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**‘I was told that I would not die from heart failure’: Patient perceptions of
prognosis communication**

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Abstract

Aim and objectives: To describe patients' experiences of communication about their heart failure prognosis and explore how these experiences affected their preferences for future communication about the prognosis.

Background: Professionals need to discuss about the heart failure prognosis with patients in order to improve their understanding of their illness and address palliative care needs.

Methods: An inductive and exploratory design was used. A total of 24 patients (75% men, 52-87 years of age) in New York Heart Association class I-III from primary outpatient care participated in focus group-, or individual semi-structured interviews. Thematic analysis was used to identify and interpret patterns in the data.

Findings: Two overarching themes, "The message sent" and "Hoping for the best or preparing for the worst", each with three sub-themes, were discovered during the thematic analysis. Many patients described that professionals had not provided them with any prognosis information at all. Other patients described professional information about prognosis that was given in an either very optimistic or very negative way. However, patients also described situations where professionals had given information in a way that they thought was perfect for them to handle, and in accordance with their preferences.

Conclusion: This study shows that patients have different experiences and preferences for communication about prognosis and uses different approaches in order to cope living with a chronic illness such as heart failure.

Keywords: heart failure, palliative care, prognosis, communication, coping

Introduction

Many patients with heart failure (HF) have a poor prognosis and are often highly symptomatic during the time they live with HF, especially in the end-of-life (Dickstein *et al.* 2008, Goodlin *et al.* 2008, Jaarsma *et al.* 2009, NICE 2010, Ponikowski *et al.* 2016). Improving communication about prognosis in HF care has been increasingly described as important as it seems only a limited number of patients have such discussions that might help them to plan for the future (Jaarsma *et al.* 2009, McKelvie *et al.* 2013). International guidelines have called for attention to the importance for health care professionals, such as physicians, nurses and other relevant professionals, to discuss prognosis with patients in order to improve their understanding of their illness and address palliative care needs of patients and their families (Jaarsma *et al.* 2009).

Background

Prognosis is in this study defined as “the expected trajectory of a disease in a specific individual” which is based on the description in the Oxford English Dictionary (Dictionary 2004). This means a conversation about what life might be like throughout the illness, often including existential matters such as symptom burden, dependency, advanced care planning, death and dying. These are topics that are often difficult to discuss, both for the patient and the professional (Barclay *et al.* 2011). Professionals have indicated that they are not comfortable discussing prognosis and often avoid these conversations because they are afraid of taking away hope and make patients anxious (Fried *et al.* 2003, Hjelmfors *et al.* 2014). Patients, on the other hand, have diverse attitudes towards prognosis conversations; some want open discussions and others do not (Barclay *et al.* 2011).

In previous studies, patients' preferences have mostly been described in terms of whether they wanted to know about the prognosis or not, when they wanted to discuss it, and who they preferred to initiate the discussion; themselves or the professional (Aldred *et al.* 2005, Caldwell *et al.* 2007, Harding *et al.* 2008, Selman *et al.* 2007). However, little is known about how HF patients actually experience prognosis communication, how their experiences can affect the way they think about their future, and also impact on their willingness to engage in prognosis communication. In addition, as there might be cultural differences in discussions about sensitive topics such as prognosis (Hjelmfors *et al.* 2015, van der Wal *et al.* 2017a, Voorhees *et al.* 2009), we were interested in knowing more about the perceptions on prognosis communication among patients in Sweden. Therefore, the aim of this study was to describe HF patients' experiences of prognosis communication and explore how these experiences affected their preferences for future communication about the prognosis.

Methods

Design

An inductive and exploratory design was used, including focus group interviews (Krueger & Casey 2009) and individual interviews (Polit & Beck 2012).

