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Pattern vs. Change: Community-based dyadic heart failure self-care

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Abstract

It is imperative that dyadic heart failure (HF) self-care be carefully examined so we can develop interventions which improve patient outcomes. The purpose of this study was to qualitatively examine how patient/informal caregiver dyads mutually engage in managing the patient's HF at home. Twenty-seven dyads were interviewed using a theoretically derived interview guide. All interviews were digitally recorded, professionally transcribed, and iterative thematic analysis conducted. Three descriptive themes emerged -Mutual engagement in self-care involves: maintaining established patterns of engagement across the lifecourse of the relationship; changing patterns according to whether it's day to day care or symptom management; and mobilizing the help of a third party as consultant. These themes reveal the dyadic conundrum – whether to change or remain the same in the face of a dynamic and progressive condition like HF. The themes suggest potential targets for intervention - interventions focused on the relationship or caregiver activation.

Keywords

qualitative; dyad; life course; symptom management; intervention

Introduction

Heart failure (HF) is a complex clinical syndrome with profound impact on the way of life of approximately 5 million people and their families in the United States (Mozaffarian et al., 2015). Currently, clinical guideline recommendations involve a combination of lifestyle modifications and medications to manage HF at home (Yancy et al., 2013). Adherence to both lifestyle modifications, for example, dietary sodium restriction and exercise, as well as

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medications such as diuretics, angiotensin-converting enzyme inhibitors, or beta blockers require active engagement (or self-care) on the part of patients and their informal caregivers such as family or friends (Riegel, Lee, & Dickson, 2012).

HF self-care includes day to day care (self-care maintenance) or adherence to treatment protocols and careful monitoring as well as self-care management or recognition and response to changes in condition. These condition changes are primarily exhibited as symptoms such as fatigue, shortness of breath, or weight gain (Riegel & Dickson, 2008). Because of poor responses to patient-only self-care interventions, there is an increasing body of work that has examined the role of informal caregivers in HF self-care (Buck et al., 2014; Strömberg & Luttik, 2015). There is also an emerging focus on dyads, or patient and informal caregiver partners in HF self-care (Bidwell et al., 2015; Buck, Mogle, Riegel, McMillan, & Bakitas, 2015; Kitko, Hupcey, Pinto, & Palese, 2014; Retrum, Nowels, & Bekelman, 2013; Sebern & Woda, 2012). What is currently known is that the type of dyadic relationship (spousal vs. adult child) (Bidwell et al., 2015), relationship quality (Buck et al., 2015; Bidwell et al., 2015), and mood states (Buck et al., 2015) are associated with higher or lower self-care engagement for both partners. Studies have also shown that self-care can be a source of conflict and distress (Kitko et al., 2014; Retrum et al., 2013); effect quality of life for both partners (Vellone et al., 2014); and that dyadic interventions result in differential self-care outcomes for each partner (patient self-care improved, caregiver did not) (Sebern & Woda, 2012). A particularly interesting finding is the presence and impact of dyadic congruence (defined as self-care agreement by both partners) on the dyad and self-care (Kitko et al., 2014; Retrum et al., 2013). While all of these studies have added to our knowledge of determinants and outcomes in dyadic self-care, what has not been carefully examined is the process by which or *how* HF dyads mutually engage in self-care. It is imperative that dyadic engagement in self-care be carefully examined so that interventions can be developed resulting in meaningful improvement in self-care outcomes. The purpose of this study was to qualitatively examine how heart failure patient and informal caregiver dyads mutually engage in managing the patient's HF at home.

Methods

Study design

This qualitative study is part of a cross-sectional mixed methods investigation of dyadic HF symptom management (R03NR014524). The Situation Specific Theory of Heart Failure Self-care (Riegel & Dickson, 2008) provided the theoretical framework for the study by providing the definition of self-care as a naturalistic decision-making process comprised of two specific domains: 1) self-care maintenance and 2) self-care management. The theory also provided the structure for the interview guide and interpretive lens for the data analysis.

