Published in final edited form as:
J Cardiovasc Nurs. 2013 ; 28(6): E37–E46. doi:10.1097/JCN.0b013e31827fcc4c.

Dyadic Heart Failure Care Types: Qualitative Evidence for a Novel Typology

Harleah G. Buck, PhD, RN, CHPN,
Assistant Professor, School of Nursing, The Pennsylvania State University, 201 Health and Human Development East, University Park, PA 16802, Phone: 814-863-3495, Fax: 814-865-3779

Lisa Kitko, RN, PhD, CCRN, and
Assistant Professor, School of Nursing, The Pennsylvania State University

Judith E. Hupcey, EdD, CRNP, FAAN
Associate Dean for Graduate Education, School of Nursing, The Pennsylvania State University

Harleah G. Buck: hgb2@psu.edu

Introduction

Heart failure (HF) is a life limiting condition which places an extraordinary burden on society, families, and individuals.[1, 2] In 2010 HF resulted in 41 billion dollars in direct and indirect costs[3]. Direct societal costs primarily involve the admission and readmission of HF patients to the acute care setting.[3] Indirect family costs involve lost wages for informal caregivers who must often choose between employment and caring for a family or friend with HF.[4] Individual costs arise from HF's known negative impact on individual's quality of life (QOL) with HF patients consistently reporting poorer QOL when compared with age matched healthy individuals.[5–7]

HF has a unique trajectory when compared with other disease populations, such as cancer or dementia, with similar symptom profiles and caregiver responsibilities.[8] This trajectory is comprised of a gradual decline in physical function with periodic exacerbations in the signs and symptoms of HF resulting in sharp drops in function.[9] Each exacerbation brings with it the possibility of death, but generally the patient survives multiple episodes, regaining some degree of function, before unexpectedly succumbing to either HF or a comorbid condition.[10] This highly uncertain trajectory makes it exceedingly difficult to extrapolate findings from other disease populations into HF and highlights the critical need for specific and targeted conceptual models and research in HF populations. This is particularly true in the effect of the patient and caregiver's interaction on HF self-care, an extremely understudied area. Relatively little is known, compared with other chronic illness populations, about the HF caregiver and even less is known about the patient and caregiver dyad and what potential effect dyadic interactions may have on HF self-care.

Self-care in HF

Adequate self-care is a key piece in maintaining individuals safely in the community.[11] HF self-care is a two part process which refers to the decisions and activities that patients engage in to maintain their health and manage HF symptoms.[12] Self-care maintenance, the first part of the process, includes adhering to a treatment plan as well as careful monitoring of the development of symptoms indicative of HF exacerbation.[13] Self-care management, the second part of the process, occurs when symptoms are perceived. This involves the cognitive processes of symptom evaluation, choice of response to the symptom, the decision to act and then evaluation of the success of that response.[13] These cognitive processes involve naturalistic decision making which engages the person's knowledge, experience, skills, and values in deciding to act and what particular action to take in response to the symptom.[13] But self-care may actually be a limited way to view this care because many individuals receive varying degrees of instrumental support from informal caregivers. An estimated 45[14]–70%[15] of the HF population have spouses/partners or family members who provide some portion of their care.[16–18] Thus, self-care can be characterized as occurring within a dyadic context.

Dyadic Engagement in HF

Social support from family and friends has consistently been associated with better outcomes with HF.[11, 16] It is well known from the psychology literature that an individual's thoughts, feelings, and actions are influenced by their social support network.[19–21] Furthermore, longtime couples are known to be better at working together to manage conflict, goals, and emotional climate than their counterparts in earlier relationships.[19] In other chronic illness populations patient and caregiver dyads have been found to share stressors and pool resources when managing the illness.[22] However, it has also been found that there are different degrees of engagement or interdependence in these dyads.[20]

Dyadic science in HF is relatively young, involving several small studies. In a cross-sectional study of HF dyads (n=58 dyads), interdependence was explored using the Actor-Partner Interdependence Model (APIM).[23] Both depression and anxiety showed significant actor effects, where the patient's own mood states impacted the patient's own QOL, but only the patient showed partner effects, where the caregiver's mood state impacted the patient's QOL. This study provides preliminary evidence for the presence of interdependence in HF dyads.

In a second cross-sectional dyadic study (n=75), supportive care from a caregiver was associated with the patient's self-care maintenance and confidence scores.[18] An intervention (n=9) to bolster this supportive care also showed improvements in patient self-care in a subsequent small pilot study.[24] Another study (n=70) which measured both patients and caregivers on HF self-care found non-significant differences between the two on sets of self-care scores, with both patients and caregivers scoring below the adequate cut point (70) on the self-care instrument.[25] The findings from these three studies taken together suggest a linkage between interdependence and both adequate and inadequate self-care.

A qualitative study[26] examined the congruence or incongruence in self-care narratives of HF dyads (n=17). Instances of congruence and incongruence in the interviews were easily identified but it was difficult to classify dyads into either of the two groups, exclusively, since dyads expressed a mix of both congruence and incongruence. However it was found that increased incongruence was more likely to result in increased reports of conflict or distress within the dyad.[26] This study suggests that dyadic HF care is a complex process encompassing co-occurring elements of congruence and incongruence within the dyad.