Data collection

A purposive sampling (Polit & Beck 2012) was used, aiming to include participants with a range in sex, age, and severity of HF to establish variation in the data. Heart failure nurses in outpatient HF clinics in two county hospitals in the south of Sweden identified eligible participants and provided names, age, and information on their

New York Heart Association Functional Classification (NYHA class). The first author sent an invitation letter to participate in the study to suitable candidates and then called them a few days later to ask if they were interested to participate in the study. Inclusion criteria were being diagnosed with HF by a cardiologist, being in NYHA class I-IV, and having no other major life threatening disease. In addition, participants needed to speak and understand the Swedish language and accept being audio recorded.

All interviews were conducted between March 2014 and March 2016. In both the focus group interviews and the individual interviews, a semi-structured interview guide with probing questions was used. Participants were asked to reflect on their experiences of and preferences for professional communication about prognosis. The questions in the interview guide were based on literature from both palliative care and heart failure care, and scrutinised by the authors and a patient with vast experience of living with HF. All interviews were audiotaped and transcribed verbatim by the first author. Additional patient demographic and medical background data was collected individually using self-reported questionnaires before the start of the interviews (Table 1). Patients taking part in the individual interviews were asked to fill in an additional questionnaire assessing the severity of their HF symptoms as information on NYHA class was missing in their medical charts.

Focus groups

The focus group interviews (n=4) with a total of 15 participants, took place at a county hospital in a medium-sized city. The first author (Ph.D. student with experience in medical education and qualitative methods) and the last author (senior researcher in palliative care, with much experience in qualitative methods) took turns

and functioned as a moderator or observer in the focus groups. The moderator led the discussion, while the observer took field notes and summarised the discussion in the end. The focus group interviews lasted 60-90 minutes.

Individual interviews

After the focus group interviews were finalised, the first author also performed individual interviews (n=9) with patients who had more severe HF symptoms. A HF nurse identified suitable patients who were enrolled in the HF clinic and provided the names and contact information to the first author. These interviews were held in the patients' homes, except for one patient who preferred to be interviewed in a quiet room at the local university. The individual interviews lasted 43-75 minutes.

Analysis

Data from both the focus group interviews and the individual interviews were merged and analysed as a whole, using thematic analysis, a method which aims to identify and interpret patterns in the data (Braun & Clarke 2013). An inductive approach was used, where codes and themes were developed directly from the data. Data was read through for familiarisation with the content, followed by a four-step process (Braun & Clarke 2013). In the initial step, extracts of data were demonstrated with a code that captured the semantic content of what the participants said, or a more latent meaning in the data. Second, codes were analysed and collated into themes that captured the central organising concept. Third, each theme was divided into sub-themes describing specific aspects of the central organising concept of each theme. In the last step, in which all co-authors participated, the codes and the full data set were revisited to determine the fit of the overarching themes and the sub-themes. Coding and development of overarching themes and sub-themes were

primarily conducted by the first, second and last author. The co-authors focused on the validation of the results by reading parts of the interviews and comparing the data with the suggested overarching themes and sub-themes. To enhance trustworthiness, the final analysis was discussed in the research group until consensus was reached.

Ethical considerations

This study followed the general guidelines considering ethical testing and research in humans that are set in the Swedish codes of statutes, Law 2003:460, , and the specific guidelines with importance for this study, i. e., the Declaration of Helsinki (version 2004) . The studies were approved by the Regional Ethical Review Board in Linköping (Dnr 2013/244-31). Written informed consent was obtained from the participants at the time of the interviews.

Results

Two overarching themes, “The message sent” and “Hoping for the best or preparing for the worst”, each with three sub-themes, were discovered during the thematic analysis.

The message sent

The first overarching theme focused specifically on the content in the communication with the professional about prognosis. It also described that patients experience communication in different ways and the consequences these experiences have on them.

Lack of information. Patients described that professionals had provided them with little or no information about their HF prognosis during their hospital visits. Some patients described that they did not know that they were suffering from a chronic

illness and therefore did not think about the HF prognosis at all. At some points, some patients had asked about their prognosis, without receiving a proper answer that they could understand. This absence of information about the prognosis left some patients with a feeling of missing out on important information. In meetings with professionals, the communication mostly focused on the treatment and management of HF, and patients described that professionals assessed symptoms and discussed proper self-care and medications.

