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Julie T. Bidwell, *Emory University*  
[Melinda Higgins](#), *Emory University*  
[Carolyn Reilly](#), *Emory University*  
Patricia Clark, *Emory University*  
[Sandra Dunbar](#), *Emory University*

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## Shared heart failure knowledge and self-care outcomes in patient-caregiver dyads

Julie T. Bidwell, PhD, RN<sup>a</sup>, Melinda K. Higgins, PhD<sup>a</sup>, Carolyn M. Reilly, PhD, RN, FAHA<sup>a</sup>, Patricia C. Clark, PhD, RN, FAHA, FAAN<sup>b</sup>, and Sandra B. Dunbar, PhD, RN, FAAN, FAHA<sup>a</sup>

<sup>a</sup>Emory University, Nell Hodgson Woodruff School of Nursing, 1520 Clifton Road, Atlanta, GA, 30322, United States

<sup>b</sup>Georgia State University, Byrdine F. Lewis College of Nursing and Health Professions, P.O. Box 3995, Atlanta, GA 30302, United States

### Abstract

**Background**—Patient’s knowledge about heart failure (HF) contributes to successful HF self-care, but less is known about shared patient-caregiver knowledge.

**Objectives**—The purpose of this analysis was to: 1) identify configurations of shared HF knowledge in patient-caregiver dyads; 2) characterize dyads within each configuration by comparing sociodemographic factors, HF characteristics, and psychosocial factors; and 3) quantify the relationship between configurations and patient self-care adherence to managing dietary sodium and HF medications.

**Methods**—This was a secondary analysis of cross-sectional data (N=114 dyads, 53% spousal). Patient and caregiver HF knowledge was measured with the Atlanta Heart Failure Knowledge Test. Patient dietary sodium intake was measured by 3-day food record and 24 hour urine sodium. Medication adherence was measured by Medication Events Monitoring System caps. Patient HF-related quality of life was measured by the Minnesota Heart Failure Questionnaire; caregiver health-related quality of life was measured by the Short Form-12 Physical Component Summary. Patient and caregiver depression were measured with the Beck Depression Inventory-II. Patient and caregiver perceptions of caregiver-provided autonomy support to succeed in heart failure self-care were measured by the Family Care Climate Questionnaire. Multilevel and latent class modeling were used to identify dyadic knowledge configurations. T-tests and chi-square tests were used to characterize differences in sociodemographic, clinical, and psychosocial characteristics by configuration. Logistic/linear regression were used to quantify relationships between configurations and patient dietary sodium and medication adherence.

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**Corresponding Author:** Julie T. Bidwell, Emory University Nell Hodgson Woodruff School of Nursing, 1520 Clifton Road, Room 431, Atlanta, GA, 30322; fax: 1+404-727-4645; phone: 1+503-756-1996; jtbidwe@emory.edu.

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**Conflicts of Interest:** None

**Results**—Two dyadic knowledge configurations were identified: “Knowledgeable Together” (higher dyad knowledge, less incongruence; N=85, 75%) and “Knowledge Gap” (lower dyad knowledge, greater incongruence; N=29, 25%). Dyads were more likely to be in the “Knowledgeable Together” group if they were White and more highly educated, if the patient had a higher ejection fraction, fewer depressive symptoms, and better autonomy support, and if the caregiver had better quality of life. In unadjusted comparisons, patients in the “Knowledge Gap” group were less likely to adhere to HF medication and diet. In adjusted models, significance was retained for dietary sodium only.

**Conclusions**—Dyads with higher shared HF knowledge are likely more successful with select self-care adherence behaviors.

### MeSH Keywords

Heart Failure; Caregivers; Self Care; Health Knowledge; Medication Adherence; Diet; Sodium Restricted

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### Introduction

Heart failure (HF) affects over 6 million Americans,<sup>1</sup> and requires consistent patient engagement in HF self-care behaviors (i.e. day-to-day adherence and appropriate symptom response) in order to maintain clinical stability and prevent hospitalization and death.<sup>2</sup> The bulk of the responsibility for HF self-care is undertaken by patients in a community setting,<sup>3–6</sup> and importantly, the foundational antecedent for successful self-care is adequate HF knowledge.<sup>5</sup> However, HF knowledge does not always translate into successful self-care.<sup>6</sup> One reason for this may be that patients often manage HF together with their family caregivers,<sup>3,7–9</sup> and thus shared caregiver and patient knowledge, rather than the patient’s knowledge alone, is likely important to fully support self-care expertise.

