

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

Tasnim Sinuff, MD, PhD, Peter Dodek, MD, MHSc, John J. You, MD, MSc, FRCPC, Doris Barwich, MD, CCFP, Carolyn Tayler, RN, BN, MSA, CON (C), James Downar, MDCM, MHSc, FRCPC, Michael Hartwick, MD, MEd, FRCPC, Christopher Frank, MD, FCFP, Henry T. Stelfox, MD, FRCPC, PhD, and Daren K. Heyland, MD, FRCPC, MSc

Department of Critical Care Medicine and Sunnybrook Research Institute (T.S.), Sunnybrook Health Sciences Centre, Toronto, Ontario; Interdepartmental Division of Critical Care Medicine (T.S.), University of Toronto, Toronto, Ontario; Center for Health Evaluation and Outcome Sciences and Division of Critical Care Medicine (P.D.), St. Paul's Hospital and University of British Columbia, Vancouver, British Columbia; Departments of Medicine, and Clinical Epidemiology & Biostatistics (J.J.Y.), McMaster University, Hamilton, Ontario; BC Center for Palliative Care (D.B.), Division of Palliative Care, Department of Medicine, University of British Columbia, Vancouver, British Columbia; Fraser Health Authority (C.T.), Surrey, British Columbia; Divisions of Critical Care and Palliative Care (J.D.), Department of Medicine, University of Toronto, Toronto, Ontario; Divisions of Critical Care and Palliative Medicine (M.H.), Department of Medicine, University of Ottawa, Ottawa, Ontario; Division of Geriatric Medicine (C.F.), Department of Medicine, Queen's University, Kingston, Ontario; Department of Critical Care Medicine (H.T.S.), Institute for Public Health, University of Calgary, Calgary, and Alberta Health Services-Calgary Zone, Calgary, Alberta; and Department of Medicine (D.K.H.), Queen's University, Kingston, Ontario, Canada

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;49:1070–1080. © 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

Address correspondence to: Daren K. Heyland, MD, FRCPC, MSc, Angada 4, Kingston General Hospital, Kingston, Ontario, Canada K7L 2V7. E-mail: dkh2@queensu.ca

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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

with patients who have advanced chronic diseases as well as discussions with healthy people who are planning for care related to unexpected illnesses.

Selection of Quality Indicators

To develop the initial list of quality indicators, we reviewed published literature from the year 2000 to 2014 to identify clinical practice guidelines, documents about quality indicators, and other best practice statements that were directly related to EOL communication and decision making for adult patients and their families in the community or hospital setting. We identified three main references^{18–20} to inform this process. From this literature review, we found that the Audit of Communication, Care Planning, and Documentation study investigators⁸ developed an initial set of 23 items that they considered to be important indicators of EOL communication and decision making.

Delphi Method

Based on the initial 23 items, we used a modified Delphi method^{21,22} to refine the list of indicators. Hence, the focus of this Delphi process was item generation to achieve consensus on a comprehensive, clinically sensible list of items. This methodology allowed us to elicit expert knowledge about a topic where evidence is limited. Consensus was sought to identify items that would measure the quality of EOL communication and decision making. To achieve this consensus, we conducted four rounds of online surveys between March 2013 and June 2013 using the web-based FluidSurveys™ platform (© 2015 FluidSurveys. All rights reserved. A SurveyMonkey product.). We initially planned to conduct three rounds of surveys. However, at the end of three rounds, we had not yet achieved consensus and stability of the results. Hence, we added a fourth round. In each round, respondents rated the importance of each item using a seven-point Likert scale ranging from 1 = very little importance to 7 = extremely important. In the first three rounds, we also included an open-ended question, asking panel members to list any additional important items that were not included in the previous list.

Starting with the second round, participants provided feedback on the results of the previous round (simplifying and clarifying), suggested new items, and repeated their rating of the importance of each item, including the new items. Each round aimed to further refine the list of items by deleting those considered less important and adding new items that were considered to be more important. We used our conceptual framework to separate the final set of items into four categories: the three components of EOL communication and decision making (ACP, decisions about goals of care and consent for medical treatments, documentation of the output of the discussions), and health care

system issues (see [Appendix](#) for detailed definitions). Conference calls were held at the end of the third and fourth rounds to determine clarity of items, to get consensus on items to delete, and to revise the conceptual framework developed as part of this study. A final report examining the study's major findings was distributed to the expert panel and their feedback was sought during the final conference call of the study.

