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Research

Role of allied health care professionals in goals-of-care discussions with hospitalized patients and perceived barriers: a cross-sectional survey

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Abstract

Background: Allied health care professionals can contribute meaningfully to goals-of-care discussions with seriously ill hospitalized patients and their families. We sought to explore the perspective of hospital-based allied health care professionals on their role in goals-of-care discussions and to identify barriers to their participation.

Methods: We surveyed allied health care professionals (social workers, physiotherapists, occupational therapists, registered dietitians, speech–language pathologists and pharmacists) on internal medicine, hematology–oncology, medical oncology and radiation oncology wards at 2 tertiary care hospitals in Hamilton, Ontario, from April 2013 to May 2014. We modified a validated questionnaire originally designed to assess barriers to discussing goals of care from the perspective of nurses, residents and staff physicians on hospital medical wards. Respondents rated the questionnaire items on a 7-point Likert scale.

Results: Of the 47 allied health care professionals invited, 32 (68%) participated: 9 physiotherapists, 7 social workers, 6 occupational therapists, 4 registered dietitians, 3 pharmacists and 2 speech–language pathologists; in 1 case, the profession was unknown. The greatest perceived barriers to engaging in goals-of-care discussions were lack of patient decision-making capacity (mean rating 5.9 [standard error (SE) 0.3]), lack of awareness of patients' previous discussions with other team members (mean rating 5.7 [SE 0.3]) and family members' difficulty accepting a poor prognosis (mean rating 5.6 [SE 0.2]). Although the respondents felt it was most acceptable for staff physicians, residents and advanced practice nurses to exchange information and reach a final decision during goals-of-care discussions, they felt it was acceptable for a broader range of allied health care professionals to initiate discussions (mean rating 4.7–5.8) and to act as decision coaches (clarifying values, weighing options) with patients and families (mean rating 5.3–6.1).

Interpretation: Allied health care professionals are willing to initiate goals-of-care discussions and to act as a decision coach with seriously ill hospitalized patients and their families. By improving interprofessional collaboration, we can engage the entire health care team in this process.

Discussing goals of care with patients with serious illness can help align care at the end of life with patients' values and priorities[1,2] and improve the quality of life for patients nearing death.[3] We consider communication and decision-making about goals of care as a conversation in which the patient or family member and the health care team establish treatment goals and agree on the use of life-sustaining technology. Unfortunately, health care teams infrequently address guideline-recommended elements of goals-of-care discussions with seriously ill patients and their family members.[4] Although most hospitalized patients with serious illnesses have thought about end-of-life care, Heyland and colleagues[5] found that only 55% reported that a member of the health care team discussed goals of care with them.

Interprofessional collaboration can improve patient care and clinical outcomes.[6] Within palliative care programs, the interprofessional team is recognized as a key enabler of holistic care.[7] Determining clear roles and expectations for each team member is fundamental when caring for patients nearing end of life.[7] A multicentre Canadian survey of hospital physicians and nurses showed that it was acceptable for advanced practice

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nurses and other allied health care professionals to participate in certain aspects of goals-of-care discussions, particularly initiating discussions and acting as a decision coach.[8] The rationale for involving allied health care professionals in end-of-life discussions is multifold. First, these professionals have more contact time with patients than do physicians. Second, the same allied health care professionals often remain involved in a patient's care throughout the hospital stay, which could improve continuity of care. Third, given the breadth of expertise across an interprofessional team, an interprofessional approach to end-of-life care may improve the quality of communication and emotional support provided to patients and families. Finally, an interprofessional approach may reduce the burden of end-of-life discussions and decision-making on physicians. Previous work showed that physicians often perceive end-of-life decision-making as a solitary responsibility, which can be stressful and overwhelming.[9] To introduce an interprofessional approach to goals-of-care discussions for hospital-based patients, it is important to first consider allied health care professionals' perspectives about participating in goals-of-care discussions. Accordingly, we conducted a study to answer the question: What do allied health care professionals perceive as their role in goals-of-care discussions, and what do they identify as barriers to participating in such discussions?

Methods

Design and setting

From April 2013 to May 2014, we conducted a cross-sectional survey of allied health care professionals on the internal medicine, hematology–oncology, medical oncology and radiation oncology wards at the Juravinski Hospital and the internal medicine wards at the Hamilton General Hospital. Both are tertiary care hospitals located in Hamilton, Ontario. These wards were purposively selected to capture clinicians who care for a high proportion of seriously ill patients.

