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Patient and Caregiver Incongruence in Advanced Heart Failure

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Abstract

The important role of caregivers in heart failure (HF) management is well documented, but few studies have explored HF patient–caregiver dyads when dyadic incongruence is evident. The purpose of this study was to determine the prevalence of incongruence between HF patient–caregiver dyads, areas of incongruence, and the impact on individuals in the dyadic relationship. Data were collected as part of a longitudinal qualitative study examining the palliative care needs of HF dyads. Interviews with dyads determined to be incongruent were further analyzed. Of the 100 dyads, 47 were identified as being incongruent. Dyads were found to be incongruent in illness management, health care issues, and end-of-life decisions. Dyads that were incongruent reported more psychosocial issues and distress within the dyad and individually. Further research is needed to determine the impact of incongruence and whether interventions to modify incongruence will lead to improved HF patient and caregiver outcomes and experiences.

Keywords

heart failure; caregiving; incongruence; qualitative

Introduction

More than five million Americans are living with or dying from heart failure (HF) (Go et al., 2013). The majority of these patients are cared for at home by informal or family caregivers. These caregivers play an essential role in providing a combination of physical, practical, and emotional care (Hauser & Kramer, 2004) that changes over the course of HF and increases in intensity when patients experience more severe symptoms (Kitko & Hupcey, 2013; Weitzner, Haley, & Chen, 2000). Illness management for HF includes regulating diet, symptoms, and medications; detecting early signs of HF exacerbations (Riegel, Vaughan Dickson, Goldberg, & Deatrck, 2007); as well as optimizing health care treatment and end-of-life (EOL) decisions. There is a growing body of evidence to support the important role of family caregivers in HF illness management. Social support from family caregivers is

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associated with better HF outcomes such as lower read-mission rates and increased compliance to medication regimens (Chin & Goldman, 1997; Dunbar et al., 2005; Happ, Naylor, & Roe Prior, 1997; Riegel et al., 2007).

The relationship between the patient and family caregiver is typically referred to as dyadic. A dyad is two individuals who have characteristic patterns of social interactions over time (Becker & Useem, 1942). As dyads interact in the role of patient and caregiver, these interactions are interdependent (Rusbult & Van Lange, 2003) and may show congruence and incongruence. Congruence is defined as consistent perceptions between the dyad regarding various aspects of the patient's illness (Retrum, Nowels, & Bekelman, 2013). Incongruence in the dyad is defined as differences in decisions, behaviors, and attitudes. Successful illness dyadic management of HF is dependent on congruent views for illness management including health care and EOL decisions. Incongruence could potentially affect illness management and may add increased burden to the family caregiver. Although evolving, there remains limited research on the role caregivers have in illness management in the context of HF and even less is known about the dyadic interactions and the impact on health care and EOL decision making.

HF Dyads

In an instrumental case study of HF patients and their spousal caregivers, Buck, Kitko, and Hupcey (2013) described five interdependent dyadic types of HF illness management: patient oriented, caregiver oriented, collaboratively oriented, complementarily oriented, and incongruent. The incongruent dyad was characterized by each member of the dyad perceiving their role differently and selecting a different dyadic type. This dyadic disconnect in perceptions between the dyad could potentially influence illness management and joint health care decision making. A qualitative study by Retrum et al. (2013) examined the congruence or incongruence in the narratives of HF dyads ($n = 17$). The researchers found both congruence and incongruence within the dyads and reported that incongruence was more likely to result in increased reports of dyadic conflict or distress.

These studies provide preliminary support that incongruence in the dyad could potentially influence HF illness management including joint health care and EOL decision making. What is not clear is the prevalence of incongruence and in what areas of the dyadic interaction incongruences exist. Understanding incongruent areas between the HF patient and their caregiver as well as its influence on HF illness management can inform clinically relevant interventions to improve the lives of HF patients and their caregivers. The purpose of this study was to determine the prevalence of incongruence between HF patients and their caregivers, areas of incongruence, and the impact on individuals in the dyadic relationship.

Method

Study Design

These data were collected as part of a longitudinal qualitative study examining the palliative care needs of HF dyads; patients and their informal caregivers when the patient had a 30% or greater prediction of 1-year mortality. Results reported here address dyads that were

found to have incongruent perspectives related to the experience of living with and dying from HF.