The importance of shared patient and caregiver knowledge is reflected in current guidelines that emphasize providing HF management education to patients and family caregivers together.<sup>10,11</sup> Similarly, Riegel’s updated Situation-Specific Theory of Heart Failure Self-Care includes the influence of “multiple players” (e.g. family members or caregivers) on patient success in self-care behaviors that require base knowledge for adherence (e.g. how to identify/prepare low-sodium foods).<sup>4</sup> However, how HF knowledge is typically shared or distributed within patient-caregiver dyads (i.e. dyadic knowledge configurations), or how dyadic knowledge configurations may be related to self-care outcomes, has not previously been examined quantitatively. This study reports the results from a secondary analysis of cross-sectional baseline data from a family partnership intervention seeking to improve self-care adherence behaviors.<sup>12</sup> Specifically, the purpose of this analysis was three-fold. First, we sought to identify configurations of shared HF knowledge in patient-caregiver dyads. Second, we sought to characterize dyads within each configuration by comparing sociodemographic factors (age, gender, race, education, comorbidities, dyad relationship type), HF characteristics (NYHA Class, HF duration and etiology, ejection fraction, previous HF hospitalization), and psychosocial factors (autonomy support, depression, quality of life). Finally, we sought to quantify the relationship between dyadic configurations of HF knowledge and patient self-care adherence to managing dietary sodium and HF medications.

HF knowledge in this study specifically refers to overall knowledge of HF pathophysiology, dietary recommendations, medications, HF symptoms, and health/adherence behaviors.

## Material and Methods

### Study Design and Recruitment

This was a secondary analysis of baseline only data (N=114 dyads) from a prospective clinical trial of a dyadic intervention to improve HF self-care outcomes. The study protocol is described in greater detail in the original publication,<sup>12</sup> was approved by the associated Institutional Review Boards for each site, and all participants provided written informed consent. In addition to the original publication of study results, which found that dietary sodium adherence, but not medication adherence, was improved in the intervention groups as compared to usual care,<sup>12</sup> four other analyses have been published using this data,<sup>13–16</sup> none of which have focused on patient-caregiver HF knowledge as a shared (i.e. dyadic) construct. Collectively, these four analyses demonstrated that the family caregiving context is an important determinant of patient outcomes and self-care adherence, and thus contributed to the development of the research aims for this paper.

HF patients and caregivers were enrolled from three outpatient heart failure clinics in the southeastern United States. In order to be eligible, patients had to be aged 30–79 years, with a confirmed HF diagnosis in the medical record and associated New York Heart Association Classification (NYHA Class) of II or III. They had to be ambulatory, optimized on medical therapy for HF, with adequate renal function (glomerular filtration rate > 30), and without contraindications to following a HF diet (low sodium). Patients were excluded if they had HF secondary to an untreated condition (e.g. hyperthyroidism, untreated tachyarrhythmias), a recent myocardial infarction (past 6 months), angina, imminent cardiothoracic surgery, cognitive impairment or major psychiatric condition (as documented in the medical record and by report), or uncorrected vision or hearing impairment that would preclude participation. Patients also had to have an informal (i.e. unpaid) caregiver who was willing and able to provide informed consent and who met the following enrollment criteria: older than 19 years of age, the primary person helping with HF self-care, frequent interaction with the patient (at least 2-3 times per week), and without conditions that might preclude participation (i.e. impaired cognition, major psychiatric diagnosis). The caregiver did not need to be a family member to participate; close friends, community members, etc. were also eligible.

Once enrolled, patient-caregiver dyads were randomized to three groups: 1) usual care; 2) patient-family education, in which patients and caregivers received HF education together, along with individualized feedback on diet and medication adherence; or 3) family partnership intervention, in which patients and caregivers received the patient-family education intervention, plus small group sessions providing tools to enhance autonomy-supportive communication and collaboration to manage heart failure together. Study outcomes (dietary sodium intake, medication adherence) were evaluated in all three groups at 4 months, followed by a maintenance intervention at 5–6 months (telephone maintenance and related newsletter involving education only or education plus family partnership intervention, depending on group allocation), and final evaluation of study outcomes at 8

months. The baseline data used in this analysis were collected prior to any intervention delivery.

### Data Collection, Variables and Measures

The data used for this analysis were collected immediately after enrollment and verified by trained research nurses. Demographic, comorbidity,<sup>17</sup> and survey data were provided by self-report, and clinical characteristics of the HF patient (i.e. NYHA Class, duration of HF, HF etiology, ejection fraction, HF hospitalization within the past 4 months) were abstracted from the medical record. The variables and measures for this analysis are listed below, and were selected based on the existing evidence and literature indicating a relationship with self-care.<sup>5,6,18</sup> Study instruments and HF self-care adherence outcomes are described in detail below.

**Heart Failure Knowledge**—Patient and caregiver HF knowledge was measured with the 27-item Atlanta Heart Failure Knowledge Test (AHFKT, version 1).<sup>19</sup> The AHFKT uses a comprehensive approach to the measurement of knowledge relating to HF, covering the following domains: pathophysiology, dietary recommendations, medications, HF symptoms, and health/adherence behaviors (e.g. physical activity recommendations, daily weights). Questions are asked in multiple choice format with nominal scaling (right/wrong), and the number of correct items are summed to generate an overall score that is standardized to range from 0–100% (percentage of correct responses). The AHFKT has good evidence for validity,<sup>19</sup> with adequate reliability in this sample (Cronbach’s  $\alpha$  of 0.84 for patients and 0.75 for caregivers, respectively).

