

# Addressing 'the elephant on the table': barriers to end of life care conversations in heart failure – a literature review and narrative synthesis

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## Purpose of review

Heart failure is a life-limiting illness, but with great uncertainty over its prognosis. Policy increasingly states the importance of discussions about end of life care between patients and their clinicians. This study reviews the extent to which there is evidence that these conversations occur for heart failure patients in practice.

## Recent findings

Although several opinion pieces and guidelines on this topic have emerged in recent years, little new empirical data have been published. Papers publishing empirical data since 2005 and other literature suggest that these conversations rarely occur. Many clinicians feel uncomfortable or lack confidence; and there is uncertainty whether patients want such discussions. Barriers and facilitators for discussions with heart failure are identified, regarding the nature of the disease, resource constraints and attitudes. The consequence is that disempowered patients rarely have such discussions: the 'elephant on the table' is rarely addressed.

## Summary

The wide range of barriers identified all hinder conversations about the end of life with heart failure patients. Individual patient preferences for the timing and content of such conversations must be respected, including the wish of some not to have such conversations at all.

## Keywords

communication, end of life, heart failure

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## Introduction

Health policy is increasingly encouraging clinicians to engage patients in discussion and planning of their end of life care (EOLC) early in the disease trajectory [1,2<sup>••</sup>]. Such advanced care planning is advocated as enabling people to exercise informed autonomy over their care in the final months of life. However, recent reviews of the literature have shown that such conversations currently rarely take place for patients with heart failure [3<sup>••</sup>,4<sup>••</sup>], and that a significant proportion of patients do not wish to have these conversations [3<sup>••</sup>]. The reasons for this gap between policy and practice are examined in this review.

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## Literature review methods

The authors undertook a systematic search of the literature, based on the recent review by Barclay *et al.* [3<sup>••</sup>] in which further details of the search strategy can be found. That search was updated for the present study with Medline, PsycInfo and CINAHL searches for papers published between January 2010 to March 2011 that contained empirical data about the attitudes of

practitioners and patients towards EOLC conversations in heart failure, and the barriers and facilitators to these discussions. This search identified a large number of studies, only one of which contained empirical data on the topic [5]. Several opinion pieces, letters and review articles were also identified, suggesting that although there is a great deal of interest in the subject, there is little new information to inform the debate and service developments. This study therefore differs from our previous review by restricting studies to those containing empirical data and recently published between January 2005 and April 2011 [6–16], adding the one more recent study [5] and placing these empirical studies in the context of other articles in a discussion of current thinking.

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## Attitudes to end of life care discussions

In practice there is uncertainty over whether patients with heart failure wish to have EOLC discussions, and neither patients nor clinicians are sure of the best time to introduce the subject. Some studies showed that the majority of patients want to discuss their prognosis, likely disease progression and future treatment [6,12,13,15],

whereas others reported a mixed picture with approximately half of participants wanting such discussions [5,15]. Some report that most patients explicitly state that they do not want to have these conversations [7,11].

Patients valued honest communication about heart failure from their health professionals [12,15]. Those who would like to have EOLC conversations want the opportunity to discuss their fears [6] and to be able to plan to ensure their families are taken care of [13]. Those who did not want to discuss EOLC issues were concerned about the anxiety such discussions would create for them [7] and their families [11].

There is a paradox in patients' preferences over timing. They would prefer discussions to occur early when they are resilient enough to deal with such issues and in case later cognitive decline affects their ability to engage in conversations; however, they do not want to think about the 'implications of a negative prognosis' when relatively well and early in the course of illness [10]. Health professionals have similar concerns regarding timing of introducing the subject, recognizing that discussions about EOLC should be introduced in the initial phases of the disease with earlier involvement from the palliative care team [16], but not wanting to cause alarm [7].

Health professionals commonly assert that 'good deaths' are more likely to occur when patients are prepared for the future through these conversations [8,9] and acknowledge that patients may wish to have discussions about prognosis and EOLC issues [7]. However, the data suggest that this rarely happens in practice.

Many clinicians prefer to wait to answer questions as patients raise them [7,14], whereas patients prefer that clinicians initiate these conversations [10]. It appears that commonly each party is waiting for the other to introduce the subject, with a consequence that 'the elephant on the table' is never addressed and these discussions do not take place. This is borne out by studies that asked heart failure patients whether these discussions had occurred: a minority [7,11,13,15] or none of the patients [12,14] reported a conversation about future care with their health professional.

### Barriers and facilitators to end of life care discussions

Policy guidelines such as those for Supportive and Palliative Care for Advanced Heart Failure [17] and the NHS EOLC Strategy [1] encourage greater communication between patients and practitioners about the end of life. Such guidance is commonly based on the cancer care literature and practice, whereas there are a number of issues specific to heart failure which influence

### Key points

- Heart failure is a chronic progressive disease with a prognosis as poor as many cancers.
- Prognosis is very unpredictable, with a high risk of sudden death in the earlier stages.
- Patients frequently have a poor understanding of the life-limiting nature of their illness.
- Practitioners are often reluctant to discuss end of life care issues, fearing causing undue anxiety and loss of hope.
- Practitioners need to elicit patients' desire for conversations about the end of life and then tailor content to their information needs.
- Such conversations are challenging and may take place over several consultations, for which personal continuity of care is essential.

whether EOLC discussions take place. Before policy and guidelines attempt to alter current practice, it is important to understand the present reality: the barriers and facilitators perceived by both heart failure patients and their health professionals need to be considered.