Statistical Analysis

The analysis was descriptive. For each item, we determined the mean and standard deviation, and median and interquartile range of the ratings of importance. Items were then ranked within each of the four categories and overall by the median. Where the medians were the same, to achieve greater separation, we used the item means to further rank the items.

Results

The initial panel comprised 28 participants, primarily physicians (68%) and researchers (54%) ([Table 1](#)). Of these, 24 participated in all rounds of the Delphi process.

Table 1
Demographic and Professional Characteristics of the Delphi Panel

Characteristics	<i>n</i> (%), <i>N</i> = 28
Age (yrs)	
30–39	10 (36)
40–49	7 (25)
50–59	6 (21)
60–69	5 (18)
Gender	
Female	13 (46)
Province of residence	
Alberta	4 (14)
British Columbia	5 (18)
Manitoba	1 (4)
Ontario	14 (50)
Quebec	4 (14)
Professional background ^a	
Physician	19 (68)
Researcher	15 (54)
Nurse	4 (14)
Administrator	2 (7)
Social worker	2 (7)
Other	
Professor	1 (4)
Ethicist	1 (4)
Educator	1 (4)
Representative of health care sector ^b	<i>n</i> (%), <i>N</i> = 24
Acute care	15 (63)
Primary care	0 (0)
Long-term care	3 (13)
Other ^c	6 (25)
Training in palliative care	<i>n</i> (%), <i>N</i> = 24
	10 (42)

^aParticipants may be counted more than once.

^bTotal is 24 and represents those participants who completed all four Delphi rounds.

^cHealth Services regional (acute, community, clinics) (1), Health Services researcher (palliative care) (1), Geriatric rehabilitation and palliative care (1), palliative care (2), NGO (1).

