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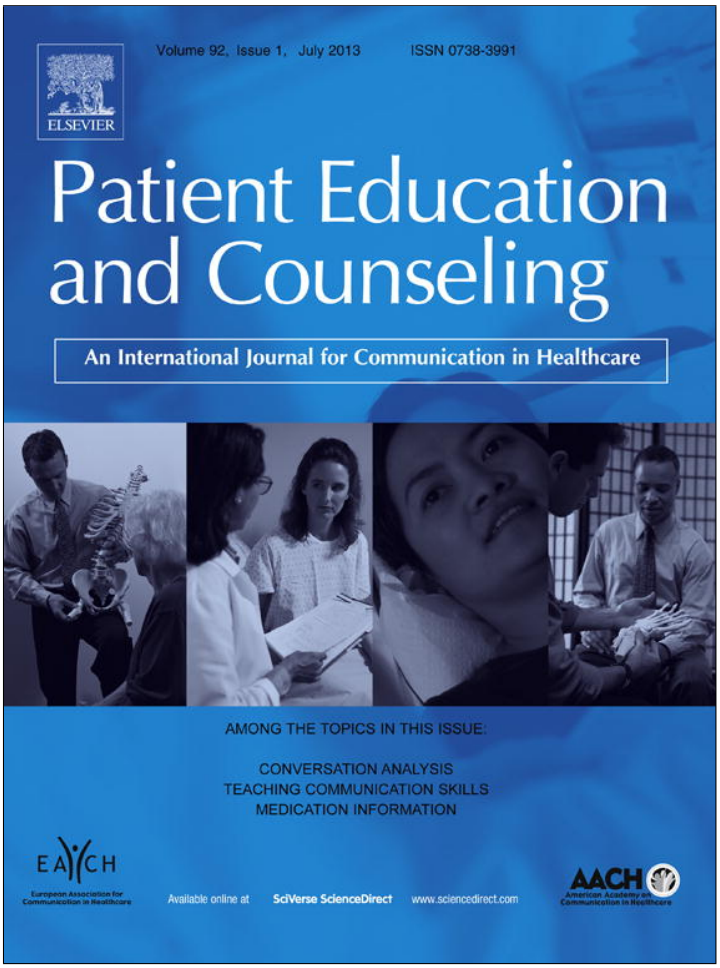

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Self Management

Comparison of self-care behaviors of heart failure patients in 15 countries worldwide

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ABSTRACT

Objective: Clinicians worldwide seek to educate and support heart failure patients to engage in self-care. We aimed to describe self-care behaviors of patients from 15 countries across three continents.
Methods: Data on self-care were pooled from 5964 heart failure patients from the United States, Europe, Australasia and South America. Data on self-care were collected with the Self-care of Heart Failure Index or the European Heart Failure Self-care Behavior Scale.
Results: In all the samples, most patients reported taking their medications as prescribed but exercise and weight monitoring were low. In 14 of the 22 samples, more than 50% of the patients reported low exercise levels. In 16 samples, less than half of the patients weighed themselves regularly, with large differences among the countries. Self-care with regard to receiving an annual flu shot and following a low sodium diet varied most across the countries.
Conclusion: Self-care behaviors are sub-optimal in heart failure patients and need to be improved worldwide.
Practice implications: Interventions that focus on specific self-care behaviors may be more effective than general educational programs. Changes in some health care systems and national policies are needed to support patients with heart failure to increase their self-care behavior.
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1. Introduction

Patients with heart failure (HF) who report more effective self-care have lower mortality and readmission rates than those who report poor self-care [1]. Self-care is a process of maintaining health through health promoting practices, symptom monitoring

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and managing symptoms when they occur [2]. HF specific self-care includes activities aimed at self-care maintenance (e.g., taking medication, exercising), symptom monitoring (e.g., monitoring weight changes) and symptom management (e.g., calling a health care provider or taking extra diuretics with symptoms of fluid retention) [2–5]. Self-care is considered important in the comprehensive management of patients with HF and is the focus of HF management programs internationally. Advice on HF self-care behaviors is often similar, regardless of the geographic location of the patient [6–8].

