

Palliative key aspects are of importance for symptom relief during the last week of life in patients with heart failure

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Abstract

Aims This study aimed to describe symptom prevalence of pain, shortness of breath, anxiety, and nausea and to identify factors associated with symptom relief in patients with heart failure during their last week of life.

Methods and results This nationwide study used data from the Swedish Register of Palliative Care and the Swedish Causes of Death Certificate Register. The sample included 4215 patients with heart failure as the underlying cause of death. Descriptive statistics and logistic regression were used to analyse data. Pain was the most prevalent symptom (64.0%), followed by anxiety (45.1%), shortness of breath (28.8%), and nausea (11.4%). Pain was the most often totally relieved (77.5%), followed by anxiety (68.4%), nausea (54.7%), and shortness of breath (37.1%). Key aspects of palliative care such as documented palliative care in the patient record, individual medication prescriptions by injection, symptom assessment with validated scales, documented end-of-life discussions with patients and/or family members, and external consultation were significantly associated with symptom relief. Relief of pain, shortness of breath, anxiety, and nausea were significantly better managed in nursing homes and hospice/inpatient palliative care compared with care in hospitals.

Conclusions The results show that key aspects of palliative care during the last week of life are significantly associated with symptom relief. Increased access to palliative care could provide a way to improve care during the last week of life for patients with heart failure. Home-based settings provided more symptom relief than hospitals, which may indicate that the latter focuses on treatments and saving lives rather than promoting life before death.

Keywords Death; End of life; Heart failure; Palliative care; Symptoms

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Introduction

Heart failure (HF) is a chronic and progressive condition with increasing prevalence worldwide.¹ Prognosis is poorer than most cancer conditions with a 5 year mortality rate between 40% and 65% amongst the USA,² the UK,³ the Netherlands,⁴ and Sweden.⁵ Advancements in HF treatment (e.g. medications, devices, and transplantation) have transformed HF

management and increased longevity.⁶ However, these therapies very rarely cure HF, and more patients with an array of debilitating symptoms endure a terminal disease state for a more extended period. Many patients with HF, especially in the advanced stages, experience greater symptom burden that impacts the quality of life and will to live that ultimately leads to more distress and suffering as unintended aftermath of increased survival.⁷

Heart failure is a substantial burden not only for individual patients but for society as a whole.⁸ Anecdotally, patients with HF at the end of life suffer more and complain of more considerable pain, shortness of breath, anxiety, depression, and confusion.⁹ Thus, symptom control and management through the implementation of palliative care are critical components of HF treatment regimen. The World Health Organization defines palliative care as an 'approach that improves the quality of life of patients and their families facing the problem associated with a life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment, and treatment of pain and other physical, psychosocial and spiritual problems'.¹⁰ Compared with cancer and other conditions, palliative care is highly underutilized in patients with HF, and providers often fail to address patients' symptomatic concerns.⁷ A recent scoping review concluded that successful interventions targeting symptom management are scarce.¹¹ Another recent systematic review concluded that there are few palliative care interventions conducted. Findings showed that compared with usual care, these interventions seem to reduce hospitalizations, but the effects on symptoms burden were modest.¹²

Our team reports that cancer patients report less shortness of breath and receive more palliative care before death than patients with HF.^{13,14} Likewise, reports have shown that clinicians are inaccurate at prognostication and in recognizing dying patients with HF.¹⁵ Therefore, there is an increased likelihood that patients who would benefit from palliative care are potentially being missed because of limited understanding of actual severity of symptoms and risk of death in patients with HF.¹⁶ Thus, it is critical to identify persons with increased risk for symptom burden at the end of life. Accordingly, the aims of this study were to (i) describe symptom prevalence of pain, shortness of breath, anxiety, and nausea and (ii) identify factors associated with symptom relief in patients with HF during the last week of life.

Methods

Design

This nationwide observational study was based on data from the Swedish Register of Palliative Care (<http://palliativ.se>) and the Swedish Causes of Death Certificate Register (the Swedish National Board of Health and Welfare, <https://www.socialstyrelsen.se/en/>). The study conforms with the principles outlined in the Declaration of Helsinki (Br Med J 1964; ii: 177) and was approved by the Regional Ethical Review Board in Umeå, Sweden (No. 08-027M/2012-451-32M/2017-351-32M).

