ORIGINAL RESEARCH ARTICLE

Self-care perception and behaviour in patients with heart failure: A qualitative and quantitative study

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Abstract

Background and objective Self-care strategies in heart failure (HF) are effective for disease management, yet adherence in many patients is inadequate. Reasons are presumably multifactorial but remain insufficiently investigated; thus, we aimed to analyse self-care adherence and associated factors in outpatients with HF.

Methods and results To measure self-care levels and explore barriers and facilitators to self-care adherence in patients with HF, quantitative study using the European Self-Care Behaviour Scale (EHFScBS-9) (n = 80; NYHA II–III, mean age 72 ± 10 years, 58% male) and qualitative study using semi-structured interviews (n = 32; NYHA II–III, mean age 73 ± 11, 63% male) were conducted. We detected lowest adherence to regular exercise (39%) and contacts with healthcare provider in case of worsening symptoms (47%), whereas adherence was highest for regular medication taking (94%). Using the EHFScBS-9 standardized cut-off score $\leq$ 70, 51% of patients reported inadequate self-care. Binary logistic regression analysis showed significant influence of education (OR = 0.314, 95% CI: 0.103–0.959) and perceived control (OR = 1.236, 95% CI: 1.043–1.465) on self-care adequacy. According to the situation-specific theory of HF self-care, most commonly reported factors affecting the process of self-care were knowledge about HF self-care behaviours (84%), experience with healthcare professionals (84%), beliefs about their expertise (69%) and habits related to medication taking (72%). Among values, working responsibilities (53%) and maintenance of traditions (31%) appeared as the most prevalent socially based values affecting motivation for self-care. Situational characteristics related to the person (self-confidence, 53%; adaptive coping strategies, 88%), problem (burdensome breathing difficulties, 56%; co-morbidities, 81%) and environment (practical support from family/caregivers, 59%; financial difficulties, 50%) were also commonly reported.

Conclusions Various factors, including health-related beliefs, habits and socially based values, need to be taken into account when planning self-care interventions in patients with HF. A patient tailored approach should be based on adequate patient evaluation, taking into consideration the particular personal and social context.

Introduction

Heart failure (HF) represents a large burden in many aspects, from epidemiology and public health aspects[1–3] to individual patient perspective and engagement.[4] Patient and caregiver active involvement in the disease management process and self-management skills have been shown to improve outcomes and health-related quality of life.[5] In clinical practice, however, many patients show inadequate levels of self-care,[6,7] and a substantial number of patients do not sufficiently respond to self-management interventions.[8]

Among the most widely used theories that provide structure for clinicians and researchers to understand the process of self-care in HF and develop theory-driven interventions are the middle-range theory of self-care of chronic illness[9] and the situation-specific theory of HF self-care.[10] Both theories identify a wide range of personal and contextual factors that hinder and support HF self-care. The middle-

range theory of self-care of chronic illness recognizes the importance of considering personal and contextual factors relevant in HF self-care (e.g. experiences and skills, motivation, habits, cultural beliefs and values, functional and cognitive abilities, confidence, support and access to care). The situation-specific theory of HF self-care recognizes that self-care decision-making process can be influenced by various situational characteristics related to the person (e.g. age, gender, ethnicity, socio-economic status and self-efficacy), problem (e.g. multi-morbidity and cognitive impairment) and environment (e.g. social support and social norms) as well as by individual's knowledge, past experiences, skills and values.

Previous studies[11,12] empirically support the importance of patient's views, values, resources and contextual factors on self-care behaviours. Furthermore, patient's views, preferences, needs and values have been stressed as an important dimension of a tailored self-care advice for HF patients by the latest self-management recommendations of the European Society of Cardiology.[13] In the last years, there is an increased recognition of the value of qualitative methods in recognizing individual patient needs,[14,15] but to our knowledge, relatively few HF studies used a combination of quantitative and qualitative methodology.[16–18] Also, the role of values on particular self-care behaviours has not been well understood so far.[19] Thus, the purpose of our study was to provide a better understanding of self-care adherence and associated factors by quantitatively exploring levels of patients' self-care behaviours and enhancing these data by qualitative findings. Adopting inductive and deductive approach in the qualitative data analysis allowed for unexpected aspects of participants' experience to emerge while following a conceptual framework of the situation-specific theory of HF self-care.[10] Specifically, our study aimed to define barriers and facilitators to particular self-care behaviours, with special emphasis on situational factors related to unique cultural background, patients' beliefs, experience, habits and values.

