

HEART FAILURE AND CARDIOMYOPATHY

Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't"

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Background: Although chronic heart failure (CHF) has a high mortality rate and symptom burden, and clinical guidance stipulates palliative care intervention, there is a lack of evidence to guide clinical practice for patients approaching the end of life.

Aims: (1) To formulate guidance and recommendations for improving end-of-life care in CHF; (2) to generate data on patients' and carers' preferences regarding future treatment modalities, and to investigate communication between staff, patients and carers on end-of-life issues.

Design: Semistructured qualitative interviews were conducted with 20 patients with CHF (New York Heart Association functional classification III–IV), 11 family carers, 6 palliative care clinicians and 6 cardiology clinicians.

Setting: A tertiary hospital in London, UK.

Results: Patients and families reported a wide range of end-of-life care preferences. None had discussed these with their clinicians, and none was aware of choices or alternatives in future care modalities, such as adopting a palliative approach. Patients and carers live with fear and anxiety, and are uninformed about the implications of their diagnosis. Cardiac staff confirmed that they rarely raise such issues with patients. Disease- and specialism-specific barriers to improving end-of-life care were identified.

Conclusions: The novel, integrated data presented here provide three recommendations for improving care in line with policy directives: sensitive provision of information and discussion of end-of-life issues with patients and families; mutual education of cardiology and palliative care staff; and mutually agreed palliative care referral criteria and care pathways for patients with CHF.

Despite improvements in the management of chronic heart failure (CHF), mortality rates remain high: 40% in the first year following diagnosis^{1–2} and 45–75% at 5 years,^{3–7} with a high risk of sudden death.^{8–9} Patients with heart disease report high prevalence of pain and symptoms, including pain (63–80%), anxiety (49%) and breathlessness (60–88%), rates similar to those for advanced malignant disease and AIDS.¹⁰ Both the SUPPORT study¹¹ and the Regional Study of Care of the Dying identified pain as a significant problem for patients with heart failure in the last days and months of their life,^{12–15} and quality of life is known to be poor.^{16–17} Studies have demonstrated low patient/physician congruity regarding advanced care preferences,^{18–20} and there is still a major lack of knowledge on how patients with CHF regard death and dying.²¹

The mortality rates and prevalence of distressing and apparently refractory symptoms make patients with CHF appropriate for palliative care.^{22–27} In the UK, CHF guidance²¹ stipulates good communication regarding prognosis and living with uncertainty, and access to palliative care expertise for symptom control and psychosocial support. However, despite policy guidelines, there is a lack of evidence regarding the best models of palliative and end-of-life care provision for patients with CHF.

This study aimed to formulate guidance and recommendations for improving end-of-life care in CHF. The objectives were to generate data on patients' and carers' preferences regarding future treatment modalities, and to investigate communication between staff, patients and carers on end-of-life issues.

METHODS

Design and setting

The qualitative methodology utilised semistructured interview data from four sources: cardiology, palliative care, patients and family members at a teaching hospital in London, UK.

Recruitment

Specialist heart failure nurses (FH and CH) recruited patients from the outpatient heart failure clinic and inpatient wards. Inclusion criteria were having a clinical diagnosis of left ventricular systolic dysfunction, with an echocardiogram showing an ejection fraction of ≤ 45 ; having New York Heart Association CHF functional classification III or IV; receiving optimal therapy; having not yet been seen by palliative care staff; and being able to communicate in English and give informed consent. Eligible family members were primary informal carers of patients with class III/IV CHF not yet been seen by palliative care.

Staff were recruited from the cardiology and palliative care teams. A purposive sampling frame addressed the role of nurses/physicians and provision of community/inpatient/outpatient care.

The study was approved by the local ethics committee, and written informed consent was obtained from the participants.

Abbreviation: CHF, chronic heart failure

Data collection

A semistructured topic guide was drafted for each of the samples. A constant comparative approach was utilised to refine focus on the most relevant clinical and patient perspectives, achieved through continuous transcribing and review of successive transcripts. This permitted examination of emergent themes in greater detail through subsequent interviews. In all, 20 patients and their families and 12 clinicians were estimated to achieve data saturation.

Patient and carer schedule themes were (1) whether they could imagine a time in the future when they would want doctors to stop focusing on prolonging life and instead concentrate on improving the quality of life; and (2) whether they had talked to staff about prognosis, treatment options in the event of a future exacerbation and about what to expect of future disease progression. Patient and carer interviews were conducted separately, at the patient's home, outpatient clinic or ward.

Staff schedule themes were (1) the palliative care needs of patients with CHF and their families; (2) communication regarding end-of-life issues; and (3) staff roles, referrals, clinical challenges and appropriate intervention.

Interviews were conducted by LS, RH and MW, and ranged from 20 to 90 min.

