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Understanding communal coping among patients and informal caregivers with heart failure: A mixed methods secondary analysis of patient-caregiver dyads



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ABSTRACT

Background: Dyads that view illnesses as shared stressors (“shared appraisal”), and collaboratively respond to it, have better outcomes. This process, known as communal coping, has received little attention in heart failure (HF).

Objectives: To examine communal coping among patient-caregiver dyads managing HF.

Methods: We conducted semi-structured interviews with 34 dyads. Shared appraisal was measured using we-ratio, as calculated with Linguistic Inquiry Word Count. We-ratio was divided into “high” and “low” for patients and caregivers, and concordance was examined. Thematic analyses were used to explore collaboration.

Results: Caregivers had higher we-ratios than patients ($p=.005$); 29.6% and 33.3% dyads were concordant on high and low “we-ratio,” respectively. In thematic analyses, we found that 1) dyads collaborated around diet, appointments, and medications, but less around physical activity; 2) dyads collaborated across all illnesses, not just HF; and 3) dyads concordant on high we-ratio reported stronger collaborations.

Conclusions: Communal coping varied by shared appraisal and collaboration. Understanding this variability may help develop tailored self-management interventions.

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Introduction

Patients with heart failure (HF) face many barriers to engaging in daily self-management recommendations. These may include functional disability, depression, lack of motivation, lack of knowledge, poor self-efficacy, failure to recognize worsening symptoms, and poor access to community resources that support physical activity and healthy eating.^{1–3} Adherence to HF self-management behaviors

is typically improved by involving a patient’s social support network, particularly informal caregivers, referred to from this point on as caregivers.^{4,5} Further, when patients and caregivers view these extensive self-management responsibilities as shared and handle the associated tasks and stressors as a team, better health outcomes for the patient and better psychological well-being for both dyad members are achieved.⁶

Multiple investigators have theorized that self-management is a dyadic rather than an individual process that comprises of appraisal of illness as a shared stressor and collaboration,^{7,8} and is influenced by interpersonal relationships.⁹ Communal coping is one such theory that conceptualizes the dyadic response between a patient and caregiver dyad to a chronic illness as the combination of 1) shared illness appraisal and 2) collaboration to manage the illness.^{6,10} Shared illness appraisal is defined as an “individual’s perception that the responsibility to manage the illness is joint or shared—that is, it is ‘our problem’ rather than ‘my problem or his/her problem’ (p. 4).” Collaboration is defined as either joint efforts of patients and caregivers, or any individual efforts that contribute towards the shared goal of disease management. Stated another way, an individual effort by one dyad

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member may be considered “collaborative” if it is in the context of a shared illness appraisal. Thus, communal coping can be thought of as a process by which shared illness appraisal and collaboration interact synergistically to produce advantageous outcomes. Evidence suggests that communal coping improves patients’ and caregivers’ psychological well-being, patient self-efficacy, stress appraisal, self-regulation, relationship quality, and clinical outcomes,^{6,11} particularly among dyads managing diabetes.^{12–15}

Among dyads managing HF, the shared illness appraisal and collaboration components of communal coping theory have been examined separately. Rohrbach et al. (2008)¹⁶ coded the number of times couples used “we” versus “I” in open-ended interviews to evaluate shared appraisal among couples managing HF. In their study, use of ‘we’ pronouns by the spouse, but not the patient, independently predicted improvement in the patient’s HF symptoms and general health. Thus, partner’s shared illness appraisal may be more predictive of health outcomes than patient shared illness appraisal. A few studies have conceptually addressed the “collaboration” aspect of communal coping.^{17–20} Nissen et al.²⁰ found that higher levels of collaboration appeared to be associated with couples’ satisfaction with their new lifestyle, shared ownership of lifestyle changes among the couple, couples’ confidence in their ability to change, and less emotional distress related to making lifestyle changes following a 6-week cardiovascular rehabilitation program. Related, Buck et al. (2013)¹⁷ identified four types of dyads based on their degree of collaboration in managing HF: Patient-oriented, caregiver-oriented, collaboratively oriented, and complementary-oriented. While they did not examine clinical outcomes, their typology highlights that collaboration varies across dyads.

This small body of work suggests that both shared illness appraisal and collaboration may be independently related to positive health and relationship outcomes among dyads managing HF. However, the literature is limited by the small number of studies in HF examining either shared illness appraisal or collaboration, and the lack of studies that address both. Understanding how each component interacts to influence self-management can help inform the development of dyadic self-management interventions that are uniquely tailored to dyads facing HF.

Thus, the objectives of the current study were to 1) examine illness appraisal by patients and caregivers using linguistic analyses, 2) explore how patients and informal caregivers describe collaboration regarding HF self-management using thematic analyses, and 3) explore themes regarding how patient/caregiver dyads describe collaboration of HF self-management based on their shared illness appraisal. For aim 1, we hypothesized that caregivers would have a higher we-ratio than patients, women would have a higher we-ratio than men, and spousal caregivers would have a higher we-ratio than non-spousal caregivers based on previous research.²¹ Aims 2 and 3 were intended to be hypothesis-generating.²²

Materials and methods

Sample and recruitment

This study represents secondary analyses of two similar mixed methods studies in which the primary aims were to determine the barriers to HF self-management and perceptions of the caregiving role in HF. Two subsamples of HF patients and their informal caregivers from previous studies were combined to form a sample of 34 patient/informal caregiver dyads. Convenience sampling was used in both studies and recruitment continued until thematic saturation was obtained regarding the primary study question. In both studies, both patients and caregivers had to provide informed consent and were provided with a \$25 incentive for participating. Study procedures were approved by the local Institutional Review Board and Research and Development committees.