Methods

Study design and participants

The study used a cross-sectional, mixed methods design,[16,17] involving quantitative (self-administered questionnaires) and qualitative (semi-structured interviews) methods. It was conducted in March 2018 to August 2019. Participants were recruited from outpatient care setting in Slovenian general hospital. Eligible patients were adults (over 18 years) with diagnosis of HF, with New York Heart Association (NYHA) functional class II–III, attending outpatient HF clinic.

Instruments and data collection

The European Self-Care Behaviour Scale (EHFScBS-9) was used for assessment of self-care behaviour.[20] The scale consists of nine items scored on a 5-point Likert scale (1 = *I completely agree*; 5 = *I completely disagree*) arranged into two domains (self-reported consulting behaviours and adherence to regimen). The possible total score ranges from 9 to 45, with higher scores indicating lower levels of self-care. Permission for Slovenian translation of the scale was obtained from the authors of the original scale. The scale was translated and back-translated following a standard procedure.[21] Two bilingual health professionals translated the questionnaire into Slovenian, whereas a professional translator undertook the back-translation. A research team reviewed the back-translation for differences in meaning with the original version. No differences in meaning were detected. Pretest with five HF patients for comprehensibility revealed no difficulties. Several studies[21] demonstrated satisfactory psychometric properties of the scale; however, inconsistencies in factorial structure of the scale across the samples were reported. We conducted the confirmatory factor analysis in the Mplus 6 program[22] using the WLSMV estimator. The proposed two-factor model (adherence to regimen, consulting behaviours[20]) had a better model fit ($\chi^2(26) = 37.4$, $P = 0.07$; RMSEA = 0.07, 90% CI: 0.00–0.13; CFI = 0.87; TLI = 0.97; WRMR = 0.68) compared with the unidimensional model, with reliability coefficients alpha of the scales 0.57 and 0.84, respectively. However, small sample size ($n < 100$–150) limits the robustness of the computation of the factor structure and results in very unstable estimates. Therefore, adequately powered study is required, and our study used scores on specific HF self-care behaviours and scale's clinically important proposed cut-off value.[23]

Perceived control in cardiac patients was assessed using a four-item Control Attitude Scale (CAS).[24] Items are rated on a 7-point Likert scale (1 = *not at all*; 7 = *very much*) (scoring is reversed on two items). The total score ranges from 4 to 28, with higher scores indicating greater perceived control.

Semi-structured interviews with patients followed the interview guide (*Table 1*), developed by the authors on the basis of the relevant scientific literature and described elsewhere.[25] Patients were asked to describe their HF self-care practices and main barriers/facilitators to effective self-management. Open-ended questions were used to guide the conversation. Additional questions were used to clarify and reflect emerging issues raised by patients to further explore their experiences. Interviews were conducted by the interviewer with experience in qualitative methods (NS) and were audiotaped and transcribed verbatim.

Using survey instruments, demographic information (age, gender, educational level, employment status, marital status) was collected from the patients.

Table 1 Interview sample questions

Sample question
- What are you doing on a daily basis to manage your condition (dealing with symptoms, specific tasks—taking medication, monitoring weight, managing appointments, etc.)?
- What makes it easier to take care of yourself? What makes it harder to take care of yourself?
- How do you judge your ability to manage your heart failure (symptoms, hospitalizations)?
- How do you know you're doing ok, and what do you do to monitor yourself?
- Which information and instructions have you received by healthcare professionals? Do you think the instructions are easy to understand, and what would help you fit the instructions into your normal activities better?

For detailed description, see [25].

Patients participated in the study as a part of a regular HF clinic visit. They were asked to complete questionnaires; while waiting for their examination, assistance was provided by nurse when necessary. Interviews were conducted following patient examination in the HF clinic. Main reason for non-acceptance were logistic reasons (e.g. organized transportation and caregiver and/or patient commitments). The final number of interviewed patients was based on data saturation criteria, that is, last five interviews being conducted without additional codes and categories.

Ethical considerations

All participants gave their written informed consent for participation in the study prior to the study. The study protocol was evaluated and approved by the National Medical Ethics Committee (Approval No. 0120-35/2018/7), and the study was conducted in accordance with the Declaration of Helsinki.