Analysis

Interviews were tape recorded, transcribed verbatim and imported into NVIVO V2 software (QSR International, <http://www.qsrinternational.com>) for thematic analysis. Each transcript was subjected to line-by-line coding (LS), with a sample reviewed by a second researcher (RH). Codes were reviewed for internal consistency and to ensure that they reported substantive and independent themes (LS and RH). Each code generated subcodes highlighting variation and discrepancy to describe the breadth of data. Codes and subcodes were tabulated and findings from each sample's data compared. The complete coding frame and sample comparison were reviewed by the whole research group, to confirm the analysis and interpretation.

RESULTS

Sample characteristics

Forty-three interviews were conducted. In all, 20 patients participated, 16 of whom were men (80%). The mean (SD) age was 69 (10.6) years; the youngest patient was aged 43 years and the eldest 83 years. Fourteen patients were New York Heart Association class III, two were class III–IV and four were class IV. The left ventricular ejection fraction ranged from 22.5 to 50, with a mean (SD) of 34% (8.33%). All except one had been previously admitted for CHF. There was a high rate of comorbidities (eg, diabetes, cancer and epilepsy) and invasive cardiac procedures. Eleven carers participated, who also reported a high rate of morbidity.

Six clinicians participated from each specialty. One specialist registrar, one consultant, two specialist inpatient nurses, and two specialist community nurses were from palliative care, three specialist nurses, two consultants and one specialist registrar were from cardiology.

Findings

End-of-life preferences

A wide range of end-of-life care preferences was reported across both patient and carer groups (table 1). Patients' responses include

I'll just have to wait and see for that [whether or not she would ever want life-prolonging treatment to be stopped]...

There's no use in my saying "Yes" and then later saying "No". (patient (henceforth P) 3A)

I wouldn't sort of say, well, "Let's keep on banging away at it and let's hope it'll get better," when I know in my heart of hearts it won't.... All they will do is prolong things, keep me going as long as they can, but when I get to the stage where I cannot walk, I cannot do anything else... I shall say "Right, time to go," and if society won't help me that way I'll do it myself. (P 5A)

Oh no, no, keep treating me. Life's sweet... I've got things to do. I've got grandchildren to think of. (P 1A)

Poor mobility was the main deciding factor for patients who said they would not want their lives to be prolonged in certain instances.

Younger patients tended to focus on the hope of living with controlled symptoms, whereas elderly patients were generally more accepting of and prepared for death. Compare:

Well, I might think about [other approaches] when I'm a lot older... At the moment I've got a lot of life in me. Well, I think I've got a lot of life in front of me; well, I want a lot of life in front of me. (P 2A, aged 59 years)

Basically things over which I have no control I refuse to worry about, because I shall go to that great big postman's sorting office in the sky. Oh no, it don't bother me in the slightest. (P 16A, aged 79 years)

Four elderly patients said they had accepted death and were ready to die, with three preferring to die at home and one in hospital:

I'm not worried now... I mean, I'm 84 now... it doesn't worry me if I die tomorrow as far as that goes, as long as I'm in here, I'm not in [the hospital]... Provided I'm at home I don't care if I go to bed tonight and don't wake up no more. (P 14A)

There was a similar range of responses from carers when asked if they would ever consider requesting treatment for the patient that focused on improving quality of life, rather than on prolonging life (table 1). Pain, quality of life and cognitive ability were reported as the deciding factors—for example,

Well, you come to the point, don't you, where you don't know whether anything else can be done... If you were saying resuscitation or something like that—I don't know that you would want to do that in the situation he's in. (carer (henceforth C) 20B)

However, some family members felt they should not take such decisions:

I always think that doctors know what they're doing, 'cause they study all this, and I wouldn't like to think that if I said "Stop doing this," and something happened because the doctors suggested doing it and I said "No"—I wouldn't want that... So, that's not my decision. (C 4B)

Only two carers reported having had recent conversations with the patient about his or her end-of-life wishes—for example, regarding resuscitation in the event of an exacerbation.

Table 1 End-of-life preferences and influencing factors

End-of-life preferences: patients (n = 20)	Influencing factors for patients (where given)	End-of-life preferences: carers (n = 11)
Would want treatment to prolong life stopped in certain circumstances (n = 9)	Mobility (n = 4)	Would want treatment to prolong life stopped in certain circumstances (n = 5)
Would always want treatment to prolong life continued (n = 4)	Age (n = 2)	Could not decide now for the future (n = 3)
Couldn't say either way (n = 2)	Pain (n = 1)	Avoided the question (n = 1)
Avoided the question (n = 2)	Ability to function physically (n = 1)	Up to the clinician (n = 1)
Could see both points of view (n = 1)	Frequency of hospitalisation and wife's situation (n = 1)	Up to the patient, although carer may override his decision (n = 1)
Preparing for death, though wanting to live (n = 1)	Quality of life and mental ability (n = 1)	
"No one can prolong life, only God" (n = 1)		

Importantly, none of the patients or carers had discussed end-of-life preferences with staff, and none appeared aware of choices or alternatives in future care:

Interviewer: Has anyone asked you how you would like to be cared for in the future, if you have a fall or another attack, problems with your breathing or a minor heart attack?

