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Patient-Nurse Communication about Prognosis and End-of-Life Care

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Abstract

Background: Although several studies advise that discussions about prognosis and end-of-life care should be held throughout the whole heart failure (HF) trajectory, data is lacking on the prevalence and practice of such discussions in HF care.

Objective: The study objective was to explore how often and why HF nurses in outpatient clinics discuss prognosis and end-of-life care in the context of patient education.

Methods: This was a descriptive and comparative study. Participants were HF nurses from Swedish and Dutch HF outpatient clinics. Measurements were taken via a survey for both quantitative and qualitative data. Additional data was collected via open-ended questions and analyzed with content analysis.

Results: Two hundred seventy-nine nurses registered 1809 patient conversations using a checklist. Prognosis and end-of-life care were among the least frequently discussed topics, whereas symptoms of HF was discussed most often. Prognosis was discussed with 687 patients (38%), and end-of-life care was discussed with 179 patients (10%). Prognosis and end-of-life care were discussed more frequently in The Netherlands than in Sweden (41% versus 34%, $p < 0.001$, 13% versus 4%, $p < 0.001$). The nurses did not always recognize prognosis and end-of-life care discussions as a part of their professional role.

Conclusions: Currently, patient-nurse communication about prognosis and end-of-life care does not seem to be routine in patient education in HF clinics, and these discussions could be included more often. The reasons for nurses to discuss these topics were related to clinical routines, the patient's situation, and professional responsibilities. To improve future care, communication with patients needs to be further developed.

Introduction

INTERNATIONAL GUIDELINES AND CONSENSUS STATEMENTS suggest that heart failure (HF) patients may benefit from palliative care, since they have a poor prognosis and often are highly symptomatic during their HF trajectory, especially at the end of life.¹⁻⁴

HF patients, as well as the public and health care professionals, often have little knowledge on the prognosis and course of HF.^{5,6} If communication on prognosis and end-of-life care is lacking or given insensitively, this might cause anxiety and uncertainty among patients and their caregivers.^{7,16,17} Higher levels of anxiety and depression are found to be related to the fear of dying trajectory. Patients can also be afraid of pain, loss of independence, and loss of dignity in the end of their life.⁷

Within the HF team it is not always clear what has previously been discussed with patients regarding prognosis and end-of-life care, or who should be responsible for such communication.^{4,8} Several European countries have implemented nurse-led HF clinics where a nurse often has a key position in the team, coordinating the overall care of HF patients. One important part of the HF nurses' clinical work is to provide psychosocial support during the HF trajectory and to provide patient education that explains the progression of HF and establishes goals for end-of-life care.^{1,9} The nurse might be the first person to detect changes in the patient's condition, including the need for palliative care, and it is therefore relevant that nurses need to have discussions with patients about preferences and needs.¹⁰

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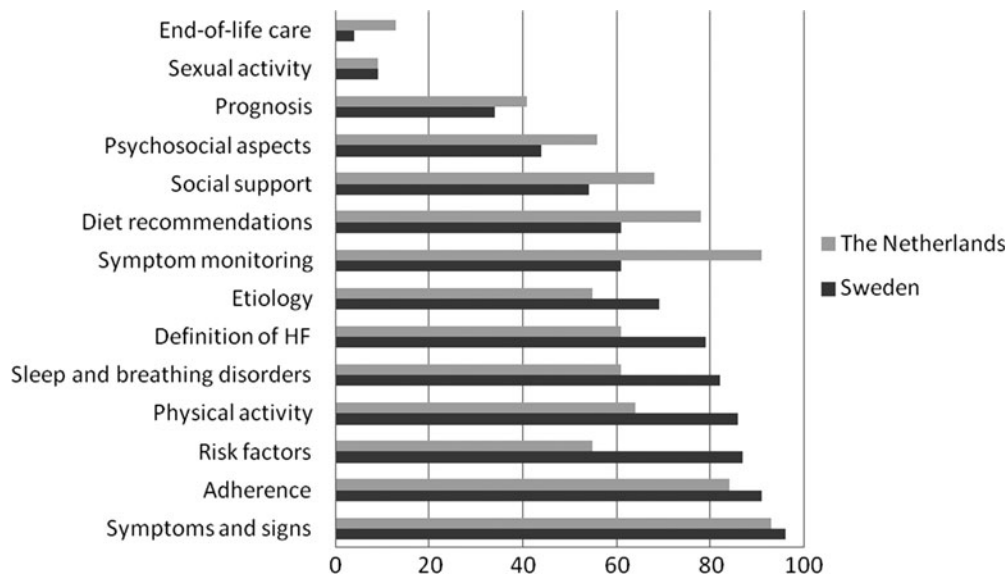


FIG. 1. Discussions of prognosis and end-of-life care in relation to other topics. HF, Heart failure.

