Original article

"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.

1. 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, Quill, & Arnold, 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).

2. 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, Momen, Case-Upton, Kuhn, & Smith, 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, Bradley, & O'Leary, 2003; Hjelmfors, Strömberg, Friedrichsen, Mårtensson, & Jaarsma, 2014). Patients, on the other hand, have diverse attitudes toward 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, Gott, & Gariballa, 2005; Caldwell, Arthur, & Demers, 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.

3. Methods

3.1. Design

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

3.2. 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. (See Table 2.)

3.3. 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

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.

discussion, while the observer took field notes and summarised the discussion in the end. The focus group interviews lasted 60–90 min.

3.4. Individual interviews

After the focus group interviews were finalised, the first author also performed individual interviews (*n* = 9) with patients who had more