

Palliative Care: A National Guideline Summary

Crystal Graening, Sandra Harbort, & Molly Hilzendeger

University of Mary

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Palliative care is defined as a special type of medical care that improves the quality of life for individuals who have a serious illness and is based on bringing relief from the symptoms it causes while including curative treatment (National Institute on Aging, 2017). Over the last 15 years, this field within healthcare has grown at a rapid rate with more hospitals having palliative care teams and palliative care being present within community settings (Center to Advance Palliative Care, n.d.). Because of this, a need to develop palliative care assessment tools has been identified (Agency for Healthcare Research and Quality, 2016).

Scope

As the Agency for Healthcare Research and Quality (AHRQ) (2016) identifies in the research protocol on this, assessment tools for palliative care are necessary because they help to identify the effectiveness and quality of care being provided.

Guidelines

Guidelines are a strong foundation for a topic. The guidelines are set forth to help direct or guide the discussion on a specific topic. The following were set as guidelines to use in evaluating palliative care:

- Structure/Process of care (e.g., continuity, communication)
- Physical Aspects of Care (e.g., pain, dyspnea)
- Psychological and Psychiatric Aspects of Care
- Social Aspects of Care (including caregiving)
- Spiritual, Religious and Existential Aspects of Care
- Cultural Aspects of Care (including cultural competence)
- Care of the Patient at the End of Life

- Ethical and Legal Aspects of Care (care planning) (AHRQ, 2016, para. 3)

Objectives

There have been various projects over the years that have compiled various palliative care assessment tools including the Toolkit of Instruments to Measure End-of-Life Care (TIME), Improving End-of-Life Care, and the PEACE Palliative Care Quality Measures projects (AHRQ, 2016). Since the PEACE project in 2007, no other updates or reviews have been done on the assessment tools used in palliative care, even though many more have been created, demonstrating a need for one (AHRQ, 2016). The use of these tools is important as is further development of them. Palliative care assessment tools will help sort through the goals that both the patient and family will have in regards to the level of functioning the patient has, whether more conservative versus curative measures want to be taken, relief from pain and suffering, independence and allowing for more time and home, and ultimately, providing the best quality of life allowing for a 'good death' (Powers, Norton, Schmitt, Quill, & Metzger, 2011).

Demographics

Our society on a whole is aging and more cares are going to need to be provided to these individuals. People are also living longer than they ever had, and it is crucial that resources like palliative care are available to help allow for an easier transition from the onset of a serious illness to the time of death (Powers et al., 2011).

Data

There is data that shows how important palliative care has become, and the individuals and families perceive it positively. The use of palliative care and the assessment tools it uses has been shown to increase the quality of care, decrease the suffering symptoms can cause, and an increase in the overall satisfaction by patients and families in the care that it allows for based on

reports on studies looking at the outcomes of this type of care (Powers et al., 2011). Further success was seen with the use of palliative care assessment tools as data demonstrates how patients and families reported satisfaction based on how consistent palliative care teams were with assessments, communication, and the focus of the care being centered on the patient and the goals that had been set (Powers et al., 2011). Efforts are needed to continue to explore the impact assessment tools within palliative care have so that these positive outcomes can continue.

Methods Used

According to the AHRQ, the method that was used to collect and select data on palliative care was extensive electronic database searches. When formulating research questions and keywords to search, all aspects of palliative care was analyzed. The questions that were formed were created in the PICO format. PICO is described by Reavy (2016) as “an acronym for a questioning strategy used with EBP projects, generally intervention or comparison projects, and it contributes to ease in finding evidence and relevance of findings” (p. 65). The PICO format determines the population, intervention, comparison, and projected outcome of an evidence-based practice question (Reavy, 2016, p. 65). This framework provided guidance for the completion of the literature searching process to aid in the development of recommendations for palliative care.

Literature searches were done utilizing Cochrane, PubMed and CINAHL databases. The research criteria included looking for systematic reviews and recent relevance of the last ten years (AHRQ, 2016). Articles were analyzed for quality, relevance, recency, and availability of evidence tables with relevant information (AHRQ, 2016).

Another search that was utilized was a Grey literature search. A Grey literature search was used to analyze websites that have created and reported evaluations of tools for palliative

care and were created in the last five years (AHRQ, 2016). Websites that were included were the University of Washington End-of-Life Care Research Program Instruments site, the City of Hope Pain & Palliative Care Resource Center, the Measurement and Caregiver Cores of the Palliative Care Research Cooperative Group, the National Palliative Care Research Center Measurement and Evaluation Tools and the Functional Assessment of Chronic Illness Therapy (FACIT) system (AHRQ, 2016). Figure 1 demonstrates the guidelines for palliative care domains for tools when research.