Respondent: No, no... And I have no idea... I tell the boy "Take me to the hospital" that's all... (P 10A)

Often, in fact, the interviewer's questions regarding end-of-life preferences were interpreted as questions about euthanasia or suicide rather than about palliative care.

Patient and carer experience

Patient, carer and staff data indicated a high prevalence of psychological morbidity among patients. Carers, in particular, reported that patients often experienced anger, frustration, anxiety and depression. Dread, guilt and anxiety were common among carers, five of whom reported fearing the patient's deterioration or death:

Can it make him seriously ill? I know he's ill, but can it make him ten times worse than what it is? Could he end up dying, basically? (C 2B)

Everything else I'm fine with, it's just worry [laughs, begins to cry]... I just dread the day when anything does happen, that's what I worry about, 'cause it will, I know it will, I just dread the time it does. (C 4B)

Discussions of patients' end-of-life preferences and thoughts or feelings about dying were a source of anxiety for carers, and were often not discussed:

There are things that I tell him we're not going to discuss, one of which is the details about what's going to happen in terms of money and things like [that]... I don't want to know anything, I don't want to discuss that. (C 22B)

Interviewer: Do you ever talk about that [not worrying about death] with your daughter?

Respondent: Yeah... I tell them, they know... They say "Don't be stupid."

Interviewer: So they don't like to talk about that?

Respondent: No. She says "The way you talk, you want me to kill you." (P 4A)

Barriers to improving end-of-life care

● Disease specific

Staff reported that the unpredictable disease trajectory prevents discussion of end-of-life issues and future care options:

In terms of speaking about death and dying issues with [CHF] patients it's much more difficult really, because again... it's difficult for us to [know] with too much certainty that this is what's going to happen. (palliative care staff (henceforth PC) 3)

Both patients and staff reported on the public perception of CHF as relatively benign in comparison with cancer:

[Discussing end of life issues] can be very difficult, because many of them may not have associated it with, or thought about, their ultimate death or dying phase, 'cause you can live with it for so long. (PC 6)

● Specialism specific

Cardiac staff confirmed that issues such as future care in the event of an exacerbation, end-of-life preferences, advanced directives or palliative care are rarely raised with patients:

They can talk about death if that's what they want to do... No, I wouldn't initiate that with a patient, but I would allow them the space to, you know, talk about it if that's what they want to talk about. (cardiac staff (henceforth Cardiac) 4)

Cardiac staff reported difficulty handling patient denial, discussing poor prognosis and dealing with emotional involvement with patients and their families. Both specialties recognised that cardiac staff often lack the communication skills necessary to handle sensitive issues such as prognosis and end-of-life preferences:

With cancer patients... if the active treatment is no longer considered appropriate then we really would insist on an oncologist spelling it out, and perhaps oncologists are maybe better trained to do it. With a cardiologist maybe it is very difficult to say, you know, "I've done all I could for you." (PC 1)

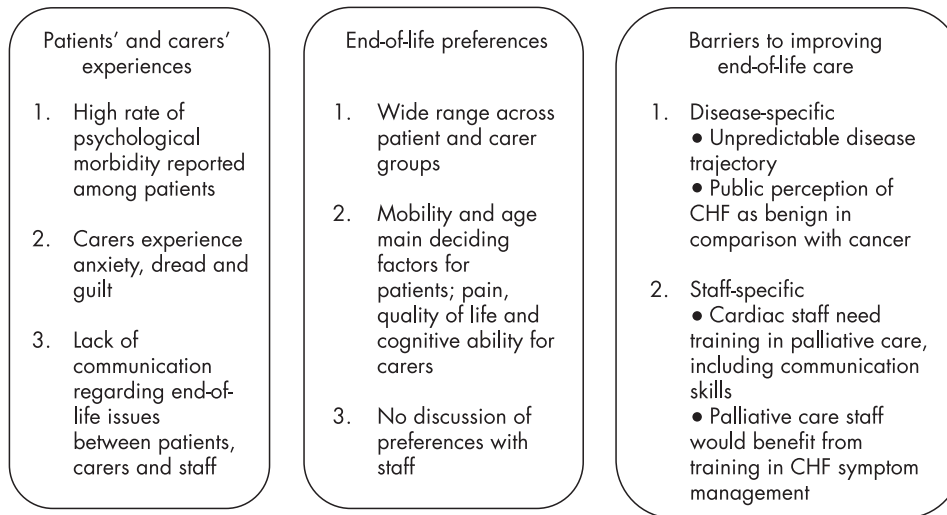


Figure 1 Integration of patient, family and clinician data regarding end-of-life care.