Study population

We invited social workers, physiotherapists, occupational therapists, registered dietitians, speech–language pathologists and pharmacists from participating wards to complete the study questionnaire.

Questionnaire development

For this study, we modified a validated questionnaire originally designed to assess barriers to discussing goals of care from the perspective of nurses, residents and staff physicians on hospital medical wards.[8] The original questionnaire was drafted based on a literature review, clinical expertise, and a conceptual framework of end-of-life communication and decision-making.[8] Feedback was obtained at a focus group conducted at a national research meeting, and the questionnaire was modified accordingly. The final draft was piloted among a convenience sample to assess feasibility and item performance.[8]

Modification of the questionnaire for use with allied health care professionals in the current study occurred over 3 stages. First, it was revised based on a literature review and the clinical expertise of the investigators. Further modifications were based on feedback obtained during pilot testing with a convenience sample of allied health care professionals. Adaptations from the original survey included creation of patient vignettes, addition of a new barrier (family members hesitate to discuss goals of care owing to your profession), removal of a barrier (uncertainty estimating prognosis) and addition of other allied health care professionals to the section asking about acceptability to participate in goals-of-care discussions (the only non-physician groups included in the original questionnaire were advanced practice nurses, bedside nurses and social workers). The final questionnaire is shown in Appendix 1, available at www.cmajopen.ca/content/6/2/E241/suppl/DC1.

Each questionnaire began with a patient vignette (Appendix 2, available at www.cmajopen.ca/content/6/2/E241/suppl/DC1) specific to the clinical setting. Respondents were asked to rate the importance of 33 barriers that could interfere with their ability to engage in goals-of-care discussions with seriously ill patients or family members like the one in the vignette. All items were rated on a 7-point Likert scale where 1 = extremely unimportant and 7 = extremely important.

The subsequent section asked respondents to rate their willingness to participate in goals-of-care discussions and the supportiveness of their work environment. All items were rated on a 7-point Likert scale where 1 = extremely unwilling and 7 = extremely willing.

The final section assessed how acceptable respondents found it was for staff physicians, residents or fellows, bedside nurses, advanced practice nurses, social workers, physiotherapists, occupational therapists, speech–language pathologists, registered dietitians and pharmacists to be involved in the following activities: initiating discussions about goals of care, exchanging information (e.g., disclosing a diagnosis or prognosis), acting as a decision coach (clarifying values, assisting in weighing options) and making a final decision about goals of care. These were rated on a 7-point Likert scale where 1 = extremely unacceptable and 7 = extremely acceptable.

Given the research question, we did not seek to capture the current frequency of conversations regarding goals of care involving allied health care professionals.

We also collected demographic data, including prior formal training and current self-assessed skill level in end-of-life discussions.

Study procedures

An investigator from the study team, in collaboration with the unit manager or nurse educator, gave a brief presentation to the allied health care professionals on the included wards about the study and questionnaire. Paper versions of the questionnaire with a unique study identification number were then distributed to all eligible participants. Personal or electronic reminders were sent to eligible participants to increase response rates. No incentives were offered for participation. As this was an observational study, no dedicated training was provided to participants. Patient and family perspectives were not sought given the scope of the study.

Statistical analysis

Categorical variables are reported as counts and percentages, and continuous variables as means and standard errors (SEs). As there were minimal missing data (Supplementary Tables 1 and 2, Appendix 3, available at www.cmajopen.ca/content/6/2/E241/suppl/DC1]), we performed a complete case analysis.

Ethics approval

This study was approved by the Hamilton Integrated Research Ethics Board.

Results

Of the 47 eligible participants, 32 (68%) returned the survey. Of the 32 respondents, 23 (72%) worked on internal medicine wards, 6 (19%) worked on hematology–oncology wards, and 3 (9%) worked on medical and radiation oncology wards (Table 1). The respondents included 9 physiotherapists (28%), 7 social workers (22%), 6 occupational therapists (19%), 4 registered dietitians (12%), 3 pharmacists (9%) and 2 speech–language pathologists (6%); 1 person (3%) did not report his/her profession.

