Barriers to Goals of Care Discussions With Seriously Ill Hospitalized Patients and Their Families
A Multicenter Survey of Clinicians

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IMPORTANCE Seriously ill hospitalized patients have identified communication and decision making about goals of care as high priorities for quality improvement in end-of-life care. Interventions to improve care are more likely to succeed if tailored to existing barriers.

OBJECTIVE To determine, from the perspective of hospital-based clinicians, (1) barriers impeding communication and decision making about goals of care with seriously ill hospitalized patients and their families and (2) their own willingness and the acceptability for other clinicians to engage in this process.

DESIGN, SETTING, AND PARTICIPANTS Multicenter survey of medical teaching units of nurses, internal medicine residents, and staff physicians from participating units at 13 university-based hospitals from 5 Canadian provinces.

MAIN OUTCOMES AND MEASURES Importance of 21 barriers to goals of care discussions rated on a 7-point scale (1 = extremely unimportant; 7 = extremely important).

RESULTS Between September 2012 and March 2013, questionnaires were returned by 1256 of 1617 eligible clinicians, for an overall response rate of 77.7% (512 of 646 nurses [79.3%], 484 of 634 residents [76.3%], 260 of 337 staff physicians [77.2%]). The following family member–related and patient-related factors were consistently identified by all 3 clinician groups as the most important barriers to goals of care discussions: family members’ or patients’ difficulty accepting a poor prognosis (mean [SD] score, 5.8 [1.2] and 5.6 [1.3], respectively), family members’ or patients’ difficulty understanding the limitations and complications of life-sustaining treatments (5.8 [1.2] for both groups), disagreement among family members about goals of care (5.8 [1.2]), and patients’ incapacity to make goals of care decisions (5.6 [1.2]). Clinicians perceived their own skills and system factors as less important barriers. Participants viewed it as acceptable for all clinician groups to engage in goals of care discussions—including a role for advance practice nurses, nurses, and social workers to initiate goals of care discussions and be a decision coach.

CONCLUSIONS AND RELEVANCE Hospital-based clinicians perceive family member–related and patient-related factors as the most important barriers to goals of care discussions. All health care professionals were viewed as playing important roles in addressing goals of care. These findings can inform the design of future interventions to improve communication and decision making about goals of care.

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Serious ill patients are increasingly exposed to potentially unwanted interventions at the end of life (EOL).1-3 In a recent multicenter study, physicians’ orders for life-sustaining treatments, such as cardiopulmonary resuscitation, were frequently inconsistent with seriously ill hospitalized patients’ wishes, with most of the discordance arising from prescriptions for EOL treatments that were more invasive than what patients preferred.4 Technology-laden EOL care is associated with decreased quality of life, lower satisfaction with EOL care, and increased family anxiety and depression.5 To enhance the quality of EOL care, seriously ill hospitalized patients and their families have identified communication and decision making about goals of care as important targets for improvement.6 We define communication and decision making about “goals of care” as a process that occurs between clinicians and a patient (or substitute decision maker) to establish a plan of care in an institutionalized setting. For seriously ill hospitalized patients, this process includes decisions about the use or nonuse of life-sustaining treatments.7 Ideally, these decisions would be informed and facilitated by preparatory advance care planning conversations between patients, their surrogate decision makers, and their usual outpatient care providers.8 Implementing interventions to improve communication and decision making about goals of care in the hospital requires an understanding of the perspectives of patients, families, and clinicians in this clinical setting.9 In particular, awareness of barriers enables the development of tailored interventions that are more likely to improve professional practice compared with standard interventions.10 We recently published a study that, together with previous studies by others, provides insight into the perspectives of seriously ill hospitalized patients and their families.4,6,11-16 However, less is known about clinicians’ perspectives about the barriers to communication and decision making about goals of care on the medical wards of hospitals.17,18 Furthermore, recent randomized clinical trials of EOL decision making have found that using trained, nonphysician facilitators increased agreement between surrogates and patients regarding goals of future care and increased congruence of EOL care with patients’ wishes.19-21 This suggests that novel models of interprofessional care may improve communication and decision making about goals of care in the hospital setting. Accordingly, we undertook a multicenter survey to determine hospital-based clinicians’ perspectives about (1) barriers that impede communication and decision making about goals of care with seriously ill hospitalized patients and their families and (2) their own willingness and the acceptability for other clinicians to engage in this process.