Registers and study variables

The Swedish Register of Palliative Care is a nationwide quality registry including all causes of deaths in Sweden, and the data are registered to improve the quality of care for all dying people, irrespective of diagnosis or care setting.^{17,18} The registry is based on the British Geriatric Society's principles of what constitutes a good death.¹⁹ During the study period between January 2014 and December 2015, the registry included 72.3% of all deaths due to HF as the underlying cause of death in Sweden. Data on care delivered during the last week of life were completed by healthcare providers after the patient's death. Healthcare providers also reported if the death was expected or not. All study variables except for underlying cause of death were taken from the registry. Outcome variables included symptom prevalence and symptom relief (pain, shortness of breath, anxiety, and nausea). Symptoms were reported as not present, totally relieved, partially relieved, not relieved at all, and unknown. Explanatory variables included assessments of pain and other symptoms using validated instruments (e.g. Visual Analogue Scale, Numeric Rating Scale, and Abbey Pain Scale) and medications prescribed by injection for symptom relief (pain, nausea, and anxiety) when needed (*pro re nata*). Data related to the decision to provide palliative care being documented in patient records, end-of-life discussions with patients and family members (not limited to the last week of life), and external consultation for symptom relief were also collected. These explanatory variables were considered key aspects of palliative care and were reported in categories of yes, no, or unknown. Age, sex, place of death, and the number of days enrolled in the care unit were also used as explanatory variables.

The Swedish Causes of Death Certificate Register covers all deaths in Sweden and is linked to the Swedish Register of Palliative Care for information about the underlying cause of death, documented by a physician, based on the International Statistical Classification of Diseases and Related Health Problems (ICD-10).

Sample

Inclusion criteria were patients with verified HF as the underlying cause of death, classified according to the International Statistical Classification of Diseases and Related Health Problems (I50.0, I50.1, and I50.9), ≥ 18 years of age, and expected death. In total, 5044 patients with HF as the underlying cause of death were registered during the study period. Of these, 829 deaths were not reported as expected and therefore excluded. Thus, the final sample included 4215 deaths.

Statistical analyses

Descriptive statistics, including frequencies, arithmetic mean values, and standard deviations or median values and quartiles, were used to present the sample and study variables. Univariate binary logistic regression analyses were used to identify factors associated with symptom relief. The outcome variables (i.e. symptom relief) were dichotomized into relieved and not relieved, while 'unknown' were recorded as missing data. Age was included as a continuous explanatory variable, while sex and variables reflecting key aspects of palliative care were included as categorical variables. The variables 'place of death' and 'number of days enrolled in the care unit' were dummy coded with 'hospital ward' and '0–3 days' as the reference category, respectively (i.e. not included in the model). All other categorical variables were binary coded with 'no' or 'female sex' as a reference category (i.e. coded as 0). The alternative 'unknown' was treated as missing data for the explanatory variables. The level of significance was set at $P < 0.05$. All analyses were conducted with Stata 16.1 (StataCorp LLC, College Station, TX, USA).

Results

Sample characteristics

The mean age of the deceased patients with HF ($n = 4215$) was 88.4 (SD = 7.9) years. A majority were females (59.4%) and had unspecified HF (ICD: I50.9) as the underlying cause of death (95.6%). Most died in nursing homes (60.4%), and 41.9% had been enrolled in that care more than 365 days before death. The decision about palliative care was documented in 79.8% of patient records, and end-of-life discussions were performed with 43.0% of patients and 69.3% of family members. Symptom assessment scales for pain or shortness of breath were seldom used (31.7% vs. 17.7%). Individual medication prescription by injection (pro re nata) was the most common for pain relief (91.1%), and for 10.9% of the patients, external consultation was used for symptom relief (Table 1).

Symptom prevalence and relief

Pain was reported as the most prevalent symptom (64.0%) in the last week of life, followed by anxiety (45.1%), shortness of breath (28.8%), and nausea (11.4%). Amongst patients with those symptoms, pain was reported as the most often totally relieved (77.5%) followed by anxiety (68.4%), nausea (54.7%), and shortness of breath (37.1%) (Table 2).

