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Complex Effects of Caregiver-Patient Relationships on Patient Self-Care in Heart Failure

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## **Introduction**

### **Background and significance**

According to the American Heart Association (Benjamin et al., 2017), an estimated 6.5 million American adults have heart failure (HF). By 2030, the prevalence of heart failure is expected to increase by 46% (Benjamin et al., 2017). Heart failure is a costly disease, in terms of human suffering and mortality as well as resources. According to the U.S. Centers for Disease Control and Prevention, about half of the people with HF die within five years of the diagnosis (Centers for Disease Control and Prevention [CDC], 2016). The cost in monetary terms is estimated at \$30.7 billion, including health care, medications and lost work time (CDC, 2016).

A major component of treating HF is nonpharmacological management and patient self-care, including dietary sodium and fluid restrictions, avoidance of tobacco use or alcohol consumption, and monitored exercise for 30 minutes five times weekly (Heart Failure Society of America, 2010). However, despite clear evidence that improved self-care leads to better quality of life and fewer hospitalizations (Lee, Moser, Lennie & Riegel, 2011), for many patients self-care like medication adherence, physical activity and low-salt diet is still suboptimal (Davidson, Inglis & Newton, 2013). Much research is being done to determine why patients do or do not adhere to self-care recommendations. These reasons are complex, as each patient's physical, social and psychological environment is unique.

In the case of chronic and progressive debilitating illness such as HF, early and effective adoption of self-care behaviors can mitigate exacerbation of symptoms like shortness of breath, fatigue and edema (Lee et al., 2011). Self-care becomes more difficult once HF symptoms have progressed to the point of creating disability, as functional and cognitive deficits make self-care more difficult or impossible without help (Riegel, Moser et al., 2017).

As the population ages and more individuals survive myocardial infarction, we have seen an increase in the number of patients surviving five years or longer with heart failure (Gerber et al., 2016). It is critical to better understand how the relationships between patients with HF and their primary caregiver can affect patient adherence to self-care. Greater understanding of this dynamic could provide insight to clinicians and public health educators endeavoring to increase active self-care, and thus improve outcomes among patients with heart failure.

Earlier literature reviews have covered factors in HF patients' self-care, but these have been broad in scope, and do not offer much detail on the interplay between caregiver and patient. One previous literature review focused on all types of social support for HF patients, including that of close family (Graven & Grant, 2013). A systematic review focusing specifically on caregiver contributions to HF self-care found 40 relevant papers from 1994 to 2012, a fact which highlights the emerging nature of this subject (Buck et al., 2015). Nonetheless, the authors pointed out the need for more research in this area. In the five years since Buck's review was completed in 2012, more studies have been published on the subject that may improve the understanding of the patient/caregiver self-care dynamic. A review of the most recent research on how informal caregivers of patients with HF affect their self-care is needed to update the knowledge base and provide more comprehensive information for healthcare providers and nurses working with these patients and families.

### **Purpose**

The purpose of this integrative literature review is to summarize and evaluate the most recent research focused on the dynamic between patients with heart failure and their caregivers (partner, spouse, family member, friend), and how that dynamic affects participation in self-care behavior. The findings also identify areas in which more research is needed, with the goal of

providing more information to nurses and clinicians as they endeavor to optimize education and outreach to improve self-care adherence in their patients with heart failure.

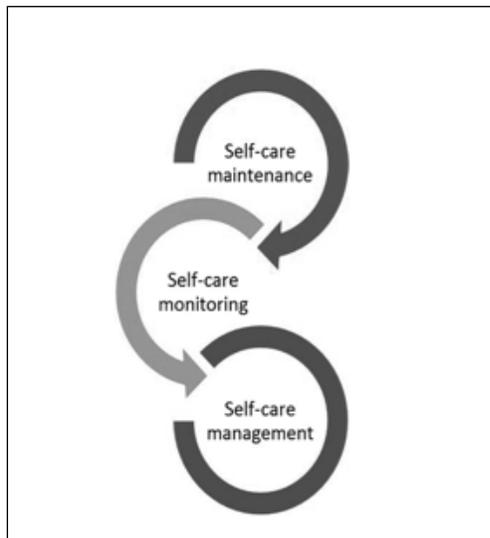
### Research questions

In order to better understand the patient-caregiver dynamic in self-care, this review is guided by the following questions: What are the effects of an informal caregiver (or partner) on the self-care maintenance, management and/or confidence in patients with heart failure? What interventions are shown to maximize the positive effect of caregivers on patient self-care?