Cardiac staff identified their training needs, including more awareness of future care options. Three cardiac staff also reported that cardiologists might concentrate on the curative and technological aspects of their work while neglecting to meet the needs of patients in their end stage:

Cardiology is a very dynamic subject and you can get a whole load of consultants, dare I say it, who are interested in all the ritzy things of putting stents in arteries and myocardial infarction, and that's saving lives, so actually when you're at the termination of life they're not so interested... They'd rather get on with the living, not the dying, do you understand? (Cardiac 1)

Mutual education of cardiology and palliative care staff was recommended by both specialties, with the aim of providing generalist care with support from and access to specialist palliative care services when necessary.

Shared care rather than handing over care... should be the model for non-malignant diseases... It's not right for palliative care to take over these specialised areas completely, but to do sort of shared care and then you share your own skills and the patient gets a better deal. (PC 5)

Breaking bad news and discussing end-of-life issues in a supportive way were specific suggested training needs for cardiac staff. Palliative care staff suggested that they would benefit from training in CHF symptom management. Members of both teams identified the need for referral criteria and care pathways to facilitate joint working. The findings are modelled in fig 1.

DISCUSSION

Despite poor prognosis for CHF, patients and carers reported very little or no discussion with staff which directly addressed their concerns in this area, and this appeared to affect their psychological morbidity. This supports the findings of other studies.^{17 18 28 29} Patients had rarely discussed their thoughts and feelings regarding death and dying with family members. The silence around end-of-life issues was a source of fear and anxiety for both patients and carers, and points to a major gap in services currently provided. However, these novel, integrated data provide guidance for improving care in line with policy directives.

Although patients with CHF and their carers are uninformed and not consulted about their end-of-life preferences, the willingness of participants to discuss their preferences in this study highlights the feasibility of raising these issues.¹⁸ This may help reduce the fear and anxiety identified among both groups.

The difficulty of prognosticating in CHF, commonly recognised in the literature,^{30 31} was found to be a barrier to discussing end-of-life issues. As Stewart and McMurray state,³² this can lead to "prognostic paralysis" and prevarication in respect to end-of-life discussions. Another major barrier relates to the reluctance of cardiac staff to recognise the need for and initiate such discussions, and their need for training in how to conduct sensitive conversations addressing future planning with patients and carers. This supports the findings of other studies.^{33 34}

We make the following three feasible and acceptable recommendations that are informed by patient, family and clinical perspectives (box 1).

1. Sensitive provision of information and discussion of end-of-life issues with patients and families, early in the course of the disease trajectory, owing to the high incidence of sudden death in this patient group.^{8 9}
2. Mutual education of staff. Training is imperative if cardiac staff are to accommodate diverse patient and family care preferences such as those found in this study, and to handle sensitive discussions of prognosis in a way that allows patients to "hope for the best, and prepare for the worst".³⁵
3. Mutually agreed palliative care referral criteria and care pathways for patients with CHF. Referral criteria and care pathways would clarify staff roles, provide routine assessment of the need for palliative care, facilitate referral to palliative care services when necessary and enable flexible care, including preferred place of death.

There are several limitations to this study. The setting has a specialist palliative care team on site, local community teams and hospices, therefore this population may be relatively well served. There is likely to have been sample bias, because of less advanced patients being recruited, although interviewing at home and in wards and clinics reduced this bias. Although not every patient had a family member, and not all of them consented to participate, the analysis showed saturation of data.

Box 1: Recommendations for clinicians

1. Improved communication
 - Sensitive discussion of end-of-life issues and preferences with patients and carers
2. Mutual education of staff
 - Communication skills training for cardiac staff
 - Training in management of chronic heart failure (CHF) symptoms for palliative care staff
 - Aim: generalist care with support from and access to specialist palliative care
3. CHF referral criteria and care pathways
 - Clarification of specialist roles and when to refer
 - Routine assessment of the needs of palliative care
 - Flexibility of care, including place of death

Through integration of data from multiple sources, the triangulation of findings has enabled a perspective on end-of-life care for patients with CHF and families that, while being broadly supportive of previous studies, is the first to investigate concurrently clinical and patient views and experiences. Further research is necessary to develop specific interventions and care pathways, and to evaluate outcomes for patients and families, including preferred place of death, pain and symptom control, spiritual and psychological well-being, and bereavement outcomes.

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