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Assessing the response of patients and spousal/partner caregivers to a new instrument measuring dyadic heart failure care types

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Abstract

Background—Nurse researchers are exploring new ways of understanding heart failure (HF), spousal/partner dyad's self care.

Aims—To assess the response to a new instrument developed to measure dyadic HF care type in HF patients and spousal/partner caregivers and explore relationships between type and other variables.

Methods—Dyads answered a written criterion referenced question related to dyadic HF care type. The relationships between the dyadic care type and sociodemographic and clinical variables were explored using χ^2 , ϕ coefficient. Degree of agreement within the dyad on particular type was assessed by kappa statistic.

Results—A total of 19 dyads were accrued. Patients were aged 71.7 ± 9.7 years (mean $\pm$ SD), male ($n=15$), and NYHA Class IIIB/IV (79%). Caregivers were aged 69.2 ± 11.7 years, female ($n=15$), married for 45.2 ± 14.1 years. HF patient and caregiver dyads were easily able to self select a dyadic type given specific criteria. Agreements ranged from 21% to 5%, by type, resulting in a kappa of 0.28 ($p = 0.025$) when patient self reported type was compared to their caregiver's type.

Conclusions—Now that we are able to measure types of dyadic HF care, understanding how dyadic care type relates to self care outcomes is needed to advance the science.

Keywords

Self-care; dyadic; research; typology

Background

Heart failure (HF), on the rise worldwide,¹ requires conscientious self care.^{2,3} Nurse researchers have taken the lead in studying the interplay between HF, patients, and spousal/partner caregivers resulting in a recent surge in HF dyadic research.^{4–11} As the data begin to

accumulate, new ways of understanding HF spousal/partner dyads and what role these dyads play in self care are being explored.

HF spousal/partner dyads report greater emotional investment and sense of responsibility for HF care when compared to parent/child dyads;⁷ however, congruence or consistency of spousal/partner dyad agreement in that care is a key factor in dyadic outcomes.^{7,12} It is not sufficient for the caregiver to be merely involved, rather that the dyad agree on the self care.⁷ In addition, dyads who share responsibility for self care report better overall self care.¹³ In a number of studies, patient and informal caregiver dyads have been found to pool their personal resources (i.e. information, energy, time) to manage chronic illnesses.¹⁴ Dyads are also known to develop habitual responses to similar situations as a means of streamlining decision making.¹⁵ From this, it can be inferred that dyads will manage HF care as they have successfully managed other complex problems in the past. For example, if the dyad has historically managed their finances together, the theoretical literature suggests that they will manage HF care, another complex task, together, whereas if one partner took sole responsibility for financial planning, that partner may be more likely to take sole responsibility for HF care. Furthermore, it can be deduced that there are a finite number of ways in which dyads can manage HF care (they can either work together or separately; one or the other can take the lead) resulting in several categories or types of dyadic HF care. However, quantifying dyadic HF care has not been accomplished to date due to the lack of robust instrumentation to measure this care. The purpose of this short report is to assess the response to this new instrument developed to measure dyadic HF care type in HF patients and spousal/partner caregivers and explore relationships between dyadic care type and other variables.

Methods

Data were accrued for a larger study (5R01NR013419-02, Hupcey, J.E. PI). The investigation was approved by the institutional review board of a health care system in the Eastern United States and conforms with the principles outlined in the Declaration of Helsinki.¹⁶ The setting included outpatient clinics from one university affiliated health care system and one large community based health system.

In seeking to develop a means to quantify this spousal/partner dyadic HF care, first, a typology was developed,¹⁷ to portray different ways in which patients and caregivers could possibly manage HF care. A 2×2 table of patient or caregiver by individual responsibility or joint responsibility resulted in four categories or dyadic HF care types: two categories in which the individual patient or caregiver managed HF alone with the acquiescence of the spouse/partner and two in which the dyad managed HF together, either collaboratively or by negotiating separate spheres of responsibility (see Table 1). Our thinking about these categories was informed by the literature from statistics,^{18,19} psychology,^{14,20} and the health sciences.^{21–23} Then an instrument was developed to measure the dyadic HF care type for the individual dyad.