What can be deduced from all of these studies is that there is early evidence for the effect of dyadic interaction on HF self-care but what role this interaction plays has not yet been fully explicated. However, what is known is that couples who collaborate in cognitive tasks, communicate effectively, and hold higher expectations of instrumental help from their partners have been found to perform better on other problem solving tasks similar to HF care.[19] Dyadic adjustment to chronic illness has been conceptualized as a transactional process in which patient and caregiver appraisal and coping interact in a dynamic fashion.[22] Contextual factors such as socioeconomics, quality of the relationship and type of chronic illness all moderate the relationships of the dyad's strategies in dealing with and adjusting to the illness.[22] Building on this understanding in other chronic illness populations, dyadic HF care can be conceptualized as a transactional process or interaction between patient and caregiver in HF self-care in which the needs, cognitions, and motives of the patient and caregiver interact with the HF context or situation. HF, where self-care is particularly rigorous- involving a daily regimen of medications, diet, and vigilance[11], is a context or situation that places enormous responsibility on both members of the dyad.

Dyadic HF Care Typology

In nursing, typologies are used as multidimensional classification systems to summarize complex phenomena into categories or types.[27] The Dyadic HF Care Typology presented in this paper was developed after examining both the conceptual and empirical literature related to dyads; drawing upon lines of common inquiry from statistics[21, 28], psychology[20, 22], and the health sciences.[17, 29, 30] The literature suggests that four basic categories of caregiving (or types) exist.[22, 28] We have operationalized these four dyadic types as patient oriented dyads, caregiver oriented dyads, collaborative dyads, and complementary dyads (Table 1). In the first two types- patient or caregiver oriented- either the patient or the caregiver takes sole responsibility for HF care with the acquiescence of the other person. In the last two types – collaborative and complementary- the dyad manages together. In the collaborative dyad, the patient and caregiver work together on the same decisions and tasks to manage HF care. While in the complementary dyad the patient and caregiver have negotiated spheres of non-overlapping responsibility (e.g. one manages medications while the other manages diet). This typology has been developed to advance the science and to help explicate possible types of dyadic HF care and the impact of these types on patient outcomes such as quality of life, re-hospitalization, and mortality. This is an early theoretical conceptualization of complex and dynamic phenomena. Future work may reveal more valences leading to the explication of further subtypes. The purpose of this paper is to provide qualitative evidence for the validity of this new typology of patient and caregiver dyadic interdependence in HF care to increase our understanding of this little studied area. The three aims of the study included: 1) *presenting exemplar cases for each of the four dyadic types in the Dyadic HF care typology;* 2) discussing how the patient's HF self-care varies among types; and 3) *conducting a content analysis of the patient and caregiver narratives*.

Methods

Instrumental case study methodology was selected to present exemplar cases for each of the four dyadic types. In this study the case is the dyad, not the individual - both patient and caregiver interviews were analyzed, coded, and then presented. Using Stake's[31] methods we selected and studied the particulars and complexity of the exemplar case so as to understand its activity within its context. We reviewed multiple cases assessing both the uniqueness and commonalities across the interviews while looking at both specificity in the interviews related to HF care practices as well as boundedness by the specific type. Each exemplar case from the data set represents a dyad's discussion of caring for HF at home in their normal environment.

Data Collection

Sample and setting—Data for this study were accrued as part of a larger study focused on the palliative care needs of HF patients and caregivers (5R01NR013419-02, Hupcey, J.E. PI). Approval for the study was obtained from the institutional review board of a large academic health center and an affiliated university in the Eastern United States. The study was conducted in this academic setting as well as a large community based health system in a neighboring city. Dyads, consisting of HF patients and their spousal/partner caregivers, were recruited from both the in-patient service and the outpatient clinics associated with these systems during 2011–2012. The dyads were identified by the HF nurse practitioners and then approached by trained research assistants who described the study and obtained consent. To be eligible for the study both members of the dyad had to be over the age of 18, able to speak English, without gross evidence of cognitive impairment that would hinder reflection on the topic, and willing to provide written consent. In addition to those criteria, the patient had to have a documented diagnosis of Stage D HF (New York Heart Association class IIIB/IV) with a <2 year predicted survival as measured by the Seattle Heart Failure Model and a willing spousal/partner caregiver.