**Autonomy Support**—Characterization of the level of caregiver support given to the patient to succeed in necessary daily HF lifestyle/adherence behaviors was measured with the patient and family versions of the 14-item Family Care Climate Questionnaire (FCCQ-P and FCCQ-F, respectively).<sup>20</sup> The guiding conceptual framework for this instrument comes from health partnerships research in Self-Determination Theory, which proposes that health behavior change, such as the change needed to adhere to HF medications or dietary recommendations, is most successful within an autonomy supportive context (i.e. a context in which the patient’s choices, feelings, and perspectives are respected by the caregiver, who offers alternatives and minimizes pressure rather than exerting control).<sup>21,22</sup> Each item is a statement about the level of autonomy support provided by the caregiver. The patient reports his/her perceptions of the caregiver’s autonomy support towards him/her, while caregivers report their perceptions of the level of autonomy support they give to the patient. Participants are asked to characterize how true each statement is for them by responding on a 7-point Likert scale, with “1” indicating that the statement is “not true at all,” and 7 indicating “very true.” Items are averaged to generate an overall score ranging from 1–7, with higher values indicating greater levels of autonomy support. The patient and caregiver versions of the FCCQ have good evidence for validity in HF family care dyads,<sup>20</sup> with adequate reliability in this sample (Cronbach’s  $\alpha$  of 0.85 for patients and 0.78 for caregivers, respectively).

**Depressive Symptoms**—Patient and caregiver depressive symptoms were measured with the 21-item Beck Depression Inventory-II (BDI-II).<sup>23</sup> Each item refers to a particular

depressive symptom, and respondents are presented with 4 statements, graded 0–3, representing the severity of that symptom: 0 indicates the respondent does not have the symptom, and 1–3 indicate increasing severity. Item responses are summed to generate an overall score ranging from 0–63, with higher values indicating greater depressive symptoms. Scoring cutoffs are as follows: 0–13 indicates minimal depression, 14–19 indicates mild depression, 20–28 indicates moderate depression, and 29–63 indicates severe depression. The BDI-II has good evidence for validity<sup>23,24</sup> with good reliability in this sample (Cronbach's  $\alpha$  of 0.92 for patients and 0.91 for caregivers, respectively).

**Patient Quality of Life**—Patient HF-specific QOL was measured with the 21-item Minnesota Living with Heart Failure Questionnaire (MLHFQ, total score).<sup>25</sup> On the MLHFQ, patients are presented with a list of HF symptoms and are asked to rate how much that symptom affects their QOL on a 6-point Likert scale, with 0 indicating it does not affect QOL, and 1–5 indicating it affects QOL “very little” to “very much,” respectively. Items are summed to generate an overall summary score ranging from 0–105, with higher values indicating worse HF-specific QOL. The MLHFQ is frequently used for measuring HF-specific QOL and has good evidence for validity<sup>25,26</sup> with good reliability in this sample (Cronbach's  $\alpha = 0.92$ ).

**Caregiver Quality of Life**—Caregiver physical health-related QOL was measured with the Physical Component Summary of the 12-item Short Form-12 (SF-12 PCS).<sup>27</sup> On the SF-12, caregivers are asked a number of questions regarding aspects of their health and functioning, with varying response scales. To generate a physical QOL summary score (the SF-12 PCS), items pertaining to physical health are weighted more heavily in score calculation. Scores are then population-normed and standardized to range from 0–100, with higher values indicating better physical QOL. The SF-12 has been used extensively in caregiving research in general and HF caregiving in particular,<sup>28–31</sup> with good evidence for validity<sup>27,32</sup> and acceptable reliability in this sample (Cronbach's  $\alpha = 0.78$ ).

**Sodium Intake**—Dietary sodium intake was measured two ways including self-report and an objective measure of 24-hour urinary sodium. Participants completed a 3-day food record (3DFR), which was reviewed by research staff for accuracy and completeness before being analyzed by a registered dietician using Food Processor SQL (version 10.2; ESHA Research). A mean daily sodium value was generated for each participant, which was then dichotomized into  $\leq 2,000$ mg or  $>2,000$ mg per day for this analysis.

Urinary sodium was measured using samples from 24-hour urine collection. Participants collected urine over a 24-hour period, concurrent with the third day of 3DFR completion. Research nurses provided written and verbal instructions, and reviewed procedures over the phone immediately prior to collection. Multivariable regression imputation incorporating body mass index (measured by research staff within the study's Clinical Research Center) and urinary volume was used to address missing data related to incomplete urine collections, and furosemide equivalents were used to correct for concomitant diuretic intake.<sup>12</sup>

**Medication Adherence**—Medication adherence was objectively measured using the Medication Events Monitoring System (MEMS), which involves tracking cap removal from

a medication bottle via embedded microchip. MEMS caps were used for a minimum of two weeks on two types of medications: a HF medication (i.e. ACE-I, ARB, or BB) and a diuretic medication. Participants also had a written calendar for indicating any times (and associated reasons) that they could not use MEMS during the monitoring period (e.g. traveling, hospitalized). After monitoring was complete, MEMS and calendar data were integrated to generate an adherence score (percentage of doses taken correctly) for each medication during the monitoring period. MEMS caps for measuring medication adherence have good evidence for reliability and validity, and have been used previously in HF populations.<sup>33–35</sup>

