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# BMJ Open

**Preferences for invasive life-sustaining interventions and decisional uncertainty among patients with advanced heart failure: Importance of understanding current treatment intent and communication with health care providers.**

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## Abstract

**Objectives:** To make informed choices about use of future invasive life-sustaining interventions patients with congestive heart failure (CHF) need to correctly understand the intent of their current treatments. We hypothesized that most patients do not understand that their current treatments are not curative. We also hypothesized that those who do understand their treatment intent will be less willing to undergo invasive life-sustaining interventions.

**Design and Participants:** As part of a larger effort, we asked 282 advanced CHF (New York Heart Association Class III and IV) patients about their willingness to undergo invasive life-sustaining treatments.

**Outcome:** To evaluate patients' understanding of their illness, we asked them whether their existing treatments would cure their heart condition.

**Results:** Approximately half of patients reported a willingness to undergo invasive life-sustaining treatments if needed. Only 22% knew that their current treatments were not curative. These patients were far less willing to undergo invasive life-sustaining interventions (OR: 0.28, 95% CI: 0.15-0.56) and were no more likely to be distressed compared to those who did not understand the intent of their treatments.

**Conclusions:** Improving patients' understanding of the intent of their current treatments can help patients make informed choices about invasive life-sustaining interventions and reduce uncertainty in their choices.

**Keywords:** heart failure; advanced care planning; treatment intent

### Strengths and limitations of the study

- The main strength of the study is that it includes a large sample of patients with advanced CHF.
- A limitation is that as data is 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 health care providers.
- It is unclear how patients interpreted the term “cure” in our survey.

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**Competing interests:** None

## Introduction

Congestive Heart Failure (CHF) is a fatal condition.<sup>1</sup> Symptomatic patients have a five-year survival rate of approximately 50% and those with very advanced disease have one-year mortality of up to 90%.<sup>2-4</sup> Given the progressive, irreversible and unpredictable nature of the disease and a high burden of physical symptoms, psychosocial and spiritual distress,<sup>5,6</sup> advanced CHF patients 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.<sup>7,8</sup>

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. To our knowledge, no data, however, exists about whether patients with advanced CHF understand that their current medical treatments including taking drugs or having surgeries or devices implanted are not curative, though evidence from advanced cancer patients suggests that most lack this understanding.<sup>9-11</sup> For cancer patients it is hypothesized that their lack of understanding results, in part, from their health care providers wariness in discussing prognosis and treatment intent for fear that it will distress patients.<sup>12,13</sup> The same is likely true for advanced CHF patients.

In this study, we first assess the extent to which advanced CHF patients are aware that their current treatments are not curative. We hypothesize that patients who discuss future treatment options such as ILSI with their provider were no more likely to understand that their current treatments are not curative, compared to 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 health care

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3 providers fear. We then assess whether advanced CHF patients who understand their current  
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5 treatments are not curative are less willing to opt for ILSI.  
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8 For many patients, the decision on whether or not to pursue ILSI should the need arise  
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10 is a difficult decision and one where many patients will make a decision with less than perfect  
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12 conviction. Greater certainty (i.e., greater conviction that the choice is right) should result  
13  
14 from being more informed about risks and benefits of future treatment options including ILSI  
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16 and therefore can be considered as an indicator of quality of informed decision-making.  
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18 Therefore as a final test, we assessed whether patients who discussed the risks and benefits of  
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20 future treatment options including ILSI with their providers were more certain in their  
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22 decisions compared to those who do not.  
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26 In the era of patient-centred care and informed decision making, these study results  
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28 will further our understanding about the need to clearly communicate to advanced CHF  
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30 patients the intent of their ongoing treatments when discussing future treatment options.  
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## 32 **Methods**

### 33 *Participants*

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36 We approached 604 CHF patients admitted in two major public hospitals in Singapore  
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38 between March 2015 and December 2016. Patients were recruited for a randomized  
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40 controlled trial in Singapore assessing the effectiveness of advance care planning. Inclusion  
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42 criteria were patients 21 years and older, Singapore citizen or permanent resident, diagnosis  
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44 of CHF and with severity of symptoms fitting New York Heart Association Class III or IV.  
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46 Exclusion criteria were patients with cognitive and/or psychiatric impairments. All  
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48 participants gave their written informed consent to participate and the study. The SingHealth  
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50 Centralised Institutional Review Board approved this study.<sup>7</sup> This paper used the data from  
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52 the baseline survey administered to all patients who consented to take part in the trial.  
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### *Survey measures*

We asked patients their willingness to undergo ILSI (e.g. intubation, mechanical ventilation, cardioversion and transfer to intensive care unit), only non-invasive interventions (e.g. oral or intravenous medications) or only comfort measures (e.g. 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 health care 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 (HADS) 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.<sup>14,15</sup>

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.<sup>16,17</sup> 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 9 items. Responses for each of the nine items on the scale were categorized 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,<sup>17</sup> Cronbach's  $\alpha$  (internal consistency reliability) for the 9 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



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3 study. A confirmatory factor analysis further confirmed this factor structure (RMSEA=0.10,  
4 CFI=0.94, TLI=0.90, SRMR=0.06, CD=0.99).  
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### 6 7 *Statistical analysis*

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9 We assessed the proportion of patients who correctly understood that their current  
10 treatments were not intended to cure them. We used a logistic regression model to test  
11 whether patients who had discussed their future treatment options including ILSI with their  
12 providers (independent variable) were more likely to understand that their current treatments  
13 are not curative (dependent variable). Analysis controlled for other patient characteristics  
14 (age (<65 years, ≥65 years); gender; time since CHF diagnosis (≤1 year, 2-5 years, 6-10  
15 years, >10 years); education; living with someone or alone; type of housing; religion; and  
16 self-rated health status (relatively healthy or seriously ill)). Type of housing was used as a  
17 proxy for socio-economic status as housing size in Singapore is found to be proportional to  
18 household income.<sup>18</sup>  
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31 To assess our hypothesis that patients who understand their current treatments are not  
32 curative (independent variable) are more likely to be psychologically distressed, we used two  
33 separate linear regression models with patient anxiety and depression scores as the outcome  
34 variables. Both models were adjusted for patient characteristics (age, gender, time since CHF  
35 diagnosis, education; living with someone or alone; type of housing; religion; and self-rated  
36 health status).  
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44 We ran a logistic regression model with the outcome variable as patients' willingness  
45 to undergo ILSI and the independent variables as patients' correct understanding of treatment  
46 intent, whether they had discussed these interventions with their providers and other patient  
47 characteristics (same as in the above models).  
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3 As the distribution of decisional conflict score (dependent variable) was skewed, we  
4 used a median regression to model this association, adjusting for patient characteristics (same  
5 as above).  
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9 We used STATA for all analyses.  
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## 11 **Results**