Worldwide, optimization of self-care is a focus of healthcare in order to improve survival and well-being as well as to prevent hospitalizations [6–9]. At the same time, there are substantial differences in health care systems, patient education approaches, and the role of nurses in HF care along with limited availability of HF management programs in some countries [10]. Country specific challenges likely exist due to lack of resources, for example, salt restricted or healthy foods may be difficult to purchase in some countries [11] and weighing scales may not be affordable. There also are cultural differences in reactions to symptoms, as described in response to symptoms of a myocardial infarction [12]. In some countries it might be difficult or unusual to access a health care provider for HF symptoms. Migration (both voluntary and forced) might also increase the complexity of self-care for individual patients [13].

In order to target and individualize specific needs of HF patients in each country, it is important to have a description of self-care practices in different countries. A first report comparing self-care in developed and developing countries found differences in self-care across counties and demonstrated that self-care was not adequate in the majority of samples studied [14]. That study focused mainly on the concepts of self-care maintenance, self-care management and self-care confidence and less on specific self-care behaviors. We know little about how comparable specific self-care behaviors are across countries, cultures and populations and therefore aimed to compare five recommended heart failure specific self-care behaviors in countries across the world.

2. Methods

This study was a secondary analysis of data on HF self-care pooled from 22 samples of HF patients across three different parts of the United States, six countries in Europe, seven in Australasia, and one in South America, totaling 5964 HF patients. The actual data were obtained from the original researchers and sent in an SPSS or excel file to the first author. A research assistant assisted with integration of the individual data files into a single file for analysis. After analysis in SPSS, the original researchers checked for appropriate reporting and interpretation of the data.

If study participants were enrolled into an intervention involving education about HF, data were included only if patients had not received a structured, planned educational intervention prior to data collection. Data had been collected with the Self-care of Heart Failure Index (SCHFI) or the European Heart Failure Self-care Behavior Scale (EHFScB). These scales address many of the same behaviors (e.g., exercise, weighing, medication taking).

SCHFI: Both the SCHFI v.4 and SCHFI v.6 were used in data collection, but the items used were essentially the same in both versions. The SCHFI v.4 is a self-report questionnaire comprised of 15 items rated on a four-point response scale and divided into three scales measuring self-care maintenance, self-care management, and self-care confidence. Scores on each scale are standardized to range from 0 to 100 with higher scores indicating better self-care. In the original testing of this instrument, construct validity was demonstrated. Reliability, tested by Cronbach's alpha was .56, .70 and .82 for the self-care maintenance, self-care management and self-care confidence scales respectively. The SCHFI has been translated into numerous languages and is used worldwide to study the self-care of HF patients. The SCHFI was updated in 2009 with the addition of 7 items, including questions about medication adherence [15,16].

EHFScB: The European Heart Failure Self-Care Behavior Scale (EHFScB scale) was developed to measure the behaviors that HF patients perform to maintain life, healthy functioning, and well-being [17]. The EHFScB has 12 items rated on a 5-point scale between 1 (I completely agree) and 5 (I completely disagree). Higher scores indicate worse self-care. Items address HF self-care maintenance (e.g., regular weighing, diet, fluids), self-care monitoring, and self-care management (e.g., warn a health care provider in case of weight gain). After initial testing of the 12 item version, a 9-item version was developed by deleting 3 items [18]. Data from both the 9-item and 12-item scale are included in the current analysis since the individual items were unchanged. Validity and reliability of both the 9-item version and the 12-item version have been tested in at least 10 other populations with different linguistic characteristics [19–23].

In this study, the scores of separate items of SCHFI and EHFScB scale were used at the item level, as shown in Table 1. In addition to data on self-care, researchers were also asked to provide basic demographic (age, gender, marital status) and clinical data (HF etiology, time since diagnosis, New York Heart Association [NYHA] functional class) and the proportion of the sample with HF of an ischemic etiology (atherosclerosis of the coronary arteries) collected in their samples. Since ischemic heart disease is the most common cause of HF we note it in Table 2.

2.1. Data analysis

Descriptive statistics were used to analyze the data on 5 self-care behaviors. The proportion of subjects reporting low self-care on each of the 5 items is reported. Low self-care was defined on the SCHFI as: never/rarely or only sometimes performing these behaviors. Low self-care on the EHFScB scale was defined as not agreeing with the statement (scores 3, 4 and 5). In 3 samples, data

Table 1
Self-care behavior items in the Heart Failure of Self-care Index and the European Heart Failure Self Care Behavior scale.