Analysis of data

The data analysis was performed using SPSS 21.0 statistical software (IBM). Descriptive statistics were used to analyse all study variables. To ease the interpretation of the EHFScBS-9, the reversed and standardized 0–100 score, with higher score meaning better self-care, was computed.[26] Based on previous studies[23] a threshold ≥70 was defined as adequate and <70 as inadequate self-care. Additionally, the proportion of participants reporting low levels of particular self-care behaviour (i.e. not agreeing with EHFScBS-9 items —answer Options 1, 2 and 3 after reversed coding of items[7]) was calculated for each item. To compare groups of patients, Pearson chi-square test, Fisher exact test, Student's t-test and Mann–Whitney U test were used as appropriate. Binary logistic regression analysis was used to investigate the effect of socio-demographic characteristic (age, gender,

married/unmarried, higher/lower education) and perceived control on the self-care using the cut-off point of 70%. $P < 0.05$ was considered statistically significant.

The transcribed interviews were analysed according to qualitative content analysis method as outlined by Elo and Kyngäs[27] and Hsieh and Shannon.[28] After an initial reading of all available transcripts (NS, JF) to get an overall impression and familiarize themselves with the content, relevant parts were extracted and preliminarily coded (i.e. given descriptive labels). According to similarities and differences, the codes were then grouped into the higher order meaning units (subcategories) and named using words that characterize their content. These were organized into categories, derived from the categories of factors identified by the situation-specific theory of HF self-care[10,12]: personal, problem-related, environmental, HF knowledge, experience and values.[19] Therefore, analysis was both a deductive, exploring issues found in previous research, and inductive process, identifying unanticipated issues raised by the participants. Identification of new contents and inconsistencies in the coding scheme were discussed by a research team, and coding scheme was adapted accordingly. Double coding of some interviews ($n = 7$) was used to test interrater agreement. In the final step of the data analysis, an informational matrix was developed to compare and contrast the emergent qualitative subcategories across the groups with adequate and inadequate self-care levels (according to the EHFScBS-9 score).

Results

Quantitative study included 80 patients with HF, mean age 72 ± 10 years, 58% male, mostly married (65%) or widowed (25%) and retired (78%). Of those, 32 patients participated in qualitative study. Results indicate (*Table 2*) that there were no significant differences in socio-demographic variables, self-reported self-care behaviours and perceived control, between patients participating and patients not participating in the interview.

The scores on the EHFScBS-9 for our study sample were overall normally distributed ($P = 0.194$). The percentage of HF patients that reported low adherence to particular self-care behaviours indicated the lowest adherence to exercising regularly (61%) and contacting healthcare provider in case of increased fatigue (63%) and weight gain of 2 kg in 1 week (58%). On the other hand, 94% of participants reported high adherence to medication taking, 89% to limiting amount of fluids, 86% to sodium restriction and 69% to daily weight monitoring (see *Figure 1*). Results and distribution of individual EHFScBS-9 item scores are available in the Appendix A1.

The average score on 0–100 EHFScBS-9 scale was 71 ± 18. Based on the proposed threshold ≥70,[23] 49% of patients

Table 2 Characteristics of participants

Demographics	All sample—qualitative research (n = 80)	Not taking part in the interview (n = 48)	Taking part in the interview (n = 32)	P (Taking part vs. not taking part in the interview)
Gender (male), n (%)	46 (58)	26 (54)	20 (63)	0.483
Age, M ± SD	72.4 ± 9.5	72.5 ± 9.7	72.9 ± 11.3	0.390
Educational level, n (%)				
Incomplete primary	5 (6)	3 (6)	2 (6)	0.321
Primary school	40 (50)	26 (54)	14 (44)	
Vocational	21 (26)	12 (25)	9 (28)	
Secondary	6 (8)	4 (8)	2 (6)	
College	2 (3)	1 (2)	1 (3)	
University	4 (5)	3 (69)	1 (3)	
Postgraduate	0	0	0	
Marital status, n (%)				
Single/never married	4 (5)	1 (2)	5 (16)	0.474
Married	52 (65)	33 (69)	19 (59)	
Divorced/separated	1 (1)	0	1 (3)	
Widowed	20 (25)	15 (31)	5 (16)	
Employment status, n (%)				
Employed (full-time or part-time)	3 (4)	2 (4)	1 (3)	0.271
Retired	64 (80)	39 (81)	25 (78)	
Unemployed	4 (5)	2 (4)	2 (6)	
Others	4 (5)	3 (6)	1 (3)	
CAS sum, M ± SD	16.1 ± 3.8	15.6 ± 3.9	16.8 ± 3.7	0.206
EHFScBS-9 sum, M ± SD	34.4 ± 6.4	35.4 ± 6.4	32.9 ± 6.1	0.093
EHFScBS-9 (0–100), M ± SD	70.7 ± 17.6	73.3 ± 17.7	66.5 ± 17.0	0.093
EHFScBS-9 < 70 (%)	51.2	49.0	54.8	0.652