Procedure—After signing the consent form the patient and caregiver were separately asked to indicate the dyadic type that best described how they cared for the patient's HF. Before selecting the dyadic type the patient and caregiver were given the definition of self-care as "Taking care of heart failure on a daily basis includes weighing with a scale, taking medications, keeping to a low salt diet, exercising, and monitoring swelling of feet and ankles". The dyad were then presented with 4 descriptive statements of the types: 1) a patient oriented category where the patient takes care of the HF without input from the caregiver; 2) a caregiver oriented category where the caregiver takes care of the HF without input from the patient; 3) a collaboratively oriented category where the patient and caregiver take care together; 4) a complementarily oriented category where the patient and caregiver take care of different aspects of the HF (for example: one may monitor weights while the other plans meals). The research assistant then instructed the patient or caregiver to select the statement that best described how they and their partner decided what to do and how to do it regarding the patient's HF care. After selecting a dyadic type each member of the dyad was asked, separately, to talk about their HF care further. This separation was to decrease the likelihood of influence from the partner. While the same interviewer interviewed both members of the dyad, the use of an interview guide and checking the narratives for references to the partner's interview, assured that the interviewer had not influenced the second partner's interview by references to the first partner's interview. The interviews ranged from 30–60 minutes (averaging 45 minutes). The interviews were unstructured, consisting of open-ended questions exploring their experiences with HF. The complete interaction was audiorecorded and transcribed verbatim by a professional transcriptionist. The files were then verified for accuracy by the interviewer reviewing the transcript word for word while listening to the audiorecording.

Data Analysis

During data analysis dyadic type was explored based on the patient and caregiver's description of the patient's HF care in the interview. In particular both the patient and caregiver were asked to indicate who provided the majority of the patient's HF care and were then invited to describe what they did. After the interviews were analyzed and then discussed by the investigators an exemplar case from each type that best described both the unique and similar experiences of each dyadic type was chosen. To be considered for selection as a case of the type, the dyad had to agree on their type. A fifth case, called incongruent and defined as a case where the patient and caregiver indicated different or incongruent dyadic types, was included to highlight that not all dyads, however, agree on their dyadic type and the particular characteristics of this incongruent type are discussed. From 19 dyads five exemplar case studies were selected to illustrate the typology of four dyadic types found in the Dyadic HF care typology - patient oriented, caregiver oriented, collaboratively oriented, and complementarily oriented dyads plus the incongruent case study. All of the dyads were discussed by the investigators and then those cases that exhibited the necessary characteristics but also highlighted a unique or perhaps, little understood variation in self-care practice were selected.

In the following section characteristics for each type from the Dyadic HF care typology are described prior to the exemplar case; the case is then presented with supporting quotes. The case is then discussed focusing on the type but also the unique features of the particular case. Certain personal identifiers have been changed to protect the privacy of the individuals but care was taken that the changes did not alter the meaning of the case study. After the cases were identified and analyzed for the typology, a content analysis was conducted on the narratives of the full sample (n=38) to provide a deeper understanding of dyadic HF care from all of the dyads. Initially, key themes were identified by with-in case analysis then examined across-cases in an iterative process.[32] Trustworthiness of the analysis and interpretation was enhanced by the independent coding of the narratives by two investigators (HB, LK) who met regularly to discuss their analysis and interpretation. Any disagreements were further discussed until agreement was reached.

Results

Sample

Nineteen dyads (n= 38 individuals), comprised of husbands and wives, were interviewed as part of this study. The mean age of the patients were 72 (SD 10) and the caregivers were 69 (SD 12). The dyads had been married, on average, 45 (SD 14) years. Fifteen of the patients were males and four were female. Seventy nine percent of the patients were classified as having moderate to severe HF (NYHA IIIB/IV) with a Seattle HF Model life expectancy average of 2.1 (SD .58) years. The majority of the caregivers (68%) reported caring for their partner two years or less. All members of the dyads self-identified as White. As reported elsewhere 47% of the dyads agreed on their dyadic type and 53% did not.

Dyadic HF Care Typology Exemplars

Case 1: Patient Oriented Dyad—The patient oriented dyad is characterized by an active, in control patient and a more passive or uninvolved caregiver. The following case study is an example of such a dyad. Mrs. H has had cardiac issues since she was a young woman but only began experiencing HF symptoms in the last few years. Her husband is her caregiver and they have been married more than 60 years. They are retired professionals in their 80s, living independently in an active retirement community. Mrs. H was recently hospitalized for shortness of breath and fatigue. When questioned, both Mrs. H and Mr. H agree that Mrs. H takes care of the majority of her HF care by herself. When describing her daily regimen she reports that she weighs herself “almost every day” but has “given up on recording them. I just kind of remember what they are.” When asked whether she monitors the swelling in her feet or ankles, she replied, “I guess”. But Mr. H responded, “She’s been monitoring it pretty closely the last month or so.” Mrs. H added, “The last couple of months.” Mr. H reported that Mrs. H doesn’t follow a low salt diet “but she doesn’t eat much salt or sugar”. Mrs. H states that she manages all of her medications by herself. Mr. H perceives that he has to help her a great deal now compared with before her HF but that she still “does everything” related to her HF care. Mr. H described their life together as one in which Mrs. H, an extravert took the lead in their socializing, career choices and child raising. Mrs. H agreed and replied that “I think that I’m not nearly as assertive as I used to be.” This illustrates the patient oriented dyadic type where the patient chooses to take care of her HF without the involvement of her husband despite her declining health and increasing symptom burden. While Mr. H. observes his wife care for her HF and is able to report what she does both Mr. H. and Mrs. H. affirm she still does everything related to HF. Her recent hospitalization suggests that she may need help with her HF care but neither she nor her husband desire changing the way that they have managed things in the past. Their pattern of sharing life involves the patient, Mrs. H leading them in joint ventures. They continue to maintain this pattern despite her waning energy and health. This case also highlights that gender plays less of a role than might be first assumed in the typology. It is the lifelong pattern rather than the gender of the participants that shapes their decisions and choices.

