

ORIGINAL ARTICLE

Agreement between Heart Failure Patients and Their Primary Caregivers on Symptom Assessment

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ABSTRACT

Background: To decrease the readmission rate of heart failure (HF) patients, patients and their caregivers (CGs) should participate in symptoms assessment. This study aimed to assess the agreement between HF patients and their CGs on symptoms assessment.

Methods: Using a correlational design, 100 HF patients with their CGs (100 dyads) were recruited from Department of Cardiology, Iranshahr, during August–December 2014. Data were collected using modified Heart Failure Symptom Survey (HFSS). Pearson and intra-class correlation coefficients (ICC) were used to analyze the degree of agreement within HF dyads, using SPSS16. The level of significance was set at 0.05.

Results: The most frequent and severe symptom assessed equally by partners was shortness of breath (SOB). Dyads had a good agreement on assessment of extremity swelling ($r=0.87$, $P\leq 0.01$, $ICC=0.861$ CI: 0.798–0.901), SOB at rest ($r=0.83$, $P\leq 0.01$, $ICC=0.775$, CI: 0.680–0.845), SOB with activity ($r=0.81$, $P\leq 0.01$, $ICC=0.795$ CI: 0.711–0.858), and feeling depressed ($r=0.77$, $P\leq 0.01$, $ICC=0.769$, CI: 0.675–0.838). 28.6% of HF dyad had a good, 50% had a moderate, and 21.4 % had a poor agreement in assessment of HF symptoms.

Conclusion: Most of the HF dyad members did not agree with each other on the assessment of symptoms. Knowledge, skills and ability of each dyad in HF symptoms assessment should be included in the patients' discharge planning and nurses must modify their misunderstanding or inability.

KEYWORDS: Agreement, Caregiver, Consensus, Heart failure, Symptom assessment

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INTRODUCTION

Heart Failure (HF) is a rising health problem, affecting about 23 million patients worldwide.¹ Despite many advances in the treatment of HF, the readmission rate is still high and it has been estimated to be between 21–69%.^{2,3} Poor general health knowledge and poor perception of symptoms by either patients or their family caregivers (CGs) are two important patient-related factors contributing to HF readmission.^{4,5} Some studies have indicated that more than 50% of HF patients have low health literacy,⁶ and only 5% of them could recognize their symptoms.⁷ Given that much of the care for HF is provided at patients' homes by family or informal CGs,⁸ reducing the readmission of HF patients is somewhat dependent on improving the knowledge of these patients and their CGs about self-care activities^{6,9} as well as participating of family members in self-care activities of HF patient, particularly symptom assessment.¹⁰ As several studies emphasized, active participation of family members in the patients' disease management in addition to reducing readmission rates can considerably improve the psychosocial, physical and social outcomes of HF.^{1,11-15}

Recent evidence indicates that family members do not participate sufficiently in the patient care,¹² particularly in symptom assessment, weight monitoring, and physical activity.¹⁶ One of the frequent reported reasons for low contribution of CGs to the self-care of HF patients is misunderstanding regarding the assessment of symptoms between patients and their CGs.^{7,17,18} Misunderstanding of symptoms can lead to inappropriate decision making about the management of symptoms by either HF patients or their CGs.¹¹ In addition, disagreement between HF patients and their CGs might lead to focusing on the wrong symptoms or mismanaging of symptoms, which ultimately can increase the likelihood of the patients' readmissions.^{10,18-20} Therefore, successful HF management may largely depend on the congruent views of both patients and CGs.¹⁸ In this regard, it

is imperative that patient and his/her CG, as a dyad, have an agreement or common understanding regarding the assessment and management of symptoms.^{7,12,17,21-24} However, based on the evidence available, it seems difficult to conclude how much patients and their primary CGs agree with each other regarding HF symptoms assessment and management.

To the best of our knowledge, only one study explored the congruence between HF patients and their CGs regarding the assessment of common symptoms of HF and found that about 43% of HF patients and their primary CGs had a moderate to high congruence on symptoms assessment.⁷ It should be mentioned that the study was conducted in a well-developed country with well-educated people using a relatively small sample. In addition, it is difficult to generalize the results of studies of foreign countries with different cultural and social context into the context of Iran. Therefore, it is important to re-examine the agreement on HF symptoms between dyads in Iranian care settings since a similar study in this regard has not been conducted in Iran yet.

