Heart failure symptom assessment and management: Can caregivers serve as proxy?

Christina Quinn, RN, DNS [Associate Professor],
Division of Nursing and Health Sciences, Gordon College, cquinn@gdn.edu

Sandra B. Dunbar, RN, DSN, FAAN [Charles Howard Candler Professor], and
Nell Hodgson Woodruff School of Nursing Emory University, sbdunba@emory.edu

Melinda Higgins, PhD [Assistant Professor/Senior bio-statistician]
Nell Hodgson Woodruff School of Nursing Emory University, mkhiggi@emory.edu

Heart failure (HF) is a disabling, chronic disease affecting more than 5.3 million Americans. Of the more than 2 million persons hospitalized annually with HF [1], 29-47% are readmitted within 6 months [2]. Many HF patients are referred to home healthcare for disease management and support. According to the National Association for Home Care and Hospice, 31% of home healthcare admissions are from persons with heart disease, including HF [3]. However, numerous caregivers care for HF patients in the community without the benefit of home healthcare [4]. Because HF requires extended, ongoing management, family members, friends, and acquaintances are increasingly assuming greater responsibilities in symptom assessment, evaluation, and decision making. This study examined the degree of congruence between HF patients and their primary caregiver (CG) on symptom assessment and self-care management behaviors. Specifically we sought to discover: Is there a difference between patient and CG on frequency and severity assessments of HF symptoms?; and, What is the degree of congruence between HF patients and CG on symptom-management behaviors (perception, evaluation, response)?

The caregiver of a person with a chronic disease such as HF is often a family member. However, in many instances, the primary caregiver can be a neighbor or a close friend. In this study, the definition of caregiver was considered broadly to include persons unrelated to the patient through marriage or genetics. This study examined these caregivers as they described their assessment and management of HF symptoms in the home environment.

Background

Although caregivers may be expected to acquire HF home care skills and knowledge, they often have had little formal training [5]. Key among these skills are monitoring and interpreting symptoms and adjusting to complex medical regimens such as dietary and medication changes [6, 7]. The problem solving abilities of the CG also influence HF self-care and outcomes [4].

Corresponding author: Christina Quinn RN, DNS, Division of Nursing and Health Sciences, Gordon College, 419 College Drive, Barnesville, GA 30204, Phone: 678 359 5583, FAX 770 358 5064, cquinn@gdn.edu.

Proxy Roles

Proxies are used in healthcare in two main ways: as decision makers and as raters. Proxy decision making – the authority or power to act for another [8] - has long been used in treatment consent processes [9]. The need for and documented designation of CGs as proxy decision makers in HF is well established [10, 11]. Increasingly, CGs are asked to monitor or interpret symptoms of a patient with a chronic disease such as HF and report their assessment findings to a health-care provider. In this role, the CG is asked to be a proxy for the patient without exercising decision making authority, although the proxy action may influence provider decisions.

Studies of CG proxy assessments report a variety of findings regarding CG-patient congruence. Caregivers have been shown to have difficulty making decisions regarding HF symptoms and very likely need to be instructed in symptom recognition [12]. A number of studies on quality of life assessments report that CG proxies rate situations as being worse than patients do. Such findings have ranged across a variety of conditions including stroke, brain cancer, and COPD [13-15, 18]. Other studies (e.g., in stroke and aphasia and in terminal lung cancer) report greater congruence but also elaborate their findings by describing the role of moderators and mediators in the congruence of assessment. For example, patient age, duration of caregiving, lack of caregiving support, and CG health may promote congruence while patient depressive symptoms appear positively associated with discordance [16, 17, 19-22].

In the cardiovascular literature, comparison of physical functioning assessment between spouses and patients in cardiac rehabilitation revealed that spousal measurements of patients' physical functioning was 10% lower than the patient's perception [23, 24]. Heart failure patients and their proxies in a palliative care setting provided similar average reports of symptom distress within all dyads; however, correlation between patient and proxy responses on symptom distress scores was reported as modest [25].

Conceptual Framework

This study employed the revised conceptual model of symptom-management by Dodd and colleagues [26]; this model describes the symptom experience in terms of perception, evaluation, and response. This model assumes that the interpretation of symptoms by a parent or CG is accurate for purposes of intervening with patients. This study also employed Interdependence Theory [27], a middle-range theory developed from Social Exchange Theory which focuses on costs and rewards that partners give and receive from each other [28]. Its components include interdependence, relationship interdependence, and correspondence of outcomes [27]. Interdependence is important when examining health behaviors in order to better understand what portion of health behavior is related to the influence of partner-patient interaction. Thus, this study used the concept of correspondence of outcomes from Interdependence Theory to examine symptom assessment congruence within dyads. Table 1 provides links between this conceptual framework, variables and measures used in this study.

