

Caregivers' contributions to heart failure self-care: A systematic review

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Abstract

Aims: The purpose of this study was to conduct a systematic review answering the following questions: (a) what specific activities do caregivers (CGs) contribute to patients' self-care in heart failure (HF)?; and (b) how mature (or developed) is the science of the CG contribution to self-care?

Methods: MEDLINE, EMBASE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), the Cochrane Library and ClinicalTrials.gov were searched using the terms heart failure and caregiv* as well as the keywords 'careers', 'family members' and 'lay persons' for studies published between 1948 and September 2012. Inclusion criteria for studies were: informal CGs of adult HF patients—either as dependent/independent variable in quantitative studies or participant in qualitative studies; English language. Exclusion criteria for studies were: formal CGs; pediatric, adult congenital, or devices or transplant CGs; mixed diagnosis; non-empiric reports or reports publishing duplicate results. Each study was abstracted and confirmed by two authors. After CG activities were identified and theoretically categorized, an analysis across studies was conducted.

Results: Forty papers were reviewed from a pool of 283 papers. CGs contribute substantively to HF patients' self-care characterized from concrete (weighing the patient) to interpersonal (providing understanding). Only two studies attempted to quantify the impact of CGs' activities on patients' self-care reporting a positive impact. Our analysis provides evidence for a rapidly developing science that is based largely on observational research.

Conclusions and implications of key findings: To our knowledge, this is the first systematic review to examine CGs' contributions in depth. Informal caregivers play a major role in HF self-care. Longitudinal research is needed to examine the impact of CGs' contributions on patient self-care outcomes.

Keywords

Self-care, self-management, symptom management, chronic illness

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Introduction

A recent evidence synthesis defined self-care as 'A range of care activities deliberately engaged throughout life to promote physical, mental and emotional health, maintain life and prevent disease... performed by the individual on their own behalf, for their families, or communities, and includes care by others' (11).¹ Self-care is generally defined, more specifically, in the heart failure (HF) literature as a health maintenance and disease management process wherein decisions and behaviors result in maintained stability, recognition of changes in condition, and thoughtful responses.^{2,3}

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The Theory of Self-care of Chronic Illness provides a current theoretical framework for conceptualizing self-care.³ This theory has three key concepts: (a) self-care maintenance, defined as behaviors used to maintain health stability; (b) self-care monitoring, defined as the process of health surveillance; and (c) self-care management, defined as the evaluative process and active response to instability when it occurs.³ Self-care activities in HF that contribute to health stability generally involve managing multiple medications, following suggested diet and fluid restrictions, engaging in daily exercise, monitoring symptoms and weight daily, managing changes in symptoms (e.g. taking an extra diuretic or calling a health care provider for guidance when experiencing early fluid overload), and navigating the health care system.^{4,5} Engaging in self-care activities in HF is essential to positive health outcomes for patients with HF⁶ and clinical guidelines specify that promoting self-care is an expectation of patient-centered, evidence-based practice.^{2,7-10}

Despite the evident importance of self-care in HF, patients do not consistently engage in these activities, thereby leading to health deterioration, poorer quality of life, hospitalizations and high mortality rates.^{2,11-14} For example, Canadian HF hospitalization rates range from 16.5 per 1000 in adults aged 65-74 years to 81.6 per 1000 in adults ≥ 85 years of age.¹⁵ HF-related hospitalizations in the USA have increased 300% from 1.3 million to 3.9 million over a 25-year period.¹⁶ In a cohort of over 9000 newly diagnosed hospitalized HF patients (mean age 76, standard deviation (SD) 11.5 years), the median survival time was 2.4 years, with a 33.1% one-year mortality and 68% five-year mortality.^{17,18} With HF increasing in prevalence worldwide¹⁹ it is estimated that HF currently consumes between 1.1-1.9% of total healthcare expenditure in developed countries with 50-74% of costs attributed to hospitalization or long term institutionalization.¹⁸ Optimizing self-care performed in home settings may provide an important bulwark against the rising cost of providing HF care in tertiary healthcare settings.

Self-care is undertaken by HF patients with varying levels of assistance from informal caregivers (CGs), such as family members or friends.^{20,21} Medication adherence,²²⁻²⁵ lower hospital re-admission rates,^{22,23} and dietary and daily weighing compliance²⁵ are all outcomes associated with social support, a frequently measured proxy for CG support. While the literature on CGs has been explored in a recent qualitative meta-synthesis of the caregiving experience,²⁶ no reviews to date have systematically assessed and described the specific activities performed by HF CGs. We cannot understand the activities of caregivers or the impact of those activities on patient outcomes without first doing a thorough review of the literature. The purpose of this systematic review was to discover whether the literature, once analyzed in totality, sheds light on the actual activities contributed by CGs and the impact

on HF patients' self-care. In addition, we sought to examine the maturity of the science in this emerging body of work. This review will provide direction for researchers as to new areas of inquiry and clinicians as to the need to mobilize this often overlooked resource. To accomplish this purpose, two specific questions were addressed: (a) what specific activities do CGs contribute to patients' self-care in HF?; and (b) how mature (or developed) is the science of the CG contribution to self-care?