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13 Of the 604 patients we approached, 282 (47%) consented to participate in the study.  
14 Average age of patients was 65 years (age range: 26 – 94 years). Patients were mainly males  
15 (78%), with at least secondary education (53%) and were Buddhists/ Taoists (37%). 12% of  
16 the patients lived alone and 21% lived in 1-2 room public housing signifying a low socio-  
17 economic status. About a quarter were diagnosed with CHF in the last one year and 40%  
18 perceived themselves to be seriously ill. 26% of the patients had clinically significant anxiety  
19 and 29% had clinically significant depressive symptoms. (Table 1)  
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29 Approximately half of our patient sample reported a willingness to undergo ILSI if  
30 needed. Only 22% correctly knew that their current treatments were not intended to cure  
31 them and 26% reported having conversations with their health care providers regarding use of  
32 ILSI. The median decisional conflict score was low at 16.7, indicating that most patients were  
33 more certain in choosing between ILSI and non-invasive/comfort measures. (Table 1)  
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40 Table 2 shows that, as hypothesized, patients who had discussed future treatment  
41 options with their health care providers, were no more likely to be aware that their current  
42 treatments were not intended to cure them (OR: 1.45, 95% CI: 0.73-2.86). Only longer  
43 duration of illness (6-10 years: OR: 3.02, 95% CI: 1.02-8.86; >10 years: OR: 2.79, 95% CI:  
44 1.06-7.36) and higher education (OR: 2.08, 95% CI: 1.04-4.18) increased the odds of patients  
45 correctly knowing that their current treatment would not cure them. Patient perception of  
46 being seriously ill also did not increase the odds of them understanding that the intent of their  
47 current treatment is not curative (OR: 0.92, 95% CI: 0.49-1.73).  
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3 Contrary to our hypothesis, patient understanding that current treatments were not  
4 curative were not associated with a greater likelihood of patients being psychologically  
5 distressed i.e. being anxious (OR, 95% CI: 0.72 (0.34 – 1.54)) or depressed (OR, 95% CI:  
6 0.70 (0.33– 1.48)). Consistent with our hypothesis, patients who understood that their  
7 treatments were not curative were far less willing to undergo ILSI (OR: 0.28, 95% CI: 0.15-  
8 0.56). (Figure 1) Consistent with our hypothesis, patient discussing future treatment options  
9 with health care providers was associated with lower decisional uncertainty ( $\beta=-5.56$ ,95% CI:  
10 -10.85 – -0.26).  
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## 21 **Discussion**

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24 This paper highlights that among symptomatic advanced CHF inpatients, only a small  
25 proportion (22%) knew that their current treatments were not intended to cure them. These  
26 results are concerning because they show that the vast majority of patients with advanced  
27 CHF were undergoing treatments, without fully realizing the intent of these treatments.  
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33 We also found that even though patients who had discussed future treatment options  
34 with their health care providers were more certain in their decision to choose or forego ILSI,  
35 they did not have any better understanding that their current treatments will not cure them.  
36 This may be because although providers may have discussed risks and benefits of future  
37 treatment options including ILSI with patients during these conversations, an explicit  
38 discussion of prognosis and treatment intent may be missing. Anecdotally we know that in  
39 most Asian communities particularly among Chinese, true prognosis is often withheld from  
40 the patient as patients and families generally believe that talking about death may bring on  
41 bad luck for the patient. Health care providers often fear that patients may become  
42 psychologically distressed after hearing that their current treatments are not intended to cure  
43 them.<sup>12,13</sup> As a result both patients and providers may be reluctant to initiate a discussion of  
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3 prognosis and treatment intent during consultations. Providers may also use ambiguous and  
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5 technical terms to talk about poor prognosis which patients may not fully understand.<sup>19,20</sup>  
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7 Previous studies have also reported that patients with advanced CHF rarely acknowledge  
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9 their poor prognosis and providers do not explicitly discuss this information with them.<sup>21,22</sup>  
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11 Our study results however indicate that this fear of explicitly discussing treatment intent may  
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13 be unfounded as patients with a correct understanding of treatment intent are neither more  
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15 anxious nor depressed compared to patients who do not have a correct understanding of  
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17 treatment intent.  
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21 Alternatively it is likely that patients may be in denial of their poor prognosis and did  
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23 not report in the survey what they had been told about their treatment intent during  
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25 consultations. In order to preserve their hope, even patients with a reasonable knowledge of  
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27 prognosis and treatment intent may not want to apply that knowledge to themselves. Because  
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29 the current study shows that patient understanding of treatment intent systematically  
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31 influences their preference for their future treatments such as use of ILSI, it is imperative that  
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33 providers address the underlying pathways that contribute to this stated lack of  
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35 understanding.  
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39 We found that even patients who considered themselves to be seriously ill did not  
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41 understand that their current treatments will not cure them. Prior literature in heart failure  
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43 also shows that patients with greater disease severity do not understand their prognosis any  
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45 better.<sup>22</sup> On the contrary, higher educated patients, and those with a longer duration of CHF  
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47 were more likely to understand that their current treatments will not cure them. Higher  
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49 educated patients may to be more active and vocal during decision making consultations, thus  
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51 encouraging their health care providers to communicate prognosis and treatment intent more  
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53 explicitly.<sup>23-28</sup> Higher educated patients may also be more encouraged and confident to  
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55 gather this information from alternative sources that provide them with medical information  
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3 e.g. literature and the internet.<sup>29,30</sup> Those with a long duration of CHF may have had more  
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5 opportunities to discuss their prognosis and have a greater number of acute illness  
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7 experiences to come to terms with the effectiveness of their treatments to cure their condition.  
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9 Results imply that especially when discussing future treatment options with less educated and  
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11 recently diagnosed patients, providers should make sure that they correctly understand the  
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13 intent of their treatments.  
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17 The main limitation of this study is that since the data is self-reported and based on a  
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19 single cross-sectional survey, causality cannot be inferred. Future analyses from this study  
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21 will examine actual use of ILSI among patients and its relationship with patient  
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23 understanding of treatment intent. Another limitation was that our survey did not include  
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25 details of what was communicated to patients by their health care providers. Lastly, it is  
26  
27 unclear how patients interpreted “cure”. This will be the focus of our future qualitative work.  
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### 30 **Conclusions**

