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Preferences on advance care planning and end-of-life care in patients hospitalized for heart failure

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Abstract

Aims   Early engagement in advance care planning (ACP) is recommended in heart failure (HF) management. We investigated the preferences of patients with HF regarding ACP and end-of-life (EOL) care, including their desired timing of ACP initiation.
Methods and results   Data were collected using a 92-item questionnaire survey, which was directly distributed to hospitalized patients by dedicated physicians and nurses in a university hospital setting. One-hundred eighty-seven patients agreed to participate (response rate: 92.6%), and 171 completed the survey [valid response rate: 84.7%; men: 67.3%; median age: 73.0 (63.0–81.0) years]. Logistic regression analyses were conducted to identify the predictors of positive attitudes towards ACP. Most recognized ACP as important for their care (*n* = 127, 74.3%), 48.1% stated that ACP should be initiated after repeated HF hospitalizations in the past year, and 29.0% preferred ACP to begin during the first or second HF hospitalization. Only 21.7% of patients had previously engaged in ACP conversations during HF management. Positive attitudes towards ACP were associated with lower depressive symptoms [two-item Patient Health Questionnaire; odds ratio (OR): 0.75, 95% confidence interval (CI): 0.61–0.92, *P*-value: 0.006], marriage (OR: 2.53, 95% CI: 1.25–5.12, *P*-value: 0.010), and a high educational level (OR: 2.66, 95% CI: 1.28–5.56, *P*-value: 0.009), but not with severity of HF (represented by Seattle Heart Failure Model risk score). Regarding EOL care, while 'Saying what one wants to tell loved ones' (83.4%), 'Dying a natural death' (81.8%), and 'Being able to stay at one's favorite place' (75.6%) were the three most important factors for patients, preferences for 'Receiving sufficient treatment' (56.5%) and 'Knowing what to expect about future condition' (50.3%) were divergent.
Conclusions   Despite patients' preferences for ACP conversations, there was a discrepancy between preference and engagement in ACP among patients hospitalized for HF. Patients' preferences regarding EOL care may differ; physicians need to consider the appropriate ACP approach to align with patients' care goals.

Introduction

Heart failure (HF) is a leading cause of cardiovascular morbidity and mortality.[1] In parallel with new developments in treatment, there is growing recognition of the importance of palliative care in HF management.[2] Advance care planning (ACP), one of the core domains of primary palliative care, involves prospective identification of a surrogate decision maker and consideration of the type of care patients would prefer, as well as their values and goals, in the event they lose decision-making capacity.[3] ACP has been proven effective in improving both patient and caregiver outcomes, including better quality of life, increased concordance between preferred and received care, and decreased rehospitalization at the end of life (EOL).[4,5] As HF has an unpredictable trajectory, timely ACP conducted when the patient is able to participate in the decision-making process should be standard in HF care.[6] Current clinical guidelines and statements for HF management recommend that cardiologists engage in ACP conversations with their patients throughout the illness course.[7,8]

However, despite these recommendations, ACP among HF patients is performed poorly or not at all.[9–11] A multisite communication intervention trial for advanced HF found a low rate (17%) of care goal discussions being conducted among patients.[9] This indicates an important modifiable gap in optimal HF patient care. Although each hospitalization is an opportunity to discuss ACP,[12] patient readiness to engage in ACP should also be considered.[3,13] Thus, determining whether hospitalized HF patients really want to discuss ACP, and if so, deciding the most appropriate timing for patients to initiate this discussion, could be the first step in promoting integration of ACP conversations into routine clinical practice. Furthermore, patients' values and care preferences should be explored prior to conducting ACP.[3] Understanding patients' perspectives towards EOL care is especially critical for effective ACP conversations[13]; however, little is known about HF patients' perspectives towards ACP and EOL care.

Thus, to close these knowledge gaps, we aimed to elucidate the following: (i) patients' preferences for and actual performance of ACP conversations, (ii) the determinants of positive patient attitudes towards ACP conversation, and (iii) the EOL care preferences of patients hospitalized for HF.

Material and methods

Study population

This was a cross-sectional observational study. Participants were consecutively recruited from hospitalized acute HF patients who completed our questionnaire between September 2017 and March 2020 at a single university hospital centre (Keio University Hospital, Tokyo, Japan). On the basis of the Framingham criteria, acute HF was defined as rapid-onset HF or a change in the signs and symptoms of HF that required urgent therapy and hospitalization.[14,15] Patients presenting with acute coronary syndrome were excluded from this study.