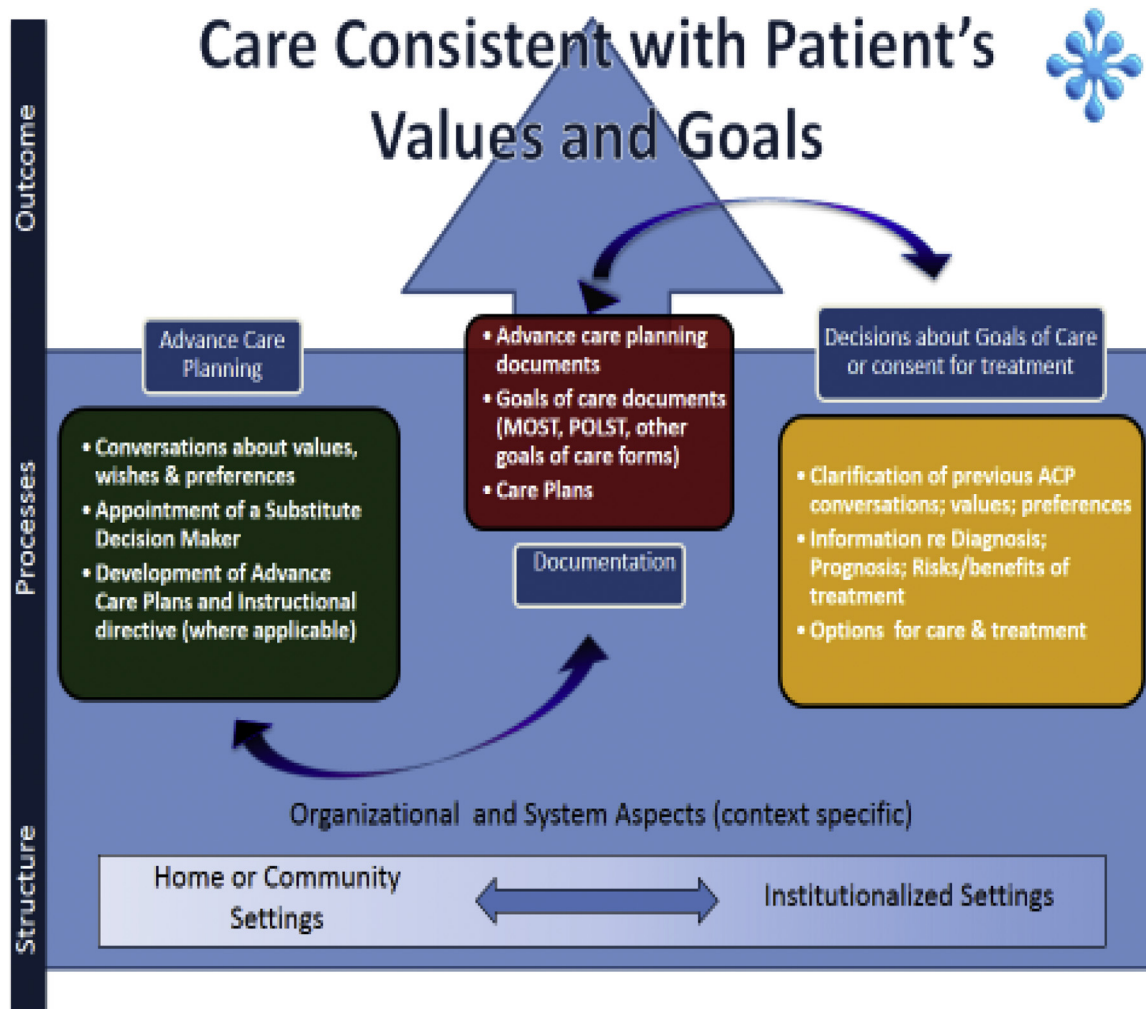


Fig. 1. Conceptual framework for improving end-of-life (EOL) communication and decision-making. The figure is intentionally not linear (Advance Care Planning [ACP] leading to Decisions about Goals of Care or Consent for Treatment leading to Documentation) as sometimes it is the requirement to fill out a form that initiates the conversation. The arrows are meant to communicate that an ACP process results in an ACP document that should be used to inform decisions about treatment options at the EOL (consenting to a treatment plan), which again, feeds back into documentation. Furthermore, within this cycle of EOL communication, with onset of illness or changing clinical conditions, discussions around goals of care may further influence ACP documents. The communication and decision-making processes are supported by institutional policy and procedures (structures). The ultimate goal is to ensure medically appropriate care received at the EOL is consistent with patient values and preferences (outcomes). MOST = Medical Orders for the Scope of Treatments; POLST = Physician Orders for Life-Sustaining Treatment. Developed by the Canadian Researchers at the End of Life Network (www.thecarenet.ca).

Relationship Between Conceptual Framework and Quality Indicators

Within this conceptual framework, the three components of EOL communication and decision making occur along a continuum, between community and institutional settings. We assumed that ACP would be conducted primarily, but not exclusively, in the community setting and that GOCD would occur primarily in institutional settings. It was expected that support for these communication processes, decisions, and documentation would be provided by structures within the health care system. To facilitate process improvement in EOL care, we focused on process measures related to the first three categories of our conceptual framework.

Quality Indicators

The second round of the survey included 11 new items suggested by panel members during round one, plus the initial set of 23 items (total of 34 items). After the fourth round, there was consensus to include 34 items, which were then divided into the four categories of our conceptual framework (Fig. 1): ACP, eight items; GOCD, 13 items; Documentation, five items; and Organization/System, eight items (Table 2).

Eleven items had a median importance score of seven (extremely important). All items had a median importance score of five (moderately important) or greater. There was a narrow spread of median