Methods

Design

A descriptive cross-sectional, correlational design was used to examine congruence in symptom assessment between HF patients and their designated CG while enrolled in home healthcare. Separate interviews between patient and CG were performed in the home setting by the researcher.

Sample

After Institutional Review Board approval from the University and approval from two corporate home healthcare agencies, subjects meeting the inclusion criteria were identified by the home health nursing staff. Eligibility criteria included patients admitted to the home health agency with a primary or secondary diagnosis of HF; age 21-85; and telephone access. Caregivers, also over the age of 21, were eligible after identification by the patient as the person with whom they discussed HF symptoms and were the most involved in their care. Caregivers could be family or friends who met this criterion. Patients and CG were excluded if either had a diagnosis of any type of dementia.

Subject recruitment began by asking the home health nurses to identify HF patients who fit the inclusion criteria and had a CG with whom they discussed HF problems. The home health nurse contacted eligible patients to inquire about willingness to have the researcher contact them to explain the study over the telephone. Once the nurse had obtained verbal consent from the patient, the researcher called to describe the study, obtain verbal consent, and make an appointment for a home visit. Written consent from the patient and CG was subsequently obtained in the patient's home prior to data collection.

Variables and Instruments

Symptom Assessment—The Heart Failure Symptom Survey (HFSS) was used to assess frequency and severity of 14 common heart failure symptoms [29]. The HFSS was chosen because it contains the symptoms experienced by most HF patients and was designed for use in evaluating a home disease management program specifically for HF patients. Each symptom was assessed using an eleven-point scale with scores ranging from 0-10 (zero indicates no experienced symptom); symptom frequency and severity scores ranged from 1-10 (10 indicates very severe or frequent). A mean symptom evaluation score was computed for each symptom (using the mean of the frequency and severity rating), with possible ranges from 0 to 10. Both patient and their designated CG filled out the HFSS referencing the past 7 days. Data were collected from each member of the dyad separately to prevent collaboration in the answers. Internal consistency reliability for the frequency and severity subscales were assessed by calculating Cronbach's alpha. The obtained values were .87 for the patient and .88 for the CG.

Self-care management and confidence—The Self-Care of Heart Failure Index (SCHFI) was used to assess self-care management and self-care confidence in both patient and CG. The SCHFI is a self-report measure comprised of 15 questions rated on a 4 point scale and divided into three subscales. Two of the subscales: self-care management and self-

care confidence were used in this study. A caregiver version was created for this study after approval by the author of the instrument [30, 31]. Internal consistency reliability for the self-care management subscale as measured by Cronbach's alpha was .51 for the patient and .68 for the FCG. If item number 6 (call the doctor or nurse for guidance) was removed from the self-care management scale, the Cronbach alpha for the patient would increase to .53. Riegel [31] has reported a Cronbach alpha of .70 for this subscale. For the self-care confidence scale, obtained alphas were .89 for the patient and .86 for the CG version. These values are similar to the alpha reported by Riegel [31] as .82 for this subscale.

Analyses

The data were collected and entered into a database using a Teleform ™ format system. Descriptive statistics were conducted to determine characteristics of the sample and to describe study variables. Spearman correlation coefficients were used to determine the degree of congruence between patient and CG using the mean symptom evaluation scores on the HFSS. A concordance correlation coefficient (CCC) was also used to determine the level or degree of agreement between the dyads of symptom evaluation scores on the HFSS. The CCC is a measure of agreement that examines how closely the actual measurements of two observers agree with one another [32, 33]. When examining the CCC, values ranging from 0.7 – 1.0 are considered good agreement, 0.4 - 0.7 reflect moderate agreement, and 0.0 – 0.4 is considered poor agreement [34].