All patients provided informed consent to participate. The study protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki and was approved by the appropriate institutional review board prior to data collection.

Socio-demographic and clinical variables

Patients' clinical variables were obtained from their electronic medical records and defined according to the West Tokyo Heart Failure Registry, an ongoing prospective multicentre cohort registry of hospitalized HF patients in Japan.[15–17] We collected data on patients' co-morbidities, aetiology of HF, previous hospital admission for HF, ejection fraction of echocardiography, use of implantable cardioverter defibrillator or cardiac resynchronization therapy, medication use at discharge, and laboratory results from close to discharge or at the time of discharge.

Procedure

After patients' HF symptoms were stabilized, our multidisciplinary HF team conducted a patient educational programme using written materials for HF instruction guidance (e.g. knowledge about HF, the importance of self-care, and ACP concept) followed by face-to-face counselling by a nurse. After participation in the programme, the patients were given discharge instructions, and the investigators (H. K., T. K., and N. N.) further explained ACP to them. Additionally, while distributing the survey questionnaire, we explained that the items on the questionnaire included ACP and EOL care preferences. In Japan, owing to the universal health coverage system, the mean length of hospital stay among HF patients is substantially longer than in Western countries.[15,16] Hence, patients were afforded time to respond to our detailed survey questionnaire after receiving their discharge instructions. Furthermore, when necessary, the patients were assisted with completing the questionnaire, and the items they did not desire to answer were left unanswered.

Survey questionnaire

The survey questionnaire included 92 questions,[18] comprising eight domains: (i) patient characteristics (socio-demographic factors including education history, living status, social support, and self-care behaviour); (ii) health status (quality of life and depression); (iii) awareness of HF trajectory; (iv) perspectives on treatment goal; (v) decision-making style; (vi) prognostic understanding and preferences for information disclosure; (vii) emergency treatment preferences; and (viii) ACP and EOL care preferences. In the present study, domains (i), (ii), and (viii) were analysed. For the health status domain, the enrolled HF patients were evaluated for quality of life using the Three-Level EuroQol Five Dimensions (EQ-5D),[19] and for depression status using the validated Japanese Patient Health Questionnaire-2 (PHQ-2).[20,21]

For the ACP preferences domain (*Table 1*), patients were asked to rate the extent to which they felt it important to choose a surrogate decision maker in the event they could not make their own treatment decisions, complete advance directives (ADs; i.e. document by which patients make provisions for EOL healthcare decisions), and take part in ACP conversation (i.e. talking with family members and healthcare providers about patients preferences regarding their future health care in cases where patients have diminished decision-making capacity) on a 7-point Likert scale (1, absolutely disagree; 2, disagree; 3, somewhat disagree; 4, unsure; 5, somewhat agree; 6, agree; and 7, absolutely agree).

Table 1 Questionnaire for hospitalized heart failure patients

Questions
1. Preferences for advance care planning
In patients with advanced HF, decision-making capacity could diminish. How would you rate the importance of these items to you?
1-A. Talking with family members and healthcare providers about your preferences regarding your future healthcare, in the event your decision-making capacity is diminished
1. Absolutely disagree 2. Disagree 3. Somewhat disagree 4. Unsure 5. Somewhat agree 6. Agree 7. Absolutely agree
If you answered 'somewhat agree', 'agree', or 'absolutely agree', when do you think is the most appropriate time to have this talk?
1. During the 1st admission for heart failure 2. During the 2nd admission for heart failure 3. After repeated admissions for heart failure in the past year 4. In situations where you feel your life is threatened 5. Other
If you answered 'somewhat agree', 'agree', or 'absolutely agree', have you talked with your family and healthcare providers?
1. Performed 2. Not performed
1-B. Designation of a surrogate decision-maker in cases where your decision-making capacity is diminished.
1. Absolutely disagree 2. Disagree 3. Somewhat disagree 4. Unsure 5. Somewhat agree 6. Agree 7. Absolutely agree
If you answered 'somewhat agree', 'agree', or 'absolutely agree', have you determined a surrogate decision-maker?
1. Determined 2. Not determined
1-C. Document by which you make provision for healthcare decision during your end-of-life care
1. Absolutely disagree 2. Disagree 3. Somewhat disagree 4. Unsure 5. Somewhat agree 6. Agree 7. Absolutely agree
If you answered 'somewhat agree', 'agree', or 'absolutely agree', have you completed this document?
1. Completed 2. Not completed
2. Preferences for end-of-life care
How would you rate the importance of these factors during the end-of-life period?
1. Absolutely disagree 2. Disagree 3. Somewhat disagree 4. Unsure 5. Somewhat agree 6. Agree 7. Absolutely agree
Receiving sufficient treatment
Dying a natural death
Saying what one wants to tell loved ones
Knowing what to expect about future condition
Dying without awareness that one is dying
Not exposing one's physical and mental weakness to family
Feeling that life is worth living
Supported by religion
Being able to stay at one's favorite place
If you rated being able to stay at one's favorite place as 'somewhat agree', 'agree', or 'absolutely agree', where do you think you would like to be for your end-of-life care?
1. Home 2. Hospital 3. Nursing facility 4. Other