Setting and sample

The study setting was a large, academic medical system in the northeast United States. Recruitment sites included an inpatient facility and outpatient clinics. Dyads were recruited between 2014–2016. All HF patients in both sites were screened for eligibility. Inclusion criteria were: patients with a documented diagnosis of HF in the electronic health record and

an identified informal caregiver, both partners had to be 21 years of age or older, able and willing to consent and then participate in interviews. Exclusion criteria were HF secondary to congenital heart disease or patient status post heart transplantation or ventricular assist device implantation. These three groups are a small and unique HF population with specific self-care protocols, unlike that larger, general HF population. All eligible dyads were approached and information about the study was provided.

Procedure

Following institutional review board approval, research assistants (RAs) were trained by the principal investigator in the study protocol and qualitative interviewing techniques. Eligible dyads were interviewed one time, after the study was explained and written consent obtained. Dyads were interviewed together to capture dyadic interaction. The dyadic interview approach was well suited to this study because it allowed the patient and caregiver a chance to respond to the interview questions and each other while also giving us the ability to observe the dyadic interactions and patterns of responses (i.e. who answered the questions, was one member of the dyad dominant, did they mutually agree on answers).

The semi-structured interview guide began with an open-ended, exploratory question about patients' and caregivers' experiences with HF (Speziale & Carpenter, 2007). This was followed by more focused questions involving day to day care (self-care maintenance), for example, *"What do you do on a day to day basis to take care of your HF at home"* and then questions asking them to describe their interactions when they noticed a change in the patient's HF (self-care management). In particular, dyads were asked to describe who is responsible for responding to HF symptoms and how they make the decisions regarding symptom management. As the study progressed more precise probes, such as *"Can you think of a time when the two of you didn't agree on what to do about worsening symptoms? Can you tell me a story about that?"* were developed to focus the interviews on specific areas identified from previous interviews, self-care theory (Riegel & Dickson, 2008), and our conceptual work (Buck, Kitko, & Hupcey, 2013). When a new probe was developed all subsequent dyads were asked to respond. In particular, we were interested in capturing whether dyads agreed or disagreed in their perspective towards self-care and how they handled any self-care disagreements.

All interviews were digitally recorded and the RA recorded field notes immediately following the interview. The audio-recordings of the interviews were transcribed verbatim by a professional transcriptionist and accuracy of the transcription was assessed by the RA who performed the interview (Sandelowski, 2000). An audit trail of memos was kept throughout the process. Recruitment continued until no new information was obtained from the dyads.

Data analysis

Interviews and analyses were conducted concurrently and iteratively. Coding of the data proceeded according to established approaches beginning with open coding then advancing to conceptual aggregation of codes with iterative thematic analytic techniques used to examine mutual engagement.(Sandelowski, 2000; Speziale & Carpenter, 2007) Consistency

of the codes and categories were established by at least two independent reviewers who were expert in qualitative analysis. To assure rigorous data analysis, interviews were first independently coded and labels given to the codes were then compared during team meetings. When codes did not match, the discrepancies were discussed until consensus was reached. Themes related to the how the dyad manages HF and whether/how management changed during an HF exacerbation emerged from these codes and categories.

Results

Sociodemographic

The sample included 27 dyads (n=54). The average dyad was comprised of a 77-year-old white male patient with a younger female caregiver. The sample was fairly evenly divided between spousal (n=15) and non-spousal (n=12) caregivers. See Table 1 for further demographic information.

How heart failure patient and informal caregiver dyads mutually engage in managing the patient's HF at home

Analysis of the narrative accounts resulted in the emergence of 3 overarching themes: Dyads mutually engage in managing the patient's HF at home: 1) according to established patterns across the life course of the relationship; 2) according to whether it's day to day care or symptom management; and 3) by mobilizing the help of a third party as consultant (Table 2). The first two themes are contextually oriented in that the context of their relationship or HF status determines how dyads mutually engage; while the last theme is process oriented in that dyadic engagement involves a mobilization process. Unless otherwise noted the themes and sub-themes were found in the narratives of both dyads who agreed on the patient's HF care and those who disagreed. Themes that are unique to one type or the other are dually noted. Each of these three themes included sub-themes, which are described below.

Theme 1: According to established patterns across the life course of the relationship

Dyads mutually engage in managing the patient's HF according to established patterns across the life course of the relationship. In this contextually oriented theme, dyads described how they cared for the patient's HF in similar ways to how they completed other complex tasks in their lives. This theme included three distinct sub-themes.