But talk about the future, you don't do that with the doctor. The doctor explains what it entails and we'll try these medicines, and do this or that. Nothing about the future, only about making you feel as good as possible. (Female, 71 years, focus group interview).

Misleading information. Patients described that they had received misleading information about their prognosis. Some professionals had given the patients a very optimistic view of a life with HF. They had glorified the prognosis, telling the patients that HF would just make them feel a little worse. This information instilled false hope in the patients and made them believe that HF would never mean the end of their lives.

I was told that I would not die from HF. (Male, 78 years, focus group interview.)

In contrast, other patients had been given a very bad prognosis, describing the worst case scenario. Professionals had talked about all those who had died from HF, giving the impression that the patients would definitively die from HF. The patients experienced this information as “blunt” even “brutal” as they often received this information in proximity to the initial diagnosis and did not feel prepared for such information. This information made the patients lose hope for the future, making them wait for death to come.

When they concluded that I have HF, I asked what I need to think about. He said ‘well, to start with you should start taking your pension as soon as possible, because 50% of people diagnosed with HF die within 6 years.’ (Female, 53 years, individual interview).

Tailored information. Described situations where professionals had given the patients information about the prognosis to an extent and in a way that they thought was perfect for them to handle, and in accordance with their preferences. Patients expressed that the professionals had understood how much information about the prognosis they wanted to hear and then provided that information, sometimes in a quite straightforward manner. Some patients had asked about their prognosis and experienced that the professionals had “tuned in” to the patients to understand the level of information required. The professionals had been able to acknowledge the patients’ concerns, thereby showing the patients that they were responsive to their needs.

Somehow, he (the doctor) must have sensed how we could communicate, I think so. I suppose that’s a trick of the trade to be able to make that contact in a fairly short space of time. (Male, 67 years, focus group interview)

Hoping for the best or preparing for the worst

The second overarching theme described patients’ understanding of HF as a chronic illness and their preferences for communication about the prognosis.

Ignorance is bliss. Described how patients preferred to avoid thinking about their HF prognosis because they did not want to lose hope about the future. They lived one day at a time, focusing on the here and now, wanting to forget about the illness altogether. The patients had an underlying understanding of HF as a serious illness, but they did not want to worry themselves by thinking about it. In communication

with a professional, the patient wished to know how to have a good life with the illness, what treatments were available to feel better, but they did not want to talk about death and dying more than what was absolutely necessary.

You think about it, how long this will work, but then you dismiss those thoughts. You live for that day and you are grateful for it. (Female, 71 years, focus group interview)

These patients also preferred to decide themselves whether they wanted to talk about their prognosis with professionals or not. The responsibility to talk and initiate a discussion about the future lies with them as patients and they must be able to choose if they want to talk or not. If they choose to do so, they will ask about it and the professionals should not bring it up before the patient.

Good news only. Patients described that they knew that HF was a chronic illness, but they felt ambivalent about discussing prognosis. These patients only wanted to receive good and positive information from the professionals as they perceived such information to be something that they could benefit from. Positive information could include the physician describing that the heart had recovered, or that there were medications or treatments that would make the patient less symptomatic, which would help them live a more normal life. Information about their prognosis that entailed something bad for the future scared these patients, and they wanted to avoid such information about their illness.

I think I would like... well, if they say it in a good way, then of course I would like to know. But if they were to say 'I don't think you have that many months left', I don't know what I would do with myself. (Female, 87 years, individual interview).

Nothing but the truth. Described that patients wanted to know the objective and absolute truth about their illness and its prognosis, and that they were afraid to live

under false expectations. For these patients, the truth about their prognosis was that they might die due to their illness. Even though the truth might hurt, they believed that knowing the truth was necessary in order to live as good a life as possible. They wanted an explicit discussion with professionals about future expectations as they felt that it was important for them to know as much as possible about their prognosis in order to take care of themselves, live the best life possible, and enjoy the time they had left. These patients also stated that if they were aware of their prognosis, they would also have the chance to inform their families and friends about the situation. Then, the family could be prepared for the day when the illness deteriorated and, in the end, the patient died.