Although several studies advise that discussions about prognosis and end-of-life care issues should be held throughout the whole HF trajectory,³ data is lacking on the prevalence and practice of such discussions in HF care. Previous research only retrospectively describe the HF practice and no data on actual day-to-day practice is known.¹¹ The objective of this study was therefore to expand on the knowledge of prevalence and practice of discussing prognosis and end-of-life care with HF patients in the context of patient education at nurse-led HF clinics, and compare this between two European countries with a long history of HF clinics, namely Sweden and the Netherlands.

Methods

Design and setting

A survey integrating both quantitative and qualitative data was conducted. Nurses collected data at 61 Swedish hospital-based HF clinics, 20 Swedish public health care centers with an HF service, and 91 Dutch hospital-based HF clinics. All hospitals in Sweden and the Netherlands and relevant Swedish public health care centers previously listed in another study were approached for participation.¹²

The study conforms with the principles outlined in the Declaration of Helsinki.¹³ It was approved by the Swedish Regional Ethical Review Board (Dnr. 2013/244-31). After consulting the Dutch Medical Ethical Committee, no additional approval was needed in the Netherlands, as no data was collected from patients or patients' medical records.

Data collection

A researcher approached the eligible HF clinics and invited the nurses to complete a short registration form for every HF patient they met in their practice during a pre-specified week, with a maximum of 10 patient registrations per nurse. The HF nurses who agreed to participate received the registration forms by mail and returned the completed ones. Reminders were sent after two weeks. The nurses were informed about confidential handling of the study data.

Using the registration form, the nurses were first asked to register which educational topics they discussed with the patient during the visit. These included important topics in self-care management recommended in the HF guidelines from the European Society of Cardiology (ESC) as essential for patients in order to perform appropriate self-care behaviors. Guideline topics include, for example, adherence to treatment, physical activity, symptom monitoring, and diet recommendations (see Fig. 1).² For each topic the nurses could check off (yes/no) in the registration form showing whether the topic was discussed with the patient. The topic of immunization was removed from the report of the data due to variation in time of data collection in the different countries.

The second part of the registration form focused on prognosis and end-of-life care and included open-ended questions to collect data on the nurses' reasons for discussing these topics or not with the patient (see Table 1). The definitions of prognosis and end-of-life care were specified in the registration form to increase validity. Prognosis was defined as "the expected trajectory of a disease in a specific individual." End-of-life care was defined as "the time when the patient mainly receives palliative care and medical treatment at the same time as the rehabilitating treatment ceases or is minimized."

The registration form was developed by the research group and validated by five experienced HF nurses. A detailed description of the validation procedure is described elsewhere.¹⁴ The registration form was translated into Dutch by a certified translation service and reviewed by a person fluent in Dutch and Swedish.

Background variables of the patients included sex, age, and New York Heart Association (NYHA) classification assessed by the HF nurse. For the Swedish patients, additional data was collected from their medical record on marital status, N-terminal pro-Brain Natriuretic Peptide (NT pro BNP) or Brain Natriuretic Peptide (BNP), duration of HF, and comorbidity. Background data of the participating HF nurses included sex, age, specialist training, and years of practice in health care, especially in HF care.

TABLE 1. QUESTIONS ABOUT PROGNOSIS AND END-OF-LIFE CARE IN THE REGISTRATION FORM

Did you discuss prognosis with this patient?

Yes No

Why/why not? _____

Do you think it is relevant to discuss prognosis with this patient?

Not at all
 Yes, as soon as possible
 Yes, but in a later stage
 Other:

Did you discuss end-of-life care with this patient?

Yes No

Why/why not? _____

Do you think it is relevant to discuss end-of-life care with this patient?

