

BMJ Open Associations between understanding of current treatment intent, communication with healthcare providers, preferences for invasive life-sustaining interventions and decisional conflict: results from a survey of patients with advanced heart failure in Singapore

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ABSTRACT

Objectives To make informed choices about use of future invasive life-sustaining interventions (ILSI), patients with congestive heart failure (CHF) need to correctly understand the intent of their current treatments. However, healthcare providers may be wary of having these discussions due to fear of distressing patients. In this study, we assessed whether patients who understand their treatment intent are less willing to undergo ILSI and are indeed more psychologically distressed.

Design, participants and outcomes As part of a cross-sectional survey conducted prior to randomising patients for a trial, we asked 282 patients with advanced CHF (New York Heart Association Class III and IV) whether they believe their existing treatments would cure their heart condition, their willingness to undergo ILSI and assessed their anxiety and depression using the Hospital Anxiety and Depression Scale.

Results Approximately half of patients reported a willingness to undergo ILSI if needed. Only 22% knew that their current treatments were not curative. These patients were far less willing to undergo ILSI (OR 0.28, 95% CI 0.15 to 0.56) and were not at a greater risk of having clinically significant anxiety (OR 0.72, 0.34 to 1.54) and depression (OR 0.70, 0.33 to 1.47) compared with those who did not understand their current treatment intent.

Conclusions Improving patients' understanding of the intent of their current treatments can help patients make informed choices about ILSI.

Trial registration number NCT02299180; Pre-results.

INTRODUCTION

Congestive heart failure (CHF) is a fatal condition.¹ Symptomatic patients have a 5-year survival rate of approximately 50% and those with very advanced disease have 1-year mortality of up to 90%.^{2–4} Given the progressive, irreversible and unpredictable

Strengths and limitations of this study

- The main strength of the study is that it includes a large sample of patients with advanced congestive heart failure.
- A limitation is that as data are self-reported and based on a single cross-sectional survey, causality cannot be inferred.
- Another limitation was that the survey did not include details of what was communicated to patients by their healthcare providers.
- It is unclear how patients interpreted the term 'cure' in our survey.

nature of the disease and a high burden of physical symptoms, psychosocial and spiritual distress,^{5 6} patients with advanced CHF are increasingly encouraged to document their preference for invasive life-sustaining interventions (ILSI) such as mechanical ventilation, intubation and cardioversion through advance directives or advance care plans.^{7 8}

To make an informed decision about ILSI, patients must first understand that, barring the very few who are able to receive a transplant, the available medical treatments will not cure the underlying heart condition. Several studies and theoretical frameworks have examined illness perceptions of patients including their beliefs about cure and its effects on treatment behaviour.^{9–16} Within this context, a few studies with patients with CHF suggest that these patients do not understand that their current medical treatments including taking drugs or having surgeries or devices implanted are not curative.^{17 18} For patients with cancer with similar beliefs, it

is hypothesised that their lack of understanding results, in part, from their healthcare providers wariness in discussing prognosis and treatment intent for fear that it will distress patients.^{19 20} The same is likely true for patients with advanced CHF. We thus assess whether patients who discuss future treatment options such as ILSI with their provider were more likely to understand that their current treatments are not curative, compared with those who had not discussed. We also test whether patients who understand that their current treatments are not curative are indeed more psychologically distressed than those who do not understand, as their healthcare providers fear. We then assess whether patients with advanced CHF who understand their current treatments are not curative are less willing to opt for ILSI.

For many patients, the decision on whether or not to pursue ILSI should the need arise is a difficult decision and one where many patients will make a decision with less than perfect conviction. Greater certainty (ie, greater conviction that the choice is right) should result from being more informed about risks and benefits of future treatment options including ILSI and therefore can be considered as an indicator of quality of informed decision-making. Therefore, as a final test, we assessed whether patients who discussed the risks and benefits of future treatment options including ILSI with their providers were more certain in their decisions compared with those who do not.

In the era of patient-centred care and informed decision-making, these study results will further our understanding about the need to clearly communicate to patients with advanced CHF the intent of their ongoing treatments when discussing future treatment options.

METHODS

Participants

We approached patients with CHF admitted in two major public hospitals in Singapore between March 2015 and December 2016. Patients were recruited for a randomised controlled trial in Singapore assessing the effectiveness of advance care planning. Inclusion criteria were patients 21 years and older, Singapore citizen or permanent resident, diagnosis of CHF and with severity of symptoms fitting New York Heart Association Class III or IV. Exclusion criteria were patients with cognitive and/or psychiatric impairments. All participants gave their written informed consent to participate in the study. The SingHealth Centralised Institutional Review Board approved this study.⁷ This paper used the data from the baseline survey administered to all patients who consented to take part in the trial.