Table 2
List of Quality Indicators

1. ACP Category				
Indicator	Ranking in ACP Category	Overall Ranking	Mean (SD)	Median (IQR)
Before hospitalization, the patient discussed his/her preferences for using or not using life-sustaining treatments with their substitute decision maker (SDM).	1	7	6.58 (.72)	7.0 (6.0–7.0)
Before hospitalization, the doctor talked to the patient and/or a family member about a poor prognosis or indicated in some way that the patient has a limited time left to live.	2	8	6.54 (.59)	7.0 (6.0–7.0)
Before hospitalization, the patient and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with their family doctor or other doctor.	3	14	6.25 (.90)	6.5 (6.0–7.0)
Before hospitalization, the patient discussed his/her preferences for using or not using medically appropriate life-sustaining treatments with other family members.	4	18	6.17 (.92)	6.0 (6.0–7.0)
The patient has formally designated, in writing, someone who they trust to be their SDM concerning medical treatment decisions in the event they are not able to do so (using appropriate legal documentation depending on jurisdiction). In case of power of attorney, it should be related to health care.	5	23	6.04 (.86)	6.0 (5.0–7.0)
Before hospitalization, a member of the health care team offered to arrange a time when the patient and his/her family could meet with the doctor to discuss the use of medically appropriate life-sustaining treatments they would want, or not want, in the event the patient's physical health deteriorates.	6	24	6.00 (1.02)	6.0 (5.0–7.0)
The patient has an advance directive or living will or has indicated in some other way (verbal, video, and so on) the medical treatments they would want (or not want) in the event they are unable to communicate for themselves as a result of a life-threatening health problem.	7	27	5.88 (.90)	6.0 (5.0–6.5)
Before hospitalization, the patient and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with other health care professionals (i.e., nurse, social worker, and spiritual carer).	8	34	4.83 (1.13)	5.0 (4.0–6.0)
2. Goals of care/scope of treatment discussion category				
Indicator	Ranking in Goals of Care Category	Overall Ranking	Mean (SD)	Median (IQR)
Since admission, a member of the health care team has talked to the patient and/or SDM about a poor prognosis or indicated in some way that the patient has a limited time left to live.	1	1	6.75 (.44)	7.0 (6.5–7.0)
Since admission, a member of the health care team has talked to the patient and/or SDM about the outcomes, benefits, and burdens (or risks) of life-sustaining medical treatments.	2	4	6.63 (.65)	7.0 (6.0–7.0)
Since admission, a member of the health care team has talked to the patient and/or substitute decision maker about outcomes, benefits, and burdens of focusing on comfort care as the goal of the patient's treatment (e.g., palliative care or treating symptoms like pain without trying to cure or control their underlying illness).	2	4	6.63 (.65)	7.0 (6.0–7.0)
Since the patient's admission, a member of the health care team has offered to arrange a time when the patient/SDM and/or their family can meet with the doctor to discuss the treatment options and plans.	4	6	6.58 (.58)	7.0 (6.0–7.0)
Since the patient's admission, a member of the health care team has asked if the patient (or SDM if patient is incapable) had prior discussions or has written documents about the use of life-sustaining treatments.	5	10	6.50 (.72)	7.0 (6.0–7.0)
Since the patient's admission, a member of the health care team has asked the patient/SDM and/or their family what is important to them as they consider health care decisions at this stage of the patient's life (i.e., values, spiritual beliefs, and other practices).	6	11	6.29 (.86)	6.5 (6.0–7.0)
Since admission, a member of the health care team has given the patient the opportunity to express their fears or discuss what concerns them.	6	13	6.29 (.81)	6.0 (6.0–7.0)

Since admission, a member of the health care team has asked the patient and/or their family if they had any questions or needed things clarified regarding the patient's overall goals of care.	8	14	6.25 (.90)	6.5 (6.0–7.0)
Since admission, a member of the health care team has asked the patient what treatments they prefer to have or not have if they develop a life-threatening illness.	9	16	6.21 (1.02)	7.0 (5.5–7.0)
Since admission, the patient has been informed that they may change their minds regarding their decisions around goals of care.	10	26	5.92 (1.02)	6.0 (5.0–7.0)
Since admission, the patient and family have been offered an opportunity to discuss with members of the health care team issues around capacity and consent with regard to advance care planning (ACP); specifically what actions would take place in the possible event of losing capacity to consent to care.	11	29	5.71 (.95)	6.0 (5.0–6.0)
Since admission, the patient and family have been offered support from the allied health care team (e.g., spiritual care, social work, and clinical nurse specialist) as needed.	12	30	5.63 (1.10)	6.0 (5.0–6.5)
Since admission, a member of the health care team provided the patient and/or their family with information about GOCD to look at before conversations with the doctor.	13	32	5.42 (1.38)	6.0 (5.0–6.0)