### Conceptual framework

This review is framed by the model of self-care in heart failure and its elaboration into the middle-range theory of self-care of chronic illness (Riegel, Jaarsma & Stromberg, 2012).

This theory describes the process of an individual's self-care, and defines various self-care



**Figure 1.** Self-care of chronic illness (Riegel, Jaarsma & Stromberg 2012)

behaviors as part of maintenance, monitoring, or management of one's illness. The theory elucidates eight factors that affect patient participation in self-care, which are experience and skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, support from others, and access to care. Some of these factors more relevant than others in the discussion of caregiver-patient dynamics.

As shown in Figure 1, three categories of self-care behaviors are depicted separately, but each is shown building toward the next to comprise three levels in progression: maintenance, monitoring and management. As framed by this theory,

this literature review characterizes the effects of caregiver presence and interaction on HF patients' self-care behaviors in all three levels.

## **Methods**

### **Research Design**

An integrative literature review was conducted to synthesize findings within the last five years regarding the impact of family caregivers on HF patients' self-care behaviors. Torracco (2005) characterizes the integrative literature review as research that "reviews, critiques, and synthesizes representative literature on a topic... such that new frameworks and perspectives on the topic are generated" (p. 356). Both quantitative and qualitative research was examined to better understand the relationships between the HF patient, their primary caregiver and/or partner, and the patient's own attitudes and participation about HF self-care behaviors.

### **Literature Search Strategies**

A search of the literature was conducted using five databases: Cumulative Index to Nursing and Health Literature (CINAHL), HealthSource: Nursing and Academic Edition, ProQuest Nursing and Allied Health, PsycINFO, and PubMed. A Boolean search was used in each database with the following keywords and construction: Heart failure (key word in abstract or title) AND self-care OR self care AND caregiver OR care giver OR partner AND self-efficacy OR self efficacy OR confidence. Keywords with and without hyphens were included in order to identify articles using either variation. Titles and abstracts of all results were reviewed for appropriateness of content and quality of information.

Papers included in the review were limited to peer-reviewed articles in journals published on or after January 1, 2013. Articles must have been available in English. Chosen articles focused on the relationship between patients and caregivers relating to HF self-care.

Papers were excluded if they focused primarily on caregiver/partner issues such as caregiver burden, education or interventions aimed at caregivers only, bypassing the relationship to the patients themselves. Studies in which the sample patients had diseases other than HF were also excluded. Finally, literature reviews, systematic reviews and meta-analyses were excluded from use as data points, although some were consulted and used for reference.

The initial search of the five databases produced a total of 181 articles. The application of the inclusion criteria brought the number to 37, and after using exclusion criteria and elimination of duplicates, a total of 18 articles were selected for review and analysis. Two of these were eliminated after analysis, as they did not assess or analyze patient self-care behavior, only those of caregivers. The final total included in the review is 16 articles. (Appendix A)

### **Data Analysis**

The data extracted from the 16 articles was sorted into a matrix display (Appendix B) organized around variables such as research purpose, study design, sample characteristics, measurement techniques, interventions, and notable findings. Measurement techniques noted include which instruments were used, if any, All data was examined for themes and patterns that could be used to answer the research question. Data collected from the search was further divided into subgroups for analysis. These groups were based on type of study (cross-sectional or interventional), types of self-care behaviors measured or observed (maintenance, management and/or confidence), and results or conclusions of the authors. Utilizing the framework of the theory of self-care of chronic illness, an overall picture of the current state of knowledge regarding the effects of patient-caregiver relationships to patient self-care was synthesized.

## Results

In reviewing 16 articles published over the last five years, three overarching categories of caregiver impact on patient self-care were noted. These were organized by findings deemed relevant to answering the research questions: 1) effects of caregiver presence itself on patient self-care behavior, 2) effects of caregiver characteristics and relationship quality on the patient's self-care, and 3) effects of educational interventions aimed at caregiver/patient dyads on self-care and/or patient outcomes.

It should be noted that while a majority of studies in this review utilized the Self-Care in Heart Failure Index (SCHFI) to quantify self-care of patients and/or caregivers, not all of them did. The SCHFI is a validated 22-item questionnaire that measures patients' behaviors and feelings regarding their own care of their heart failure. The items are described as self-care maintenance: usual daily or weekly behaviors patients should engage in to stay symptom-free; self-care management: patient ability to recognize worsening symptoms and to take steps to remedy them; and self-care confidence (or self-efficacy): the patient's feelings about his or her ability to perform HF self-care and manage illness (Riegel, Lee, Dickson & Carlson, 2009). For the purposes of this literature review, patient behaviors identified in the index as self-care maintenance, such as medication adherence, physical activity, and eating a low-salt diet are recognized as patient self-care, whether measured by SCHFI or by other means.

