

Self-care, symptom experience, needs, and past health-care utilization in individuals with heart failure: results of a cross-sectional study

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Aims

Self-care in heart failure (HF) is generally sub-optimal and impacts morbidity and mortality. To describe self-care prevalence and explore its relationships with symptom experience, patient needs, and health-care utilization in a Swiss hospital providing regional secondary care.

Methods and results

Cross-sectional study, convenience sample of individuals with HF from four campuses of one regional Swiss hospital. Self-care was assessed via the Self-Care of Heart Failure Index (SCHFI) and the European Heart Failure Self-care Behaviour Scale (EHFScBS), symptom experience via the M.D. Anderson Symptom Inventory–HF (MDASI-HF) and needs via the Heart Failure Needs Assessment Questionnaire (HFNAQ). Healthcare utilization reflected the preceding year's hospitalization incidence. A cut-off level of $\geq 70\%$ indicated adequate self-care. We analysed SCHFI, EHFScBS, MDASI-HF and HFNAQ scores' relationships with hospitalizations using Spearman's rho correlation; no prior hypotheses were stated. Sample of 310 individuals with HF (37.4% female; mean age 76.8; 55% NYHA III). Adequate self-care maintenance, management, and confidence were reported by 24%, 10%, and 61%, respectively. The sample's mean number of experienced symptoms was 12.8 (SD 4.0) and 14.0 (SD 5.8) for needs. Over the previous year, 269 hospitalizations had occurred (median: 0, IQR 1). Hospitalizations positively correlated with self-care; symptom experience with needs. Neither symptom experience nor needs correlated with hospitalizations.

Conclusion

The findings indicated low self-care levels and suggest a need for increased support to maintain physiological stability, manage symptoms and prevent hospitalizations. This study is the first of its kind in Switzerland and among few studies worldwide to report on self-care, symptom experience, needs, and health-care utilization. Interventional studies are warranted considering baseline self-care capabilities, symptoms, and needs of individuals with HF.

Keywords

Heart failure • Self-care • Symptom experience • Needs • Hospitalizations

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Implications for practice:

- Low self-care levels remain common in persons with heart failure
- Few persons take countermeasures in case of symptom experience
- Self-care confidence does not reflect self-care management capacities
- Needs should be evaluated in persons with heart failure
- Interventional studies should take low self-care baseline data into consideration

Introduction

Heart failure (HF) is a serious, complex condition associated with high mortality, morbidity, and frequent hospital admissions.¹ Self-care is 'the process of maintaining [one's own] health through health-promoting practices and managing illness'.² (p. 195) It has been suggested that self-care practices such as medication adherence, exercise, and weight management activate cardioprotective mechanisms, e.g., by limiting inflammatory processes and reducing congestion, thereby complementing medical treatment, delaying HF progression, and ultimately optimizing HF patient outcomes.³ Consequently, alongside both pharmacological and non-pharmacological/non-device HF treatment, self-care patient education has been recommended as an integral component of state-of-the-art HF treatment.¹

Internationally, many persons with HF have reported poor self-care practices⁴ and strong links between increased self-care and improved prospects of event-free survival have been provided.^{5,6} For example, in a cross-sectional study with 22 samples of 5964 participants from the USA, South Africa and 13 countries across Europe and Australasia, in 16 and 14 of the 22 samples, more than 50% of participants reported irregular weight monitoring and low exercise levels respectively.⁴ The impacts of such sub-optimal self-care have been well demonstrated. In a sample of 195 participants, Lee *et al.*⁵ showed that those who engaged in average or better self-care ran a significantly lower event risk compared to those whose self-care was below average. More recently, again, in a prospective cohort study of 459 participants, those reporting above-average symptom response behaviours experienced significantly fewer events at 12 months compared to those reporting poor symptom responses.⁶

In spite of the wealth of international self-care data, related data are rare in Swiss settings. Among the world's health-care systems, Switzerland's ranks as one of the most expensive as a proportion of national output.⁷ Yet, the expense does not automatically produce high-quality patient-centred care. Indeed, cost-saving strategies are on the top agenda of hospital administrators and include restrictions in time-consuming tasks not directly related to patient care. Therefore, safeguarding and improving self-care support of individuals with HF in Switzerland will require current, reliable contextually specific data. Additionally, baseline data are critical to develop, test and implement complex interventions⁸ such as those delivering self-care support. The aims of this study were to describe the prevalence of self-care practices and to explore the relationships between self-care and symptom experience, patient needs, and healthcare utilization.

Methods

Design

We used a cross-sectional correlational design for the study. The investigation conforms with the principles outlined in the Declaration of Helsinki. The study was approved in 2015 by the regional ethical commission (CER-VD; study number: 222/15; PB_2016-02623).

Setting and sample

We conducted the study at four campuses of a non-university hospital offering regional secondary care for patients with HF in internal medicine, outpatient cardiology, and cardiac rehabilitation in Western Switzerland.

We recruited a convenience sample of adult patients (>17 years of age) diagnosed with HF in NYHA functional classes II–IV, hospitalized (all-cause) in internal medicine or cardiac rehabilitation or visiting the cardiology outpatient department, and speaking French or German. We excluded patients who suffered from an immediately life-threatening or end-stage terminal illness, were awaiting cardiac surgery, or showed signs of cognitive impairment (clinical judgement) that would preclude written informed consent.