Given the fact that symptoms assessment by patients and/or their CGs is vital for successful management of HF,¹ and because the available evidence about agreement on symptoms assessment between HF patients and their primary CGs is inconclusive, further studies are required to understand the extent of congruence and/or incongruence among them. Accordingly, the objectives of the present study were: (1) ranking HF symptom as perceived by the patients and their primary CGs; (2) assessing the agreement between HF patients and their CGs on symptoms assessment; and (3) grading the level of agreement within HF dyads regarding symptoms assessment.

MATERIALS AND METHODS

This cross-sectional, correlational study was conducted during August–December 2014.

To find the degree of agreement between two independent observers with a predetermined effect size of 0.50 (at least 50% agreement between two observers), a significant alpha of 0.05 and a statistical power of 0.80, the desired sample size for each group was calculated to be 85. We increased the sample size to 100 subjects for each group (HF patients and CGs). In the present study, any layperson acting as a patient's partner or family member was referred to as a CG, such as a spouse, adult child, sibling, or unmarried partner. The CG needed to be currently living with the patient. The paired patient and CG are referred to as a dyad. A consecutive sampling approach was used to recruit 100 HF patients accompanied by their dedicated CGs (n=100) from the Department of Cardiology, Khatam-Al-Anbia University Hospital, Iranshahr, Iran. This hospital is the main center for the treatment of most medical surgical diseases in the southeast of Iran.

Eligible patients were all adults aged 18 or over with an established medical diagnosis of HF. The CG was included after identification by the patient as the person who was most involved in patient care. The CG must be capable of caring for the patient. Patients and CGs were excluded if they had an established medical diagnosis of dementia. The study was approved by the institutional review board of the local Human Research Review Committee (No, 89-2197). Patients and their primary CGs provided a written informed consent.

Socio-demographic features of patients and CGs were collected via an investigator-developed questionnaire. Patients' clinical information was obtained from the medical record. The HFSS was used to assess the frequency and severity of 14 common symptoms of HF experienced by patients.²⁵ Previously, the HFSS has been validated in several studies.^{7,26} This 11-point scale comprises four subscales, including frequency, severity, interference with physical activity, and interference with enjoyment of life. The first two subscales assess the frequency and severity of HF symptoms, and the second two subscales measure the disease interference

with daily life. Based on the purposes of the present study, we used the modified version of the HFSS. The modifications included omission of the "interference with physical activity" and "interference with enjoyment of life" subscales. Scores for each symptom ranged from 0 to 10, with 0 indicating no experienced symptom. For each experienced symptom, its frequency and severity scores ranged from 1 to 10, with 10 indicating a very frequent or severe symptom. A mean score for each symptom was computed using the average of the frequency and severity rating for determining and ranking the most terrible symptoms.

Because HFSS has not been validated in Iran, the translation-back-translation technique was adopted. First, the questionnaire was translated from English into Persian by two bilingual nursing experts; then, the results were translated from Persian back into English. Slight improvements were made to the phrasing to increase the comprehension of the instrument.

The content validity of the modified version of the HFSS was determined by a group of experts in HF, including four cardiologists, four nurses, and two researchers of the present study. The index of content validity (CVI) of four subscales was calculated, and two subscales ("symptom frequency" and "symptom severity") with CVIs of more than 80% were selected. Internal consistency reliability for the frequency and severity subscales was assessed by calculating Cronbach's Alpha for the data acquired from the pilot study using 10 dyads. The obtained values were 0.76 and 0.78 for the patients and 0.79 and 0.75 for the CGs, respectively. Inter-rater reliability by intra-class correlation coefficient (as percentage of agreement among the 10 data collectors) was 0.89.