CAS, Control Attitude Scale; EHFScBS-9, European Heart Failure Self-Care Behaviour Scale. Percentages may not total 100 due to missing data or rounding; $P < 0.05$ was considered statistically significant.

Figure 1 Percentage of heart failure patients (n = 80) reporting low adherence to particular self-care behaviours (not agreeing with EHFScBS items—answer Options 1, 2 and 3 after reversed coding of items). HCP, healthcare provider.
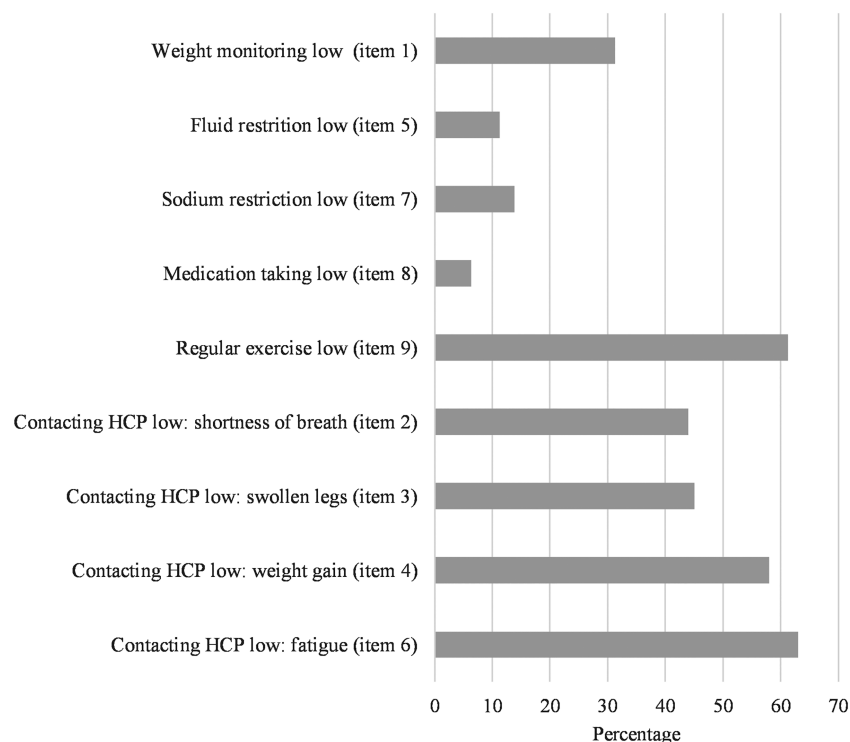
reported adequate (mean of 86 ± 10) and 51% inadequate levels of self-care (mean of 56 ± 10). Those with adequate self-care reported significantly better adherence to all self-care behaviours ($P < 0.05$–0.001) but limitation of fluid

intake (Item 5; $P = 0.33$) and medication taking (Item 8; $P = 0.24$), where between-group differences were non-significant. The results of binary logistic regression analysis indicate significant association of educational level and perceived control with adequate self-care (*Table 3*), with the model explaining 19.8% of variance in the outcome.

Summary of all influences on self-care that were identified through the analysis of interviews, informed by the theoretical framework of the situation-specific theory of HF self-care, is available in *Table 4*. Most commonly mentioned influences were related to knowledge about HF self-care behaviours (84%), experiences with previous admissions (50%) and healthcare professionals (84%), values of being healthy (50%) and socially responsible (53%), beliefs about healthcare

Table 3 Binary logistic regression analysis of factors associated with adequate self-care (EHFScBS-9 ≥ 70) among heart failure patients in Slovenian hospital (*n* = 80)

Variables	OR	95% CI	P
Gender (male)	0.788	(0.252–2.465)	0.683
Age	0.983	(0.919–1.051)	0.983
Education (<high school)	0.314	(0.103–0.959)	0.042
Marital status (without partner)	0.762	(0.323–4.676)	1.229
Perceived control (CAS)	1.236	(1.043–1.465)	0.014