For both studies, patient participants were eligible if they had an active diagnosis of HF (ICD9 code 428.XX), and had at least one HF-related visit to the respective recruitment facility in the previous year. Patient participants in both studies were excluded if they reported using a paid caregiver. In addition, patient participants were excluded if they were in active cancer treatment, or had cognitive impairment documented in their medical chart. Eligibility criteria for the caregiving relationship (spouse or significant other only versus any family member or friend) differed between the two studies and are described below.

For the first study, we recruited 17 patients with HF, and their caregivers, from a major Veterans Affairs (VA) Health Care facility. In this study, patient participants were required to have a spouse or significant other as their primary caregiver. This study subsample and recruitment procedures are described elsewhere.⁹ Research staff first identified medically eligible patients from the VA Decision Support System (DSS) registry. Staff then recruited participants via letters and follow-up phone calls.

For the second study, we recruited 17 patients with HF and at least one caregiver from a single cardiologist’s practice in a university hospital HF clinic. Medically eligible patients were identified using the hospital’s electronic health record system and recruited at clinic appointments. In this study, patient participants were asked to identify a family member or friend who was their primary caregiver and who was willing to be interviewed for the study.

Interviews

For both subsamples, interviews were first conducted jointly with the patient-caregiver dyad and then with each individual alone. This method ensured that each participant had an opportunity to share information and perspectives privately, while still being able to capture interpersonal dynamics and interactions.²³ Quotes reported from all interviews were selected with within-dyad confidentiality in mind. Interviews lasted approximately 45 minutes including both the dyadic interview and the individual interview. The interview guides were designed to elicit how interpersonal factors contribute to managing HF, including social support, relationship quality, collaboration, communication, individual and dyadic coping of HF, and barriers to self-management.⁹ Interviews were audio recorded and transcribed by a professional transcription service. The interviewer maintained detailed notes during each interview to assist with coding and analyses. Interviews were conducted until thematic saturation around the barriers and facilitators of self-management was reached, and no new themes were identified.

Measures

Demographics

Demographic information including age, sex, marital status, race, ethnicity, education, employment, and income, and depression (PHQ-9)²⁴ were collected from all participants by self-report questionnaire.

Shared illness appraisal

Use of first-person singular pronouns (‘I’) and use of first-person plural pronouns (‘we’) was used to assess shared illness appraisal, as has been done in previous studies.^{16,21,25,26}

Interviewers

Two masters’ level women, one woman who was in a masters’ program, and the PI who has a PhD (RT) conducted interviews. The PI identifies as Indian, while the other interviewers identify as non-Hispanic White, Indian American, and Korean American. The PI, a clinical health psychologist who has worked with HF patients and their families for over 10 years, trained all interviewers. The PI reviewed

recordings of all interviews and provided individual feedback to ensure close adherence to the interview guide. Interviewers were trained to ask questions in a neutral, non-biased manner.

Data analyses

We employed a mixed methods approach to address analyses of all three objectives. We first used linguistic analyses to quantify the extent to which HF is perceived as a shared problem by patients and caregivers. Linguistic Inquiry Word Count (LIWC),²⁷ a text analysis program was used to process transcripts word-by-word and yield a percentage of all words in the transcript that fell into 'I' or 'We' pronoun categories. We-talk (we/total word use), I-talk (I/total word use), and we-ratio [We-talk/(I-talk + we-talk)] variables were computed in SPSS (Version 24, 2017). Independent samples t-test were used to examine differences based on caregiving status, gender, and caregiving relationship using SPSS. We-ratio was used to categorize each participant as either having a high we-ratio or low we-ratio, based on whether they fell within the upper 50% or lower 50% of the sample (median split), respectively. The small sample size precluded having more than two categories (e.g., tertiles). This categorization was then used to determine whether members of each dyad were concordant in terms of we-ratio.

We used thematic analyses²⁸ to explore how patients and caregivers describe collaboration regarding HF self-management. The research team developed a deductive coding scheme that was guided by Communal Coping theory.⁶ This scheme was enhanced by identifying inductive codes rooted in a close reading and analysis of interview transcript data. One primary coder (JW) coded all interviews, developed the study codebook, and was responsible for newly developed codes. Inductive codes were added to the codebook iteratively, and all transcripts were then reviewed for newly developed codes. Parallel independent coding (a coding consistency check in which a second coder independently codes raw data without seeing the initial

codes developed by the primary coder)²⁹ was used to ensure reliability and minimize coder drift (reduction in coding reliability over time due to the adoption of coding biases and less rigorous application of coding criteria).³⁰ A second coder (CG) coded 20% of the interviews using the same codebook. Initial agreement between the primary and secondary coders was 66%. Coders discussed discrepancies until the percent agreement was above 70%.³¹ Analyses were conducted using ATLAS.ti (v7.5.12).

Finally, we combined the shared illness appraisal and collaboration results to develop a richer understanding of communal coping among HF patients and their caregivers. We first characterized dyads based on concordance of their we-ratio, or illness appraisal. Categories included: 1) dyads that were concordant on high we-ratio, 2) concordant on low we-ratio, 3) discordant where patient had a low and caregiver had a high we-ratio and 4) discordant where caregiver had a low and patient had a high we-ratio. Transcripts were coded in ATLAS.ti based on which of the categories dyads fell into. We then examined interviews within each category using thematic analysis to compare the collaborations around self-management behaviors across each group.

