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Shared Care Dyadic Intervention: Outcome Patterns for Heart Failure Care Partners

Margaret D. Sebern and Aimee Woda

Abstract

Up to half of heart failure (HF) patients are readmitted to hospitals within 6 months of discharge. Many readmissions are linked to inadequate self-care or family support. To improve care, practitioners may need to intervene with both the HF patient and family caregiver. Despite the recognition that family interventions improve patient outcomes, there is a lack of evidence to support dyadic interventions in HF. Thus, the purpose of this study was to test the Shared Care Dyadic Intervention (SCDI) designed to improve self-care in HF. The theoretical base of the SCDI was a construct called Shared Care. Shared Care represents a system of processes used in family care to exchange support. Key findings were as follows: the SCDI was acceptable to both care partners and the data supported improved shared care for both. For the patient, there were improvements in self-care. For the caregivers, there were improvements in relationship quality and health.

Currently 5.7 million Americans are living with heart failure (HF), 670,000 new cases are diagnosed each year, and the cost of providing HF care ranks among the leading U.S. health care expenditures (Lloyd-Jones et al., 2009). Because of prevalence, cost, and patients' preference to avoid hospitalization, there has been a growing emphasis on individuals and families taking a more active role in managing their disease at home (Molloy, Johnston, and Witham, 2005). To improve care, the Heart Failure Society of America (HFSA, 2006) recommended that practitioners assess and intervene with both HF patients and family caregivers (referred to as care partners here). However, in a recent literature review only two HF intervention studies included both care partners; one study was qualitative (Duhamel, Dupuis, Reidy, and Nadon, 2007) and the other was a pilot test of a dyadic intervention (Dunbar et al., 2005). The purpose of the study reported here was to test a theory-based intervention, the Shared Care Dyadic Intervention (SCDI), designed for HF care partners to improve specific relationship processes used to exchange care and assistance. The theoretical basis of the intervention was Shared Care. Shared Care represents a system of processes (communication, decision making, and reciprocity) used in family care to exchange care and assistance (see Figure 1). The study's goal was to evaluate the feasibility of the SCDI in a home setting and to examine outcomes for both care partners.

Heart Failure Shared Care: Conceptual Framework and Extant Research

Family care refers to unpaid assistance to patients in their home by relatives and friends (Archbold, 2004). Family care by its nature involves two people in a close relationship who mutually influence each other. Family care is an important clinical issue because family relationships are known to affect self-care in HF, adherence to treatment, mortality, and morbidity (Coyne et al., 2001; Dunbar, Clark, Quinn, Gary, and Kaslow, 2008).

Family care encompasses a variety of relationship processes; however, in prior research communication, decision making, and reciprocity were identified as important processes associated with improved health outcomes (Sebern, 1996). Shared Care communication is the exchange of information and advice between care partners. Decision making is a patient's capacity to seek information and be involved in decisions about his or her care. Reciprocity is the extent to which care partners give and receive care and assistance. Shared Care does not assume that there is equal exchange of care or assistance. Rather Shared Care is a pattern of three relationship processes shaped by the context and needs of each care partner. For example, a family caregiver may listen and verify a patient's description of symptoms (communication), support the patient's decision to notify a primary care provider (decision making), and drive to the drugstore to pick up a new prescription (reciprocity). The patient decides to report his or her symptoms to a health care professional (communication and decision making) and expresses gratitude and appreciation for caregiver's assistance (shared care communication and reciprocity).

The Shared Care Instrument-3 (SCI-3) was developed to measure the construct Shared Care. Theoretical and operational definitions for the SCI-3 were synthesized from fieldwork with family care partners and a review of the literature (Sebern, 2005a, 2005b). Data from field studies testing the psychometrics of the SCI-3 supported a three-factor structure for Shared Care as originally conceptualized for both care partners (Sebern, 2008). Construct validity was supported by positive and significant correlations between components of care partners' Shared Care and dyadic relationship quality (Sebern, 2008) and mutuality (Sebern, 2005a).

Components of Shared Care have been studied separately by researchers. These researchers reported that communication (Pruchno, Burant, and Peters, 1997), decision-making satisfaction (Deimling, Smerglia, and Schaefer, 2001), and reciprocity (Beach, Schulz, Yee, and Jackson, 2000)

influenced relationship quality, mood, depressive symptoms, and well-being. For example, Lyons, Zarit, Sayer, and Whitlatch (2002) reported that discrepancy about problem behaviors in family care contributed to relationship strain and poor mental health outcomes. Riegel, Lee, Dickson, and Carlson (2009) identified decision making as a major component of self-care in heart failure. Reinhardt (2001) suggested that an inability to reciprocate in family care predicted patient depression. In contrast, opportunities to reciprocate in family care contributed to positive outcomes (Davey and Eggebeen, 1998). Family caregivers who provided care without strain had lower anxiety and depression, and an increased sense of control, compared to persons who did not provide family care (Beach et al., 2000). Although prior research identified the importance of components of Shared Care, the study reported here is unique in that all three processes were explored together with both care partners.

Shared care is conceptually linked to social support because relationship processes are a context for the expression and receipt of support, and a source of personal meaning (Reis and Collins, 2000). Social support is defined as the provision and exchange of emotional, informational, and/or instrumental resources in response to perceiving another's need. Social support is proposed to affect health through its influence on emotions, cognitions, behavior, and the neuroendocrine system (Cohen, Gottlieb, and Underwood, 2000). Not all relationships are supportive. Negative aspects of close relationships include criticism, strain, and lack of reciprocity (Krause, 2005). For the exchange of support, it is necessary to have specific support processes operating within the relationship. Although social support is important to health, the exact processes operating in close relationships contributing to health is unknown (Dunbar et al., 2008; Murberg, 2004; Reis and Collins, 2000).