Table 1 Sample characteristics and key aspects of palliative care ($n = 4215$)

Age, mean (SD)	88.4 (7.0)
Age categories, n (%)	
18–79	454 (10.8)
≥ 80	3761 (89.2)
Sex, n (%)	
Female	2505 (59.4)
Male	1710 (40.6)
Type of heart failure (ICD-10), n (%)	
Congestive HF (I50.0)	30 (0.7)
Left ventricular HF (I50.1)	157 (3.7)
Unspecified HF (I50.9)	4028 (95.6)
Place of death and type of setting, n (%)	
Home care	346 (8.2)
Nursing home	2546 (60.4)
Hospital ward	1109 (26.3)
Hospice/inpatient palliative care	168 (4.0)
Other	46 (1.1)
Number of days enrolled to the care unit, median (q1–q3)	161 (10–953)
Number of days enrolled to the care unit, n (%)	
0–3 days	506 (12.0)
4–14 days	759 (18.0)
15–30 days	342 (8.1)
31–365 days	843 (20.0)
>365 days	1765 (41.9)
Documented palliative care in patient records, n (%)	
Yes	3365 (79.8)
No	511 (12.1)
Unknown	339 (8.0)
Medical prescription by injection (pro re nata), n (%)	
Pain (opioids)	
Yes	3840 (91.1)
No	354 (8.4)
Unknown	21 (0.5)
Anxiety	
Yes	3638 (86.3)
No	538 (12.8)
Unknown	39 (0.9)
Nausea	
Yes	2827 (67.1)
No	1318 (31.3)
Unknown	70 (1.7)
Pain assessment with validated scales, n (%)	
Yes	1338 (31.7)
No	2595 (61.6)
Unknown	282 (6.7)
Symptom assessments with validated scales other than pain, n (%)	
Yes	747 (17.7)
No	3052 (72.4)
Unknown	416 (9.9)
Documented palliative care in patient records, n (%)	
Yes	3365 (79.8)
No	511 (12.1)
Unknown	339 (8.0)
End-of-life discussions with patients, n (%)	
Yes	1814 (43.0)
No	1851 (43.9)
Unknown	550 (13.1)
End-of-life discussions with family members, n (%)	
Yes	2919 (69.3)
No	891 (21.1)
Had no family member	76 (1.8)
Unknown	329 (7.8)
External consultation for symptom relief, n (%)	
Yes	460 (10.9)
No	3590 (85.2)
Unknown	165 (3.9)
Pro re nata, i.e. medication prescribed to be taken when needed	

HF, heart failure; SD, standard deviation.

Table 2 Symptom prevalence and symptom relief during the last week of life (*n* = 4215)

	All patients, <i>n</i> (%)	Patients with symptoms, <i>n</i> (%)
Pain		
No	1288 (30.6)	
Yes, but totally relieved	2089 (49.6)	2089 (77.5)
Yes, partly relieved	599 (14.2)	599 (22.2)
Yes, not relieved at all	8 (0.2)	8 (0.3)
Unknown	231 (5.5)	
Shortness of breath		
No	2788 (66.1)	
Yes, but totally relieved	449 (10.7)	449 (37.1)
Yes, partly relieved	733 (17.4)	733 (60.5)
Yes, not relieved at all	30 (0.7)	30 (2.5)
Unknown	215 (5.1)	
Anxiety		
No	1861 (44.2)	
Yes, but totally relieved	1301 (30.9)	1301 (68.4)
Yes, partly relieved	577 (13.7)	577 (30.4)
Yes, not relieved at all	23 (0.6)	23 (1.2)
Unknown	453 (10.8)	
Nausea		
No	3298 (78.2)	
Yes, but totally relieved	262 (6.2)	262 (54.7)
Yes, partly relieved	195 (4.6)	195 (40.7)
Yes, not relieved at all	22 (0.5)	22 (4.6)
Unknown	438 (10.4)	

Factors associated with symptom relief

Factors associated with symptom relief are presented in *Table 3*. No significant associations were found between sex and symptom relief. At the same time, higher age was associated with better relief in pain [odds ratio (OR) = 1.03], shortness of breath (OR = 1.03), and anxiety (OR = 1.03), but not in nausea.