Results

Demographic characteristics of the sample are presented in Table 1. We had New York Heart Association (NYHA) ratings for 13 of the 17 patients from the Stanford sample and did not collect this data from the VA sample. We found that 1 patient had NYHA Class I, 10 patients had Class II, 1 patient had Class III, and 1 patient had Class II-III HF. To address aim 1, we first examined shared illness appraisal using LWIC (Fig. 1). Consistent with our hypotheses, caregivers had a higher average we-ratio than patients, $t(52) = -2.96, p = .005$. In contrast to our hypotheses, there were no significant differences in we-ratio between men and women [$t(52) = -1.29, p = .20$] or between spousal and non-spousal caregivers [$t(52) = -0.88, p = .38$].

Table 1
Demographic characteristics of the sample

Characteristic	Overall (n = 54)	Patients (n = 27)	Caregivers (n = 27)
Age, years, Mean (SD)*	64.18 (12.6)	66.51 (12.7)	61.7 (12.1)
Male, n (%)	23 (42.6)	21 (77.8)	2 (7.4)
Heart Failure Severity			
Marital Status, n (%)			
Married/Partnered	39 (72.2)	19 (73.1)	20 (83.3)
Divorced/Separated	6 (11.1)	4 (15.4)	2 (8.3)
Single/Widowed	5 (9.3)	3 (11.5)	1 (4.2)
Race/Ethnicity, n (%)			
White	37 (71.2)	18 (66.7)	19 (76.0)
Black	4 (7.7)	3 (11.1)	1 (4.0)
Other	11 (21.1)	6 (22.2)	5 (20.0)
Hispanic/Latino, n (%)	15 (30.0)	6 (24.0)	9 (36.0)
Highest Education, n (%)			
8th grade or less	4 (7.7)	1 (3.7)	3 (12.0)
High school graduate or GED	8 (15.4)	5 (18.5)	3 (12.0)
Some college or 2-year college degree	30 (57.7)	14 (51.9)	16 (64.0)
4-year college degree or more	10 (19.2)	7 (25.9)	3 (12.0)
Employment Status, n (%)			
Employed	12 (23.1)	4 (14.8)	8 (32.0)
Retired	25 (48.1)	15 (55.6)	10 (40.0)
Unemployed	4 (7.6)	1 (3.7)	3 (12.0)
On disability	11 (21.2)	7 (25.9)	4 (16.0)
Household's Financial Situation, n (%)			
After paying the bills, still have enough for special things that one wants	23 (44.3)	11 (40.7)	12 (48.0)
Have enough money to pay the bills, but little spare money to buy special things	20 (38.5)	11 (40.7)	9 (36.0)
Have money to pay the bills, but only because one has to cut back on things	7 (13.5)	3 (11.1)	4 (16.0)
Have difficulty to pay the bills, no matter what one does	2 (3.8)	2 (7.4)	0 (0.0)
Caregiver is Patient's Romantic Partner, n (%)			22 (81.5)
Depression PHQ-9, % > 10	31.6	34.6	25.0

Patient Health Questionnaire-9, PHQ-9.

* $P < .05$.

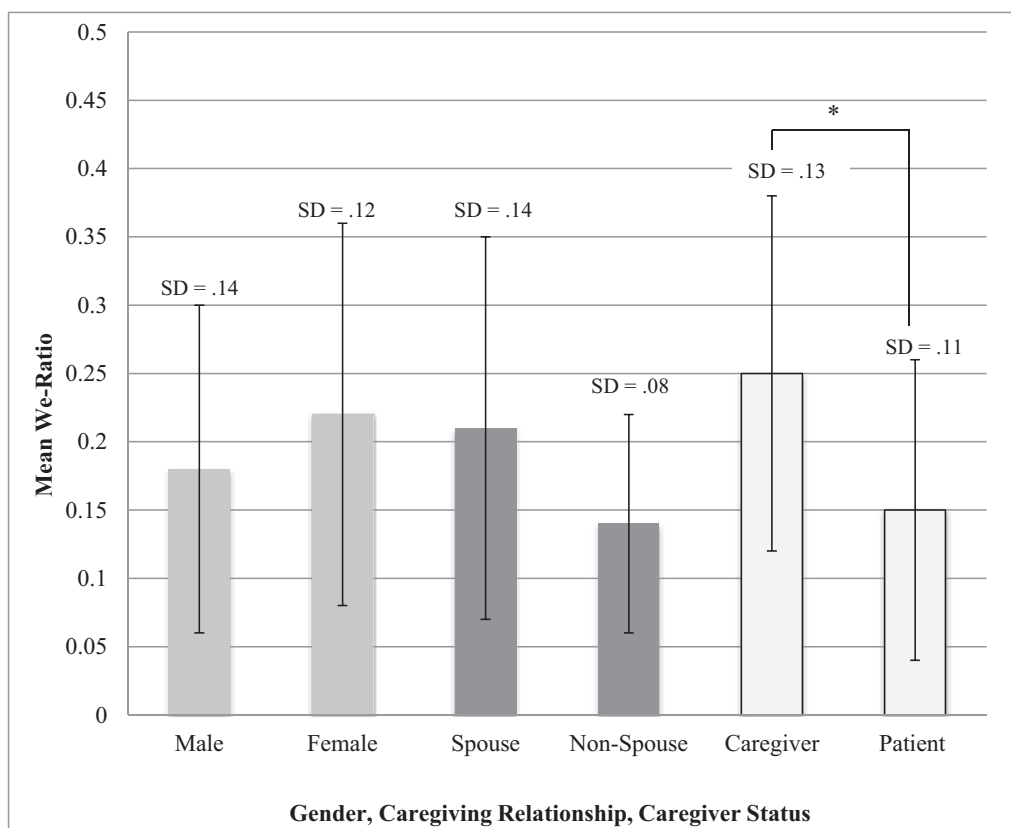


Fig. 1. We-ratio mean across gender, caregiving relationship, and caregiver status * $p < .05$.