In prior work, Shared Care processes were positively associated with better self-care in HF. Data from HF care partners supported moderate correlations between patient Shared Care decision making and self-care maintenance ($r = .65, p < .05$). In addition, caregiver decision making ($r = .37, p < .05$) and reciprocity ($r = .35, p < .05$) were associated with patient self-care confidence (Sebern and Riegel, 2009). These findings suggest that augmenting Shared Care processes might be a way to improve self-care.

Correlational evidence suggests an association between family support and self-care in HF (Dunbar et al., 2008; Riegel, Moser, et al., 2009). Riegel, Lee, and colleagues (2009) define self-care in HF as a decision-making process involving the choice of behaviors that maintain physiological stability (self-maintenance), the response to HF symptoms when they occur (self-management), and the patient's self-care confidence to engage in each phase of self-care (Riegel, Lee, et al., 2009). Self-care contributes to adherence, lower hospitalization rates, and better patient outcomes (Riegel, Moser, et al., 2009).

Several researchers tested education and disease management interventions that targeted individual HF patients and self-care. Jaarsma and colleagues (2008) and Powell and colleagues (2010) reported that disease management interventions did not reduce HF deaths or hospitalizations compared with standard follow-up. Allen and Dennison (2010) conducted a meta-analysis of randomized controlled trials (RCTs) of patient education and behavioral counseling interventions for coronary artery disease and heart failure patients. Both behavioral and disease-focused outcomes were evaluated. Forty-three percent of reviewed interventions had no significant effect on the study outcomes. The authors suggested that the lack of significant findings was due to small sample sizes, inadequate doses, or improved outcomes in the usual care group. However, those educational and disease management interventions may have failed to achieve significant effects because the family caregiver was not included in the intervention.

Other researchers suggested that the best interventions to improve self-care in HF may involve mobilizing the resources of both partners (Molloy et al., 2005; Reis and Collins, 2000; Riegel, Moser, et al., 2009). Martire, Lustig, Schulz, Miller, and Helgeson (2004) reviewed family interventions for care partners managing heart disease and other chronic illnesses. Overall, Martire and colleagues reported small to medium effect sizes for interventions but found stronger effect sizes for interventions that

targeted both partners' relationship processes. Dunbar and colleagues (2005) evaluated the family partnership intervention (FPI), which taught caregivers how to create an autonomous, supportive environment for patients. The FPI was effective in reducing the primary outcome of the study, dietary sodium intake. Duhamel and colleagues (2007) conducted a qualitative study of an HF family intervention, reporting that a family intervention allowed spouses to obtain a better understanding of each other's experience and to alleviate suffering.

Whitlatch, Judge, Zarit, and Femia (2006) tested the Early Diagnosed Dyadic Intervention (EDDI), which provided a structured, one-on-one, and dyadic intervention for care partners who were in the early stages of dementia. The intervention taught communication and decision-making skills and assisted the dyad to develop a care plan based on a mutual understanding of each other's values and preferences. These researchers concluded that targeted communication about care values and preferences can improve the well-being of care partners. With these authors' permission, components of EDDI were modified and included in the SCDI. For example, we modified the communication skills training, engaged care partners in decision making about a care plan for HF, and added content on reciprocity skills. We believed that modified EDDI components would strengthen Shared Care processes.

In addition to Shared Care, depression and anxiety are thought to both contribute independently to poor outcomes seen in patients with HF (Frasure-Smith and Lesperance, 2008; Konstam, Moser, and De Jong, 2005; Pinquart and Sorensen, 2003). Konstam et al. (2005) reported that depression and anxiety were neglected in the literature because of an emphasis on physical symptom recognition and management rather than on the patient's perspective of the effects of HF on his or her daily living. Most of the evidence related to prevention or treatment of depression in HF patients is from low-quality observational studies (Lane, Chong, and Lip, 2005; O'Hea, Houseman, Bedek, and Sposato, 2009). Caregivers of HF patients are also reported to be at risk for depression (Chung, Pressler, Dunbar, Lennie, and Moser, 2010). Thus, research is needed to investigate how shared care and psychological context may influence outcomes for both care partners. In the SCDI study, depression and anxiety were assessed for both care partners, and appropriate referrals were made.

Although self-care in HF addresses a patient's experience, it does not incorporate the caregiver's experience. For this reason, the concept of preparedness has been introduced to describe a caregiver's perceived readiness to participate in care, as a result of home care nursing intervention (Archbold, Stewart, Greenlick, and Harvath, 1990). Schumacher, Stewart, and Archbold (2007) reported that in cancer caregivers, preparedness and relationship quality moderated the effects of caregiving on adverse caregiver outcomes.

In summary, the above evidence supports the importance of assessing both care partners' mood, and that Shared Care processes may improve self-care and outcomes for both care partners. The SCDI will screen and refer for depressive symptoms and anxiety, and target Shared Care processes. The proposed influence of the SCDI on care partner outcomes can be summarized as follows: By strengthening Shared Care processes, we expect better self-care in HF, caregiver preparedness, and relationship quality. We believe that self-care, preparedness, and relationship quality will influence the health status for both care partners. The SCDI addressed gaps in the literature in that it (a) ensured participants with co-occurring depression received adequate care and referral, (b) tested a dyadic intervention to improve Shared Care in a context of family management of HF, (c) assisted care partners to develop a plan of care to meet current and future needs, and (d) measured outcomes for both.

Purpose

The purpose of this study was to evaluate the feasibility of the SCDI and describe effect sizes and outcome patterns for the care partners. Our research questions were as follows:

1. Was the SCDI feasible to implement and acceptable to both care partners?
2. What were effect sizes and outcome patterns for (a) Shared Care, (b) self-care in HF, (c) preparedness, (d) dyadic relationship quality, and (e) health status?

