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Patterns and predictors of patient and caregiver engagement in heart failure care: A multi-level dyadic study

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ABSTRACT

Background: Heart failure is a burdensome clinical syndrome, and patients and their caregivers are responsible for the vast majority of heart failure care.
Objectives: This study aimed to characterize naturally occurring archetypes of patient-caregiver dyads with respect to patient and caregiver contributions to heart failure self-care, and to identify patient-, caregiver- and dyadic-level determinants thereof.
Design: Dyadic analysis of cross-sectional data on patients and their caregivers.
Setting: Outpatient heart failure clinics in 28 Italian provinces.
Participants: 509 Italian heart failure patients and their primary caregivers.
Methods: Multilevel and mixture modeling were used to generate dyadic averages and incongruence in patient and caregiver contributions to heart failure self-care and identify common dyadic archetypes, respectively.
Results: Three distinct archetypes were observed. 22.4% of dyads were labeled as novice and complementary because patients and caregivers contributed to different aspects of heart failure self-care that was generally poor; these dyads were predominantly older adults with less severe heart failure and their adult child caregivers. 56.4% of dyads were labeled as inconsistent and compensatory because caregivers reported greater contributions to the areas of self-care most insufficient on the part of the patients; patients in these dyads had the highest prevalence of hospitalizations for heart failure in the past year and the fewest limitations to performing activities of daily living independently. Finally, 21.2% of dyads were labeled as expert and collaborative because of high contributions to all aspects of heart failure self-care, the best relationship quality and lowest caregiver strain compared with the other archetypes; patients in this archetype were likely the sickest because they also had the worst heart failure-related quality of life.
Conclusion: Three distinct archetypes of dyadic contributions to heart failure care were observed that represent a gradient in the level of contributions to self-care, in addition to different approaches to working together to manage heart failure. Interventions and

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clinical programs that involve heart failure dyads should tailor strategies to take into consideration these distinct archetypes and their attributes.

What is already known about the topic?

- Patients with heart failure vary considerably in their self-care.
- Caregivers are thought to play a major role in supporting heart failure self-care.

What this paper adds

- There are three archetypes of patient and caregiver contributions to heart failure self-care.
- The three archetypes represent gradient in both the level of engagement in self-care and different approaches to working together to manage heart failure.

1. Introduction

Along with the worldwide growth of the elderly population, the number of adults affected by the clinical syndrome of heart failure will likely increase (Najafi et al., 2009). The costs associated with the treatment of heart failure are also projected to increase markedly over the next two decades (Heidenreich et al., 2013). Evidence-based therapies are essential to improve outcomes among adults with heart failure (McMurray et al., 2012); but, patients are responsible for the vast majority of heart failure care. That is, self-care of heart failure (i.e., patients' adherence to prescribed therapies and their ability to recognize and respond to symptoms effectively) is critical to the management of chronic heart failure (Moser et al., 2012; Riegel et al., 2011a,b). Patients with heart failure vary considerably in their self-care, however, and self-care is generally inadequate among adults with heart failure worldwide (Jaarsma et al., 2013). Thus, strategies that aim to enhance and support effective heart failure self-care behaviors are essential (Riegel et al., 2011a,b).

Caregivers are thought to play a major role in supporting heart failure self-care; but, the science supporting this claim is quite limited (Buck et al., 2014). There are many ways in which caregivers can be incorporated into heart failure care planning and contribute to heart failure self-care. These include helping patients prepare low-sodium meals, develop systems for taking all medications as prescribed and practice what to do when heart failure symptoms occur, as well as directly monitoring for signs and symptoms of worsening heart failure; it is also recommended that heart failure caregivers be included in all appointments with healthcare provider (Riegel et al., 2009). Exactly how this works in practice, however, is not well understood. What is known is that heart failure patients and caregivers who take a collaborative approach to heart failure management have better outcomes like better caregiver quality of life [QOL] (Pressler et al., 2013) and less caregiver strain (Hwang et al., 2011; Luttik et al., 2007a,b), whereas a gap between the patient's and caregiver's appraisal of symptoms and respective contributions to care leads to inadequate symptom management (Janssen et al., 2012; Quinn et al., 2010; Retrum et al., 2013; Rohrbaugh et al., 2008; Sebern and Riegel, 2009). Thus, how patient-caregiver dyads function together in their contributions to care is an important consideration in the overall management of heart failure. Although a typology of self-care has been identified previously among heart failure patients (Dickson et al., 2008; Riegel et al., 2011a,b), common and distinct archetypes of patient-caregiver dyads, their attributes, and their determinants are still being explored (Buck et al., 2013).

Accordingly, this study aimed to identify and characterize archetypes (i.e., naturally occurring patterns) of heart failure patient-caregiver dyads with respect to patient and caregiver contributions to self-care. This study also aimed to identify additional patient-, caregiver- and dyadic-level factors that were helpful in determining which of the observed archetypes the dyad was most likely to embody.

2. Methods

2.1. Study design

This was a secondary analysis of cross-sectional data collected during a study of Italian heart failure patients and their caregivers (Cocchieri et al., 2014; Vellone et al., 2014). The aims of the original study were to describe and identify socio-demographic and clinical determinants of self-care behaviors among Italian adults with heart failure. In brief, 1192 heart failure patients were enrolled from outpatient centers in 28 Italian provinces. Participants were 18 years of age or greater and had a confirmed diagnosis of heart failure; in accordance with evidence-based guidelines (McMurray et al., 2012), all diagnoses were made by treating cardiologists based on echocardiographic evidence confirmed with clinical evidence (i.e., signs of heart failure like edema or elevated filling pressures and common symptoms of heart failure like dyspnea). Patient participants also had no acute cardiovascular events in the preceding 3 months by inclusion criteria. Participants were excluded solely on the basis of obvious dementia. Caregivers in this study were defined as the unpaid person (inside or outside the family) who provides the most informal care to a person affected by heart failure, was identified as such by the patient and designated by the heart failure patient as the primary caregiver. Caregivers in this study were designated by the heart failure patient as the primary caregiver, accompanied the patient to the enrollment visit and were willing to participate in the study. All questionnaire data were