Variables and measurement

We extracted the following socio-demographic and clinical variables from the patients' medical records: sex, age, and New York Heart Association classification, left ventricular ejection fraction, time since HF diagnosis, and comorbidity. As elements of comorbidity, data on depressive symptomatology, anxiety, and cognitive impairment were assessed via either medical record notes or reports by the responsible health-care professionals. We supplemented these variables with data from a questionnaire on education and nationality.

Self-care was measured using the 22-item Self-Care of Heart Failure Index (SCHFI), v6.2, which measures self-care maintenance, management, and confidence over the past month^{9,10} (see Figure 2A–C for specific items). Following the *Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes measures* procedures,^{11,12} we translated the SCHFI from the original English into a French (for Switzerland) and a German (for Switzerland) version. The scale scores computed for each subscale were standardized to percentages (possible range: 0–100), with higher scores indicating better self-care. Mean score and standard deviation for each subscale were calculated⁹ and individual items presented (Figure 2A–C) in order to provide descriptive information on self-care. The SCHFI was developed in accordance with accepted self-care theory.¹³ Its psychometric properties have been confirmed based on an Italian sample of 659 HF patients¹⁰ and a US sample of 629 HF patients.¹⁴ Item difficulty levels have been evaluated as adequate and the risk of social desirability responses has been assessed as minimal.⁹ Additionally, we used the French and German versions of the 12-item European Heart Failure Self-care Behaviour Scale (EHFScBS).¹⁵ Originally developed as a 20-item self-administered questionnaire,¹⁶ the EHFScBS

was later refined first into a 12-item, then a 9-item version.¹⁵ Widely used in European samples,⁴ it is available in 14 languages including French and German.¹⁷ On 5-point scales ranging from I completely agree (1) to I completely disagree (5), the EHfScBS allows patients to rate how well they have adhered to their regimens, asked for help when necessary, and adapted their daily activities (see *Figure 2D* for items). No recall period has been specified. The scale scores computed for each subscale were standardized to percentages (possible range: 0–100),¹⁸ with higher scores indicating lower levels of self-care. In order to provide more comprehensive information on self-care, thereby facilitating comparison with data reported elsewhere, we calculated not only the mean score and standard deviation for each subscale¹⁶ but presented also the individual item scores (*Figure 2D*). We made minor adaptations to the phrasings of both the French (for France) and the German (for Germany) versions to match Swiss-French and -German usage. While psychometric properties of both the 9-item^{18,19} and 12-item EHfScBS have been assessed and reviewed,²⁰ we used the 12-item version for this study in order to include the 12-item version's items on adapting daily activities (not included in the 9-item version).

Symptom experience was measured via the M.D. Anderson Symptom Inventory–Heart Failure (MDASI–HF) instrument.^{21,22} The MDASI–HF measures symptom severity via 21 items and symptom distress (i.e. the degree to which symptoms interfere with daily life) via six items. All items are rated on 11-point scales (0 = not present to 10 = as bad as you can imagine/0 = did not interfere to 10 = interfered completely). The prevalence of symptoms was determined based on non-zero responses on the 11-point symptom severity scale, with possible scores ranging from 0 to 21 symptoms. Symptom items were presented individually.²³ The mean of individual symptom ratings yields an overall symptom severity score; averaging the HF-specific symptom subscale scores provides an HF symptom severity score; and the mean of the six symptom interference items gives the overall symptom distress score²² (see *Figure 3A, B* for items). Using severity descriptors, scores can be interpreted as mild (scores <5), moderate (scores 5 to 6) and severe (scores > 6).²³ As the MDASI–HF was only available in English, we translated and culturally adapted it^{11,12} for French- and German-speaking patient groups and changed the recall period from 24 h to the past week (an option suggested by the author).²²

Perceived needs of patients with HF for support (subsequently referred to as 'needs') were assessed using the 30-item Heart Failure Needs Assessment Questionnaire (HFNAQ).²⁴ The HFNAQ measures HF patients' perceived support needs concerning four domains, with one subscale devoted to each: physical impediments (10 items e.g. feeling thirsty), psychological issues (9 items e.g. feeling down or depressed), social/interpersonal issues (8 items e.g. feeling bored or useless), and existential issues (3 items e.g. fears of death and dying). On a five-point Likert-type scale [range: 1 ('hardly ever') to 5 ('almost always')], each item assessed the frequency over the preceding week of the respondent perceiving a need for support. We modified the original scale slightly to add a response option allowing respondents to indicate if a particular situation of perceived support need was not experienced (non-experienced situation, score 0). The mean of individual needs item scores (of 1–5) was calculated within each domain as well as for the total scale.²⁴ The prevalence of needs was determined by summing up all responses ≥ 1 on the five-point response scale, resulting in a possible number of needs situations ranging from 0 to 30. As necessary, we culturally adapted and translated^{11,12} the original English version to fit Swiss speakers of French and German.

Prior health-care utilization was measured via the patients' medical records, which noted all-cause hospitalizations (cardiac and non-cardiac reasons), during the year prior to their study enrolment.