Not at all
 Yes, as soon as possible
 Yes, but in a later stage
 Other:

Analysis

Descriptive statistics were used to describe the sample and the responses to the study variables. Data from Sweden and the Netherlands were compared using Student's *t*-tests and chi-square tests. Outcomes were considered statistically significant when $p < 0.05$, with Bonferroni correction for multiple testing. SPSS 20.0 (IBM, Armonk, NY) was used to analyze the data. Additional qualitative data from open-ended questions were analyzed using a conventional content analysis approach.¹⁵ The procedure of the analysis included a comprehensive review of the data, where the coding and the categories derived directly from the data.¹⁶ Initially, all data was read through to obtain a sense of the whole. Next, meaning units from the data were condensed into codes and sorted under subcategories, depending on the relationship between the codes. After that, the subcategories were explored for underlying meaning and linked together into categories. The categories emerged from the text through analysis of the meaning of the subcategories, and also by linking back to the research question. To enhance trustworthiness, each step in the analysis was discussed in the research group until consensus was reached.

Results

Background characteristics of the HF nurses

In total, 279 HF nurses registered 1 or up to 10 patient conversations each during November 2012 and January 2014. There were 113 nurses from Sweden (response rate 83%) and 166 nurses from the Netherlands (response rate 80%) (see Fig. 2). The majority of the nurses were women (90%), the mean age was 50 years (± 8), and 87% had a specialist education, mainly in cardiology or intensive care nursing. Ten percent had special education in discussing prognosis and 13% in discussing end-of-life care. On average, the nurses had worked for 27 ± 11 years in health care and 10 ± 7 years with HF patients. On average, the nurses spent 52% of their working hours in HF care. The Swedish nurses were slightly older (51 ± 9 versus 49 ± 8 , $p = 0.038$) and had worked longer with HF patients than the Dutch nurses (11 ± 12 versus 9 ± 8 , $p = 0.001$). The Dutch nurses more often had a specialist education (92% versus 80%, $p = 0.003$) and worked more hours in HF care each week (58% versus 42%, $p < 0.001$) than the Swedish nurses.

Background characteristics of the patients

Conversations with 611 Swedish and 1198 Dutch HF patients were registered. The mean age of the patients was 71 ± 12 , 62% were men, and the majority of the patients (88%) were in NYHA class II or III (see Table 2). Among the Swedish patients there were more men (68% versus 59%, $p < 0.001$) than among the Dutch patients, and they were two years younger (70 ± 12 versus 72 ± 12 , $p = 0.001$).

Practice of discussing prognosis and end-of-life care in a patient education context

Prognosis was discussed with 687 of the patients (38%) and end-of-life care with 179 of the patients (10%). For the 1060 patients (62%) with whom prognosis was not discussed, nurses reported that this could be relevant to discuss in the future in 70% of the patients. Similarly, for the 1552 patients (90%) with whom end-of-life care was not discussed, nurses reported that it could be relevant to discuss this topic later on in 75% of the patients.

The Swedish nurses discussed on average 9 ± 3 topics with the patients during an HF clinic visit and the Dutch nurses on average 8 ± 3 topics ($t = 2, 96$, $p = 0.003$). The least frequently discussed topics in both countries were end-of-life care, sexual activity, and prognosis (see Fig. 1).

Prognosis was more often discussed with the Dutch patients compared to the patients in Sweden (41% versus 34%, $p < 0.001$); a significant difference was also seen in conversations about end-of-life care (13% versus 4%, $p < 0.001$). The Swedish nurses more often reported that it was not at all relevant to discuss prognosis (11% versus 5%, $p < 0.001$) and end-of-life care (22% versus 7%, $p < 0.001$), while the Dutch nurses to a greater extent indicated that prognosis and end-of-life care should be discussed as soon as possible (27% versus 20%, $p < 0.001$, 13% versus 5%, $p < 0.001$).

Reasons for discussing or not discussing prognosis and end-of-life care with the HF patient

In the conventional content analysis of about 3100 answers, three categories with underlying subcategories were