Due to the potential ranking of zero on a symptom, four possible categories of dyadic agreement were identified: both members of the dyad agreed there was no symptom (score 0,0); both report and rate the symptom; CG reports the symptom but patient does not report the symptom; patient reports the symptom and CG does not report the symptom. Chi Square was used to determine if these four categories differed when recognizing and reporting the presence of a symptom. Additionally, in order to determine if either patients or CG scored higher on a specific symptom, paired t-tests were performed on the symptom evaluation scores within dyads on all 14 symptoms and 95% confidence intervals were obtained. Differences in mean scores on the self-care management and self-care confidence subscales of the SCHFI between patient and CG were analyzed using paired t-tests.

Results

One hundred forty-five eligible home health patients were contacted. Of these, 34% refused during the initial telephone contact stating they were too busy, had too many people coming to their home already, or felt poorly. Five of the patients that refused stated that they did not have HF even though the patient chart clearly stated HF was a primary diagnosis. Thirteen (9%) refused or cancelled after an appointment was scheduled, and 1 dyad refused at the time of the home visit. Some of the reasons for declining to participate were similar to Pressler et al.'s [35] study of family caregiver outcomes with HF patients. A total of 70 dyads, plus an additional five CG and 4 patients completed this study. Caregivers or patients whose partner did not complete their study information were not included in this analysis.

The mean age of HF patients was 71±9.6 years, New York Heart Class (NYHC) III (68%), and primarily female (60%). Caregivers were 57±15 years in age and 76% female. The

majority of CG were spouses; however, there were several other persons identified as CG such as siblings (4.3%) and friends (21%) (See Table 2 for summary of all demographics). Seventy-six percent of patients reported having HF for greater than two years.

Table 3 summarizes the patient and CG mean symptom severity score and the ranking. The top three most distressing symptoms reported by both patient and CG were fatigue, shortness of breath (SOB) with activity, and extremity edema. After the top three ranked symptoms, dyads differed for the remaining symptoms.

The Spearman's correlation coefficient was used to assess the degree of congruence on symptom evaluation scores from the HFSS. Dyads had the strongest correlation for congruence on extremity edema, difficulty concentrating, and dizziness. When the data were analyzed by examining dyads in which the CG and patient did not co-reside, they were also highly congruent on symptoms such as extremity edema (Spearmans' Rho 0.55, p=.04) and SOB at rest (Spearman's Rho 0.58, p=.031). Lower congruence among all dyads (less than .40) was found on feeling depressed, SOB waking you up at night, and SOB when lying down. Poorest and least significant congruence was noted on symptoms of bloating, and worsening cough (Table 4). Level of agreement using the CCC found low congruence on similar symptoms as in the Spearman's correlation with the addition of fatigue (Table 4).

Paired t-tests on the symptom evaluation scores within dyads indicated that patients' ratings of extremity edema were on average one point higher than CGs' (mean difference=.97; p=. 01; 95% CI=0.19-1.74). In addition, the symptom of feeling depressed showed a trend toward significance (mean difference=-.81; p=.07; 95% CI = -1.69-0.079) indicating that the CG score was approximately one point higher than the patient's score. The symptom of feeling depressed was further examined through a Chi Square test which documented that 21 dyads (30%) were discordant about recognizing the presence of depression (chi square = 8.25, p=.004). For example, in 20% of the dyads, the CG reported the patient had the symptom of depression when the patient did not report having it; and 10% of patients reported having the symptom of depression when the CG did not report it.

Patient and CG scores on the SCHFI self-care management scale were not significantly different from one another (t test 1.71; p=.09). However, the patient and CG scores on the SCHFI self-care confidence showed a trend toward significance (t test 1.90, p=.06). Table 5 summarizes these results.

Discussion

This study found that the three most distressing symptoms reported congruently by both HF patient and CG were fatigue, SOB with activity, and extremity edema. These findings are consistent with common symptoms that are assessed upon hospitalization of HF patients [1, 36, 37].

In terms of the degree of congruence between HF patients and CG on symptom assessment, correlations were moderate to high (Spearman's Rho>.40) within dyads on 6 of the 14 (43%) symptoms related to HF (extremity edema, difficulty concentrating, dizziness, chest fluttering, chest pressure and SOB at rest). Interestingly, of those dyads in which patients

and CGs did not co-reside, 14 (20%) were also highly congruent with the HF patient on symptoms such as extremity edema and SOB at rest indicating a high degree of CG involvement and knowledge of HF symptoms. Although this is the first study to specifically examine HF symptom assessment within dyads, these results are similar to studies in the oncology literature in which family caregivers provided reliable symptom ratings in patients with advanced cancer [20, 21].