Self care activity	SCHFI item	EHFScB-item
Restrict salt intake	How routinely do you eat a low salt diet (never/rarely–always/daily)	I eat a low salt diet (completely agree-completely disagree)
Physical activity	How routinely do you do some physical activity (never/rarely–always/daily)	I exercise regularly (completely agree-completely disagree)
Regular weighing	How routinely do you weigh yourself (never/rarely–always/daily)	I weigh myself every day (completely agree-completely disagree)
Flu shot	How routinely do you try to avoid getting sick (e.g., flu shot, avoid ill people)? (never/rarely–always/daily) Or: having an influenza vaccination annually	I get a flu shot every year (completely agree-completely disagree)
Medication	How often do you forget to take one of your medicines? (never/rarely–always/daily)	I take my medication as prescribed (completely agree-completely disagree)

SCHFI, Self-care of Heart Failure Index; EHFScB, European Heart Failure Self Care Behavior scale.

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Table 2
Descriptive data per country.

Sample	*N*	Scale	Site and design	Mean age (yrs)	Female	Married[a]	NYHA I/II/III/IV	Median time since diagnosis months	% ischemic etiology
Europe									
Spain	963	EHFScB12	HFC[b]	67 ± 13	28%	69%	6/66/27/1	7	53%
Italy									
Italy1	609	EHFScB12	OPC/other[b]	73 ± 12	43%	53%	22/37/32/9	41	46%
Italy2	210	EHFScB12	HFC/PC[b]	76 ± 6	43%	61%	0/45/48/7	–	57%
Netherlands	967	EHFScB12	Hosp[c]	71 ± 11	38%	–	0/5/51/44	–	43%
Sweden									
Sweden1	147	EHFScB9	HFC[c]	71 ± 11	33%	64%	4/59/34/3	–	29%
Sweden2	100	EHFScB9	H[c]	81 ± 9	38%	52%	0/12/80/8	–	65%
Sweden3	155	EHFScB12	HFC[c]	71 ± 11	24%	100%	5/27/53/15	–	40%
Germany									
Germany1	135	SCHFI	Hosp/HFC[c]	77 ± 6	57%	59%	30/48/22/0	48	25%
Germany2	90	EHFScB9	Hosp/HFC[b]	63 ± 12	27%	66%	6/55/36/3	–	48%
Serbia	106	SCHFI	Other[c]	76 ± 5	32%	–	16/80/4/0	72	55%
North America									
US North East	280	SCHFI	Hosp[b]	62 ± 12	36%	57%	4/19/59/18	50	69%
US South East	351	SCHFI	H[b]	60 ± 12	33%	56%	7/41/41/10	60	52%
US Mexican South West	134	SCHFI	Hosp[c]	72 ± 11	54%	60%	0/19/46/35	–	52%
South America									
Brazil	106	EHFScB12	Hosp[b]	62 ± 13	35%	70%	5/28/52/13	60	36%
Australia									
Australia									
Australia1	572	SCHFI	Hosp/H[c]	70 ± 13	36%	62%	0/57/31/11	24	59%
Australia2 Hosp[b]	143	SCHFI		71 ± 11	27%	53%	0/50/43/7	–	56%
Asia									
Japan	127	EHFScB12	OPC[b]	64 ± 16	31%	72%	25/55/20/0	29	27%
Israel	42	EHFScB12	HFC[b]	62 ± 9	21%	88%	0/24/69/7	–	83%
Vietnam	126	EHFScB9	Hosp[b]	70 ± 8	52%	46%	–	–	–
Hong Kong	167	SCHFI	HFC[b]	72 ± 21	61%	43%	7/46/46/2	–	25%
Thailand	400	SCHFI	Hosp/HFC[b]	65 ± 14	48%	76%	8/30/33/29	27	55%
Taiwan	34	SCHFI	Hosp[b]	61 ± 18	41%	59%	6/68/24/3	11	29%

EHFScB, European Heart Failure Self-care Behavior; SCHFI, Self-care of Heart Failure Index; NYHA, New York Heart Association; HFC, Heart Failure clinic; OPC, outpatient clinic; PC, Primary Care; Hosp, hospital; H, Home; other, Cardiovascular Day Hospital, research clinic.
[a] Married or cohabiting.
[b] Data collected as part of a descriptive study.
[c] Data collected as part of a Randomized Controlled Trial.

were collected with both the SCHFI and the EHFScB scale (Hong Kong, Brazil and Italy). Only data from one of the scales (the one with the most complete items) was used in analysis (EHFScB in Italy and Brazil; SCHFI in Hong Kong). In some samples no data were collected on self-care related to medication adherence as a result of using the 15 item version of the SCHFI and in some samples no data were collected on the item about obtaining a yearly flu shot due to use of the 9-item version of the EHFScB scale.