3. Documentation category

Indicator	Ranking in Documentation Category	Overall Ranking	Mean (SD)	Median (IQR)
Documentation of a Goals of Care is present in the medical record.	1	2	6.71 (.55)	7.0 (6.5–7.0)
The Goals of Care present in the medical record is consistent with the patient's stated preferences.	1	3	6.71 (1.08)	7.0 (7.0–7.0)
If the hospital uses a standardized folder or other strategy to locate ACP/Goals of Care documents in the medical record, these are present in the medical record.	3	9	6.54 (.66)	7.0 (6.0–7.0)
Documentation of the outcomes of ACP conversations (including any prior expressed wishes, diaries, and power of attorney documents) is present in the patient's medical record.	4	18	6.17 (1.05)	6.5 (6.0–7.0)
Since admission, a member of the health care team has helped the patient and/or their family access legal documents to communicate the patient's ACPs.	5	33	5.17 (1.13)	5.0 (5.0–6.0)

4. Organizational/System Category

Indicator	Ranking in Organizational Category	Ranking in Total Score	Mean (SD)	Median (IQR)
A mechanism is in place to enable access to the most current ACP/GOCD documents with the patient in other settings within the health care system (i.e., electronic medical record and paper files).	1	12	6.29 (.69)	6.0 (6.0–7.0)
Institution uses a standardized folder or other strategy to locate ACP/Goals of Care documents in the medical record.	2	16	6.21 (.88)	6.0 (6.0–7.0)
The Institution ensures that clinical staff has access to the necessary professional development resources to ensure ACP facilitation skills can be attained or maintained.	3	20	6.13 (.74)	6.0 (6.0–7.0)
The Institution has documented ACP policies and/or procedures.	4	21	6.08 (.83)	6.0 (6.0–7.0)
The Institution has policies and procedures in place so that "high-risk" (as defined by the institution) patients participate in ACP/GOCD processes.	5	22	6.08 (.93)	6.0 (5.0–7.0)
The Institution has a continuous quality improvement initiative that audits and provides feedback to teams on specific ACP elements outlined in previous items.	6	25	5.96 (.95)	6.0 (5.0–7.0)
Institution management evaluates ACP knowledge and skills amongst relevant staff.	7	28	5.75 (.85)	6.0 (5.0–6.0)
The Institution has a process in place whereby patients with a specific disease, such as advanced chronic obstructive pulmonary disease, cancer, neurological disease, or heart failure are offered disease-specific advance directives.	8	31	5.46 (1.22)	6.0 (5.0–6.0)

GOCD = Goals of Care Discussion.

importance scores between the overall highest and lowest rated indicators as well as those within each subgroup.

The highest rated indicator overall was “Since admission, a member of the health care team has talked to the patient and/or substitute decision maker about a poor prognosis or indicated in some way that the patient has a limited time left to live (from the GOCD domain, mean score 6.75).” The top rated indicators in each category were:

1. ACP—Before hospitalization, the patient discussed his/her preferences for using or not using life-sustaining treatments with their substitute decision maker.
2. GOCD—Since admission, a member of the health care team has talked to the patient and/or substitute decision maker about a poor prognosis or indicated in some way that the patient has a limited time left to live.
3. Documentation (two indicators tied for first rank) - Documentation of a GOCD is present in the medical record; and the goals of care present in the medical record are consistent with the patient’s stated preferences.
4. Organizational/system—A mechanism is in place to enable access to the most current ACP/GOCD documents with the patient in other settings within the health care system (i.e., electronic medical record and paper files).

The two lowest rated indicators, with median scores of 5.0, were:

1. ACP—Before hospitalization, the patient and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with other health care professionals (i.e., nurse, social worker, or spiritual care; median score of 5.0 [4.0–6.0]).
2. Documentation—Since admission, a member of the health care team has helped the patient and/or their family access legal documents to communicate the patient’s ACPs (median score of 5.0 [5.0–6.0]).