The data were collected through a face-to-face, fully structured interview with participants. All interviews took place in the hospital several hours (about 5-8 hours) before the patients' discharge. We interviewed the patients first, and subsequently interviewed

their CGs separately. During the interview, the researcher explained the study's aims and gave directions to the participants about what they were being asked to do. Patients and CGs responded orally to the HFSS items (symptoms) and the researcher recorded their responses. For each symptom, the researcher asked participants about the frequency and severity of symptoms experienced in the last week prior to hospitalization. Patients and their designated CGs rated the symptoms between zero to 10 based on the frequency and severity of the symptoms. After the interview, all 14 symptoms were scored and the mean of the frequency and severity for each symptom was calculated by the researchers for determining and ranking the most terrible symptoms as well as other aims of the study.

All statistical analyses were performed using SPSS 16 software (IBM Corp., USA). Preliminary analyses were conducted to assess the missing data and assumptions

for statistical tests. We used frequencies and percentages for categorical data and mean±standard deviation for continuous variables to determine the characteristics of the sample. The symptoms of HF were ranked based on the mean scores of frequency and severity. Pearson's correlation coefficient was calculated to quantify the linear association between symptoms. The level of statistical significance was set at 0.05.

In clinical studies, intra-class correlation (ICC) and concordance correlation coefficient (CCC) are often reported as methods of evaluating the agreement between different observers.^{27,28} We used the ICC to determine the level or degree of agreement within the dyads using the HFSS symptom scores. To judge the degree of ICC, values ranging from 0.70–1.0 signified a good agreement, 0.4–0.69 reflected a moderate agreement, and values of 0.0–0.39 reflected a poor agreement.^{7,27} The study flow chart is illustrated in Figure 1.

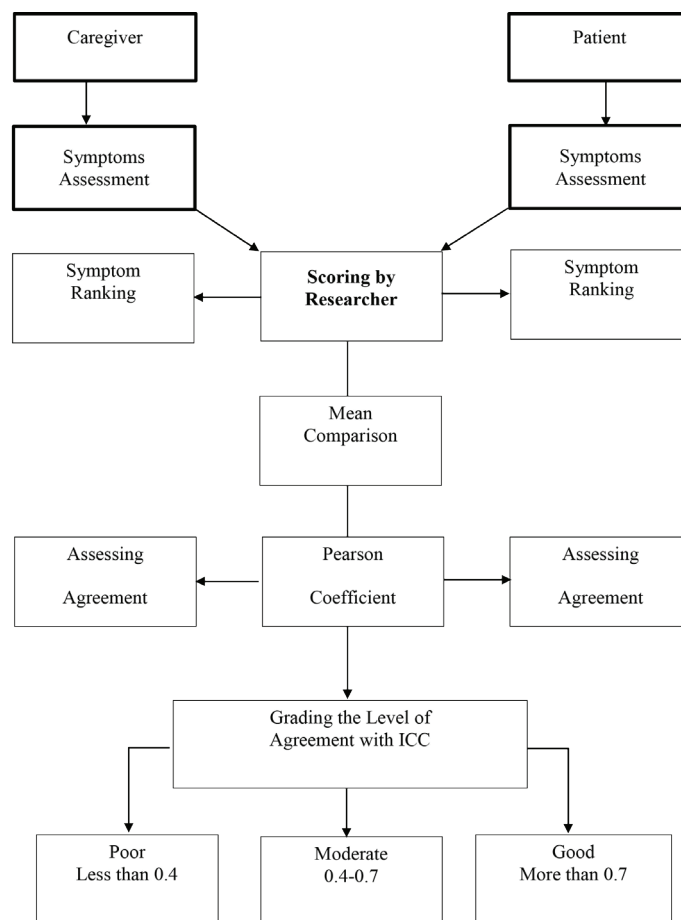


Figure 1: The Study Flow Chart

RESULTS

Sample Characteristics

One hundred eligible patients with their primary CGs were enrolled in the study, and all one hundred dyads completed this study (200 participants). The mean±SD age of HF patients and CGs were 66.26±11.99 and 38.07±14.32 years, respectively. The patients' group subjects were approximately 28 years older than their CGs. Most of the patients were male, while most of the CGs were female. More than 85% of all the participants were married. More than 80% of patients were classified as New York Heart Association (NYHA) class II and III. All CGs lived with their patients, and the mean time of provided care by CGs was 13h and 15 min per 24h. The majority of CGs (69%) were adult children of the patients. The demographic, clinical characteristics and descriptive data for the patient and CG variables are listed in Table 1.