HF, heart failure.

Patients who scored 5 or more for each item were asked whether they had actually established a surrogate decision maker, completed their ADs, and engaged in ACP conversation. The patients with positive attitudes towards ACP (those who scored 5 or more) were also asked to choose what they felt was the most appropriate timing for initiating ACP (1, during the first admission for HF; 2, during the second admission for HF; 3, after repeated admissions for HF in the past year; 4; in situations where they felt their lives were threatened; and 5, other). Further assessments regarding the preference for ACP conversations stratified by presence of previous HF hospitalization, HF severity [Seattle Heart Failure Model (SHFM)-predicted 1 year survival rate and New York Heart Association functional classification], and age were performed. The definitions of ACP and ADs were based on the statement for treatment of elderly HF patients presented by the Japanese Heart Failure Society.[22]

For the EOL care preferences domain (*Table 1*), questionnaires comprised nine components adopted from the Good Death Inventory (GDI), an established self-administered questionnaire focusing on bereaved caregivers' perspectives that has been widely used in EOL care for cancer. This material was produced by collecting responses towards 70 potential attributes of a good death, which were generated based on previous works.[23–26] The Japanese concept of a good death constitutes 10 core domains that, in qualitative studies, most Japanese individuals consistently rated as important, and 8 optional domains that were not as consistently rated as important. Thus, the short version of the GDI consists of 18 representative items from each domain, the validity and reliability of which have been confirmed.[27] In order to explore EOL preferences that could differ among patients, we selected all eight optional domain items and one core domain item ('Being able to stay at one's favorite place'), which were modified to be presented from the patient's perspective. In the context of a hypothetical EOL setting, patients were asked to respond to each item on a 7-point Likert scale (1, absolutely disagree; 2, disagree; 3, somewhat disagree; 4, unsure; 5, somewhat agree; 6, agree; and 7, absolutely agree). Further, for patients who indicated a preference for 'Being able to stay at one's favorite place', another question regarding specific favourite places during EOL was also added: 'Where do you think you would like to be for your EOL care?' (1, home; 2, hospital; 3, nursing facility; and 4,

other). The questions within the domains for ACP and EOL care preferences were originally created and further developed through in-depth discussion among the investigators, including board-certified cardiologists (H. K. and T. K.), a nurse certified in chronic HF care (N. N.), and a behavioural scientist and board-certified psychologist (D. F.).

Patient recruitment

Among the 342 HF patients admitted at our university hospital, which is an advanced tertiary medical institution, we excluded patients who could not complete the questionnaires (e.g. unconsciousness, *n* = 9, 2.6%; severe cognitive impairment, *n* = 79, 23.1%; mental health disorder, *n* = 14, 4.1%; and language barrier, *n* = 4, 1.2%), had other end-stage life-threatening diseases (*n* = 7, 2.0%), or died while hospitalized (*n* = 15, 4.4%). Furthermore, for patients who were admitted to our hospital more than once and completed repetitive surveys during the study period, those subsequent surveys were excluded (*n* = 12, 3.5%). Consequently, a total of 202 patients were approached by our questionnaire survey. Among them, 15 patients refused to answer the questionnaire. In addition, nine patients who were unable to answer the questionnaire owing to early discharge and seven patients who did not respond to the question regarding ACP and EOL care preferences were excluded. In total, 171 patients were enrolled in this study.

