

# Barriers to goals of care discussions with hospitalized patients with advanced heart failure: feasibility and performance of a novel questionnaire

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## Abstract

**Aims** Good end-of-life communication and decision-making are important to patients with advanced heart failure (HF) and their families, but their needs remain unmet. In this pilot study, we describe the feasibility and performance of a novel questionnaire aimed at identifying barriers and solutions to improve communication and decision-making about goals of care for hospitalized patients with advanced HF.

**Methods** We distributed questionnaires to staff cardiologists, cardiology trainees, and cardiology nurses who provide care for HF patients at a Canadian teaching hospital. The questionnaire asked about the importance of various barriers to goals of care discussions. It also asked participants to rank their willingness to engage in goals of care discussions and their views on other clinicians could engage in such discussions.

**Results** Of 76 clinicians, 44 (58%) completed the questionnaire (median completion time, 17 min). Individual survey questions had few missing responses (0% to 2%) for questions about barriers to goals of care discussions. There was appreciable discrimination of the importance of different barriers (mean scores 2.2 to 6.0 on a 7-point scale). Preliminary data suggest that clinicians perceive patient and family factors, such as difficulty accepting a poor prognosis, as the most important barriers preventing goals of care discussions.

**Conclusions** In this pilot study, we have demonstrated the feasibility of a novel questionnaire to be used in a larger multi-centre study of end-of-life HF care. Essential information will be obtained to inform the design and evaluation of interventions that seek to improve communication and decision-making about goals of care with HF patients.

**Keywords** Heart failure; Communication; Goals of care; Decision-making; End-of-life care

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## Introduction

Heart failure (HF) affects an estimated 38 million patients worldwide, of whom 5% to 10% have reached an advanced stage of illness with an average life expectancy of 6 to 12 months.<sup>1,2</sup> While the use of technology and life-sustaining

therapies near the end of life (EOL) is increasing, many patients with HF would prefer treatment aimed at improving quality of life and symptoms.<sup>3–5</sup> Technology-laden EOL care is associated with poorer ratings of quality of life, lower ratings of satisfaction with EOL care, and increased family anxiety and depression.<sup>6</sup> Furthermore, the use of intensive

technology at the EOL incurs significant costs, placing increased strain on finite healthcare resources.

Current HF guidelines emphasize the need to re-establish goals of care at clinical milestones, including hospital admission.<sup>7–9</sup> At such times, previously expressed wishes and values need to be clarified and translated into goals of care, defined here as decisions relating to the use, non-use or deactivation of life-sustaining technologies, including cardiac devices such as implantable cardioverter-defibrillators (ICDs). Deactivation of ICDs poses a unique challenge in the care of patients with advanced HF as they near the EOL.<sup>10</sup>

Previous studies have provided insights into the perspectives of seriously ill hospitalized patients with HF, and their families, and have identified that EOL communication and decision-making are important to patients and families, but their needs related to these issues remain unmet.<sup>3,4,11,12</sup> Before developing tailored solutions to improve communication and decision-making about goals of care for hospitalized patients with advanced HF, there is a need to also understand the barriers and facilitators to this process from clinicians' perspectives. The DECISION-Making about Goals of Care for Hospitalized Patients with Heart Failure (DECIDE-HF) study is a multi-centre study designed to identify barriers and solutions to improve communication and decision-making about goals of care for patients with advanced HF from the perspectives of cardiology clinicians (staff cardiologists, cardiology fellows, and cardiology nurses), and to elicit their perspectives about the acceptability for different groups of clinicians to engage in goals of care discussions. The purpose of this paper is to report on the feasibility of a novel questionnaire and the performance of the questionnaire items piloted at a single centre prior to its use in the multi-centre DECIDE-HF study.