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33 Despite the limitations, our findings demonstrate that patients with advanced CHF do  
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35 not understand that their ongoing treatments will not cure them. Those who understand that  
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37 their ongoing treatments will not cure them are far less likely to choose ILSI compared to  
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39 others. We also provide preliminary support for the possibility that clinicians may not be  
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41 discussing treatment intent with patients during conversations regarding future treatment  
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43 options. We also show that patients who know that their ongoing treatments will not cure  
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45 them are not more likely to be distressed compared to those not aware. Findings suggest that  
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47 to enable patients with advanced CHF to make informed treatment choices about their future,  
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49 patients and health care providers should be encouraged and educated respectively to be more  
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51 proactive in discussing clearly the intent of patients’ current treatment.  
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3 **Author contributions:** CM conceptualized the study along with DS, FJ, and EAF. All  
4 authors contributed to interpretation of data, manuscript writing and revising the manuscript  
5 for publication.  
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10 **Data sharing statement:** No additional data are available.  
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## References

1. Ho KK, Pinsky JL, Kannel WB, Levy D. The epidemiology of heart failure: the Framingham Study. *Journal of the American College of Cardiology*. 1993;22(4 Suppl A):6a-13a.
2. Stewart S, MacIntyre K, Hole DJ, Capewell S, McMurray JJV. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *European journal of heart failure*. 2001;3(3):315-322.
3. Hershberger RE, Nauman D, Walker TL, Dutton D, Burgess D. Care processes and clinical outcomes of continuous outpatient support with inotropes (COSI) in patients with refractory endstage heart failure. *Journal of cardiac failure*. 2003;9(3):180-187.
4. Rose EA, Gelijns AC, Moskowitz AJ, et al. Long-term use of a left ventricular assist device for end-stage heart failure. *N Engl J Med*. 2001;345(20):1435-1443.
5. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. *Circulation*. 2009;120(25):2597-2606.
6. Aldred H, Gott M, Gariballa S. Advanced heart failure: impact on older patients and informal carers. *Journal of advanced nursing*. 2005;49(2):116-124.
7. Malhotra C, Sim DK, Jaufeerally F, et al. Impact of advance care planning on the care of patients with heart failure: study protocol for a randomized controlled trial. *Trials*. 2016;17(1):285.
8. Gillick MR. Advance care planning. *The New England journal of medicine*. 2004;350(1):7.
9. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012;367(17):1616-1625.
10. Eidingen RN, Schapira DV. Cancer patients' insight into their treatment, prognosis, and unconventional therapies. *Cancer*. 1984;53(12):2736-2740.

- 1  
2  
3 11. Mackillop WJ, Stewart WE, Ginsburg AD, Stewart SS. Cancer patients' perceptions  
4 of their disease and its treatment. *British journal of cancer*. 1988;58(3):355-358.  
5
- 6  
7 12. Yanwei L, Dongying L, Zhuchen Y, Ling L, Yu Z, Zhanyu P. A double-edged sword:  
8 Should stage IV non-small cell lung cancer patients be informed of their cancer  
9 diagnosis? *Eur J Cancer Care (Engl)*. 2017.  
10  
11
- 12  
13 13. Kim SY, Kim JM, Kim SW, et al. Does awareness of terminal status influence  
14 survival and quality of life in terminally ill cancer patients? *Psychooncology*.  
15 2013;22(10):2206-2213.  
16  
17
- 18  
19 14. Herrmann C. International experiences with the Hospital Anxiety and Depression  
20 Scale--a review of validation data and clinical results. *J Psychosom Res*.  
21 1997;42(1):17-41.  
22  
23
- 24  
25 15. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety  
26 and Depression Scale: An updated literature review. *Journal of Psychosomatic*  
27 *Research*. 2002;52(2):69-77.  
28  
29
- 30  
31 16. Linder SK, Swank PR, Vernon SW, Mullen PD, Morgan RO, Volk RJ. Validity of a  
32 low literacy version of the Decisional Conflict Scale. *Patient Educ Couns*.  
33 2011;85(3):521-524.  
34  
35
- 36  
37 17. AM OC. User Manual - Decisional Conflict Scale.  
38  
39  
40  
41 [https://decisionaid.ohri.ca/docs/develop/User\\_Manuals/UM\\_Decisional\\_Conflict.pdf](https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf).  
42  
43
- 44 18. (DOS) SDoS. Key Household Income Trends, 2016 2017;  
45  
46 [http://www.singstat.gov.sg/docs/default-source/default-document-](http://www.singstat.gov.sg/docs/default-source/default-document-library/publications/publications_and_papers/household_income_and_expenditure/pp-s23.pdf)  
47 [library/publications/publications\\_and\\_papers/household\\_income\\_and\\_expenditure/pp](http://www.singstat.gov.sg/docs/default-source/default-document-library/publications/publications_and_papers/household_income_and_expenditure/pp-s23.pdf)  
48 [-s23.pdf](http://www.singstat.gov.sg/docs/default-source/default-document-library/publications/publications_and_papers/household_income_and_expenditure/pp-s23.pdf).  
49  
50
- 51  
52 19. Chapman K, Abraham C, Jenkins V, Fallowfield L. Lay understanding of terms used  
53 in cancer consultations. *Psycho-Oncology*. 2003;12(6):557-566.  
54  
55  
56  
57