Recruitment and Sampling

The sample was recruited at two large medical centers in Central Pennsylvania. Patient recruitment criteria included the following: age >18, a confirmed diagnosis of HF, a 30% or greater prediction of 1-year mortality using the Seattle Heart Failure Model (Levy et al., 2006), no gross cognitive deficits that may limit insightful reflection, and an identified informal/family care-giver > 18 years of age, who also consented to participate. Purposive sampling was used to identify patients who met the inclusion criteria and who varied in terms of demographics and caregiver relationship (i.e., spouse, child, or friend). A total of 100 HF dyads were recruited in the parent study of which 47 dyads were found to have areas of incongruence.

Data Collection

The study was approved by the appropriate institutional review boards. Following informed consent, semi-structured interviews were independently conducted with the patient and their caregiver. Trained research team members conducted participant interviews in a private setting of the hospital, clinic, or the participant's home. A semi-structured interview guide was used. Patients and caregivers were asked what it was like living with or caring for someone with HF, their role in HF illness management, decision making, and advance care planning. Participants were also asked if they were in agreement versus disagreement with the other member of the dyad when health care decisions were made and how disagreements affected them.

Data Analysis

Interviews were digitally recorded. A certified transcriptionist transcribed the interviews verbatim. Research team members cleaned the interviews to remove any identifying information, verified accuracy, and entered the text into HyperResearch (ResearchWare Inc., 2001) qualitative software.

Members of the research team (J.E.H., L.A.K., M.P., and C.P.) independently read the interviews to determine if incongruence between the dyad was present. Incongruence was established when the patient and caregiver expressed differing views on living with HF. The interviews with incongruent dyads were further analyzed using an iterative thematic approach. Patient and caregiver transcripts were initially read independently and then as a dyad resulting in the identification of tentative areas of incongruence. Each member of the team further analyzed the dyadic pair of interviews to determine where incongruence occurred and the impact on the patient, caregiver, and HF experience.

Trustworthiness of the research process was addressed by using the criteria of credibility, dependability, and confirmability (Lincoln & Guba, 1985). All data were collected using the same semi-structured interview guide. Initial coding was conducted independently, followed by member checks among the coders with consensus reached on which dyads exhibited

incongruence. Once incongruent dyads were identified, the team performed independent thematic analyses and then a group analysis to reach thematic consensus.

Results

Demographics

Of the 100 dyads, 47 in the parent study were identified as being incongruent. These 47 participants' ages ranged from 39 to 88 years ($M = 68.1$) for patients and 28 to 88 years ($M = 62.4$) for caregivers. Patients were predominantly male ($n = 34$) and caregivers were predominantly female ($n = 39$). The sample self-identified as primarily non-Hispanic Caucasian. There was minimal or no difference in demographics (age, race, gender) between the incongruent sample from the entire parent sample data set. In the analysis of the caregiver data, there is a minimal difference between the incongruent and the congruent group. A T test was completed with a T value of 2.52 and a p value of .01. The patient data also demonstrated little to no difference between groups with a T value of 1.61 and a p value of .10. Gender was also analyzed with a chi-square table, which demonstrated no difference between incongruent and congruent groups with a p value of .76 and using the fisher exact test the p value is .80. The relationship of the dyad (parent, child, or spousal) did not influence incongruence. When adjusting for patient–caregiver relationship, there was no difference between the incongruent dyads and the parent sample. Not all 47 dyads were incongruent in all of the identified themes, but each dyad displayed incongruence in at least one of the themes.

Major Themes

Three themes were identified as areas of incongruence in the dyad. These themes were as follows: illness management, health care issues, and EOL decisions. Each of the themes will be discussed below.

Illness management—Dyads often had differing views on the management of HF, which resulted in incongruence within the dyad. A consistent theme throughout the interviews was caregivers' frustration with the patient's non-compliance to diet, exercise, medications, and daily symptom monitoring.

A dyad discussed incongruent views in which the caregiver wished the patient would follow medical advice and be more active:

Caregiver: The doctor's said that with this new treatment he should be walking, I encourage him to walk all day, hoping it will make him feel better.

Patient: She nags all day long for me to walk more, I cannot get it through her head that I do not have enough energy. That is the main thing we fight about.

Incongruence between the dyad regarding compliance with the medical regimen persisted with this dyad:

Caregiver: I keep after him. He gets mad at me but I don't care. I hate nagging but it works sometimes. He said I am going to ask that doctor about using salt ... and liquid. I said well I guess he will tell you the same thing.

Patient: I drink a little bit too much water or whatever you know. Of course she gets on me about it ... I didn't drink a whole bottle ... I'm not going to dehydrate myself.

Another caregiver described her distress related to her husband's noncompliance:

Caregiver: He just would not listen to me or the doctors, it was very hard on me watching him do what he did, he missed out on so much ... the grandkids. I am mad at him for how poorly he cared for himself and the hard time he gave me for trying to do it.