We next examined within-dyad concordance in we-ratio. For 29.6% ($n = 8$) of dyads, both patients and caregivers' we-ratios fell within the upper 50% of the sample. For 37% ($n = 10$) of dyads, caregivers had a we-ratio that fell within the upper 50% of the sample and patients had a we-ratio that fell within the lower 50% of the sample. For 33.3% ($n = 9$) of dyads both patients and caregiver's we-ratio fell within the lower 50% of the sample. There were no dyads where patients had a high we-ratio and caregivers had a low we-ratio. Means and standard deviations of we-ratios are presented in Table 2.

We next identified emergent themes relevant to collaboration within dyads. Three themes were identified 1) Collaboration depends on the specific self-management behavior (aim 2); 2) Collaboration extends beyond HF and includes managing the health of both patients and caregivers (aim 2) and 3) Collaboration varies by whether dyads agree that HF is a shared problem (aim 3). Representative quotes from patients and caregivers are presented in Table 3 for Themes 1 and 2 and in Table 2 for Theme 3.

Theme 1: Collaboration depends on the specific self-management behavior

Dyads often established routines of working together to manage HF. However, collaboration tended to involve each member of a dyad engaging in specific tasks independently rather than engaging in all tasks together and depended on specific health behaviors. Dyads reported collaborating around diet, managing medications, and attending appointments, but less so around physical activity.

Diet

Patients with HF often reported facing multiple dietary restrictions. Patients and caregiver's who were living together often ate meals together, and typically both partners followed a low-salt diet. Caregivers, usually female, were commonly responsible for purchasing food and preparing meals.

Medications

Patients and caregivers frequently reported collaborating to manage medication adherence. Caregivers supported patients by helping organize medications and reminding patients to take medications. Some dyads reported that as time went on since initial diagnosis, patients became increasingly responsible for their own medication regimens. Caregivers were often aware of patient's medication regimen and often caregivers were also managing their own chronic health conditions and were required to engage in some similar daily self-management behaviors such as taking medications.

Medical appointments

It was common for caregivers to report attending medical appointments with patients. During medical appointments with patients, caregivers actively engaged in conversation, asking questions and making sure information was communicated correctly. Attending medical appointments together was also a way that information and knowledge was shared among patients and caregivers.

Physical activity

By contrast, physical activity was frequently perceived as an individual responsibility. Many patients reported being active in the past, but reported current difficulty being active because of reduced functioning. Caregivers tended to be less encouraging of physical activity and in fact perceived physical activity to be potentially harmful and did not want patients to 'overdo it.'

Theme 2: Collaboration extends beyond HF and includes managing the health of both patients and caregivers

Sometimes HF was just one of several health conditions the dyad was collaborating to manage. Some participants discussed that multiple comorbid conditions made management of HF more difficult, for

Table 2
Means and standard deviations of we-ratio and representative quotes regarding collaboration by concordance of we-ratio

	Caregiver low we-ratio (N = 9) M = 0.12, SD = 0.04	Caregiver high we-ratio (N = 19) M = 0.31, SD = 0.12
Patient	N = 9 dyads	N = 8 dyads
Low we-ratio (N = 18) M = 0.09, SD = 0.04	<p>"When I moved here I made friends with some people who live in the same apartment complex that I lived in before I moved in with my mom. And I also have some close friends through a group that I joined called Zipper Sisters. It's this group for women with congenital heart disease." – Patient</p> <p>"I used to frustrate him I think because I asked too many questions. And I questioned what he was doing, because I have dealt with this particular congestive heart failure with two other people [...] And I just questioned some of the things that he was doing, and it turned out that one of the things that I questioned was wrong and it's been corrected. So now we get along better now." – Caregiver</p>	<p>"Yeah, I can't do [clean] the bathroom anymore. [I can't] bend down. I mop and my back hurts. I can't do that no more. And vacuum cleaner, I'm drawn up, do it, but I'm tired. So I let her come and do it." – Patient</p> <p>"You have to be stern with the [patients]. You have to make them do things. Push them to do stuff because they have a tendency of not—they just sit and they don't want to do anything at first. Even today, I tell [my husband] to get up and do his stuff. They have to be told a lot of the time. It's really hard on the wife because it changes your whole life." – Caregiver</p>
Patient High we-ratio (N = 8) M = 0.27, SD = 0.12	N = 0 dyads	N = 10 dyads
		<p>"It's very, very complicated to keep on top of it. But he [takes his medications] now because I have everything in a special box. One box for the pills he takes in the morning. One box for the pills he takes twice a day, morning and night. And [another] box for just night pills. And when he gets low, he tells me and I call [the pharmacy]." – Caregiver</p> <p>"I think we both are [responsible for managing heart failure]. We do everything together. We shop together. We exercise together. When you see Mr. X, you see Mrs. X and when you see Mrs. X you see Mr. X. We have a good look into the future." – Patient</p>

Note: Quotes pertain to Theme 3.

example by requiring additional dietary restrictions. Patients often mentioned experiencing comorbid health conditions which usually involved collaboration by caregivers. In addition, caregivers were often managing their own health conditions in conjunction with the patient's health conditions. Further, HF patients and caregivers commonly noted that managing mental health conditions was challenging and often also a collaborative process. For example, one spousal caregiver reported that her husband (the HF patient) helps monitor her mental health symptoms and helps identify when she should seek medical attention.