Survey measures

We asked patients their willingness to undergo ILSI (eg, intubation, mechanical ventilation, cardioversion and transfer to intensive care unit), only non-invasive interventions (eg, oral or intravenous medications) or only comfort

measures (eg, reasonable measures to offer food or fluids, oxygen and medication for comfort) in future. To assess whether patients had discussed ILSI with their providers, we asked patients if they had discussed these treatment options with their healthcare provider (yes/no). We also assessed understanding of treatment intent by asking patients whether they thought that their existing treatments would cure their heart condition (yes/no/not sure). We used the anxiety subscale and depression subscale of the Hospital Anxiety and Depression Scale to assess patient's psychological distress. Patients with a cut-off score of 8 or more on the two subscales were classified as having clinically significant anxiety or depressive symptoms.^{21 22}

We used a low-literacy version of the decisional conflict scale to gauge patients' uncertainty regarding their choice between ILSI, non-invasive interventions and comfort measures.^{23 24} As the scale was administered to assess decisional uncertainty in choosing between these three options, we removed the first item of the scale asking whether the patient knew which options were available to him/her, resulting in a total of nine items. Responses for each of the nine items on the scale were categorised as yes (score=0), no (score=4) and not sure (score=2) and total score was divided by 9 and multiplied by 25. Scores ranged from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Similar to the original scale,²⁴ Cronbach's α (internal consistency reliability) for the nine items was 0.80. Consistent with the original scale, an exploratory factor analysis with promax rotation found four factors, namely being informed, values clarity, support and uncertainty. The only difference with the original version was that one item that loaded on the support subscale (Do you have enough advice to make a choice?) in the original scale loaded on the informed subscale in our study. A confirmatory factor analysis further confirmed this factor structure (Root Mean Square Error of Approximation (RMSEA)=0.10, Comparative Fit Index (CFI)=0.94, Tucker Lewis index (TLI)=0.90, Standardized Root Mean Square Residual (SRMR)=0.06).

Statistical analysis

We assessed the proportion of patients who correctly understood that their current treatments were not intended to cure them. We used a logistic regression model to test whether patients who had discussed their future treatment options including ILSI with their providers (independent variable) were more likely to understand that their current treatments are not curative (dependent variable). Analysis controlled for other patient characteristics (age (<65 years, >65 years); gender; time since CHF diagnosis (<1 year, 2–5 years, 6–10 years, >10 years); whether or not patient had a cardiac device implanted; education; living with someone or alone; type of housing; religion; and self-rated health status (relatively healthy or seriously ill)). Type of housing was used as a proxy for socioeconomic status as housing size in Singapore is found to be proportional to household income.²⁵

To assess whether patients who understand their current treatments are not curative (independent variable) are

more likely to be psychologically distressed, we used two separate linear regression models with patient anxiety and depression scores as the outcome variables. Both models were adjusted for patient characteristics (age, gender, time since CHF diagnosis, whether or not patient had a cardiac device implanted, education, living with someone or alone, type of housing, religion and self-rated health status).

We ran a logistic regression model with the outcome variable as patients' willingness to undergo ILSI and the independent variables as patients' correct understanding of treatment intent, whether they had discussed these interventions with their providers and other patient characteristics (same as in the above models).

As the distribution of decisional conflict score (dependent variable) was skewed, we used a median regression to model this association, adjusting for patient characteristics (same as above).

We used STATA Version 15 for all analyses.

Patient and public involvement

Patients, patient advisors and public were not involved in the development of the research questions, in the design of the study or in the recruitment of study participants.

RESULTS

Of the 1954 patients referred to the study, 1665 were screened for eligibility, 696 were found to be eligible and 604 were approached to take part in the study. Of these, 282 (46.7%) participated in the study. Average age of patients was 65 years (age range: 26–94 years). Patients were mainly men (78%), with at least secondary education (53%) and were Buddhists/Taoists (37%). 12% of the patients lived alone and 21% lived in 1–2 room public housing signifying a low socioeconomic status. About a quarter were diagnosed with CHF in the last 1 year, 40% perceived themselves to be seriously ill and 26% had a cardiac device implanted (either an implantable cardioverter defibrillator or a pacemaker). Twenty-six per cent of the patients had clinically significant anxiety and 29% had clinically significant depressive symptoms (table 1).