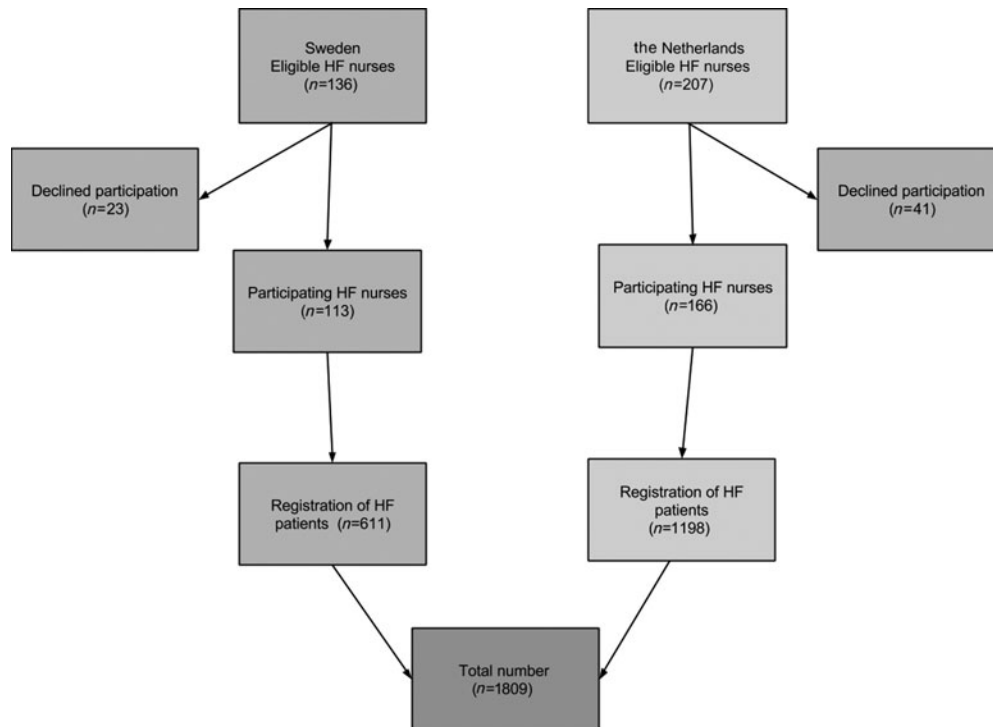


FIG. 2. Flowchart of the HF clinic and nurses participating in the study and the number of patient visits registered. HF, Heart failure.

identified, describing the HF nurses' reasons for discussing or not discussing prognosis and end-of-life care with HF patients (see Table 3).

Prognosis and end-of-life care discussions are guided by clinical routines throughout an anticipated HF trajectory. This category describes the idea of an anticipated course of HF, indicating that there are specific occasions during the course of HF that are more suitable for discussing prognosis and end-of-life care. The nurses discuss prognosis and end-of-life care mostly when the patient is believed to be approaching the end of life or when there are deteriorations and worsening HF symptoms, as reflected by the statement, "Old man in NYHA class IV with multimorbidities—it seemed relevant given the status of the patient." The nurses also reported that they sometimes discuss prognosis with the patient in order to point out the seriousness of HF and the importance of adhering to treatment. "It was a part of the prognosis discussion—what might happen if the patient did not adhere to the prescribed treatment." Nonetheless, there was no common opinion among the nurses about the right time for these discussions. Several nurses stated that it is not appropriate to discuss these matters at the patient's first visit to the HF clinic, while others described prognosis and end-of-life care as general information and hence should be discussed at the patient's first visit to the HF clinic.

Prognosis and end-of-life care discussions should be tailored to the specific patient's situation. This category describes that the nurses discuss prognosis and end-of-life care according to each individual patient's situation. Nurses

described that other matters are of greater importance than prognosis and end-of-life care, such as improving self-care, titration of medication, adherence to treatment or comorbidity. "Focus entirely on possibilities to live a life as good as possible despite diseases, emphasizing self-care." Some nurses also reported that the patients should be responsible for initiating a discussion about prognosis and end-of-life care, and that they do not find it relevant to discuss these topics unless the patients ask questions and indicate that they are prepared to discuss it.

Patients' characteristics both hinder and facilitate discussions of prognosis and end-of-life care. Sometimes psychosocial or cognitive problems or language issues are barriers for discussing these topics. "The patient was anxious; therefore I was not comfortable discussing it." Some nurses reported that prognosis and end-of-life care is not discussed at the HF clinic, as the patients often are stable or have mild HF. "The patients who visit me at the HF clinic are not in a stage where you discuss prognosis or end-of-life care." The nurses sometimes suggested that it can be relevant to initiate conversations about these topics, for example if the patient is deteriorating or is considered for a device implantation. However, maintaining the patient's hope for the future is prioritized. Especially if the patient is feeling down, the conversation should then focus on possibilities, to help the patients concentrate on things they still want to achieve in life, despite living with a chronic illness.

