



Effective Health Care

Assessment Tools in Palliative Care Nomination Summary Document

Results of Topic Selection Process & Next Steps

- A systematic review on the topic, *Assessment Tools in Palliative Care*, is not feasible due to the limited data available at this time; however, it will be considered for a potential technical brief by the Effective Health Care (EHC) Program.
- To see a description of a technical brief, please go to <http://effectivehealthcare.ahrq.gov/index.cfm/research-for-policymakers-researchers-and-others/>.
- If this topic is developed into a technical brief, key questions will be drafted and posted on the AHRQ Web site. To sign up for notification when this and other EHC Program topics are posted, please go to <http://effectivehealthcare.ahrq.gov/index.cfm/join-the-email-list1/>.

Topic Description

Nominator(s): Individual

Nomination Summary: The topic was nominated by a physician interested in outcomes associated with quality indicators for palliative care. Quality indicators are often focused, process measures that are used to identify variations in care. For example, a quality indicator can measure whether a patient's pain was brought to a comfortable level within 48 hours.

We identified limited evidence about the link between quality indicators and patient and caregiver outcomes. Thus, with consultation from experts, we focused on assessment tools in palliative care.

The experts suggested that a review on assessment tools in palliative care would be an important and more feasible topic and a significant contribution to knowledge of palliative care. Valid assessment tools in palliative care can provide important prognostic information and provide information on a patient's quality of life, level of pain, and mental health. These tools may also assess patient and caregiver satisfaction or palliative care processes including communication, cultural competence in staff, and continuity of care. Assessment tools may be used to help evaluate the desired outcomes of a quality indicator. For example, a pain assessment tool may be used to determine a baseline level of pain and assess whether pain had been brought to a comfortable level.

Staff-Generated PICO

Population(s): Individuals receiving palliative care and their families

Intervention(s): Assessment tools, questionnaires, instruments, and scales

Comparator(s): Those listed above (i.e., compared to each other), informal or minimal

assessment

Outcome(s): 1) Patient outcomes including physical health (e.g., pain, fatigue, dyspnea), mental health (e.g., depression, distress), and satisfaction; 2) Caregiver outcomes including grief, quality of life, mental health, physical health, and satisfaction; 3) Process outcomes including communication, cultural competence, and continuity of care

Key Questions from Nominator: Based on discussions with experts, the following Key Question was developed for the revised scope of the topic brief:

What is the evidence base supporting the use of palliative care assessment tools?

Considerations

- The topic meets EHC Program appropriateness and importance criteria. (For more information, see <http://effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/how-are-research-topics-chosen/>.)
- The need for palliative care spans across multiple clinical conditions including cancer, heart failure, chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's, and other conditions. Estimates suggest that 69-82% of individuals will need palliative care in their lifetime.
- Palliative care interventions can be categorized into multiple domains including those addressing: processes (e.g., assessment), physical symptoms (e.g., pain, fatigue, dyspnea), psychological and psychiatric symptoms (e.g., depression, distress), social, spiritual and religious, cultural, and ethical and legal concerns or issues.
- The need for palliative care spans across multiple clinical conditions including cancer, heart failure, chronic obstructive pulmonary disease (COPD), kidney failure, Alzheimer's, and other conditions. Estimates suggest that more than 80% of individuals will need palliative care in their lifetime. Outcomes assessed in palliative care can include patient outcomes, such as physical health (e.g., pain, fatigue, dyspnea), mental health (e.g., depression, distress), and satisfaction; caregiver outcomes, including grief, quality of life, mental health, physical health, and satisfaction; and process outcomes, including communication, cultural competence, and continuity of care
- Assessment tools play an important role in palliative care. Tools may be used to collect prognostic information and information on outcomes as well as evaluate processes. Evidence-based, validated assessment tools are needed to ensure that the tools accurately evaluate the desired outcomes of interest. However, there is uncertainty regarding the evidence base behind these tools as well as uncertainty regarding the effectiveness of these assessments.
- We identified two relevant reviews
 - The PEACE (Prepare, Embrace, Attend, Communicate, Empower) Project, sponsored by the Centers for Medicare & Medicaid Services (CMS), developed a set of quality measures and data collection tools for palliative care providers. Hanson et al., (2010) reports the results of the PEACE Project literature review of clinical instruments in palliative care. The review identified instruments and evaluated them using a structured scoring guide for psychometric properties. A total of 39 instruments scoring at or above the 75th percentile were recommended for use. The tools were categorized by domain. They found few instruments to measure cultural

- aspects of care, structure and process of care, continuity of care. They noted the limited evidence that the instruments were responsive to improved practices.
- Stiel et al., (2012) reviewed instruments for outcome assessment in palliative care. They examined the outcomes measured, and critically appraised the instruments. They found a minority of instruments validated. The review concluded that the wide scope of available instruments makes it difficult to recommend a universal set of tools and that a conceptual framework may be needed.
 - We did not identify sufficient evidence for a systematic review, but another product such as a technical brief, may be possible. However, it is important to note that many of the tools are not specifically developed for palliative care and can be used across a variety of care settings.