- 1  
2  
3 20. Fallowfield LJ, Jenkins VA, Beveridge H. Truth may hurt but deceit hurts more:  
4 communication in palliative care. *Palliative medicine*. 2002;16(4):297-303.  
5  
6  
7 21. Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung  
8 cancer or cardiac failure: prospective qualitative interview study of patients and their  
9 carers in the community. *Bmj*. 2002;325(7370):929.  
10  
11  
12  
13 22. Allen LA, Yager JE, Funk MJ, et al. Discordance between patient-predicted and  
14 model-predicted life expectancy among ambulatory patients with heart failure. *Jama*.  
15 2008;299(21):2533-2542.  
16  
17  
18  
19 23. Hamann J, Neuner B, Kasper J, et al. Participation preferences of patients with acute  
20 and chronic conditions. *Health expectations : an international journal of public*  
21 *participation in health care and health policy*. 2007;10(4):358-363.  
22  
23  
24  
25 24. Flynn KE, Smith MA, Vanness D. A typology of preferences for participation in  
26 healthcare decision making. *Social science & medicine (1982)*. 2006;63(5):1158-  
27 1169.  
28  
29  
30  
31  
32 25. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical  
33 decision making: a narrative review. *Patient Educ Couns*. 2006;60(2):102-114.  
34  
35  
36  
37 26. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in  
38 decision making. A national study of public preferences. *Journal of general internal*  
39 *medicine*. 2005;20(6):531-535.  
40  
41  
42  
43 27. Arora NK, McHorney CA. Patient preferences for medical decision making: who  
44 really wants to participate? *Medical care*. 2000;38(3):335-341.  
45  
46  
47  
48 28. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical  
49 decision making: a review of published surveys. *Behavioral medicine (Washington,*  
50 *DC)*. 1998;24(2):81-88.  
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3 29. Koo K, Farlinger C, Johnson S, Syed KA. Patient Education Level and Utilization of  
4 Internet Resources by Patients in Orthopedic Hip and Knee Consultations. *Open*  
5 *Journal of Medical Psychology*. 2013;Vol.02No.01:7.  
6  
7  
8  
9 30. Diaz JA, Griffith RA, Ng JJ, Reinert SE, Friedmann PD, Moulton AW. Patients' Use  
10 of the Internet for Medical Information. *Journal of general internal medicine*.  
11 2002;17(3):180-185.  
12  
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3 **Figure Legends**  
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5 **Figure 1: Association between patient preference for invasive life sustaining**  
6 **interventions and patient's current understanding of treatment intent and having**  
7 **conversations with health care providers.**  
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12 Results based on logistic regression analysis for patient perception of health status, age,  
13 gender, time since CHF diagnosis, education, living arrangement, type of housing, and  
14 religion,  
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3 **Tables**  
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5 **Table 1. Sample characteristics (n=282)**  
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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)
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)

Clinically significant anxiety	74 (26.2)
Clinically significant depressive symptoms	81 (28.7)

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

	Correct understanding of treatment intent*	
	Odds ratio	95% CI
Discussed future treatment options with a healthcare provider (Ref: Did not discuss with a healthcare provider)	1.45	0.73 – 2.86
Patient perception of them being seriously ill (Ref: Perceive themselves to be relatively healthy)	0.92	0.49 – 1.73
>= 65 years old (Ref: < 65 years old)	0.57	0.30 – 1.10
Duration of heart failure 2-5 years (Ref: <= 1 year)	2.17	0.73 – 6.46
Duration of heart failure 6-10 years (Ref: <= 1 year)	3.02 †	1.02 – 8.86
Duration of heart failure > 10 years (Ref: <= 1 year)	2.79 †	1.06 – 7.36
Female (Ref: Male)	0.37	0.13 – 1.04
Secondary or above education (Ref: Primary or below education)	2.08 †	1.04 – 4.18
Living with someone (Ref: Living alone)	0.89	0.29 – 2.74
3-5 room/executive public housing (Ref: 1-2 room public housing)	0.99	0.38 – 2.60
Private housing/bungalow (Ref: 1-2 room public housing)	1.82	0.51 – 6.53
Christian (Ref: No religion/Free thinker)	1.71	0.44 – 6.67
Buddhist/Taoist (Ref: No religion/Free thinker)	1.45	0.42 – 5.05
Muslim (Ref: No religion/Free thinker)	1.66	0.47 – 5.82
Hindu/Sikh (Ref: No religion/Free thinker)	2.80	0.72 – 10.96

\* Analysis performed using logistic regression; † p<0.05

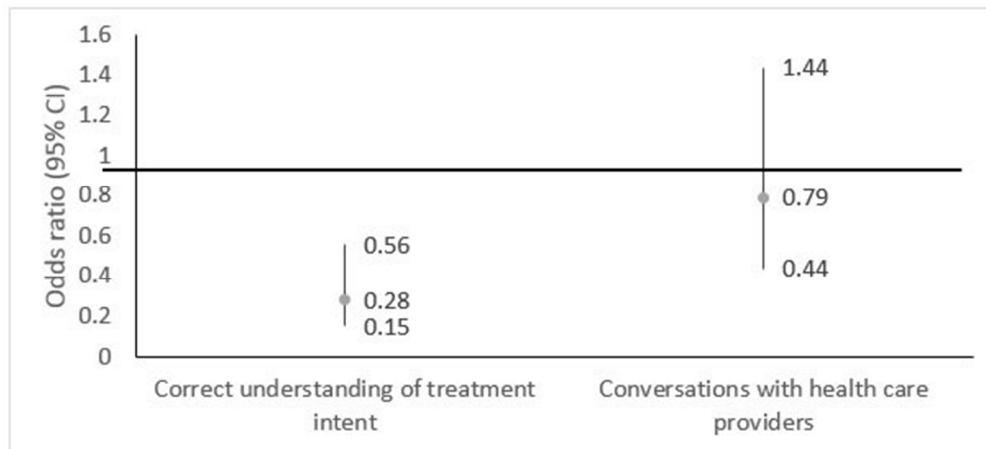


Figure 1: Association between patient preference for invasive life sustaining interventions and patient's current understanding of treatment intent and having conversations with health care providers. † Results based on logistic regression analysis for patient perception of health status, age, gender, time since CHF diagnosis, education, living arrangement, type of housing, and religion.