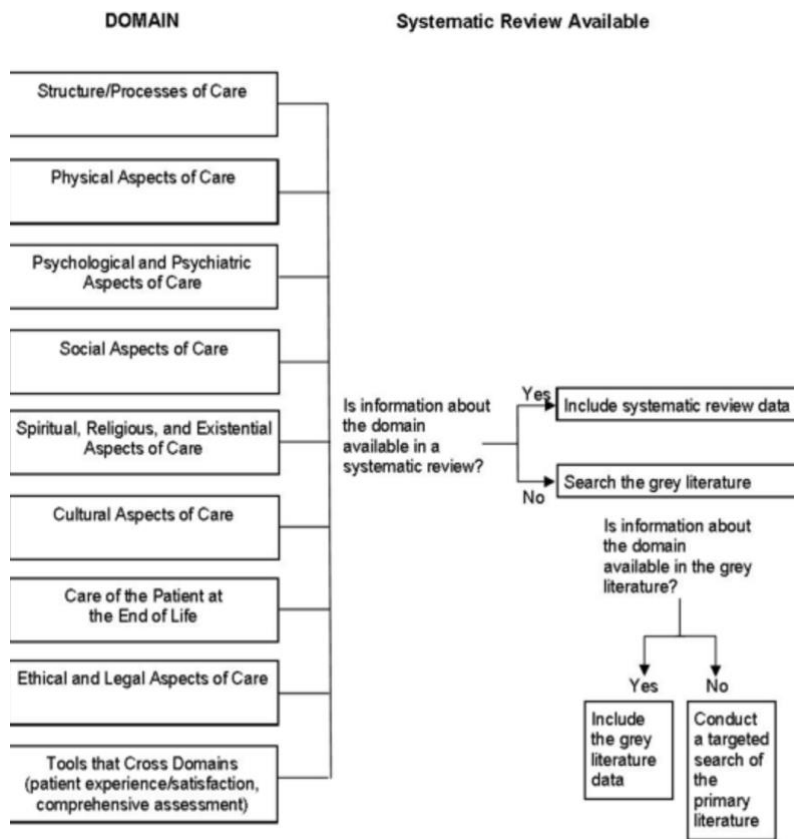


Figure 1. Search flow Based on National Consensus Project Clinical Practice Guidelines for Palliative Care Domains for Tools (AHRQ, 2016).

Research was also conducted through key informant interviews. These interviews focused on perspectives and issues that were not available from researching sources through the

process described above. The interviews were conducted in small groups with caregiver advocates receiving a separate call. The key informants included leading palliative care researchers and quality experts applying tools in relevant populations and settings including the intensive care unit, oncology, pediatrics, heart failure, geriatrics and bereavement (AHRQ, 2016).

Number of Sources

When analyzing the number of sources utilized to create the palliative care guidelines, inclusion criteria was followed. Figure 2 represents the inclusion criteria that was utilized.

Category	Criteria
Content	Evaluates palliative care assessment tools used in palliative care (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 (see definition below); All diseases, age groups and settings
Study design	Systematic reviews; For interventions, include systematic reviews of prospective, controlled trials
Language/ Country	English/ United States
Admissible evidence	Published literature only for reliability, validity, and responsiveness

Figure 2. Inclusion Criteria. (AHRQ, 2016).

After reviewing the guideline, an exact number of resources that was utilized was not noted. A statement was made that numerous databases, websites, and key informant interviews were utilized to obtain information. Thirty-one references were shown in the guideline, however it was stated that not all websites and key informant interviews that were utilized in the guideline were listed in the reference list.

Rating Scheme for Strength

As stated previously, literature searches were quality assured by cross-checking the reference list of articles that were relevant to the study, filtering through the articles, and only obtaining full copies if relevant to the topic of palliative care. From the database research nothing older than ten years was utilized and from the Grey literature research nothing was utilized that was older than five years (AHRQ, 2016). The guideline did not specifically state what type of rating scheme was utilized.

Cost Analysis

The guideline stated that a cost analysis was reviewed and published. The guideline was funded by Contract No. HHS 290-2015-00006-I from the AHRQ and the United States Department of Health and Human Services, but no exact costs were listed (AHRQ, 2016).