Methods

Eligibility criteria

The development and analysis phase of this project was guided by criteria set forth by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. The PRISMA statement involves both a standardized checklist of items and a figure capturing the flow of information through the systematic review.^{27,28} Manuscript headings in this paper reflect the PRISMA criteria. Eligibility criteria were developed a priori by the investigators and were selected to assure the most inclusive sample of studies for review. Both the type of patient/CG sample and study were vetted based on the inclusion and exclusion criteria reported in the following section.

Sample

Included studies examined informal CGs of adult patients with HF either as the outcome variable or a unit of measurement in a quantitative study or as a participant in a qualitative study. Excluded were: (a) all formal CGs, (b) informal CGs of pediatric patients, adult congenital heart disease patients, or patients with ventricular assist device or cardiac transplant since they constitute unique subpopulations of HF patients who would likely have different responsibilities related to patient self-care from the general HF population,²⁹ and (c) mixed diagnosis populations (for example, HF, Chronic Obstructive Pulmonary Disease, and cancer in the sample) as findings were sometimes aggregated, making it difficult to ascertain disease-specific results.

Study design

Included were papers reporting empiric data in the English language using qualitative, quantitative or mixed methods. Secondary analyses of data were included. Excluded were publications such as opinion pieces, editorials and letters to the editor, policy, health services delivery, or organizational papers; as well as reports publishing duplicate results. The gray literature, such as conference proceedings or unpublished material, was not specifically targeted.

Information sources and search

The literature was searched using MEDLINE, EMBASE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), the Cochrane Library and ClinicalTrials.gov using the most inclusive terms, 'heart failure' and 'caregiv*', for study reports published between 1948 (earliest date available) and September 2012. Other potential search terms such as 'carers', 'family members', and 'lay persons', did not provide any additional results.

Study selection

A two-step process was used to determine the final group of papers to be included in the review. In step 1, two investigators with expertise in systematic reviews (HGB, KH), reviewed abstracts using inclusion/exclusion criteria. Once again, the focus was including as many studies as possible, if either reviewer chose to include an abstract, or was unable to make a determination based on the abstract, the study was included in the second step. Studies reporting secondary analysis from an original study were also included if they had a unique research question and provided further insight into the phenomena of interest. A random sample of 85 abstracts (31% of the total sample) was selected a priori to assess for inter-rater reliability using the kappa statistic.^{30,31} Agreement was achieved for 81 (96.4%) abstracts, yielding a kappa of 0.91. Initial disagreement for the remaining four (4.7%) abstracts was then reviewed concurrently by both investigators and consensus reached. The remaining abstracts were then divided between the two reviewers (HGB, KH) and reviewed independently. In step 2, the full text of each paper was evaluated by two reviewers from the team of doctorally prepared nurse scientists. Any disagreements between reviewers were handled, once again, by reviewing the papers together until consensus was reached. Included papers were then abstracted using a form developed for this review.

Data collection process

The main data elements to be extracted were derived from the study questions. These included year of publication, geographic setting, study design, sample size and age, relationship of the CG to care recipient, living arrangement (together, apart, how far apart), self-care measure used and data source, CG contribution to self-care (activity, time allotment, and percentage of effort), analytic approach, other variables measured (quantitative studies), main study findings of qualitative themes from the study. The data extraction form was first piloted by two authors (HGB, KH). Subsequent study reviewers (co-authors on this manuscript) then received the data form with a fully abstracted example of a quantitative and qualitative paper and their

group of papers to be abstracted. Each paper was abstracted by one reviewer and the data confirmed by a second member of the team. For quality assurance purposes, 10% of the papers received a full abstraction by two members. A third member (RW), not involved in the abstraction, reviewed each paper abstraction for consistency and accuracy. Quality monitoring checks included: (a) confirmation of eligibility at each phase (abstract screening, full-text screening, and abstraction), (b) use of at least two team members at each level of screening or abstraction, and (c) agreement of the full team on all included papers and analyses.

