

Association between awareness of disease incurability and patient-reported outcomes in heart failure: A cohort study

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INTRODUCTION

- The unpredictable trajectory of heart failure (HF) & the ongoing risk of sudden death necessitates early involvement of HF patients in care plans.
- Involving patients in shared decision-making requires patients to be aware of disease incurability.

OBJECTIVE

- To examine the **awareness of disease incurability** among HF patients over 24 months.
- To examine the associations of awareness of disease incurability & **patient characteristics**.
- To examine the associations between awareness of disease incurability with patient-reported **distress, emotional well-being (EWB) & spiritual well-being (SpWB)**.

METHOD

Participants: HF patients (NYHA Class 3/4) were recruited from the inpatient wards. Participants were followed up once every 4 months for 24 months.

Awareness of disease incurability: Participants were classified as being **aware, unaware, or uncertain about disease curability**.

Distress, EWB, SpWB:

Distress: Distress thermometer (0 to 10), higher score indicates higher distress

EWB: FACT-G (0 to 24), higher score indicates better EWB

SpWB: FACIT-Sp (0 to 48), higher score indicates better SpWB

Analysis: Associations between awareness of disease incurability and participant characteristics were examined using mixed-effects multinomial logistic regression. Associations between disease incurability awareness and patient outcomes (emotional well-being and spiritual well-being) were assessed using mixed-effects linear regressions.