Case 2: Caregiver Oriented Dyad—The caregiver oriented dyad is characterized by an active, in control caregiver and a passive or declining patient. The second case study provides an example of this. Mr. Y has HF related to an earlier MI suffered when he was in his 40s. He also has diabetes, hypertension, and osteoarthritis, common comorbidities in the HF population. His wife is his caregiver and they have been married 50+ years. They are both in their 70s and are retired from blue collar jobs. Mrs. Y still works several days a week in a part time food service job. When asked how long she has been a caregiver she states, “Forever”. Both Mr. and Mrs. Y agree that she takes care of the majority of his HF care. When questioned, Mr. Y states, “Well she takes care of everything there….I can do everything I want to with her permission.” But when interviewed separately Mrs. Y reports a different perception of her role as caregiver. She affirms that she, alone, watches his diet, takes care of his medications, and makes doctor’s appointments. She then provides a detailed report of Mr. Y’s non-adherence with her care – from eating what he wants when she is out of the house to cancelling doctor’s appointments that she has made that he doesn’t feel like keeping. Mrs. Y describes Mr. Y as “bull headed” and states that, “I’m not going to fight all the time. So I really try for so long and then I kind of give up….then I get back in the picture with him to help him….but he goes back to his old ways eventually.” Mrs. Y told a story about a doctor calling her to tell her that Mr. Y would die if he didn’t change his non-adherence but then she added, “He’s still here”. Mrs. Y sums up her caregiving role by stating, “He’s a very hard patient to take care of, I don’t know how others are but he is very hard to take care of.” This case highlights the nuances in caregiver oriented dyads. Mrs. Y takes responsibility for Mr. Y’s care because she perceives that he wouldn’t take care of himself. She blames his heart damage on his delaying treatment when he had a myocardial infarction and tries to make sure that he now eats properly and takes his medications – but he continues to live his life as he desires. Mr. and Mrs. Y continue to share life and struggle with issues of control and responsibility in the manner in which they have throughout their marriage; with her feeling responsible yet having little control over his choices. This case highlights that dyads that are caregiver oriented still need the buy-in or cooperation of the patient to successfully carry out HF care.

Case 3. Collaboratively Oriented Dyad—The collaborative dyad is characterized by both members being actively engaged in both the decisions and actions related to HF self-care. The third case study describes how this dyad interacts collaboratively in self-care. Mr. M has been diagnosed with HF for about a decade and currently has an ejection fraction of 15%. His caregiver is his wife. They are in their 70s and retired from the military. Mr. M is being treated for another life-limiting disease in addition to HF. Both Mr. and Mrs. M agree that they share his care equally. Because of their careers they have always worked together on housework and yard work. Mrs. M reports that as Mr. M has become weaker his isn’t able to help as he has in the past and that this is upsetting to him, “he’s so frustrated and then he’s, you know, demanding and then I get frustrated. But we know we got to do this together as a team.” As Mr. M weakens he reports that his “attitude is totally negative. I don’t care no more, not much like I used to about doing things.” Mrs. M tries to encourage him by drawing his attention to their mutual decline when she says, “I try to explain to him you know that we’re both getting older….we’re all slowing down. He has his drawbacks with his illnesses and I have my drawbacks. We just handle them together.” Mr. and Mrs. M illustrate the lifelong pattern of mutuality of the collaborative dyad and how difficult it is for the patient in a collaborative dyad to let go of that mutuality and accept a more caregiver oriented type of care. They have always shared life as equals and Mr. M struggles as this pattern is changing.

Case 4. Complementarily Oriented Dyad—The complementary dyad is characterized by both members being actively engaged but in non-overlapping spheres of self-care. The fourth case study illustrates how dyads “divide and conquer” HF self-care. Mr. P is a retired educator who is struggling with cognitive decline as well as his HF. For this reason the dyad was interviewed together. He is in his early 60s with an ejection fraction of 20%. His caregiver is his wife, who is 5 years younger and still works fulltime. Both Mr. and Mrs. P agree that they share responsibility for different aspects of his HF care. In the interview they even negotiate the answer to this question, with Mr. P selecting the complementary type, but then discussing it with Mrs. P. Together they then discussed how they divide up the tasks by who is responsible for what and came to a mutual agreement; they take responsibility for different tasks. Mrs. P takes the lead on his diet and arranging doctor appointments and transporting him to them. Mr. P manages his daily weights and medications. In this narrative vignette and in others in their interview they repeat this process over and over – one or the other will take the lead on the decision depending on the topic and then seek the agreement of the other. Maintaining this type is becoming more difficult as Mr. P’s cognitive and physical status declines. Household tasks that he used to perform such as vacuuming and paying bills are now too difficult for him. Mrs. P is tired and frustrated as she juggles a fulltime paying job and her unpaid job as a caregiver. She particularly mentions how difficult it is for her to pay bills as this was always Mr. P’s responsibility and she doesn’t like to do it. Mrs. P remembers how they previously shared life, “That first year that you retired, you did a lot of the housework…made dinner...” Mr. P responds with guilt stating, “…the last thing that I gave up was that. I couldn’t even do that anymore.” In trying to maintain this pattern Mr. P continues to manage his medications, a task that he may no longer be cognitively able to accomplish, putting him at risk for HF exacerbation. This dyad’s narrative suggest that they are in the midst of a shift from a long established pattern of sharing different aspects of their life to a more caregiver oriented dyadic type. Both express dissatisfaction with this when Mrs. P states, “We don’t have any choice” about the change and Mr. P adds, “I wish that I could do my stuff…”.