Ranking the Symptoms of Heart Failure

HF symptoms were ranked using the mean score of frequency and severity of the 14 symptoms reported by patients and their primary CGs. As shown in Table 2, shortness of breath (SOB) with activity (exertional dyspnea) was the most frequent and severe symptom, which was similarly identified by both patients and their CGs. Bloating abdomen (distention) was ranked as less frequent and severe.

In terms of symptoms ranking, HF dyads gave similar importance to the frequency and severity of SOB with activity, SOB at sleep, SOB when lying down, difficulty sleeping, fatigue, extremity swelling, and bloating abdomen. On the other hand, 50% of the symptoms were ranked differently.

The mean score for all types of SOB was 7.74, which falls into the category of high severity based on the HFSS. As displayed in Table 3, the patients and CGs similarly

Table 1: The Demographic and Clinical Characters of Patients (N=100) and CGs^a (N=100)

Variable		N of HF patients	N of CGs
Time of HF ^b Diagnosis	<1 year	36	-
	>1 year	64	-
NYHA ^c Class	I	4	-
	II	62	-
	III	17	-
	IV	17	-
Device	No	77	-
	Pacemaker	9	-
	ICD ^d	14	-
Sex	Male	58	33
	Female	42	67
Marital status	Single	4	15
	Marriage	90	85
	Divorce	3	0
	Widow	3	0
Relationship to patient	Son	-	33
	Daughter	-	36
	Sibling	-	4
	Spouse	-	20
	Mother or father	-	7
Educational level	Uneducated	70	49
	Primary (<5 th grade)	26	16
	(6 th -12 th grade)	4	20
	1-2 years college	0	0
	Graduate or higher	0	15

Values are presented as N (number) and each N of items equals the percentage. ^aCaregivers; ^bHeart failure; ^cNew York Heart Association; ^dImplantable cardioverter-defibrillator

Table 2: Patient and CG^a Mean±SD Scores of Sign and Symptoms (N=100 Dyads)

Sign and symptom	Patients (N=100)			CGs (N=100)		
	Frequency	Severity	Total score	Frequency	Severity	Total score
SOB ^b with activity	8.46±1.81	8.12±1.53	8.29±1.68	7.84±1.65	8.38±1.87	8.11±1.83
SOB at rest	8.62±1.73	7.10±1.93	7.86±1.83	7.00±1.93	8.06±2.43	7.53±2.23
SOB lying down	6.77±2.63	7.35±1.74	7.06±2.49	6.40±2.83	6.20±1.92	6.30±2.40
Difficulty sleeping	6.40±2.81	6.50±3.13	6.45±3.07	6.70±2.98	5.90±3.25	6.30±3.01
Fatigue	6.80±4.65	5.30±3.83	6.05±4.45	5.85±3.64	6.19±2.45	6.02±3.07
Irregular heart beat	4.36±2.43	6.00±2.83	5.18±2.68	4.40±2.26	4.60±2.65	4.50±2.54
Chest pressure	5.26±3.53	5.00±2.95	5.13±3.14	4.10±2.53	5.00±2.83	4.55±2.67
SOB wake up at night	5.32±3.26	4.90±3.13	5.11±3.22	5.86±2.05	5.20±2.29	5.53±2.11
Depressed	4.78±2.83	5.24±3.05	5.01±2.94	6.10±3.35	3.78±1.95	4.94±3.12
Dizziness	4.08±2.67	4.90±2.93	4.49±2.84	5.86±3.13	4.32±2.20	5.09±3.01
Worsening cough	4.03±3.24	3.75±2.83	3.89±3.11	4.2±3.24	3.66±2.92	3.93±3.09
Forgetfulness	4.13±3.11	4.45±2.93	4.29±2.99	3.2±2.83	4.78±3.36	3.99±3.32
Extremity swelling	4.22±3.93	4.00±2.83	4.11±3.86	2.6±2.70	2.82±3.83	2.71±3.75
Bloated abdomen	3.38±2.93	3.00±3.83	3.19±3.60	1.40±1.90	2.80±2.90	2.10±2.83