Theme 3: Collaboration varies by whether dyads agree that HF is a shared problem

Our final theme combined our shared illness appraisal findings and collaboration findings to evaluate communal coping.

Dyad concordant on high we-ratio

When we-ratio was in the upper 50 percentile for both patients and caregivers, participants generally discussed a high degree of collaboration, shared behavioral effort, and being well-adjusted to the demands of HF. Further, these dyads tended to discuss changes over time regarding their caregiving dynamic; specifically, that over time they have developed a system that works for them in terms of collaborating and/or diving up tasks.

Dyad concordant low we-ratio

Dyads in which both the caregiver and patient's we-ratio fell within the lower 50 percentile, often discussed relying on many others in addition to one caregiver for support. Some also discussed experiences of a caregiver being overbearing, or too involved in the past.

Dyad discordant on we-ratio with caregiver high we-ratio, patient low we-ratio

For dyads in which caregiver's we-ratios were in the upper 50 percentile and patient's we-ratios were in the lower 50 percentile,

caregivers discussed feeling overwhelmed, helpless, and unappreciated. Some patients in these dyads also discussed a decrease in functioning of the patient, which in turn created more responsibility for the caregiver. Some caregivers in these dyads felt that they had more responsibility than the patient.

Discussion

The goal of our exploratory, hypothesis-generating study was to characterize both the shared illness appraisal and collaboration components of communal coping among dyads managing HF. We found that caregivers used more we-talk than patients, suggesting that caregivers saw HF as more of a shared stressor than patients. Using thematic analyses, we found that collaboration among patients and caregivers varies based on the specific self-management behavior. We also found that collaboration extends beyond HF, and that dyads helped each other in managing their respective physical and mental health conditions. When comparing patient-caregiver dyads across concordance of shared illness appraisal (we-ratio), dyads varied based on whether patients and caregivers were concordant on high we-ratio, discordant on we-ratio, or concordant on low we-ratio. Dyads concordant on high we-ratio often discussed being highly collaborative and having a dynamic that evolved over time, while dyads concordant on low we-ratio discussed having multiple people who provide support in addition to caregivers. Dyads discordant on we-ratio were characterized by poor patient's health, and frequent reports of caregiver stress.

Our finding that caregivers used more we-talk than patients suggests that caregivers may perceive HF self-management as a shared responsibility more so than patients. This finding is consistent with previous studies in other clinical populations.^{16,21,32} Karan et al.²¹ suggest that in the context of health, the use of we-language communicates support and leads to positive outcomes. While our study did not find significant differences between men and women, or between types of caregivers, we were limited by our small samples of male caregivers, female patients, and non-spousal caregivers. Future studies may recruit a larger and more diverse sample to further

Table 3
Representative Quotes Regarding Collaboration among Dyads (Aim 2)

Theme 1: Collaboration by Specific Self-Management Behavior	
Diet	He does not eat any red meat and I follow his diet. I support him by not bringing home things that he can't eat, that would tempt him. [...] All I do is cook the food without salt and then add my seasonings when we're going to eat on my plate. – Caregiver
Medications	I'm just the one that reminds us both that we have to take our pills, because especially at night when he's tired, sometimes he tends to forget, so I say, "Did you take your pills?" – Caregiver
Medical appointments	[I attend medical appointments] for support and also to have certain things taken care of because I'm aware of certain symptoms and certain things and he won't always tell the doctor [...]. I allow him [the patient] and the doctor to interact and do their thing. Then towards the end before we leave, I ask the doctor, "May I ask a couple of questions?" And then I'll ask a few questions that are of concern to me about his health. Can we possibly do this option or etc., etc., and then go from there. – Caregiver
Physical activity	I used to be really, really hyper. [My wife] does try to get me to slow down because with this Fitbit it lets me know that I'm really overdoing it. I can go 8,000 to 10,000 steps a day quick. She's always telling me, "You need to rest; you need to stop doing what you're doing." – Patient
Theme 2: Collaboration across multiple conditions among both patients and caregivers	
Patient Comorbid Health Condition	"And at the change of the diet for the kidney cancer, we refined and readjusted what we eat now because of his kidney surgery. He had his left kidney removed completely and he has one partial right kidney." – Caregiver
Patient Comorbid Mental Health Condition	"He'll lose his temper. It could be from the PTSD. He'll lose his temper when he talks to people about phone problems or whatever and I just have to grab the phone from him and finish taking care of it because he gets so mad." – Caregiver "I would say the pain management and the PTSD probably together [are the most difficult to manage] because they can be really bad if they amp up" – Patient
Caregiver Health Condition	"My wife has had cancer. Colon cancer and liver cancer, stage IV. She's recuperating" – Patient "Well, I was diagnosed [with cancer] in August. Went through the chemo, the surgery in December. More chemo. And then we were actually able to move back home to Tulare, that's when he started in. So I was kind of recuperating. Falling and breaking my ankle. And then he started having problems, was in the hospital a few times. Now we're both back on our feet." – Caregiver
Caregiver Mental Health Condition	"We work together because sometimes he'll notice that I'm getting manic before I do. It's easy for me to think that's depression. But I'll kind of sense I'm getting kind of hyper, energetic. Like I feel like I'm getting wired up or something. I'll ask his opinion. "Honey, am I getting manic-y, am I getting irritable and agitated? What do you think?" And so he'll give me his input and I will see my psychiatrist right away when the symptoms start." – Caregiver