## Methods

### Study participants and setting

To assess the feasibility and performance of the DECIDE-HF questionnaire, we distributed the questionnaire to the following clinicians at Hamilton General Hospital, Hamilton, Ontario, Canada: staff cardiologists; cardiology fellows, defined as postgraduate clinical trainees in adult cardiology, excluding visiting or non-clinical (research only) fellows; and full-time or part-time nurses (including advance practice nurses/nurse practitioners, and licenced/registered practical nurses). To be eligible, clinicians' practice had to include the provision of inpatient care to patients with HF. The study was approved by the Hamilton Integrated Research Ethics Board. Informed consent was implied by the clinicians' completion of a study questionnaire.

### Study questionnaire

The HF-specific questionnaire for this study was adapted from one developed for a recently completed study which focused on clinicians' perspectives on goals of care discussions for patients admitted to general medical units.<sup>13</sup> To establish the content validity and clinical sensibility of those original questionnaires (physician and nurse versions), instrument development was based on: literature review; a conceptual framework of interprofessional shared-decision making;<sup>14,15</sup> consultation with research network members with expertise in internal medicine, nursing, critical care, palliative care, shared decision-making, and psychometrics; and, external consultation in focus groups or one-on-one interviews with internal medicine staff physicians, internal medicine residents, and nurses from internal medicine hospital wards. To adapt these questionnaires for use in the DECIDE-HF study, we obtained electronic feedback from and held teleconferences with investigators from our research team with expertise in HF care, medical ethics, and palliative care to add HF-specific items (e.g. about understanding the role of an ICD and its deactivation), and to remove or modify original items to ensure that the questionnaire was relevant to the context of HF.

The questionnaire includes sections asking respondents to: (i) rate the importance of various barriers to communication and decision-making about goals of care using a 7-point Likert scale (1 = extremely unimportant; 7 = extremely important); (ii) rate their own willingness and their perceptions about the acceptability for other clinicians to engage in different aspects of goals of care discussions using a 7-point Likert scale (1 = extremely unwilling, 7 = extremely willing; 1 = extremely unacceptable, 7 = extremely acceptable); and, (iii) provide demographic information (see Appendix S1 for physician and nurse versions of the study questionnaire).

### Study procedures

In our prior questionnaire-based research with hospital-based clinicians,<sup>13</sup> physicians and residents expressed a preference for an electronic web-based format and nurses expressed a preference for a paper-based format; therefore, in the current study, staff cardiologists and cardiology fellows used a predominantly electronic format (FluidSurveys, Ottawa, Canada) and cardiology nurses used a paper-based format. For the electronic format, we used a validated method adapted for web-based questionnaires to maximize response rates involving an e-mail pre-notice, e-mail invitation letter and survey link, e-mail reminder and replacement survey link for initial non-responders, and a second e-mail reminder and replacement survey link for persistent non-responders.<sup>16</sup> For the paper format, we distributed questionnaires to nurses when they were on the hospital ward and we used a similar, structured approach to follow up with non-responders as described for the electronic format.

## Feasibility and performance of questionnaire

To assess feasibility and questionnaire performance, we examined the following outcomes: (i) response rate; (ii) questionnaire completion time (data available for the electronic format only), reported as the median and interquartile range; (iii) percentage of missing responses for survey questions about barriers (importance of barriers will be the primary outcome for our future larger study); and, (iv) the distribution of responses for the items about barriers, including assessment for potential floor and ceiling effects (i.e. greater than 50% of respondents giving an ‘extremely unimportant’ or ‘extremely important’ response, respectively, for each item).

## Statistical analysis

Study participants are described using proportions for categorical variables and means and standard deviations for

continuous variables. Participants’ responses to 7-point Likert scale items related to the importance of different barriers to goals of care discussions, and the willingness and acceptability of other clinicians to participate in different aspects of goals of care decision-making are presented as mean scores. We calculated the proportion of missing responses for each questionnaire item about barriers and, to assess for potential floor and ceiling effects, calculated the proportion of respondents rating each given barrier as either ‘extremely unimportant’ or ‘extremely important’.