One sub-theme was when one member of the dyad (patient or caregiver) was more active and one was more passive in the care. An example of this active vs. passive sub-theme was found in a mother/adult daughter dyad where the mother was the patient and more active. The adult daughter, in her late 20s, in response to a question about what she does when she notices a change in her mother replied, "*I look over and say, Mom, you're swollen. She says I took a furosemide already. I say, Alright. That's the conversation.*" When probed about what she, the caregiver, does if they disagree on next steps when her mother didn't respond to the diuretic; she responded to her mother [not the interviewer], "*I guess that's what it is because I'm not going to argue with you. I'm done.*" The patient confirmed this, "*If I want to do it, I want to do it.*" The patient and caregiver agreed that the caregiver provided meaningful support in household activities like cooking and cleaning but was not active in

day to day HF care or decision making when the patient became symptomatic. The dyad also agreed that this was the normal pattern throughout their lives.

A second sub-theme was when both members were equal participants in the HF care. A spousal dyad (husband is patient) provided an example of this sub-theme. When the dyad was asked how they respond to the patient's symptoms the patient stated, "*Together*" and the caregiver concurred, "*Together we do.*" This sub-theme predominated in the dyads who agreed on self-care.

The third sub-theme was when the patient reported a past pattern (generally when the patient was more active) while the caregiver reported a new pattern (they collaborate or the caregiver is more active). This is the only sub-theme in the data which was found in the dyads who disagreed and was not found in the dyads who agreed. A patient in a spousal dyad, when asked about exercise (i.e. a self-care recommendation for HF), reported, "*We work in the yard a lot.*" But the caregiver quickly clarified this with, "*Yeah, but sporadic really the yard stuff, now.*" When another spousal dyad was asked about diet the female patient reported cooking but the male caregiver responded, "*Yeah she usually would cook. I would say not in the past couple of weeks [since the last hospitalization] has she done it. She's had problems and it's dropped off.*" This disconnect between a current pattern and a past pattern may be a function of the patient retaining hope that their pattern will return to normal now that their HF is under control and so report past patterns rather than current patterns. Or it could be that the caregiver is more aware of the patient's progressive HF than the patient. Some of their seeming disagreement on who cares for the patient's HF may arise out of this disconnect between the patient's hope to return to an old normal and the caregiver's focus on the new normal.

Theme 2: According to whether it's day to day care or symptom management

Dyads also mutually engage in managing the patient's HF according to whether it's day to day care (self-care maintenance) or symptom management (self-care management). In this contextually oriented theme dyads described how their engagement in HF care changes (or doesn't) depending on whether it involves routine care such as maintaining a low sodium diet, taking medications, and daily weights or whether it involves recognizing symptoms, evaluating them, and especially deciding how to respond. Dyads' narratives gave evidence of 3 sub-themes with minor variants.

The first sub-theme is that the situation overrides the established pattern and the dyad escalates their response when the patient become symptomatic. For example, one female patient in a patient/adult child dyad stated, "*When it doesn't feel that bad I try to work it out.*" However, when the same patient becomes short of breath, "*My daughter calls and checks and says call 911*". This sub-theme of the situation overriding the established pattern has two distinct variants. The caregiver can step up or take over the decision making when the patient becomes symptomatic and the normal pattern shifts from collaboration to caregiver led as noted above. Or the dyad engages another party to help with the decision making. One male caregiver in a spousal dyad stated, "*We called her primary care provider and asked for advice based on what we're seeing*". This sub-theme of engaging another party during exacerbation was only found in the dyads who agreed. Dyads who agreed on

self-care were more likely to reach outside the dyad when the patient became symptomatic. This suggests that agreement frees the dyad to engage with other individuals who will help them whereas disagreement may paralyze the dyad in a state of inaction.

The second sub-theme is that the established pattern over-rides the crisis. This can also be accomplished in one of two ways. The patient can remain in charge even as s/he becomes more and more symptomatic and the dyad doesn't shift from their day to day pattern. In one spousal dyad the male patient stated, *"If I notice my ankles are swollen I'll take an extra furosemide"*. When the caregiver was asked if she had any input she said, *"No"*. Or the dyad continues to collaborate but the caregiver doesn't step up and take over the decision making. In a second spousal dyad the patient reported, *"Well it's back and forth until we get it straightened out [the decision what to do next] Yes, no. Yes, no until we come to the conclusion, let's do this."* The caregiver confirms, *"Yeah"*. Once again, this sub-theme only occurred in the dyads who agreed. Dyads who agreed reported remaining collaborative even as the situation deteriorated highlighting the power of the life course pattern.