Statistical analysis

Continuous variables were expressed as means ± standard deviations or a median with an inter-quartile range (IQR), which were dependent on distribution characteristics. Categorical variables were expressed as numbers (percentages). Regarding ACP and EOL care preferences, patients were divided into those with positive attitudes (somewhat agree, agree, and absolutely agree) and those with negative attitudes (absolutely disagree, disagree, somewhat disagree, and unsure) towards each item. Overall, missing data were rarely observed (≤5%), with the exception of the percentage of lymphocytes (10.5%). Laboratory values were imputed as median values. Data with missing responses to the questionnaire were eliminated from the analysis. To predict the 1 year survival rate, the SHFM scores were calculated in accordance with the statistical model validating the use of the SHFM in Japanese hospitalized HF patients.[17] Univariable logistic regression analyses were conducted to elucidate the determinants of a positive attitude towards ACP conversation in HF patients. For all statistical analyses, significance was defined as *P* < 0.05. Graphical data were created using GraphPad Prism 8. Data were analysed using SPSS Version 26 (IBM Corp., Armonk, NY, USA).

Results

Patient clinical characteristics

Participants' demographic data are shown in *Table 2*. Enrolled patients were all Japanese and predominantly men (67.3%), with a median age of 73.0 (IQR: 63.0–81.0) years

Table 2 Baseline characteristics

Variables	
Demographics	
Age (years)	73.0 (63.0–81.0)
Male, *n* (%)	115 (67.3)
Japanese, *n* (%)	171 (100)
Body mass index (kg/m^2)	20.6 (18.7–23.4)
University education or more, *n* (%)	80 (46.8)
Married, *n* (%)	113 (66.1)
Living alone, *n* (%)	41 (24.0)
Medical history, *n* (%)	
Hypertension	91 (53.2)
Diabetes mellitus	64 (37.4)
Dyslipidaemia	67 (39.2)
Atrial fibrillation	112 (65.5)
Chronic obstructive pulmonary disease	22 (12.9)
Stroke	26 (15.2)
Cancer	42 (24.6)
Aetiology of HF, *n* (%)	
Ischaemic	39 (22.8)
Dilated	31 (18.1)
Valvular	40 (23.4)
Arrhythmia-induced	12 (7.0)
Other aetiology	49 (28.7)
Previous HF admission, *n* (%)	84 (49.1)
NYHA at discharge III and IV, *n* (%)	54 (31.6)
Vital signs at discharge	
Heart rate (b.p.m.)	73.2 ± 13.0
Systolic blood pressure (mmHg)	104.0 (94.0–116.0)
Echocardiographic parameters	
Left ventricular ejection fraction (%)	44.1 (31.3–59.5)
Laboratory data at discharge	
Haemoglobin (g/dL)	12.3 ± 2.3
Sodium (mEq/L)	139.4 (137.4–141.0)
Uric acid (mg/dL)	7.0 (5.9–8.1)
BUN (mg/dL)	24.3 (19.5–34.7)
Creatinine (mg/dL)	1.20 (0.93–1.63)
BNP (pg/mL)	405.1 (208.5–733.7)
Lymphocyte (%)	22.0 (17.8–26.7)
Total cholesterol (mg/dL)	166.1 (137.0–190.0)
Medication or device therapy, *n* (%)	
Loop diuretics	147 (86.0)
Beta-blockers	143 (83.6)
RAS inhibitors	102 (59.6)
Mineralocorticoid receptor antagonists	89 (52.0)
Statin	67 (39.2)
Allopurinol or febuxostat	76 (44.4)
ICD	15 (8.8)
CRT	10 (5.8)
SHFM-estimated 1 year survival rate (%)	94.2 (90.9–96.3)

BNP, brain natriuretic peptide; BUN, blood urea nitrogen; CRT, cardiac resynchronization therapy; HF, heart failure; ICD, implantable cardioverter defibrillator; NYHA, New York Heart Association functional classification; RAS, renin–angiotensin system; SHFM, Seattle Heart Failure Model.
Data are shown as mean ± standard deviation, median with inter-quartile range, or number (percentage).

and median left ventricular ejection fraction of 44.1% (IQR: 31.3–59.5%). Of these, 84 patients (49.1%) had a history of HF hospitalization. Median SHFM-estimated 1 year survival rate was 94.2 (90.9–96.3).

