, 1991. 7(2): p. 6-9.
4. Modonesi, C., et al., Impact of palliative care unit admission on symptom control evaluated by the Edmonton Symptom Assessment System. *Journal of Pain & Symptom Management*, 2005. 30(4): p. 367-373.
5. Tierney, R.M., et al., Relationships between symptom relief, quality of life, and satisfaction with hospice care. *Palliative Medicine*, 1998. 12(5): p. 333-344.
6. Melzack, R., The McGill Pain Questionnaire: major properties and scoring methods. *Pain*, 1975. 1(3): p. 277-99.
7. Melzack, R., The short-form McGill Pain Questionnaire. *Pain*, 1987. 30(2): p. 191-7.
8. Melzack, R., J.G. Ofiesh, and B.M. Mount, The Brompton mixture: effects on pain in cancer patients. *Can Med Assoc J*, 1976. 115(2): p. 125-9.
9. Warden, V., A.C. Hurley, and L. Volicer, Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc*, 2003. 4(1): p. 9-15.
10. Campbell M. Psychometric Testing of a Respiratory Distress Observational Scale. *J Pall Med* 2008; 11:44-50.
11. Hoekstra, J., et al., The symptom monitor. A diary for monitoring physical symptoms for cancer patients in palliative care: feasibility, reliability and compliance. *J Pain Symptom Manage*, 2004. 27(1): p. 24-35.
12. Gauvain-Piquard A, Rodary C, Resvan A, Serbouti S The development of the DEGR(R): A scale to assess pain in young children with cancer, *Eur J P* 2006. 3(2):165-176.
13. Kiely,DK, Volicer,L, Teno,J, Jones,RN, Prigerson,HG, Mitchell,SL: The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis.Assoc.Disord.* 20:176-181, 2006
14. Bjorner, J.B., et al., Use of item response theory to develop a shortened version of the EORTC QLQ-C30 emotional functioning scale. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 2004. 13(10): p. 1683-1697.
15. Ford, M.E., S.L. Havstad, and C.S. Kart, Assessing the reliability of the EORTC QLQ-C30 in a sample of older African American and Caucasian adults. *Qual Life Res*, 2001. 10(6): p. 533-41.

- 
16. Kaasa, T., et al., Inter-rater reliability of formally trained and self-trained raters using the Edmonton Functional Assessment Tool. *Palliat Med*, 2000. 14(6): p. 509-17.
  17. Kaasa, S., et al., The EORTC core quality of life questionnaire (QLQ-C30): validity and reliability when analysed with patients treated with palliative radiotherapy. *Eur J Cancer*, 1995. 31A(13-14): p. 2260-3.
  18. Stromgren, A.S., et al., Pain characteristics and treatment outcome for advanced cancer patients during the first week of specialized palliative care. *Journal of Pain & Symptom Management*, 2004. 27(2): p. 104-113.
  19. Cella, D.F., et al., The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol*, 1993. 11(3): p. 570-9.
  20. Montoya, M., et al., Objective evaluation of physical function in patients with advanced lung cancer: a preliminary report. *J Palliat Med*, 2006. 9(2): p. 309-16.
  21. Thomson, J.E., The place of spiritual well-being in hospice patients' overall quality of life. *Hospice Journal*, 2000. 15(2): p. 13-27.
  22. Kristjanson, L.J., Validity and reliability testing of the FAMCARE Scale: measuring family satisfaction with advanced cancer care. *Soc Sci Med*, 1993. 36(5): p. 693-701.
  23. Kristjanson, L.J., et al., Family members' care expectations, care perceptions, and satisfaction with advanced cancer care: results of a multi-site pilot study. *J Palliat Care*, 1997. 13(4): p. 5-13.
  24. Ringdal, G.I., M.S. Jordhoy, and S. Kaasa, Measuring quality of palliative care: Psychometric properties of FAMCARE Scale. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 2003. 12(2): p. 167-176.
  25. Cohen, S.R., et al., Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. *Palliative Medicine*, 1997. 11(1): p. 3-20.
  26. Cohen, S.R., et al., The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliat Med*, 1995. 9(3): p. 207-19.
  27. Lo, R.S.K., et al., Quality of life of palliative care patients in the last two weeks of life. *Journal of Pain & Symptom Management*, 2002. 24(4): p. 388-397.
  28. Byock, I.R. and M.P. Merriman, Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index. *Palliat Med*, 1998. 12(4): p. 231-44.
  29. Steele, L.L., et al., The quality of life of hospice patients: patient and provider perceptions. *Am J Hosp Palliat Care*, 2005. 22(2): p. 95-110.
  30. Williams, A., et al., A randomized controlled trial of meditation and massage effects on quality of life in people with late-stage disease: a pilot study. *Journal of Palliative Medicine*, 2005. 8(5): p. 939-952.

