Heart failure patients’ future expectations and their association with disease severity, quality of life, depressive symptoms and clinical outcomes

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SUMMARY

Background: Although treatment of heart failure (HF) patients has improved, prognosis still remains poor. Current HF Guidelines recommend communication about prognosis with all patients. Little is known about HF patients’ awareness of their shortened life expectancy. Aim: To explore HF patients’ future expectations and to examine whether these expectations are associated with disease severity, quality of life, depressive symptoms and clinical outcomes. Method: Patients randomised to the intervention groups of the COACH study, who were at the end of HF hospitalisation, were asked about their future expectations. Patients were divided into three groups: patients expecting improvement/stabilisation, patients expecting deterioration and those not knowing what to expect. Depressive symptoms were measured by CES-D and quality of life with the Ladder of Life and RAND-36. Results: Six hundred and seventy eight patients (age 70 ± 12; 41% female patients; LVEF 33% ± 15) participated in the study. Most patients (56%, N = 380) expected improvement or stabilisation, 8% (N = 55) expected deterioration and 21% (N = 144) did not know what to expect for the future. Patients who expected to deteriorate were significantly older, experienced a lower quality of life and more depressive symptoms compared with patients in the other two groups. They also had a higher mortality rate, both after 18 and 36 months, and had more HF admissions. No association with severity of the disease (NYHA-class, LVEF, BNP levels) was found. Conclusion: Many hospitalised HF patients are not aware of their poor prognosis. Depressive symptoms, poor quality of life, increased mortality and rehospitalisation were related to expected deterioration. Improvement of communication about prognosis with HF patients is needed in the future.

Introduction

Heart failure (HF) is a common cardiac condition with an estimated prevalence of 2–3% in both Europe and the USA. HF is also one of the most common reasons for hospitalisation in the developed world, with approximately 5% of medical admissions in Europe attributable to HF (1,2).

Although the treatment of patients with HF with reduced ejection fraction has significantly improved during the last decades (3), prognosis still remains poor, worse than most common forms of cancer, with a mortality rate of 59% within 5 years (4).

Heart failure is a progressive disease with an often unpredictable course. HF can change from periods of crisis with deterioration to a more chronic phase and finally a terminal phase (5).

Patients may suffer from several exacerbations during their disease trajectory, frequently accompanied by re-hospitalisations, extra visits to a healthcare professional or a need for home care or hospice facilities. It was previously found that elderly patients with HF often think about death with some patients being severely afraid of dying, and several wished for an extended life and many expressed death as something natural and as a relief from sufferings (6). However, it was quite common that patients with HF feared that they would not receive care to keep their dignity and achieve symptom relief (6). To some extent, this might reflect that patients are aware that their condition is likely to deteriorate. On the other hand, the general public is not aware of the poor prognosis of HF (7) and therefore patients and their
families may have unrealistic expectations about the future life expectancy. Recent HF guidelines advise to include a dialogue about prognosis in HF patients, so patients can make realistic decisions for the future (1). The Heart Failure Association of the European Society of Cardiology stated that patients with HF (including patients in a chronic condition in New York Heart Association (NYHA) class I–III) (Table 1) should have clear explanation about their condition, including information about their prognosis (5). At this moment, there is little knowledge to what extent such a conversation takes place and how aware patients are of their prognosis or of the expected course of HF. A study of Barnes et al. (8) on communication of prognosis reported that only a few of the 44 HF patients that were interviewed, had a discussion about prognosis with a healthcare professional. In the same study, healthcare professionals from primary care stated to be reluctant to discuss the terminal aspect of HF with their patients, especially in an early stage of the disease.

During the HF trajectory, many patients suffer from depressive symptoms (9), which may influence patients’ awareness or the willingness of healthcare professionals to talk about prognosis. Healthcare professionals may also be afraid to take away hope or find it difficult to discuss the subject because of the unpredictable course of the disease with frequent periods of deterioration. Another reason to avoid the subject can be related to healthcare providers knowledge on palliative care or their own attitude towards death and coping with death (10,11).

Information on patients’ own expectation about their disease trajectory might help to develop ways to discuss this with future patients and their families.