Data collection

We recruited patients with HF either during hospitalization in the hospital's internal medicine and cardiac rehabilitation units or while visiting the cardiology outpatient clinic. Master prepared or research nurses screened inpatient medical records for eligibility. Eligible outpatients were referred by a research nurse in the cardiology outpatient clinic. The research nurses informed eligible patients about the study and obtained written informed consent. Participants then supplied socio-demographic information not available via their medical records and completed paper/pencil versions of the SCHFI v6_2, EHfScBS, MDASI–HF, and HFNAQ. If preferred, instead of self-completing the forms, participants completed them during a face-to-face encounter with the research nurse with the option that the nurse could read the items and fill in the participant's responses. Patients' medical records showed health-care utilization over the past year. Two research assistants extracted all questionnaire datasets and entered them into the electronic database; 10% of all entered data were randomly selected and double-checked, and any errors corrected.

Statistical analyses

We analysed data using descriptive and correlational statistical methods. Demographic and clinical variables as well as self-care level, symptom experience, and needs were described, as appropriate, in terms of frequencies, central tendencies and dispersions. A cut-off level of 70% (which is suggested to relate to better clinical outcomes^{9,19}) was set to indicate adequate self-care levels regarding questionnaire data. Relationships between the self-care variables, symptom experience, needs, and all-cause hospitalizations were explored using Spearman's rho correlations. No prior hypotheses were stated. We considered P -values <0.05 as statistically significant. All calculations were performed using SAS 9.4 (SAS Institute, Cary, NC, USA).

Results

Between 19 October 2015 and 22 December 2017, we assessed the eligibility of 896 patients. Of this number, 310 were enrolled and provided informed consent. Of the remainder ($n = 586$), 21% ($n = 123$) declined to participate, 53% ($n = 312$) were ineligible, and 26% ($n = 151$) could not be enrolled for other reasons, e.g., already having been discharged ($n = 67$) (*Figure 1*). Participants were recruited from three internal medicine units ($n = 264$, 85.1%), one rehabilitation ward ($n = 20$, 6.5%), and one cardiology outpatient department ($n = 26$, 8.4%). The sample consisted of 310 individuals with HF (37.4% female; mean age 76.8 years; 55% in NYHA Class III), *Table 1* provides the sample's socio-demographic and clinical characteristics.

Table 2 presents descriptive results of self-care, symptom experience and needs.

Self-care

Self-care results for the SCHFI v6.2, with subscales measuring *self-care maintenance*, *self-care management* and *self-care confidence* (*higher reported scores indicate better self-care*).

We found a mean self-care maintenance score of 56.9 (SD = 15.4), a mean self-care management score of 29.60 (SD = 22.9), and a mean self-care confidence score of 71.7 (SD = 25.1). Respectively 76%, 90%, and 39% of participants had inadequate self-care levels (standardized scores ≤ 70) for self-care maintenance, management and confidence. *Figure 2A–C* shows the individuals items' prevalence of self-