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31. Mystakidou, K., et al., The "Palliative Care Quality of Life Instrument (PQLI)" in terminal cancer patients. *Health Qual Life Outcomes*, 2004. 2(1): p. 8.
  32. Yun, Y.H., et al., Patient-reported assessment of quality care at end of life: development and validation of Quality Care Questionnaire-End of Life (QCQ-EOL). *Eur J Cancer*, 2006. 42(14): p. 2310-7.
  33. Curtis, J.R., et al., A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage*, 2002. 24(1): p. 17-31.
  34. Patrick, D.L., R.A. Engelberg, and J.R. Curtis, Evaluating the quality of dying and death. *J Pain Symptom Manage*, 2001. 22(3): p. 717-26.
  35. Sulmasy, D.P., et al., A scale of measuring patient perceptions of the quality of end-of-life care and satisfaction with treatment: the reliability and validity of QUEST. *Journal of Pain & Symptom Management*, 2002. 23(6): p. 458-470.
  36. Wilson, K.G., et al., Structured interview assessment of symptoms and concerns in palliative care. *Can J Psychiatry*, 2004. 49(6): p. 350-8.
  37. Teno, J. M., et al. "Validation of Toolkit after-Death Bereaved Family Member Interview." *J Pain Symptom Manage* 22.3 (2001): 752-8.
  38. Connor, S. R., et al. "Measuring Hospice Care: The National Hospice and Palliative Care Organization National Hospice Data Set." *J Pain Symptom Manage* 28.4 (2004): 16-28.
  39. Connor, S. R., et al. "Family Evaluation of Hospice Care: Results from Voluntary Submission of Data Via Website." *J Pain Symptom Manage* 30.1 (2005): 9-17.
  40. Morita, T., et al., Communication Capacity Scale and Agitation Distress Scale to measure the severity of delirium in terminally ill cancer patients: a validation study. *Palliat Med*, 2001. 15(3): p. 197-206.
  41. Alexopoulos, G.S., et al., Cornell Scale for Depression in Dementia. *Biol Psychiatry*, 1988. 23(3): p. 271-84.
  42. Kurlowicz, L.H., et al., A psychometric evaluation of the Cornell Scale for Depression in Dementia in a frail, nursing home population. *Am J Geriatr Psychiatry*, 2002. 10(5): p. 600-8.
  43. Kroenke, K., R. L. Spitzer, and J. B. Williams. "The Phq-9: Validity of a Brief Depression Severity Measure." *J Gen Intern Med* 16.9 (2001): 606-13.
  44. Lowe, B., et al. "Responsiveness of the Phq-9 to Psychopharmacological Depression Treatment." *Psychosomatics* 47.1 (2006): 62-7.
  45. Robinson, J. A., and G. B. Crawford. "Identifying Palliative Care Patients with Symptoms of Depression: An Algorithm." *Palliative Medicine* 19.4 (2005): 278-87.