**Methods**

**Setting**

We conducted a cross-sectional study on the medical teaching units (MTUs) of 13 hospitals in the Canadian provinces of British Columbia, Alberta, Manitoba, Ontario, Quebec, and Newfoundland and Labrador between September 2012 and March 2013. We defined an MTU as a general internal medicine patient care unit where staff physicians supervise and teach medical students and residents within the context of patient care. The institutional ethics review board at each participating center approved the study. Informed consent was implied through completion of the self-administered questionnaire in response to an invitation to participate voluntarily in our study.

**Participants**

We invited staff physicians, residents, and nurses from participating centers to take part in this study according to the following eligibility criteria: (1) staff physicians providing care to patients on an MTU, (2) residents enrolled in the internal medicine postgraduate training program (visiting residents on elective were excluded), and (3) nurses (registered nurses, licensed practical nurses, or registered practical nurses) employed full time or part time on an MTU. We invited all eligible clinicians at each center to participate, with the exception of centers with more than 50 nurses, where we selected a random sample of 50 nurses using a computer-generated list of random numbers.

**Questionnaire Development**

Physician-specific (staff physician or resident) and nurse-specific versions of the questionnaire were created because some items were specific to only 1 professional group. Questionnaire development occurred in 3 stages. First, a core group of investigators created an initial draft based on a literature review, our conceptual framework of interprofessional shared decision making in EOL care,22-23 and their own clinical expertise. The initial draft was presented to a focus group (75 minutes) at a national research network meeting consisting of 23 individuals (physician, nurse, and nonclinician health researchers and health policy decision makers with expertise in palliative and EOL care, general internal medicine, critical care, primary care, shared decision making, and psychometrics) to obtain feedback about the content and structure of the questionnaire. On the basis of this feedback, a revised version was created and taken for consultation with front-line clinicians (60-minute sessions with a focus group of 7 nurses, and one-on-one interviews with 8 staff physicians and 2 medical residents) on the MTU at Hamilton General Hospital, Hamilton, Ontario, Canada. To obtain feedback about the clinical sensibility, face and content validity of each item, and about any items that should be removed or added. A final draft was pilot-tested with a convenience sample of 16 nurses and 16 physicians (8 staff physicians and 8 residents) from the MTU at Hamilton General Hospital to assess feasibility (mean [SD] completion time, 12.7 [3.5] and 13.6 [7.6] minutes for nurses and physicians, respectively) and item performance (no floor or ceiling effects were observed) and to provide a final opportunity for input on the questionnaire items. The final version of the questionnaire (Appendix in the Supplement) was translated into French using a professional translation service. The French version was reviewed by bilingual members of the study team to ensure accuracy of translation.

The first section of the questionnaire began with a clinical vignette (Box) and then asked respondents to rate the importance of 21 barriers to goals of care discussions with seri-
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Introduction

A 70-year-old patient who has severe COPD (on home oxygen), is housebound, and requires assistance for most activities of daily living is admitted to the medical ward under your care with an exacerbation of their COPD. The patient’s acute symptoms have resolved. You are uncertain about the patient’s goals of care and preferences regarding the use (or nonuse) of life-sustaining technology. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of the following barriers in preventing you from talking to them and/or their family members about the patient’s goals of care.

Abbreviation: COPD, chronic obstructive pulmonary disease.

Results

Questionnaires were returned by 1256 of 1617 eligible clinicians, for an overall response rate of 77.7% (512 of 646 nurses [79.3%], 484 of 634 residents [76.3%], 260 of 337 staff physicians [77.2%]). Study participants had a mean (SD) age of 35.4 (10.7) years, were most often trained in Canada (n = 984 [78.3%]), and, with the exception of residents, had been in practice for a mean (SD) 10.5 (9.3) years. Of the 260 staff physicians, all worked clinically as general internists (a mean [SD] 17.5 [11.9] weeks per year attending on an MTU), 135 (51.9%) with no other specialty and 125 (48.1%) with additional specialties; additional specialization was predominantly in critical care medicine (n = 38) and respirology (n = 28). Most participants (n = 757 [60.3%]) reported that they had not received formal training in discussing goals of care (Table).

