

# JOHNS HOPKINS Assessment Tools for Palliative Care



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# Background

- · Assessment tool: Psychometrically evaluated data collection instruments completed by patients/caregivers
- There are many existing palliative care (PC) assessment tools and compilations; 1-4 however, no recent reviews have comprehensively addressed PC assessment tools across domains

# **Objectives**

- Summarize the characteristics of palliative care assessment tools and describe how these tools have been applied for clinical care, quality indicators, and evaluation of interventions
- Identify needs for future palliative care assessment tool development and evaluation

### Methods

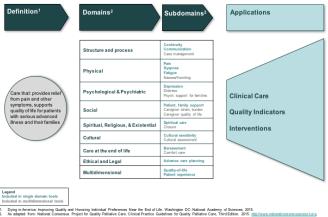
#### **Data Sources**

- Interviews with Key Informants representing patient/caregiver and provider perspectives
- ·Systematic reviews of palliative care assessment tools using PubMed, CINAHL, Cochrane, PsycINFO and PsycTESTS from January 2007 to August 2016
- Supplemental search of reviews and websites

#### **Review Methods**

- Tools organized by National Consensus Project Clinical Practice Guidelines for PC domains (Figure 1)
- ·Included the most relevant, recent, and highest-quality systematic reviews per domain

Figure 1. Conceptualization of domains and applications of PC assessment tool



### Conclusions

- We identified more than 150 assessment tools addressing most domains of PC
- Few to no tools address the spiritual, ethical, cultural, or patient-reported experience domains
- Responsiveness of different tools to change and comparisons between tools have not been evaluated
- Future research should:
  - 1. Develop/test tools addressing domains w/o tools
  - 2. Test tools in PC populations, particularly spiritual
  - 3. Evaluate responsiveness of tools for all domains
  - 4. Improve use of PC tools in clinical care and QI
- Report: www.effectivehealthcare.ahrq.gov/reports/final.cfm Correspondence: Ms. Sarina Isenberg, PhD Candidate, Johns Hopkins Bloomberg School of Public Health, sisenbe2@jhu.edu
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# Results

### **Key Informants**

#### 2 Caregiver advocates:

- •Tools may have meaningful info for clinicians, but have minimal impact on patients/families
- •Each encounter or survey start with the clinicians identifying the patient/family's "biggest concern", and modify surveys to empower patient/family

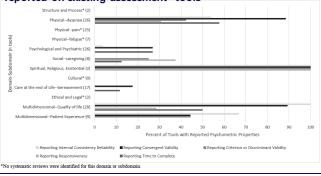
### 7 Providers Who are Experts in PC and tools:

- Tools are not used enough in clinical delivery or as quality indicators because of feasibility challenges
- NCP domains do not address some crucial aspects of PC (e.g., advance care planning, referral timing)

#### Systematic Review

- Included 10 systematic reviews of PC assessment tools (7 for domains and multidimensional tools,5-11 and 3 for applications of tools)12-14
- We identified 146 tools (98 from systematic reviews and 48 from other sources)
- Key gaps included the following:
  - No systematic review for the subdomain of pain and lack of many tools on structure and process, cultural, ethical/legal, and patientreported experience domains
  - Only 2 tools for the spiritual domain were evaluated in PC populations
  - Among multidimensional tools, none contained cultural domain items
  - Information on internal consistency reliability, construct validity, and usability was available for many tools, but few studies evaluated responsiveness, or compared tools (Figure 2)
- Only 6 studies evaluated the use of tools in clinical practice and only 1 quality indicator with a specified assessment tool
- Among 43 PC interventions, only 23 PC assessment tools were used for evaluation 14

Figure 2. Evidence map of % of psychometric properties reported on existing assessment tools



### Selected References

- Teno J. Toolkit of Instruments to Measure End of Life Care (TIME) Center for Gerontology and Health Care Research. Brown Medical School. 2001.
- 2. 3. Mularski RA, et al. Health Serv Res. 2007 Oct;42(5):1848-70.
- Dy SM, et al. J Am Geriatr Soc. 2008 Jan;56(1):124-9.
- Hanson LC, et al. J Palliat Med. 2010 Oct;13(10):1253-60.
- Dorman S, et al. Palliat Med. 2007 Apr;21(3):177-91 6. Ziegler L, et al. J Pain Symptom Manage. 2011;41(3):619-36.
- Michels CT, et al. Palliat Med. 2016 Jan;30(1):23-44. Selman L, et al. J Pain Symptom Manage. 2011 Oct;42(4):604-22. Sealey M, et al. Palliat Med. 2015 Jul;29(7):577-89. 8.
- Albers G, et al. Palliat Med. 2010 Jan;24(1):17-37.
- Lendon JP, et al. J Pain Symptom Manage. 2015 May;49(5):904-15
- Antunes B, et al. Palliat Med. 2014 Feb;28(2):158-75.

  De Roo ML, et al. J Pain Symptom Manage. 2013 Oct;46(4):556-72. 13.
- Kavalieratos D, Corbelli J, Zhang D, et al. JAMA 2016;316(20):2104-