51x23mm (300 x 300 DPI)

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# BMJ Open

**Associations between understanding of current treatment intent, communication with health care 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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<b>Primary Subject Heading</b>:	Palliative care
Secondary Subject Heading:	Cardiovascular medicine, Communication
Keywords:	heart failure, advanced care planning, treatment intent, decisional conflict, health communication

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3 **Title:** Associations between understanding of current treatment intent, communication with  
4 health care providers, preferences for invasive life-sustaining interventions and decisional  
5 conflict: Results from a survey of patients with advanced heart failure in Singapore  
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10 **First author's surname:** Malhotra  
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12 **Short title:** Understanding current treatment intent  
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14

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43 **Total word count:** 4211  
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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, health care 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 randomizing patients for a trial, we asked 282 advanced CHF (New York Heart Association Class III and IV) patients 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: 0.15-0.56) and were not at a greater risk of having clinically significant anxiety (OR: 0.72 (0.34 – 1.54) and depression (OR: 0.70 (0.33– 1.47)) compared to 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.

**Keywords:** heart failure; advanced care planning; treatment intent

### Strengths and limitations of the study

- The main strength of the study is that it includes a large sample of patients with advanced CHF.
- A limitation is that as data is 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 health care providers.
- It is unclear how patients interpreted the term “cure” in our survey.

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**Competing interests:** None

## Introduction

Congestive Heart Failure (CHF) is a fatal condition.<sup>1</sup> Symptomatic patients have a five-year survival rate of approximately 50% and those with very advanced disease have one-year mortality of up to 90%.<sup>2-4</sup> Given the progressive, irreversible and unpredictable nature of the disease and a high burden of physical symptoms, psychosocial and spiritual distress,<sup>5,6</sup> advanced CHF patients 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.<sup>7,8</sup>

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.<sup>9-16</sup> 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.<sup>17,18</sup> For cancer patients with similar beliefs it is hypothesized that their lack of understanding results, in part, from their health care providers wariness in discussing prognosis and treatment intent for fear that it will distress patients.<sup>19,20</sup> The same is likely true for advanced CHF patients. 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 to 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 health care providers fear. We then assess whether advanced CHF patients who understand their current treatments are not curative are less willing to opt for ILSI.

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3 For many patients, the decision on whether or not to pursue ILSI should the need arise  
4 is a difficult decision and one where many patients will make a decision with less than perfect  
5 conviction. Greater certainty (i.e., greater conviction that the choice is right) should result  
6 from being more informed about risks and benefits of future treatment options including ILSI  
7 and therefore can be considered as an indicator of quality of informed decision-making.  
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9 Therefore as a final test, we assessed whether patients who discussed the risks and benefits of  
10 future treatment options including ILSI with their providers were more certain in their  
11 decisions compared to those who do not.  
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21 In the era of patient-centred care and informed decision making, these study results  
22 will further our understanding about the need to clearly communicate to advanced CHF  
23 patients the intent of their ongoing treatments when discussing future treatment options.  
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## 28 **Methods**

### 29 *Participants*

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

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3 We asked patients their willingness to undergo ILSI (e.g. intubation, mechanical  
4 ventilation, cardioversion and transfer to intensive care unit), only non-invasive interventions  
5 (e.g. oral or intravenous medications) or only comfort measures (e.g. reasonable measures to  
6 offer food or fluids, oxygen and medication for comfort) in future. To assess whether patients  
7 had discussed ILSI with their providers, we asked patients if they had discussed these  
8 treatment options with their health care provider (yes/no). We also assessed understanding of  
9 treatment intent by asking patients whether they thought that their existing treatments would  
10 cure their heart condition (yes/no/not sure). We used the Anxiety subscale and Depression  
11 subscale of the Hospital Anxiety and Depression Scale (HADS) to assess patient's  
12 psychological distress. Patients with a cut-off score of 8 or more on the two subscales were  
13 classified as having clinically significant anxiety or depressive symptoms.<sup>21,22</sup>

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15 We used a low-literacy version of the decisional conflict scale to gauge patients'  
16 uncertainty regarding their choice between ILSI, non-invasive interventions and comfort  
17 measures.<sup>23,24</sup> As the scale was administered to assess decisional uncertainty in choosing  
18 between these three options, we removed the first item of the scale asking whether the patient  
19 knew which options were available to him/her, resulting in a total of 9 items. Responses for  
20 each of the nine items on the scale were categorized as yes (score=0), no (score = 4) and not  
21 sure (score =2) and total score was divided by 9 and multiplied by 25. Scores ranged from 0  
22 (no decisional conflict) to 100 (extremely high decisional conflict). Similar to the original  
23 scale,<sup>24</sup> Cronbach's  $\alpha$  (internal consistency reliability) for the 9 items was 0.80. Consistent  
24 with the original scale, an exploratory factor analysis with promax rotation found four  
25 factors, namely being informed, values clarity, support and uncertainty. The only difference  
26 with the original version was that one item that loaded on the support subscale (Do you have  
27 enough advice to make a choice?) in the original scale loaded on the informed subscale in our

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3 study. A confirmatory factor analysis further confirmed this factor structure (RMSEA=0.10,  
4 CFI=0.94, TLI=0.90, SRMR=0.06, CD=0.99).  
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### 6 7 *Statistical analysis*