understand the variability in communal coping across various populations.³³

Collaboration between patients and caregivers depended on the specific self-management behavior. Similarly, Buck et al. (2018)¹⁹ also identified differences across self-management behaviors, although they found that patients were commonly responsible for their own day-to-day care and partners were commonly responsible for responding to patient's symptom exacerbations. In our study, participants generally spoke more of collaborating around diet, attending medical appointments and medication adherence, and spoke less about collaborating with regard to physical activity.

The benefit of collaborating on diet, medical appointments, and medication regimens may be more immediately salient (e.g. avoiding fluid retention) than behaviors such as physical activity that may take longer to produce noticeable benefits. It may also be easier to accommodate differing preferences for diet (e.g. using different seasonings) than for physical activity. Differing abilities and preferences regarding physical activity, and the presence of other comorbidities, may make activity collaboration especially difficult among patients and caregivers. Our results also indicate that caregivers may hinder physical activity even though regular physical activity is recommended for improvement of HF symptoms and quality of life.³³ Several previous studies discussing collaboration of HF self-management, do not mention physical activity or exercise.^{5,19,34} It is possible that this recommendation is counterintuitive to some individuals as physical activity may temporarily produce discomfort. Providing physical activity recommendations³⁵ with caregivers present, and involving caregivers in identifying and problem-solving barriers to physical activity may alleviate this barrier.

Patients and caregivers collaboratively managed multiple comorbid medical and mental health conditions. Often the person identified as the 'caregiver' for the purposes of our study was also facing their own health conditions. Thus, it may benefit patients for healthcare providers to consider how self-management recommendations may fit into the management of their collective health conditions, for example, taking medications at the same time. Collaboration in mental health management seemed to benefit to dyads. This is consistent with Bouldin et al. (2018), who used latent class analysis to categorize HF patient/caregiver dyads based on communication and relationship factors. They characterized dyad's relationships as 'collaborative,' 'antagonistic,' 'avoidant,' or 'distant.' Patients in the 'avoidant' and 'distant' groups had the highest rates of depression, suggesting that patient's mental health may impair communication with the caregiver.³⁶ Given that mental health status is typically lower among those with cardiovascular disease,³⁷ and among users of the VA healthcare system,³⁸ exploring communal coping in the context of mental health is an important opportunity for dyadic interventions.

Collaboration also varied based on concordance of shared illness appraisal. Among dyads who were concordant on high we-ratio, participants often reported being highly collaborative and engaging in a high degree of joint behavior effort. Similar to prior work, some participants discussed that their dynamic around collaboration had evolved over time.^{39,40} It is possible that dyads concordant on high we-ratio have been managing HF longer and have therefore had more time to develop a system of self-management that is adaptive for them. It is also possible that dyads concordant on high we-ratio had a stronger relationship, which led to improved collaboration. In support of this, Lee et al.³⁴ identified better relationship quality among patient/caregiver dyads that collaborated in all aspects of self-management.

Among dyads that were discordant on we-ratio, caregiver's we-ratio fell within the upper range, and patient's we-ratio fell within the lower range. In our sample, dyads with discordant we-ratios tended to discuss decreased function of the patient and caregiver burden. Therefore, in these dyads, patients and caregivers may perceive patients to be less able to take responsibility for self-management. One hypothesis is that caregivers may take on responsibility and consequently, be more susceptible to caregiver burden. There were no dyads where the caregiver fell within the lower 50 percent of the sample and the patient's we-ratio fell within the upper 50 percent of the sample. This is consistent with previous studies in diabetes,⁴¹ and may suggest that patients who seek collaborative self-management support from caregivers received it.

For dyads in which the patient and caregiver both fell within the lower range of we-ratio, it was common for participants to speak about having one or more other people providing caregiving support to them. This makes sense as collaborations may be shared among several individuals rather than primarily among a dyad. Other studies have suggested that communal coping likely extends beyond dyads and may include other family members and friends; however, there is very little work on this topic.⁶

Limitations

This study is novel in that it uses multiple methodologies to examine both the shared illness appraisal and collaboration components of communal coping among a sample of patients with HF and their caregivers. However, the results of this study should be considered in the context of several limitations. First, our measure of shared illness appraisal did not take into account the context in which pronouns were used or the tone of speaker, which may alter the meaning of the pronoun. However, automatic text analyses circumvent the social-desirability reporting biases present among self-report measures and are considered a valid implicit measure of shared illness appraisal.^{21,42} Second, we assessed concordance on we-ratio using median split since our sample size was not adequate to examine the upper and lower quartiles of we-ratio. Third, this study was conducted as a secondary data analysis of two parent studies that were not designed to answer the specific research questions explored in the current study. Fourth, interview guides for the studies were not identical and may have elicited different information between the two samples. Future work could build on our results by recruiting more participants, using validated measures of HF self-management, and developing interview guides to specifically explore communal coping.