The aim of the study was therefore to explore HF patients’ perception of their future life expectations.

| Research questions |
|--------------------|
| How do HF patients perceive their expectations of the future? |
| What are differences in disease severity, quality of life and depressive symptoms between patients who expect improvement/stabilisation, patients who expect deterioration and patients who do not know what to expect? |
| What is the relationship between patients’ future expectations and clinical outcome? |

| Method |
|--------|
| Design |
| The study used a descriptive, cross-sectional design and is a subanalysis with baseline data from the COACH (Coordinating Study evaluating Outcome of Advising and Counselling in Heart Failure) study, a Dutch multi-centre study on the effect of education and counselling in HF patients. The design and outcome of the COACH study that were published earlier are described below in brief (12,13). |

| Data collection |
|-----------------|
| Patients in the COACH study were randomised into three groups [control group with visits to the cardiologist, basic intervention (visits to the cardiologist and follow up by the HF nurse) and intensive intervention (visits to the cardiologist and monthly contact with the HF nurse, including two home visits and a multidisciplinary advice)]. Inclusion criteria of the COACH study were an admission for HF, evidence of a structural underlying heart disease and age ≥ 18 years. Exclusion criteria were participation in another study, a planned or recent invasive cardiac intervention or inability to complete questionnaires. The study complies with the Declaration of Helsinki. The Medical Ethical Committee has approved the research protocol and all patients gave written informed consent. |

Perception of life expectancy was part of the nurse assessment in the COACH study, undertaken at baseline by the HF nurse for patients in both intervention groups. This assessment was developed by two experts in HF nursing. Since patients in the control group were only followed up by the cardiologist and not by the HF nurse, no nurse assessment took place. Therefore, patients in the control group are not included in this subanalysis. The COACH intervention started after this baseline nurse assessment. At the start of the COACH study intervention, it was unknown which information about their prognosis patients actually received in an earlier stage. All HF nurses worked in an outpatient setting and were
specialised in HF care. In the nurse assessment, patients were questioned by the HF nurse about their expectations regarding their condition on three issues. First, they answered the question: ‘What are your future expectations concerning your illness?’ The responses of the patients were taken as ‘open-ended’ and were afterwards categorised by the HF nurse in the following options ‘I will recover’, ‘I hope I remain stable for a while’, ‘I think I will deteriorate slowly’, ‘I think I will die soon’, ‘I don’t know’ and one open-ended answer. Secondly, patients were asked whether they were generally worried about their future expectations (yes/no). Finally, they were asked how satisfied they were with the current situation with possible answers ‘satisfied’, reasonably satisfied’ or ‘unsatisfied’. After the patients had answered, the assigned HF nurse, who is responsible for the care of the patient, assessed whether she or he estimated that the expectation of the patient was realistic or not.

Presence of depression was assessed with The Centre for Epidemiologic Studies Depression (CES-D) scale, a validated 20-item instrument to measure depressive symptoms (14) at baseline. A score ≥ 16 indicates the presence of depressive symptoms. Quality of life was assessed with the Ladder of Life, which is a general measure of global well-being with a score between 0 (worst possible life imaginable) to 10 (best possible life imaginable) (15). Finally, patients completed the RAND-36, measuring eight dimensions of quality of life. For this analysis, question 11-C of the RAND-36 was used (‘I expect my health to get worse’) with possible answers ‘definitely true’, ‘mostly true’, ‘don’t know’, ‘mostly false’ or ‘definitely false’. All questionnaires were completed by the patients themselves, if necessary with the help of an independent data collector, who was not involved in the care of the patient.

Disease severity was assessed by the HF nurse using the NYHA functional class (Table 1). Also, Left Ventricular Ejection Fraction (LVEF, the fraction of outbound blood pumped with each heartbeat which is a measure of the pump-function of the left ventricle) and baseline BNP levels (Brain Natriuretic Peptide secreted by the ventricles of the heart in response to excessive stretching of the muscle cells and due to this often elevated in HF patients) were collected from the patients’ medical records. (16). Data on clinical outcomes (mortality and HF hospitalisation) were also collected from the patients’ medical records and were judged by an end-point committee in the main study.