Table 4 Identified factors influencing heart failure self-care in our study

Core categories of factors identified by the situation-specific theory of heart failure self-care	Categories	Subcategories with *n* of study participants mentioning
HF knowledge, experience, values	HF knowledge	Misconceptions about disease (*n* = 5); lack of knowledge (fluid intake: *n* = 6; diet: *n* = 2; HF general: *n* = 5; contacting healthcare provider: *n* = 14)
	Experience	Previous admissions (*n* = 16); experience with health professionals (positive: *n* = 21; negative: *n* = 3; different opinions of healthcare professionals: *n* = 3)
	Self- related[a] values affecting motivation	Motivated by life circumstances (maintaining a healthy lifestyle: *n* = 12; maintaining financial balance: *n* = 1); motivated by personal feelings (self-direction: *n* = 9; pleasure: *n* = 7; being healthy: *n* = 16)
	Other-related[b] values affecting motivation	Motivated by social benefits (social recognition: *n* = 7; socialization: *n* = 4); motivated by social obligations (responsibilities: *n* = 17; observing traditions: *n* = 10; obedience: *n* = 9)
	Beliefs	Beliefs about healthcare professionals (trust in the expertise: *n* = 12; lack of confidence in the expertise: *n* = 4; prescribe too many pills: *n* = 6; fear of doctors: *n* = 1; health professionals are too busy: *n* = 3; importance of good communications skills of healthcare professionals: *n* = 4; importance of having the same healthcare professional to develop trust: *n* = 4); beliefs about local healthcare system (long waiting times: *n* = 3); beliefs about pharmacotherapy (negative effect to health: *n* = 2)
	Habits	Eating habits (*n* = 11); drinking habits (*n* = 5); physical activity habits (*n* = 15); medication taking (*n* = 23); self- monitoring habits (*n* = 19); working habits (*n* = 12)
Personal	Affect, personality	Self-care confidence (trust in own self-care abilities: *n* = 10; lack of trust in own self-care abilities: *n* = 7); positive attitude, optimism (*n* = 6); personality traits (*n* = 3); coping strategies (acceptance: *n* = 11; active coping: *n* = 13; distraction: *n* = 3; religion: *n* = 2; humour: *n* = 2; avoiding social activities: *n* = 4)
Problem	Co-morbidities	Diabetes (*n* = 5); depressive symptoms (*n* = 3); vision problems (*n* = 3); hearing problems (*n* = 2); chronic kidney disease (*n* = 2); hypertension (*n* = 1); asthma (*n* = 1); arthritis (*n* = 1); others (*n* = 8)
	Cognitive status	Cognitive decline (*n* = 6)
	Functional status	Breathing difficulties (*n* = 18); tiredness (*n* = 7); lack of physical strength (*n* = 6); lack of appetite (*n* = 2); thirst (*n* = 6); sleep difficulties (*n* = 7)
Environmental	Social support	Family, caregiver support (emotional support: *n* = 9; practical help: *n* = 19; conflicts, limiting autonomy: *n* = 7; burden of taking care for someone else: *n* = 2); social support (positive social experiences: *n* = 13; negative social experiences *n* = 3)
	Circumstances	Difficult interpersonal situation (*n* = 7); financial difficulties (lower income: *n* = 6; extra costs: *n* = 9); specific living situation (assisted living, living far away from facilities, etc. *n* = 6)

[a]Categorization of self-care factors identified by the situation-specific theory of HF self-care adapted from Riegel et al.[10] and Koirala et al.[12]
[b]Categorization of values affecting motivation adapted from Karimi and Clark.[19]

professionals expertise (69%) and habits related to physical activity (47%), medication taking (72%) and self-monitoring (59%). Among most commonly mentioned influences related to situational characteristics were self-care confidence (53%), adaptive coping strategies (88%), burdensome breathing difficulties (56%), co-morbidities (81%), practical support from family/caregivers (59%) and financial difficulties (50%). Our findings related to influences that enhance or impede specific self-care behaviours (with illustrative quotations) are provided below.

Weight monitoring

Majority (*n* = 19) of the patients reported compliance to self-monitoring weight and pulse. The most frequently mentioned facilitators to the regular weighting were increased knowledge (i.e. knowing why this is important; *n* = 3) and the use of a self-monitoring diary (*n* = 5) to daily record measurements. On the other hand, some patients reported they find it difficult to develop new habits (*n* = 2; '… if I don't weight myself first thing in the morning, I forget about it …'), have no equipment (*n* = 3) or prefer using other skills to monitor their HF symptoms (*n* = 2; '… when my pants feel tight I know that I am bloated …').