## Results

Study questionnaires were returned by 44 of 76 eligible clinicians for a response rate of 58%. The response rate for staff cardiologists was 58% (23/40); 73% for cardiology fellows (11/15); and 48% for cardiology nurses (10/21). The median completion time for the electronic version of the

**Table 1** Performance of questionnaire items about barriers to goals of care discussions

Barrier	Importance score, mean (SD)	Range, (min, max)	Missing responses, n (%)	‘Extremely unimportant’ responses, n (%)	‘Extremely important’ responses, n (%)
Patient does not have advance directive	5.0(1.9)	(1,7)	0	2 (4%)	15 (34%)
Advance directive lacks sufficient detail	4.7(1.8)	(1,7)	0	2 (4%)	7 (16%)
Patient difficulty accepting poor prognosis	5.6(1.2)	(2,7)	0	0	11 (25%)
Patient difficulty understanding limitations/ complications of LST	5.8(1.1)	(2,7)	0	0	12 (27%)
Patient lacks capacity to make goals of care decisions	5.7(1.1)	(2,7)	0	0	10 (23%)
Family members’ difficulty accepting loved one’s poor prognosis	6.0(1.3)	(2,7)	1 (2%)	0	20 (46%)
Family members’ difficulty understanding limitations/complications of LST	5.8(1.3)	(2,7)	1 (2%)	0	16 (36%)
Lack of agreement amongst family members about goals of care	5.8(1.1)	(3,7)	0	0	16 (36%)
Language barriers	5.4(1.3)	(2,7)	0	0	12 (27%)
Cultural differences	5.5(1.0)	(3,7)	0	0	7 (16%)
Patient or family member difficulty understanding role of an ICD	5.3(1.1)	(3,7)	0	0	8 (18%)
Uncertainty in estimating prognosis	4.8(1.5)	(2,7)	0	0	5 (11%)
Lack of training to have these conversations	3.6(1.9)	(1,7)	0	7 (16%)	3 (7%)
Desire to avoid being sued	3.2(1.8)	(1,7)	0	11 (25%)	3 (7%)
ICD deactivation is unethical	2.4(1.6)	(1,7)	0	19 (43%)	1 (7%)
ICD deactivation represents physician assisted suicide	2.2(1.7)	(1,7)	0	23 (52%)	2 (5%)
Desire to maintain hope	3.8(1.6)	(1,7)	0	6 (14%)	2 (5%)
Lack of time	4.8(1.6)	(1,7)	0	1 (2%)	6 (14%)
Lack of availability of substitute decision maker(s)	5.4(1.1)	(3,7)	0	0	6 (14%)
Uncertainty about who is the substitute decision maker	5.1(1.3)	(2,7)	0	0	5 (11%)
Lack of appropriate location (confidential/private)	4.3(1.8)	(1,7)	0	2 (5%)	4 (9%)
Lack of pre-existing relationship with patient/family	4.5(1.5)	(1,7)	0	2 (5%)	3 (7%)
Unaware of what other team members have said	5.2(1.3)	(2,7)	0	0	7 (16%)
Healthcare team disagreement about goals of care	5.0(1.5)	(2,7)	0	0	7 (16%)

LST, life-sustaining therapies; ICD, implantable cardioverter–defibrillator. There were 44 returned questionnaires ( $n = 44$ ).

questionnaire was 17 min (interquartile range 10 to 22;  $n = 30$ ). The respondents included 23 staff cardiologists (8.7% female), 11 cardiology fellows (9.1% female), and 10 cardiology nurses (90% female). The mean (standard deviation) age of participating staff cardiologists, cardiology fellows, and cardiology nurses was 47.6 (8.7) years, 31.6 (3.0) years, and 39.5 (12.4) years, respectively. Thirteen (57%) staff cardiologists, 5 (46%) cardiology fellows, and 9 (90%) cardiology nurses were white and 12 (52%), 5 (45%), and 10 (100%) were of Christian religious background, respectively.