Method

A one-group quasi-experimental design was used to answer the research questions. Purposive sampling was used to enroll care partners. Eleven care partner dyads with a patient diagnosis of HF were recruited from a Midwestern home health care agency. A sample of 10 dyads was considered adequate to meet the purpose of a feasibility study and estimate effect sizes. The study was conducted between June 2007 and June 2008. Family dyads participated for 12 weeks. The study was conducted in participants' homes. University and the health care organizations' institutional review boards approved the study.

Sample, Setting, and Procedures

Candidates for this study were HF care partners who were older than age 21 years. The family caregivers resided with or near the patient. To help ensure care partners would be able to fully participate in the intervention, candidates were excluded if any of the following were present: (a) terminal state, (b) significant sensory, cognitive, or motor disabilities, (c) inability to read, write, or speak English, or (d) requirement of in-home continuous professional care.

The home care agency assisted the research staff to attain access to care partners. If care partners were eligible and interested in the study, home care staff notified the research staff, who then arranged a home visit to obtain informed consent and collect baseline data. Our original plan for data collection included face-to-face or over-the-phone interactions. Most of the data collection was done face-to-face rather than over the phone, because this approach was preferred by the participants. The intervention was delivered by PhD and master's-prepared nurses with clinical background in the management of HF.

Measures

Descriptive data collected at baseline for both care partners included role, family function, HF knowledge, years of education, and satisfaction with income. For the patient, cognitive status was assessed with the Mini Mental State Exam (Borson, Scanlan, Watanabe, Tu, and Lessig, 2005). HF knowledge was measured at baseline with the Dutch HF Knowledge Scale (Jaarsma et al., 1999). To better describe care partners' broader context of support, the Feetham Family Function scale (FFFS) was used to measure interpersonal, family, and community support at baseline. An indirect discrepancy score (difference between the desired level of support and the actual level) was calculated for the FFFS, which is considered an important measure of family function (Sawin and Harrigan, 1994). Reliability and validity of process and outcome measures are summarized in Table 1.

Process measures. Unintended effects of the intervention were monitored, and included anxiety, depressive symptoms, emergent care, and mortality. Anxiety and depressive symptoms were assessed at baseline, during Week 4, and at the end of the intervention, and appropriate referrals were made based on the scores. Anxiety and depressive symptoms were measured with the State-Trait Anxiety Scale (STAI; McDowell, 2006) and Patient Health Questionnaire-9 (PHQ-9), respectively (Kroenke, Spitzer, and Williams, 2001). Emergent care utilization was measured at the start of each session with the Outcome Assessment Information Set emergent care items (Centers for Medicare and Medicaid Services, 2007). Specifically, we assessed whether the patient was rehospitalized, or if the patient made any emergency visits to the hospital, doctor's office, or outpatient facility during the course of the intervention. We also assessed reasons for emergent care and mortality.

To assess if the intervention was received as intended, we used the Shared Care Instrument–3 (SCI-3), Values and Preferences Scale, and Session Satisfaction Scale. The SCI-3 has three subscales that measured communication, decision making, and reciprocity (Sebern, 2008). Shared Care Communication is a five-item scale that measures communication within the dyad. Shared Care Decision Making is a six-item scale that measures level of patient involvement in decisions about his or her care. Shared Care Reciprocity is an eight-item scale that measures partnership within the dyad. It was expected that Shared Care would increase as a result of the intervention. Values and Preferences Scale (Whitlatch, Piiparinen, and Feinberg, 2009) assessed the patient’s ranking of importance of four areas of care values related to well-being. It was expected that understanding care values would contribute to better communication and decision making. The Session Satisfaction Survey was used at the end of each session to assess satisfaction as well as perceived benefits and limitations, which allowed us to see where the intervention was most and least helpful.

Outcome measures. Outcomes included (a) self-care in HF (patient), (b) preparedness (caregiver), (c) relationship quality/strain (both), and (d) health status (both). Self-care was measured with the three subscales of the Self-Care of Heart Failure Index (SCHFI; maintenance, management, and self-confidence; Riegel et al., 2004). The preparedness subscale from the Home Care Effectiveness Scale was used to measure caregiver preparedness (Archbold, 2004). Both care partners’ appraisals of their relationship quality were measured with the Dyadic Relationship Scale (DRS). Care partners independently reported the extent to which they experienced strain (e.g., anger towards the other) and quality aspects (e.g., learned good things about myself) in the past month (Sebern and Whitlatch, 2007).

Patient health status was measured with the Kansas City Cardiomyopathy Questionnaire (KCCQ), which is a disease-specific health status measure that quantifies a person’s perspective of disease impact on daily life. The KCCQ has six subscales (physical limitations, symptoms, social limitations, self-efficacy, quality of life, and functional status), and two summary scales (clinical summary and overall summary scale). The clinical summary combines the total symptoms and physical function scales to replicate the New York Heart Association (NYHA) classification scale. The overall summary scale is the mean of physical function, total symptoms, social limitations, and quality of life.

Caregiver health status was measured with Rand SF-36. The SF-36 was developed as part of the Medical Outcomes Study (MOS; Ware and Sherbourne, 1992). The SF-36 has eight subscales (physical function, general health, role limitations due to physical and emotional health, emotional well-being, social functioning, fatigue, and pain). Higher scores on all the instruments indicated better health status, except for family function, relationship strain, anxiety, and depression, where higher scores indicated poorer health or family function.

Shared Care Dyadic Intervention (SCDI). The SCDI is a structured, one-on-one and dyadic intervention for care partners managing HF. Each care partner dyad participated in seven sessions, which were conducted in either a joint or mixed format. In joint sessions, the interventionist and care partners met together for the entire time. Mixed format sessions began and ended jointly, but also included time for separate meetings with the interventionist. Although the SCDI was a structured intervention, the interventionist could digress if unexpected needs arose (e.g., new symptoms).