## Data Analysis

Descriptive statistics were used to characterize the sample. To identify configurations of shared HF knowledge in patient-caregiver dyads, we used a two-step process involving both dyadic multilevel and latent class approaches.<sup>9,36</sup> It should be noted that this analysis is exploratory, as limited research in dyadic HF knowledge precluded a priori effect size estimation, and power analysis in latent class modeling is heavily dependent on anticipated classes. However, latent class analysis in HF family care dyads has been done successfully with samples substantially smaller than 100 dyads.<sup>36</sup> First, dyadic univariate multilevel modeling in HLM (version 7; Scientific Software International) was used to quantify HF knowledge within a dyadic context by generating empirical bayes estimates of the *average level* of knowledge in each dyad, as well as the magnitude and direction of *incongruence* in knowledge (i.e. difference between patient and caregiver knowledge scores, and which member of the dyad scored higher), adjusting for dyadic interdependence and measurement error.<sup>37,38</sup> Second, latent class mixture modeling in MPlus (version 7.31; Muthén and Muthén) was used to identify naturally-occurring patterns in dyadic knowledge (average and incongruence) across dyads in the sample. The following criteria were used to compare and select the best fit model for the data (e.g. 3-class versus 2-class model): 1) significant Lo-Mendell-Rubin adjusted likelihood ratio test (LMRT  $p < 0.05$ ); 2)  $n$  within each observed pattern no less than 5% of the sample; 3) model convergence (entropy) closest to 1.0; and 4) posterior probabilities for most likely class assignment closest to 1.0.<sup>39–41</sup> Once a best-fit latent class model was identified, identified configurations were named based on their characteristics (dyadic average, incongruence), with all authors providing feedback and agreeing upon final configuration titles. T-tests and chi-square tests (or nonparametric equivalents, as appropriate) were used to describe unadjusted differences in patient and caregiver demographic, clinical, and psychosocial characteristics and adherence behaviors by identified dyadic knowledge pattern. Finally, logistic and linear regression were used to examine relationships between shared dyadic knowledge and patient adherence behaviors, adjusting for age, gender, education level, relationship type, NYHA class, and depressive symptoms.

## Results

The clinical and demographic characteristics of the sample and comparison across patterns of dyadic knowledge (average and congruence) are presented in Table 1. Patients and caregivers were in their mid-fifties on average, and the majority were African American.

Most patients were male, and most caregivers were female, and a slight majority of patient-caregiver dyads were spousal. Patients were primarily NYHA Class II, with less than half reporting a HF hospitalization within the previous 4 months.<sup>12</sup>

In the dyadic multilevel model of patient and caregiver AHFKT scores, the average level of HF knowledge in dyads was  $70.1\% \pm 1.1$ , with patients typically reporting higher scores than their caregivers. The average magnitude of incongruence between patients and caregivers was  $4.9\% \pm 1.3$  (robust standard errors,  $p < 0.001$  for both estimates). There was also significant variability across dyads in the estimates of both dyadic average knowledge and incongruence (variance component = 8.2,  $\chi^2(1,110) = 993.5$ ,  $p < 0.001$  and variance component = 9.3,  $\chi^2(1,110) = 364.7$ ,  $p < 0.001$ , respectively), supporting further examination using latent class modeling.

In the subsequent latent class mixture model, two naturally-occurring patterns of shared HF knowledge in dyads were identified (entropy = 0.73; posterior probabilities all  $> 0.86$ ; LMRT = 11.7,  $p = 0.02$ ): a “Knowledgeable Together” group ( $n = 85$  dyads, 74.6%) characterized by higher shared knowledge (dyad average AHFKT score =  $74.7\% \pm SE 1.1$ ) and less incongruence (patient  $>$  caregiver), and a “Knowledge Gap” group ( $n = 29$  dyads, 25.4%) characterized by lower shared knowledge (dyad average AHFKT score =  $57.6\% \pm SE 1.8$ ) and greater incongruence (also patient  $>$  caregiver) (Figure 1). Dyads were more likely to be in the “Knowledgeable Together” group if they were White and more highly educated (both patients and caregivers), if the patient had a higher ejection fraction, fewer depressive symptoms, and better autonomy support, and if the caregiver had better QOL (Table 1). All self-care outcomes were worse, on average, in the “Knowledge Gap” group, but in unadjusted comparisons these differences were only statistically significant for dietary sodium intake and HF medication adherence (both moderate effect sizes, Table 2). In adjusted models, the “Knowledge Gap” group was 71% less likely to adhere to a stringent low sodium diet ( $< 2$ gm sodium/day), but the effect was no longer significant ( $p = 0.08$ ) for lower medication adherence (both moderate effect sizes, Table 2).