Patient preferences for and actual performance of advance care planning

Figure 1 presents the questionnaire results regarding patients' preferences for and the actual performance of ACP conversations. Among 171 respondents, 127 (74.3%) recognized the importance of discussing ACP. Notably, only 21.7% of patients with positive attitudes towards ACP previously had an actual ACP conversation during their HF management (*Figure 1A*). Among the patients with positive attitudes towards ACP, 48.1% thought the discussion should be initiated after repeated hospitalizations for HF in the past year, and 29.0% responded with during the first or second HF hospitalization (*Figure 1B*). Only 17.6% of patients thought that ACP conversations should not be initiated until the terminal disease phase. Among 16 patients with positive attitude towards the initiation of ACP conversation during the first HF hospitalization, only four patients (25.0%) had performed ACP conversation. Among 11 patients who had both previous HF hospitalization and positive attitude towards the initiation of ACP conversation during the second HF hospitalization, three patients (27.3%) actually performed ACP conversation. Regardless of whether patients had been admitted to the

hospital for HF prior to their current hospitalization, >70% of patients had positive attitudes towards ACP, of which ~20–25% reported previously having an actual ACP conversation (Supporting Information, *Figure S1A*). Stratification by HF severity and age also demonstrated that most patients (73–77%) recognized ACP as important for their care; however, 17–30% had previously engaged in ACP conversations (Supporting Information, *Figure S1B–S1D*). Further analysis concerning ACP preference among five groups according to age (≤49, 50–59, 60–69, 70–79, and ≥80 years) demonstrated that participants' preferences did not differ among different age groups (*P* = 0.235; Supporting Information, *Figure S2*).

Supporting Information, *Figure S3* shows patients' perspective towards designating a surrogate decision maker. Approximately 70% of respondents answered that determining a surrogate decision maker in advance was important, among which 69.5% had actually done so. Regarding patients' perspectives towards ADs, 53.8% considered ADs to be important, while only 4.9% of patients completed ADs.

Determinants of positive attitudes towards advance care planning conversation

Univariate logistic regression analyses showed that lower PHQ-2 scores [odds ratio (OR) 0.75, 95% confidence interval (CI) 0.61–0.92], marriage (OR 2.53; 95% CI 1.25–5.12), and a high educational level (OR 2.66; 95% CI 1.28–5.56) were associated with positive attitudes towards ACP conversation;

Figure 1 Patients' preferences and engagement in advance care planning (ACP) conversations. (A) The proportions of patients' preferences and actual performance of ACP conversations in patients hospitalized for heart failure. (B) The proportion of patient-expected optimal timing for ACP initiation among patients with positive attitudes towards ACP conversation. (C) Relationship between Seattle Heart Failure Model (SHFM)-predicted 1 year survival rate and attitudes towards ACP conversation. Bar denotes medians, boxes denote inter-quartile ranges, and whiskers extend to 1.5 inter-quartile range. Dots represent each patient's 1 year survival rate.
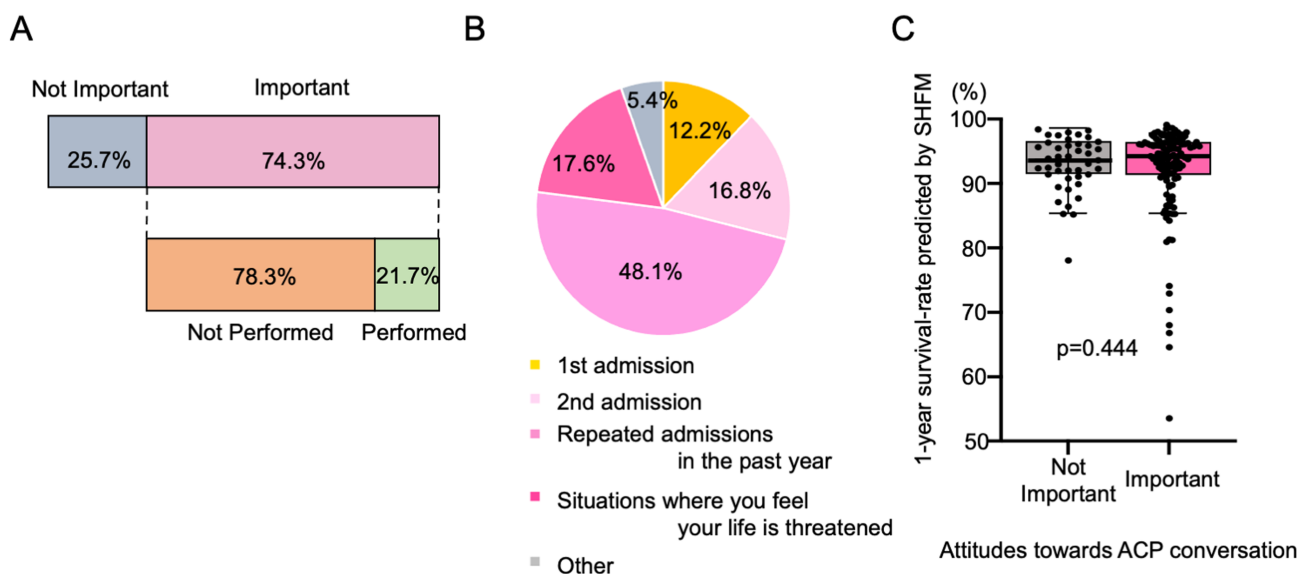
however, previous history of HF hospitalization and SHFM risk scores were not (*Table 3*). SHFM-estimated 1 year survival rates did not differ between patients with and without positive attitudes towards ACP (*Figure 1C*).