3. Results

3.1. Demographics

Data were collected from small and large samples ranging in size from 34 patients (Taiwan) to 967 (Netherlands). In 12 samples the EHFScB scale was used to collect data, in 10 the SCHFI. Data were collected in heart failure clinics, home setting, outpatient departments, hospitals and research clinics. Data were collected from descriptive (cross-sectional or longitudinal) studies and from randomized control trials (pharmacological or non-pharmacological interventions) (Table 2). The mean age of the samples ranged from 60 years in an American sample to 81 years in one of the Swedish studies. All studies included both male and female patients (Table 2). The mean age of the total population was 69 with 38% female patients. Data had been collected in patients from all NYHA classes, mostly in NYHA classes II–III.

3.2. Self-care

Table 3 and Fig. 1 describe the results of the scoring on the separate items. The data reflect the percentage of persons in each sample who have difficulty with each self-care item.

Medication: In all samples most of the patients reported that they took their medication as prescribed. The median reported percentage of patients in the samples reporting not taking their medication was 7%, reflecting that in half of the 22 samples 7% or less of the patients reported not performing this self-care behavior. The highest number of patients who reported not taking their medication on a regular basis or as prescribed was the sample from Israel. On the EHFScB scale, 19% of this sample did not agree with the statement 'I take my medication as prescribed'. (Fig. 1A)

Exercise: Self-reported exercise levels were low in most of the samples. Low rates of exercise (never/rarely/only sometimes on SCHFI or score >2 on the EHFScB scale) ranged from 36% in one of the samples from Germany to 90% in one of the Italian samples and 89% in the sample from Brazil. In 16 of the 21 samples, more than 50% of the patients reported low exercise levels (median 54%) (Fig. 1B).

Weight monitoring: Weight monitoring (daily or routinely, see Table 1) was irregular in most samples, with the lowest number of people not weighing themselves regularly reported in one of the Australian samples (24% reported not weighing) and the highest percentages of not weighing in the samples in Hong Kong (95% reported not weighing) and Brazil (89%). In 16 samples, less than

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Table 3
Low self-care per country. Low self-care was defined on the Self-care of Heart Failure Index as: never/rarely or only sometimes performing these behaviors. Low self-care on the European Heart Failure Self-care Behavior Scale was defined as not agreeing with the statement (scores 3, 4 and 5).

Sample	*N*	Exercise Low %	Weight monitoring Low %	Flu shot Low %	Medication Low %	Sodium restriction Low %
Europe						
Spain	963	62	78	40	3	25
Italy						
Italy1	609	54	60	23	15	35
Italy2	210	90	68	35	8	26
Netherlands	967	44	62	18	2	18
Sweden						
Sweden1	147	61	67	–	7	56
Sweden2	100	82	34	–	0	40
Sweden3	155	62	59	38	1	35
Germany1	135	40	54	35	6	49
Germany2	90	36	48	–	3	60
Serbia	106	51	73	45	13	48
North America						
US North East	280	43	39	17	2	26
US South East	351	66	61	30	–	44
US Mexican South West	134	74	82	40	13	41
South America						
Brazil	106	89	89	53	9	36
Australia						
Australia 1	572	47	24	16	–	23
Australia 2	143	51	54	26	10	37
Asia						
Japan	127	53	46	52	2	45
Israel	42	57	71	57	19	60
Vietnam	126	41	43	–	10	22
Hong Kong	167	83	95	75	–	63
Thailand	400	53	83	37	–	53
Taiwan	34	68	74	53	–	91

half (median 61%) of the patients weighed themselves regularly, with large differences between the countries (Fig. 1C).

Flu shot: Receiving an annual flu shot varied widely among the countries; 16–75% of patients reported not getting an annual flu shot (median 38%). Countries with the highest percentage of patients not receiving a flu shot were Hong Kong, Israel, Brazil, Taiwan and Japan (Fig. 1D).