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46. McCusker, J., Development of scales to measure satisfaction and preferences regarding long-term and terminal care. *Med Care*, 1984. 22(5): p. 476-93.
  47. Cleary, P.D., et al., Patients evaluate their hospital care: a national survey. *Health Aff (Millwood)*, 1991. 10(4): p. 254-67.
  48. Coleman, E.A., E. Mahoney, and C. Parry, Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Med Care*, 2005. 43(3): p. 246-55.
  49. Beckwith, B.E., et al., Identification of spouses at high risk during bereavement: A preliminary assessment of Parkes and Weiss' Risk Index. *Hospice Journal*, 1990. 6(3): p. 35-46.
  50. Kristjanson, L.J., et al., Evaluation of the Bereavement Risk Index (BRI): a community hospice care protocol. *Int J Palliat Nurs*, 2005. 11(12): p. 610, 612-8.
  51. Robinson, J.A. and G.B. Crawford, Identifying palliative care patients with symptoms of depression: an algorithm. *Palliative Medicine*, 2005. 19(4): p. 278-287.
  52. Broadhead, W.E., et al., The Duke-UNC Functional Social Support Questionnaire. Measurement of social support in family medicine patients. *Med Care*, 1988. 26(7): p. 709-23.
  53. Herndon, J.E., 2nd, et al., A longitudinal study of quality of life in advanced non-small cell lung cancer: Cancer and Leukemia Group B (CALGB) 8931. *Control Clin Trials*, 1997. 18(4): p. 286-300.
  54. Cooper, B., G. J. Kinsella, and C. Picton. "Development and Initial Validation of a Family Appraisal of Caregiving Questionnaire for Palliative Care." *Psychooncology* 15.7 (2006): 613-22.
  55. Hogan, N.S., D.B. Greenfield, and L.A. Schmidt, Development and validation of the Hogan Grief Reaction Checklist. *Death Stud*, 2001. 25(1): p. 1-32.
  56. Warner, S.C. and J.I. Williams, The Meaning in Life Scale: determining the reliability and validity of a measure. *J Chronic Dis*, 1987. 40(6): p. 503-12.
  57. Holland, J.C., et al., A brief spiritual beliefs inventory for use in quality of life research in life-threatening illness. *Psychooncology*, 1998. 7(6): p. 460-9.
  58. O'Connor, A.M., Validation of a decisional conflict scale. *Med Decis Making*, 1995. 15(1): p. 25-30.
  59. Song, M. and S.M. Sereika, An evaluation of the Decisional Conflict Scale for measuring the quality of end-of-life decision making. *Patient Education & Counseling*, 2006. 61(3): p. 397-404.
  60. Engelberg, R., L. Downey, and J.R. Curtis, Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. *J Palliat Med*, 2006. 9(5): p. 1086-98.
  61. Linn, M.W. and B.S. Linn, The rapid disability rating scale-2. *J Am Geriatr Soc*, 1982. 30(6): p. 378-82.
  62. Doorenbos, A.Z., et al., Psychometric evaluation of the cultural competence assessment instrument among healthcare providers. *Nursing Research*, 2005. 54(5): p. 324-331.

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63. Schim, S.M., et al., Development of a cultural competence assessment instrument. *Journal of Nursing Measurement*, 2003. 11(1): p. 29-40.
64. Anderson, F., et al., Palliative performance scale (PPS): a new tool. *J Palliat Care*, 1996. 12(1): p. 5-11.
65. Head, B., C.S. Ritchie, and T.M. Smoot, Prognostication in Hospice Care: Can the Palliative Performance Scale Help? *Journal of Palliative Medicine*, 2005. 8(3): p. 492-500.
66. Olajide, O., et al., Validation of the palliative performance scale in the acute tertiary care hospital setting. *J Palliat Med*, 2007. 10(1): p. 111-7.

This material was prepared by The Carolinas Center for Medical Excellence (CCME), the Medicare Quality Improvement Organization for North Carolina, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. 8SOW-NC-PEACE-08-03