Amongst the returned questionnaires ( $n = 44$ ), there were very few missing responses for items about the importance of barriers to discussions about goals of care (0% to 2%) (Table 1). For 10 of the 24 items about barriers, respondents used the entire range of responses on the Likert scale (1 = not at all important; 7 = extremely important). With the exception of the item 'ICD deactivation represents physician assisted suicide' (which 52% of respondents rated as an 'extremely unimportant' barrier), there was no evidence of floor or ceiling effects for the items about barriers. There was appreciable separation in the mean importance scores for the various barriers to goals of care discussions, enabling discrimination between the most and least important barriers (range of mean importance ratings, 2.2 to 6.0). Participants' responses about barriers to goals of care discussions, willingness to take part in different aspects of goals of care discussions, and acceptability of clinicians to engage in goals of care discussions are summarized in Figures 1, 2, and 3, respectively.

Preliminary data from our pilot study suggest that cardiology clinicians perceive patient and family-related factors to be the

most important barriers to goals of care discussions with hospitalized patients with advanced HF. The most important barrier identified from our pilot questionnaire relates to family members' difficulty accepting their loved one's poor prognosis. Patient and family members' difficulty understanding the limitations and complications of life-sustaining therapy are also felt to be amongst the most important barriers. In contrast, ICD related barriers, cardiology clinicians' own skills, and system factors are perceived to be less important barriers (Figure 1). Our preliminary data also suggest that respondents were willing to initiate discussions, exchange information, and make final decisions with patients regarding goals of care and ICD deactivation, with nurses being more willing than staff physicians (Figure 2). Respondents rated it as highly acceptable for staff cardiologists to initiate and finalize discussions, exchange information, and act as decision coaches (Figure 3). Of non-physician clinicians, advance practice nurses were deemed the most acceptable to be involved in decision-making about goals of care (Figure 3).

## Discussion

We have developed a novel questionnaire and demonstrated its feasibility for use in a larger, multi-centre study of end-of-life HF care. The majority of eligible individuals (nearly 60%) completed our questionnaire. Completion of individual questionnaire items was good, with very few missing responses for the items about the importance of barriers to goals of care discussions (the primary outcome for the larger study).

**Figure 1** Importance of barriers to discussions about goals of care. Respondents rated the importance of various barriers to communication and decision-making about goals of care using a 7-point Likert scale (1 = extremely unimportant; 7 = extremely important). Abbreviations: FM = family member; LST = life sustaining therapies; ICD = implantable cardioverter defibrillator; SDM = substitute decision maker.

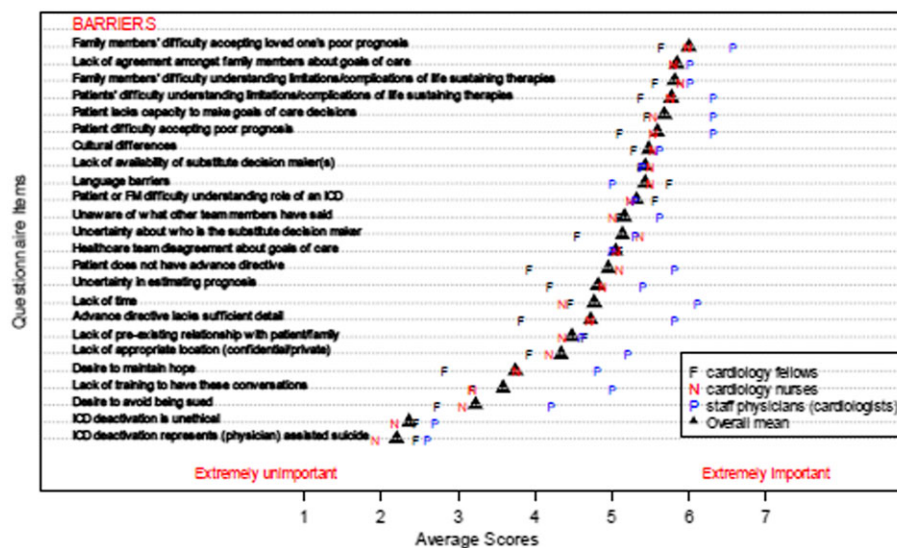


Figure 2 Health care professionals' willingness to engage in different aspects of communication and decision-making about goals of care.