Perceived barriers to goals-of-care discussions

The respondents identified a lack of patient decision-making capacity to make goals-of-care decisions as the most important barrier preventing the respondent from talking to a patient or family about goals of care (mean rating 5.9/7 [SE 0.3]). Six of the top 8 barriers were patient- and family-related factors: lack of patient decision-making capacity, family member difficulty in accepting poor prognosis, lack of family agreement on goals of care, patient difficulty accepting poor prognosis, family member difficulty in understanding the limitations of life-sustaining therapy and patient difficulty understanding the limitations of life-sustaining therapy (Figure 1, Supplementary Table 1, Appendix 3). The most important system or external factor representing a barrier was a lack of awareness of previous discussions between the health care team and the patient or family (mean rating 5.7 [SE 0.3]).

Respondents rated regulations from professional associations (mean rating 5.1 [SE 0.4]) and a lack of training in end-of-life communication (mean rating 4.9 [SE 0.3]) as somewhat important barriers. Only 4 respondents (12%) reported having received prior training in goals-of-care discussions. Respondents identified that multiple physicians caring for the same patient (mean rating 5.5 [SE 0.2]), lack of physician time (mean rating 5.4 [SE 0.3]) and lack of communication skills (mean rating 5.3 [SE 0.3]) as somewhat important to very important barriers related to physicians.

Perceived roles in goals-of-care discussions

Respondents stated that they would be somewhat willing to act as a decision coach in goals-of-care discussions (mean rating 5.1/7 [SE 0.2]) (Figure 2, Supplementary Table 2, Appendix 3). Respondents rated themselves as somewhat willing to neutral regarding initiating goals-of-care discussions (mean rating 4.7 [SE 0.3]), making a final decision about the goals of care (mean rating 4.5 [SE 0.3]) and exchanging information about diagnosis and prognosis (mean rating 4.3 [SE 0.3]). However, they

Table 1: Participant characteristics

Characteristic	No. (%) of respondents* *n* = 32
Age, yr, mean ± SD	38.3 ± 7.6
Sex	
Female	24 (75)
Male	6 (18)
Missing	2 (6)
Years of experience, mean ± SD	7.3 ± 4.9
Trained in Canada	28 (88)
Ward	
Medical oncology, radiation oncology	3 (9)
Hematology–oncology	6 (19)
Internal medicine	23 (72)
Training background	
Physiotherapist	9 (28)
Social worker	7 (22)
Occupational therapist	6 (19)
Registered dietician	4 (12)
Pharmacist	3 (9)
Speech–language pathologist	2 (6)
Missing	1 (3)
Prior formal training in goals-of-care discussions	4 (12)
Self-reported rating of skill in having goals-of-care discussions, mean ± SD†	2.7 ± 1.1
Self-reported rating of priority in gaining skill in having goals-of-care discussions, mean ± SD‡	3.6 ± 1.0
Religious affiliation	
Roman Catholic	10 (31)
Protestant Christian	9 (28)
Other Christian	1 (3)
Jewish	1 (3)
None	9 (28)
Missing	2 (6)
Rating of importance of spirituality in respondent's life, mean ± SD§	5 ± 1.5

Note: SD = standard deviation.
*Except where noted otherwise.
†On a 5-point Likert scale where 1 = limited, 2 = fair, 3 = average, 4 = very good and 5 = expert.
‡On a 5-point Likert scale ranging from 1 (low priority) to 5 (high priority).
§On a 7-point Likert scale ranging from 1 (extremely unimportant) to 7 (extremely important).

generally felt neither supported nor unsupported to participate in these roles (mean rating 3.7–4.3).

The respondents identified different degrees of acceptability for each professional group to be involved in certain aspects of goals-of-care discussions. They rated it as very acceptable for registered nurses (mean rating 5.8/7 [SE 0.1]) and social workers (mean rating 5.8 [SE 0.2]) to initiate goals-of-care discussions, whereas they rated it as somewhat acceptable for the remaining allied health care professionals to initiate such discussions. It was deemed most acceptable for registered nurses and social workers to participate in any of the identified roles, followed by physiotherapists and occupational therapists, speech–language pathologists and registered dietitians, and, finally, pharmacists. Finally, respondents rated the acceptability for all allied health care professionals to initiate goals-of-care discussions and to act as a decision coach higher than that of exchanging information or making final decisions about the goals of care.