Sodium restriction: Self-care with regard to a sodium restricted diet varied more across the countries than other self-care behaviors. Between 18% and 91% (median 40%) of patients reported not adhering to a low salt diet. (Never/rarely/only sometimes on SCHFI or score >2 on the EHFScB scale.) Countries where the highest percentage of patients reported following a sodium restricted diet were the Netherlands (18%), Vietnam (22%) and Australia (23%). Countries with the highest percentage of patients not restricting their sodium intake were Taiwan (91%) and Hong Kong (63%) (Fig. 1E).

4. Discussion and conclusion

4.1. Discussion

This international study of important HF self-care behaviors demonstrates that there is wide variability in HF self-care across countries, but that there is markedly poor adherence to most self-care behaviors regardless of country. Self-care behavior regarding medication adherence and exercise was similar in most countries, but we found large variations in adherence to weight monitoring, salt restriction and receiving an annual flu shot.

Culture is important to consider with regard to performance of self-care behaviors among patients with HF and delivery of support to perform self-care. We define culture as a set of shared attitudes, values, goals, and practices that characterize an institution, organization, or group [24]. Although we realize that within a country several cultures might exist and even within cultures, subcultures might have different values, use of the word culture rather than country fits the goal of our descriptive study. Numerous researchers have studied self-care previously, but results have not been compared across nations, across culturally diverse populations and across health care systems. We undertook this large-scaled comparison of divergent samples with unique health care systems and cultures to provide insight in possible similarities and differences in HF self-care across the world. This study adds to previous comparisons between self-care in developed and developing countries [14] and provides a broad reflection on international self-care that may help us to identify factors related to self-care behaviors and explore possible interventions to improve specific self-care behaviors worldwide.

Several explanations can be given for the differences in HF self-care across the different samples. Self-care occurs in a context, which in this case refers to locations and countries of the participants. The self-care described in this article represents the behaviors and beliefs characteristic of a wide variety of cultures or social and ethnic groups from around the world. Besides the services (e.g., access to education in HF clinics) available in each country, every group surveyed probably has distinct cultural norms and practices surrounding foods and traditions that influenced their self-care [25].

Across all samples, we found high self-care in medication taking. Although we realize this is self-reported adherence which might not completely reflect actual practice, it is interesting to see that it was similar in all the samples. The local investigators reflected that in most of their cultures people have a strong belief in the benefits of medicine and have a ‘doctor knows best’

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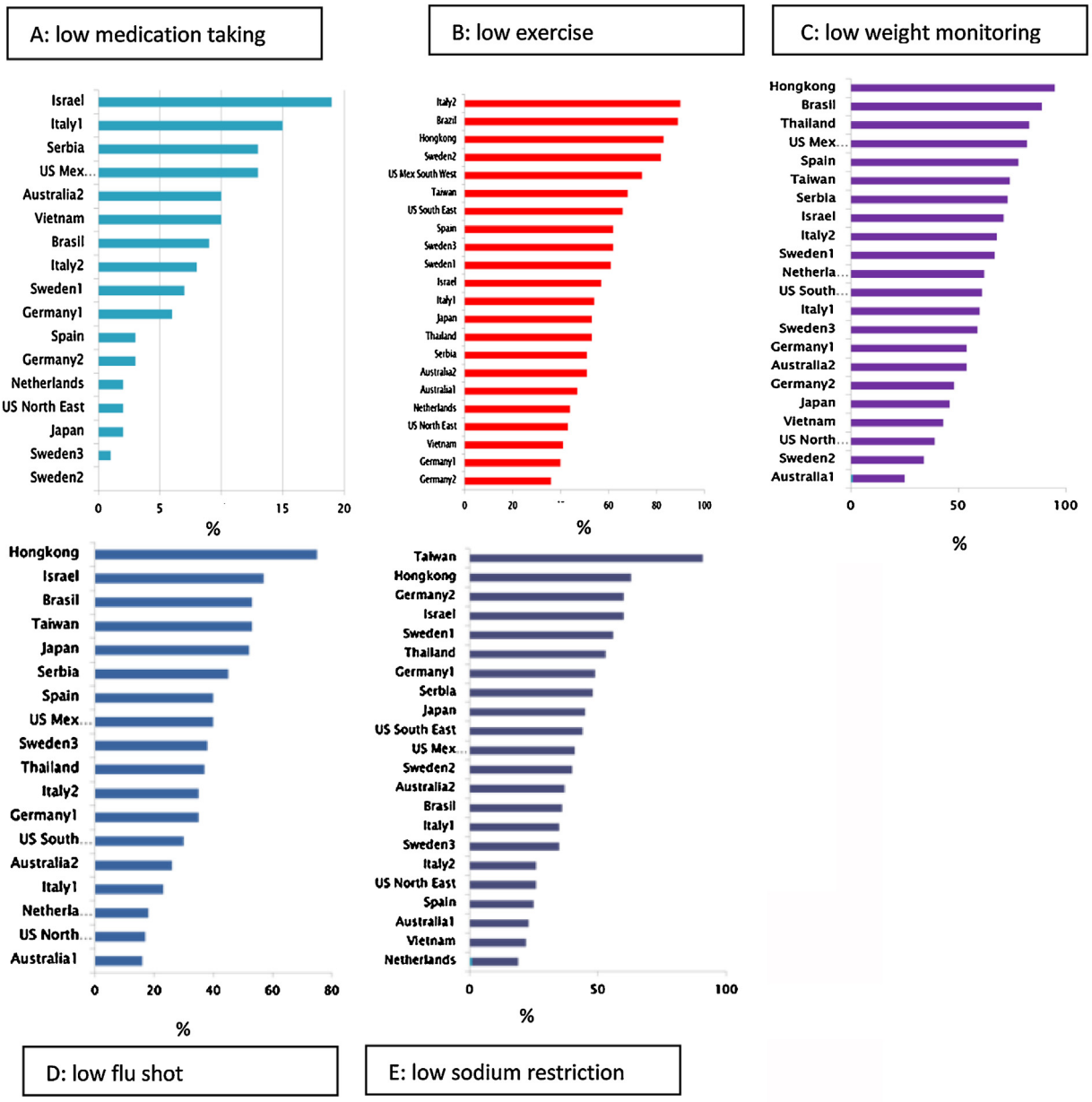