Each session ranged in length from 60 to 120 min and was structured in a similar way, starting with both members of the dyad together in order to review session goals and questions/concerns (opening phase). The session then moved to the middle phase, where care partners met jointly or separately with the interventionist to engage in session-specific material. Each session ended with the final phase, in which care partners came together to review material discussed in the session, address any remaining questions, preview the upcoming session, and develop personal goals to work toward prior to the next session. A summary of intervention sessions are in Table 2.

Evaluation Methods for Feasibility

We used the following strategies to answer Research Question 1: What is the feasibility of the SCDI? Components of feasibility are fidelity, unintended effects, and participant satisfaction. Fidelity reflects the degree to which the operationalized treatment protocol was delivered, and treatment receipt and enactment by participants. High fidelity is an essential element in determining that the intervention can be reproduced and replicated in other settings (Burgio et al., 2001).

To ensure treatment delivery, the SCDI manual was developed, reviewed, and followed in each session. Electronic records were used to document session attendance, completion of tasks within each session, and total amount of time for each session. The manual and checklists monitored congruence between the plan for providing the SCDI and the way it was actually delivered. Care partners were also given copies of all worksheets and educational materials used with the SCDI. The unintended effects, anxiety and depressive symptoms, were monitored at baseline, during Week 4, and at the end of the intervention. Emergent care episodes and mortality were assessed at the start of each session.

Three measures were used to assess treatment receipt and enactment by participants. First, the Shared Care Instrument–3 (SCI-3) was used to measure the three relationship processes the intervention was designed to influence: communication, decision making, and reciprocity (Sebern, 2008). The second measure, Values and Preferences Scale (Whitlatch et al., 2009), assessed the patient's ranking of importance of four areas of care values related to well-being. This ranking was done at Session 3. After ranking each area, patients responded as to how much they perceived that their caregiver understood their values and preferences. This scale was also given to caregivers at Session 3; however, they were asked to rank the areas in terms of what they believed the patient's perceptions were (not their own). The Values and Preferences Scale was used to assess, discuss, and integrate care values and preferences into the care plan process. The third measure used was a session satisfaction survey. This survey was used at the end of each session to assess satisfaction as well as perceived benefits and limitations.

Evaluation Methods for Effect Sizes and Outcome Patterns

Statistical analysis was performed using SPSS 17.0 software. Data cleaning and analysis of missing data was conducted prior to statistical analysis. Most of missing data was due to patients who had difficulty answering questions over the telephone. Descriptive statistics were used for demographic data. Statistically significant results were not expected because of the small sample size and lack of a control group. However, we examined the data for effect sizes, clinically meaningful change, and direction of that change (e.g., improved, declined, no change). A nonparametric Wilcoxon test for two related samples was used to describe means and standard deviations at baseline and the end of the intervention and direction of change. Effect sizes were calculated using Cohen's d , which measures the standardized difference between the means of two variables. Effect sizes of .20, .50, and .80 correspond to small, medium, and large effects, respectively (Gravetter and Wallnau, 2008). Positive d values indicate that the SCDI was associated with greater improvement on a particular outcome from baseline.

Clinically meaningful scores were based on the literature. For the SCHFI, a change of 8 points is considered clinically meaningful (Riegel, Lee, et al., 2009). For the KCCQ, a change of 5 points is clinically meaningful (Flynn et al., 2009). Archbold (2004) reported that a clinically meaningful preparedness score was between 2 and 4, suggesting that working with the intervention nurse improved a caregiver's readiness to participate in care between some and a great deal. For the PHQ-9, a score of 10 or greater is considered the cutoff for referral to a mental health professional to rule out major depression (Kroenke et al., 2001).

Results

Eleven pairs of HF care partners consented, and two withdrew. One patient who withdrew had a depression screening above the cutoff score and was referred to her primary care provider. The other withdrew because of hospitalization. The caregiver of the depressed patient requested to continue participation in the study when the patient withdrew. We agreed to this request, yielding a total of 9 care partner dyads and 1 caregiver (19 participants).

The frequencies of descriptive information for care partners are summarized in Table 3. The patients were on average 80 years old (*SD* 9.5), five were female, and six were African American. More than half of the patients reported comorbidities (hypertension, diabetes, arthritis, or stroke). Only a few reported urinary tract infections or cancer. Six of the patients had at least a high-school education and self-reported a comfortable income. The average patient HF knowledge score was 69%, average MMSE score was 25.6 (*SD* 5), and family functioning discrepancy score was 22 (*SD* 13). Three patients were rated as NYHA Class 1 or 2, and seven patients were Class 3 or 4. Patients took a median of 15 medications. The average duration of the relationship between the care partners was 44 years (*SD* 18). When asked if they thought of themselves as a caregiver, care receiver, both, or neither, nine patients stated they were either a caregiver or both caregiver and care recipient.

Caregivers were on average 61 years old (*SD* 19), 10 were female, and 6 were African American. Eight caregivers had at least a high-school education and reported a comfortable income. Their average HF knowledge score was 81%. Their mean FFS discrepancy score was 14.5 (*SD* 14), suggesting that caregivers were more satisfied with family functioning than were patients. Seven caregivers reported a chronic illness, with the most frequent being hypertension, followed by arthritis and diabetes. A few reported urinary tract infections and 1 had sickle cell anemia. When asked if they thought of themselves as a caregiver or care receiver, only 2 caregivers perceived their role as both a caregiver and receiver. Compared to the patients, caregivers had more HF knowledge and satisfaction with family support, but fewer caregivers perceived their role as care receiver.