Although extremity edema was the most congruent symptom between patient and CG, patient scores on the symptom of extremity edema were on average one point higher than the CG. This finding suggests the need for the CG to validate their findings regarding extremity edema with the HF patient. It also suggests an area in which nurses might educate CGs on various assessment cues that could indicate increasing edema, such as tight shoes or socks or a decrease in their ambulatory ability. With the symptom of depression, the CG score was on average approximately one point higher than the patient's score. In addition, 30% of dyads were discordant when recognizing the presence of depression. Depression has been noted to be an important factor influencing HF [38, 39], and Dunbar et al [4] suggest it is also important in family models of HF care. The fact that 30% of the dyads were discordant on depression ratings suggests the need for greater attention to depression assessment and management.

Regarding self-care management and self-care confidence, both patient and CG had low mean scores on these SCHFI subscales. Adequacy of self-care has been described by Riegel et al. [40] as a standard score of 70 on either subscale of the SCHFI. In this study, neither the patient nor CG achieved this level on either subscale. This finding suggests the need for clinical and research interventions to increase both HF patients and CG knowledge of self-care management of symptoms and confidence in their ability to recognize and evaluate HF symptoms.

Study limitations to this study should be acknowledged. The findings are specific to HF patients enrolled in home health-care with an identifiable CG. Although the CG was defined as the person who was most involved in the HF patient's care, information on the strength and quality of the relationship was not obtained. Also, patients were referred from home health nurses who may have recommended patients who were more willing to participate in research than patients with more difficult home situations. In addition, this was a cross-sectional study which limits any causal conclusions between the study variables and HF outcomes. However, analysis of trends from this study will provide information for developing interventions to improve HF patient and CG ability to recognize and evaluate HF symptoms.

Summary

Study findings further illuminate the use of proxies in HF symptom assessment. Based on moderate levels of correlations on several HF symptoms in this study, the CG as proxy appears to be a fairly consistent substitute for patient responses such as extremity edema, difficulty concentrating and dizziness in this home health setting.

Least congruence was found on several symptoms that may indicate HF decline: SOB at night, SOB lying down, worsening cough, and bloated abdomen. This may indicate that the CG may not be the best proxy with these symptoms since several of them are subtle.

In this first study of HF/CG symptom congruence, it is important to notice which symptoms are more difficult for the CG to recognize. This recognition could lead to education in the home health and community settings on the more subtle signs of HF. In addition, encouraging the CG to validate his or her findings with the HF patient should be emphasized. Thus, greater caregiver preparation for symptom assessment is warranted to improve congruence for future symptom assessment.

Implications for research and practice

The findings of this study have important implications for nurses caring for HF patients in home health nursing as well as in community or outpatient settings. Since this is the first study to specifically examine congruence in symptom assessment with HF/CG dyads, the information can be used by researchers and clinicians to plan future studies to determine if the findings are consistent with a larger population of HF patients. In particular, the symptoms having the least congruence may be the ones to target in an intervention study making the CG more aware of the subtleties of symptoms and also the importance of validating the symptoms. Caregiver symptom assessment must include the subtle signs of HF that may not be easily recognized by another.

Acknowledgments

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Table 1

Conceptual framework with variables and measures

Theory	Concept	Variable	Measurement
Symptom management Theory	Symptom experience: Perception of symptoms	HF symptom frequency and severity	HFSS[*]
	Symptom experience: Evaluation of symptoms	HF symptom frequency and severity	HFSS
	Symptom experience: Response to symptoms	Self care management and confidence	SCHFI[*]
Interdependence Theory	Correspondence of outcomes: Symptom assessment congruence	HF symptom frequency and severity	HFSS