Incongruent Dyads Case 5—The incongruent dyad is characterized by each member selecting a different dyadic type. The fifth case study illustrates how each member of the dyad may perceive their responsibility for HF care differently. Mr. L and his caregiver, Mrs. L are retired educators in their 80s. They have been married more than 50 years. Mr. L was fairly healthy until 4 years ago when he was admitted to the hospital with shortness of breath. Since that time he has multiple admissions for HF. He reports that he takes 18 pills a day and spends most of his time in his recliner; he also suffers from peripheral vascular disease with circulatory deficits and renal involvement. Mrs. L is in good health and very knowledgeable about Mr. L’s clinical course since his first coronary bypass graft procedure 20 years previously. When they were interviewed separately Mr. L stated that Mrs. L helps him with “everything” and, “I couldn’t do it without her” as he selected the collaboratively oriented dyadic type. But when questioned about who makes the doctor’s appointments, refills prescriptions, and pays the bills, Mr. L replies, “I do that”. He evens arranges for Mrs. L’s prescriptions to be filled. When the researcher asked if Mrs. L would ever caution him about some activity he stated, “No.” Despite Mr. L selecting the collaborative type, Mrs. L, clearly reported that, “He pretty much does everything” as she selected the patient oriented dyadic type. She offers this comment as convincing proof, “He even drove himself to the hospital…He shouldn’t have.” But she went on to report that “I noticed him labored breathing long before he did. As a matter of fact, he tries to tell you that’s normal, that was ok.” So in this dyad the patient sees them working together to maintain his HF but the caregiver, while observing him closely and noting changes, merely watches while he continues to manage his HF and their life by himself. This disconnect in the perception of the dyad as to who is responsible for the patient’s HF care places the patient at risk for poor outcomes as his condition continues to deteriorate. While this pattern of sharing life may have contributed to a long, successful relationship it now hinders the caregiver from stepping in and engaging more actively.

An Overarching Theme: Sharing Life

A major, overarching theme of *Sharing Life* emerged from content analysis of the total sample's narratives. Recurrent themes describing sharing life included being connected by each other (sharing synchronicity), being connected by other people, and being connected by intangibles such as faith, loss, and identity across the span of the relationship. These connections are not linear but instead planar, creating a network or pattern in which the dyad conducts life.

Each dyad gave concrete examples of sharing life in their narratives. One patient described how he and his spouse connect to each other by helping each other with mental stimulation as they age stating, **"**We used to watch a lot of movies and remember the old from when I was a kid. She'd say remember who used to play in that movie?**"** A caregiver described how she and her spouse are connected by family, "…we have one son and his family that lives in the same town, another son and his family live [further] away.**"** A second caregiver discussed a family business that connected them by shared family members and business opportunities. Sharing life also involves being connected by faith, loss, and identity, one example of this is when a patient stated, **"**We're people of faith, me and my wife… We had a good life, good times. Many, many more good times than bad….but we lost two kids out of five. We have three." However, the dyads also described how difficult it became for them when they were no longer able to share some part of life, such as household tasks or leisure activities as they had in the past. One caregiver reported, "I'm doing double things cause they are things he can't do himself, so I've got to do it. It's tiring, it's frustrating."

Discussion

This study explores possible types of dyadic HF care suggested by the Dyadic HF care typology and how these types are experienced by patients and caregivers. Exemplar cases of dyadic types were presented to increase our understanding. Then the overarching theme derived from the content analysis of the narratives, S*haring Life,* is presented. The issues of how dyads shift, or change from one dyadic type to another type is explored, as well as, what effect incongruence in the dyad's perception of their type may have on their HF care. The cases illustrate how long-term dyads attempt to share the patients HF care according to the pattern that they have shared in other parts of their lives over the trajectory of their relationship. These couples try to react to the novel situation of the patient's declining ability to contribute to his/her own care by maintaining their habitual pattern until forced to shift. This original pattern may or may not have involved the dyad working together.