Symptom relief for all symptoms except for nausea was better managed in home care (range OR = 1.59–3.19), nursing homes (range OR = 1.89–2.29), and hospice/inpatient palliative care (range OR = 2.33–7.73) compared with hospital wards. For nausea, symptom relief was better managed in a nursing home (OR = 1.82) and hospice/inpatient palliative care (OR = 7.73) compared with the hospital ward.

More days enrolled in a care unit was associated with symptom relief, except in nausea. Being enrolled more than 14 days was significantly associated with symptom relief in pain (range OR = 1.40–2.04) and shortness of breath (range OR = 2.35–3.71). Symptom relief in anxiety was significantly associated with being enrolled for more than 365 days (OR = 1.69).

Having a decision about palliative care documented in the patient record and individual medication prescriptions by injection were both significantly associated with relief in pain (OR = 3.53 vs. 6.52), shortness of breath (OR = 3.53 vs. *n/a*), anxiety (OR = 2.93 vs. 3.14), and nausea (OR = 2.43 vs. 3.26). Assessments with validated scales for pain were significantly associated with relief in pain (OR = 1.85), shortness of breath (OR = 1.81), anxiety (OR = 1.51), and nausea (OR = 1.98). The

use of validated scales for other symptoms was significantly associated with better relief in all symptoms (range OR = 1.72–2.23) except in nausea. End-of-life discussions with patients as well as with family members were significantly associated with relief in pain (OR = 1.46 vs. 2.05), shortness of breath (OR = 1.60 vs. 1.80), anxiety (OR = 1.39 vs. 1.76), and nausea (OR = 2.09 vs. 1.96).

Significant associations were found between less use of external consultation and poorer symptom relief in pain (OR = 0.66) and anxiety (OR = 0.67).

Discussion

This nationwide study is to our best knowledge the first that has identified factors associated with relief in symptoms of pain, shortness of breath, anxiety, and nausea in patients with HF during their last week of life. Key aspects of palliative care were of great significance for symptom relief. When it was explicitly decided and documented in the patient record that palliative care should be provided, when symptoms were assessed with validated scales, and when individual medication by injections were prescribed, patients with HF were significantly better symptom relieved. Importantly, conducting end-of-life discussions with patients and/or family members as well as less use of external consultations were significantly associated with better symptom relief. Symptom relief was significantly better managed in nursing homes and hospice/inpatient palliative care units compared with hospital wards.

Table 3 Factors associated with symptom relief, based on univariate binary logistic regression reported with odds ratio and 95% confidence interval

	Pain	Shortness of breath	Anxiety	Nausea
Age	1.03 (1.01–1.04)***	1.03 (1.01–1.04)**	1.03 (1.01–1.04)***	1.01 (0.98–1.04)
Sex (male sex)	0.89 (0.73–1.07)	0.88 (0.70–1.12)	0.86 (0.70–1.04)	0.75 (0.51–1.10)
Place of death				
Hospital ward	Ref	Ref	Ref	Ref
Home care	1.59 (1.12–2.26)*	3.19 (2.03–5.02)***	2.40 (1.59–3.61)***	1.66 (0.84–3.26)
Nursing home	2.02 (1.64–2.49)***	2.29 (1.76–2.97)***	2.21 (1.77–2.77)***	1.82 (1.16–2.87)**
Hospice/inpatient palliative care	2.81 (1.68–4.71)***	3.47 (2.09–5.78)***	2.33 (1.44–3.79)**	7.73 (2.13–28.00)**
Other	2.35 (0.88–6.26)	1.30 (0.39–4.29)	7.16 (1.63–31.34)**	1.09 (0.28–4.30)
Number of days enrolled to the care unit				
0–3 days	Ref	Ref	Ref	Ref
4–14 days	1.23 (0.87–1.73)	1.43 (0.97–2.12)	0.72 (0.50–1.05)	0.77 (0.35–1.64)
15–30 days	2.04 (1.33–3.12)**	3.71 (2.33–5.89)***	1.23 (0.80–1.90)	1.19 (0.52–2.70)
31–365 days	1.40 (1.01–1.95)*	2.35 (1.55–3.55)***	1.26 (0.87–1.83)	1.38 (0.66–2.87)
>365 days	2.00 (1.47–2.71)***	2.78 (1.92–4.03)***	1.69 (1.19–2.39)**	1.82 (0.92–3.60)
Documented palliative care in patient records	3.53 (2.66–4.69)***	2.61 (1.79–3.80)***	2.93 (2.13–4.03)***	2.43 (1.32–4.48)**
Individual medication by injection (pro re nata) ^a	6.52 (4.15–10.24)***	n/a	3.14 (2.05–4.81)***	3.26 (1.93–5.51)***
Pain assessment with validated scales	1.85 (1.51–2.27)***	1.81 (1.39–2.34)***	1.51 (1.22–1.86)***	1.98 (1.32–2.96)**
Symptom assessments with validated scales ^b	2.23 (1.69–2.94)***	1.72 (1.24–2.39)**	1.72 (1.32–2.24)***	1.50 (0.91–2.46)
End-of-life discussions with patients	1.46 (1.20–1.77)***	1.60 (1.25–2.06)***	1.39 (1.13–2.17)**	2.09 (1.41–3.10)***
End-of-life discussions with family members	2.05 (1.64–2.55)***	1.80 (1.32–2.45)***	1.76 (1.38–2.24)***	1.96 (1.25–3.05)**
External consultation for symptom relief	0.66 (0.51–0.85)**	0.96 (0.69–1.33)	0.67 (0.51–0.89)**	0.89 (0.53–1.46)