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9 We assessed the proportion of patients who correctly understood that their current  
10 treatments were not intended to cure them. We used a logistic regression model to test  
11 whether patients who had discussed their future treatment options including ILSI with their  
12 providers (independent variable) were more likely to understand that their current treatments  
13 are not curative (dependent variable). Analysis controlled for other patient characteristics  
14 (age (<65 years, ≥65 years); gender; time since CHF diagnosis (≤1 year, 2-5 years, 6-10  
15 years, >10 years); whether or not patient had a cardiac device implanted; education; living  
16 with someone or alone; type of housing; religion; and self-rated health status (relatively  
17 healthy or seriously ill)). Type of housing was used as a proxy for socio-economic status as  
18 housing size in Singapore is found to be proportional to household income.<sup>25</sup>  
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31 To assess whether patients who understand their current treatments are not curative  
32 (independent variable) are more likely to be psychologically distressed, we used two separate  
33 linear regression models with patient anxiety and depression scores as the outcome variables.  
34 Both models were adjusted for patient characteristics (age, gender, time since CHF diagnosis,  
35 whether or not patient had a cardiac device implanted, education, living with someone or  
36 alone, type of housing, religion, and self-rated health status).  
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44 We ran a logistic regression model with the outcome variable as patients' willingness  
45 to undergo ILSI and the independent variables as patients' correct understanding of treatment  
46 intent, whether they had discussed these interventions with their providers and other patient  
47 characteristics (same as in the above models).  
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3 As the distribution of decisional conflict score (dependent variable) was skewed, we  
4 used a median regression to model this association, adjusting for patient characteristics (same  
5 as above).  
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9 We used STATA for all analyses.  
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### 11 12 13 *Patient and Public Involvement*

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15 Patients, patient advisors and public were not involved in the development of the research questions,  
16 in the design of the study or in the recruitment of study participants.  
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### 20 21 **Results**

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23 Of the 1954 patients referred to the study, 1665 were screened for eligibility, 696  
24 were found to be eligible and 604 were approached to take part in the study. Of these 282  
25 (46.7%) participated in the study. Average age of patients was 65 years (age range: 26 – 94  
26 years). Patients were mainly males (78%), with at least secondary education (53%) and were  
27 Buddhists/ Taoists (37%). 12% of the patients lived alone and 21% lived in 1-2 room public  
28 housing signifying a low socio-economic status. About a quarter were diagnosed with CHF in  
29 the last one year, 40% perceived themselves to be seriously ill and 26% had a cardiac device  
30 implanted (either an implantable cardioverter defibrillator or a pacemaker). 26% of the  
31 patients had clinically significant anxiety and 29% had clinically significant depressive  
32 symptoms. (Table 1)  
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46 Approximately half of our patient sample reported a willingness to undergo ILSI if  
47 needed. Only 22% correctly knew that their current treatments were not intended to cure  
48 them and 26% reported having conversations with their health care providers regarding use of  
49 ILSI. The median decisional conflict score was low at 16.7, indicating that most patients were  
50 more certain in choosing between ILSI and non-invasive/comfort measures. (Table 1)  
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3 Table 2 shows that patients who had discussed future treatment options with their  
4 health care providers were no more likely to be aware that their current treatments were not  
5 intended to cure them (OR: 1.45, 95% CI: 0.73-2.87). Only longer duration of illness (6-10  
6 years: OR: 2.98, 95% CI: 1.01-8.82; >10 years: OR: 2.73, 95% CI: 1.01-7.40) and higher  
7 education (OR: 2.07, 95% CI: 1.03-4.17) increased the odds of patients correctly knowing  
8 that their current treatment would not cure them. Patient perception of being seriously ill also  
9 did not increase the odds of them understanding that the intent of their current treatment is  
10 not curative (OR: 0.92, 95% CI: 0.49-1.73).  
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20 Contrary to our hypothesis, patient understanding that current treatments were not  
21 curative were not associated with a greater likelihood of patients being psychologically  
22 distressed i.e. being anxious (OR, 95% CI: 0.72 (0.34 – 1.54)) or depressed (OR, 95% CI:  
23 0.70 (0.33– 1.47)). Consistent with our hypothesis, patients who understood that their  
24 treatments were not curative were far less willing to undergo ILSI (OR: 0.28, 95% CI: 0.14-  
25 0.55). Consistent with our hypothesis, patient discussing future treatment options with health  
26 care providers was associated with lower decisional uncertainty ( $\beta$ =-5.56, 95% CI: -8.61 – -  
27 2.50).  
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## 40 Discussion

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42 This paper highlights that among symptomatic advanced CHF inpatients, only a small  
43 proportion (22%) knew that their current treatments were not intended to cure them. These  
44 results are concerning because they show that the vast majority of patients with advanced  
45 CHF were undergoing treatments, without fully realizing the intent of these treatments.  
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51 We also found that even though patients who had discussed future treatment options  
52 with their health care providers were more certain in their decision to choose or forego ILSI,  
53 they did not have any better understanding that their current treatments will not cure them.  
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3 This may be because although providers may have discussed risks and benefits of future  
4 treatment options including ILSI with patients during these conversations, an explicit  
5 discussion of prognosis and treatment intent may be missing. Anecdotally we know that in  
6 most Asian communities particularly among Chinese, true prognosis is often withheld from  
7 the patient as patients and families generally believe that talking about death may bring on  
8 bad luck for the patient. Health care providers often fear that patients may become  
9 psychologically distressed after hearing that their current treatments are not intended to cure  
10 them.<sup>19,20</sup> As a result both patients and providers may be reluctant to initiate a discussion of  
11 prognosis and treatment intent during consultations. Providers may also use ambiguous and  
12 technical terms to talk about poor prognosis which patients may not fully understand.<sup>26,27</sup>  
13 Previous studies have also reported that patients with advanced CHF rarely acknowledge  
14 their poor prognosis and providers do not explicitly discuss this information with them.<sup>28,29</sup>  
15 Our study results however indicate that this fear of explicitly discussing treatment intent may  
16 be unfounded as patients with a correct understanding of treatment intent are neither more  
17 anxious nor depressed compared to patients who do not have a correct understanding of  
18 treatment intent.