Important factors during end-of-life care in advanced heart failure

Figure 2 shows the questionnaire results regarding factors perceived as important during their EOL in advanced HF. The Top 3 items identified were 'Saying what one wants to tell loved ones' (83.4%), 'Dying a natural death' (81.8%), and 'Being able to stay at one's favorite place' (75.6%). In contrast, patients' preferences were divergent for 'Receiving sufficient treatment' (56.5%), 'Knowing what to expect about future condition' (50.3%), and 'Not exposing one's physical and mental weakness to family' (44.7%). Those who considered being 'Supported by religion' as an important factor accounted for <20%. Regarding the item 'Being able to stay at one's favorite place', while 61.5% of patients wanted to stay at home, 29.6% answered that it would be preferable to be at a hospital for EOL care.

Supporting Information, *Figure S4* shows the proportion of patients with positive attitudes towards ACP among those with positive attitudes towards each EOL component. Interestingly, a large proportion of patients with positive attitudes towards each EOL component also considered ACP conversations to be important. Particularly, among patients with positive attitudes towards 'Knowing what to expect about future condition' and 'Supported by religion', who accounted for <55% of the total cohort, >85% showed positive attitudes towards ACP.

Discussion

The present study demonstrated the following key points: (i) though most HF inpatients considered ACP conversations to be important, few actually conducted them; (ii) having a positive attitude towards ACP conversation was associated with lower depression and higher educational levels, but not with estimated prognosis; and (iii) 'Saying what one wants to tell loved ones', 'Dying a natural death', and 'Being able to stay at one's favorite place' were the most important factors for EOL, although patients' preferences towards 'Receiving sufficient treatment' and 'Knowing what to expect about future condition' varied.

To our knowledge, this was the first study to use a hospitalized HF patient cohort to investigate the preferred and actual engagement in ACP conversations. In our cohort, there was a contradiction between patients' preferences for ACP and its actual performance, which is consistent with previous studies of patients with other medical conditions.[28,29] A survey of oncology outpatients in two Australian cancer treatment centres revealed that most respondents considered discussing ACP to be important; however, uptake rates were relatively low.[28] A meta-analysis targeting palliative care for adult patients with congenital heart disease revealed that only 1–28% had actually participated in ACP discussions, despite their strong preference towards ACP.[29] The willingness of many patients to engage in ACP conversations, including patients with HF,

Table 3 Determinants of those who considered 'ACP conversation was important' among patients' characteristics

Variables	OR	95% CI	*P*-value
Age (per each year increase)	1.00	0.97–1.03	0.890
Male	0.94	0.45–1.97	0.879
Hypertension	1.19	0.60–2.36	0.620
Dyslipidaemia	1.17	0.58–2.39	0.657
Diabetes mellitus	1.60	0.77–3.35	0.212
Atrial fibrillation	1.12	0.55–2.28	0.763
Chronic obstructive pulmonary disease	3.93	0.88–17.53	0.073
History of stroke	0.93	0.36–2.39	0.880
History of cancer	0.71	0.33–1.52	0.374
Previous heart failure admission	0.95	0.48–1.89	0.893
LVEF (per each % increase)	1.01	0.99–1.03	0.388
NYHA III and IV	1.14	0.54–2.40	0.736
BNP (per each pg/mL increase)	1.00	1.00–1.00	0.882
SHFM-estimated 1 year survival rate (per each % increase)	0.97	0.92–1.03	0.358
Quality of life (per each EQ-5D score increase)	4.40	0.64–30.12	0.131
Depression (per each PHQ-2 score increase)	0.75	0.61–0.92	0.006
University education or more	2.66	1.28–5.56	0.009
Married	2.53	1.25–5.12	0.010
Having children	1.97	0.91–4.27	0.086
Living alone	0.58	0.27–1.24	0.160

ACP, advance care planning; BNP, brain natriuretic peptide; CI, confidence interval; EQ-5D, EuroQol Five Dimensions; LVEF, left ventricular ejection fraction; NYHA, New York Heart Association functional classification; OR, odds ratio; PHQ-2, Patient Health Questionnaire-2; SHFM, Seattle Heart Failure Model.