Discussion

Improving EOL communication and decision making are high priorities from the perspectives of patients and their families,¹ and experts in palliative and EOL care.²³ We cannot begin to improve these processes until we have some measures of success. Accordingly, we convened a panel of experts to develop definitions, a conceptual framework, and a list of indicators to measure the quality of EOL communication and decision making. Because EOL communication takes place

mostly in times of crisis or transition, such as hospital admission,²⁴ we focused on processes that occur or could be measured on admission to acute care settings. Our conceptual framework illustrates the inter-relationships among ACP, GOCD, documentation, and the health care system that supports these processes. The 34 quality indicators identified through our modified Delphi process mapped onto each of these four categories. It is notable that our expert panel considered a large number of items to be extremely important, with very little spread in importance scores for the items overall or within domains. This ceiling effect makes it difficult to assess the relative importance of each quality indicator.

Our conceptual framework complements that published by Stewart et al.²⁵ The framework of Stewart et al.²⁵ describes the inter-relationships between patients, processes of care, structures of care, and outcomes of care at the EOL. Outcomes of care (e.g., quality of life, quality of dying, and satisfaction with care) are seen as functions of patient-specific variables at the EOL (clinical status, social supports, and so on), the processes of care patients undergo (such as the communication and decision-making process), and the structures in which these processes occur (buildings, health care professionals, support services, and so on). Complementing Stewart et al, our conceptual framework highlights specific elements of structure, processes, and outcomes of care related to EOL communication and decision making. Intrinsic to our conceptual framework is a set of definitions that ensure a common language for all stakeholders involved in improving EOL communication and decision making. The applicability or generalizability of these definitions and the conceptual framework to all clinical settings remains an open question.

Our study is the first of many steps in developing a robust set of validated quality indicators that will ultimately help guide quality measurement in the area of communication and EOL care. The contribution of the present study is to highlight the key process measures associated with care at the EOL that focus on patients’ values and preferences. The comprehensive list of items that we have developed will require validation in subsequent research to assess the relative importance of each item. Indeed, we suspect that our current list may be too long for routine clinical or administrative use. Further item reduction should come from studies within specific sectors (acute, long-term, or primary care) or by specific stakeholders (patients, decision makers, or clinicians). For each of these settings and for each of these stakeholders, different items may be of varying levels of importance.

There are a number of important next steps in the process of validation of this scoring system. This

would include a survey to test face validity across a wider group of stakeholders (patients, their families, and health care providers across settings). For those indicators that do have face validity, the next step would be to develop criteria (i.e., target population, numerator, denominator, threshold, risk adjustment strategy, and so on) and measure construct and criterion validity and reliability so that they can be operationalized as performance measures to actually measure care. Specifically, criterion validity needs to be established and can be done by demonstrating a relationship between the quality indicators and patient-reported experience measures such as those previously developed in the validated Canadian Health Care Evaluation Project (CANHELP) instrument.^{1,26} Ultimately, it will be important to determine whether measuring these quality indicators facilitates improvements in patient-centered EOL care. Although further research is needed, there is evidence that interventions designed to improve communication and decision making can be effective in improving patient-centered outcomes.²⁷

Our study has several strengths. First, we used an explicit literature search to inform the initial selection of items for the scoring system. Second, we used a Delphi process and explicit scoring of importance. Third, our team included both clinicians and researchers to refine the items that were ultimately selected. Therefore, the final list of indicators has both face and content validity. Further validation of these quality indicators would include comparison with other forms of patient-reported experience measures (the CANHELP satisfaction instrument²⁶) or health care provider assessments of EOL care (such as the Quality of Death and Dying score²⁸). These indicators and future scoring systems derived from them may provide important metrics for health care organizations to use as quality indicators for both ACP and goals of care decision making and related documentation. Ultimately, the use of these indicators should be shown to be associated with improved decision making that leads patients to receive care consistent with their values and preferences.

Our study also has a number of limitations. Although our rating system allowed us to rank items based on degree of importance, these final rankings reflected the composition of the group participating in the Delphi process. As most participants were physicians who work in acute care environments (Table 1), the rankings could be biased toward processes that occur in hospital, rather than in the community. Furthermore, the narrow spread of importance scores precluded an understanding of the relative importance of different items.

Conclusions

We have used best available evidence and a rigorous process to develop definitions, a conceptual framework, and a comprehensive list of quality indicators for evaluation of the quality of ACP, GOCD, documentation, and system supports for EOL care. Measurement of these indicators may inform initiatives to enhance the quality of EOL care. Further work will be needed to identify practical and contextualized criteria to assess the quality of EOL care processes within different sectors and stakeholder groups.