How or if dyads successfully shift from one dyadic type to another is a question that needs further exploration. As the patient's dependence on the caregiver increases the caregiver must decide whether to react out of self-interest or the patient's interest. Securely attached dyads have been found to exhibit greater resilience and positive outcomes when dependence increases within the relationship while insecure dyads react with distrust and destructive tendencies.[34] Cases 1 (patient oriented), 2 (caregiver oriented), and 5 (incongruent) are resisting changing how they share their lives placing the patient at risk, while in Case 3 (collaborative dyad) the caregiver attempts to say that nothing has changed (shifted), that they are still in this together, while the reality is that she is providing more and more of the HF care and her husband responds negatively to the change in their pattern. In Case 4 (complementary dyad) the dyad has begun to shift because of the patient's cognitive changes but both are struggling with the patient expressing guilt while the caregiver expresses frustration.

This study adds to what other researchers have found in HF dyadic studies. Sebern[24, 29, 35] has developed and tested a construct of shared care, defined as a system of three relationship processes -communication, decision making, and reciprocity used by dyads to exchange care and assistance,[24] and refined it over several studies. Shared care, as described by Sebern, does not presume an equal exchange between the partners[24] and acknowledges the context and needs of each member of the dyad[24], as does the Dyadic HF care typology. What the overarching theme of Sharing Life, from this study, adds to our conceptualization of dyadic interaction in self-care is a life course understanding about the effect of established patterns of interdependence developed over the trajectory of the relationship on the dyad's current HF care. Our study found that dyads shared the patient's HF care as they have shared their lives, for better or for worse (as in Case 2). What the Dyadic HF care typology adds to this conceptualization of care is that there may be qualitatively different "kinds" of dyadic care-with one partner or the other taking the lead in HF care or the dyad working together in one of two ways. It is recommended that future studies measure dyads from each type using Sebern's shared care instrument to explore the interplay of dyadic type with the construct of shared care. For example, it is logical to infer that relationally oriented types will score higher on the shared care processes than the individually oriented types; but this is currently unknown. The idea of different kinds of dyadic care may be an important distinctive when it comes to tailoring dyadic interventions. Assessing the dyad's lifelong pattern to ascertain who takes the lead, how the other responds, what they do when faced with a novel situation, and how they have handled past complex tasks and stressors and then tailoring the intervention to the dyads' particular pattern may improve responses to symptom management interventions.

In addition, this study supports the findings of Retrum, Nowels, and Bekelman[26] that congruence or consistency in perspective, is an important element in dyadic HF management. In keeping with their findings that some dyads are congruent or incongruent in their statements regarding the challenges of living with HF, our earlier work in this sample found that only 47% of the dyads were congruent in reporting how they chose to manage their HF.[33] This concept of congruence is important for several reasons. As identified by Retrum and colleagues, it is potentially modifiable. Interventions can be developed to increase congruence. However, what our works adds to this is that any intervention will need to change the habits that dyads have developed over the life time of the relationship. In advanced HF the dyad may not have the time (or energy) necessary to accomplish this change. It might be more efficacious and efficient to add supportive care enabling the dyad to maintain their particular pattern for a longer time. In addition to modifiability, a second important facet of incongruence is that it may help to explain some of what is now called non-compliance. If each member of the dyad perceives the other member as the responsible party when receiving information related to the plan of care, neither member may implement the recommendation. Or, as in Case 5, encouraging the caregiver to monitor the patient closely for shortness of breath is wasted effort because she is already doing that – but has found reporting it to her incongruent partner futile. Further study is needed into this intriguing finding.

Implications for practice

The primary implication for clinical practice is for the clinician to understand that HF does not affect the patient alone but rather that it affects the patient as part of a family system. In addition, HF self-care is not something that a patient conducts alone but that it is an activity that often occurs within a dyadic context. While our study focused on spousal partners, the work of other researchers[16, 24, 25] in more diverse informal caregiving populations support many of the findings of our study. As clinicians we need to assess the patterns used by the patient and caregiver previously in handling responsibilities and stressors using this information to develop plans of care that work with their normal patterns and not against them. Viewing the caregiver as both a co-recipient as well as co-provider of care with the patient may help us to think more holistically in this area.

Implications for research

There is a need to better understand the naturalistic decision making process used by patients and caregivers in HF self-care. If self-care is to be a key component for maintaining HF patients in the community we need to understand better how and why patients make the decisions that they make. This study has taken one step in that line of inquiry by introducing both a novel typology of dyadic care and the major theme of the narratives, *Sharing Life*. Future studies are needed to measure the relationships between the dyadic types and HF outcomes such as self-care expertise, quality of life, and event free survival. The typology, itself, should be tested in both quantitative studies and larger, more diverse populations. In addition, there is a need for longitudinal studies to better understand what impact shifting dyadic type has on patient outcomes. At this time there is no data examining dyadic "shift"; a concept which may help to explain why some dyads are more successful in managing HF further along in the progression of the condition than others.