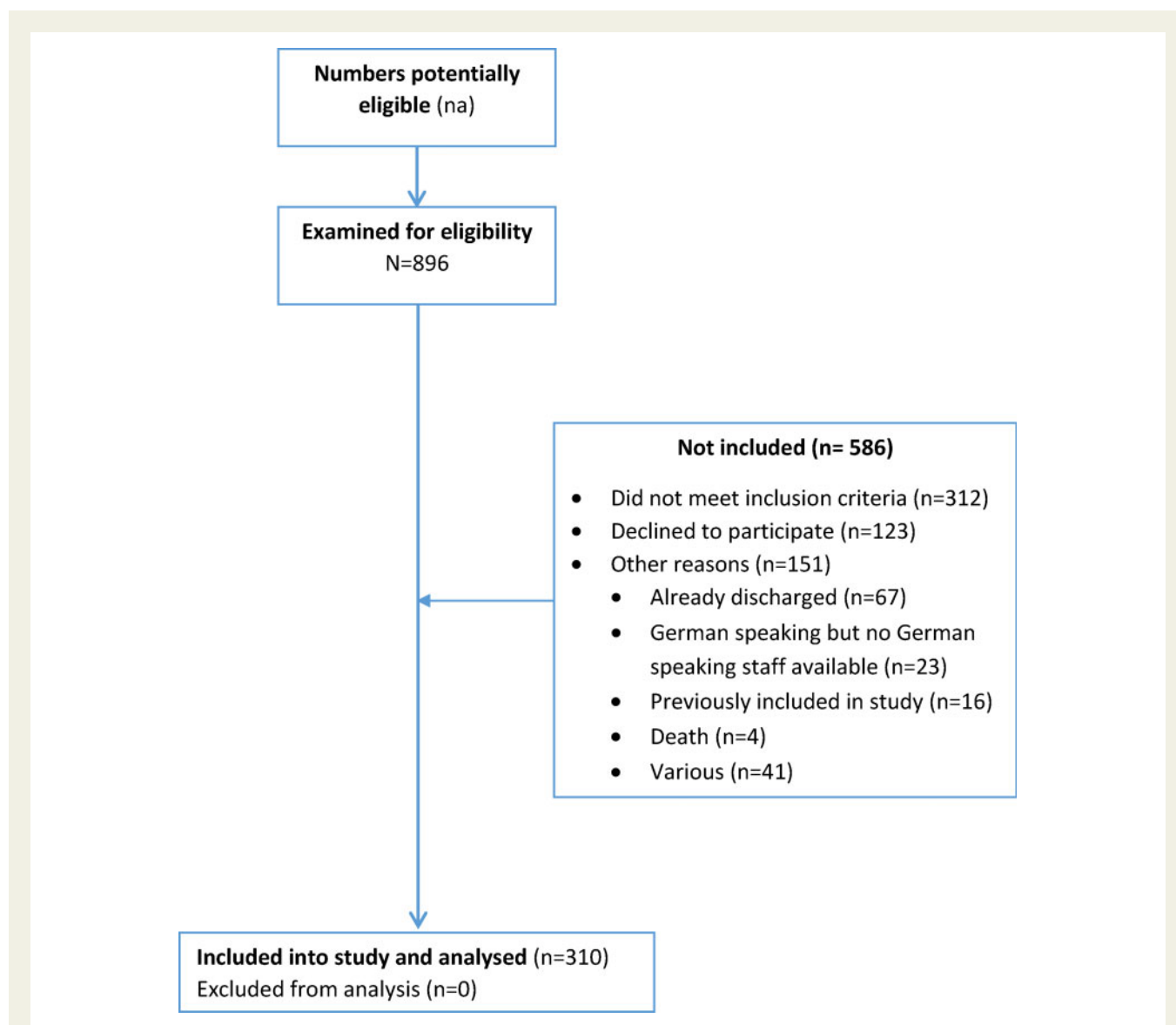


Figure 1 Study flow diagram. Recruitment period: 19.10.2015–22.12.2017.

care maintenance, management, and confidence as assessed via the SCHFI.

Self-care maintenance

The participant reports' mean score for self-care maintenance was 56.9 (SD = 15.4). A high proportion of participants reported never/rarely performing self-care activities to maintain physiological stability. For example, 83% of participants reported never/rarely asking for low salt diet when eating out, 47% of participants reported never/rarely weighing themselves, 42% reported never/rarely doing physical exercise, and 35% reported never/rarely checking their ankles for swelling. While 95% and 93% of participants respectively reported always/daily taking medications as prescribed and keeping doctors' appointments, 2.6% and 2%, respectively reported never/rarely doing so (Figure 2A).

Self-care management

Regarding self-care management, 285 participants reported dyspnoea or oedema over the past month; and participants reports' mean score for self-care management was 29.60 (SD = 22.9). Half of these patients reported not having recognized either dyspnoea or oedema as key symptoms of HF and 60% did not try any countermeasures when experiencing them. Notably, 43% of patients reported that they were not likely to call a doctor or nurse for guidance, and 62%, 70%, and 83% of patients, respectively reported not likely reducing salt, regulating fluid intake or taking an extra water pill in case of dyspnoea or oedema (Figure 2B).

Self-care confidence

In contrast, the participants reports' mean score for self-care confidence was 71.7 (SD = 25.1). A high percentage of participants had high confidence in their self-care abilities, with only 6% reporting no/

Table 1 Demographic and clinical characteristics of individuals with HF (N = 310)

	Frequency (%)	Mean (SD)
Sex		
Women	116 (37.42)	
Men	194 (62.58)	
Age (in years)		76.78 (11.15)
Nationality		
Swiss	286 (92.29)	
Other European	21 (6.77)	
Non-European	3 (0.97)	
Education (in years)		
Less than obligatory school (<9 years of school)	14 (4.58)	
Obligatory school (9 years of school)	141 (46.08)	
Secondary school	123 (40.20)	
Tertiary school	28 (9.15)	
NYHA classification ^a (n = 309)		
II	66 (21.36)	
III	170 (55.02)	
IV	73 (23.62)	
Left ventricular ejection fraction (EF) ^b (%) (n = 273)		42.36 (16.13)
HFpEF (HF with preserved, > 50% EF)	103 (37.59)	
HFmEF (HF with mid-range, 49–39% EF)	46 (16.79)	
HFrEF (reduced HF, < 40% EF)	125 (45.62)	
Time since diagnosis (n = 300)		
Less than 1 year	81 (27.00)	
1–5 years	134 (44.67)	
5 years or longer	69 (23.00)	
Unspecified	16 (5.33)	
Comorbidity		
Hypertension	229 (73.87)	
Renal disease	195 (62.58)	
Depressive symptomatology or anxiety ^c	122 (39.35)	
Previous myocardial infarction	119 (38.39)	
Diabetes	111 (35.81)	
Cognitive impairment ^c	63 (20.32)	
Cerebrovascular disease	54 (17.42)	
Cancer	43 (13.87)	

^aNew York Heart Association classification

^bTerminology for HF with preserved, mid-range and reduced ejection fraction as defined by the ESC¹

^cAny note in medical records or reported by health-care professionals in charge.

low confidence that they would follow their care teams' treatment advice and 23% reporting no/low confidence that they would take appropriate measures to relieve their symptoms (Figure 2C).