Health care issues—Dyads reported incongruence in relation to health care issues regarding when to seek treatment, services at home, and further future medical treatments or interventions. A male patient had been admitted several times for shortness of breath and fluid overload over the past month due to worsening renal function. The caregiver (wife) was presented with the option of hospice prior to discharge, an offer that the caregiver refused. When asked about why she did not accept hospice during an interview, she stated,

Caregiver: I said no that I can manage everything by myself, I figured he would feel better if I could do things for him like bathing him, I can handle everything myself, in fact I told the doctor not to mention the word hospice to him ... I am 89 years old but I would rather take care of him myself.

When the patient was asked about the need for services, he stated,

Patient: I am getting worse and cannot do much for myself, I wish someone could come in and help (wife's name) take care of me. She is getting run down.

In the majority of the cases, caregivers were proactive in adhering to the prescribed regimen, which often conflicted with patient's views. This led to tension in the dyad and role confusion/frustration for the caregiver:

Caregiver: I knew he was getting short of breath and needed to be seen but he refused to let me call the office. It got to the point where I called 911 ... I am worried (patient's name) will be upset with me when he realizes what I did.

Incongruent perceptions between the dyad regarding when to seek medical care were also evident in this exemplar quote:

Caregiver: If he would just let me know ahead of time a lot of stuff could be prevented.

Patient: She does so much for me now—I hate to bother her every time I am not feeling well.

Incongruent perceptions were also evident when family caregivers thought about their future role and increasing care demands the fear that they will not be able to continue to provide adequate care:

Caregiver: I will say to (patient's name) do you know what the outcome is going to be if you don't take your insulin ... you are going to lose your leg or something else. Yep that's what he says to me. Yep that might happen. I said I'm not going to

be able to care for you. You're going to go into a nursing home ... he might be thinking about that stuff but he is not really dealing with it. He does not want to talk about it and I don't want him to get upset with his heart being weak.

EOL decisions—Incongruence within the dyad also affected EOL decision making. Incongruence with advance care planning between the dyad was commonly reported in this theme. In a joint spousal dyadic interview, the following exemplar quotes highlight incongruence within the dyad in terms of advance directives:

Caregiver: I don't like those.

Patient: She doesn't, I do. I'm looking for someone here before I go into surgery to do that, because you know to me it's important.

Caregiver: What if I don't want to do this?

Patient: When would you like to do it? I mean who do you think I'd feel more comfortable with knowing they had my life in their hands, you, or someone else?

Caregiver: I would put my life in your hands but I don't want... I can't be the one to say no, I just can't.

Patient: But if I put my wishes down on paper then it would be up to you to make sure wishes are carried out.

Caregiver: We can talk about this tomorrow.

Patient: Well it's got to be brought back up.

Incongruence between the dyad was also evident in EOL decision making when treatment options were presented by the health care team as the patient entered the EOL phase. A caregiver talks about her husband consenting to have a left ventricular assist device (LVAD) implanted as destination therapy:

Caregiver: I would not have chosen the LVAD, that's his decision ... it's his body ... it's his control. I am not mad at him for choosing the LVAD, but I would have died first.

Impact of incongruence on the dyadic relationship—Incongruent dyads reported more psychosocial issues, tension, and distress individually and within the dyad. Patients' noncompliance with the medical regimen led to a high level of discord in the dyadic relationship. A spousal caregiver of a patient with frequent admissions due to noncompliance with the medical regimen expressed her frustration when asked what happened during visits to the doctor:

Caregiver: He looks at me sometimes and tells me to keep my mouth shut. I have to go away once a day to my girlfriends and have lunch with her ... or I would lose my sanity.

Another caregiver details the impact of dyadic incongruence related to non-compliance with the medical regimen on her as an individual:

Caregiver: (Patient's name) could care less ... I think sometimes he gets pleasure out of just the shear I don't want to say argument but the combative. So there are times when you know it's like God give me patience because I need it with him ... I find that extremely frustrating.

When incongruence was evident in the dyad, the impact on the dyad continued to be apparent at subsequent interviews, with participants often bringing up areas of incongruence and the impact on the dyad without direct prompts during the interview process. A caregiver described her feelings of frustration throughout several different interviews regarding her husband's refusal to stop smoking:

Caregiver: You haven't asked me about the smoking ... I don't know why he went back to it. I'm just very upset about it ... You know it's a sad tough thing to go through because he's frustrated with himself and I get frustrated because he gets frustrated. It's a dramatic thing for both parties. I look at it this way he's made his choice and he just doesn't give a damn.