Future research directions

Further, future work using larger samples and quantitative measures is needed to test the hypotheses generated from this study. For example, it is possible that participants with non-spousal caregivers may benefit from individual rather than dyadic interventions, interventions that increase shared illness appraisal may improve health outcomes, and physical activity adherence may be an important target for dyadic intervention development. Another future direction is to examine engagement in specific health behaviors by concordance on we-ratio. Understanding potential moderators such as psychiatric comorbidity and HF severity are also important future directions that would build on our study. While our study excluded those with cognitive impairment, cognitive impairment is common among HF patients and may be an important consideration for future work.⁴³

Conclusion

This study adds to literature on communal coping and self-management of HF by describing differences in collaboration based on different

self-management behaviors and highlights that patients and caregivers affected by HF are often facing multiple medical and mental health conditions. It also integrates the components of shared illness appraisal and collaboration with a HF population. Continued work in this area will contribute to identifying intervention targets that can help patients and caregivers capitalize on interpersonal dynamics to improve their health.

Supplementary material

Supplementary material associated with this article can be found, in the online version at doi:10.1016/j.hrtlng.2019.05.008.

Appendix

Stanford sample interview guide

Hello [interview participant name], my name is [interviewer name]. Thank you for taking the time to talk with us today.

We are talking with you because we want to understand how patients with heart failure and their friends and family members work together to manage health care. Over the next little while, I'll be asking you several questions. There are no wrong answers. People have different experiences and points of view, and we want to hear them all. Your comments will be kept confidential. Your participation is voluntary and you can ask to skip a question or to stop the interview at any time.

We will give you a gift card of \$25 after the interview and surveys are complete as a thank you for your participation. Do you have any questions?

In order to make sure we capture all of the information you give us, we would like to record this call. Okay, to confirm, I'm starting the recording. **[Hit record button.]**

[Generic prompts: If responses are limited or require clarification, probes may be used to elicit more detailed responses. Probes should use words or phrases presented by the participant using one of the following formats:

1. **What do you mean by _____?**
2. **Can you tell me more about _____?**
3. **Can you give me an example of _____?**
4. **Can you tell me about a time when _____?]**

A. Introduction

1. Can you tell me what it is like to live with a heart condition? **For Family:** Can you tell me what it is like having a loved one with a heart condition? When were you told you had HF?
2. Managing a heart condition can be complicated. What do you [patient, family] do to manage the heart condition?
3. How many hours a day would you say you think about your/patient's heart failure?
4. What are some other health conditions you are also managing? Do roles change based on what condition you are helping with?

B. Roles

5. Who is involved in helping the patient? What is their relationship with the patient? Where do they live? (if more than 1, get details of all of them)
6. What are the specific tasks that people have undertaken to help [patient]?
 - a. Who talks with the doctors, or other providers?
 - b. Are there other people who are at a distance that call to check in or provide support?

C. Communication between Patient and Family

7. How often do you [patient/family] communicate with each person? (get details of all involved)
8. How do you communicate? Email, text, phone, in person, Facebook, etc.

- a. (If more than 1) do you prefer one method of communication more than others?
- b. Do you use different methods of communication for different reasons?
- 9. What are some pros/cons of the different methods that you use to communicate?
 - a. Is there a way that you like better than others?
- 10. How well would you say you work with each other to make sure that [patient] is taken care of?
 - a. Is there anything that gets in the way of you helping [patient]?
- 11. How often do you interact with each other when you're not talking about health?
- 12. When you are not talking about their health, what do you talk about?

D. Communication with providers

- 13. When [patient] has a question at home, who is the person who calls the provider?
- 14. Who is the person the provider most often speaks with?
- 15. When there is a doctor's appointment often do you [patient] bring a family or friend?
 - a. What is their role?
- 16. Does [family member] wait in the waiting room, or come to the exam room?
 - a. How does it change your interaction when they come to the exam room?
 - b. Prompt-how does it help or hinder?

E. Technology

- 17. How do you keep track of your medical information? (test results, reports from multiple doctors)
 - a. Do you need help keeping track of it?
 - b. Do you [family] ever help you keep track of medical information?
- 18. Are there electronic tools that you use that have been helpful? Any that didn't work?
- 19. Do you use the internet at all to look up information about HF? What made you go to the internet for information?
 - a. When, how often do you use the internet?
 - b. Was it useful/what did you learn?
 - c. Positive/negative outcomes of consulting the internet?
- 20. Did it affect how you manage your condition or how you explain it to others around you?
- 21. Do you use social media (such as Facebook, Instagram, Twitter, etc.)? If yes, do you use it to communicate around your heart failure and health?
 - a. Have you used it to update your "family" about your condition?
 - b. To receive support?
 - c. How often?
 - d. Positive/Negative outcomes?
- 22. Has using these tools affected how you manage HF? How?

F. Motivators of Caregiving [For Family]

- 23. What are some reasons why you agreed to help [patient]?
 - a. Personal relationship? Cultural expectations?
- 24. Was there anyone else who would have helped if you were not there? Do you feel like you have a choice?
- 25. What role does love and affection play in your relationship with the patient?
 - a. Has that changed since their dx?
 - b. How, how not?
- 26. What role does empathy play in your relationship with the patient?
 - a. Has that changed since their dx? How?
 - b. How is it the same?

Veterans Affairs sample interview guide

Hello [Mr./Ms. interview participant name],
My name is [interviewer name].

Thank you for taking the time to talk with us today.

We are asking for your input because we are **planning new programs** that might change the way we support people with health conditions like chronic heart failure. One of our goals is to better include and **support spouses that are** involved with your health care. **We asked you and your spouse to talk with us** because you both have experience managing chronic heart failure, and you both have an interest in your health care.