You want to be able to plan for the future, what is left of it, and tell your family how ill you are. (Male, 67 years, focus group interview).

Discussion

This study showed that patients had diverse experiences of prognosis information and also different preferences for such communication. In the literature it is suggested that professionals need to be prepared to discuss prognosis with the patient and the family, and the uncertainty of the prognosis should be acknowledged and planned for (Goodlin 2009, Tanner *et al.* 2011). However, patients described that prognosis often was not addressed in the communication with health care professionals. This has also been reported in previous studies (Garland *et al.* 2013, Low *et al.* 2011). Previous research has demonstrated that professionals often find it difficult to initiate prognosis discussions with patients, and often avoid these conversations because they are afraid of taking away hope and make patients anxious (Barclay *et al.* 2011, Momen & Barclay 2011). This leaves many patients unaware of

the often poor prognosis, and not knowing what to expect in the future (Wal *et al.* 2016). This highlights the importance of improved patient education and information about prognosis (Rogers *et al.* 2000, Ziehm *et al.* 2016). Patients in this study also described that when professionals did discuss prognosis, their outlook was often very optimistic or very negative. This illustrates the professionals' difficulties to have these conversations, where they either avoid to acknowledge the seriousness of the illness or try to make patients aware, but do this in a blunt way. This also indicates that many professionals lack the necessary communication skills to discuss prognosis in a good way, which has been reported before (Selman *et al.* 2007, van der Wal *et al.* 2017b). It has been suggested that in communication about prognosis, professionals should individualise their approach and adapt to each patient's needs and preferences (Irving *et al.* 2013, Parker *et al.* 2007). The depth of prognosis information wanted by patients varied in this study, which has also been found in other studies (Caldwell *et al.* 2007, Klindtworth *et al.* 2015). Some patients do not want to talk about the future at all and might become worried or offended by the topic, which needs to be respected. From cancer care we also know that the degree of honesty about the prognosis needs to be tailored to the individual patient. It is important for professionals to find out how much information the patient wishes to receive as some patients may only want to face part of the truth as a way of maintaining hope (Friedrichsen *et al.* 2011).

In this study, patients also described receiving information about their prognosis where the professionals had "tuned in" to the patient and provided information (positive or negative) in a way that the patient was ready for. From previous research we know that patients often want professionals to be open and honest about their prognosis, thereby helping them to plan ahead and be prepared for a time when their

HF deteriorates (Caldwell *et al.* 2007). However, it is important that these discussions are balanced with hope and professionals' assurance to work with the patient to try to prolong life and improve quality of life (Whellan *et al.* 2014). Many patients also prefer the professionals to initiate the communication as it is part of their professional role and responsibility (Agård *et al.* 2004, Barclay *et al.* 2011).

This study also shows that patients' understanding of HF as a chronic illness differed. As reported in previous studies (Low *et al.* 2011, Wal *et al.* 2016), many patients did not know that HF is a chronic illness and therefore showed little interest in discussing the prognosis. A lack of information from professionals about the seriousness of HF is probably one reason for this unreflective thinking. Other patients had an understanding of the seriousness of HF but chose not to think about it or preferred to only focus on good news about the prognosis. On the other hand, other patients found it crucial to know the absolute truth about their prognosis. Some patients might feel hopeful about the future if they do not think or talk about their prognosis. Other patients feel more confident about the future and have a better quality of life if they have more knowledge and a better understanding of their illness. They have accepted their situation; dying seems like the natural end to their illness and they do not fear talking about it. These different approaches to discussing prognosis might be ways for these patients to cope with and mentally manage the threat that HF poses to them, something that has been described in other studies (Buetow *et al.* 2001, Caldwell *et al.* 2007, Murberg & Bru 2001). Some patients seem to accept their illness, and they confront and share their concerns about it in a practical way. They might make plans for end-of-life and discuss these with family and professionals. Other patients are instead in a state of denial, and have difficulties accepting the illness, the diagnosis and the possible implications.