## Discussion

In this analysis of 114 HF patient-caregiver dyads, we found, on average, a significant amount of incongruence in HF knowledge between patients and caregivers. Patients tended to have better HF knowledge than their associated caregivers. However, there was also a significant and substantial amount of variability around dyadic incongruence in knowledge, as well as average dyad level of knowledge. Using latent class mixture modeling, we found that this variability was partially explained by two naturally occurring patterns of dyadic knowledge configurations: a pattern in which both members scored highly and with less incongruence in scores, and a pattern in which both members had relatively poor scores and with greater incongruence between patient and caregiver. Profiles of dyadic incongruence in HF self-care have recently been identified;<sup>7,9,42</sup> however, profiles of dyadic HF knowledge have not, to our knowledge, been quantified. Given that HF knowledge is considered the foundation of successful self-care,<sup>5</sup> we believe this is a unique and notable contribution to the self-care literature.

Interestingly, in both identified HF knowledge profiles, the patient had higher knowledge scores than the caregiver on average. A recent study conducted with a European sample identified configurations of HF self-care behaviors (rather than HF knowledge) and found that the caregiver almost universally reported higher participation or contribution to self-care behaviors than the patient.<sup>9</sup> It is possible that caregivers in general attempt to make strong contributions to self-care regardless of their foundational knowledge levels, but it is also possible that differences in the demographic and clinical characteristics (in particular, older patient age, greater proportion of male caregivers, fewer spouses, culture effects, and greater proportion of NYHA III/IV patients in the European study) drive this opposing effect. Regardless, further investigation of HF self-care and knowledge profiles together in dyads are warranted, particularly to determine whether caregivers may be taking the lead in self-care without the requisite levels of foundational knowledge to do so successfully. Furthermore, while there is an established cut-point for adequate HF knowledge in individuals (80% on the AHFKT)<sup>43</sup>, it is unknown whether the cut-point for adequate dyadic average knowledge might be different. Work must also be done to determine whether differences in patient-caregiver relationship type or other demographic or clinical factors moderate dyadic average knowledge or the magnitude/direction of dyadic incongruence.

We identified several characteristics that were associated with dyadic knowledge configuration, which we will discuss in the following order: race and education, ejection fraction, depressive symptoms, autonomy support, and caregiver QOL. The race effects in this study are consistent with the literature, given disparities that have been observed in general cardiovascular health knowledge by race, with African Americans often exhibiting less health knowledge compared to Caucasians, regardless of education. This is potentially due to racial disparities in healthcare access or the quality of care/education.<sup>44–46</sup> The education effects are also consistent with the literature, given the relationship between education level and health literacy, which are distinct but intertwined constructs consistently associated with disease-related knowledge.<sup>47–49</sup> There may also be income/economic effects that we did not capture in this study.

Lower ejection fraction and higher depressive symptoms were associated with poorer dyadic knowledge. These relationships are likely an overall function of disease severity, given that EF is typically an indicator of advanced HF,<sup>10</sup> and worse disease severity is commonly related to worse depression.<sup>50</sup> Dyads containing physiologically sicker patients tended to fall into the group with worse average knowledge. This is somewhat consistent with both our overall understanding of the relationship between depressive symptoms and HF self-care, as well as a recent study examining knowledge in hospitalized HF patients.<sup>5,51</sup> Ideally, the caregiver would compensate for patient knowledge deficits as HF becomes more severe and the patient develops more complex care needs, leading to another dyadic knowledge configuration altogether (i.e. one in which caregiver knowledge is higher than the patient, thus bolstering the dyad average), yet this did not appear to be the case in our sample. In terms of depression specifically, it is also possible that depression in one member of the dyad inhibits collaborative knowledge uptake and/or communication at the dyadic level.<sup>14,42</sup>

HF patients in the “Knowledgeable Together” group perceived greater autonomy supportive communication from their family caregiver. In terms of autonomy support, how the patient

perceives the caregiver's support (i.e. empowering the patient to make good decisions about HF management, rather than trying to control their behavior or failing to respect the patient's wishes) may be a reflection of the degree to which patients and caregivers are "on the same page" about the patient's HF, since it reflects shared communication and trust in disease management, as well as shared goals<sup>20</sup> – both of which require shared foundational knowledge. However, this is a novel finding, as autonomy supportive communication is rarely measured in either individual or dyadic studies of HF self-care. Thus, future research using a measure of autonomy support may be useful in elucidating mechanisms of successful self-care in a family context.