Fluid restriction

Interviewed patients stated they find restricting fluid intake difficult due to different reasons: the lack of knowledge either regarding how much liquid contains different food (*n* = 2) or regarding the management of co-morbidities (*n* = 4; '… I drink 1,5 liter of water per day, I should not drink more … but I should drink more water because of my kidney disease …'), experiences of thirst (*n* = 6; '… My body asks for liquids …'), habits (*n* = 3; '… I don't measure how much I drink. When I'm thirsty, I drink …') and pleasure (*n* = 2; '… I drink as much as I like …'). On the other hand, some patients reported that habits (*n* = 2; '… I drink little for my whole life …') and avoiding social activities help them adhere to the recommendations (*n* = 1; '… I avoid visits … cannot find anything good for me there…') and they are motivated by their value of being healthy (*n* = 2; '… I would drink more, but I don't dare because I don't want to get worse …').

Sodium restriction

The lack of knowledge about healthy diet (*n* = 2; i.e. how much salt contains processed food), practical reasons (*n* = 4; i.e. cannot afford to cook separate meals), financial reasons (*n* = 3; '… I try to eat healthy - a little less pork, we also buy fish, if it was cheaper, we could afford it more often …'), pleasure and habits, interconnected with traditional cuisine (*n* = 7; '… we eat food cooked in traditional way … I salt normally. I know it is not healthy, but otherwise it is tasteless …') were the most commonly mentioned barriers. On the other hand, some patients mentioned habits that support healthy diet (*n* = 4; (caregiver) cooking healthy food for longer time due to other health conditions such as diabetes) and being motivated by their value of being healthy (*n* = 2; '… you need to stick to that if you want to be healthy …').

Medication taking

Most of the patients reported good adherence to medical regimen (*n* = 23), due to developed medication schedule (i.e. placing all medicines in a box and prepare medicines one night before) that became part of their daily routine, few of them (*n* = 3) mentioned practical support from their informal caregiver. Beliefs about healthcare professionals and medication that may enhance (*n* = 3; '… You should take medicines to avoid getting worse …') or impede (*n* = 8; '… Doctors prescribe too many pills …', '… Too many pills are bad for my liver …') adherence were mentioned.

Regular exercise

Regarding regular physical activity, patients reported difficulties due to co-morbidities (*n* = 5), avoiding exercise in wintertime to avoid flu (*n* = 4; '… I don't want to go for a walk in the winter, when it is cold outside …'), avoiding falls (*n* = 3), not being self-confident regarding how much effort is allowed (*n* = 3; '… I fear physical efforts, I'm not self-confident enough yet …'). Difficulties to establish new habits (*n* = 8; '… to tell you the truth, you give up sometimes …') that can indicate the value of maintaining healthy lifestyle were mentioned as well. Additionally, informal caregiver support and/or involvement in physical activity (*n* = 7) and pre-existing habits (*n* = 12; daily physical activity, used to being outdoors) emerged as facilitators.

Contacting healthcare provider in case of worsening symptoms

Some patients stated they would contact their healthcare provider if/when they would experience shortness of breath (*n* = 4), discomfort/pain (*n* = 4), tightness in chest (*n* = 1) or sudden weight gain (*n* = 1). Patients' answers, however, indicated that many of them (*n* = 14) would delay seeking professional care for as long as possible and would contact healthcare provider when symptoms are intolerable (i.e. in the sudden event of deteriorating; '… I would call the doctor in the case of emergency … it should feel really bad …'). Among the reasons for this, lack of knowledge (*n* = 4), lack of experience (*n* = 3), lack of trust in healthcare providers

(n = 3; '… why go there. They will tell me the same things again …'), relatives that are healthcare professionals (n = 2) and valuing responsibilities (n = 4; i.e. continuing with work for as long as possible) were mentioned.

Table 5 highlights recognized self- and other-related values[19] and their possible impact on HF self-care behaviours, indicated by the interviewed HF patients. Among other-related values, maintaining traditions and social responsibility were mentioned by the highest number of interviewed patients. Among self-related values, this pertains to values of being healthy and maintaining healthy lifestyle.