Barriers to Goals of Care Discussions as Perceived by Clinicians on Medical Teaching Units

Figure 1 presents barriers to goals of care discussions in order of importance, as rated by participants (raw scores are presented in eTable 1 in the Supplement). Of the 21 barriers, 13 were rated somewhat important or higher; none were rated between very important and extremely important. Rank ordering of the barriers by importance was similar across the 3 clinician groups (Spearman correlation coefficients, 0.87, 0.89, 0.95 for nurse vs physician, nurse vs resident, physician vs resident rankings, respectively) (eFigure in the Supplement). Rank ordering was also similar between staff physicians with and without other specialties (Spearman correlation coefficient, 0.97). The following family member–related and patient-related factors were consistently identified by all 3 clinician groups as the most important barriers to goals of care discussions: family members’ or patients’ difficulty accepting a poor

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prognosis, family members’ or patients’ difficulty understanding the limitations and complications of life-sustaining treatments, lack of agreement among family members about goals of care, and patients’ lack of capacity to make decisions about goals of care. Clinicians perceived their own skills and system factors as relatively less important barriers. Fear of litigation was the least important barrier. Although rank ordering of barriers was similar across the 3 clinician groups, nurses’ ratings of importance for each barrier were consistently higher than staff physicians’ or residents’ ratings (eTable 1 and eFigure in the Supplement).

Importance ratings for questions about barriers that were directed only to nurses or only to staff physicians are shown in eTable 2 in the Supplement. Nurses rated physicians’ lack of time to discuss goals of care and multiple physicians providing care for a single patient as other important barriers; however, these barriers were perceived as less important than the aforementioned patient and family member factors. Insufficient remuneration was not reported by staff physicians as an important barrier to goals of care discussions.

**Perceptions of Interprofessional Roles in Communication and Decision Making About Goals of Care**

Figure 2 presents clinicians’ ratings of their own willingness to engage in different aspects of communication and decision making about goals of care, and nurses’ perceptions of work environment support for their engagement in these activities. Staff physicians and residents were more willing than nurses, and staff physicians more willing than residents, to engage in communication and decision making about goals of care. Nurses felt neither supported nor unsupported in their work environment to engage in communication and decision making about goals of care.

Figure 3 presents clinicians’ ratings of acceptability for different professional groups to engage in different aspects of communication and decision making about goals of care (raw scores are presented in eTable 3 in the Supplement). All study participants viewed staff physicians and residents as the most acceptable professional groups to engage in communication and decision making about goals of care. However, participants also viewed it as acceptable for advance practice nurses, nurses, social workers, and other allied health care professionals to be involved in several aspects of communication about goals of care—particularly initiating goals of care discussions and acting as a decision coach—whereas they rated it as relatively less acceptable for these groups to engage in final decision making. Of the 3 professional groups participating in our study, nurses were most accepting of various clinician groups being involved in discussing goals of care, and staff physicians more accepting than residents.

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<th>Table. Participant Characteristicsa</th>
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<td><strong>Characteristic</strong></td>
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<td><strong>Age, mean (SD) [n]</strong></td>
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<td><strong>Sex, No. (%)</strong></td>
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<td><strong>Importance of spirituality/religion in life, mean (SD) [n]</strong></td>
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<td><strong>Formal training in goals of care discussions, No. (%)</strong></td>
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Abbreviation: NA, not applicable.

* Percentages may not total 100% because of rounding.

a Rated using a 7-point Likert scale (1 = extremely unimportant; 7 = extremely important).
Discussion

In this national, multicenter survey, we found that hospital-based staff physicians, residents, and nurses perceive family member–related and patient-related factors as the most important barriers to discussing goals of care with seriously ill hospitalized patients and their families. Barriers related to clinicians’ own skills and system factors were considered relatively less important. Whereas participants believed that it was most acceptable for staff physicians to be involved in final decision making about goals of care with patients and their families, they also believed that a range of clinician groups could play a role in several other key activities, including initiating goals of care discussions and acting as a decision coach.