The SCDI was successfully implemented. Documentation of the SCDI delivery, receipt, enactment, and satisfaction supported the SCDI's feasibility. Most care partners participated in all sessions. Two caregivers missed a total of three sessions, because of hospitalization (for exacerbation of sickle cell anemia) and other appointments. On average, it took 10 weeks from enrollment to complete seven sessions. The average time for each session was 1.6 hr. We allowed 1- or 2-week intervals between sessions to meet the needs of participants.

A measure of feasibility is intervention satisfaction. Care partners' average satisfaction with each session was 6.3 (with 1 being the lowest and 7 being the highest). Open-ended questions on the satisfaction survey asked participants to list any benefits and/or limitations, which allowed us to evaluate where the intervention was least and most beneficial. Patient reported benefits included clarifying values and preferences, realizing they are cared for, learning where to seek help, learning how to manage the physical and emotional components of HF, and engaging in session discussions. Patients reported a few limitations including: repetition of content, confusion regarding medications, and difficulty remembering everything.

Caregiver benefits included learning how to improve their own health, communicate with the doctor, manage their anxiety and patient's depressive symptoms, and the worksheets. Caregivers also stated that they benefited by learning how the patient thinks. For example, one caregiver stated it was helpful to understand how important it was for the patient to feel useful. Limitations reported were repetition of content, excessive length of some sessions, and unclear goals. Overall, these ratings and comments indicated that sessions were highly acceptable to both care partners. The comments about limitations informed our revision of the SCDI.

We analyzed patterns in the Shared Care variables to assess treatment receipt and enactment. Care partner's Shared Care variable means, standard deviations, number of improved cases, and effect sizes are reported in Table 4. Four patients had improved communication scores, five patients had improved decision-making scores, and three patients had improved reciprocity scores. The effect size for communication was small, with no effect on decision making. The moderate but negative effect size for reciprocity was contrary to our expectations.

The data also supported positive change in caregiver Shared Care variables. Seven caregivers had improved communication, and decision making and reciprocity both improved in four caregivers. There were small effect sizes for communication, decision making, and reciprocity (see Table 4). The small but negative effect size for reciprocity was contrary to our expectations.

Adverse events monitored during the intervention were anxiety, depressive symptoms, emergent care (patient), and mortality. Anxiety and depressive symptoms scores were within normal ranges at baseline and Week 8. One patient was referred for depressive symptoms at Week 4. Patients tended to have fewer depressive symptoms at baseline ($M = 6$) than at Week 8 ($M = 7.8$). Four patients had reported more depressive symptoms at Week 8 ($d = 0.61$). There was minimal change between baseline anxiety and Week 8 anxiety ($d = 0.15$). Anxiety scores reflect a low level of anxiety (ranging from *not at all* to *somewhat* anxious). Compared with patients, caregivers had few depressive symptoms at baseline ($M = 2.1$) and Week 8 ($M = 2.2$). Caregiver anxiety was low throughout the intervention (baseline $M = 1.3$ and Week 8 $M = 1.4$; see Table 5).

Nine episodes of emergent care were reported by five patients. Patients reported they used the hospital emergency room ($n = 4$), had non-routine doctor's office visits ($n = 3$), or outpatient emergency visits ($n = 2$). Reasons provided for emergent care episodes were cardiac problems ($n = 2$), respiratory and shortness of breath ($n = 2$), bleeding ($n = 2$), and diabetes control ($n = 1$). Two patients were hospitalized, one for a renal tumor and the other for internal bleeding. One caregiver was hospitalized for an exacerbation of sickle cell anemia. Emergent care and hospitalizations were not caused by the SCDI. No care partners died during the study period.

Patterns in Patient Outcomes

The patient outcome variable means, standard deviations, number of improved cases, and effect sizes are reported in Table 6. Positive patterns were observed on SCHFI subscales. For example, six patients had improved self-maintenance ($d = 0.39$), three patients had improved self-management ($d = 0.48$), and four had improved confidence ($d = -.01$). Based on scoring directions, self-management was calculated for patients who reported they had symptoms (e.g., dyspnea) in past month, and only four patients reported symptoms. Changes in self-maintenance and management were moderate, with a clinically meaningful change in self-care management (7.9 points), indicating that patients experiencing symptoms improved in the management of their symptoms. Contrary to what was expected, only two patients reported improved relationship quality ($d = -0.25$) and less negative relationship attributes ($d = -0.15$).

There was a clinically meaningful decline in KCCQ clinical status (6.4 points), and four patients had a lower clinical status at the end of the intervention ($d = -0.26$). There was a positive pattern for KCCQ quality of life subscale, with five patients reporting increase in quality of life ($d = 0.19$), which approached a clinically meaningful change (4.9 points). These effect sizes suggest a progression of the disease with small improvements in quality of life.

Patterns in Caregiver Outcomes

Caregiver outcome variable means, standard deviations, number of improved cases, and effect sizes are reported in Table 7. The preparedness score was clinically meaningful ($M = 2.9$, $SD = 0.72$), reflecting perceptions that the SCDI improved caregiver readiness to participate in care between some and a great deal. Six caregivers reported improved relationship quality ($d = 1.25$). Seven reported decrease in negative relationship attributes ($d = -0.99$). Data supported improved status for SF-36 subscales: (a) emotional well-being improved for five caregivers ($d = 0.51$), (b) nine had improvement in fatigue ($d = 0.52$), and (c) eight had improvement for pain ($d = 0.90$). The data supported differential benefits from the SCDI for the caregivers compared to the patients.

Discussion

The purpose of this study was to evaluate the feasibility of the SCDI and examine effect sizes and outcome patterns for both care partners. The SCDI was acceptable to both Caucasian and African American care partners in their home setting as evidenced by session participation, satisfaction, qualitative comments, and minimal unintended effects. Both care partners reported that they benefited from learning about their condition, mutual discussion of care values and preferences, and the care planning sessions.