Self-care results for the EHFScBS, with subscales measuring adherence to the medical regimens, asking for help and adapting daily activity (Figure 2D; higher reported scores mean poorer self-care). Participant reports' mean overall self-care score was 41.09 (SD = 16.38). Mean item scores were 54.41 (SD = 31.58) for asking for help, 40.52 (SD = 17.64) for adherence to their medical regimens, and 16.27 (SD = 22.06) for adapting daily activities to their capacities. Contacting a doctor or nurse in case of fatigue or weight gain were the highest-scored (= poorest) self-care items on the asking for help

subscale, with daily weight checks receiving the highest (= poorest) scores on the adherence subscale (Figure 2D), a finding similar to that obtained on the SCHFI maintenance scale's corresponding item.

Symptom experience and needs

The sample's mean number of experienced symptoms was 12.8 (SD = 4.0), i.e., of 21 possible symptoms, participants reported having experienced 60% (SD = 19%) of them over the previous week. The overall mean symptom severity score was 3.26 (SD = 1.50); the mean HF symptom severity score was 3.09 (SD = 1.78), both of which designate mild symptom severity.²³ The most severe symptoms were shortness of breath (mean = 6.0, SD = 2.98) and fatigue (mean = 5.69,

Table 2 Descriptive results of self-care, symptom experience, and needs

	Mean (SD)
Self-care (SCHFI v6.2) ^a	
Self-care maintenance subscale score	56.9 (15.4)
Self-care management subscale score	29.60 (22.9)
Self-care confidence subscale score	71.7 (25.1)
Self-care (12-items EHFSBS) ^a	
Total score	41.09 (16.38)
Adherence to the medical regimen subscale score	40.52 (17.64)
Asking for help subscale score	54.41 (31.58)
Adapting daily activities subscale score	16.27 (22.06)
Symptom experience (MDASI-HF)	
Overall symptom severity score	3.26 (1.50)
HF symptom severity subscale score	3.09 (1.78)
Symptom distress subscale score	3.96 (2.32)
Perceived support needs (HFNAQ)	
Overall perceived support needs (total score)	2.0 (0.7)
Physical needs subscale score	2.1 (0.8)
Psychological needs subscale score	1.9 (0.8)
Social/interpersonal needs subscale score	2.1 (0.9)
Existential/spiritual needs subscale score	2.1 (1.1)

Notes: ^aHigher SCHFI subscale scores mean higher self-care; higher EHFSBS scores mean lower self-care. EHFSBS, European Heart Failure Self-care Behaviour Scale; HFNAQ, Heart Failure Needs Assessment Questionnaire; MDASI-HF, M.D. Anderson Symptom Inventory – Heart Failure; SCHFI, Self-care of Heart Failure Index, v6.2.

SD = 2.91), followed by lack of energy, dry mouth, and difficulty sleeping without pillows (Figure 3A). The sample's prevalence of symptoms interfering with life was 4.51 (mean = 4.51, SD = 1.52), i.e., of 6 possible items on symptoms interfering with activities of daily life, participants reported having experienced a mean of 73% (mean = 73%, SD = 26%) over the previous week. The overall mean symptom distress level was 3.96 (SD = 2.32) with the highest distress levels for symptoms that interfered with walking (mean = 5.88, SD = 3.22), and the lowest to symptoms that interfered with interpersonal relations (mean = 1.9, SD = 2.7) (Figure 3B).

Perceived needs of patients with heart failure for support

The sample had a mean of 14.0 needs (mean, SD = 5.8), i.e., participants reported having felt a need for support for about half of the listed situations (30-item HFNAQ). For those needs situations experienced by members of the sample, the mean frequency score was 2 (SD = 0.7), corresponding to participants' 'sometimes' having felt a need for support. This frequency is also consistent across the four HFNAQ domains (physical issues: mean = 2.1, SD = 0.8; psychological issues: mean = 1.9, SD = 0.8; social/interpersonal issues: mean = 2.1, SD = 0.9; and existential/spiritual issues: mean = 2.1, SD = 1.1). This is equivalent to participants rating that, on average, they had 'sometimes' experienced a need for support across the four HFNAQ domains.

Hospitalizations

Over the year prior to study enrolment, participants ($n = 310$) had 269 all-cause hospital admissions; the hospitalizations' median was 0 (IQR 1, range 0–7). Slightly more than half of participants (50.3%) had none; 29% experienced one and 11.6% two. The final 9.1% had three to seven hospitalizations each, accounting for roughly 10% ($n = 28$) of all-cause hospitalizations for the entire sample.

Relationships

Table 3 depicts the correlations between prior hospitalizations, the various self-care variables (i.e. SCHFI self-care maintenance, management, confidence sub-scores; EHFSBS total score, and sub-scores on adherence to medical regimens, asking for help, adapting daily activities), symptom experience [MDASI-HF symptom severity (all and HF-specific symptoms) and symptom distress score] and the needs variables (HFNAQ total score and the physical, psychological, social, existential subscores).