### **Caregiver presence and patient self-care**

Four studies focused mainly on how the presence of a caregiver (or in some cases, described as a partner or close friend/family member who provides support) correlates with the behavior of a patient with heart failure (Gerhardt, Weidner, Grassman and Spaderna, 2013;

Holden, Schubert and Mickelson, 2014; Nguyen et al., 2017; Verma et al, 2017). Two of these were chiefly concerned with the self-care behavior of physical activity and exercise, and both found that the presence itself of a partner or caregiver-type person had positive association with patient physical activity, although causality was not established (Gerhardt et al., 2013, Verma et al., 2017).

Gerhardt et al.'s (2013) study of patients with heart failure in Germany and Austria found that "social support" had a limited positive effect on physical activity. In this study, "emotional support" was measured by asking questions such as "Is there someone available to you who shows you love and affection?" The authors elicited the finding of "social support for physical activity" by asking patients "do family members or friends give you helpful reminders to engage in physical activity?" They found that emotional and social support did not correlate with patients' amount of physical activity, except in cases where the patient also was reporting physical and/or emotional distress. A post hoc analysis by Verma et al. (2017) also found that patients with heart failure who also had a partner who lived with them had better adherence to exercise therapy compared to patients without a partner.

The presence of a caregiver or care partner sometimes seemed to have an overall positive effect, but perhaps at the expense of the patients' own confidence. A study by Nguyen et al. (2017) on barriers to technology use in older patients with heart failure did not focus specifically on caregivers, yet found during qualitative investigation that care partners often learned more about how to identify and manage the signs and symptoms of heart failure than the patients did. It was further noted that care partners were more likely to ask questions of health care providers, and that patients often relied on them to do so. These patient participants with caregivers also indicated a lack of confidence to make health care decisions on their own.

While having a family caregiver is generally considered of benefit to patients with heart failure, it is not universally true. Holden et al. (2014) used an ergonomic model to analyze barriers to patient self-care. Fourteen of the 30 patients in the study had caregivers who also participated. While these caregivers were typically helpful by assisting with medication management, transportation, and communication with providers, they also could be a source of self-care barriers. These were noted as “modeling unhealthy behavior” and “putting the patient in bad circumstances.” For example one spouse tempted his partner by bringing fried chicken into the house for dinner, while an adult son described sneaking salt into his mother’s food to make it taste better. Some caregivers, generally spouses rather than adult children, also had physical or cognitive limitations and themselves lacked self-care skills, especially involving dietary and fluid restrictions.

### **Characteristics of the caregiver and patient self-care maintenance**

Three studies demonstrated a caregiver effect associated with patient self-care maintenance. The emotional state of the caregiver could be linked to reduced self-care by the patient. One study found evidence that anxiety and depression in the caregiver are associated with poorer patient self-care maintenance (Buck, Mogle, Riegel, McMillan & Bakitas, 2015). In other words, the worse the emotional state of the caregiver, the less likely the patient was to adhere to daily self-care. This was particularly interesting given that the patient’s own anxiety and depression did not show a similar association with their own self care (Buck, Mogle, et al., 2015).

A similar relationship between caregivers’ mental/emotional state and patients’ physical self-care behaviors was also noted in a 2014 study in which better self-care maintenance in patients was associated with better mental quality of life in spousal caregivers (Vellone et al.). In

this case, using the Actor-Partner Interdependence Model it seemed that the partner effect was seen to originate from the patient and extend to the caregiver. As the authors put it, this finding “captures statistically the energy and emotions that caregivers put into their efforts to support self-care in their loved ones,” (Vellone et al., 2014).

Health literacy of the caregiver also demonstrated a correlation with patients’ self care. A 2014 study by Levin, Peterson, Dolansky and Boxer found when caregivers scored poorly on a health literacy task (answering questions about a food label), their patients had poorer scores for self-care maintenance on the SCHFI. With caregivers who demonstrated adequate ability on the label-reading task, the patients appeared more likely to carry out necessary HF self-care behavior (Levin et al., 2014). The association did not extend to patient self-care management or confidence.