Limitations

Several limitations must be acknowledged. First, the participants in this study were exclusively White and spousal. It is recommended that future studies explore the effect of race/ethnicity and different types of relational dyads on these dyadic types. A second limitation is that this sample was accrued at a large, suburban academic medical center. The experiences of rural HF patients and caregivers with poorer access to health care may diverge from this sample. Once again, further research is needed in this area. A further limitation is related to our sampling frame. All of the patients in our study were diagnosed with NYHA class IIIb-IV HF. The typology was supported in this population; future work will test it in earlier stages of HF.

Conclusion

In summary, the purpose of this paper was to provide preliminary qualitative evidence for the validity of a new typology of patient and caregiver dyadic interdependence in HF care and present exemplar cases of the typology. Patient centered care is care that focuses on communication, partnership, and health promotion. In communicating with our patients we can assess for their particular style of sharing life with their caregiver and then, with them, develop plans of care utilizing their preferred style to promote health even during advanced stages of HF.

Acknowledgments

Funding source: NIH/NINR 5R01NR013419-02, Hupcey, J.E. PI

Rachel Wion, MS, RN for assistance in preparing data for analysis

References

1. Kaul P, McAlister FA, Ezekowitz JA, et al. Resource Use in the Last 6 Months of Life Among Patients With Heart Failure in Canada. Arch Intern Med. 2010 archinternmed.2010.2365.

2. Unroe KT, Greiner MA, Hernandez AF, et al. Resource Use in the Last 6 Months of Life Among Medicare Beneficiaries With Heart Failure, 2000–2007. Arch Intern Med. 2010 archinternmed. 2010.2371.
3. Roger VL, Go AS, Lloyd-Jones DM, et al. Heart Disease and Stroke Statistics—2012 Update. Circulation. 2011
4. Luttik ML, Blaauwbroek A, Dijker A, Jaarsma T. Living With Heart Failure: Partner Perspectives. Journal of Cardiovascular Nursing. 2007; 22:131–137. [PubMed: 17318039]
5. Buck HG, Lee CS, Moser DK, Albert N, Lennie T, Bentley B, Worrall-Carter L, Riegel B. The Relationship between Self-care and Health Related Quality of Life in Older Adults with Moderate to Advanced Heart Failure. Journal of Cardiovascular Nursing. 2012; 27:8–15. [PubMed: 21558868]
6. Garin O, Ferrer M, Pont A, et al. Disease-specific health-related quality of life questionnaires for heart failure: a systematic review with meta-analyses. Qual Life Res. 2009; 18:71–85. [PubMed: 19052916]
7. Heo S, Moser DK, Lennie TA, Zambroski CH, Chung ML. A comparison of health-related quality of life between older adults with heart failure and healthy older adults. Heart Lung. 2007; 36:16–24. [PubMed: 17234473]
8. Hupcey JE, Penrod J, Fenstermacher K. Review Article: A Model of Palliative Care for Heart Failure. American Journal of Hospice and Palliative Medicine. 2009; 26:399–404. [PubMed: 19357374]
9. Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. Journal of the American Geriatrics Society. 2002; 50:1108–1112. [PubMed: 12110073]
10. Engelfriet PM, Hoogenveen RT, Boshuizen HC, van Baal PHM. To die with or from heart failure: a difference that counts. European Journal of Heart Failure. 2011; 13:377–383. [PubMed: 21216785]
11. Riegel B, Moser DK, Anker SD, et al. State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. Circulation. 2009; 120:1141–1163. [PubMed: 19720935]
12. Riegel B, Dickson VV. A situation-specific theory of heart failure self-care. Journal of Cardiovascular Nursing. 2008; 23:190–196. [PubMed: 18437059]
13. Riegel B, Lee CS, Dickson VV. Self care in patients with chronic heart failure. Nat Rev Cardiol. 2011 advance online publication.
14. Rockwell JM, Riegel B. Predictors of self-care in persons with heart failure. Heart Lung. 2001; 30:18–25. [PubMed: 11174364]
15. Harkness K, Demers C, Heckman GA, McKelvie RS. Screening for Cognitive Deficits Using the Montreal Cognitive Assessment Tool in Outpatients ≥65 Years of Age With Heart Failure. The American Journal of Cardiology. 2011; 107:1203–1207. [PubMed: 21310371]
16. Dunbar SB, Clark PC, Deaton C, Smith AL, De AK, O'Brien MC. Family education and support interventions in heart failure: a pilot study. Nurs Res. 2005; 54:158–166. [PubMed: 15897791]
17. Dunbar SB, Clark PC, Quinn C, Gary RA, Kaslow NJ. Family influences on heart failure self-care and outcomes. Journal of Cardiovascular Nursing. 2008; 23:258–265. [PubMed: 18437068]
18. Sebern M, Riegel B. Contributions of supportive relationships to heart failure self-care. European Journal of Cardiovascular Nursing. 2009; 8:97–104. [PubMed: 18706865]
19. Hoppmann C, Gerstorf D. Spousal Interrelations in Old Age: A Mini-Review. Gerontology. 2009; 55:449–459. [PubMed: 19346740]
20. Berg CA, Meegan SP, Deviney FP. A Social-contextual Model of Coping with Everyday Problems across the Lifespan. International Journal of Behavioral Development. 1998; 22:239–261.
21. Kenny DA, Cook W. Partner effects in relationship research: Conceptual issues, analytic difficulties, and illustrations. Personal Relationships. 1999; 6:433–448.
22. Berg CA, Upchurch R. A developmental-contextual model of couples coping with chronic illness across the adult life span. Psychol Bull. 2007; 133:920–954. [PubMed: 17967089]
23. Chung ML, Moser DK, Lennie TA, Rayens MK. The effects of depressive symptoms and anxiety on quality of life in patients with heart failure and their spouses: Testing dyadic dynamics using