Approximately half of our patient sample reported a willingness to undergo ILSI if needed. Only 22% correctly knew that their current treatments were not intended to cure them and 26% reported having conversations with their healthcare providers regarding use of ILSI. The median decisional conflict score was low at 5.6, indicating that most patients were more certain in choosing between ILSI and non-invasive/comfort measures (table 1).

Table 2 shows that patients who had discussed future treatment options with their healthcare providers were no more likely to be aware that their current treatments were not intended to cure them (OR 1.45, 95% CI 0.73 to 2.87). Only longer duration of illness (6–10 years: OR 2.98, 95% CI 1.01 to 8.82; >10 years: OR 2.73, 95% CI 1.01 to 7.40) and higher education (OR 2.07, 95% CI 1.03 to 4.17) increased the odds of patients correctly knowing

Table 1 Sample characteristics (n=282)

Characteristics	N (%)
Age: mean (SD)	64.6 (13.1)
<65 years	140 (49.7)
>65 years	142 (50.4)
Gender	
Male	220 (78.0)
Female	62 (22.0)
Education	
Primary or below	133 (47.3)
Secondary or above	148 (52.7)
Duration of heart failure	
≤1 year	68 (24.1)
2–5 years	54 (19.1)
6–10 years	49 (17.4)
>10 years	111 (39.4)
Living arrangement	
Living alone	34 (12.1)
Living with someone	248 (87.9)
Type of housing	
1–2 room public housing	60 (21.3)
3–5 room/executive public housing	197 (69.9)
Private housing/bungalow	25 (8.9)
Religion	
Christian	40 (14.2)
Buddhist/Taoist	104 (36.9)
Muslim	78 (27.7)
Hindu/Sikh	31 (11.0)
No religion/free thinker	29 (10.3)
Patient self-rated health status	
Relatively healthy	170 (60.3)
Seriously ill	112 (39.7)
Presence of a cardiac device	72 (25.5%)
No device	210 (74.5)
Implantable cardioverter defibrillator	64 (22.7)
Pacemaker	8 (2.8)
Patient preference for future treatments	
Invasive life-sustaining interventions	140 (49.7)
Non-invasive interventions/comfort care	142 (50.3)
Patient understanding of treatment intent	
Current treatments cannot cure heart condition	62 (22.0)
Current treatments can cure heart condition	150 (53.2)
Not sure	70 (24.8)
Discussed treatment options with a healthcare provider	
No	209 (74.1)
Yes	73 (25.9)
Decisional conflict score: median (IQR)	5.6 (16.7)
≤75 percentile	213 (75.53)
>75 percentile	69 (24.47)

Continued

Table 1 Continued

Characteristics	N (%)
Clinically significant anxiety	74 (26.2)
Clinically significant depressive symptoms	81 (28.7)

that their current treatment would not cure them. Patient perception of being seriously ill also did not increase the odds of them understanding that the intent of their current treatment is not curative (OR 0.92, 95% CI 0.49 to 1.73).

Contrary to our hypothesis, patient understanding that current treatments were not curative were not associated with a greater likelihood of patients being psychologically distressed, that is, being anxious (OR, 95% CI 0.72 (0.34 to 1.54)) or depressed (OR, 95% CI 0.70 (0.33 to 1.47)). Consistent with our hypothesis, patients who understood that their treatments were not curative were far less willing to undergo ILSI (OR 0.28, 95% CI 0.14 to 0.55). Consistent with our hypothesis, patient discussing future treatment options with healthcare providers was associated with lower decisional uncertainty (β =-5.56, 95% CI -8.61 to -2.50).

DISCUSSION

This paper highlights that among symptomatic advanced CHF inpatients, only a small proportion (22%) knew that

their current treatments were not intended to cure them. These results are concerning because they show that the vast majority of patients with advanced CHF were undergoing treatments, without fully realising the intent of these treatments.

We also found that even though patients who had discussed future treatment options with their healthcare providers were more certain in their decision to choose or forego ILSI, they did not have any better understanding that their current treatments will not cure them. This may be because although providers may have discussed risks and benefits of future treatment options including ILSI with patients during these conversations, an explicit discussion of prognosis and treatment intent may be missing. Anecdotally, we know that in most Asian communities particularly among Chinese, true prognosis is often withheld from the patient as patients and families generally believe that talking about death may bring on bad luck for the patient. Healthcare providers often fear that patients may become psychologically distressed after hearing that their current treatments are not intended to cure them.^{19 20} As a result, both patients and providers may be reluctant to initiate a discussion of prognosis and treatment intent during consultations. Providers may also use ambiguous and technical terms to talk about poor prognosis which patients may not fully understand.^{26 27} Previous studies have also reported that patients with advanced CHF rarely acknowledge their