Fig. 1. Percentages of low self-care behaviors per country.

philosophy. Furthermore, medications (for the elderly) are subsidized in several countries and in some countries home care nurses support patients to organize their medication schedule. Although the reported data on self-care in medication taking are high, education and support to appropriately use medication is still needed. In many populations older adults often use non-prescription and inappropriate drugs or forget to take their medication [26–29]. Patients may use herbal medication or traditional medication in addition to prescribed pharmacotherapy and may not be aware of drug interactions [30]. In some countries patients use herbal medications/traditional medicine as a supplement or do not trust "western medication" since they feel it is made of chemical ingredients that come with many side effects [31,32].

In contrast to the high level of medication taking self-care behavior across samples, a consistently low level of exercise was found across the samples. In most samples more than half of the patients did not exercise regularly. This is in line with findings of the general older population in several countries. For example, in Brazil one third of individuals over 65 years of age do not engage in any kind of physical activity [33] and only 36% of Australians aged 75 years and over walk for exercise [34]. In Italy, 31% of elderly men and 51% of elderly women do not engage in physical activity during their free time [35] and in Taiwan, only 44% of elders engage in regular exercise [36]. At the same time it is known that older persons who exercise gain health benefits, so this self-care behavior is important for healthy elders. For HF patients, however, it is not always easy to begin exercising if this is not a typical behavior, due to symptoms [37]. In addition, the climate (e.g., cold weather in Sweden, rain in the Netherlands and heat in countries like Italy, Australia and Israel) can make it difficult for patients to leave their homes to engage in exercise. Within countries and continents differences can be seen due to cultural perceptions about exercise, climate, and available resources. For example, in the US samples, exercise was least common among the Hispanic patients enrolled in the southwestern US in spite of balmy weather,

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suggesting that cultural factors influenced behavior in this sample. Although some countries have rehabilitation programs or sport groups for cardiac patients, not all HF patients have access to these programs, and not all healthcare providers recommend this activity or tell patients how to do it [37].

Similar difficulties with regular weighing were observed in almost all of our samples. Realizing that these patients had not received any special education about their HF suggests that many may not have been aware of the importance of symptom monitoring. In several countries we included in the study, most people have a scale at home, although this seems to be more common in the younger and healthier population than in the sick and the elderly. At the same time, there might be countries in which purchasing a weighing scale is not on the priority list of family expenses and people sometimes would go to primary care clinics near their home to measure their weight. Barriers to purchasing scales include the cost associated with them, especially among pensioners and people from a low socio-economic background, and those who are vision impaired and need a costly talking scale.