The third sub-theme, context overrides crisis was evidenced by one dyad, which engaged a paid caregiver and didn't need to shift from their day to day pattern. The paid caregiver made decisions when the patient became symptomatic.

Theme 3: By mobilizing the help of a third party as consultant

Finally, dyads mutually engage in managing the patient's HF by mobilizing the help of a third party or consultant. In this process-oriented theme dyads described reaching out to family members, friends, and clinicians when they were unsure what to do next anytime during self-care. Twenty of the 27 dyads reported contacting formal consultants such as an office nurse or informal consultants such as family members or friends. In one spousal dyad when the caregiver (wife) wanted to call the doctor but the patient did not, the caregiver reports, *"He'll fight against not to call, especially – not as far as the doctor, but if you'd have to call for an ambulance and take him to the ER he'll fight as long as he can against that."* When the interviewer asked who won the fight the caregiver states, *"I [step up]. I call one of the children"*. The theme differs from the earlier sub-theme, of engaging another party to help with the decision making, in that this theme of mobilizing the help of a third party occurred any time during the HF care not just when there was a crisis. For example, dyads who discussed using a consultant in crisis did not always discuss using a consultant for day to day care. However, all dyads who discussed using a consultant in day to day care discussed using a consultant in crisis suggesting that using a consultant was part of their normal process.

Discussion

The purpose of this study was to examine how patient and informal caregiver dyads mutually engage in managing the patient's HF at home. This is the first study, to our knowledge, which sought to examine "the how" or process of mutual engagement in self-care from the perspective of both partners. Three descriptive themes emerged- mutual engagement in self-care involves: maintaining (or not) established patterns of engagement across the life course of the relationship; changing (or not) according to whether it's day to

day care or symptom management; and mobilizing (or not) the help of a third party as consultant. Taken together these themes and their sub-themes reveal the dyadic conundrum – whether to change or remain the same in the face of a dynamic and progressive condition like HF.

Particularly striking in the narratives was the relative stability of the dyads at a time when they needed to be nimble –as the patient’s condition began to deteriorate. The strength of the influence of life course patterns or habits is evident in all of the interviews whether the dyad is in agreement or not. If one member of the dyad was more active in day to day care, particularly if it is the patient, and one member more passive prior to the onset of HF it is difficult or impossible for either member to override that pattern even when it is desperately needed. It is equally difficult for dyads to shift from a patient managed day to day pattern into a caregiver managed crisis mode, particularly if this is not their life course pattern. And yet, despite the critical need for dyads to shift during the downward trajectory of HF and their seeming resistance to this shift, dyads are also resilient – almost three-quarters of this sample mobilized the help of outside resources (including 911) in the midst of a crisis. But the question exists, is this the best time to call for help or would an earlier call or a more empowered dyad result in decreased use of emergent care?

The findings from this study support our earlier work (Buck, Kitko, & Hupcey, 2013) in a unique sample. That earlier dyadic study uncovered an overarching qualitative theme of sharing life, defined as members of the patient/informal caregiver dyad being connected to each other by their shared history, shared relationships with others, and shared intangibles such as faith, loss, and identity. Once again, in this second sample, we saw the same pattern – HF and its self-care occurs within the larger context of the long-term relationship between the patient and caregiver, whether spousal or other types of relationship. It is difficult for the dyad to adapt if self-care requires them to break or re-negotiate that long-term pattern.

The findings from this study add to earlier conceptual work conducted by Moser and Watkins (2008) which posited that individual self-care decision making is influenced by illness and health experiences throughout the life course. What our study adds to this individual conceptualization is that these life course factors influence dyads as well as individuals. The findings from this current study also add to earlier multi-level dyadic work. Lee and colleagues (2014) modeled three distinct dyadic HF self-care archetypes from a large, cross-sectional dataset in which novice HF self-care dyads complemented each other’s self-care, inconsistent dyads compensated for each other, and expert dyads collaborated with each other. What our study adds to this is the understanding that these archetypes most likely reflect how the dyad responded in similar, detail oriented tasks over the course of the relationship (Rusbult & Van Lange, 2003).