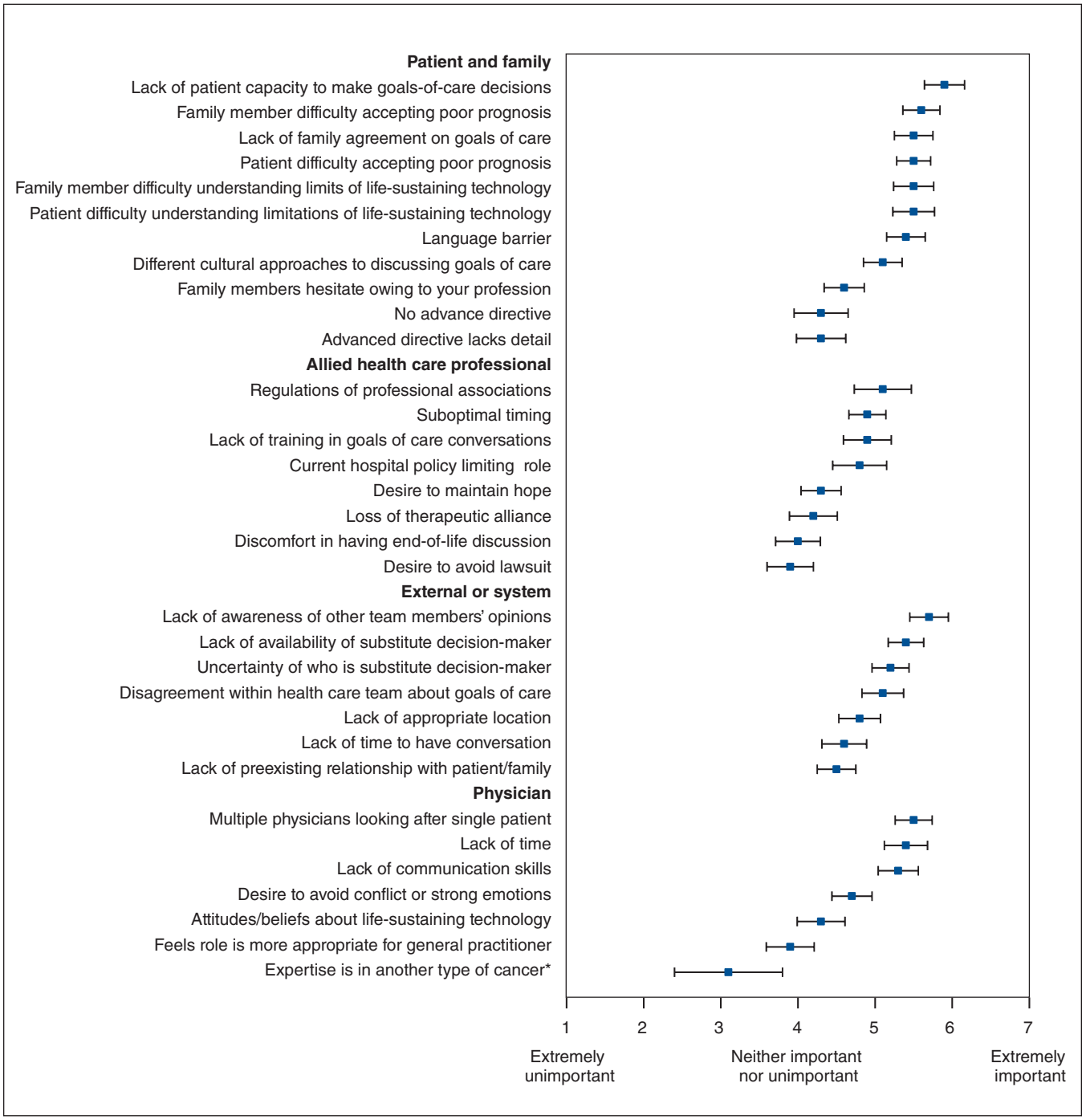

Figure 1: Mean ratings of hospital-based allied health care professionals regarding importance of barriers to goals-of-care discussions. Error bars = standard error. *Asked only to those working on hematology–oncology or medical oncology wards.