Comparison of answers between the interview participants with inadequate (n = 17) and adequate self-care (n = 15) (according to the EHFScBS $\leq$ 70 cut-off) revealed that the majority of participants with inadequate self-care reported about experiences with previous admissions and positive experiences with healthcare professionals. Compared with the group with adequate self-care, more participants in this group expressed trust in the healthcare system and pharmacotherapy. More of them valued obedience to authorities, indicating they might leave decision making to healthcare professionals. Difficulties with changing lifestyle were also more commonly reported in this group, suggesting they might not have the necessary skills for behaviour change or might less actively participate in HF management. Furthermore, financial difficulties and somewhat more noticeable difficulties with meeting social support needs (i.e. being motivated by social recognition, avoiding social activities and receiving negative caregiver support) were identified in this group.

Discussion

This is one of the rare studies using quantitative and qualitative approach to identify HF patients' beliefs, experience,

habits and values as well as situational factors on the self-care adherence. This seems of particular relevance, as the study was conducted in the environment[29] where health indicators consistently show poorer levels of health and health-related behaviours and lower socio-economic standard, compared with other parts of Slovenia.[30] Other research[31,32] indicated particular challenges to self-care in such environments (i.e. limited economic resources, reduced use of HF care and lower levels of education). Our research substantially added to this, identifying various influences on particular self-care behaviours. According to the situation-specific theory of HF self-care,[10] beliefs about healthcare professionals, habits and socially based values (especially the importance of work and food preferences) were among the most commonly reported factors affecting decision-making process of self-care. Also, personal factors such as less active participation in HF management and environmental factors such as financial difficulties and difficulties with meeting social support needs seemed to contribute to inadequate self-care.

Our results indicate that approximately half of the included HF patients might be classified as having inadequate self-care, whereas only perceived control and educational level showed significant influence on self-care adequacy (*Table 3*). Similarly, other studies indicate the importance of perceived control, but the findings regarding associations between self-care and other socio-economic variables seem to be inconsistent —although, apart from age, obtained associations are mostly non-significant (for review see literature[12,33]). Our findings (*Figure 1*) regarding the high level of medication taking self-care behaviour and lower levels of exercise are consistent with results reported in the international study by Jaarsma and colleagues.[7] Among the reasons for difficulties with regular physical activity, lack of self-confidence, avoiding physical activity in the winter to prevent illness (value of being healthy) and difficulties in establishing new habits (value of maintaining a healthy lifestyle) emerged. Studies show[34] that group

Table 5 Identified values and their possible impact on heart failure self-care

Self-care behaviour	Impede self-care	Enhance self-care
Weight management		Self-direction, being healthy, obedience
Fluid restriction	Pleasure, socialization, maintaining traditions (alcohol)	Self-direction, maintaining a healthy lifestyle, obedience
Sodium restriction	Pleasure, maintaining financial balance, socialization, maintaining traditions (diet)	Self-direction, maintaining a healthy lifestyle, obedience
Medication taking	Being healthy	Being healthy, obedience
Regular exercise	Being healthy, maintaining traditions (work-related)	Self-direction, maintaining a healthy lifestyle
Consultation behaviour	Social recognition, social responsibility, maintaining traditions (unwillingness to visit a doctor)	Obedience (relatives are health professionals)

Classification of values adapted from Karimi and Clark[19]; self-direction, motivated by active decision making, autonomy and the need for control; pleasure, motivated by pursuit of pleasure; being healthy, motivated by the value of being healthy (not getting worse); maintaining healthy lifestyle, motivated by the desire to have a normal life (despite the disease); maintaining financial balance, motivated by the pursuit of financial balance; social recognition, motivated by a desire to be recognized in terms of your earlier public competency image; socialization, motivated by spending time with family and friends; social responsibility, motivated by work/family responsibilities (valuing these responsibilities more than self-care activities); maintaining traditions, motivated by maintenance of customs, ideas of someone's culture; obedience, motivated by following others instructions.

exercise programmes have shown success in addressing these challenges, improving exercise self-efficacy and supporting regular activity engagement of HF patients.

Patients' habits seemed to be an important facilitator of medication and self-monitoring adherence. On the downside, some patients reported that their existing lifestyle habits might impede their self-care adherence.[9] For example, adherence to healthy diet appeared to be hindered by eating habits, interconnected with socially based values of spending time with family/friends and maintaining traditions.

