Original Article

Development and Psychometric Properties of a Survey to Assess Barriers to Implementing Advance Care Planning in Primary Care

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Abstract

Context. Valid and reliable measurement of barriers to advance care planning (ACP) in health care settings can inform the design of robust interventions.

Objective. This article describes the development and psychometric evaluation of an instrument to measure the presence and magnitude of perceived barriers to ACP discussion with patients from the perspective of family physicians.

Methods. A questionnaire was designed through literature review and expert input, asking family physicians to rate the importance of barriers (0 = not at all a barrier and 6 = an extreme amount) to ACP discussions with patients and administered to 117 physicians. Floor effects and missing data patterns were examined. Item-by-item correlations were examined using Pearson correlation. Exploratory factor analysis was conducted (iterated principle factor analysis with oblique rotation), internal consistency (Cronbach's alpha) overall and within factors was calculated, and construct validity was evaluated by calculating three correlations with related questions that were specified a priori.

Results. The questionnaire included 31 questions in three domains relating to the clinician, patient/family and system or external factors. No items were removed due to missing data, floor effects, or high correlation with another item. A solution of three factors accounted for 71% of variance. One item was removed because it did not load strongly on any factor. All other items except one remained in the original domain in the questionnaire. Cronbach's alpha for the three factors ranged from 0.84 to 0.90. Two of three a priori correlations with related questions were statistically significant.

Conclusion. This questionnaire to assess barriers to ACP discussion from the perspective of family physicians demonstrates preliminary evidence of reliability and validity. J Pain Symptom Manage 2018;55:12–21. © *2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Primary care, surveys, psychometrics, barriers, communication

Background

Advance care planning (ACP) is a communication process wherein people plan for a time when they cannot make decisions for themselves. It includes reflection, deliberation, and determination of a person's values and wishes or preferences for treatments at the end of life and communication between an individual and his or her loved ones, future substitute

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Accepted for publication: August 3, 2017.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2017.08.003

decision makers, and health care providers about these values and wishes.[1] When people have engaged in ACP, they are more likely to report higher quality of life near end of life, rates of depression and anxiety among bereaved family members are likely to be lower,[2] and there are significantly lower health care costs.[3]

Family practice is the setting where longitudinal relationship-centered care across the life cycle is provided for most patients.[4] ACP discussions initiated in the primary care setting could ensure that patients and families are better prepared to make future in-the-moment decisions they may face elsewhere in the health care system. Patients have an expectation that their family physician will initiate such discussions.[5–7] In a 2014 systematic review of the effectiveness of ACP interventions, only 10 of 113 included studies were conducted in community or outpatient settings, the remainder being conducted in institutional settings such as hospital.[8] It is recognized that ACP discussions should happen in the community and in primary care,[5,9,10] however, such discussions occur infrequently between patients and health care providers in primary care.[6,11,12] Approximately half of Canadian adults have engaged in some type of end-of-life discussion with family members or friends,[13] however across numerous countries, estimates of occurrence of patient-physician discussions range from 9% in the general adult population to less than 50% among patients in the last three months of life.[11,13,14]

To increase the quantity and quality of ACP in primary care, interventions guided by knowledge of the specific barriers to and facilitators of ACP in this setting are needed. Reducing barriers that impede best practices is optimal for improving health care delivery.[15] To adequately understand such barriers, valid, reliable assessment methods are needed.[16] A systematic review of studies that examined perceived barriers of ACP for general practitioners rated the quality of studies but did not report information on the rigor of development of the questionnaire instruments used in the studies, and the magnitude of perceived barriers could not be reported due to the variability in methods across studies.[7] Surveys to measure barriers that will inform the design of robust interventions should have reasonable psychometric properties.[17] The objective of this report is to describe the development and psychometric evaluation of a questionnaire instrument to measure the presence and magnitude of perceived barriers to ACP discussion with patients from the perspective of primary care physicians.

Methods

Questionnaire Development

The purpose of the questionnaire was to identify and quantify the barriers to having ACP discussions in primary care as perceived by family physicians. We followed the structure of a previously published questionnaire on barriers to goals of care discussions that was administered to hospital physicians, residents, and nurses, using the same formatting and instructions for completion, the same response scales and conceptual grouping of categories of barriers, and a similar open-ended question asking about what would help enable discussions. Details of the development and face and content validity of the hospital setting questionnaires have been described previously.[18] We provided a preamble to the primary care questionnaire to indicate it was asking primary care providers about ACP in their practice. The first page provided a definition of ACP based on a published framework of end-of-life (EOL) communication and decision-making as deliberation and determination of a person's values and wishes or preferences for treatments at the end of life, communication among an individual, his or her loved ones and future substitute decision maker(s), communication among an individual and his or her health care provider(s), and documentation of wishes.[1]

Item Generation. To generate the barriers items for the first draft, we used items from the acute care version that were of relevant to any setting and health care provider (e.g., lack of time and lack of training). Next, we consulted a systematic review of 15 studies of barriers to doing ACP as reported by primary care physicians.[7] We reviewed the tabulated barriers in that review, and two authors (M.H. and D.K.H.) generated items to correspond to them. We grouped the items into three areas relating to the clinician, patient/family, and system or external factors, with a separate heading for each group of questions.

With the questionnaire first draft, we conducted two focus groups; one with researchers from our study team (family physicians, critical care physicians, a geriatrician, and palliative care physicians) conducted first, and a second with family physicians in a group practice in the community to further refine items to assure content validity and wording clarity. Clinicians taking part in the focus groups completed the questionnaires themselves in order to stimulate discussion. Two of the authors (M.H. and D.K.H.) facilitated the groups, asking whether items were clearly worded and how to revise if unclear, whether there were redundant or irrelevant items in the context of primary care that should be removed, and whether there were items that should be added. A formal qualitative analysis of the focus groups was not done. The authors recorded notes on the feedback on items and wording.

Survey Administration

Details of the questionnaire administration have been described previously.[19] In brief, we conducted a