Prior hospitalizations correlated significantly with better self-care maintenance and self-care adherence, as indicated by sub-scores on both self-care instruments ($\rho = 0.28$, $P < 0.0001$, SCHFI maintenance; and $\rho = -0.24$, $P < 0.0001$, EHFSBS adherence). Symptom experience (i.e. symptom severity, HF symptom severity, and symptom distress subscores) correlated significantly with needs regarding overall, physical, psychological, social, and existential issues (range: $\rho = 0.20$ – 0.58 , $P < 0.0004$ for the various HFNAQ and MDASI-HF variables). Thus, as symptoms' severity and distress increase, the frequency of overall perceptions increases not only regarding support needs but also regarding each of the four needs dimensions. Symptom experience did not correlate with self-care ratings either from any of the SCHFI subscales or from the EHFSBS total or sub-scores. Further, needs did not correlate with self-care except for existential needs that correlated positively with self-care management. Neither symptom experience nor needs correlated significantly with prior hospitalizations.

Discussion

In this cross sectional study of 310 individuals with HF, we found a high prevalence of low self-care levels, and a positive relationship between symptom experience and needs. Hospitalization incidence correlated with self-care but not with symptom experience or needs.

In line with large international studies reporting on low self-care levels worldwide,⁴ this initial study—the first of its kind in Switzerland—showed that, even in a healthcare system ranked among the world's best,⁷ poor self-care is common in individuals with HF. Our data indicate low levels for all but two self-care items, medication taking and keeping physicians' appointment, which also previously reached highest levels.⁴ Yet, these results may be biased by participants' subjective assessment of self-care adherence possibly resulting in underreporting of medication and appointment keeping non-adherence. Yet, subjectivity is inherent to patient-reported outcome (PRO) measures, which have become accepted endpoints in clinical HF research as well as in modern HF treatment approaches to capture the patient's experience.²⁵

Notably, a large proportion of participants reported not performing measures to monitor physiological stability, e.g., weighing



Figure 2 (A) Individual items' prevalence of self-care maintenance (SCHFI, $n = 308$). Notes: Listed below are common instructions given to persons with heart failure. How routinely do you do the following? Five-point scale ranging from 1 (never or rarely) to 5 (always or daily). (B) Individual items' prevalence of self-care management (SCHFI, $n = 308$). Notes: Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies? Five-point scale ranging from 1 (not likely) to 5 (very likely). (C) Individual items' prevalence of self-care confidence (SCHFI, $n = 303$ to 305). Notes: In general, how confident are you that you can. Five-point scale ranging from 1 (not confident) to 5 (extremely confident). (D) Individual items' prevalence of self-care measured via the EHfScBS ($n = 301$ to 302). Notes: EHfScBS=The European Heart Failure Self-Care Behaviour Scale. Five-point Likert scale ranging from 1 (I completely agree) to 5 (I don't agree at all).