Ref, reference category.

^aPro re nata, that is, medication prescribed to be taken when needed. Not applied for shortness of breath in the register.

^bSymptoms other than pain.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

Further, higher age and more days enrolled in the care unit were also of significance.

The present study showed that a great majority of the patients with HF suffered one or more symptoms during the last week of life and that these symptoms are often not sufficiently relieved. While pain was the most prevalent, less than one-third of the patients in the present study were reported to have shortness of breath during the last week of life. This result is somewhat surprising because shortness of breath commonly is reported in more than half of patients with HF and increase at end of life.^{20,21} Thus, it seems that problems with shortness of breath decrease close to death in persons with HF. Although shortness of breath was less prevalent than expected, just about one-third was not sufficiently symptom relieved. Opiates are commonly recommended to relieve shortness of breath in palliative care,²² but a study by Setoguchi *et al.* showed that patients with HF are less likely to receive prescriptions of opiates than patients with cancer.²³ In the present study, over 90% of the patients were reported to have individual prescription of opiates by injection for pain, but no information is recorded about prescriptions for shortness of breath. It cannot be excluded that treatments that might improve shortness of breath, such as optimal HF medical therapy, might have been negated to patients with HF during the last week of life. However, it should be noted that shortness of breath was better managed in home care, nursing homes, and hospice/inpatient palliative care compared with hospital wards. Unsatisfactory symptom

relief during the last week of life has also been reported in patients with other severe conditions such as end-stage kidney disease (56%) and neurological diseases (61%).^{24,25}

All key aspects of palliative care in the present study prove to be of great importance for symptom relief. Actually, decision and documentation of a palliative care approach, symptom assessments, prescriptions of individual medication when needed, end-of-life discussions, and the use of external consultations are all suggested indicators by the British Geriatric Society of what constitutes a good death.¹⁹ With an attempt to integrate a palliative approach in the care of people with cardiovascular disease, a study using a Delphi process recently suggested several hypothetical quality indicators focusing purely on palliative care. The indicators were sorted into the two major themes: symptom palliation and support decision process. Subcategories included, for example, aspects related to symptom screening and management as well as decision making and communication with patients and families.²⁶ These indicators are closely related to the key aspects that proved to improve symptom management in our study and were suggested by the authors as useful for the initiation and enhancement of palliative care for patients with cardiovascular disease. This underlines the importance of discussing prognosis and patient preferences earlier in the illness trajectory. It should be noted that the initiation of palliative care is not just a question about knowledge, experience, and willingness from the perspective of healthcare professionals but also the perspective of patients. In an interview

study with patients with HF, respondents demonstrated enthusiasm for components of palliative care but were ambivalent about the service by name. They had minimal understanding of palliative care and conflated it with hospice. Those who expressed interest in palliative care highlighted the value of an intimate and continuous relationship with their cardiology team. They expressed having great confidence in their HF providers and their expert understanding of their disease. They could only acknowledge a referral to specialist palliative care if they experienced a dramatic loss of independence or if there were no more treatment options, as defined in collaboration with their cardiology team.²⁷