Sample

The sample included dyads consisting of a HF patient and their spousal/partner caregiver. Patients were identified by clinicians, then screened and recruited by trained research assistants. Eligible dyads had to be over the age of 18, English speaking, alert and oriented, and provide written consent. In addition, the patient had to have a documented diagnosis of end-stage refractory HF (New York Heart Association (NYHA) class IIIB/IV) in the medical record at time of consent and an identified primary spousal/partner caregiver.

Procedure

Spousal/partner dyads were recruited from 2011 to 2012 in the outpatient clinics associated with the involved health care systems. After identification by clinicians, dyads were initially contacted in the clinics by the research assistants who described the study to them and obtained informed consent. Both the patient and caregiver forms were designed at a ninth grade readability level. Self care was defined 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 patient and caregiver were then instructed to circle one and only one category that best described how they and their partner take care (decide what to do and how to do it) of the patient's HF. The four categories of dyadic care type provided were: 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 collaborative category where the patient and caregiver take care together; 4) a complementary 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 patient and caregiver, separately, completed the instrument in order to determine who provided routine daily self care maintenance activities involving treatment adherence and symptom monitoring.² Research assistants were instructed to observe and note if the dyads had any difficulty understanding the categories or needed clarification at any point.

Data analysis

All statistical analyses were conducted using SPSS version 19. After assessing for missing or non-normally distributed data, descriptive statistics (mean $\pm$ SD) of patient and caregiver sociodemographic (age, gender, years married, time caregiving), clinical variables (patient NYHA class), and dyadic care type were first assessed. Although this feasibility study was not sufficiently powered to detect the existence and strength of the relationships between the dyadic care type and sociodemographic and clinical variables, these were explored using nonparametric measures (χ^2 , ϕ coefficient). Finally the degree of agreement within the dyad on particular type selected was assessed using a kappa statistic. The strength of the agreement was determined according to Landis and Koch's criteria.²⁴

Results

A total of 19 dyads were included in this study. Sociodemographic and clinical characteristics of the dyads were as follows. Patients in this sample were typical for HF patients, mean age of 71.7 $\pm$ 9.7 years, male ($n=15$), and NYHA Class IIIB/IV (79%). Caregivers were slightly younger (69.2 $\pm$ 11.7 years), female ($n=15$), reported having been married for a mean of 45.2 $\pm$ 14.1 years, and had served as a caregiver for two years or less (68%). All patients and caregivers self identified as White.

When patients were asked to select a preferred dyadic care type (Table 2), the collaborative type was the most frequently selected ($n=10$), followed by patient oriented ($n=5$), caregiver oriented ($n=2$), and complementary ($n=2$). When caregivers were asked (Table 3), they selected both the patient oriented ($n=6$) and complementary ($n=6$) most frequently, followed by collaborative ($n=5$), and caregiver oriented ($n=2$). When non-parametric statistics (χ^2 , ϕ coefficient) were assessed exploring the existence and strength of the relationship between the patients' self reported dyadic care type and the patient's age, gender, years married, or NYHA class, no significant relationships were found. Nor were there any significant relationships found between the patients' dyadic care type and the caregiver's age, gender, years married, or years caregiving. The analysis was then repeated with caregivers' self

reported dyadic type and both the patients' variables and their own. Once again there were no significant relationships.

The only relationship of interest in these analyses was the relationship between the caregivers' self selected dyadic care type and the patients' NYHA class ($\phi .82$, p NS) but the relationship was not as expected, in that six caregivers selected a patient oriented dyadic care type while the patient's NYHA class (IIIB/IV) indicated a significant amount of HF disease burden. Of the nine patients with NYHA class IV HF, only one caregiver indicated that they (the caregiver) took care of the majority of the patient's HF care. When patient self reported dyadic care type was compared with their caregiver's dyadic care type the agreements ranged from 21% to 5% (Table 4) and resulted in a kappa of 0.28 ($p = 0.025$) denoting a fair strength of agreement.²⁴

Conclusion

Our main finding is that HF patient and caregiver dyads responded with ease to the new instrument and were able to self select a dyadic care type given specific criteria. Despite a relatively impaired patient population (NYHA class IIIB/IV), they had no difficulty understanding the question or selecting the category that best described their particular type. The research assistants reported that a few dyads vacillated between the collaborative (work together on the same things) and complementary (work together on separate things) types. We were concerned that the two 'joint responsibility' types were conceptually close (and perhaps indistinguishable to a lay person), but when given the instruction to 'just select the one that best describes how you and your partner take care (decide what to do and how to do it) of your (or your partner's) HF,' they were able to select one type over the other and then used stories to confirm their selection.