### **Caregiver-patient relationship quality/congruency and patient self-care confidence**

The research found several examples of studies that attempted to tease out the complex interaction between the quality of the patient-caregiver relationship and self-care behaviors in the patient (and often the caregiver as well). There were varied measures of relationship quality—some were just simple questions, others attempted to outline personality types or dyadic types and find associations with self-care assessments. Results were mixed, indicating that there is not an easy way to categorize caregiver-patient relationships. Self-care confidence, as the most subjective of the SCHFI-measurable items, appears to have the most frequent association with relationship quality in HF patient-caregiver dyads.

Lyons et al. (2015) found that, like the studies mentioned above, the mental state of the caregiver correlated with patient self-care. In this instance, patients (and caregivers as well) reported lower self-care confidence when the caregiver experienced poor mental health.

However, Lyons et al. (2015) also found that a good patient-caregiver relationship had a positive association with self-care. The patient's perception of the quality of the relationship was significantly associated with both patients' and caregivers' levels of self-care confidence. Better relationships (as experienced by the patient) seem to lead to greater confidence in handling heart failure day-to-day care and issues.

Mutuality, described as the degree to which a relationship is characterized by affection, shared activities and values, and empathy, is another term used to evaluate a caregiver-patient relationship (Hooker, Schmiede, Trivedi, Amoyal & Bekelman, 2017). Hooker et al. (2017) hypothesized that greater mutuality would be associated with greater self-care confidence and greater self-care maintenance. This hypothesis was confirmed in that greater feeling of mutuality did correspond to greater self-care confidence. However, the study found no significant partner effects; patient and caregiver perceptions of mutuality did not relate to the other's confidence, only to one's own confidence (Hooker et al., 2017). Even so, patients who feel as though they have a good quality relationship do not likely come to that conclusion without reason, so the effect of a good relationship with a caregiver may still be a valid caregiver-based influence on patient self-care and well being.

Some studies attempted to categorize patient-caregiver dyads to identify relationship patterns that might affect heart failure self-care. Lee et al. (2014) analyzed 509 Italian patient-caregiver pairs, and identified three "archetypes" in how each pair handled HF care of the patient. These types exhibited a gradient of contributions to self-care. The type with the least amount of self-care was labeled "novice and complementary," as patients and caregivers provided different aspects of HF self-care, with patients doing more maintenance behaviors and

caregivers doing more management behaviors. These dyads were primarily composed of older adults with less severe heart failure symptoms and their adult children.

The second and most common archetype was labeled “inconsistent and compensatory.” This type of dyad had better levels of self-care maintenance, but a greater disparity in contributions to symptom management and confidence between patient and caregiver. The type is characterized by more frequent hospitalizations as caregivers attempt to compensate for patients’ failure to recognize early symptoms of exacerbation. The type is associated with the highest level of caregiver strain (Lee et al., 2014).

The greatest engagement in all aspects of self-care, which correlated with highest average relationship quality as rated by the subjects, was found in the dyad type the authors called “expert and collaborative.” These caregivers contribute to maintenance and management more than patients, but the two seem to share a high level of response to increased HF symptoms. Patients in this group had the lowest quality of life and likely were the sickest. Even so, caregiver strain was lowest in this type of dyad, despite their significant contributions to self-care, which the authors believe testifies to the high quality of their relationships (Lee et al., 2014).

Congruency, or agreement between relationship partners as to the nature of the relationship, was found to be an important element in HF self-care. A 2017 study by Buck, Hupcey, Mogle and Rayens analyzed 55 dyads for self-care and relationship quality. Patients in this study with a spouse caregiver had better self-care self-efficacy (confidence) than those in nonspousal dyads. The quality of the relationship as measured did not demonstrate a similar effect in patients, although it did in caregivers. Of further interest, dyads in this study were categorized as either relationally oriented, individually oriented, or as disparate (patient reported

one type and caregiver reported the other). Analysis demonstrated that whether the dyads were relationally or individually oriented did not affect self-care scores as much as whether or not the dyad agreed on their particular type. In other words, whether the patient and caregiver worked alone or collaboratively on HF self-care was not as important as whether they both agreed on what was actually occurring. As the authors stated, “It is possible that when a patient indicated that his caregiver provides the majority of his care on the DSMT, but his caregiver indicates that the patient provides the majority of his own care, neither is actually providing any care,” (Buck, Hupcey, Mogle et al., 2014).