The results of this study further strengthen the need for palliative care for patients with HF. Recently, Mosoiu *et al.*, in their systematic review, argued that palliative care for patients with HF constitutes a healthcare emergency as increasing evidence shows that palliative care in HF improves outcomes for patients and caregivers. The authors suggest that palliative care, because of the unpredictability of HF and difficulty in prognostication, should be introduced at the point of diagnosis. They stress the need for early introduction of basic education in palliative care needs in the training of cardiology staff, focusing several of the key aspects that in our study actually proved to relieve symptoms, that is, decision making, symptom management, and communication.²⁸ This is in line with a comprehensive knowledge synthesis, which clarifies the understanding of a palliative care approach in the care of people with chronic life-limiting conditions. The authors point out that not all patients will need specialist palliative care. Instead, a palliative approach should be used through integration into systems and models of care that do not specialize in palliative care.²⁹ Consequently, the system of care should involve collaboration between the expertise of HF as well as specialists in palliative care to ensure the possibilities to address the range of needs of patients and their family caregivers. Palliative care knowledge also has to be adapted to the specific care needs of patients with HF. A recently published position paper from the Heart Failure Association of the European Society of Cardiology describes in detail the important role of symptom assessment and symptom management and an integrated approach of palliative and end-of-life care.²² Thus, a palliative approach should both apply knowledge and adapt it to the uniqueness of disease profiles. Likewise, Touzel and Shadd propose a conceptual model, bridging philosophical definitions and clinician behaviours, to guide the broad implementation of a palliative approach, on both system and clinical levels. According to this model, palliative care interventions focus on the whole person and quality of life and also acknowledge mortality.³⁰

Conceptual models can contribute to clarification about in what way a palliative care approach can be used for patients with HF. Jaarsma *et al.* discuss in a recent editorial comment the unclarity of terms used in palliative care and argue that

misunderstandings about the terms might be present amongst professionals who provide care for patients with HF and their family members, contributing to a lack of palliative care. The authors thus suggest that there still might be worries and uncertainty about the term palliative care.³¹ Leaning towards the models of Sawatzky *et al.*²⁹ and Touzel and Shadd,³⁰ palliative care can be understood as care applied in longer periods for patients with HF and not as care only for patients who are imminently dying.

Study limitations

This study has some methodological limitations that the readers should consider. Most importantly, healthcare professionals, not the patients themselves, complete the end-of-life questionnaire. Thus, data about symptom prevalence and symptom relief during the last week reflect the professional perspective, not necessarily the patient's experiences. Recall bias cannot be excluded because the end-of-life questionnaire is completed after death. Only six symptoms are reported in the Swedish Register of Palliative Care, of which two were excluded in the present study, that is, death rattle (i.e. respiratory secretion) and confusion. Even if important symptoms such as pain, anxiety, shortness of breath, and nausea were included, the limited number of symptoms may not reflect the full range of symptoms that are common in patients with HF. Related to this, the Swedish Register of Palliative Care covers all types of deaths, and no data for specific diagnoses, such as HF, are therefore recorded. Thus, a lack of important clinical data, such as aetiology, morbidity, treatment, presence of left ventricular assist device, and ICD, is a major limitation of the study. Univariate binary logistic regression analyses were conducted instead of multiple models because several of the explanatory variables were related to each other and caused problems with multicollinearity, demonstrated with the variance inflation factor (>2). Finally, the design of the study did not allow drawing any causal conclusions about the findings. Considering the limitations, it should be acknowledged that the study is nationwide and has a large sample size with high coverage of patients with HF as the underlying cause of death. Also, the Swedish Register of Palliative Care, including the end-of-life questionnaire, is regularly validated.

Conclusions

The results show that key aspects of palliative care during the last week of life are associated with symptom relief. Increased access to palliative care could provide a way to improve care during the last week of life for patients with HF. Home-based settings provided more symptom relief than hospitals, which may indicate that the latter focuses on

treatments and saving lives rather than promoting life before death.

Conflict of interest

None declared.

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