I'll be asking you several questions. There are **no wrong answers**. People have different experiences and points of view, and we want to hear them all.

We won't identify you as a participant. Your comments will be kept **confidential**.

Your participation is **voluntary** and you can ask to skip a question or to stop the interview at any time.

We will mail you each \$25 after the interview and surveys are complete as a thank you for your participation.

Do you have any questions?

In order to make sure we capture all of the information you give us, we would like to record this call. The audio-file for the recording will be stored directly to restricted access file on the VA intranet. Is this okay with you? **[Hit record button.]** Okay, to confirm, I'm starting the recording. Is this ok with you?

[Generic prompts: If responses are limited or require clarification, probes may be used to elicit more detailed responses. Probes should use words or phrases presented by the participant using one of the following formats:

1. **What do you mean by _____ ?**
2. **Can you tell me more about _____ ?**
3. **Can you give me an example of _____ ?**
4. **Can you tell me about a time when _____ ?]**

Notes: Throughout the interview, check in with other partner (i.e. do you have anything to add, do you agree, etc.) Encourage equal participation by asking both partners to answer questions.

Patient – Caregiver Attributes:

- 27. **For both patient-caregiver** Can you tell me a little bit about yourself?
- 28. Can you tell me what it is like to live with a heart condition? (for spouse-what is it like being with someone with a heart condition)
- 29. What do you [patient, partner] do to manage the heart problem?
- 30. Can you tell me the type of things the doctors have told you to do for your heart failure?
- 31. Who is most responsible for managing [medical recommendations]?
- 32. How many hours a day do you spend managing [condition]?
- 33. In addition to managing the heart problem, what chores do you [patient, partner] usually do around the house?
- 34. A lot of people find it hard to keep up with all the things they need to do for their disease.
 - a. How difficult or easy is it for you?
 - b. How often do you forget to do what the doctor said?
 - c. How about times when you remembered, but just didn't feel like it?
 - d. How would you feel about get a small prize when you did everything you were supposed to? So for example, if you took all your medications on time, you would get tickets to a movie or a gift care. Would that help you remember better?

35. What gets in the way (or makes it difficult) to manage the heart problem?
 - a. Spouse-What gets in the way of helping to manage [patient] heart problem?
36. What helps you take care of the heart problem/ (what makes it easier to manage)?
 - a. Spouse-What helps you to take care of [patient] heart problem?

So, what about a time when you could not do those helpful things (ie, if said routine-so what if you are on a trip), how do you manage your heart problem in those times?

37. Can you think of anything that the VA can do to help you manage your health? (or to help caregiver manage patient's health)
38. Is there anyone else who helps care for [patient]? If so, how? Where do those people live?
39. Does [patient] have more than one condition? Which is the most challenging to manage?
40. When you [patient/partner] feel stressed, how does that affect self-management?
41. How do you work together to manage the stress caused by this condition?
 - a. What do you do to lower stress?
 - b. What do you do to prevent stress?
 - c. What do you do to have fun?
42. When you manage HF, what tasks do you think you need the most help with?
43. The last time you attended a medical appointment, did you (spouse) come with (patient)? Does your spouse come into the exam room? Describe what happened at the visit (probe for spousal involvement if not readily apparent)
44. If there is a medical visit that your spouse doesn't attend, do they ask you afterwards about what happened at the visit?
45. How do you keep track of your medical information? (test results, reports from non VA doctors)
 - a. Do you need help keeping track of it?
 - b. Does your spouse ever help you keep track of medical information?
46. Do you [and your partner] use any VA computer programs? (myHealthvet, telehealth, secure messaging)? Does your spouse help you use the programs?
 - a. Would it be helpful if your spouse helped you use VA computer programs more often?
 - b. What makes it difficult for your spouse to help you use VA computer programs?
47. Do you [patient] take care of your partner? How? What kind of things can pt do to help/provide support for spouse?
 - a. Follow up-re illness perspective or intimacy perspective. Let participants know that these are sensitive topics, but it is an important part of the human experience.

For partner/caregiver:-make private or separate interview

48. As a partner/ caregiver, what are some challenges that have come from your involvement in [patient] heart failure care?
 - a. Has there been a silver lining (i.e. brought you closer together?)
49. What is it like to be a caregiver? What would you tell a new couple/spouse with this diagnosis? What advice would you give to other caregivers?
50. Do you feel appreciated for taking care of [patient]?

Sometimes caregivers are not acknowledged or get very little information; can you please tell me about your experience?

51. Would you [partner] be willing to be more involved on HF management? Why, or why not?

We talked about a lot, but what else do you think we need to understand about living with heart failure? Are there any questions or topics I didn't ask about that you'd like to talk about?

Do you [patient,spouse] have anything else to add? We talked about a lot. Thank you so much for your time. If going directly to 1 on 1, make sure other partner leaves the room so participants can talk 1–1 with us to clarify answers or provide additional information.

Close with Q/A, explain next steps (if participating in intervention, talk about sending back questionnaires before we can schedule session 1

One on One interview guide

Hello [Mr./Ms. interview participant name],

Thank you for taking the time to talk with us today.

We are asking for your input to ensure that the answers we collected from the previous interview were correct and for you to provide any feedback or additional information.

Follow up with guide above to clarify answers, discrepancies, etc.

(E.G.: On question 3 you answered [x], can you please clarify this answer?

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