Our principal finding that clinicians perceive patient and family member factors as the most important barriers to goals of care discussions complements the findings from a Canadian multicenter study of seriously ill hospitalized patients and family members from many of the same participating sites. In the latter study, few patients and family members (22% and 24%, respectively) reported that a member of their hospital care team had asked about their preferences for EOL care. Findings from our study suggest that certain patient and family
member factors may deter clinicians from engaging in goals of care discussions (eg, family members’ and patients’ difficulty accepting a poor prognosis or understanding the nature of life-sustaining treatments).

We also found that, although hospital-based clinicians currently view staff physicians as the most acceptable group to make final decisions about goals of care with patients and their families, they also believe that many other clinician groups, including advance practice nurses, nurses, social workers, and other allied health care professionals, can be involved in other key aspects of goals of care discussions, such as initiating goals of care discussions and acting as a decision coach. It is important to recognize that these ratings of acceptability may simply reflect current norms as opposed to optimal care delivery, and future work could seek to optimize interprofessional team members’ roles in addressing goals of care. Although nurses in our study felt neither supported nor unsupported to engage in communication and decision making about goals of care, there is growing interest in improving the quality of health care and shared decision making through greater interprofessional collaboration within multidisciplinary health care teams.23,27,28 Our findings underscore and support recent calls for more and better training for all clinicians in having EOL discussions.29,33,34 Communication skills training and tools that enhance clinicians’ ability to build rapport, listen with empathy, and discuss prognosis—along with its inherent uncertainty—could help clinicians to better support patients and families through decisions about goals of care.29,35 Second, our findings also suggest that interventions aimed at improving patient and family preparedness to engage in goals of care discussions will be an important aspect of future interventions. We found that patients’ and families’ difficulty understanding the limitations and complications of life-sustaining treatments, patients’ lack of capacity to make decisions about goals of care, and lack of agreement among family members about goals of care were among the most important barriers to goals of care discussions. To
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overcome these barriers, decision aids that assist with advance care planning and increase knowledge about life-sustaining treatments, such as cardiopulmonary resuscitation, may be helpful.36 Indeed, novel web-based decision aids, designed for populations with low health literacy, are being evaluated for their potential to increase patient and family engagement in advance care planning.37 It is crucial, however, that such tools not be considered as a replacement for meaningful communication among clinicians, patients, and families. Rather, use of decision support tools can precede, facilitate, and support subsequent goals of care discussions that clinicians need to have with their patients and their families. Recent randomized clinical trials of EOL decision making, including one in a hospital setting, have found that trained, non-physician advance care planning facilitators increased agreement between surrogates and patients about goals for future care and increased congruence between patients’ wishes and the EOL care that they received.19-21 Our finding that hospital-based clinicians support the involvement of many health care professional groups in certain aspects of goals of care discussions suggests that future interventions may include an expanded role for interprofessional team members in facilitating communication and decision making about goals of care with seriously ill hospitalized patients and their families.

Our study has several strengths, including a response rate of nearly 80% and a survey development process that enhanced the content validity and clinical sensibility of our questionnaire. In addition, a large sample size and participation from multiple sites increases the generalizability of our findings. Our study also has limitations. First, despite the high response rate and multicenter design of our study, our findings may not be representative of other settings, such as hospitals outside Canada, nonteaching hospitals, nonmedical inpatient units, or outpatient settings. Second, we asked respondents to rate the importance of barriers on the basis of their recall of past experience; thus, it is possible that participants were disproportionately influenced by infrequent but memorable interactions with patients and families when rating the importance of barriers, and it is also possible that respondents underestimated the impact of clinician and system factors. Multicenter, prospective collection of empirical data about barriers from actual encounters with a representative sample of clinicians and patients could address these limitations but would be highly resource intensive and was not within the scope of our study.

Conclusions

By identifying the most important barriers, our study helps to prioritize next steps for future work aimed at improving goals of care discussions with seriously ill hospitalized patients and their families. Promising interventions include more and better communication skills training for clinicians, conversation guides for discussion of prognosis, decision aids to support advance care planning, and greater involvement of the interprofessional health care team in this important process of care. Given the diversity of barriers to goals of care discussions, any single intervention is unlikely to succeed on its own. Multifaceted interventions directed at patients and their families, clinicians, and the health care system will likely be necessary to achieve this important goal.

ARTICLE INFORMATION


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Author Contributions: Drs You and Heyland had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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**Correction:** This article was corrected online February 19, 2015, for error in the first sentence of the Methods section.

**REFERENCES**