A year later, a mixed methods study with two of the same authors investigated further to understand HF self-care in the context of the dyadic relationship. The study found that caregiver-patient dyads whether individually or relationally oriented tend to continue to follow patterns established early on, often with the patient having better self-care maintenance (day-to-day habits) and the caregiver stepping in for self-care management when symptoms worsen (Buck, Hupcey, Wang, et al., 2018). Most of these participants had inadequate self-care as measured by SCHFI or CC-SCHFI, but those dyads who did demonstrate adequate self-care also showed a reluctance to change from their life course pattern. If the patient had always been in charge of daily maintenance, the caregiver was reluctant to take over, even if worsening patient condition warranted it (Buck, Hupcey, Wang, et al., 2018).

### **Effects of patient-caregiver educational interventions**

Four different studies tested educational interventions aimed at systematically including family caregivers in standard patient education on heart failure self-care. Results were mixed, but overall the more in-depth targeted interventions seemed to demonstrate more success. A Swedish study by Liljeroos, Agren, Jaarsma, Arestedt and Stromberg (2015) followed 155 spousal dyads,

randomized into one control and one interventional group, over 24 months. The authors assessed physical health, depression, and perception of control of the two cohorts at baseline, and then again after 24 months. In the interim, the control group received usual care and patient instruction. The intervention focused on changing thoughts and behavior and on implementing strategies for self-care behaviors. It was delivered in three modules through nurse-led face-to-face counseling, a computer-based program and written materials. Sessions took place at two, six and 12 weeks after hospital discharge. After 24 months, the two groups showed no difference in outcomes, mortality, depression or perceived control. Both groups experienced improved control at the same amount. The authors pointed out that patient and partners in the intervention group participated together as equals (Liljeroos et al., 2015), but that the control group may also have received some joint education at medical follow up visits. The intervention may not have been far better than usual care in this case.

A Lebanese study presented better patient self-care and outcomes after a family educational intervention (Deek et al., 2017), although only in the short term. A randomized controlled trial of 256 patients were split into control and interventional groups. The interventional group received one comprehensive family-centered educational session at the hospital bedside on self-care and symptom management, including caregiver instruction on medication, weighing, and managing symptoms. Both the experimental and control groups received resources including a digital scale, medication box, a calibrated bottle and a diary. Follow up data was collected 30 days after discharge. Hospital readmission within 30 days was significantly lower in the interventional group. While self-care scores for both groups improved over baseline, there was a significantly larger improvement in maintenance and confidence in the intervention group than in the control (Deek et al., 2017).

Trials of longer and more involved patient-caregiver education interventions also demonstrated improvements in patient self-care along with improvements in that of caregivers. These interventions seemed designed to not only educate patients and caregivers about medical needs, but also to improve communication and the dynamic between the two partners. Sebern and Woda's 2012 study evaluated the feasibility and effects of a structured shared care dyadic intervention (SCDI) on 9 dyads (plus one caregiver). The intervention consisted of seven weekly one-on-one interactive sessions of 60 to 120 minutes, conducted at the patient's home, either in joint or mixed (separate caregiver and patient) format. The researchers found that patient self-care maintenance and management scores were improved when measured three months after the intervention, as well as quality of life. Caregiver outcome patterns supported improved relationship quality and health status (Sebern & Woda, 2012). While this was a small study of a relatively intensive intervention, the results are promising for the more intensive and individualized approach.

In a randomized controlled study of 117 dyads by Stamp et al. (2015), two types of educational intervention and a control were studied, to test effects on measures of family functioning and patient self-care. Dyads were randomized to receive family partnership intervention, patient-family education, or usual care. Usual care consisted of normal education from their healthcare providers, plus pamphlets from the Heart Failure Society of America. Patient-family education added a one-hour one-on-one education session, plus a two-hour group education session and a telephone booster session after four months. The family partnership intervention (FPI) included all of the above, with the addition of two two-hour sessions that focused on teaching the dyads how to support each other's roles, including family problem solving and autonomy support techniques. The intervention offered some coaching of the family

caregiver which aimed to “decrease negative criticism of the HF patient,” (Stamp et al., 2015), and it seems to have worked to improve patient self-care markers. The researchers found that in all groups, positive family functioning was associated with patient confidence regarding diet, and motivation regarding medication adherence and dietary adherence (Stamp et al., 2015). They further found that the FPI group significantly improved that confidence and motivation after four months, whereas the other two groups did not change. The FPI intervention enhanced patient motivation and confidence regardless of whether family functioning was good or not at baseline.

