Review Article

Measuring Experience With End-Of-Life Care: A Systematic Literature Review

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Abstract

Context. Increasing interest in end-of-life care has resulted in many tools to measure the quality of care. An important outcome measure of end-of-life care is the family members' or caregivers' experiences of care.

Objectives. To evaluate the instruments currently in use to inform next steps for research and policy in this area.

Methods. We conducted a systematic review of PubMed, PsycINFO, and PsycTESTS® for all English-language articles published after 1990 using instruments to measure adult patient, family, or informal caregiver experiences with end-of-life care. Survey items were abstracted and categorized into content areas identified through an iterative method using three independent reviewers. We also abstracted information from the most frequently used surveys about the identification of proxy respondents for after-death surveys, the timing and method of survey administration, and the health care setting being assessed.

Results. We identified 88 articles containing 51 unique surveys with available content. We characterized 14 content areas variably present across the 51 surveys. Information and care planning, provider care, symptom management, and overall experience were the most frequent areas addressed. There was also considerable variation across the surveys in the identification of proxy respondents, the timing of survey administration, and in the health care settings and services being evaluated.

Conclusion. This review identified several comprehensive surveys aimed at measuring the experiences of end-of-life care, covering a variety of content areas and practical issues for survey administration. Future work should focus on standardizing surveys and administration methods so that experiences of care can be reliably measured and compared across care settings. J Pain Symptom Manage 2015;■:■–■. *© 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

End-of-life care, assessment, family caregivers

Introduction

The 2010 Affordable Care Act's emphasis on health care quality through payment reform underscores the need to systematize approaches to assess performance and quality of care. This is particularly relevant to evaluating care at the end of life, a time period with considerable variation in health care utilization and quality[1,2] and when health care systems are challenged to respond effectively to the intense needs of seriously ill persons. Evaluating the end-of-life care experience presents unique challenges, including the frail and impaired condition of most patients that may

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preclude their participation in the assessment process and compels a reliance on proxy (i.e., family member or informal caregiver) reporting,[3–5] In addition, end-of-life care encompasses a wide range of services important to patients and families, from symptom management to spiritual support to bereavement care,[6,7] necessitating a multidimensional assessment approach. Because transitions in care are frequent[8] and use of various settings is common, assessment approaches also must capture organizational diversity, be applicable across multiple settings, and pose questions that enable the respondent to differentiate between care received in different settings.

Despite these challenges, surveys of experience of end-of-life care have been developed and used for quality improvement and research purposes. A better understanding of existing evaluation approaches and surveys can help to identify gaps in measurement and inform future policy decisions regarding quality and performance improvement. To identify all available surveys that cover this important component of quality, we undertook a comprehensive literature review of existing publicly available surveys and measures of patient, family, or informal caregiver experience and satisfaction with care at the end of life. Our review characterizes the areas of care that are included in available surveys and describes how proxy respondents are identified, the timing and method of survey administration, and the type of health care setting being assessed.

Methods

Search Strategy

We systematically reviewed the published literature on patients', families', or informal caregivers' experiences with end-of-life care.[9–11] We searched PubMed, PsycINFO, and PsycTESTS® for English-language articles published between January 1, 1990 and June 6, 2012. We further limited our search to studies of adults (aged older than 18 years) and used a combination of the following search terms to identify the various ways end-of-life care is conceptualized in the literature: "hospice" OR "palliative care" OR "end of life care" AND questionnaire OR telephone OR phone OR email OR survey OR surveys OR tool OR tools AND experience OR quality of health care OR experiences OR experienced OR satisfaction OR satisfied OR unsatisfied AND patient OR patients OR mother OR father OR mom OR dad OR parent OR parents OR guardian OR guardians OR caregiver OR caregivers OR spouse OR wife OR husband OR partner.

We also searched the gray literature (e.g., New York Academy of Medicine Gray Literature Report, Google, and the National Quality Measures Clearinghouse) using a similar search strategy for surveys or measures of family or informal caregiver experiences of end-of-life care. To identify additional resources, we reference-mined articles identified through the initial search and drew on members of our study team who are experts in the area of end-of-life care quality measurement (K. A. L. and J. M. T.) and an additional expert reviewer.

Article Selection

We included articles that 1) measured areas of patient, family member, or informal caregiver satisfaction and experience with end-of-life care and 2) included survey questions or instruments regarding patient/caregiver satisfaction or experience with end-of-life care. We excluded studies of pediatric populations and health care provider satisfaction with end-of-life care. Two reviewers, S. C. A. and A. M. W., a health services researcher and a palliative care clinician, respectively, with systematic review methodology experience first conducted independent dual review of identified references by title and abstract. Articles selected for full-text review were divided and independently screened by three reviewers (S. C. A., A. M. W., and R. A. P.). All articles included after full-text screening were divided and abstracted by study, survey, and survey question into a data abstraction file.

Data Analysis

First, we abstracted survey items from all 51 surveys in all of the selected articles to provide a general overview of the content areas covered by each survey. The research team first developed an initial list of potential content areas based on 1) our combined expertise in end-of-life care and 2) the National Consensus Project for Quality Palliative Care[12] and the National Quality Forum.[13] Three reviewers (S. C. A., A. M. W., and J. P. L.) independently coded a sample of survey questions and met to review differences in coding and reach consensus on a revised coding scheme. The same reviewers repeated this process with a second sample of survey questions to develop a final coding scheme. The remaining survey questions were then divided between the reviewers and coded according to this scheme, with regular group meetings to review the process and achieve agreement. One reviewer (J. P. L.) conducted a final quality check by reviewing each of the survey items within each content area for consistency. Items that were misclassified were reconciled and reclassified into the most appropriate content area based on the final coding scheme.

Second, for feasibility, we used a subset of surveys that were published in two or more selected articles