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

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3 We found that even patients who considered themselves to be seriously ill did not  
4 understand that their current treatments will not cure them. Prior literature in heart failure  
5 also shows that patients with greater disease severity do not understand their prognosis any  
6 better.<sup>29</sup> On the contrary, higher educated patients, and those with a longer duration of CHF  
7 were more likely to understand that their current treatments will not cure them. Higher  
8 educated patients may to be more active and vocal during decision making consultations, thus  
9 encouraging their health care providers to communicate prognosis and treatment intent more  
10 explicitly.<sup>30-35</sup> Higher educated patients may also be more encouraged and confident to  
11 gather this information from alternative sources that provide them with medical information  
12 e.g. literature and the internet.<sup>36,37</sup> Those with a long duration of CHF may have had more  
13 opportunities to discuss their prognosis and have a greater number of acute illness  
14 experiences to come to terms with the effectiveness of their treatments to cure their condition.  
15 Results imply that especially when discussing future treatment options with less educated and  
16 recently diagnosed patients, providers should make sure that they correctly understand the  
17 intent of their treatments.  
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36 The main limitation of this study is that since the data is self-reported and based on a  
37 single cross-sectional survey, causality and generalizability cannot be inferred. Future  
38 analyses from this study will examine actual use of ILSI among patients and its relationship  
39 with patient understanding of treatment intent. Another limitation was that our survey did not  
40 include details of what was communicated to patients by their health care providers. Lastly, it  
41 is unclear how patients interpreted “cure”. This will be the focus of our future qualitative  
42 work.  
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## 51 **Conclusions**

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3           Despite the limitations, our findings demonstrate that patients with advanced CHF do  
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5 not understand that their ongoing treatments will not cure them. Those who understand that  
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7 their ongoing treatments will not cure them are far less likely to choose ILSI compared to  
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9 others. We also provide preliminary support for the possibility that clinicians may not be  
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11 discussing treatment intent with patients during conversations regarding future treatment  
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13 options. We also show that patients who know that their ongoing treatments will not cure  
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15 them are not more likely to be distressed compared to those not aware. Findings suggest that  
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17 to enable patients with advanced CHF to make informed treatment choices about their future,  
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19 patients and health care providers should be encouraged and educated respectively to be more  
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21 proactive in discussing clearly the intent of patients' current treatment.  
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4 authors contributed to interpretation of data, manuscript writing and revising the manuscript  
5 for publication.  
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## References

1. Ho KK, Pinsky JL, Kannel WB, Levy D. The epidemiology of heart failure: the Framingham Study. *Journal of the American College of Cardiology*. 1993;22(4 Suppl A):6a-13a.
2. Stewart S, MacIntyre K, Hole DJ, Capewell S, McMurray JJV. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *European journal of heart failure*. 2001;3(3):315-322.
3. Hershberger RE, Nauman D, Walker TL, Dutton D, Burgess D. Care processes and clinical outcomes of continuous outpatient support with inotropes (COSI) in patients with refractory endstage heart failure. *Journal of cardiac failure*. 2003;9(3):180-187.
4. Rose EA, Gelijns AC, Moskowitz AJ, et al. Long-term use of a left ventricular assist device for end-stage heart failure. *N Engl J Med*. 2001;345(20):1435-1443.
5. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. *Circulation*. 2009;120(25):2597-2606.
6. Aldred H, Gott M, Gariballa S. Advanced heart failure: impact on older patients and informal carers. *Journal of advanced nursing*. 2005;49(2):116-124.
7. Malhotra C, Sim DK, Jaufeerally F, et al. Impact of advance care planning on the care of patients with heart failure: study protocol for a randomized controlled trial. *Trials*. 2016;17(1):285.
8. Gillick MR. Advance care planning. *The New England journal of medicine*. 2004;350(1):7.
9. Goodman H, Firouzi A, Banya W, Lau-Walker M, Cowie MR. Illness perception, self-care behaviour and quality of life of heart failure patients: A longitudinal questionnaire survey. *International Journal of Nursing Studies*. 2013;50(7):945-953.

10. Mohammad A-SA, Ala A, Issa H, Beshar G, Donna F. Illness perception in patients with coronary artery disease: A systematic review. *International Journal of Nursing Practice*. 2016;22(6):633-648.
11. Timmermans I, Versteeg H, Meine M, Pedersen SS, Denollet J. Illness perceptions in patients with heart failure and an implantable cardioverter defibrillator: Dimensional structure, validity, and correlates of the brief illness perception questionnaire in Dutch, French and German patients. *Journal of Psychosomatic Research*. 2017;97:1-8.
12. Yu-Ping L, Gill F, Karen S, JP LR. Misconceived and maladaptive beliefs about heart disease: a comparison between Taiwan and Britain. *Journal of Clinical Nursing*. 2009;18(1):46-55.
13. Furze G, Roebuck A, Bull P, Lewin RJP, Thompson DR. A comparison of the illness beliefs of people with angina and their peers: a questionnaire study. *BMC Cardiovascular Disorders*. 2002;2:4-4.
14. Grace SL, Krepostman S, Brooks D, et al. Illness perceptions among cardiac patients: Relation to depressive symptomatology and sex. *Journal of psychosomatic research*. 2005;59(3):153-160.
15. Hale ED, Treharne GJ, Kitas GD. The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? *Rheumatology*. 2007;46(6):904-906.
16. Diefenbach MA, Leventhal H. The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*. 1996;5(1):11-38.