Quantitative results, indicating lower adherence to contacting healthcare provider in case of HF worsening, were confirmed by qualitative findings that patients normally under-report symptoms[35] and delay seeking help for as long as possible, till they are highly symptomatic. This could be attributable to the lack of knowledge about HF and its management and reluctance of seeking professional help,[36] motivated by beliefs about healthcare professionals, reluctance to be burdensome[37] and socially based values—such as working responsibility and avoiding judgement by others when not working. Overall, valuing maintenance of traditions and valuing working responsibilities emerged as the most commonly reported socially based values affecting motivation for self-care. Similar to some other studies,[36] many HF patients reported they want to continue with work due to responsibility and fear of being perceived as lazy by local community. Their answers indicate that work is considered an integral part of life and one of the most important values in this local environment. Therefore, emphasizing behavioural activation and providing circumstances in which patients may continue with their work activities (i.e. completing activities at slower place and selecting activities requiring less effort) could result in better quality of life and self-care ability.[15]

Another crucial part of HF self-management appeared to be perceived control over disease. Generally, HF patients reported experiencing moderate levels of perceived control. However, qualitative study revealed lack of confidence in some domains (physical activity, fluid intake, managing deterioration) that should be systematically addressed in future educational interventions and materials.[38] Moreover, addressing aspects of adaptive coping (i.e. acceptance and active coping[39]) and disease adjustment mentioned by interviewed HF patients could provide a starting point for discussion in psychosocial interventions.[40] According to the results, special attention should be paid to HF patients having difficulties with meeting social support needs (i.e. avoiding social activities, receiving negative caregiver support or no support). Offering (support) groups where HF patients can exchange views and understandings[13] and encouraging their involvement in community interventions[41] and social activities (i.e. community work and church attendance) might be beneficial for their self-care adherence and quality of life. However, in order to be able to deliver services that are responsive to HF patients' diverse need, individualized needs assessment by experienced healthcare professional should be implemented into routine practices.

Strengths and limitations

The strength of this study is simultaneous use of quantitative and qualitative methods in same patients. Our sample size could be perceived as insufficient, but when taking a closer look at the other published qualitative studies concerning self-care of HF patients (see Siabani and colleagues for the review[15]), less than 25% of studies reported sample sizes above 30 participants. On the downside, not all HF patients included in the quantitative part of the study participated in the qualitative one. Also, when interpreting results, it needs to be taken into account that findings obtained from qualitative research may not be generalizable in the same way as quantitative. Further research, quantitatively exploring habits, values and their role in self-care adherence is needed.

Conclusions

Our study provides the insights into HF self-care adherence levels and influences to optimal self-care management, as perceived by HF patients. A patient-tailored approach should be guided by HF patients' input, taking into consideration various factors, including health-related beliefs, habits and socially based values.

Acknowledgements

Conflict of interest

None declared.

Funding

Appendix 1

Table A1 Heart failure self-care descriptive statistics (reversed coding) (*n* = 80)

	Item (reversed coding)	*M* ± *SD*	1 I don't agree at all	2	3	4	5 I completely agree
1	I weigh myself every day	4.07 ± 1.32	7.5	7.5	16.3	7.5	61.3
2	If my shortness of breath increases, I contact a hospital, my doctor or nurse	3.54 ± 1.52	17.5	8.8	17.5	15.0	41.3
3	If my feet/legs become more swollen than usual, I contact a hospital, my doctor or nurse	3.59 ± 1.48	16.3	5.0	23.8	13.8	41.3
4	If I gain 2 kg in 1 week, I contact a hospital, my doctor or nurse	2.99 ± 1.73	35.0	8.8	13.8	7.5	35.0
5	I limit the amount of fluids I drink (not more than 1.5–2 L/d).	4.62 ± 0.83	1.3	2.5	7.5	10.0	78.8
6	If I experience increased fatigue, I contact a hospital, my doctor or nurse	3.03 ± 1.66	31.3	6.3	25.3	2.5	35.0
7	I eat a low-salt diet	4.50 ± 0.94	2.5	2.5	8.8	15.0	71.3
8	I take my medication as prescribed	4.77 ± 0.90	5.0	0.0	1.3	0.0	93.8
9	I exercise regularly	3.31 ± 1.32	12.5	10.0	38.8	11.3	27.5

EHFScBS-9, European Heart Failure Self-Care Behaviour Scale. Higher scores imply better self-care behaviour. Low self-care is defined as not agreeing with items (answer Options 1, 2 and 3 after reversed coding of items).

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