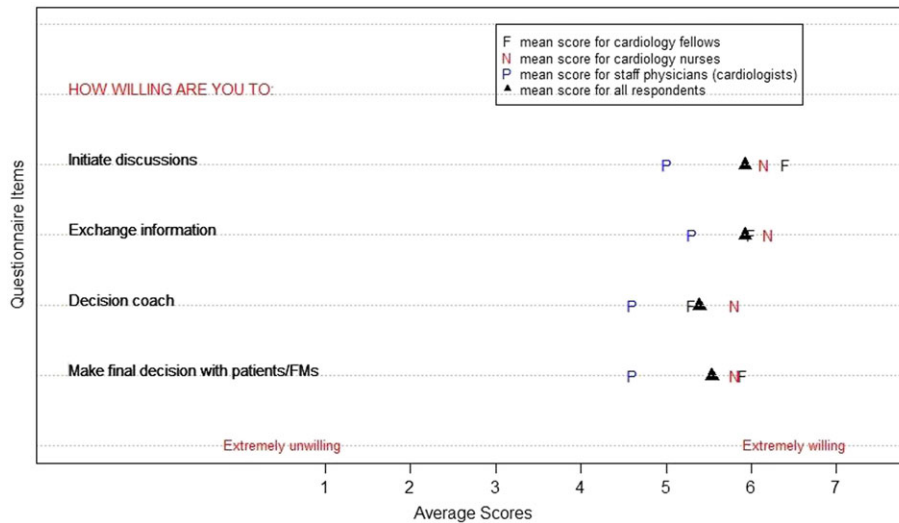
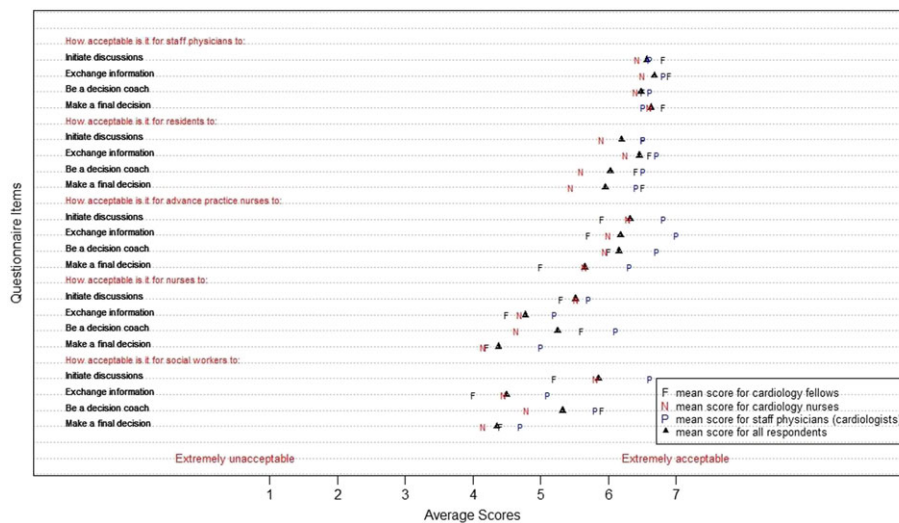


Figure 3 Acceptability of health care professionals to engage in different aspects of communication and decision-making about goals of care.



There was a good spread of importance ratings across these barriers, thus enabling discrimination between the most and least important barriers.