Data of 685 patients randomised in the basic and intensive intervention of COACH were included in this subanalysis.

Data analysis
For the current analysis, patients were divided in patients ‘expecting improvement/stabilisation’ in case they answered ‘I will recover’ or ‘I hope I remain stable’ and those ‘expecting deterioration’ if they answered ‘I think I will die soon’ or ‘I think I will deteriorate slowly’. Patients who answered ‘I don’t know’ were included in the analysis as a separate group. Eighty-four patients in the study population gave an open answer which could be recoded to one of the other answer categories on the question about their future expectations. Ninety-nine patients (15%) gave more than one answer or gave an open answer that could not be recoded and were therefore excluded in the analysis on differences in life expectancy.

Descriptive statistics were used to characterise the sample. To assess differences in future perspectives between patients who expect improvement/stabilisation, those expecting deterioration and patients who do not know, ANOVA with post hoc analysis for continuous variables and chi-squared tests with post hoc analysis for categorical variables were performed with adjustment for multiple testing.

Results
Clinical and demographic data
Seven of the 685 patients in the COACH intervention groups did not answer the question about the expectations regarding the future. Therefore, data of 678 hospitalised HF patients were used for the current analysis. The mean age of the study population was 70 (±12), 36% were female patients, with a mean LVEF of 33% (±14). Half of the patients were in NYHA Class III–IV. Most of the patients (42%) had HF because of coronary artery disease and 24% was diagnosed with cardiomyopathy. A total of 38% of patients had depressive symptoms at baseline (Table 1). All-cause mortality was 25% (N = 172) after 18 months and 40% (N = 273) after 36 months.

Perceived future expectations and HF nurses estimate of this perception
With regard to the question ‘What are your expectations concerning your illness the coming time’, most of the patients (39%) answered that they hoped to remain stable for a while. Twenty-five percent did not know what to expect, 11% stated that they thought they would deteriorate slowly and 13% of the patients thought they would recover (e.g. they would be cured). Ten patients thought they would die soon (Figure 1).
Almost a quarter of all patients (N = 157) reported that they were worried about their future. Thirty per cent of patients were satisfied and 52% were reasonably satisfied with their current situation.

**Differences between patients expecting improvement/stabilisation, patients expecting deterioration and those who do not know what to expect**

The answers of 99 patients could not be recoded to one of the answering categories; 43 patients gave more than one answer, the other 56 patients made remarks that could not be recoded for example ‘maybe a surgery is possible’, ‘treatment options are not clear yet’, ‘get used to limitations’ or ‘just go on breathing’. Finally, 579 were included in this analysis. A total of 8% (N = 55) of all patients expected improvement or stabilisation, while 56% (N = 380) expected deterioration. Twenty-one per cent (N = 144) did not know what to expect for the future.

Patients expecting deterioration had a longer history of HF than those expecting improvement or stabilisation (4.3 vs. 2.5 years; p = 0.01) or those who do not know what to expect for the future (4.3 vs. 2.1; p = 0.01). They were also older (75 vs. 70; p < 0.01) and had more previous HF admissions than patients in the other groups (1.1 vs. 0.5/0.4; p < 0.01) (Table 3).

There were no differences in disease severity, assessed by NYHA functional class, LVEF and BNP levels at baseline between the three groups. It should be stated, however, that BNP levels were only available in 55% of the patients.

Patients who expected deterioration had a lower quality of life score on the Ladder of Life, were more worried about their future expectations, and were more often unsatisfied with their current situation compared with those expecting improvement/stabilisation. However, 62% of patients who expect deterioration reported to be satisfied or reasonably satisfied. Regarding the RAND-36 question, 82% of the patients who expect deterioration answered that they expected their health to get worse, compared with 38% of patients expecting improvement or stabilisation (p < 0.01) (Table 2).

Patients who expected deterioration finally reported more depressive symptoms compared with patients in the other groups (19 vs. 16/14; p < 0.01), although there were no significant differences in the amount of patients with a CES-D score >16 (Table 2).