Actor-Partner Interdependence Model. Journal of Psychosomatic Research. 2009; 67:29–35. [PubMed: 19539816]

24. Sebern MD, Woda A. Shared Care Dyadic Intervention: Outcome Patterns for Heart Failure Care Partners. West J Nurs Res. 2011
25. Quinn C, Dunbar SB, Higgins M. Heart failure symptom assessment and management: can caregivers serve as proxy? Journal of Cardiovascular Nursing. 2010; 25:142–148. [PubMed: 20168194]
26. Retrum JH. Patient and Caregiver Congruence: The Importance of Dyads in Heart Failure Care. The Journal of cardiovascular nursing. 2012
27. Crane, DR.; Marshall, ES. Handbook of families & health : interdisciplinary perspectives. Sage Publications; 2006.
28. Cook WL, Kenny DA. The Actor-Partner Interdependence Model: A model of bidirectional effects in developmental studies. International Journal of Behavioral Development. 2005; 29:101–109.
29. Sebern M. Shared Care, elder and family member skills used to manage burden. Journal of Advanced Nursing. 2005; 52:170–179. [PubMed: 16164478]
30. Grey M, Knafl K, McCorkle R. A framework for the study of self- and family management of chronic conditions. Nursing outlook. 2006; 54:278–286. [PubMed: 17027605]
31. Stake, RE. The art of case study research. Thousand Oaks: Sage Publications; 1995.
32. Ayres L, Kavanaugh K, Knafl KA. Within-case and across-case approaches to qualitative data analysis. Qualitative health research. 2003; 13:871–883. [PubMed: 12891720]
33. Buck, HG.; Zambroski, C.; Hupcey, J. Can Spousal Heart Failure Patients and Caregivers Self-report their Dyadic Care Type Given Criteria?. in review
34. Rusbult CE, Van Lange PA. Interdependence, interaction, and relationships. Annu Rev Psychol. 2003; 54:351–375. [PubMed: 12415073]
35. Sebern MD. Explication of the construct of shared care and the prevention of pressure ulcers in home health care. Research in Nursing and Health. 1996; 19:183–192. [PubMed: 8628907]

What's New

Findings

- A new typology of patient and caregiver dyadic interdependence in HF care is presented: patient oriented, caregiver oriented, collaboratively oriented, complementarily oriented
- A major theme of *Sharing Life* infused the dyad's narratives. Long-term dyads attempt to share the patients HF care according to the pattern that they have shared in other parts of their lives over the trajectory of their relationship
- Dyads described how difficult it became for them when they were no longer able to share some part of life as they had in the past.

Clinical Implications

- HF self-care is not something that a patient conducts alone but it is an activity that often occurs within a dyadic context.
- Clinicians need to assess the patterns used previously by a dyad in handling responsibilities and stressors to develop plans of care that work with dyad's patterns and not against them..

Table 1

Dyadic Interdependence in HF care Typology

Dyadic Type	**Defining feature**	**Subtypes**	**Characteristics**	**Context**
Patient oriented dyads	The patient takes care of the majority of their self-care without input from the caregiver	The patient may either choose to take control their HF care without the involvement of the caregiver ***OR*** The caregiver may choose to be uninvolved in the HF care	Individually oriented	Most common early in the HF trajectory (Stage A & B)
Caregiver oriented dyads	The caregiver, not the patient, takes care of the majority of the patient's self-care without input from the patient	The patient may defer all care decisions and actions to the caregiver ***OR*** The caregiver may take responsibility for the care from the patient	Individually oriented	Most common in the last stage (D) of HF where patients are no longer able to care for their own HF
Collaboratively oriented dyads	Patients and caregivers actively and together make decisions and take action when needed to maintain and manage the patient's HF	This collaboration reflects either a healthy ***OR*** Unhealthy (enmeshed) collaboration determined by dyadic report and successful HF outcomes	Relationally oriented	Found across the trajectory of HF but less frequently in the advanced stages of HF
Complementarily oriented dyads	The patient and caregiver have negotiated spheres of non-overlapping responsibilities for HF care	One takes the lead on a particular activity (for example HF care) whilethe other takes the lead on another activity (ADLs or IADLs) ***OR*** The patient and caregiver may have differential functional or cognitive limitations resulting in one taking the lead on decision making while the other provides the actual behavior when cued	Relationally oriented	Found across the trajectory of HF but less frequently in the advanced stages of HF