### **Discussion**

Findings of this review reveal that caregivers affect patient self-care in many ways—not all of them directly or in ways that might be expected. Clearly, it is well accepted that caregivers play a key role in the care of patients living with heart failure, yet the self-care effects of a caregiver are not universally beneficial or even predictable. Sometimes the simple presence of a partner or partner/caregiver may actively or passively improve self-care behaviors like regular exercise in patients with heart failure, as indicated in the studies by Gerhardt, et al. (2013) and Verma, et al. (2017). However, it is possible that a caregiver might also make self-care harder for patients. As noted above, Holden et al. (2014) found at least one caregiver actively sabotaging the low-salt requirement, putting his mother’s health at risk even though his intention in the short term was probably only to help.

Interestingly, factors present in the caregiver that seem to be independent of the relationship have been demonstrated to correlate with patient confidence in their own self-care ability. The mental and emotional health of caregivers was shown to be positively associated with patient self-care (Buck, Mogle, et al., 2015). It makes some sense that patients with caregivers who are experiencing anxiety or depression would feel less confident about their own

self-care ability, and caregivers who were feeling better about life and more capable at health literacy tasks were associated with patients who had higher scores on self-care maintenance (Vellone, Chung, et al, 2014; Levin et al., 2014). This suggests that when treating patients with heart failure, one should focus close attention on the caregiver as well as the patient.

A common element of high-quality caregiver-patient relationships as described in the reviewed studies is good communication. Dyads who shared similar views about the nature of their relationship and about who was responsible for which elements of care seemed to have the best self-care results (Lee, et al., 2014; Buck, Hupcey, Mogle, et al., 2014; Buck, Hupcey, Wang, et al., 2018). However, when self-care patterns appeared to be working well, dyads were unlikely to want to alter their division of labor in the face of disease progression. It is possible that the patient-caregiver pairs who felt that they were effective at self-care would not want to acknowledge that the illness might be getting worse. These dyads would be good candidates for additional support and education from nurses and therapists.

The findings from this review can address the question: how best to provide education and support? The results of the interventional studies reviewed showed that simply including caregivers in the usual patient education (as done in the Liljeroos study) may not necessarily make a difference. Patients and caregivers benefited the most from intensive interventions, which not only presented disease-specific health information, but also offered one-on-one sessions and communication coaching specific to each member of the dyad. These interventions (Sebern and Woda, 2012; Stamp et al., 2015) acted to improve the relationship between patient and caregiver by treating them as a team. Some “coaching” of caregivers in how to communicate with patients in ways to promote patient confidence and autonomy was offered, and seemed to work well. It

stands to reason that when patients are more engaged, and feel their caregiver communicates well, self-care may be less daunting for both.

Interventions like these take time and money to develop and implement, which might be a barrier. However, the cost of patient and caregiver education programming could be paid back many times by reductions in heart failure exacerbations and hospital visits.

### **Limitations**

Many studies in this review were limited by the preponderance of spousal caregivers. One can imagine there are differences in the relationship nature and quality between spousal and parent-child relationships. And other types of informal caregivers—friends, other relatives—were much less common in these studies, and their relationships may not fit into either the spouse/partner or parent/child typology. These types of dyads might have different characteristics and needs, and the trends seen here may not apply to them. Also, most studies were cross-sectional rather than interventional or qualitative. These were able to show demographic data, but less able to hone in on non-demographic factors and qualities that made one dyad exhibit good self-care while another did not. At this stage in research, a few well-considered qualitative studies might be needed to point the way for larger development and testing of interventions.

### **Conclusion**

The work of HF self-care is critical to maintaining patient health and promoting quality of life. Effective self-care requires diligence and motivation. Often patients are in poor health, may have other comorbidities and even experience some cognitive decline. Encouragement and keeping patients motivated to carry on with self-care like daily weights, medication requirements, physical activity and strict dietary restrictions is one way caregivers can help their

loved ones. Caregivers can also help more directly by preparing food, sorting medications, transporting patients to medical appointments, and recognizing symptoms that might require medication adjustments or a call to the provider.

Nurses and clinicians who want to improve the inadequate self-care performance of patients with heart failure have begun to recognize the influence and contribution of informal patient caregivers. However, even the best caregiver cannot be expected to make up for a patient who lacks motivation or confidence. New perspectives on this interplay will be useful to nurses and clinicians seeking to motivate patients and improve the effectiveness of patient self-care and HF outcomes. Given that heart failure is a progressive disease, scrupulous daily self-care is crucial to extending lifespan and “healthspan” in patients.

Further investigation should elucidate the qualitative characteristics of successful caregiver-patient partnerships and should follow up to determine best evidence-based practice in patient, caregiver and family education and support to improve HF self-care.