**Relationship between perceived future expectations and clinical outcome**

Looking at outcome variables, patients who expected deterioration had a significantly higher mortality rate after 18 and 36 months, compared with patients expecting improvement or stabilisation or those who do not know what to expect (65% vs. 39%/37%; p < 0.01) (Table 3). In Figure 2, survival curves for the three groups are presented. Moreover, patients expecting deterioration also had more HF re-admissions (0.8 vs. 0.3/0.4; p < 0.01), more days hospitalised for HF (66 vs. 21/20; p < 0.01) and a higher number of unfavourable days, defined as days hospitalised for HF or death during 18 months (166 vs. 88/83; p < 0.01) (Table 2).

**Discussion**

The main findings of this study were that many patients hospitalised with HF were not aware of the severity of their condition and poor prognosis.
Although a quarter of all patients were worried about the future, most of the patients were (reasonably) satisfied with their current situation. Patients who expected to deteriorate had worse outcome, with a higher mortality rate and also experienced a lower quality of life and more depressive symptoms, compared with patients expecting improvement or stabilisation and patients who did not know what to expect. No relationship between expectations and disease severity was found.

Table 2 Baseline characteristics of all patients (N = 678) and between patients with a longer or shorter life expectancy and patients who do not know (N = 579)

|                                | All patients (N = 678) | Expect improvement/stabilisation (N = 380) | Expect deterioration (N = 55) | Do not know (N = 144) | p-value |
|--------------------------------|------------------------|-------------------------------------------|-------------------------------|-----------------------|---------|
| Age (±SD)                      | 70 ± 12                | 70 ± 12                                   | 75 ± 10                       | 70 ± 11               | <0.01   |
| Female (%)                     | 36                     | 37                                        | 31                            | 40                    | NS      |
| Living with a partner (%)      | 60                     | 61                                        | 47                            | 57                    | NS      |
| LVEF (±SD)                     | 34 ± 14                | 33 ± 14                                   | 35 ± 16                       | 34 ± 14               | NS      |
| BNP (N = 318)                  | 1155 ± 863             | 1153 ± 833                                | 1282 ± 911                    | NS                    |         |
| NYHA functional class (%)      |                        |                                           |                               |                       |         |
| II                             | 49                     | 52                                        | 33                            | 55                    | NS      |
| III–IV                         | 50                     | 48                                        | 63                            | 44                    |         |
| Duration of disease (y ± SD)   | 2.6 ± 4.4              | 2.5 ± 4.1                                 | 4.3 ± 4.7                     | 2.1 ± 3.9             | <0.01   |
| Aetiology heart failure (%)    |                        |                                           |                               |                       |         |
| Coronary artery disease        | 42                     | 42                                        | 49                            | 39                    | NS      |
| Cardiomyopathy                 | 24                     | 23                                        | 20                            | 26                    |         |
| Hypertension                   | 15                     | 16                                        | 7                             | 17                    |         |
| Valvular disease               | 9                      | 8                                         | 11                            | 10                    |         |
| Previous HF admissions, mean (±SD) |                  |                                           |                               |                       |         |
| No admission (%)               | 68                     | 68                                        | 56                            | 75                    | <0.01   |
| 1 (%)                          | 19                     | 19                                        | 16                            | 19                    |         |
| > 1 (%)                        | 13                     | 13                                        | 27                            | 6                     |         |
| Comorbidities (%)              |                        |                                           |                               |                       |         |
| COPD                           | 27                     | 25                                        | 45                            | 24                    | <0.01   |
| Diabetes                       | 27                     | 30                                        | 27                            | 24                    | NS      |
| Stroke                         | 10                     | 10                                        | 11                            | 10                    | NS      |
| CES-D score                    | 15 ± 11                | 16 ± 11                                   | 19 ± 11                       | 14 ± 10               | 0.01    |
| Depressive symptoms (%)        | 38                     | 37                                        | 53                            | 33                    | 0.06    |
| Ladder of life                 | 6.3 ± 1.9              | 6.4 ± 1.9                                 | 5.6 ± 1.8                     | 6.6 ± 1.8             | <0.01   |
| Worried about                  | 23                     | 16                                        | 38                            | 37                    | <0.01   |
| future expectations (%)         | 82                     | 88                                        | 62                            | 78                    | <0.01   |
| Satisfied/reasonably satisfied with current situation (%) | 30 | 32 | 15 | 33 |         |
| Satisfied                      | 52                     | 56                                        | 47                            | 45                    |         |
| Reasonably satisfied           | 13                     | 7                                         | 33                            | 19                    |         |
| Unsatisfied                    | 52                     | 56                                        | 47                            | 45                    |         |
| RAND-35 Q 10 c (I expect my health to get worse) (%) | 21 | 24 | 4 | 21 |         |