Caregiver health-related QOL in this sample was generally lower than national norms, and especially low in the "Knowledge Gap" group. In these dyads, poor physical health-related QOL in the caregiver may reflect a "who is the truly the caregiver?" dynamic, in which the labels "patient" and "caregiver" may not actually reflect who is truly taking care of whom. Caregivers have often been called the "hidden patients" because their own physical and mental health can be compromised, either due to the stress of the caregiving role, or independently.<sup>52,53</sup> It is possible that in dyads with poor caregiver health-related QOL, the caregiver may not be capable of adequate individual knowledge uptake or collaborative learning, leading to incongruence and contributing to overall poor average knowledge in the dyad. Similarly, caregivers with poor physical QOL may be unable to work together with the patient to meet the goals of self-care. For example, they may be physically unable to assist with grocery shopping and preparing low sodium meals, which may make the patient less likely to adhere to a low sodium diet.<sup>54</sup>

In general, we observed worse self-care adherence behaviors for dyads within the "Knowledge Gap" configuration, but statistically significant differences were observed only in terms of stringent dietary sodium adherence (<2g) and HF medication adherence. In adjusted models, significance was retained in the model predicting dietary sodium, but not HF medication adherence. However, our null findings may be a function of sample size. Importantly, our findings are similar to another recent dyadic study in HF that found that better patient knowledge was important to self-care adherence, but only in concert with patient and caregiver agreement on how HF disease management was handled within the dyad.<sup>55</sup>

On an individual level, two recent studies demonstrate that HF patients and caregivers believe that adequate HF knowledge is an important aspect of maintaining clinical stability. Specifically, one study found that most patients hospitalized for HF believed that their hospitalization was preventable, and identified a lack of knowledge and non-adherence as precipitating factors.<sup>56</sup> Similarly, another study found that HF caregivers typically believe that they can better support patients to engage in good self-care if they themselves have the requisite knowledge.<sup>57</sup> Notably, better caregiver HF knowledge has been associated with greater caregiver support for patient self-care adherence behaviors.<sup>58</sup>

This study has several implications for clinical practice and research. In terms of clinical practice, this study provides insight into which patient-caregiver dyads may need greater support to improve HF knowledge. In particular, assessment of low educational attainment

or African American race may be a risk factor for poor overall HF knowledge within the dyad, and targeted intervention to support these dyads may be appropriate. Additionally, patients with greater disease severity may have poorer knowledge in a setting of increasingly complex care needs, and this study demonstrates that caregivers may not be able to readily compensate. Patients and caregivers managing worsening HF likely need additional education and self-care support, regardless of how long the dyad has been managing HF together. HF is a disease that progresses over years, and initial education when the patient is in earlier stages may not be adequate and reeducation as the patient condition declines may be needed. Also, greater patient depression – which is often elevated in physiologically sicker patients – likely should be treated in order for individual or dyadic knowledge interventions to be most effective. Also, dyads in which the caregiver is struggling with his/her own physical health may need additional support with HF management.

In terms of research implications, which interventions may be most effective for dyads is an opportunity for future research, as very few studies have been conducted at the dyadic level. However, there is evidence that HF self-care management programs can be more successful when they include components that improve HF knowledge along with promotion of increased family involvement.<sup>54,59</sup> Given that within-dyad congruence around communication and management of HF in general (i.e. symptom management, care needs, disease progression, end-of-life issues) is an important consideration in understanding patient and caregiver behaviors and outcomes,<sup>42</sup> it is reasonable to recommend that patient and caregiver congruence in terms of HF knowledge should also be assessed and further studied as part of the growing body of dyadic observational and interventional work in HF self-care. Furthermore, dyadic studies involving HF knowledge and self-care should also include measures of self-care efficacy/confidence, as knowledge alone is not sufficient to change behavior, and self-care confidence likely has additional protective effects in HF dyads.<sup>60,61</sup> Overall, studies with larger dyad sample size and with joint collection of data on patient and caregiver knowledge along with the dyad's approach to HF self-care and associated self-care confidence are necessary to enhance our understanding of how to identify and support patients and caregivers together towards successful disease management behaviors.

This analysis has limitations, the most obvious of which is sample size. We observed numerical differences with moderate effect sizes for multiple adherence outcomes; however, further exploration in larger samples is needed. Furthermore, based on findings in other studies of HF self-care in dyads, there may be additional naturally-occurring groupings<sup>7,9,42</sup> that were not represented in our sample, either due to size or relatively homogeneous clinical characteristics. For example, it is not unreasonable to hypothesize that there is also a subset of dyads in which caregivers score higher on knowledge tests as they compensate for patient knowledge deficiencies in the face of advancing illness. In a related vein, this is a cross-sectional analysis, and, interestingly, disease-specific knowledge in HF likely decreases over time, at least in patients with one or more hospitalizations.<sup>51</sup> Further observational, longitudinal work examining the dynamics of changing dyadic HF knowledge as disease progresses will be important in informing how to best provide patient-family education as HF becomes increasingly challenging to manage. Another limitation of this study is how we chose to qualify adherence to dietary sodium restrictions. Current guidelines recommend at

least some level of dietary sodium restriction for HF patients.<sup>10</sup> However, the specific recommendations for daily intake in HF patients are a matter of substantial debate, and thus we chose the <2g cutoff suggested for patients with moderate-to-severe symptoms, given the increasing importance of self-care in reducing clinical event-risk as HF worsens.<sup>2,62</sup> However, this is an area of developing science, and given the high likelihood of variability in dietary sodium recommendations, future studies in self-care adherence behaviors should measure both the patient's actual dietary intake and the level of restriction has been recommended for them by their HF physician,<sup>10,62</sup> and/or their own self-reported adherence to a "low-sodium diet."<sup>63</sup>

## Conclusions

In this analysis of HF knowledge and adherence behaviors in patient-caregiver dyads, we found that dyads tended to fall into two distinct configurations of shared HF knowledge: a pattern characterized by higher average dyad knowledge and greater congruence between patient and caregiver, and a pattern characterized by lower average dyad knowledge and greater incongruence. Multiple demographic, clinical, and psychosocial characteristics were associated with configuration membership. Importantly, poorer dyad knowledge was associated with lower adherence to dietary sodium recommendations. This work adds to the existing body of literature suggesting that the caregiving relationship is an important aspect of HF self-care, and that dyadic research and interventions in HF education and self-care are warranted.