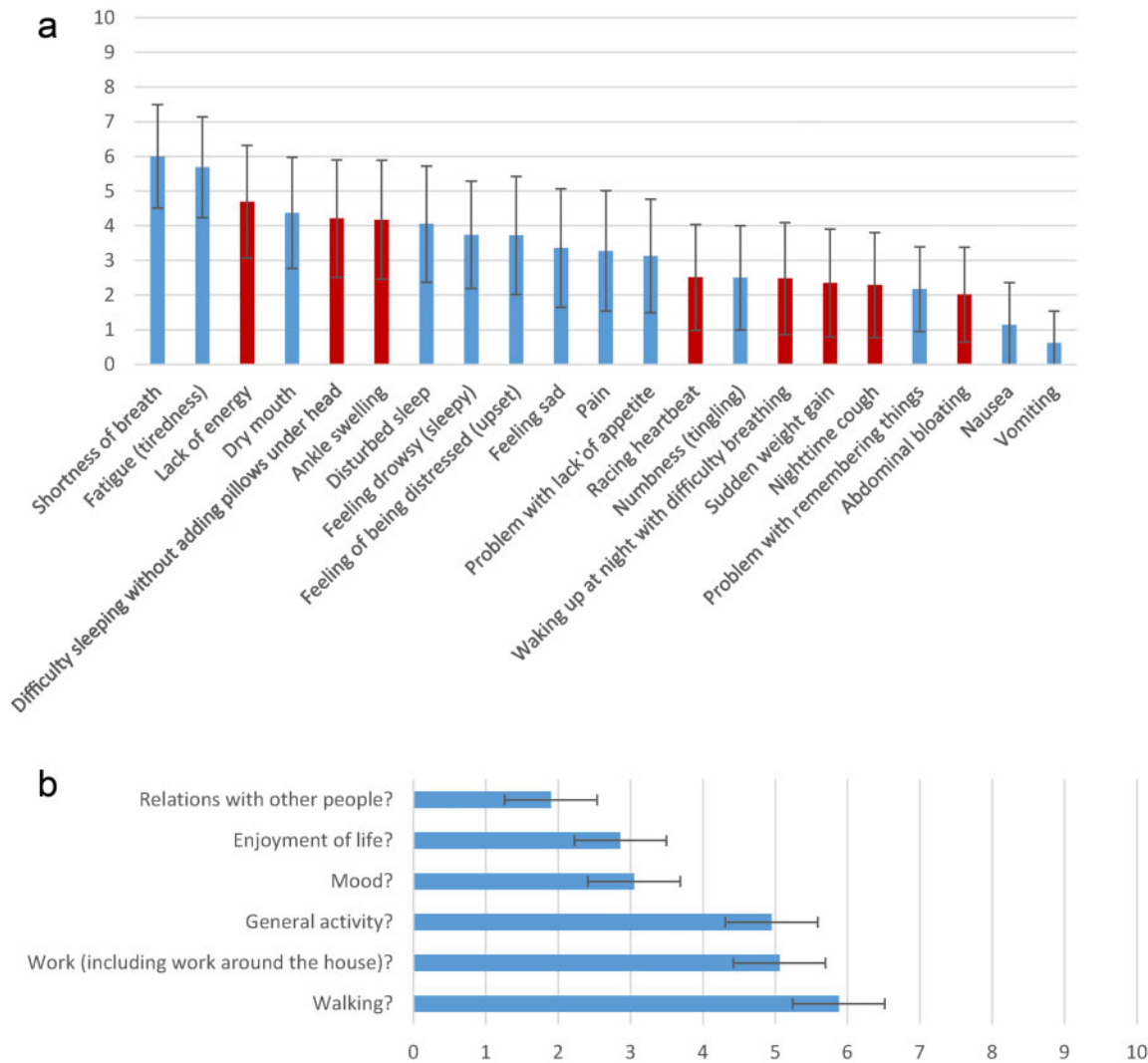


Figure 3 (A) Symptom severity M.D. Anderson Symptom Inventory – Heart Failure (MDASI-HF, $n = 306$ to 308). Notes: 0 indicates 'not present'; 10 indicates as bad as you can imagine; bars in red colour are considered HF-specific symptoms; scores can be interpreted as mild (scores <5), moderate (scores of 5 – 6) and severe (scores >6) using severity descriptors.²³ (B) Symptom distress M.D. Anderson Symptom Inventory – Heart Failure (MDASI-HF, $n = 303$ to 306). Notes: Symptoms frequently interfere with how we feel and function. How much have your symptoms interfered with the following items in the last week? 0 = did not interfere; 10 = interfered completely.

themselves or checking for ankle swelling; and where symptoms occurred, countermeasures such as limiting fluid intake were rarely taken. Moreover, a large proportion of participants reported not consulting their doctor or nurse in cases of dyspnoea or peripheral oedema.

These results demand attention for several reasons. First, low self-care levels such as poor consulting behaviours have been shown to relate to more HF events,^{5,6} yet in our study, lower self-care was associated with less prior hospitalizations. Second, consistent with the results of international studies, the magnitude of low self-care—fewer than a quarter of participants achieved adequate self-care maintenance, with only a tenth reporting acceptable management levels—may indicate widespread under-treatment regarding patient self-care education and support.¹

Indeed, to improve outcomes in high-risk individuals with chronic HF, the ESC guideline recommends incorporating self-care education and support into multidisciplinary care management programs for their follow-up¹ and numerous methods have been described to deliver patient self-care education.^{26–28} Interestingly, a large proportion of patients reported adequate self-care confidence. Self-care confidence, i.e., the 'confidence in one's ability to perform self-care'¹³ (p. 1) has been described to influence the relationship between self-care and outcomes; improving self-efficacy is therefore a common goal of patient education programmes. However, our sample's self-care management was considerably lower than its confidence would suggest. This finding suggests that self-care confidence neither replaces support for self-care management nor reflects self-care capacities.

Table 3 Significant relationships between self-care, symptom experience, needs, and prior hospitalizations

		Hospitalizations			Self-care variables			Needs			Symptom experience				
		SCHFI			EHFScBS			HFNAQ			MDASI-HF				
		Maintenance	Management	Confidence	Adherence	Asking for help	Adapting daily activities	Total score	Physical needs	Psychological needs	Social needs	Existential needs	Severity (all symptoms)	Severity (HF symptoms)	Distress
Hospitalizations		1.00													
Self-care variables															
	SCHFI	0.26													
	Maintenance	1.00	-0.55												
	Management		1.00	0.34											
	Confidence			1.00											
	Adherence				1.00										
	Asking for help					1.00									
	Adapting daily activities						1.00								
	Total score							1.00							
Needs															
	HFNAQ							1.00							
	Total score								1.00						
	Physical needs									1.00					
	Psychological needs										1.00				
	Social needs											1.00			
	Existential needs												1.00		
Symptom experience															
	MDASI-HF														
	Severity (all symptoms)													0.48	0.54
	Severity (HF symptoms)													0.49	0.42
	Distress													0.35	0.48
	Severity (HF symptoms)													0.20*	0.26
	Distress													1.00	0.52
	Severity (all symptoms)													1.00	0.52
	Severity (HF symptoms)													1.00	0.52
	Distress													1.00	1.00

Spearman correlation coefficients at strengths > |0.19| are depicted only; all statistically significant at $P < 0.0001$, except* $P < 0.0004$; inverse relationships between the EHFScBS total score and, respectively, the SCHFI Maintenance and the SCHFI Management subscales is due to a difference in scoring: while higher EHFScBS scores indicate lower self-care, higher SCHFI subscale scores indicate higher self-care.