The presented number are mean±SD. ^aCaregiver; ^bShortness of breath

Table 3: Patient and CG^a Ranking of Sign and Symptoms (N=100 Dyads)

Sign and symptom	Patient rank	Mean±SD	CG rank	Mean±SD
SOB ^b with activity	1	8.29±1.68	1	8.11±1.83
SOB at rest	2	7.86±1.83	2	7.53±2.23
SOB lying down	3	7.06±2.49	3	6.30±2.40
Difficulty sleeping	4	6.45±3.07	4	6.30±3.01
Fatigue	5	6.05±4.45	5	6.02±3.07
Irregular heart beat	6	5.18±2.68	10	4.50±2.54
Chest pressure	7	5.13±3.14	9	4.55±2.67
SOB wake up at night	8	5.11±3.22	6	5.53±2.11
Depressed	9	5.01±2.94	8	4.94±3.12
Dizziness	10	4.49±2.84	7	5.09±3.01
Worsening cough	11	3.89±3.11	12	3.93±3.09
Forgetfulness	12	4.29±2.99	11	3.99±3.32
Extremity swelling	13	4.11±3.86	13	2.71±3.75
Bloated abdomen	14	3.19±3.60	14	2.10±2.83

^aCaregiver; ^bShortness of breath

reported and ranked the symptoms of 1-5, 13, and 14. However, the patients and CGs reported differently for the rest of the symptoms.

Congruent/Agreement Assessment and Grading

First, the Pearson correlation coefficient was used to assess the agreement between symptom assessment scores. Next, the ICC was used to measure the degree of agreement with in the dyad members. The level of agreement for the first four symptoms (28% of symptoms) was greater than .70 with in the HF dyads, indicating

a good agreement. Fifty percent of symptoms (7 of the 14 symptoms) had a moderate agreement (ICC 0.40–0.69). Three symptoms had poor congruence (ICC<0.4). Table 4 depicts the ICC among the HF dyads. We found that 28.6% of HF dyad members had a good agreement, 50% had a moderate agreement and 21.4 % had a poor agreement in the assessment and recognition of HF symptoms. Thus, about 78% of HF dyad members had a moderate to good agreement; about 70% had a moderate to poor agreement in symptoms assessment.

Table 4: HFSS Symptom Agreement between the Patient and CG^a (N=100 Dyads)

Symptom	Pearson coefficient	P value*	Intra-class Correlation Coefficient, 95% CI	Degree of agreement
Extremity swelling	0.87	<0.001	0.861 (0.798–0.901)	Good
SOB ^b during rest	0.83	<0.001	0.775 (0.680–0.845)	
SOB with activity	0.81	<0.001	0.795 (0.711–0.858)	
Depression	0.77	<0.001	0.769 (0.675–0.838)	
SOB lying down	0.72	<0.001	0.684 (0.522–0.791)	Moderate
Dizziness	0.69	<0.001	0.680 (0.553–0.775)	
Bloated abdomen	0.66	<0.001	0.609 (0.435–0.732)	
Fatigue	0.65	<0.001	0.646 (0.515–0.747)	
Worsening cough	0.65	<0.001	0.644 (0.514–0.745)	
Chest pressure	0.64	0.011	0.618 (0.479–0.727)	
Difficulty sleeping	0.61	0.030	0.606 (0.466–0.716)	
Forgetfulness	0.60	0.060	0.387(0.355–0.710)	Poor
SOB, wake up at night	0.41	<0.001	0.369 (0.188–0.526)	
Irregular heart beat	0.32	<0.001	0.314 (0.130–0.477)	