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## Appendix A

## Table of Papers

<b>Author, Year, Country</b>	<b>Purpose</b>	<b>Study Design, Model</b>	<b>Sample</b>	<b>Measurements</b>	<b>Findings</b>
Buck, Hupcey, Mogle, Rayens 2017 United States	Examine differences between dyadic types relative to patient self-care management	Quantitative cross sectional correlation, Actor-Partner Independence Model (APIM)	55 dyads: 63.6% spousal 37 relationally oriented, 14 disparate, 4 individually oriented	Personal and dyadic characteristics, Dyadic Symptom Mgmt Type (DSMT) relationship quality, HF knowledge, self-care (SCHFI)	Congruence (CG and Pt agree on who provides care) is most important to caregiver engagement and high quality self-care Patients with spousal CG have higher self-efficacy
Buck, Hupcey, Wang, et al. 2018 United States	Understand HF self-care with context of dyadic engagement	Cross sectional, mixed quantitative and qualitative. Theory of HF self-care	27 dyads Patients 56% male, mean age 77. CGs 74% female, mean age 66. 52% spousal, 26% child. 100% white	Dyadic symptom management scale, SCHFI, interview narrative	Patients and CGs continue relationship patterns in HF self care. Dyads find it difficult to change pattern. Adequate self-care decreases ability to adapt to change in patient's health status
Buck, Mogle, Riegel, et al. 2015 United States	Describe dyadic characteristics of mood and relationship perception, relate to HF self-care	Quantitative cross sectional data, APIM	40 patients, 31 CGs, hospitalized	Brief symptom inventory and pt health questionnaire, Dyadic adjustment scale, SCHFI	CG anxiety and depression associated with decreased Pt SC maintenance, yet Pt mood state did not show effect. CG mood states and perception of relationship also affects CG engagement SCHFI score below adequate
Deek et al.	Evaluate effect of	Intervention: CG	256 patients; n=130	SCHFI, Medical	Rehospitalizations within 30

2017 Lebanon	involving family CG in self-care of pts on risk of rehospitalization	(in addition to patient) received education and resources on HF self-care 30 day follow up	in control and n=126 interventional, randomized. Mean age of patient was 67, 55% male	outcome study Short form, SHARE index, medical records	days were significantly fewer in the intervention group (n=10, 9%, vs. n=20. 19%), which also had greater improvement in SC maintenance and confidence than control group
Gerhardt et al. 2013 Austria and Germany	Examine contributions of facilitators and barriers to physical activity in pts with advanced HF	Correlational data analysis	231 ambulatory pts waiting for new heart	Self-reported physical activity (PA), ESSi social support instrument, HADS-D anxiety/depression scale	Social support increases PA, but only in presence of barriers (depression, severe physical symptoms) Social support is not CG, but “family member/friend who gives helpful reminders to engage in PA”
Holden et al. 2014 United States	Apply systems model to understand barriers to self-care by elderly HF pts and CGs	Mixed method analysis, Patient Work System	30 HF pts and 14 HF CGs. Pts 57% male, average age 74 CGs 6 spouses 8 adult children	Interviews, observations, surveys, medical records	Some CGs have negative effect on pt SC; model unhealthy behavior, put pt in challenging circumstance
Hooker et al. 2017 United States	Examine relationships between pt and CG perceptions of mutuality and pt SC and CG contribution to SC	Cross sectional secondary analysis from baseline data of clinical trial; APIM, linear regression	99 dyads. Pts 79% male, CGs 81% female. 60% CGs spousal	15-item Mutuality Scale of the Family Caregiving Inventory, SCHFI, CC-SCHFI	No significant partner effects; however mutuality and self-confidence associated with pt self-care and CG burden. Suggests pts who perceive good relationship with CG have more SC confidence
Lee et al. 2014 Italy	Identify and characterize archetypes (patterns) of pt-	Correlational; dyad archetypes with HF self-care	509 dyads, 34% spousal, 53.4% child. Pts 55.4% male, average age	SCHFI, CC-SCHFI, and interview determinants of dyadic contributions	3 dyad archetypes observed; gradient in total contribution to HF self-care. Suggests that as disease progresses,