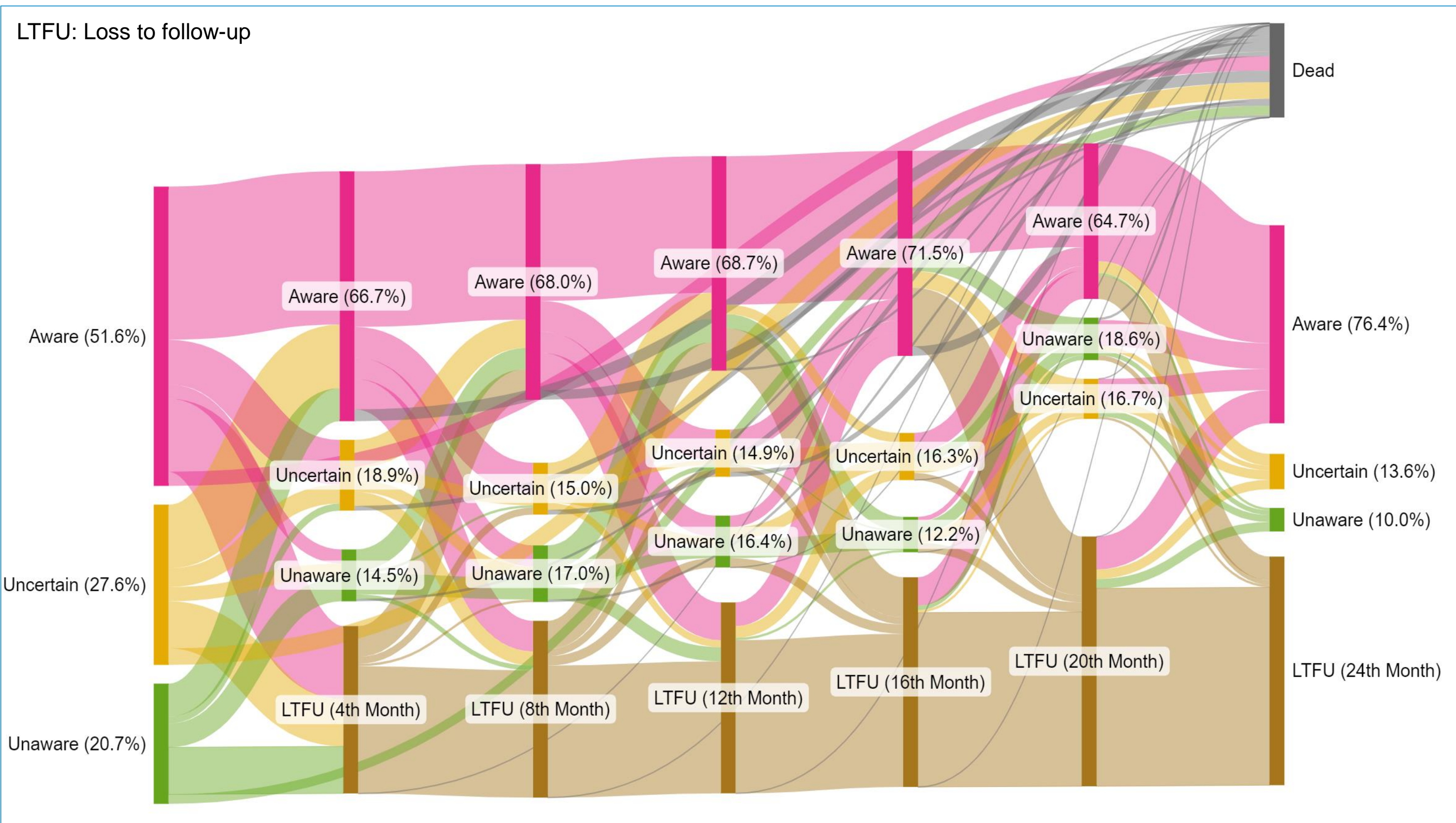
RESULTS

Table 1. Participant characteristics (N=251).

Characteristics	Mean ± SD / n (%)
Age at baseline	66.5 ± 11.9
Sex: Male	180 (71.7)
Ethnicity: Chinese	165 (65.7)
Education: Above primary vs. Primary or below	121 (48.2) vs. 130 (51.8)
Mortality:	
Patients died within 1 year	41 (16.3%)
Patients died within 2 years	56 (22.3%)

- Male participants (71.7%) and Chinese (65.7%) formed the majority of the sample.
- About half (51.8%) had primary school education or no formal education.
- About a-quarter of patient died within the 2-year study period.

Fig 1. Awareness of disease incurability across 24-month study period.



- The proportion of patients who were aware of disease incurability was 51.6% at baseline, and increasing to 76.4% at the 24th month.
- Fig 1 reveals that **patients' understanding of disease incurability changed during the course of the disease**, including patients who switched from being aware at baseline to being uncertain or unaware at the follow-up assessments.

Table 2. Associations (RRR) between awareness of disease incurability & participant characteristics.

	Ref: Unaware of disease incurability	
	Aware	Uncertain
Female (Ref: male)	1.72	1.65
Malay (Ref: Chinese)	0.22 ***	0.44 **
Indian (Ref: Chinese)	0.26 ***	0.40 **
Other ethnicity (Ref: Chinese)	0.12 **	0.42
Education higher than primary school (Ref: primary school or lower)	2.00 **	1.30
Age	1.04 ***	1.02
Married (Ref: not married)	1.42	1.36
Working (Ref: not working)	0.63	0.54 **
Financial difficulty score	1.18 **	1.08
Symptom burden score	1.08 ***	1.07 ***
Participated in treatment decision-making (Ref: Did not participate)	2.13 ***	0.82
Adequate self-care confidence (Ref: inadequate)	5.06 ***	0.78
Time (months since recruitment)	1.08 ***	1.01
Proximity to death: Passed away within 4 months after the last study assessment (Ref: alive for at least 4 months after assessment)	0.80	1.45

** < 0.05, *** < 0.001, RRR: Relative risk ratio

- Compared to being unaware of disease incurability, **Malays (RRR=0.22) & Indians (RRR=0.26)** are less likely to be aware. Those with **adequate self-confidence (RRR=5.06)**, **participated in treatment decision-making (RRR=2.13)**, had **higher education (RRR=2.00)**, **financial difficulty (RRR=1.18)** & **higher symptom burden (RRR=1.08)** were more likely to be aware.
- Compared to being unaware, patients with **higher symptom burden (RRR=1.07)** were more likely to be uncertain about disease incurability while **Malays (RRR=0.44)**, **Indians (RRR=0.40)**, & employed individuals (RRR=0.54) were less likely to be uncertain than being unaware.

Table 3. Associations of disease incurability awareness with distress, emotional well-being, and spiritual well-being.

	Distress (β)	Emotional well-being (β)	Spiritual well-being (β)
Unaware	Ref	Ref	Ref
Aware	-0.03	0.76 **	0.69
Uncertain	0.34	-0.03	-3.16 ***

- Compared to being unaware of disease incurability, **being aware was associated with higher EWB (β = 0.76)** while **being uncertain about disease incurability was associated with poorer SpWB (β = -3.16)**.

CONCLUSIONS

- The implications of our research underscore the importance of addressing uncertainty regarding disease incurability among patients with heart failure.
- Recognizing the potential negative associations with uncertainty, additional efforts are warranted to enhance the dissemination of accurate information about disease incurability within this patient population.

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