One important limitation in this study is that despite our efforts to include even the most severely ill patients, none of the participants were in NYHA class IV and the perspectives of the patients in this study might not reflect those of patients with the most advanced HF. Analysing data derived from both focus group interviews and individual interviews was one way to enhance credibility through triangulation and can be considered as a strength in this study.

To conclude, one important part of HF professionals' clinical work is to provide patient education that explains the progression of HF and establishes goals for care (Jaarsma *et al.* 2009, Ponikowski *et al.* 2016) but discussing prognosis according to the patient's preferences, seems to be a delicate task. It is important for professionals to adapt their communication to the needs and preferences of patients. When professionals act as if ignorance is bliss, keeping important information from the patient, they might deprive the patient from being able to plan ahead and be prepared for a time when their condition is deteriorating. At the same time, some patients prefer to ignore the idea they might die from their HF, and they prefer to live one day at the time. Other patients may wish for a little more information, but only the good information about their prognosis. In discussions with patients, health care professionals need to respect the strategies used by patients to cope with living with a chronic illness such as HF. An individual approach is emphasised in the communication as it has been suggested that knowledge about the illness is not always beneficial to all patients, at all times (Jackson *et al.* 2013). Each patient has a personal experience of the illness, which might be similar, or not, to other patients' experiences. At the same time, professionals need to be ready to support the patient in their situation in the best way, according to their needs and situation and try to understand what impact HF has on each individual patient and adopt the care and

communication to each individual (Olano-Lizaraga et al 2016). Future research needs to explore and test interventions to optimise patient-professional communication about prognosis and also evaluate the possibility to make professionals more comfortable and confident in communicating with patients about prognosis.

Contributions

All authors were involved in the design of the study, analysing data and writing the paper.

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Table. 1. Semi-structured interview guide used in focus group interviews and individual interviews

- 1) How do you think about your future, living with Heart Failure?**
- 2) Have you ever talked to any health care professional about the Heart Failure prognosis and how the future might be?**
 - How was that discussion?
 - Who talked to you?
 - What did that conversation mean to you?
 - Did you want to talk?
 - What did you answer?
 - Did you ask anything?
 - Why/why not?
 - How did you feel?
 - What were your reactions
 - Why did you react as you did?
- 3) Who do you think should discuss this with you?**
 - What is important for you in such conversations?
 - How would you like the conversation to take place?
 - What should be discussed?
 - What support would you need?
 - Who would you want to join you in such conversation?
- 4) Are there any barriers for communication about the Heart Failure trajectory?**
 - Do you have any ideas how to overcome these barriers?
 - Why is it difficult to talk?
 - Are there any facilitators for such communications?
 - Is there anything one should not talk about?
- 5) Is there anything else you would like to discuss that we have not talked about yet?**

Table 2. Background characteristics of the participants in the study.

N=24	
Sex n, (%)	
Males	18 (75%)
Females	6 (25%)
Focus group interviews n, (%)	15 (63%)
Individual interviews	9 (37%)
Age years, mean	52-87, 73
Marital status n, (%)	
Married/living with partner	15 (63%)
NYHA classification n, (%)	
I	5 (21%)
II	10 (42%)
III	9 (37%)
IV	0 (0%)
Time with HF* n, (%)	
<1 year	3 (13%)
1-2 year	7 (30%)
3-5 year	6 (26%)
>5 year	7 (30%)
ICD/CRT n, (%)	9 (34 %)
Education* n, (%)	
Elementary school	10 (47%)
Upper secondary school	3 (14%)
University	8 (38%)
Work* n, (%)	
Yes	3 (14%)
Retired	18 (85%)

NYHA, New York Heart Association; HF, Heart Failure;
 ICD, implantable cardioverter defibrillator, CRT *Cardiac resynchronisation therapy*, *Contains missing data.