Interpretation

In this survey conducted at 2 tertiary care hospitals, we found that allied health care professionals viewed it as acceptable to be involved in certain aspects of goals-of-care discussions with seriously ill hospitalized patients. Respondents identified patient and family factors as the most important barriers to such discussions. None of the proposed barriers to engaging in goals-of-care discussions specific to allied health care professionals (e.g., regulations of professional associations, suboptimal timing, lack of training) were ranked as very or extremely important, which suggests that these were considered less important. Although respondents felt it was acceptable for allied health care

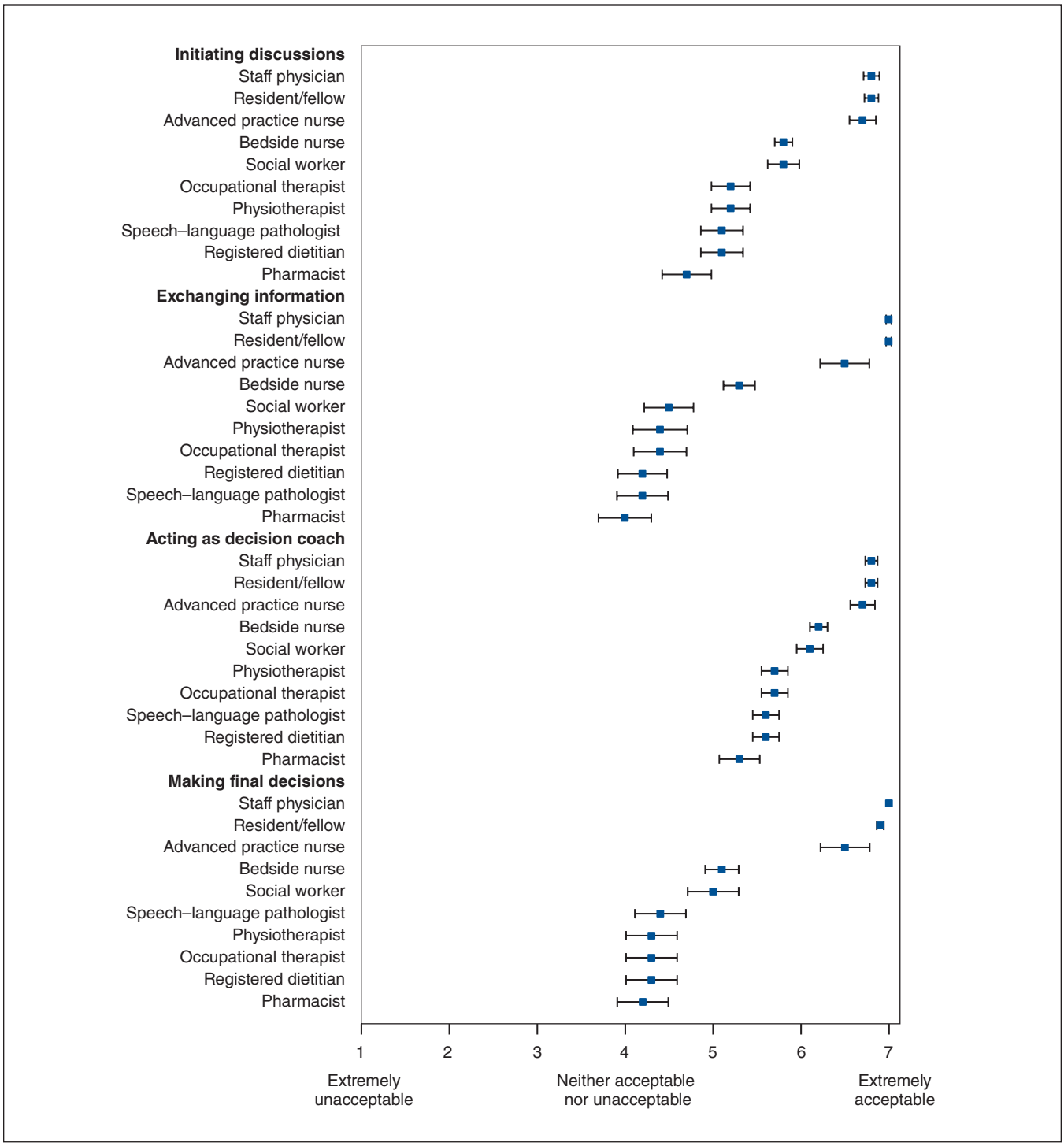

Figure 2: Mean ratings of acceptability for various health care professionals to participate in goals-of-care discussions through initiating discussions, exchanging information, acting as a decision coach and making final decisions. Error bars = standard error.

professionals to initiate discussions and to act as a decision coach, they did not feel supported in these roles within their work environment.