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## Abbreviations List

**HF**

heart failure

**QOL**

quality of life

**New York Heart Association Class**

NYHA Class

**AHFKT**

Atlanta Heart Failure Knowledge Test

**FCCQ**

Family Care Climate Questionnaire

**BDI-II**

Beck Depression Inventory-II

**MLHFQ**

Minnesota Living with Heart Failure Questionnaire

**SF-12 PCS**

Physical Component Summary of the Short Form-12

**3DFR**

3-day food record

**MEMS**

Medication Events Monitoring System

**ACE-I**

angiotensin-converting-enzyme inhibitor

**ARB**

angiotensin receptor blocker

**BB**

beta blocker

**LMRT**

Lo-Mendell-Rubin adjusted likelihood ratio test

**SE**

standard error

**gm**

gram

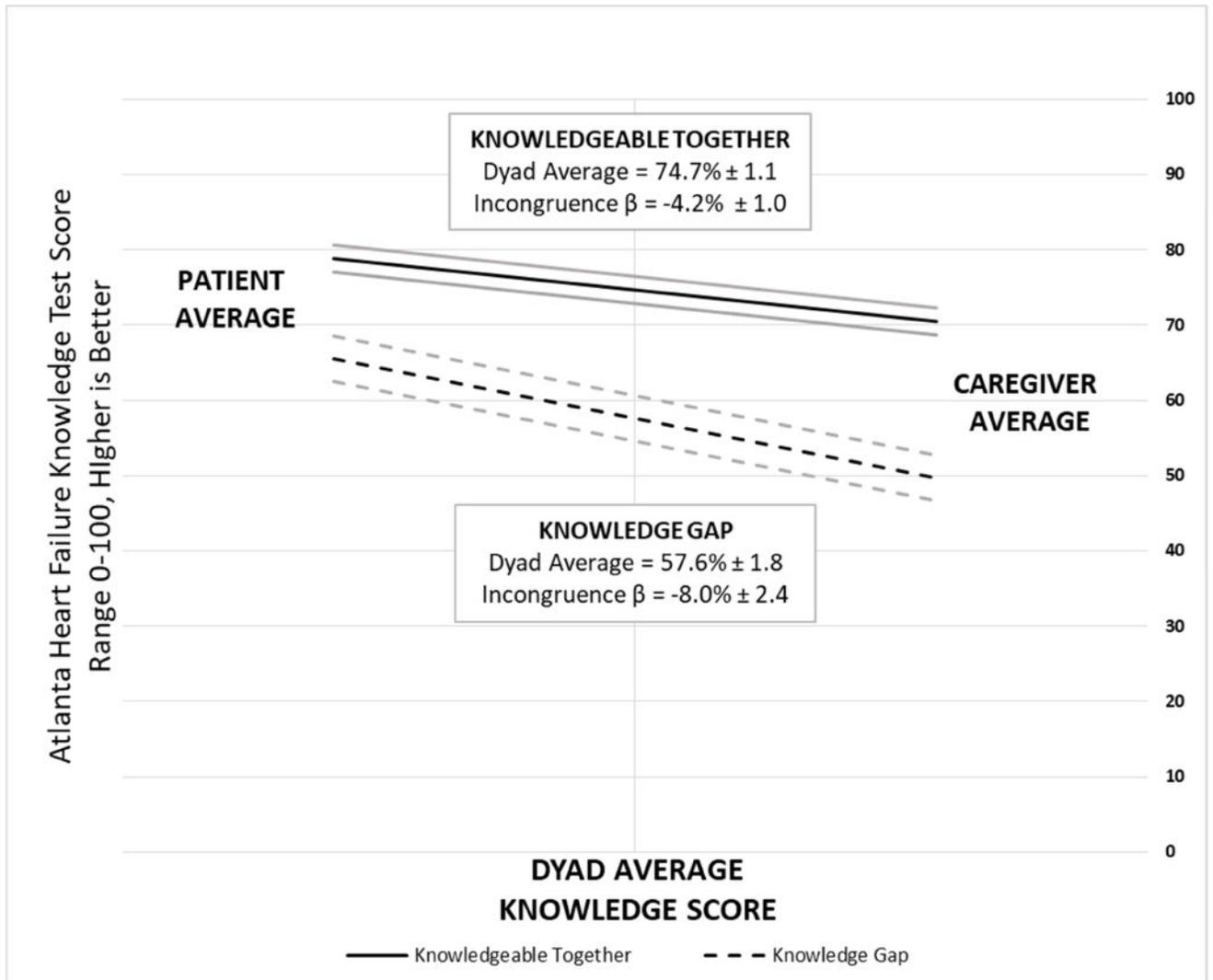
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**Figure 1. Dyadic Heart Failure Knowledge Configurations**  
 Dyadic average and incongruence are the intercept and slope displayed here, respectively, with robust standard errors.