	CG dyads with respect to pt and CG self care		75.6, CGs 52.2% female, average age 56.9	to self care	CG takes on greater SC and pt takes less
Liljeroos et al., 2015 Sweden	Determine the 24-month effect of a supportive educational program for HF pts and CGs	Interventional self-care education of pt and CG together, with 24-month follow up	155 dyads, all spousal, pts average age 69/72, mostly male, dyads randomized to 71 in intervention and 84 in control	Questionnaires; 36-item HF-36, Beck depression inventory, control attitude scale	Intervention did not show effect on health, depression, or perceived control in pts after 24 months
Levin et al., 2014 United States	Measure health literacy in pts and CGs, determine effects on HF self-care	Quantitative statistical analysis, paired t tests	17 dyads, pts 58.8% female, mean age 80.2, 64.7% African American; CGs 70.6% female, 64.7% African American	IADL, SCHFI, Newest Vital Sign, health literacy questions and task, KC cardiomyopathy questionnaire	CGs with lower score on health literacy task correlated to pt lower SC maintenance, not pt SC management or confidence CGs have greater health literacy than pts; both scored adequate for SC maintenance but not mgmt or confidence
Lyons et al. 2015 Italy	Identify individual and dyadic determinants of HF SC confidence	Secondary analysis of cross-sectional study	329 dyads where CG is spouse or child. Pt mean age 76.8, 56% male; CG mean age 58.3, 54% female	Confidence subscales of SCHFI, minimal status exam MN living with HF, relationship quality, caregiver burden	PT perception of relationship quality associated with Pt SC confidence CG poor mental health and spousal CG correlates to lower pt SC confidence
Nguyen et al. 2017 Canada	Identify potential barriers to technology use in supporting self-care in older HF	Mixed methods, interview and questionnaire	18 pts/10 CGs; 15 pt/8 CGs Canada	SCHFI, KAQ, pt activation measure, Montreal cognitive assessment, short literacy/numeracy	Many pts unwilling to ask questions of providers; pts willing to do self-care but rely on CGs to ask questions CGs often more involved

	pts			scale	than pts in learning S/S of HF
Sebern et al. 2012 (2013) United States	Evaluate feasibility and effects of Shared Care Dyadic Intervention (SCDI)	Interventional, feasibility, quasi experimental— one group. Intervention is 7 structured sessions, 60-120 minutes, joint or mixed	9 dyads + 1 CG, pts 55% female, mean age 80. CGs 100% female, mean age 61	MMSE, Dutch HF knowledge, Feetham family function scale, State-Trait anxiety scale, PHQ-9, Shared Care instrument, SCHFI, KCCQ	Intervention is acceptable to both pt and CG, Data supported improved shared care for both pt and CG. Pt improved self-care maintenance, mgmt, and QOL
Stamp et al., 2015 United States	Examine family functioning related to self-care confidence, and whether FPI increases SC confidence	Interventional experimental, 3 groups: control (usual care), patient-family education, and Family Partner Intervention (FPI)	117 dyads randomized to three groups; 32 left the study	Treatment Self-Regulation Questionnaire (TSRQ), Perceived confidence scale, Family assessment device questionnaire	Pt confidence and motivation for self-care (diet and medication adherence) enhanced by Family Partner Intervention. Poor family function contributes to lower SC confidence
Vellone et al., 2014 Italy	Explore how self-care contributes to QOL in HF pts and CGs	Cross-sectional correlational , APIM	138 spousal dyads; pts 67.4% male, mean age 73.6; CGs 67.4% female, mean age 70.4	SCHFI, CCSCHFI, SF-12 for quality of life, medical records	Better self-care maintenance in pt associated with better mental QOL in CG; better CG confidence associated with poorer physical QOL in pt. Not as much of dyadic effect as expected
Verma et al. 2017	Investigate partner status and socioeconomic status association with outcomes	Post hoc analysis from HF-ACTION clinical trial	2331 HF patients	Demographic data, Beck depression score	Pts with a partner had better adherence to exercise therapy

QOL = Quality of Life

SCHFII = Self Care of Heart Failure Index

CC-SCHFII = Caregiver Contribution to Self Care of Heart Failure Index

APIM= Actor-Partner Interdependence Model

## Appendix B

Diagram of Study Selection and Review Process

Number of studies in first search	CINAHL N=20	ProQuest N= 121	HealthSource N=6	PsycINFO N= 7	PubMed N=27
Studies meeting inclusion criteria	14	12	4	3	5
Studies remaining after exclusion criteria	11	4	3	2	3
Remaining after duplicates excluded	11	3	1	1	2
Number of studies from database	11	3	1	1	2
Remaining after articles reviewed for relevance to research question	9	3	1	1	2
Total studies from database searches after title/abstract reviews using inclusion, exclusion criteria and eliminating duplicates			16		