Original Article

Improving End-of-Life Communication and Decision Making: The Development of Conceptual Framework and Quality Indicators

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Abstract

Context. The goal of end-of-life (EOL) communication and decision making is to create a shared understanding about a person's values and treatment preferences that will lead to a plan of care that is consistent with these values and preferences. Improvements in communication and decision making at the EOL have been identified as a high priority from a patient and family point of view.

Objectives. The purpose of this study was to develop quality indicators related to EOL communication and decision making.

Methods. We convened a multidisciplinary panel of experts to develop definitions, a conceptual framework of EOL communication and decision making, and quality indicators using a modified Delphi method. We generated a list of potential items based on literature review and input from panel members. Panel members rated the items using a seven-point Likert scale (1 = very little importance to 7 = extremely important) over four rounds of review until consensus was achieved.

Results. About 24 of the 28 panel members participated in all four rounds of the Delphi process. The final list of quality indicators comprised 34 items, divided into the four categories of our conceptual framework: Advance care planning (eight items), Goals of care discussions (13 items), Documentation (five items), and Organization/System aspects (eight items). Eleven items were rated "extremely important" (median score). All items had a median score of five (moderately important) or greater.

Conclusion. We have developed definitions, a conceptual framework, and quality indicators that researchers and health care decision makers can use to evaluate and improve the quality of EOL communication and decision making. J Pain Symptom Manage 2015;■:■−■. © *2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Advance care planning, modified Delphi study, end-of-life care, palliative care, communication, decision making, quality indicators

Introduction

Improvements in communication and decision making at the end-of-life (EOL) have been identified as a high priority from a patient and family point of view.[1] The main goal of EOL communication and decision making is to create a shared understanding about a person's values and care preferences that will lead to a plan of care that is congruent with these

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values and preferences. In EOL situations, most patients lack the capacity to make these decisions,[2] but patients who have participated in advance care planning (ACP) are more likely to receive care that reflects their preferences.[3] ACP is associated with higher quality of life and higher satisfaction with care among patients, lower rates of depression and anxiety among bereaved family members,[3] and significantly lower health care costs.[4] Accordingly, health care organizations worldwide have established policies for ACP.[5–7] To be effective, decisions made in the process of ACP must be available when the patient has a life-threatening illness. These plans are frequently not available or not requested; this is a missed opportunity to improve EOL care.[8]

There remain important gaps in EOL communication and decision making for sick, elderly patients who are admitted to acute care institutions.[8] The inadequate discussions and/or documentation of the goals of care is an error of omission,[9] and this omission often results in more invasive care than that is desired by the patient.[8,10] Improving communication and decision making has the potential not only to improve patient-centered care and reduce harm but also to reduce health care costs. Unfortunately, very few health care organizations measure the quality of EOL care in general, and specifically, aspects of EOL communication and decision making.[11] Although much has been done to develop quality indicators in the broad field of palliative/EOL care,[12] we are unaware of any other quality indicators specifically related to EOL communication and decision making.

Quality indicators are one type of performance measure used to drive quality improvement in health care.[13,14] Quality indicators are defined as "norms, criteria, standards and other direct qualitative and quantitative measures used in determining the quality of health care".[15] Although there has been clear progress and measurement of performance in other areas of health care, there is no consensus about indicators related to EOL communication and decision making.[13,14] Accordingly, we posit that to improve EOL communication and decision making, we must be considerate of the following elements, namely ACP, a communication process wherein a capable patient discusses their values, wishes and preferences with their substitute decision maker and/or a member of the health care team, to prepare for future decisions or in case the patient cannot make decisions for him/herself; and Goals of Care Discussions (GOCD), which occur between a physician, patient, and/or a substitute decision maker in an institutionalized setting to obtain informed consent for a plan of care; and documentation of these discussions and plans that must be present across time and place in the health care system. Therefore, the aim of this study was to first develop a conceptual framework and standardized definitions and then a list of indicators that might be used to assess the quality of communication and decision making at the EOL within the acute care setting.

Methods

Panel Members

To develop quality indicators to evaluate communication and decision making at the EOL, we convened a multidisciplinary panel of experts from Canadian networks of health care professionals and researchers who work in palliative or EOL care. Most of the panel comprised individuals involved in the inpatient management of acutely ill patients, which was consistent with the setting of where the communication and decision making occurs. The sample of experts was a purposive sample,[16] identified by two of the authors (D. K. H. and T. S.). Inclusion criteria for selecting panel members were expertise in clinical health services research and/or practice as it relates to EOL communication and decision making, ACP, or palliative care.

A letter of invitation was sent to the potential participants clearly stating the aim of the study, the research technique, a description of the tasks, an estimated time of completion for each round of surveys, and the confidentiality of the opinions and feedback provided by each of the panel respondents. A total of 28 participants who responded to the research team stating that they would like to participate in the study were included. Ethics approval for the study was obtained from the Research Ethics Board at Queen's University.

Development of Definitions and a Conceptual Framework

We developed a conceptual framework to guide the panel review to ensure that key domains were captured and organize the quality indicators. Conceptual frameworks have an important role in informing quality measurement.[17] To ensure clarity and consistency in our discussions and to guide the development and categorization of indicators, we used iterative electronic, telephone, and in-person facilitated discussions among the panel members to develop standard definitions and a conceptual framework for EOL communication and decision making (Appendix). All panel members were invited to participate in these discussions; 18 panel members made up the core group that developed the conceptual framework. To facilitate the development of the conceptual framework, a priori we defined EOL communication and decision making as a clinical interaction, which includes discussion of death and dying as part of the progression of illness or a potential outcome despite treatment efforts. It is not limited to the terminal stages of dying and includes discussions about care