Discussion

This was one of the first studies to qualitatively explore the perceptions and experiences of HF patients and their family caregivers as a dyad and one of the first to include non-spousal caregivers. Incongruent dyadic perspectives had a negative impact on HF management. It is often assumed that when a family caregiver is identified, the dyadic relationship is congruent and illness management occurs without difficulty or conflict. Yet, the presence of incongruence had an impact on the dyadic relationship resulting in tension and distress as a result of the conflicting views. Dyadic incongruence is not typically considered or assessed in spite of previous research describing the influences of the family relationship on chronic disease outcomes (Weihs, Fisher, & Baird, 2002). Determination of incongruent perceptions between patients and their caregivers is an important assessment that could affect HF illness management, health care, and EOL decisions and should be addressed.

Incongruence was also evident surrounding EOL decision making with members of the dyad expressing conflicting views. Although these Stage D HF patients have frequent re-admissions for HF exacerbations, advance care planning discussions typically do not occur with health care providers (Murray et al., 2002). Practitioners participating in advance care planning discussions should determine if incongruence exists within the dyad as conflicting views may affect important decisions necessary at the EOL. Incongruence within the dyad may also account for surrogate decision makers incorrectly predicting patient preferences at the EOL (Shalowitz, Garrett-Mayer, & Wendler, 2006). Lack of advance care planning discussions may also affect caregivers during their grieving process. Further research is needed to determine the impact of incongruence on both patients and caregivers.

Dyadic incongruence not only affects HF illness management but also has negative effects on the caregiver. Caregivers in incongruent dyads reported increased levels of tension and psychosocial distress both individually and within the dyad adding to the potential burden in an already burdensome role. This finding highlights the importance of health care providers,

viewing the caregiver as not only a co-provider but also a co-recipient of care (Hupcey, Fenstemacher, Kitko, & Fogg, 2011).

Research regarding the HF dyadic relationship in the context of illness management is relatively new and this study further supports similar HF dyadic studies. M. Sebern and Riegel (2009) developed the concept of shared care in which dyads exchange care and assistance through communication, decision making, and reciprocity. A dyadic measurement tool also developed by M. D. Sebern and Woda (2012) assesses patient and caregiver needs, but incongruence and its impact on shared care are not addressed. Buck et al. (2013) presented a typology of patient and caregiver dyadic interdependence. The incongruent dyad typology was described as a disconnect between the dyad in views regarding HF illness management. This dyadic disconnect resulted in poor patient outcomes and was consistent with our findings. In addition, this study supports the finding of Retrum et al. (2013), who found that incongruence and lack of communication in the patient–caregiver dyads affected HF disease management, perceived care needs, and EOL planning.

Limitations

Limitations of the study include racial/ethnic homogeneity of the sample, consisting primarily of non-Hispanic, Caucasian participants. Future work should include a more diverse sample in terms of race and ethnicity. The primary focus of the interviews was on the needs of advanced HF dyads. The interview guide would have been strengthened with additional questions that focused on relational aspects within the dyad. No data were collected on relationship quality or conflict resolution within the dyad which would have provided more depth to the analysis.

Conclusion

This study advances our understanding of HF caregiving process from the dyadic perspective and documents the high prevalence of incongruence within the dyad. Several important areas related to HF illness management were affected by incongruence. Incongruence affected not only the patient but also the family caregiver. The importance of both the patient and family caregiver as co-providers and co-recipients in the process of illness management is underscored by this work. Dyadic relationship dynamics that may not be evident to health care providers are likely exerting influences on patient and caregiver's behaviors. It is often assumed by health care professionals that when caregivers are identified, they are active willing participants in the HF illness management. This study highlights the impact of incongruence within the dyad, the potential negative outcomes on illness management, and the impact on EOL planning and decision making for both the patient and family caregiver. Home care treatment plans and compliance to those regimens are based on an assumption of a congruent relationship within the dyad and may not have the intended outcomes if the dyad is incongruent. Incongruence within the dyad also has the potential to complicate EOL planning, resulting in surrogate decisions not in line with patient wishes. Further research is needed to determine the impact of incongruence and the influence that interventions to modify incongruence might have on improved outcomes for the patient and family caregiver. Additional dyadic studies are needed to further explicate

this process and provide additional information on how prevalent incongruence is within the dyad and how it affects illness management. Future work will provide the foundational information for quantitatively measuring incongruence and the development of specific interventions to modify incongruence to improve HF patient and caregiver outcomes.

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