Figure 2 Important factors identified by patients for their end-of-life care in advanced heart failure.
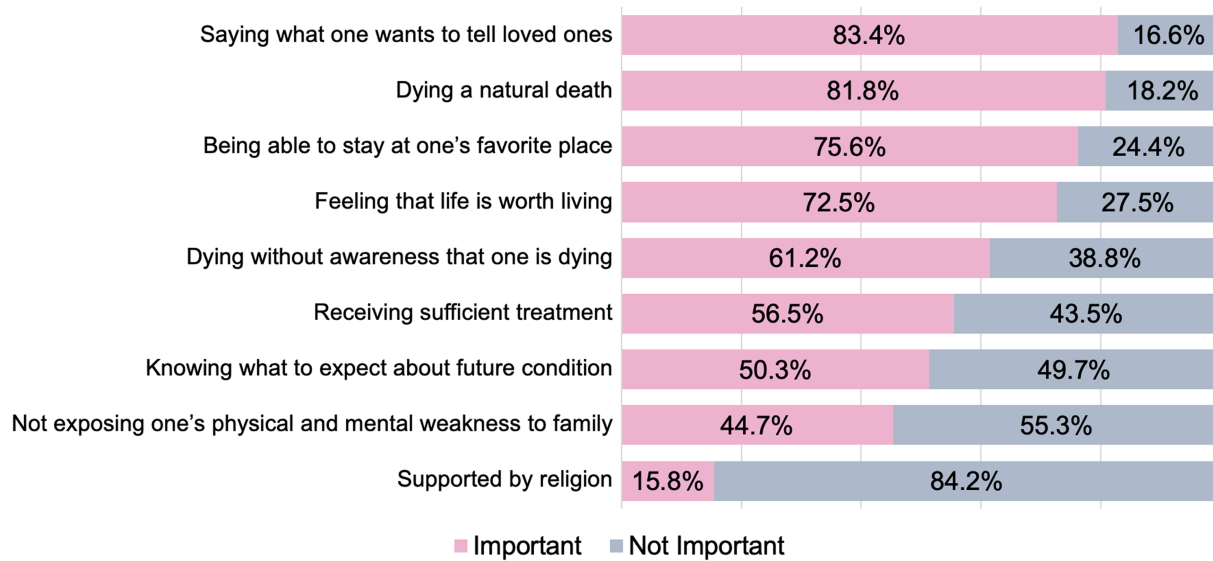
suggests a universal gap in current ACP practice. In our study, the majority of patients had positive attitudes towards designating a surrogate decision maker, and many had actually done so. Identifying surrogate decision makers is the first step in shared decision making and ACP.[13] As most HF patients demonstrated positive attitudes towards ACP, physicians should support these patients and their surrogate decision makers to allow for more profound communication regarding patients' goals, values, and treatment preferences, which could close the gap between patients' preferences and actual engagement in ACP conversations.

As mortality risk increases with each subsequent hospitalization,[16] hospital discharge planning is an opportunity for ACP conversations. Notably, ~70% of HF inpatients in our study considered that the optimal time to initiate ACP conversations was the second admission or repeated admissions for HF in the past year. As ACP requires time and emotional energy, these discussions are often deferred until more urgent and less favourable occasions, leading to impaired decision making.[12] ACP without patient's readiness does more harm than good[30]; however, the implementation of ACP led to an improvement in patients' depression[31] and higher satisfaction with the quality of EOL care.[32] Current scientific statement from the American Heart Association recommends that event-driven 'milestones' (e.g. worsening HF prompting hospitalization or initiation of intravenous inotropic support) should trigger ACP conversations.[12] Although determining the appropriate timing of these conversations is a formidable challenge, its timing could be comprehensively determined by HF severity as well as patients' preferences regarding these conversations. It may be necessary to promote early ACP conversations with a multidisciplinary approach

during routine care for hospitalized patients with positive attitudes towards its early initiation. This will facilitate shared decision making regarding complex therapeutic options and palliative care that aligns with patients' personal values.