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Appendix

Definitions for End-of-Life Communication and Decision Making

We define end-of-life (EOL) communication and decision making as a clinical interaction, which includes discussion of death and dying (e.g., as part of progression of illness or a potential outcome of treatment). It is not limited to the terminal stages of dying and includes discussions about care with patients who have advanced chronic disease as well as discussions with healthy people who are planning for care related to unexpected illnesses. The EOL communication and decision making comprises the following process steps or elements: 1) Advance care planning (ACP); 2) Goals of care discussions and related decisions; and 3) Documentation of these discussions and decisions/plans.

1 Advance Care Planning

Definitions

The 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. By values, we mean an expression of a person's overarching philosophies or priorities in life. Wishes and preferences are used interchangeably and refer to specific preferred options for treatments or health states. These expressions are generally made outside of the clinical context and are not to be misconstrued as a medical decision; a medical decision requires consideration as to whether the wishes and preferences are clinically indicated. The ACP includes communication among an individual, their loved ones, future substitute decision maker(s), and health care provider(s) about these values and wishes. It may result in the naming of a person to make decisions for the patient, should they become incapable, and the specification of treatments they do or do not want at the end-of-life. It may also result in a written expression of wishes and preferences (advance care plans), although verbal or other expressions are also useful.

Context

In some provinces, this process may lead to the option of a written instructional directive or living will (specific instructions for treatments to be used or not used, or choices for future medical care), whereas these documents do not have legal standing in many other provinces and have limited clinical utility. The ACP should occur principally in home and community settings with everyone but especially among those who have advanced medical illness and their families and/or substitute decision makers.

2 Decisions about Goals of Care and Consent for Medical Treatments

Definition

This is also a communication process but is different from ACP as it usually occurs in an institutionalized setting, follows a prescribed communication process according to local laws or health care acts governing informed consent, and results in (a) medical decision(s). This process involves a competent patient or, if incapable, with a substitute decision maker as legally prescribed (possibly the person nominated in the ACP). When dealing with substitute decision makers and making decisions about the patient's medical treatment, consideration needs to be given as to how the patient's prior expressed wishes or directives apply to the current situation and/or are "clinically indicated."

Elements of this decision-making encounter include:

- Understanding of the illness (including curable, incurable, and chronic illnesses), including trajectory and prognosis, and potential outcomes of treatment options (including quality of life) from the perspectives of the patient, the family (including the surrogate decision maker), and the health care team.
- Expression of the person's values and what has meaning for him/her, and the goals of care identified in the current context of care.
- Fears the person may have, including concerns about the disease trajectory and, ultimately, the dying process.
- Disease and/or symptom thresholds that may inform when to change goals of care.
- Understanding how the person and/or their surrogate decision maker prefer to make decisions (their desired role).
- Recommendations by healthcare team members regarding the potential benefit and harm of life-sustaining treatments given the patient's clinical situation and their values and wishes for care.
- Ensuring that medical decisions regarding care are clinically indicated, made and aligned with the patient's goals for their care, and adequately translated into care plans and medical orders.
- Obtaining consent to provide treatment or to withhold treatment (should include discussions on resuscitative measures, options for care without resuscitative measures, and care focused on comfort and support for the family).

These conversations are enacted through a physician order for scope of treatment (including use or non-use of life-sustaining treatments) that may guide current management (e.g., primary focus on comfort measures) or future management (e.g., use of cardiopulmonary resuscitation in the event of cardiac arrest). These orders should specify both interventions that are not going to be done (i.e., this patient is not for resuscitation) and interventions that are to be done (i.e., provide support for family).

3 Documentation of the Output of the Discussion and Decision

Various documents such as Physician Orders for Life-Sustaining Treatments, Medical Orders for the Scope of Treatments, Goals of Care Designations, or other “levels of care” forms are used to document medical orders. Henceforth, we will use Goals of Care Documents to refer to all documents that capture the medical orders resulting from previous ACP and discussions about goals of care and consent for medical treatment as described previously. Other forms used to document patients’ wishes, for example, “advance care plans” or “advance directives” or “living wills,” are not medical orders although are important documents to include in this section.