**Table 1**

Clinical and Demographic Characteristics of HF Patients and Caregivers, with Differences by Dyadic Heart Failure Knowledge Configuration

	<b>Total Sample (n=114) M±SD n(%)</b>	<b>Knowledgeable Together (n=85) M±SD n(%)</b>	<b>Knowledge Gap (n=29) M±SD n(%)</b>	<b>Difference by Knowledge Group (p-value)</b>
<b>Sociodemographic Characteristics</b>				
Patient age	55.8± 10.3	56.3± 10.5	54.3± 9.7	0.38
Caregiver age	52.0± 13.5	51.6± 12.9	52.9± 15.6	0.67
Female patient	42(36.8%)	32(37.7%)	10(34.5%)	0.76
Female caregiver	93(82.3%)	70(83.3%)	23(79.3%)	0.63
African American patient	66 (57.9%) (	42 (49.4 %)	24 (82.8 %)	<b>&lt;0.01</b>
African American caregiver	67 (59.3 %)	43 (51.2 %)	24 (82.8 %)	<b>0.01</b>
Spousal caregiver	60(53.1%)	49(58.3%)	11(37.9%)	0.06
Patient college education	54(47.4%)	45(52.9%)	9(31.0%)	<b>0.04</b>
Caregiver education college	55(48.7%)	48(57.1%)	7(24.1%)	<b>&lt;0.01</b>
Patient Charlson	3.0± 2.2	3.0± 2.0	3.2± 2.7	0.62
Caregiver Charlson	0.9± 1.4	0.8± 1.3	1.0± 1.6	0.43
<b>Patient Heart Failure Characteristics</b>				
NYHA Class III	32(28.1%)	25(29.4%)	7(24.1%)	0.59
Years with HF	3.9± 1.3	3.9± 1.4	4.0± 1.3	0.72
Non - Ischemic HF	92(81.4%)	67(78.8%)	25(89.3%)	0.22
Ejection Fraction	27.0± 13.7	28.8± 14.0	20.5± 10.7	<b>0.02</b>
HF Hospitalization	42(38.2%)	30(35.7%)	12(46.2%)	0.34
<b>Psychosocial Characteristics</b>				
Patient - perceived Autonomy Supportive Relationship	5.8± 0.9	6.0±0.7	5.3±1.2	<b>&lt;0.01</b>
Caregiver - perceived Autonomy Supportive Relationship	6.0±0.7	6.0±0.7	5.8±0.7	0.29
Patient Depression	12.9± 9.8	11.7± 8.8	16.6± 11.8	<b>0.05</b>
Caregiver Depression	8.2±7.8	8.1± 8.0	8.5± 7.3	0.81
Patient QOL	50.1± 22.8	48.5± 20.8	55.1± 27.7	0.18
Caregiver QOL	44.1± 13.3	45.5± 12.9	38.2± 13.4	<b>0.04</b>

Note: NYHA: New York Heart Association; HF: heart failure; QOL: quality of life

**Table 2**

Differences in Dietary and Medication Adherence by Dyadic Heart Failure Knowledge Configuration – Unadjusted and Adjusted Results

Outcome	Knowledgeable Together (n=85) M±SD n(%)	Knowledge Gap (n=29) mean±SD n(%)	Unadjusted t-statistic / $\chi^2$ p-value Effect Size	Adjusted Model* $\beta$ ±SE / OR(95%CI) p-value Effect Size
Sodium Intake 2g	33(39.0%)	5(17.2%)	$\chi^2$ (1,114)=4.5 <b>p=0.03</b> d=0.41	OR=0.29(0.09–0.98) <b>p=0.04</b> d=.68
24hr Urine Sodium	3680.21±1680.241	4188.46±2057.54	t(111)= - 1.32 p=0.19 d=0.28	$\beta$ =219.17±361.36 p=0.54 d=0.12
HF Medication Adherence (MEMS)	86.1±23.9	72.9±31.3	t(100)=2.21 <b>p=0.03</b> d=0.51	$\beta$ = - 11.46±6.56 p=0.08 d=0.45
Diuretic Adherence (MEMS)	81.8±30.1	73.7±36.3	t(93)=1.08 p=0.28 d=0.26	$\beta$ = - 10.48±8.30 p=0.21 d=0.33

\* Controlling for patient age, gender, education level, patient-caregiver relationship type (spousal/nonspousal), NYHA Class, and patient depressive symptoms (BDI-II total score). Furosemide equivalents were also included in the model predicting 24hr urine sodium.