Prognosis and end-of-life care discussions are directed by professional responsibilities. This category describes that the nurses did not perceive discussing prognosis or end-of-life care as a part of their role as a nurse,

TABLE 2. BACKGROUND CHARACTERISTICS OF THE HF PATIENTS WHO VISITED THE HF CLINICS

Background characteristics	Sweden (n=611)	The Netherlands (n=1198)
Gender, male (n, %)	414 (68%)	693 (58%)
Age, years (mean ± SD)	70 ± 12	72 ± 12
Marital status —married/living with partner (n, %)	397 (65%)	NA
NYHA classification (n, %)		
I	53 (9%)	101 (9%)
II	284 (49%)	495 (45%)
III	223 (39%)	431 (40%)
IV	15 (3%)	63 (6%)
Months with HF (mean ± sd)	28 ± 43	NA
NT-proBNP (median, IQR)	1970 (3687)	NA
BNP	498 (827)	
Comorbid diseases (n, %)		
Endocrinology	129 (29%)	NA
Respiratory/lung	86 (19%)	
Musculoskeletal	58 (13%)	
Cancer	50 (11%)	
Renal diseases	32 (7%)	
Psychiatric	25 (6%)	
Gastrointestinal	25 (6%)	
Other*	46 (10%)	

NYHA, New York Heart Association; HF, Heart Failure; N-proBNP, N-terminal pro-Brain Natriuretic Peptide; BNP, Brain Natriuretic Peptide. NA, Not Available, this was not collected in the Dutch data; IQR, interquartile range.

*Other includes haematology, neurology, infections, skin disease, lupus and liver disease.

indicating that they perceive these discussions to be beyond their responsibility and authority. "It's not my place as a nurse." Most of the nurses stated that physicians should be the first to discuss prognosis and end-of-life care with the patient, preferably by using a break-point conversation. "Should be discussed during hospitalization or at a visit to the physician."

Discussion

This is the first study registering the prevalence of discussing prognosis and end-of-life care with patients in HF care. The main findings were that prognosis and end-of-life care (together with sexual activity) were the three least frequently discussed topics in both Sweden and the Netherlands. Furthermore, many of the HF nurses in both Sweden and the Netherlands expressed that the reasons for discussing or not discussing these topics depended on external circumstances outside their professional role as a nurse, on several factors related to the patient, or on factors in the course of the illness.

Overall, prognosis was discussed in 38% of the patient conversations, and end-of-life was discussed in 10%. This low prevalence was in line with previous research reporting a

lack of these conversations.^{17,18} More than half of the patients (56%) were in lower NYHA classes (I–II), and many nurses reported that prognosis and end-of-life care could be relevant to discuss in the future in these patients. However, it is known from the literature that HF patients sometimes prefer to discuss the HF trajectory and their future care at times when they are in a stable physical and/or cognitive state, in order to be able to respond and process the information they receive. Most of all, they prefer the professionals to initiate these conversations; and considering this, the opportunity to discuss prognosis and end-of-life care must be available at all stages of HF care, including in the lower NYHA classes.^{18,19}

This study illustrates similarities and differences in HF nurses' practice of discussing prognosis and end-of-life care at Swedish and Dutch HF clinics. The most commonly discussed topic in both countries was symptoms and signs of HF, but the Dutch patients were reported to have discussed prognosis and end-of-life care to a greater extent than the Swedish patients. Compared to the Swedish nurses, the Dutch nurses more often found it relevant to discuss these topics as soon as possible with their HF patients. These differences might be explained by cultural factors that can influence clinical practice, e.g., openness to talk about sensitive subjects.²¹ Other differences between the HF care in these countries include the larger number of specialist educated nurses in the Netherlands and different educational systems. These combined with the finding that the nurses in the Netherlands reported relatively more hours in the HF clinic per week might indicate different levels of knowledge and experience between the nurses from the different countries.