The non-significant findings from the analysis of the relationships between the selected dyadic care type and both personal or partner variables are not unexpected as this small study was not powered to detect a relationship. Future work will explore these relationships in greater depth. Of particular concern is the subset of caregivers who indicated that they considered the patient to be primarily responsible for their own HF care despite advanced HF. This finding calls for future exploration. Whether the patient is not willing to engage the caregiver as the HF progresses or whether the caregiver does not engage needs to be better understood. It can be argued that patient oriented dyadic types that may have successfully managed HF in earlier stages of the condition need to shift to one of the joint management types. Furthermore, it is theorized that ultimately all dyads end up with a caregiver oriented type as the patient becomes less and less able to contribute to their own care. Dyads that are unable to manage this shift may be particularly vulnerable to failures in self care.

The lack of agreement between patients and caregivers on dyadic care type is equally intriguing, and yet, troubling. Although the limitations of the kappa statistic are acknowledged,²⁵ a kappa of 0.28 indicates only a fair degree of agreement²⁴ between the patient and caregivers, but the p value, given the small sample size, indicates an increased likelihood that this kappa is not due to chance. The relationship between agreement and successful self care needs further exploration. It would move the science forward if it were found that when both partners are working from a different mental model of who is responsible for the care, poorer outcomes result.

One limitation of the current study is the lack of diversity in the sample. Future study is needed to assess the response to this new instrument measuring dyadic HF care in a more diverse population. HF remains a costly condition for both health care systems and for human beings. There is a need to understand factors that may impact self care decision making for patients and caregivers. Of particular interest is how the dyad's care type

(whether the patient or caregiver takes the lead or they collaborate) relates to self care. This paper has presented a new instrument to measure dyadic HF care types and provided preliminary evidence for the usability of the instruments with participants. The next step is to understand how the dyadic care types relate to self care outcomes.

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Table 1

Dyadic care typology.

HF care management	Dyadic types	Statement
Individual management	Patient oriented	I take care of the majority of my heart failure without any input from my spouse/partner
	Caregiver oriented	My spouse/partner takes care of the majority of my heart failure without any input from me
Joint management	Collaboratively oriented	We take care of the majority of my heart failure together
	Complementarily oriented	We take care of different aspects of my heart failure

Table 2

Patient self reported dyadic care type.

Patient self reported dyadic care type	Statement	<i>f (%)</i> ^a
Collaboratively oriented	We take care of the majority of my heart failure together	10 (53%)
Patient oriented	I take care of the majority of my heart failure without any input from my spouse/partner	5 (26%)
Caregiver oriented	My spouse/partner takes care of the majority of my heart failure without any input from me	2 (11%)
Complementarily oriented	We take care of different aspects of my heart failure	2 (11%)

^aDescending order by frequency.

Table 3

Caregiver self reported dyadic care type.

Caregiver self reported dyadic care type	Statement	<i>f (%)</i> ^a
Patient oriented	My spouse/partner takes care of the majority of his/her heart failure without any input from me	6 (32%)
Complementarily oriented	We take care of different aspects of his/her heart failure	6 (32%)
Collaboratively oriented	We take care of the majority of her/her heart failure together	5 (26%)
Caregiver oriented	I take care of the majority of his/her heart failure without any input from my spouse/partner	2 (11%)

^aDescending order by frequency.

Table 4

Self reported dyadic care type agreement.

Self reported dyadic care type agreement	<i>f (%)</i> ^a	<i>k</i>
Collaborative	4 (21%)	
Patient oriented	3 (16%)	
Caregiver oriented	1 (5%)	
Complementary	1 (5%)	
Kappa		0.28 (<i>p</i> = 0.025)

^aDescending order by frequency.