Data supported the importance of Shared Care for both partners. For the caregiver, the SCDI had more of an effect on communication and decision making. For the patient, the SCDI had more of an effect on decision making. Other researchers have reported similar results from dyadic interventions, such as improved communication and a better understanding of each other's experience (Duhamel et al., 2007; Dunbar et al., 2005; Whitlatch et al., 2006).

For the patient, self-care maintenance and management and disease-specific quality of life were the most sensitive outcomes to the SCDI. There was a clinically meaningful improvement in self-management. Small effect sizes were observed for self-maintenance, management, and disease-specific quality of life. Other work supports these findings. For example, Shared Care processes were associated with better self-care in HF (Sebern and Riegel, 2009). Bocchi et al. (2008) reported improved quality of life after an HF disease management and educational intervention. Both self-care and quality of life are often listed as nurse-sensitive outcomes (Duffy and Hoskins, 2003).

Compare with caregivers, patients reported less improvement in Shared Care reciprocity, relationship quality, and health status. Some background variables may have contributed to these patterns. For example, patients experienced more depressive symptoms, less satisfaction with family function, and six of the nine patients had advanced HF (Stages 3 and 4). In addition, most patients viewed that their role included giving and receiving care ($n = 9$). With a decline in health status, HF patients may require more assistance and be less able to reciprocate. To maintain or improve relationship quality, patients may need help finding meaning in their declining health and different ways to reciprocate within the limitation of their functional ability (e.g., express appreciation for assistance, talk about common past experiences, participate together in pleasant activities). Other researchers have reported negative aspects of being a care receiver and the importance of reciprocity for psychological well-being (Liang, Krause, and Bennett, 2001; Newsom, 1999). Thus, interventions that assist the patient in finding meaning in declining health and ways to reciprocate when receiving assistance may be important to their outcomes.

Caregiver outcome patterns supported improved relationship quality, preparedness, and health status. Caregiver effect sizes were strongest for relationship quality, emotional health, pain, and fatigue. Other studies have supported the benefits of dyadic interventions for caregivers' well-being (Martire et

al., 2004; Newsom, 1999). These different outcome patterns reinforce the importance of measuring outcomes for both care partners.

There are several limitations to this study. Because of lack of statistical power, causality cannot be inferred. Second, we described patterns for both care partner outcomes; these patterns must be interpreted with caution and cannot be generalized. Based on the findings from this study, we revised the SCDI to increase content on reciprocity skills, pleasant activities, clarified the goals for each session, and reduced repetitive content. Because of the persistence of patients' subclinical depressive symptoms, we plan to add a mental health consultant on our research team. This consultant will collaborate with the research team to ensure appropriate care is received for participants' anxiety and depression symptoms.

This study did support the feasibility of delivering a dyadic intervention in a home setting. Replicating this study in a larger, fully powered sample will help clarify the mechanism through which Shared Care facilitates self-care and improves outcomes for both care partners. We plan to submit a National Institute for Nursing Research grant proposal to test the revised SCDI with a fully powered sample of home health care HF patients and their family caregivers.

Declaration of Conflicting Interests

The authors declared no conflicts of interests with respect to the authorship and/or publication of this article.

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Figures and Tables

Figure 1: Shared care conceptual model

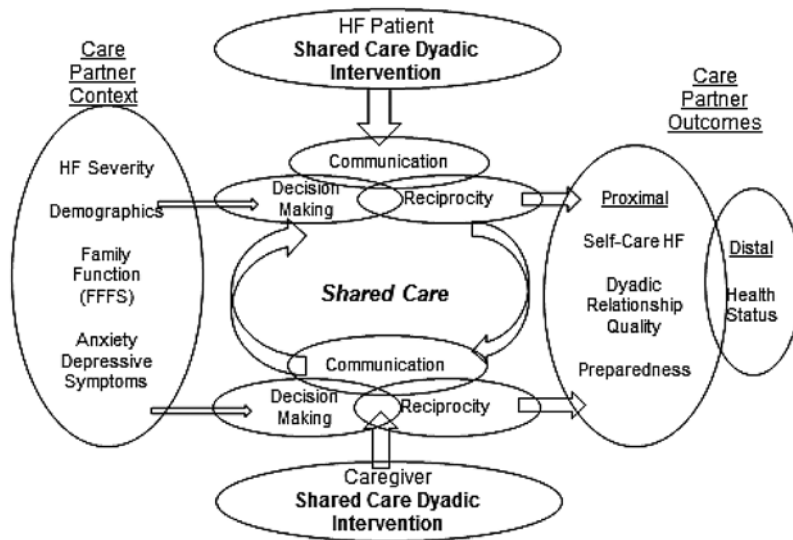


Table 1:**Table 1.** Process and Outcome Measures

Variable (Items)	Measure and Internal Consistency	Validity (Factor Loadings)
Shared Care (19)	Communication (PT, 0.85; CG, 0.90)	0.58-0.86
	Decision making (PT, 0.83; CG, 0.83)	0.42-0.78
	Reciprocity (PT, 0.68; CG, 0.79)	0.38-0.74
State Anxiety (20)	STAI (0.88)	Factor analysis
PHQ-9 (10)	PHQ-9 (0.89)	Cutoff score ≥ 10
Self-Care HF (22)	Self-management (0.70)	0.29-0.62
	Self-maintenance (0.55)	
Home care effectiveness (CG 9)	Self-confidence (0.82)	0.49-0.79
	Preparedness to give care (0.92)	0.56-0.85 ^a
Dyadic Relationship (PT, 10; CG, 11)	DRS Strain (PT, 0.84; CG, 0.89)	0.58-0.84
	DRS Quality (PT, 0.86; CG, 0.85)	0.49-0.88
CG health status (36)	MOS SF-36 physical health (0.93)	Population M (SD)
	Physical function (10 items) 0.93	70.6 (27)
	Role function physical (4 items) 0.84	52.9 (40)
	Role function emotional (3 items) 0.83	65.7 (40)
	Energy fatigue (4 items) 0.93	52.1 (22)
	Emotional well-being (5 items) 0.90	70 (21.9)
	Social function (2 items) 0.85	78.7 (25.4)
	Pain (2 items) 0.78	70.7 (25.4)
	General health (5 items) 0.78	56.9 (21.1)
PT health status (23)	Perceived change in health (1 item)	
	MOS SF-36 mental health (0.84)	
	KCCQ Clinical summary (0.93)	Construct and concurrent validity
	KCCQ Overall summary (0.95)	