From the three categories that emerged in the content analysis, we further learned that there were several reasons for having or not having these discussions, which were related to clinical routines, the patient's situation, or professional responsibilities. Prognosis and end-of-life care were discussed in the HF clinic if something had taken place in the patient's HF care pathway, often depending on external circumstances outside the nurses' professional role. The nurses did not always acknowledge prognosis and end-of-life care discussions as a part of their role as a nurse, indicating that they perceived these discussions to be beyond their responsibility and authority. If the patients initiated a conversation about prognosis or end-of-life care, the nurses discussed the topic in order to meet the patients' wishes and needs. This is confirmed in other studies¹⁸ and in our previous survey describing the same Swedish HF nurses' perspectives on discussing prognosis and end-of-life care with HF patients, where the nurses concluded that it was easier to discuss these topics when the patient asks questions about it.¹⁴

It is important to consider what consequences these reasons for having or not having these discussions might have for the care provided for the patients. With the current developments of the nursing profession adopting more autonomous roles and with emergence of team leadership,^{20,21} it was surprising to find that many nurses thought prognosis and end-of-life care discussions to be beyond their role as a nurse. HF nurses have a key position within the HF team and can be encouraged to take a leadership role in assessing HF patients' needs and preferences. Thus, they could take more

TABLE 3. REASONS FOR DISCUSSING OR NOT DISCUSSING PROGNOSIS AND END-OF-LIFE CARE WITH HF PATIENTS

<i>Code</i>	<i>Subcategory</i>	<i>Category</i>
Will be discussed at deteriorations Should be discussed when the patient is hospitalized	In a later stage of the illness	Prognosis and end-of-life care discussions are guided by clinical routines throughout an anticipated HF trajectory
Point out the seriousness of the illness Point out the importance of adherence Discussed at the first or final visit at the HF clinic	Part of patient education	
Medications are still being titrated The conversation focused on self-care The patient had other diseases or issues that were more important The patient will have an ICD/CRT	Other matters of greater importance	Prognosis and end-of-life care discussions should be tailored to the specific situation of the patient
The patient asked Not relevant for a nurse to discuss if the patient does not initiate a discussion The patient was not open to discuss that yet	Patient should initiate the discussion	
The patient was still investigated or recently diagnosed The patient was not at the end of life The patient was young The patient had psychosocial problems The patient was too healthy The patient's HF was stable The patient had worsening HF symptoms The patient had cognitive problems Language issues	Patients' characteristics hinder or facilitate discussion	
Discussed in a supportive manner Do not want to take away hope	A wish to preserve the patient's hope for the future	
Not the nurse's place It is not my job	Not the nurse's main role and responsibility	Prognosis and end-of-life care discussions are directed by professional responsibilities
Physician should discuss first Break-point conversation first	Physician should initiate and lead the discussions	

CRT, cardiac resynchronization therapy; HF, heart failure; ICD, implantable cardioverter defibrillator.

responsibility for discussing prognosis and end-of-life care with HF patients. They might also consider introducing palliative care and discussions about patient preferences for future care earlier in the HF trajectory, regardless of the patient's age or NYHA class, as suggested earlier.²²

Professionals often find it difficult to choose the right time for initiating prognosis and end-of-life discussions with patients, and they often avoid these conversations, because they are afraid of taking away hope and cause anxiety in patients,¹⁸ which was also found in our study. Previous research reports that nurses who have additional education on discussing sensitive topics, for example sexual activity, are more comfortable and active in discussing these topics with their patients.²³ Hence, HF nurses working with HF patients might benefit from more education in discussing prognosis and end-of-life care. Communication tools might also help them to initiate conversations about prognosis and end-of-life care and prepare them for discussions about these topics throughout the whole HF trajectory, not only when the patient asks questions or is deteriorating.²⁴ Patients' preferences, information needs, and choices with regard to their care may change over the course of HF, necessitating regular open discussions.⁸

Although we conducted some basic content and face validity testing, we are aware of the validity limitations of the self-reported registration form used. This study was a national survey from two countries with long traditions of nurse-led HF clinics and with a high response rate in both countries. The findings can therefore be generalized to HF care in Sweden and the Netherlands. However, the prevalence and practice of discussing HF prognosis and end-of-life care may be different in other countries and cultures.

In conclusion we propose to include prognosis and end-of-life care discussions more often in patient education at nurse-led HF clinics. These discussions fit in the goals of the HF clinic, namely to improve patient outcomes through psychosocial support and to provide patient education that explains HF progression and establishes goals for end-of-life care.^{1,9,25} Future research should further explore and test interventions to optimize patient-nurse communication about prognosis and end-of-life care, and be sensitive to cultural differences.

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Author Disclosure Statement

No competing financial interests exist.

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