You and colleagues[8] identified similar key barriers in a study exploring staff physicians', residents' and registered nurses' perspectives of barriers to goals-of-care discussions on medical teaching units. This suggests a shared perception among health care professionals that patient and family factors are important barriers to these discussions, which emphasizes the importance of working with patients and families to create a shared understanding of the prognosis and their values, preferences and concerns. Lack of awareness of what other members of the health care team had said was the most important systemic barrier identified, which suggests that improvements in interprofessional communication will be important in optimizing the quality of end-of-life care. The findings support the notion that physicians' lack of time and communication skills are somewhat to very important barriers to goals-of-care discussions. We also identified frequent physician handovers as a barrier. Allied health care professionals often remain longitudinally involved with a patient's care, which presents an opportunity for their enhanced involvement in goals-of-care discussions, especially with patients with complex conditions.

Finally, respondents indicated that the regulations of their professional associations were a somewhat important barrier to engaging in goals-of-care discussions with patients. This probably reflects a lack of understanding of their respective governing bodies' position statements on this issue. In 2010, a Canadian task group published competencies for social workers' involvement in hospice palliative care, with the goal of enhancing professional development and educational curricula.[10] Speech-Language & Audiology Canada recently published a position statement stating that speech–language pathologists are uniquely qualified to provide essential services in end-of-life care.[11] There are similar position statements from the Canadian Association of Occupational Therapists and the Canadian Physiotherapy Association.[12,13] For end-of-life care to be comprehensive, involvement of appropriate allied health care professionals is necessary, and it appears that their professional associations are supportive of this model. However, we found that lack of training was a somewhat important barrier to the involvement of allied health care professionals in end-of-life discussions. A strategic plan for hospice, palliative and end-of-life care in Canada was published in 2009 that cited the need for initial and continuing education for physicians and allied health care professionals in providing end-of-life care.[14,15] A shift in educational competencies to include end-of-life care will help equip the next generation of allied health care professionals to participate in these discussions.[10] Continuing education courses would also be valuable to allied health care professionals already in practice.

Our finding that respondents found it acceptable for allied health care professionals to initiate discussions and act as a decision coach is consistent with the results of a previous survey. Heyman and Gutheil[16] examined social workers' involvement in end-of-life planning and found that initiating a goals-of-care discussion was the most cited social work role (72.5%), followed by facilitating decision-making (31.5%). It also aligns with You and colleagues'[8] finding that staff physicians and residents considered it acceptable for registered nurses and social workers to initiate discussions and act as a decision coach; however, results were mixed regarding other allied health care professionals. This shows a relatively shared perspective among physicians and allied health care professionals about which members of the interprofessional team are the most appropriate to engage in goals-of-care discussions. Despite this, our respondents felt neither supported nor unsupported to participate in goals-of-care discussions in their work environment. It will be necessary to clarify roles and expectations within the health care team in order to provide holistic interprofessional end-of-life care.[7]

Limitations

Our study is limited by its small sample, which led to limited representation of each allied health care professional group. We used a modified questionnaire, and, although we applied a systematic approach during the revision of the questionnaire, this study did not explore the reliability or validity of the modified tool. The survey was distributed in 2 teaching hospitals in Hamilton, and the responses may not be generalizable to allied health care professionals practising at other centres or nonacademic institutions.

Conclusion

Allied health care professionals believe it is acceptable for them to participate in goals-of-care discussions with seriously ill hospitalized patients and their families by initiating discussions and acting as decision coaches. Interventions to improve communication among interprofessional team members and to further train allied health care professionals in having goals-of-care discussions merit further study. It will be important to assess patient and family perspectives on involving allied health care professionals in these discussions. There are many creative ways to envision integrating the entire health care team to provide holistic end-of-life care. This may help to improve the emotional support and the quality of the communication experience for health care providers, patients and families at the end of life.

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Contributors: Yudong Liu, Sukhbinder Dhesy-Thind and Parveen Wasi conceived and designed the study. Sukhbinder Dhesy-Thind and Parveen Wasi acquired the data. Leslie Martin, Ameen Patel, Alexandra Patel, Matthew Patel and John You analyzed the data. Katrina Piggott, Arthur Wong, Alexandra Patel and Matthew Patel interpreted the data. Leslie Martin drafted the manuscript. All of the authors revised the manuscript critically for important intellectual content, gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

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