SD, standard deviation; LVEF, left ventricular ejection fraction; BNP, brain natriuretic peptide; NYHA, New York Heart Association; COPD, chronic obstructive pulmonary disease; CES-D, Centre for Epidemiologic Studies Depression.

A quarter of all patients in the study did not know what to expect for the future and more than one out of 10 even thought that they would recover. The latter results are consistent to a study on patient-predicted life expectancy in ambulatory HF patients that reported that 9% of HF patients thought they will be cured (17). Most of the patients in the study by Allen and co-workers (63%) overestimated their life expectancy compared with a model-predicted life expectancy. Another recent study in 100 HF patients
reported that the mean life expectancy as estimated by themselves was 82.86 years (18). In a study using quantitative and qualitative data on thoughts about death in elderly patients with HF, however, 64% of the patients reported that they often thought about death (6). Most of these patients (38%) thought about death as part of a natural part of life and only a minority (13%) expressed death as a relief from symptoms as pain or shortness of breath. The mean age of that study population was 70 years and all patients were recently hospitalised for HF.

Table 3 Differences in 18 months follow-up data between heart failure patients with a longer or shorter life expectancy and patients who do not know (N = 579)

|                                | Expect improvement/stabilisation (N = 380) | Expect deterioration (N = 55) | Do not know (N = 144) | p-value |
|--------------------------------|-------------------------------------------|-------------------------------|-----------------------|---------|
| Mean number of days hospitalised for HF | 21 ± 87                                   | 66 ± 152                     | 20 ± 78               | < 0.01  |
| Mean number of unfavourable days* | 88 ± 174                                  | 166 ± 152                    | 83 ± 161              | < 0.01  |
| Time (days) to HF hospitalisation | 409 ± 203                                 | 272 ± 223                    | 416 ± 193             | < 0.01  |
| Mean number of HF admissions after discharge | 0.3 ± 0.6                                 | 0.8 ± 1.1                    | 0.4 ± 0.9             | < 0.01  |

*Unfavourable days are days exposed to a primary end-point (HF hospitalisation or death) during 18 months follow up.

Figure 2 Survival curves for time to death after 36 months for the three groups

(mean age 70; LVEF 33%; 36% in NYHA-III–IV) reported that the mean life expectancy as estimated by themselves was 82 ± 8.6 years (18). In a study using quantitative and qualitative data on thoughts about death in elderly patients with HF, however, 64% of the patients reported that they often thought about death (6). Most of these patients (38%) thought about death as part of a natural part of life and only a minority (13%) expressed death as a relief from symptoms as pain or shortness of breath. The mean age of that study population was 70 years ± 10 and all patients were recently hospitalised for HF,
which makes them comparable to patients in our study.

Patients who expected deterioration had a higher mortality rate after 36 months, compared with those expecting improvement of stabilisation (65% vs. 39%; p < 0.01) and those who do not know what to expect (65% vs. 37%). They also had a higher amount of HF hospitalisations (0.8 vs. 0.3/0.4; p < 0.01). Patients who expected to deteriorate were older, had a longer history of HF with more previous HF admissions and more often had COPD compared with patients in the other groups, which may partly explain some of the differences in worse outcome. However, it also mirrors that those with poorer outcomes were less optimistic about their life expectancy. We did not find differences in disease severity (NYHA-class, LVEF and BNP levels) between the three groups. This is an indication that future expectations of the patients depend more on their age and previous experiences with the disease (length of the disease and HF admissions) than with the actual severity of the disease.