- 1  
2  
3 17. Horowitz CR, Rein SB, Leventhal H. A story of maladies, misconceptions and  
4 mishaps: effective management of heart failure. *Social science & medicine (1982)*.  
5 2004;58(3):631-643.  
6  
7
- 8  
9 18. Rogers AE, Addington-Hall JM, Aberly AJ, et al. Knowledge and communication  
10 difficulties for patients with chronic heart failure: qualitative study. *Bmj*.  
11 2000;321(7261):605-607.  
12  
13
- 14 19. Yanwei L, Dongying L, Zhuchen Y, Ling L, Yu Z, Zhanyu P. A double-edged sword:  
15 Should stage IV non-small cell lung cancer patients be informed of their cancer  
16 diagnosis? *Eur J Cancer Care (Engl)*. 2017.  
17  
18
- 19 20. Kim SY, Kim JM, Kim SW, et al. Does awareness of terminal status influence  
20 survival and quality of life in terminally ill cancer patients? *Psychooncology*.  
21 2013;22(10):2206-2213.  
22  
23
- 24 21. Herrmann C. International experiences with the Hospital Anxiety and Depression  
25 Scale--a review of validation data and clinical results. *J Psychosom Res*.  
26 1997;42(1):17-41.  
27  
28
- 29 22. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety  
30 and Depression Scale: An updated literature review. *Journal of Psychosomatic*  
31 *Research*. 2002;52(2):69-77.  
32  
33
- 34 23. Linder SK, Swank PR, Vernon SW, Mullen PD, Morgan RO, Volk RJ. Validity of a  
35 low literacy version of the Decisional Conflict Scale. *Patient Educ Couns*.  
36 2011;85(3):521-524.  
37  
38
- 39 24. AM OC. User Manual - Decisional Conflict Scale.  
40 [https://decisionaid.ohri.ca/docs/develop/User\\_Manuals/UM\\_Decisional\\_Conflict.pdf](https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf).  
41  
42
- 43 25. (DOS) SDoS. Key Household Income Trends, 2016 2017;  
44 <http://www.singstat.gov.sg/docs/default-source/default-document->  
45  
46  
47  
48  
49  
50  
51  
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56  
57  
58  
59  
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- [library/publications/publications\\_and\\_papers/household\\_income\\_and\\_expenditure/pp-s23.pdf](#).
26. Chapman K, Abraham C, Jenkins V, Fallowfield L. Lay understanding of terms used in cancer consultations. *Psycho-Oncology*. 2003;12(6):557-566.
  27. Fallowfield LJ, Jenkins VA, Beveridge H. Truth may hurt but deceit hurts more: communication in palliative care. *Palliative medicine*. 2002;16(4):297-303.
  28. Murray SA, Boyd K, Kendall M, Worth A, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *Bmj*. 2002;325(7370):929.
  29. Allen LA, Yager JE, Funk MJ, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. *Jama*. 2008;299(21):2533-2542.
  30. Hamann J, Neuner B, Kasper J, et al. Participation preferences of patients with acute and chronic conditions. *Health expectations : an international journal of public participation in health care and health policy*. 2007;10(4):358-363.
  31. Flynn KE, Smith MA, Vanness D. A typology of preferences for participation in healthcare decision making. *Social science & medicine (1982)*. 2006;63(5):1158-1169.
  32. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. *Patient Educ Couns*. 2006;60(2):102-114.
  33. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. A national study of public preferences. *Journal of general internal medicine*. 2005;20(6):531-535.
  34. Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? *Medical care*. 2000;38(3):335-341.

- 1  
2  
3 35. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical  
4 decision making: a review of published surveys. *Behavioral medicine (Washington,*  
5 *DC)*. 1998;24(2):81-88.  
6  
7  
8  
9 36. Koo K, Farlinger C, Johnson S, Syed KA. Patient Education Level and Utilization of  
10 Internet Resources by Patients in Orthopedic Hip and Knee Consultations. *Open*  
11 *Journal of Medical Psychology*. 2013;Vol.02No.01:7.  
12  
13  
14  
15 37. Diaz JA, Griffith RA, Ng JJ, Reinert SE, Friedmann PD, Moulton AW. Patients' Use  
16 of the Internet for Medical Information. *Journal of general internal medicine*.  
17 2002;17(3):180-185.  
18  
19  
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## 26 Tables

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28 **Table 1. Sample characteristics (n=282)**

30 Characteristics	31 N (%)
32 Age: Mean (SD)	64.6 (13.1)
33 <65 years	140 (49.7)
34 ≥65 years	142 (50.4)
35 Gender	
36 Male	220 (78.0)
37 Female	62 (22.0)
38 Education	
39 Primary or below	133 (47.3)
40 Secondary or above	148 (52.7)
41 Duration of heart failure	
42 ≤= 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)	
<= 75 percentile	213 (75.53)
> 75 percentile	69 (24.47)
Clinically significant anxiety	74 (26.2)
Clinically significant depressive symptoms	81 (28.7)

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

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

Hindu/Sikh (Ref: No religion/Free thinker)	2.79	0.71 – 10.91
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\* Analysis performed using logistic regression; †  $p < 0.05$

For peer review only

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation		Page no.
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	<input checked="" type="checkbox"/>	1, 2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	<input checked="" type="checkbox"/>	2
<b>Introduction</b>				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	<input checked="" type="checkbox"/>	4, 5
Objectives	3	State specific objectives, including any prespecified hypotheses	<input checked="" type="checkbox"/>	4, 5
<b>Methods</b>				
Study design	4	Present key elements of study design early in the paper	<input checked="" type="checkbox"/>	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	<input checked="" type="checkbox"/>	5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	<input checked="" type="checkbox"/>	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	<input checked="" type="checkbox"/>	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	<input checked="" type="checkbox"/>	6, 7
Bias	9	Describe any efforts to address potential sources of bias	<input checked="" type="checkbox"/>	7
Study size	10	Explain how the study size was arrived at	NA	Addressed in the protocol paper (reference 7)
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	<input checked="" type="checkbox"/>	7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	<input checked="" type="checkbox"/>	7,8
		(b) Describe any methods used to examine subgroups and interactions	NA	
		(c) Explain how missing data were addressed	NA	
		(d) If applicable, describe analytical methods taking account of sampling strategy	NA	
		(e) Describe any sensitivity analyses	NA	
<b>Results</b>				
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	<input checked="" type="checkbox"/>	8
		(b) Give reasons for non-participation at each stage	NA	



		(c) Consider use of a flow diagram	NA	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	<input checked="" type="checkbox"/>	17-19
		(b) Indicate number of participants with missing data for each variable of interest	<input checked="" type="checkbox"/>	17-19
Outcome data	15*	Report numbers of outcome events or summary measures	<input checked="" type="checkbox"/>	17-19
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	<input checked="" type="checkbox"/>	20
		(b) Report category boundaries when continuous variables were categorized	<input checked="" type="checkbox"/>	17-20
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	<input checked="" type="checkbox"/>	
<b>Discussion</b>				
Key results	18	Summarise key results with reference to study objectives	<input checked="" type="checkbox"/>	8,9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	<input checked="" type="checkbox"/>	11
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	<input checked="" type="checkbox"/>	11
Generalisability	21	Discuss the generalisability (external validity) of the study results	<input checked="" type="checkbox"/>	11
<b>Other information</b>				
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	<input checked="" type="checkbox"/>	12

\*Give information separately for exposed and unexposed groups.