Note: PT = patient; CG = caregiver; STAI = State-Trait Anxiety Scale; PHQ-9 = Patient Health Questionnaire-9; DRS = Dyadic Relationship Scale; MOS SF = Medical Outcomes Study-Short Form; KCCQ = Kansas City Cardiomyopathy Questionnaire.

^aInteritem correlations.

Table 2. Overview of Sessions

Session No. Title (Format)	Week No. (Time)	Description
Pre-session Assessment (Individual)	Week 0 (120 min)	Prior to the start of the sessions, the interviewer will obtain informed consent and conduct a standardized pre-session assessment to gather data about the dyad and the care situation. Both care partners are screened for depressive symptoms and anxiety.
Session 1 Understanding Self-Care in HF (Joint)	Week 1 (120 min)	<p>SCDI interventionist creates an environment that is comfortable, safe, and friendly. Care partners meet jointly to address questions they have about self-care in HF, medications, symptom, and results of depression screening discussed with appropriate referral. Decision-making skills introduced in the context of managing HF.</p> <p>The following topics are included:</p> <ol style="list-style-type: none"> Heart action plan Eating healthy with HF Living with HF Staying active Understanding food labels Spice it up without salt Low cholesterol, saturated fats, sodium What the medications mean How to take correct weight <p>Communication and reciprocity skills are introduced and will be practiced in subsequent sessions. (1) Keep it short and simple (KISS). (2) Listen. (3) Paraphrase. (4) Compromise. (5) Express appreciation to people who assist you.</p> <p>Develop personal goal to work toward prior to the next session.</p> <p>Tools: HF self-care worksheets</p>

Table 2. (continued)

Session No. Title (Format)	Week No. (Time)	Description
Session 2 Taking Care of Yourself— Taking Care of Each Other and Barriers to Receiving Help (Mixed)	Week 2 (90 min)	Assess emergent care episodes, other difficulties, and progress made on goal identified in the previous session. Building on Sessions 1, care partners are introduced to the concept of taking care of oneself as a way of managing the stresses of a chronic illness. Care partners learn the concept of pleasant activities and discuss strategies for building activities into their daily routines as a way of promoting health and well-being. Reciprocity skills introduced in context of pleasant activities they do together. Barriers to pleasant activities are discussed. Develop personal goal to work toward prior to the next session. Tools: Barriers to Pleasant Activities and Solutions Worksheet
Session 3 Care Values and Preferences (Mixed)	Week 3 (90 min)	Assess emergent care episodes, other difficulties, and progress made on goal identified in the previous session. SCDI interventionist and care partners meet together and separately to explore their care values and preferences for care tasks. Communication, decision-making, and reciprocity skills presented in the context of care values and preferences. Discussions provide the foundation for future sessions in working out a care plan. Develop personal goal to work toward prior to the next session. Tools: Care Values, Preferences for Care Tasks Assessments, Circles Diagrams, Magnet Boards
Session 4 Care Preferences (Mixed)	Week 4 (75 min)	Assess emergent care episodes, other difficulties, and progress made on goal identified in the previous session. Based on identification of care values in Session 3, care partners and interventionists engage in a care planning exercise that involves looking at the possible tasks that they may need help with in the future and the preference for who would provide that help.

Table 2. (continued)

Session No. Title (Format)	Week No. (Time)	Description
Session 5 Family and Friends (Together)	Week 5 (90 min)	<p>The Circles worksheet is used to represent assistance from caregiver, family, and paid help. Once the initial plan is constructed, interventionist leads the dyad through steps in identifying ways of decreasing the load on the caregiver and encourages seeking help from other sources that would be acceptable to both. Care partners discuss issues of communication, decision-making, and reciprocity skills in the context of care planning. Develop personal goal to work toward prior to the next session.</p> <p>Tools: Preferences for Care Tasks, Circles Worksheet, Magnet Boards</p> <p>Assess emergent care episodes, other difficulties, and progress made on goal identified in the previous session.</p> <p>Building on previous sessions, particularly the care plan exercise and pleasant activities strategy, the dyad explores the help and assistance that might be available from family in the future. Discuss supplementing the help provided by the caregiver and other family members with formal, paid help (communication and decision-making skills). The dyad will identify strategies for finding services and anticipate barriers. Care partners discuss issues of communication, decision making, and reciprocity. For example, they explore effective ways to communicate with family and health professionals about care-related concerns and changes associated with HF.</p> <p>Develop personal goal to work toward prior to the next session.</p> <p>Tools: Helper's Worksheet.</p>
Session 6 Community Resources (Mixed)	Week 6 (120 min)	<p>Assess emergent care episodes, other difficulties, and progress made on goal identified in the previous session.</p> <p>This session continues the discussion of implementation of the care plan, by supplementing the help provided by family members with formal, paid assistance. The care partners will identify strategies for finding services and anticipate barriers. Care</p>

Table 2. (continued)

Session No. Title (Format)	Week No. (Time)	Description
Session 7 Looking to the Future (Together)	Week 7 (120 min)	<p>partners discuss issues of communication, decision making, and reciprocity, and when it might be appropriate to seek the help from formal support. Complete the Helper's Worksheet.</p> <p>Develop personal goal to work toward prior to the next session.</p> <p>Assess emergent care episodes, other difficulties, and progress made on goal identified in the previous session.</p> <p>Review communication, decision making, and reciprocity skills covered from previous sessions and the plans participants have for the future. Care partners review and follow up on the issues that arose in previous sessions, and end with a discussion of how far they have come since Session 1.</p>
Postsession assessment T2 (Individual)	Week 12 (3 months 120 min)	<p>An interviewer conducts the final standardized postsession assessment to gather data about the dyad and the care situation 3 months after the initial SCDI session.</p>

Note: SCDI = Shared Care Dyadic Intervention.

