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Title: The impact and experience of cardiac cachexia in advanced heart failure patients and their caregivers.

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Topic: Chronic Heart Failure

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Background: Cardiac cachexia is a multifactorial wasting syndrome, which is characterised by unintentional weight loss, a reduction in skeletal muscle mass, and reduced quality of life. There is a paucity of qualitative research outlining the impact and experience of cardiac cachexia in advanced heart failure patients and their caregivers. Research in this area may promote a better understanding of the syndrome, enhance current treatment strategies, and highlight priorities for patient care.

Purpose: To qualitatively investigate the impact and experience of cardiac cachexia in advanced heart failure patients and their caregivers.

Methods: Semi-structured interviews were performed with advanced heart failure (NYHA functional class III-IV) patients meeting diagnostic criteria for cardiac cachexia (number (*n*) = 8) and their caregivers (*n* = 5). Interview questions followed a "laddered style approach", with a focus on determining the experience of cachexia for patients and carers, and its impact on their daily lives. Interviews were digitally recorded and transcribed verbatim. Average

interview duration was 43 (15-64) minutes. Data were thematically analysed, using the 6-step approach of Braun & Clarke. Themes were developed and refined by several members of the research team to ensure rigor.

Results: Four key themes were developed from the data. 1) **“Changed relationship with food and eating”**: patients with cachexia referred to eating as something they now ‘make’ themselves do without enjoyment, often just to placate their caregiver. Caregivers noted this change in habit and were concerned about inadequate nutritional intake due to the patient’s lack of interest in food. 2) **“Not me in the mirror”**: patients struggled with their appearance and had a negative perception of themselves, linked to their weight loss. Caregivers were similarly aware of the physical changes in their loved ones and emotionally impacted. 3) **“Lack of understanding regarding cachexia”**: despite the patient and caregivers’ concerns, they had a perception that healthcare professionals were just *‘fobbing you off’*. Even though weight loss was noted and distressing to patients and caregivers, there was little clinical recognition of it, nor any advice or support from the clinical team regarding management. 4) **“Uncertainty regarding the future”**: patients and caregivers recognised cachexia as a bad sign, and many expressed concerns about their future health and prognosis.

Conclusion: These novel qualitative findings highlight the severe impact of cardiac cachexia on the daily lives of patients and caregivers, and demonstrate their limited understanding of the syndrome. To improve care, professionals need to recognise and discuss cachexia with heart failure patients and caregivers, supporting them to cope with prognostic implications and develop more effective management strategies.

Abstract pictures:

Table I. Participant characteristics for semi-structured interviews.

Identifier	Age	Gender	NYHA class	CCI value	Caregiver also interviewed?	Caregiver gender	Caregiver relationship	Interview location
Patient 1	72	M	NYHA 4	7	Y – Caregiver 1	F	Wife	Home
Patient 2	76	M	NYHA 3	9	Y – Caregiver 2	F	Wife	Home
Patient 3	61	M	NYHA 4	4	N	-	-	Home
Patient 4	46	F	NYHA 4	4	Y – Caregiver 3	M	Partner	Telephone
Patient 5	71	F	NYHA 3	5	N	-	-	Home
Patient 6	85	M	NYHA 3	5	Y – Caregiver 4	F	Wife	Home
Patient 7	88	F	NYHA 3	6	N	-	-	Telephone
Patient 8	77	M	NYHA 4	8	Y – Caregiver 5	F	Wife	Telephone

NYHA = New York Heart Association, CCI = Charlson Comorbidity Index

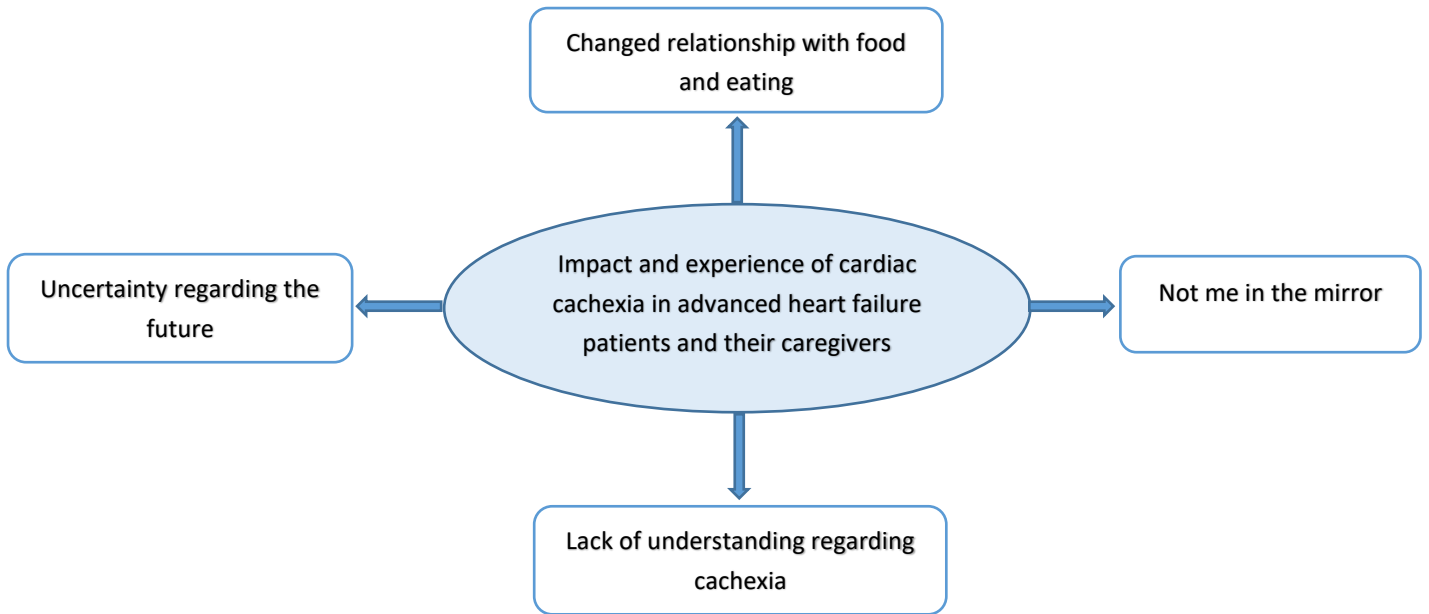


Figure 1. Key themes from semi-structured interviews.