### The unpredictability of heart failure

Some issues relate to the nature of the disease. Heart failure has an uncertain trajectory. The fact that in the early stages around 50% die suddenly presents formidable communication challenges: gradual but unpredictable deterioration in heart function is more common in advanced stages [18]. Thus prognostication is difficult [7,9,12,14], which makes it harder to talk about EOLC issues, especially when some patients would like to 'know more accurately when they would die' [6]. Several markers of advanced heart failure might signal to practitioners a need to raise EOLC issues (given below) [19<sup>o</sup>].

Indicators of advanced heart failure that might prompt EOLC conversations (based on Davidson *et al.* [19<sup>o</sup>]):

- (1) One or more episodes of exacerbation of heart failure that have led to hospital admission
- (2) New York Heart Association Class four heart failure
- (3) Decline in function and mobility
- (4) Unexplained weight loss
- (5) Resting pulse rate greater than 100 beats/min.
- (6) Raised serum creatinine (>150  $\mu\text{mol/l}$ )
- (7) Low serum sodium (<135 mmol/l)
- (8) Low serum albumen (< 33 g/l)
- (9) High dose of loop diuretic (e.g. furosemide  $\geq 160$  mg daily)

For many patients, heart failure is one of the multiple comorbidities typical of aging [7,13], some of which may cause greater symptomatic discomfort, with clinicians frequently anticipating that the patient may die of

something else first [7]. Heart failure may not seem an important diagnosis to the patient, as the term does not carry the same overtones of mortality as does the mention of cancer. Once heart failure becomes advanced, it can become more difficult for patients to participate in EOLC conversations as symptoms such as fatigue [10] and cognitive impairment [12] become manifest.

If a patient has indicated that they want to be fully informed about the likely course of their disease and their prognosis then the increased risk of sudden death cannot be ignored; this conversation needs to occur earlier in the disease, when the risk of sudden death is greater. However, knowledge of this totally unpredictable catastrophic event can cause a great deal of anxiety for the patient, which clinicians are keen to avoid [7].

#### **Time and resource constraints**

Lack of continuity of care is a major barrier to EOLC conversations. Throughout the course of their illness, patients may see a large number of clinicians, with consequent uncertainty as to what issues have been previously discussed [7,12,20<sup>\*</sup>]. Clinical records tend to focus on biomedical aspects of care and communication between disciplines can be poor [12,16]. Knowledge of patients, developed from long-term relationships with them, is particularly valued by nurses [16]. This lack of continuity in care is in part due to the multiple comorbid conditions heart failure patients often exhibit, requiring care from different specialists; however, it is also inherent in the organization of some health systems.

Health professionals report that they lack time to have such complex discussions [12,16]. Patients are also aware of the time constraints affecting their clinicians, citing these as one of the reasons that EOLC discussions do not take place [6,10,11]. As well as lacking time, some clinicians themselves feel they lack the necessary communication skills [14] and knowledge of heart failure [7] for these conversations, highlighting their own educational needs.

#### **Attitudes to death and dying among health professionals**

Conversations around prognosis are sometimes seen as 'taboo' [10]. These are, without doubt, very difficult consultations to have. Nurses report that some doctors in the acute setting are uncomfortable with discussing death [8]; clinicians' own fears of dying influence their ability to talk about the subject, believing that patients would not want to discuss such matters [16]. Clinicians fear causing anxiety to patients [7]; patients fear causing anxiety for themselves [11] and their families [6] and hesitate to put their clinicians in 'an uncomfortable position' [10].

Cardiology specialists' primary focus on therapeutic management of heart failure and its symptoms limits the consideration of psychosocial needs [9,12] and may give patients false hope. This may be particularly so for those listed for heart transplantation [8]. This 'therapeutic imperative' of much heart failure treatment may be one factor that results in many deaths occurring in hospital, rather than at home or in hospices where the majority of heart failure patients would prefer to die 'given the opportunity and support' [21,22<sup>\*</sup>]. Clinicians involved in palliative care provision (not specifically for heart failure patients) reported in a recent study [20<sup>\*</sup>] that it is rare for noncancer patients to receive 'a phased transition in which active and palliative approaches were adopted concurrently'.

It can be difficult for community clinicians to be certain that the hospital team will not be able to do something to 'pull the patients back from the brink'; as a result, many patients in a terminal crisis are admitted acutely 'just in case' there is something that can be done. Many UK General Practitioners reported in 2002 that few resources were available in the community for the care of heart failure patients compared with services for cancer patients [23]. This position remains largely unaltered today. Clinicians express concern over raising with patients their preferences for EOLC, such as a desire for death to take place at home, as such services are often inadequately provided: these concerns are a further barrier to conversations about transitions to palliative and EOLC [20<sup>\*</sup>].