Patients, families, and healthcare providers could have different perspectives regarding what factors are important at the EOL[33]; therefore, sharing patients' perspectives on EOL is integral to successfully improving the care of terminal patients. A strength of our study was that we identified HF inpatients' perspectives towards EOL care, using a questionnaire based on the GDI, consisting of potential attributes Japanese individuals may feel necessary for a good death.[23,27] Our findings have several clinical implications. First, healthcare providers should know that HF inpatients expect to have communications with people close to them, be in their preferred surroundings, and feel that their life was worth living, which is consistent with findings on other diseases, such as cancer and chronic obstructive pulmonary disease.[23,34] Second, HF patients' preferences during EOL varied regarding 'Dying without awareness that one is dying'. Thus, despite international recommendations for prognostic communications for HF patients,[35] cardiologists should pay attention to the delicate balance between patients' preference towards 'Knowing what to expect about future condition' and towards 'Dying without awareness that one is dying'. Third, although ~80% patients preferred a natural death, preferences regarding 'Receiving sufficient treatment' during EOL varied. For patients with positive preferences for both factors, ACP conversation is mandatory to ensure that patients receive care that is in line with their preferences (e.g. natural death and sufficient treatment from the perspective of individual patients). Fourth, although

understanding patients' goals and values remains challenging, hospitalized HF patients could use our questionnaire to express the factors they find important for EOL care. Given that there is considerable variability in EOL preferences,[36] we believe that patients' preferences and values should be regularly assessed. To reflect patients' preferences and goals, educational and training programmes for medical professionals that facilitate specialized knowledge and skills concerning ACP and EOL care are essential.[37] The importance of these issues has been emphasized in EOL care, especially in recent years.[37–39]

Limitations

There were some limitations to the present study that should be considered when interpreting the results. First, this study was conducted in a single centre with a small number of patients; consequently, statistical power may not have been sufficient to detect any negative outcomes. Second, the study's cross-sectional design limits our ability to clarify changes, if any, in patients' attitudes or preferences towards ACP hereafter. Notably, patients can revise their preferences based on changes to their health condition[36]; further studies will be needed to evaluate changes in attitudes and preference towards ACP and EOL care. Third, we did not investigate patients' personality traits or wishes for specific treatment or care (e.g. palliation of symptoms or implantable cardioverter defibrillator deactivations). Questions regarding with whom (among medical providers) patients would desire to discuss ACP were not included. In addition, our study's design hindered us from quantitatively assessing the effect of this survey on the patients' psychological disturbances, using the validated questionnaires (i.e. PHQ-2). Fourth, our findings might be unique to Japan, where the penetration of and attitudes towards the concept of ACP is significantly different than in Western countries.[11] Because HF is an international health-related problem, further studies with international collaboration are needed to reassess our findings across different religions and cultural contexts. However, our study demonstrated patients' positive attitudes and preferences towards engaging in ACP conversations and that hospitalized HF patients preferred these discussions to be initiated in the early disease stage; these findings cast new light on the controversial topic of at what point ACP conversations should be initiated.

Conclusions

In conclusion, the majority of patients in the present study considered ACP to be essential and preferred ACP conversations to be initiated during the early stage, rather than the end stage, during the HF trajectory. As patients' preferences regarding EOL care can differ, physicians need to consider the appropriate approach to ACP, including the timing of initiation, for hospitalized patients with HF.

Conflict of interest

Funding

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Figure S1. Patients' preferences and engagement in ACP conversations in various subgroups categorized according to the presence of previous HF admission (A), SHFM-predicted one-year survival rate (B), NYHA (C), and age (D).
ACP: advance care planning, HF: heart failure, SHFM: Seattle Heart Failure Model, NYAH: New York Heart Association functional classification.
Figure S2. Patients' preferences of ACP conversations among five groups categorized according to age.
ACP: advance care planning.
Figure S3. Patients' preferences and actual performance of designating of a surrogate decision-maker and completing advance directives.
Figure S4. Bubble plot representation of the relationship between ACP preferences and EOL preferences. The horizontal axis shows the proportion of patients with positive attitudes towards ACP among those with positive attitudes towards each EOL component. The proportion of patients with positive attitudes towards each EOL component is represented through the size of the bubbles.
ACP: advance care planning, EOL: end-of-life.

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