Clinical Implications

The findings from these study have direct bearing on current clinical practice. During any assessment of a HF patient in the outpatient or inpatient setting, it is relatively simple to ask about how they and their informal caregiver are managing things at home. Listening for some of the themes found here (i.e. who is more active, who more passive; what do they do when they disagree on the patient’s HF care) will help to identify patients and families

potentially at risk for self-care failures at home. Once these “potentially at risk dyads” are identified there are three possible directions to take with next steps. First, a clinician could suggest, a couple’s intervention which focuses on helping the dyad understand their own relationship’s strengths and weaknesses. Such an intervention could include assessing the dyad’s normal patterns for handling complex tasks; then providing information on the progressive nature of HF; and finally helping the dyad develop new strategies to handle self-care as the patient becomes more debilitated. This might give the dyad the tools needed to shift from an active patient model to an activated caregiver model as HF progresses. In the second case, if the caregiver doesn’t feel adequate in providing self-care support, additional HF care education with a focus on caregiver management of symptoms delivered to both members of the dyad might enable the dyad to shift from their day to day pattern into a caregiver managed pattern when HF exacerbations occur. Lastly, in those dyads in which the caregiver isn’t able to or may not want to engage with the patient in self-care, it might be more beneficial to refer the patient to outpatient palliative care for the needed support.

Limitations

Several caveats should be kept in mind when reviewing our findings. While our sample is fairly similar to other HF research samples, it is homogenous and comprised of white, lower-to-middle income adults in one clinical setting. This homogeneity may have contributed to premature data saturation. It is recommended that our findings be validated in larger, heterogeneous samples. However, strengths of our study include the use of a theoretical framework to inform the study and joint interviews which allowed us to capture verbal and nonverbal dyadic interaction.

Conclusion

We examined dyadic engagement in HF self-care, uncovering 3 distinct themes which highlight the stability and resilience of patient and informal caregiver dyads. Interventions are needed which work with and not against existing dyadic patterns. This is one potential way to improve future patient self-care outcomes in HF.

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Table 1

Sample Demographic Characteristics

Characteristics	Patient (n=27)	Caregiver (n=27)
	Mean (SD) or proportion	Mean (SD) or proportion
Age (in years)	76.6 (9.6)	64.12 (14.3)
Gender (n=Female)	12	20
Dyadic Relationship (n)		
Spouse		15
Adult child		7
Other (friend, relative)		3
Unknown		2
Race/Ethnicity (%)		
White	100%	100%
Black		
Education (n)		
HS or less	20	15
Some college *	2	6
College or advanced degree	5	6
Income to make ends meet (n)		
More than enough	6	7
Enough	16	13
Not enough	5	5
Unknown	0	2

Note. SD-standard deviation; HS- high school

* Some college-attended college but no degree conferred

Table 2

Thematic Analysis

How HF patient and informal caregiver dyads mutually engage in self-care		
Theme	Subthemes with variants	Dyad agrees/disagrees on self-care
1) According to established patterns across the lifecourse of the relationship	One (patient or caregiver) is more dominant (actor), one more passive (partner)	Found in <u>both</u> dyads who agree or disagree
	Both members equal participants	Found in <u>both</u> dyads who agree or disagree
	Patient reports using past patterns /Caregiver corrects and reports new patterns	Found <u>only</u> in dyads who disagree
2) According to whether it's day to day care (self-care maintenance) or symptom management (self-care management)	Symptom crisis over-rides established pattern (dyad escalates) V.1 Caregiver steps up (dyad shifts from maintenance style) V.2 Dyad mobilizes outside help in crisis	Found in <u>both</u> dyads who agree or disagree V.2 Found <u>only</u> in dyads who agree
	Established pattern over-rides crisis V.1 Patient remains in charge (dyad doesn't shift from maintenance style) V.2 Dyad continues to collaborate but doesn't escalate (dyad doesn't shift from maintenance style)	Found in <u>both</u> dyads who agree or disagree V.2 Found <u>only</u> in dyads who agree
	Context over-rides crisis	Found in dyad with paid caregiver
3) By mobilizing the help of a third party/consultant	Informal consultant – family member/friend	Found in <u>both</u> dyads who agree or disagree
	Formal consultant- office nurse or physician	Found in <u>both</u> dyads who agree or disagree

Note. HF- heart failure, V. – variant