Although patients who expected deterioration, also reported a worse quality of life and more depressive symptoms, it was remarkable that 59% of the patients who expected deterioration, still were satisfied or reasonably satisfied with the current situation, compared with 82% in patients expecting improvement/stabilisation (p < 0.01). It is possible that patients learn to adapt to their life expectations in a certain way during the course of the disease and therefore still are satisfied with their current situation. Although many patients were satisfied, almost a quarter (N = 157) reported that they were worried about their future expectations. This is not surprising since all patients in the study were hospitalised for HF, meaning that they went through a period of worsening symptoms probably confronting some of them with the uncertainty about the course and understanding of the severity of the disease. HF nurses can play an important role in discussing these concerns with their patients and guiding them to deal with their worries by giving emotional support and helping patients to set goals for the coming time.

In the group of patients who thought they will recover and those who hoped to remain stable, 23% of the patients died within 18 months, and 39% within 3 years, reflecting the severity of the disease and poor prognosis of HF in this study population.

The HF Guidelines of the European Society of Cardiology that were applicable at the time of our study (19), described that prognosis should be discussed with HF patient and their family, but no further explanation about the content of this discussion was given. In more recent HF guidelines (1), it is emphasised that important prognostic factors should be discussed to motivate patients to adhere to treatment and that ‘an open discussion with the patient and family may assist in making realistic and informed decisions regarding treatment and future plans’. In a position statement on palliative care in HF (5) it is emphasised that patients in NYHA I–II should be given a clear explanation about their condition, including treatment and prognosis. In patients with more severe HF (NYHA-III–IV), prognosis and the course of the disease should be discussed more in detail, including recommendations for completing an advanced care plan. This implies that somewhere in the course of the disease, prognosis and end of life should be discussed with the patient.

Our study data illustrate that many HF patients do not know what to expect for the future, not even in a population with a mean history of HF of 2.6 years and during a hospitalisation for HF. It is possible that HF patients in our study are not well informed about their prognosis and life expectancy, which was also concluded in other studies (6,17,18). This is an important reason to improve communication with the patient and caregiver about the severity and the course of the disease, prognosis and end of life care.

In daily practice, it can be questioned which healthcare provider should discuss these topics with the patient. A recent study in Sweden on 111 HF nurses, showed that most nurses (69%) felt that the physician (cardiologist, general practitioner) had the main responsibility to discuss prognosis with the patient, although around 90% of the nurses at some point discussed prognosis with their patients. Important barriers to discuss prognosis or end of life care were, for example, the unpredictability of the disease (77%), fear of taking away patients’ hope (62%) and inadequate time for such conversation (52%) (20).

Another question is at what time point prognosis should be discussed with the patient and caregivers. A qualitative study including 25 HF patients (mean age 70; 40% in NYHA-III–IV), showed that patients wanted to know their prognosis, although the subject was not discussed with most of them (21). Kraai et al. concluded that patient preferences regarding quality and quantity of life might change over time and that the subject should be discussed regularly, for example during important treatment decisions or when the clinical condition of the patient changes (18).

In the future, more research is needed to study patients’ preferences regarding the time of discussing prognosis with them. Finally, education for healthcare providers about discussing prognosis with HF patients will be needed.
Heart failure patients’ future expectations and associated factors

Methodological aspects

The strength of this study is that it concerns a large sample of hospitalised HF patients in a daily life setting. The study also has several limitations. In the first place, a nurse assessment instead of a validated questionnaire was used to assess patients’ expectations about the future. Even so, the study was not specially designed to evaluate patients’ awareness of prognosis or life expectancy. Finally, patients’ expectations regarding the future were assessed at the end of a HF hospitalisation. This may have influenced the answers because patients probably felt better just before discharge resulting in a more optimistic view at the future.

Conclusion

In this study, we found that HF patients who expected to deteriorate had worse outcome, with a high mortality rate and also experienced a lower quality of life and more depressive symptoms. No relationship was found with severity of the disease. Communication about prognosis with patients with HF should be improved in the future, including education for healthcare providers about the subject.

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