[*] both patient and caregiver filled out these instruments

HF = heart failure

HFSS = heart failure symptom survey

SCHFI = self care of heart failure index

Table 2

Characteristics of Patients and Caregivers

		HF Patient N=70	
Time with HF diagnosis			
	Less than 2 years	20 (28.5%)	
	Greater than 2 years	50 (76.4%)	
NYHA Class			
	Class I	0	
	Class II	22 (31.4%)	
	Class III	48 (68.6%)	
Pacemaker/ICD			
	Pacemaker	11 (15.7%)	
	ICD	9 (12.8%)	
		HF Patient N= 70	**Caregiver** N=70
Age			
	20-39	0	10 (14.2%)
	40-59	10 (14.2%)	28 (39.9%)
	60-79	48 (68.5%)	27 (41.1%)
	80-89	12 (17.1%)	5 (7.1%)
Gender			
	Female	42 (60%)	53 (75.7%)
	Male	28 (40%)	17 (24.3%)
Marital Status			
	Married/partner	31 (44.2%)	29 (41.4%)
	Single	5 (7.1%)	41 (58.5%)
	Divorced	13 (18.5%)	
	Widowed	21 (30%)	
Relationship to the patient			
	Spouse		30 (43.4%)
	Daughter		19 (27.5%)
	Son		3 (4.3%)
	Sibling		3 (4.3%)
	Friend or Other		15 (21.3%)
Patient Residence			
	Patient lives alone	14 (20%)	
	Patient and family member live together		56 (80%)
Ethnic Background			
	African American	29 (41.4%)	29 (41.4%)
	Asian	1 (1.4%)	0
	Caucasian	40 (57.1%)	41 (58.5%)

Educational Level			
	6th grade or less	4 (5.7%)	
	6-12th grade	19 (27.1%)	10 (14.3)
	High school graduate	26 (37.1%)	27 (38.6)
	Technical college	4 (5.7%)	3 (4.3)
	1-4 years college	13 (18.6%)	17 (24.3)
	College graduate	2 (2.9%)	13 (18.5)
	Post College	2 (2.9%)	

Table 3

Patient and Caregiver Ranking of Symptoms (N=70 dyads)

Symptom	Patient Rank	Patient Mean (SD)	Caregiver Rank	Caregiver Mean (SD)
FATIGUE	1	6.27 (3.2)	1	6.60 (3.1)
SHORTNESS OF BREATH w/ACTIVITY	2	5.62 (3.2)	2	5.46 (3.5)
EXTREMITY SWELLING	3	5.49 (3.9)	3	4.52 (3.7)
DIFFICULTY SLEEPING	4	4.56 (4.2)	5	4.25 (3.9)
DEPRESSED	5	3.45 (3.4)	4	4.26 (3.5)
DIZZINESS	6	3.43 (3.3)	6	3.46 (3.5)
FORGETFULNESS	7	3.42 (3.4)	8	3.35 (3.5)
SHORTNESS OF BREATH AT REST	8	3.14 (3.7)	9	2.97 (3.3)
BLOATED ABDOMEN	9	2.82 (3.5)	7	3.43 (3.9)
SOB LYING DOWN	10	2.43 (3.3)	10	2.58 (3.3)
CHEST PRESSURE	11	2.27 (3.3)	12	2.19 (3.0)
WORSENING COUGH	12	2.10 (3.4)	11	2.24 (3.4)
SHORTNESS OF BREATH WAKE UP AT NIGHT	13	1.45 (2.9)	13	2.08 (3.2)
IRREGULAR HEART BEAT	14	1.43 (2.8)	14	1.86 (2.9)

Key: possible range 0-10

Table 4

HFSS Symptom Congruence (N=70 dyads)

	Spearmans (p-value)	Concordance Correlation Coefficient with 95% Confidence Interval
Extremity Edema	.65 (.0001)	.620 (.406 - .767)
Difficulty concentrating	.50 (.0001)	.488 (.243 - .674)
Dizziness	.49 (.0001)	.480 (.233 - .668)
Chest Fluttering	.47 (.0001)	.455 (.208 - .648)
Chest Pressure	.47 (.0001)	.443 (.187 - .641)
SOB at rest	.42 (.0001)	.391 (.127 - .603)
Fatigue/Lack of energy	.40 (.001)	.398 (.137 - .608)
SOB w/activity	.40 (.001)	.446 (.192 - .644)
Difficulty Sleeping	.40 (.001)	.414 (.154 - .620)
Depressed or feeling down	.39 (.001)	.404 (.151 - .609)
SOB wake up at night	.36 (.010)	.305 (.037 - .533)
SOB lying down	.31 (.010)	.330 (.056 - .557)
Worsening Cough	.22 (.07)	.152 (-.134 - .413)
Bloated Abdomen	.08 (.51)	.055 (-.224 - .325)

Table 5
Self-care management and confidence scores (SCHFI)

	Patient Mean (SD)	Range of scores for patient	Caregiver Mean (SD)	Range of scores for caregiver
Self care management	57.9 (15.8)	25-92	62.6 (19.3)	16-100
Self-care confidence	60.5 (19.0)	25-100	66.8 (18.3)	31-100

N = 70