Recent studies provide insights into patient and family member perspectives on communication about goals of care in advanced HF,<sup>3,4,11,12</sup> but comparatively little is known about the perspective of cardiology clinicians. Before designing and evaluating interventions to improve decision-making about goals of care for patients with advanced HF, an understanding of clinicians' perceived barriers is needed so that interventions can be tailored to overcome these barriers.<sup>17</sup> Some studies have reported on the perceived barriers to

EOL decision-making in HF from clinician perspectives. However, these were predominantly single-centre, qualitative studies which provided an exploration of barriers but did not measure their relative importance. Moreover, most of these studies were conducted in an era before the widespread use of ICDs and focused largely upon HF patients in the outpatient general practice setting. The number of cardiology clinicians included in most studies was small, with little representation from the hospital setting.<sup>18-25</sup>

Our preliminary data suggest that cardiology clinicians perceive patient and family-related factors to be the most important barriers to goals of care discussions with

hospitalized patients with advanced HF, and may perceive ICD related barriers, their own skills, and system factors as less important. While most respondents were willing to be involved in all aspects of discussions regarding goals of care and ICD deactivation, those who self-reported as being more willing and those identified as more acceptable to have these discussions were not the same group of clinicians. Nurses were more willing than staff physicians to participate in discussions regarding goals of care whereas staff cardiologists were deemed by respondents in our questionnaire to be the most acceptable. However, we would caution that our findings are preliminary data from a single-centre feasibility study and will require further evaluation in a larger, more representative sample of cardiology clinicians.

In a recent study on general medical wards, physicians and nurses perceived the most important barriers to EOL discussions to be patients' and family members' difficulty accepting a poor prognosis, lack of understanding of the risks, benefits, and likely outcomes of life-sustaining treatments such as cardiopulmonary resuscitation, and lack of agreement amongst family members about goals of care.<sup>13</sup> However, the care of patients with advanced HF near EOL is fraught with distinct challenges, such as the undulating trajectory of illness, and issues related to ICD deactivation. Clinical practice guidelines recommend that information regarding ICD deactivation be discussed with patients prior to implantation and with any significant change in patient status to ensure ongoing ICD use is consistent with the patient's goals of care.<sup>26,27</sup> However, some physicians question whether ICD deactivation is legal or ethical,<sup>28</sup> view ICD deactivation as morally distinct from other forms of treatment withdrawal,<sup>29</sup> or, in some cases, believe that it is equivalent to physician-assisted suicide or euthanasia.<sup>30</sup> The DECIDE-HF study will provide insights about the relative importance of ICD deactivation issues as barriers to discussions about goals of care with HF patients. Given these unique aspects of HF care, as well as the high prevalence of HF, it is imperative that we elicit the experiences and perspectives of cardiology clinicians in order to identify the most relevant barriers to EOL discussions in the HF context and identify potential solutions.

There are limitations to our study questionnaire. First, although the majority (nearly 60%) of eligible individuals completed our questionnaire, we recognize that there is a risk of response bias. Specifically, non-responders may have different perspectives on EOL issues in advanced HF than those who responded to our questionnaire. To maximize response rates and minimize this risk of bias, we used a systematic method for following-up with non-responders and made the study questionnaire available in both paper and web-based formats. We will also use lessons learned in our feasibility study and further funding to enhance response rates in the larger, multi-centre study (e.g. implement strategies to provide nurses with protected time to complete

the survey with the intention of improving nurses' response rates which were the lowest of all participants). Second, our study focuses on teaching hospitals, and our findings may not be generalizable to outpatient clinics or community hospitals.

Having established the feasibility of our study procedures in our pilot study, we are now prepared to undertake the multi-centre DECIDE-HF study to assess barriers to goals of care discussions from the perspectives of clinicians who care for patients with advanced HF. Knowledge of barriers, and their relative importance, will inform the design and evaluation of tailored interventions aimed at reducing these barriers, and improving the quality of communication and decision-making about goals of care with seriously ill hospitalized patients with HF, and their families.

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## Conflict of interest

None declared.

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## Supporting information

Supporting information may be found in the online version of this article.

**Appendix S1.** Physician version of study questionnaire.

**Appendix S2.** Nurse version of study questionnaire.

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