Table 2 Multivariable model of patients' correct understanding of treatment intent (n=281)

	Correct understanding of treatment intent*	
	OR	95% CI
Discussed future treatment options with a healthcare provider (Ref: did not discuss with a healthcare provider)	1.45	0.73 to 2.87
Patient perception of them being seriously ill (Ref: perceive themselves to be relatively healthy)	0.92	0.49 to 1.73
Presence of a cardiac device	1.07	0.53 to 2.15
≥65 years old (Ref: <65 years old)	0.58	0.30 to 1.11
Duration of heart failure 2–5 years (Ref: ≤1 year)	2.12	0.69 to 6.47
Duration of heart failure 6–10 years (Ref: ≤1 year)	2.98 †	1.01 to 8.82
Duration of heart failure >10 years (Ref: ≤1 year)	2.73 †	1.01 to 7.40
Female (Ref: male)	0.37	0.13 to 1.05
Secondary or above education (Ref: primary or below education)	2.07 †	1.03 to 4.17
Living with someone (Ref: living alone)	0.89	0.29 to 2.74
3–5 room/executive public housing (Ref: 1–2 room public housing)	0.99	0.38 to 2.60
Private housing/bungalow (Ref: 1–2 room public housing)	1.84	0.51 to 6.69
Christian (Ref: no religion/free thinker)	1.70	0.44 to 6.66
Buddhist/Taoist (Ref: no religion/free thinker)	1.46	0.42 to 5.14
Muslim (Ref: no religion/free thinker)	1.66	0.47 to 5.84
Hindu/Sikh (Ref: no religion/free thinker)	2.79	0.71 to 10.91

*Analysis performed using logistic regression.

†P<0.05.

poor prognosis and providers do not explicitly discuss this information with them.^{28 29} Our study results however indicate that this fear of explicitly discussing treatment intent may be unfounded as patients with a correct understanding of treatment intent are neither more anxious nor depressed compared with patients who do not have a correct understanding of treatment intent.

Alternatively, it is likely that patients may be in denial of their poor prognosis and did not report in the survey what they had been told about their treatment intent during consultations. In order to preserve their hope, even patients with a reasonable knowledge of prognosis and treatment intent may not want to apply that knowledge to themselves. Because the current study shows that patient understanding of treatment intent systematically influences their preference for their future treatments such as use of ILSI, it is imperative that providers address the underlying pathways that contribute to this stated lack of understanding.

We found that even patients who considered themselves to be seriously ill did not understand that their current treatments will not cure them. Prior literature in heart failure also shows that patients with greater disease severity do not understand their prognosis any better.²⁹ On the contrary, higher educated patients, and those with a longer duration of CHF were more likely to understand that their current treatments will not cure them. Higher educated patients may be more active and vocal during decision-making consultations, thus encouraging their healthcare providers to communicate prognosis and treatment intent more explicitly.^{30–35} Higher educated patients may also be more encouraged and confident to gather this information from alternative sources that provide them with medical information, for example, literature and the internet.^{36 37} Those with a long duration of CHF may have had more opportunities to discuss their prognosis and have a greater number of acute illness experiences to come to terms with the effectiveness of their treatments to cure their condition. Results imply that especially when discussing future treatment options with less educated and recently diagnosed patients, providers should make sure that they correctly understand the intent of their treatments.

The main limitation of this study is that since the data are self-reported and based on a single cross-sectional survey, causality and generalisability cannot be inferred. Future analyses from this study will examine actual use of ILSI among patients and its relationship with patient understanding of treatment intent. Another limitation was that our survey did not include details of what was communicated to patients by their healthcare providers. Lastly, it is unclear how patients interpreted 'cure'. This will be the focus of our future qualitative work.

CONCLUSIONS

Despite the limitations, our findings demonstrate that patients with advanced CHF do not understand that their

ongoing treatments will not cure them. Those who understand that their ongoing treatments will not cure them are far less likely to choose ILSI compared with others. We also provide preliminary support for the possibility that clinicians may not be discussing treatment intent with patients during conversations regarding future treatment options. We also show that patients who know that their ongoing treatments will not cure them are not more likely to be distressed compared with those not aware. Findings suggest that to enable patients with advanced CHF to make informed treatment choices about their future, patients and healthcare providers should be encouraged and educated, respectively, to be more proactive in discussing clearly the intent of patients' current treatment.

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