Guideline Validation

The guideline states that a peer review was conducted by an independent researcher, and the feedback was incorporated back into the guideline.

Major Recommendations/Findings

Palliative care assessment tools allow clinicians to better serve patients and their families. It serves clinicians by helping to determine patient needs/concerns and goals of care important to the patient and their family. Effective assessment tools help patients by opening the lines of communication between the care team and the patient for a more satisfying care outcome. Findings recommended assessments be made short and simple to reduce patient time requirements and question fatigue. A single question assessment was preferred, using the example, “are you depressed?” as an assessment question to identify mood (Stiel, Kues, Krumm & Elsner, 2011). Asking the patient his/her biggest concern helps to understand what is

important to patients and their families, this can lead to better communication and set the tone for the patient's goals for their care going forward in treatment planning (AHRQ, 2016).

Another recommendation was additional assessment tools to accommodate pediatric populations and non-oncology patients as many studies utilized are in the oncology palliative care setting. "Palliative care should be provided to patients with any serious or advanced illness, independent of prognosis or disease specific treatment" (Swami & Case, 2018, p. 184).

More tools are also needed in assessing the needs of cultural groups, ethical and legal domains, spiritual, religious and existential domains (AHRQ, 2016). An expanded population, prolonged life and global travel allow for easier relocation. Cultural competency and excellent communication are required more than ever as people may be located far from support systems and rely on their care team's understanding of what is important to them. Electronic data systems incorporating palliative assessment tools for point of care entry that can be shared among team disciplines could assist with these items as many assessments are still done in paper form that may not efficiently get transmitted between members of the care team (Kamal et al., 2016).

Lastly, evaluating tools and tool responsiveness is recommended to assist with further development and testing of tools in patient populations with few existing or no existing assessment tools in clinical care and as quality indicators (AHRQ, 2016). Effectiveness is difficult to note when there is not enough comparison material.

Limitations/Harms/Contraindications

Contraindications were noted to palliative care assessment. Cited were lack of time, staff, funding and administrative support to implement effective palliative care programs where there currently are none (Swami & Case, 2018). This makes for difficult use of assessment tools.

There were no harms found; however, one could conclude that the next item may be considered a

harm or a contraindication. Many of the current assessments employ numerous questions and are quite lengthy. This makes utilizing them overwhelming and brings to mind the accuracy of responses in a patient population who likely have physical, cognitive and psychological impairments (Stiel et al., 2011). If accurate, this may make the time-consuming assessment distressing to the patients. Patients and caregivers agreed this was overwhelming and indicated the assessments may benefit the clinician asking and not necessarily benefit the patient (AHRQ, 2016). In the above recommendations, a preference for a single question assessment was noted. Some assessment items, such as determining quality of life aspects, may be difficult to deduce adequate conclusions in a single question format (Stiel, et al., 2011).

In conclusion of the limitations, it was felt that tools were excluded that were not specifically studied in palliative care populations, multiple versions of tools that were studied may exist but not always noted and tools were not evaluated for responsiveness (AHRQ, 2016).

Benefits

There are many benefits to implementing palliative care practices. Utilizing effective assessment tools allows for better implementation of care interventions and strategies to improve care. The tools help to identify the most important and distressing concerns of the patient and their family which may be different from what the care team believes the most distressing issues may be. It allows for more personalized medicine by identifying patient specific needs for making patient specific decisions, improve patient outcomes, quality of life and survival (Kamal, et al., 2016).

Hospitals, care systems, patients and insurers are continually more concerned with costs, payment matters and reimbursement issues. Effectively identifying and implementing palliative care interventions reduces unnecessary emergency room visits, hospital admissions and non-

advantageous use of intensive care (Swami & Case, 2018). This leads to better patient satisfaction and less overwhelming of the healthcare system which benefits everyone.

Conclusion

Palliative care is an important aspect on the continuum of care that requires assessment tools to determine and implement interventions to address. Interventions include structure/process of care, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, spiritual, religious and existential aspects of care, cultural aspects of care, care at the end of life and ethical and legal aspects of care (AHRQ, 2016, para. 3). Utilizing studies and reviews of those studies to measure the effectiveness of the available tools and making improvements to existing tools or add new tools is imperative. The created tools are vital to continue to offer and successfully expand the use of palliative care. An aging population and greater longevity of life give palliative care the opportunity to increase individualized patient centered care and decrease the cost burden to both the patients and the healthcare system.

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