*Pearson correlation test

^aCaregiver; ^bShortness of breath

DISCUSSION

The most frequency and severe symptoms ranked similarly by both HF patient and CG were SOB with activity, SOB at sleep, SOB when lying down, difficulty sleeping, fatigue, extremity swelling, and bloated abdomen. Surprisingly, while majority of the participants in our study were uneducated, they could similarly rank approximately half of the HF symptoms. In assessing and grading the level of agreement on symptoms assessment of HF between dyads, we found that extremity swelling had the highest degree of agreement. Thereafter, SOB during rest, SOB with activity, and depression were the most congruent symptoms within the dyads, respectively. Assessment of forgetfulness, SOB at night, and irregular heartbeat had the poorest agreement within the dyads. In comparing our results with other studies, a similar study found that most of HF patients and their primary CGs did not agree with each other on symptoms assessment. That study was conducted in a community setting in a well-developed country to identify the ability of family members to act as a HF patient's proxy. Its findings showed a moderate to high congruence within the dyads on the assessment of extremity edema, difficulty concentrating, dizziness, chest fluttering, chest pressure, and SOB,⁷ which were different from our findings.

Of possible reasons for these differences are that these two studies were conducted in two different countries with different populations, cultures, educational levels, and ethnics. Due to the low educational level of people in our region, the high level of disagreement within the dyad members was not unexpected. Nevertheless, our participants only ranked and assessed about the half of the symptoms differently. In contrast, only a small proportion of participants of the aforementioned study⁷ had a low level of education. Nonetheless, the prevalence of incongruence within HF dyads was high. Another qualitative study examined the congruence with in HF dyads; however, its findings are not directly comparable with our results because they did not assess the pathophysiological symptoms of HF as we did. That study evaluated the challenges of living with HF and found most of dyads expressed some degree of ambiguity in HF symptoms' perception.¹⁷ Despite these differences, the overall findings showed varying levels of disagreement regarding the symptoms assessment within the HF dyads.

Many studies have emphasized the importance of recognizing symptoms. Previous studies found that seeking treatment for worsening symptoms of HF was influenced by patients and their CGs' ability to understand, assess, and manage those symptoms.^{19,20,29-31} In

addition, several studies showed that failure to understand and respond appropriately to worsening HF symptoms by patients or their family members is associated with delay in seeking treatment.^{20,32,33} Based on what has been discussed so far, we suppose that the disagreement within the dyads might delay the prompt action of either HF patients or CGs regarding symptoms management. Given that most patients with HF are elderly with some physical or cognitive disabilities, much attention must be paid to empowering CGs in terms of symptoms assessment and management. There is an essential need for extending the knowledge and skills of the dyads about HF symptoms assessment and management. Nurses are in a key position to assist and encourage HF patients and their family members in making appropriate self-care decisions regarding to the symptoms management, as well as to educate or promote helpful lifestyle behaviors. In this regard, nurses must take responsibility to educate and support HF patients and their family members, either at hospital or at home care facilities. Nurses are recommended to determine the ability of each dyad member in symptoms assessment and management prior to hospital discharge and modify any misunderstanding or inability to manage symptoms adequately.

The research sample was limited to HF patients admitted to the local hospital because of lack of a home care setting in the region, and that the strength of the relationship between patient and his/her CG was unknown. However, we were convinced that the dedicated CG was usually involved in the care of his/her patient at the hospital and at home. In addition, future work should include patients with diverse cultural, racial, and ethnic background countries to find whether these variables can interfere with the symptoms assessment ability of the patient and their primary CGs.

CONCLUSION

Most of the HF dyad members did not agree with each other on the assessment of symptoms. These

areas of disagreement highlighted the need for HF dyad education. Extending the knowledge and skills of dyads regarding HF symptoms should be included in patients' discharge planning and nurses must determine the ability of each dyad member in symptoms assessment and management and modify any misunderstanding or inability. We assume that some variables may interact with the level of agreement within HF dyads, including educational background, cognitive function, history of HF, the patient's and CG's ages and genders, comorbid diseases—particularly depression, the patient's and CG's number of children, and marital status. Further studies are needed to be undertaken while considering these variables. In addition, the associations between the level of education as well as cultural background with symptoms assessment and management merit further research.

Increasing the agreement within the dyads on symptom assessment by timely education, continuous support, and planned evaluations is recommended. Nurses can use our findings to prioritize the educational needs of patients and their families to enhance the patient and CG skills and abilities, and to teach them how to recognize symptoms and how to manage them. Accordingly, researchers can design an interventional study to make patients and CGs more responsive to HF symptoms.

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Conflict of Interest: None declared.

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