#### **'The disempowered patient'**

Patients' knowledge of heart failure is frequently poor, with little understanding about the condition [6,12]. Several factors appear to contribute to this. The condition is seen as 'relatively benign in comparison with cancer' [14]: in the mind of the public it does not carry the same threat of death as cancer and is rarely understood to be a terminal condition. A diagnosis of cancer is often followed by questions regarding prognosis; cancer is widely perceived to be a 'terminal' disease even though many cancers are treatable. In contrast, patients do not seem to recognize heart failure as a terminal disease, due to lack of public knowledge about the condition. Health professionals often struggle to find appropriate language to explain the condition to patients; 'heart failure' is at times avoided as too bleak [7], with more euphemistic term being employed, which, although appreciated by patients [10], appears to contribute to a lack of awareness of the life-limiting nature of the condition. Patients also use vague terms to describe their condition [13]; some do not even know their illness is characterized as 'heart failure' [6].

Nurses express concern that doctors are reluctant to inform patients of heart failure's life-limiting nature

[9,16]. Health professionals' primary focus on medical management contributes to this lack of patient understanding, leaving patients feeling it would be inappropriate to initiate EOLC discussions, or even being unaware that such a discussion would be relevant to them.

The lack of knowledge, along with a concern that they may be seen as 'demanding patients' who ask difficult questions and take up too much of time leads to what Barclay *et al.* [3\*\*] describe as 'the disempowered patient'. Patients may wish to have discussions, but feel unable to initiate them or know what questions to ask.

The association between patients' knowledge of heart failure and their desire for information should be considered. In some studies patients were unaware of the terminal nature of the disease, either describing their shock when their clinician had raised the subject [13] or stating that EOLC issues were not relevant to them, despite having been admitted to hospital due to heart failure [15]. Although patients may lack understanding of heart failure, many also indicate a desire for EOLC discussions [4\*\*]. However, their lack of awareness of the terminal nature of heart failure would mean that they would have little understanding of what the discussions would cover. Patients who state they want more information may be unaware of the impact and implications of the information they would receive.

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#### Facilitating end of life care discussions

The literature in this review contained few suggestions concerning the ways to enable such conversations to take place. Clinicians need to use their judgement and tailor information to each patient's need [7]. Patients often want repeated opportunities to discuss prognosis [10], an approach which would allow different aspects to be covered as they became more comfortable with the subject. When discussions occur, patients want easily understandable information to be given honestly and sensitively [12,14].

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#### Conclusion

The research literature reviewed in this study identifies numerous barriers to open communication with heart failure patients about the end of life, which is the first step on the EOLC pathway outlined in the NHS EOLC strategy [1]. If this goal is to be achieved, a cultural shift will be needed within society in general, and the healthcare professions in particular, allowing the end of life to be discussed more frankly, and allowing people to prepare for it.

The question, however, remains whether this policy goal is either desirable or achievable in practice. There would

be tidiness for healthcare professionals if open communication was the norm, but that would be to impose EOLC discussions on those patients who do not desire a conversation now, or with a particular professional, or even at all. There are some patients that do not desire prognostic information, particularly concerning the 50% chance risk of sudden death in earlier stages of heart failure, or do not wish to have such conversations at all. These wishes have to be respected. The difficulty is how to ascertain when patients do not want conversations, and when they do want conversations but do not know how to indicate this to professionals.

Lack of knowledge around heart failure and poor communication skills [7,14] were identified as barriers; increasing availability of education and training should help healthcare professionals become more comfortable with these discussions. However, if healthcare professionals feel there is a lack of resources for their patients, as mentioned by Murray *et al.* [23], the effect will be limited, as clinicians may be uncomfortable about initiating these potentially distressing conversations if they do not believe they will result in patients receiving EOLC in the manner or place of their choice.

Howlett [22\*] states that there is a 'care gap' throughout all stages of the disease of heart failure, especially when it comes to palliative care, and that EOLC issues need to be routinely incorporated into patients' care. If EOLC discussions were initiated early in the disease trajectory they could, potentially, become a normal part of the discourse, allowing awareness on the part of patients of the nature of the disease and giving them a chance to state their preference for future involvement in decision-making. A loss of hope and increased anxiety may result from such discussions, especially at an early stage when patients feel well; there must be emphasis on how to manage the symptoms of the disease to avoid the feeling that nothing more can be done. It is therefore vital that patient preferences, including whether they want an EOLC discussion or not, are elicited early on, with flexibility to change plans as patients' preferences change. 'These complex, difficult and value laden decisions... should not be made as the patient is being placed in the back of an ambulance' [19\*], especially if the patient would have wanted an opportunity to prepare for the end of life.

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##### Conflicts of interest

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## References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 000–000).

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