Third, a large proportion of this sample (40%) presented depressive symptomatology, which has been described as a barrier to self-care abilities.²⁹ This makes it a critical concern for self-care patient education. Our study did not assess relationships between depressive symptomatology and self-care. However, considering a 2016 meta-analysis' finding that in a subgroup of HF patients with moderate/high depression, self-management interventions actually correlated with reduced survival, applying self-management strategies in these patients warrants caution.³⁰ Finally, the positive relationship between previous hospitalizations and higher self-care levels may indicate that the experience of hospitalization makes patients more attentive to self-care practices. Or, a prior hospitalization reflects more patient education relating to self-care. It is also possible that some patients consider going to the hospital a self-care practice (i.e. a consulting behaviour). Also, prior hospitalizations reflect a more severe disease status, which naturally demands higher involvement in self-care activities.³¹ Indeed, several interventional studies have reported on the positive relationship between self-care and hospitalization, implying that hospitalizations do not accurately reflect the value of self-care support.³² While these results' implication certainly warrants further attention, this question was beyond the scope of this study.

We further report a notable number of symptoms and needs situations, which we assessed alongside symptom experience across physical, psychological, social, and existential dimensions. Other studies have reported mean symptom numbers ranging between 7 and 19.³³ In our study, dyspnoea and fatigue were experienced as the most intense symptoms; symptom experience-related distress in daily life was highest for the impact of symptoms affecting walking. As symptom experience may impact self-care capabilities, it has recently been proposed that symptom experience be integrated into self-care behaviours.³⁴ However, while previous research has found symptoms such as dyspnoea predictive of hospitalization,³⁴ the current study did not find any relationship between symptom experience and either self-care or past hospitalizations. Instead, our data indicated a relationship between symptom experience and needs situations, with a major association between symptom severity and overall needs. This finding could be explained, in part, by this sample's high levels of comorbidity and advanced NYHA classifications. Notably, almost 80% of participants were in NYHA classes III–IV, a proportion exceeding those of many other HF studies but similar to that of a clinical HF population. Importantly, in line with recent advocacy by the ESC and other scientific societies, the strong association between symptom severity and needs implies that symptom experience and needs in individuals with chronic HF should be systematically assessed.³⁵ Moreover, the same sources recommend the inclusion of palliative care alongside cardiology treatment, ideally early on the disease trajectory, which increase with the disease progression. This aims at decreasing symptom burden, addressing needs and ultimately improving the patient's quality of life.³⁵ Although the question of including palliative care goes beyond the scope of this study, our findings regarding symptom experience and needs warrant further exploration.

Limitations

This study had several limitations. First, we used a convenience sample; however, the data collection duration covered both all working days and all four seasons, resulting in a sample with characteristics

typical for a clinical HF population. Second, the cross-sectional design and use of retrospective measurement of hospitalizations prohibits any causal interpretation of relationships. A prospective follow-up is needed to assess the impact of self-care on the incidence of HF events in our setting and to validate the cut-off level used to discriminate between adequate and inadequate self-care. Also, health-care utilization data were specific to the study settings and included neither hospitalizations in other hospitals nor visits to outpatient facilities. Including this more comprehensive data collection would probably have led to higher scores for health-care utilization. Third, bias is an inherent flaw in the use of PRO measures, usually resulting in underreporting of poor outcomes. However, with our sample, this would suggest that this group's self-care levels are even lower than reported. Also, while the respective PRO measures have been well validated in their original language versions, psychometric properties of the French and German (for Switzerland) versions used in this study have not yet been assessed. It is therefore possible that the results are impacted by reliability and validity issues pertaining to the translated versions. While translation of the instruments according to Wild's et al.'s principles of Good Practice for the translation and cultural adaptation process of Patient-Reported Outcome Measures¹¹ likely minimizes related issues, full evaluations of their psychometric should still be conducted. Finally, in our study settings, limited specialized HF care with low degree of cardiology involvement and lack of heart failure nurses providing systematic self-care patient support/education programs were in place for most of our study period. Self-care levels may be higher in settings that have such programs (e.g. some university hospitals, outpatient clinics with higher involvement of dedicated cardiologists and specialized HF nurses) and reports of findings of such programs implemented in routine HF care would be valuable. On the same time, the study's results call for action for more specialized interdisciplinary HF care in primary hospital settings.

For clinical practice, setting priorities regarding the various patient self-care education activities may be appropriate. In line with ESC recommendations¹ and patient preferences/priorities, and based on individual assessments of self-care activities, improving medication adherence, increasing physical activity and developing symptom management skills may be approached as top-priority tasks. Furthermore, it may be necessary to focus more on supporting patients' self-care than on increasing their confidence in their ability to perform self-care. To this end, patient self-care support should go beyond counselling to include direct hands-on support, with consideration for how symptom experience affects self-care capabilities. Finally, in line with systematic scarcities for resources for focusing on patient-centred care, we recommend having physicians prescribe self-care education and support, as this would allow the investment necessary to realize such support.

To conclude, the findings of this Swiss study add to the international literature by demonstrating low self-care levels in individuals with HF. Overall, the evidence base on self-care in HF is firm enough that we can now move from observational to interventional studies. In light of the high self-reported number of inadequate self-care activities, important symptom experience and needs, future studies should take such baseline data into consideration when designing self-care support interventions.

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