Table 3. Care Partners' Background and Context

	Patient (n)	Caregiver (n)
Gender: Female	5	10
Race		
White	5	5
Black	6	6
Education: Completed high school	6	8
Financial status		
I am comfortable with my income	6	7
I have just enough to make ends meet	2	3
I don't have enough to make ends meet	3	1
Relation to the other		
Spouse or partner	3	4
Son, nephew, daughter, friend, grandchild	3	7
Parent, aunt, or grandparent	3	0
Role: Caregiver or receiver		
Primary caregiver	1	7
Both caregiver and receiver	9	2
Neither	1	2
Chronic illnesses		
HF	10	0
Hypertension	9	6
Stroke	5	0
Diabetes	9	3
Arthritis	7	4
Urinary tract infections	1	2
Sickle cell anemia	0	1
Cancer	2	0
HF classification		
HF class 1-2	3	—
HF class 3-4	6	—
Number of medications (<i>Mdn</i>)	15	

Note: HF = heart failure.

Table 4. Patterns of Care Partner's Shared Care

	<i>n</i>	Baseline <i>M</i> (<i>SD</i>)	Intervention End <i>M</i> (<i>SD</i>)	Care Partner Increase From Baseline	Effect Size
Communication					
Patient	7	3.8 (1.20)	3.9 (0.84)	4	0.10
Caregiver	10	4.3 (1.10)	4.7 (0.67)	7	0.44
Decision making					
Patient	7	5.0 (0.54)	5.0 (0.60)	5	0.00
Caregiver	10	4.6 (1.20)	4.9 (0.93)	4	0.28
Reciprocity					
Patient	7	5.0 (0.58)	4.5 (0.82)	3	-0.70
Caregiver	10	5.4 (0.51)	5.3 (0.75)	4	-0.16

Table 5. Care Partner's Anxiety and Depressive Symptoms

	Baseline M (SD)	Intervention End M (SD)	Care Partner Decrease From Baseline	Effect Size
STAI (anxiety)				
Patient	1.6 (0.67)	1.7 (0.70)	3	0.15
Caregiver	1.3 (0.34)	1.4 (0.35)	2	0.29
PHQ-9 (depression) ^a				
Patient	6.0 (4.1)	7.8 (6.3)	3	0.61
Caregiver	2.1 (2.8)	2.2 (2.7)	4	0.04

Note: STAI = State-Trait Anxiety Scale; PHQ-9 = Patient Health Questionnaire-9.

^aPHQ-9 > 10 cutoff for referral.

Table 6. Patient Outcomes

	Baseline M (SD)	Intervention End M (SD)	Patient Improved From Baseline	Effect Size
Self-maintenance (<i>n</i> = 9)	55.5 (16.4)	61.3 (12.8)	6	0.39
Self-management (<i>n</i> = 4)	62.2 (20.5)	70.1 (10.7)	3	0.48
Self-confidence (<i>n</i> = 9)	65.7 (12.6)	65.6 (9.2)	4	-0.01
DRS positive (<i>n</i> = 6)	3.0 (0.50)	2.9 (0.30)	2	-0.25
DRS negative (<i>n</i> = 6)	2.0 (0.63)	1.9 (0.72)	2	-0.15
KCCQ (<i>n</i> = 9) summary score	60.9 (23.5)	59.5 (17.2)	5	-0.07
KCCQ clinical score	62.7 (27.2)	56.3 (22.2)	3	-0.26
KCCQ quality of life	62.9 (28.5)	67.5 (21.0)	5	0.19
KCCQ self-efficacy	75.0 (19.7)	76.3 (19.2)	4	0.11

Note: Direction of change = Wilcoxon rank sum; Clinically meaningful = SCHFI 8-point change from baseline; KCCQ 5 point change from baseline; DRS = Dyadic Relationship Scale; KCCQ = Kansas City Cardiomyopathy Questionnaire; SCHFI = Self-Care of Heart Failure Index.

Table 7. Caregiver Outcomes

	Baseline <i>M</i> (<i>SD</i>)	Intervention End <i>M</i> (<i>SD</i>)	Caregiver Improved From Baseline	Effect Size
Preparedness (<i>n</i> = 10)	NA	2.9 (0.72)	NA	NA
DRS positive	2.7 (0.44)	3.3 (0.52)	6	1.25
DRS negative	2.1 (0.55)	1.6 (0.46)	7	0.99
SF-36 general health	55.4 (17.8)	52.4 (19.7)	1	-0.16
SF-36 physical function	77.5 (28.3)	78.0 (24.7)	2	0.02
SF-36 emotional	84.4 (13.9)	90.4 (9.2)	5	0.51
SF-36 fatigue	57.5 (25.0)	70.5 (25.2)	9	0.52
SF-36 pain	66.5 (20.2)	84.0 (18.7)	8	0.90

Note: Direction of change Wilcoxon Rank Sum. DRS = Dyadic Relationship Scale; SF-36 = (Medical Outcomes Study) Short Form-36.