The differences observed in the different parts of the world related to the self-care behavior of getting a flu shot are probably related to public awareness, policy and resources. And, in some countries poor (health) literacy might play a role. In terms of public awareness, it may be that not all HF patients are aware of the risks of influenza complications or the relationship between the flu and deterioration of HF, which might explain low adherence to this self-care behavior. On the other hand, in several countries an annual flu shot is free and provided locally by a primary healthcare provider or the public health service. In several countries in our study patients are routinely reminded to get a flu shot by their primary provider or at the HF clinic [8,38]. However, this is not the case in all countries and also not for all age groups. In some countries, only older people over age 65 will be included in these campaigns. In other countries, some (uninsured) patients still need to pay a small amount.

Similar to the local factors explaining differences in flu shots, adherence to a low salt diet may be related to difference in national HF guidelines, local food policies, available resources, and individual responses to suggested dietary changes. Although HF guidelines are inconsistent in the strength of their recommendation regarding the need for a strict sodium restriction of 2000 mg (or less) for all HF patients [6,7], sodium restriction remains important in the management of heart failure [39].

Looking at the different countries involved, current salt intake in many countries is between 9 and 12 g/day. A moderate reduction in salt intake to the recommended level of 5–6 g/day would be consistent with the maximum intake recommended by the World Health Organization for all adults [40]. In our study it was most difficult for patients from the Eastern/Asian countries to follow a salt restriction self-care recommendation. This might be due to differences in guidelines for chronic HF (e.g., the Japanese guidelines recommend an average daily salt intake $\leq$7 g among patients with mild to moderate HF [41] or to the difficulty of preparing or purchasing salt restricted food (e.g., Kosher food is often high in sodium [42]) or prepared food in markets or local restaurants might be very high in sodium content.

In some countries governmental or non-governmental organizations have addressed the sodium issue and national recommendations and policies exist. Some countries have populations-based campaigns aimed at reducing dietary sodium [43,44]. For example, in Thailand, the national campaign "Reduce Sodium Intake-to-Stop Chronic Disease" was implemented a few years ago with television and broadcasting media, Internet, posters, and booklets [45]. There is still a lack of clarity in the optimal sodium restriction, and healthy citizens, HF patients and health care providers struggle to know what is best. For example, different recommendations exist. For example in Sweden the recommended salt intake is 7 g of salt per day for men (2.8 g sodium) and 6 g salt per day for women [46] while in the Netherlands the recommended salt intake is 6 g a day for both men and women [47]. Even within countries there are several cultural habits that might call for separate approaches. For example, preliminary results from an ongoing study of 3850 adults living in the north, center and south of Italy, showed that the average intake of salt among Italians is 11 grams in males and 8 g in females daily [48]. That study also showed that salt intake is higher in the south than in the north of Italy.

Cultural differences might also exist regarding setting priorities between the various self-care behaviors. Knowledge about these priorities might help health care providers understand the motives of patients to implement certain self-care behaviors easily (e.g., diet) while others might not be implemented (e.g., symptom monitoring) [49].

Although this study is the first study comparing HF self-care internationally on a large scale in a typical older, chronic heart failure population, we realize that there are some limitations that suggest caution in interpreting our results. First, this was a secondary analysis of existing data from studies applying different inclusion and exclusion criteria, study designs and the data collected were for different aims and from different recruitment sites. Second, we pooled data that were collected with 2 different instruments. We therefore chose to use only the items that covered the same topics and not to include other self-care behaviors that were described differently in the two instruments. Thus, we realize that we did not paint the total picture of self-care behavior. We also did not have insight on patients' previous knowledge or experience with HF. In other words, in some countries patients might have obtained better information about HF self-care (e.g., in primary care, during hospitalization, in outpatient HF clinics). In some situations patients may have been so new to the diagnosis that they had not had an opportunity to practice self-care as yet.

4.2. Conclusion

Most self-care behaviors are poor and can be improved in HF patients. Several differences exist across and within cultures, continents and countries. A general improvement of the quality and the content of the education provided is needed to improve HF self-care of patients. Further changes in some health care system and national policies are needed in order to strengthen the possibilities for patients with HF to increase their self-care behavior.

4.3. Practice implications

Patients with heart failure need to cope with a lifelong regimen that involves more than simply medication taking. The lifestyle changes require support to help patients learn how to deal with the consequences of this chronic illness. Importantly, the support needed appears to differ by country. Specific self-care behaviors need a country- and culture-specific approach.

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