Data items

To establish what activities would be determined to be 'CGs contributions to self-care' and to theoretically situate the findings, we mapped the particular CG contribution to the tenets of the Theory of Self-care of Chronic Illness.³ This provided a theoretically-derived consistent standard against which to measure every activity. Examples of activities, such as following a plan of care for self-care maintenance are provided (Table 1). After the activities were identified and theoretically categorized, a content analysis across papers ($n=40$) was conducted using accepted methods³² to answer the two questions. This involved categorizing data across all studies to answer question 1. For question 2 (studies addressing CGs contribution to HF self-care) the study design and methodology for each study was analyzed.

Synthesis of results

A meta-synthesis approach³³ was used to interpret the activities linked to the mid-range theory, then analyze the nature and relationships between the activities and finally draw conclusions about the higher order abstractions. Noblit and Hare's³³ methodology was selected as appropriate to our purpose of interpreting, and re-interpreting the findings of individual studies in the light of all of the other studies.

Additional analysis

The quality of the papers was evaluated using the Critical Appraisal Skills Program (CASP) checklists (appropriate to the particular method of the paper).³⁴ CASP provides valid, standardized criteria with which to evaluate methodologic decisions and study outcomes. We ranked the studies as low, moderate, or high quality based on these criteria. Three authors (HGB, KH, and RW) independently evaluated the papers. Ten percent of the papers were evaluated by more than one author. In keeping with all analyses for this review, any disagreement was handled by reviewing the papers together. No articles were excluded based on CASP ranking.

Table 1. Categories of caregiver (CG) contributions linked to the middle-range Theory of Self-care of Chronic Illness.

Key concepts	Definition	Examples	Related CG activities from the reviewed studies
Self-care maintenance	Behaviors to improve or maintain health	Healthy lifestyle (i.e. exercise, smoking cessation, dental care, sleep hygiene, mood, stress reduction)	Exercise (39–41, 45, 50, 51, 54)
	Adherence to a mutually derived set of evidence based therapies	Following plan of care (i.e. medications, diet, flu shots, fluid restriction, alcohol restriction)	Reduce salt in food (52) Following diet orders (35, 41, 45, 47, 50–52) Fluid restriction (45, 50) Medications (35, 38–41, 44–52) Information management (53) Arranging resources (35, 38, 45, 50) Motivational care (45, 50, 56) Symptom monitoring (35–41) Blood pressure monitoring (44, 52) Regular weighing (45, 50–52) Monitoring fatigue (40, 51) Monitoring edema (40, 51) Monitoring SOB (40, 49, 51) Data entry into tele-management (52)
Self-care monitoring	Normal, routine, focused, health surveillance	Daily weights, monitoring for s/s of shortness of breath (SOB), fatigue, edema	Recognizing changes in skin color, swelling ankles, and breathlessness (40)
	Recognition that a change in condition has occurred	Recognizes s/s fluid overload	Shared care reciprocity (42, 71)
Self-care management	Symptom evaluation	Comprehends the meaning of the change in condition, simulates options, and chooses a response	Give extra diuretic (40) Information seeking from HCPs (35, 44, 45, 50) Contacting HCPs for help (38–40, 44, 45, 47, 49–51) Shared care reciprocity (42, 71)
	Treatment implementation	Taking an extra diuretic, consulting with a Health care provider (HCP)	Shared care reciprocity (42, 71)
	Treatment evaluation		Shared care reciprocity (42, 71)

Results

Study selection

The search identified 278 unique papers (Figure 1). Two hundred and thirty-four were excluded during this step. A total of 44 full text papers were reviewed; four were excluded. Finally, 40 papers reporting 30 unique studies were analyzed for the purposes of this review.

Study characteristics

The included papers (qualitative $n=17$; quantitative $n=23$) were published between 1994–2012 in disease or discipline-focused journals, primarily cardiac or nursing journals and represented a total of $n=1318$ patients and $n=1625$ CGs (Table 2). Eight different countries (USA,

$n=20$; Netherlands, $n=6$; Canada, $n=4$; Scotland, $n=4$; UK, $n=2$; Sweden, $n=2$; Australia, $n=1$; Norway, $n=1$) were represented in the papers. The relationship of CGs to patients included spouse/partners, children, siblings, parents, nieces, neighbors, grandchildren, and friends (Tables 4 and 5; available online at cnu.sagepub.com/supplemental).

Caregiver activities and impact on patient self-care

The activities of the CGs were first analyzed as individual activities (Tables 4 and 5; available online at cnu.sagepub.com/supplemental), then theoretically categorized (Table 1) and finally synthesized to deepen our understanding of CGs' contributions (Table 3, Figure 2). After that, the impact of

CGs' contributions on patient self-care was examined in the two studies found to address this. Overall, one could say that CGs contribute to patients' self-care in diverse ways.

A small number of articles ($n=7$) used the general terms 'symptom monitoring/management'³⁵⁻⁴¹ or 'shared care'^{42,43} ($n=2$) without specifying the actual care/contributing activity.

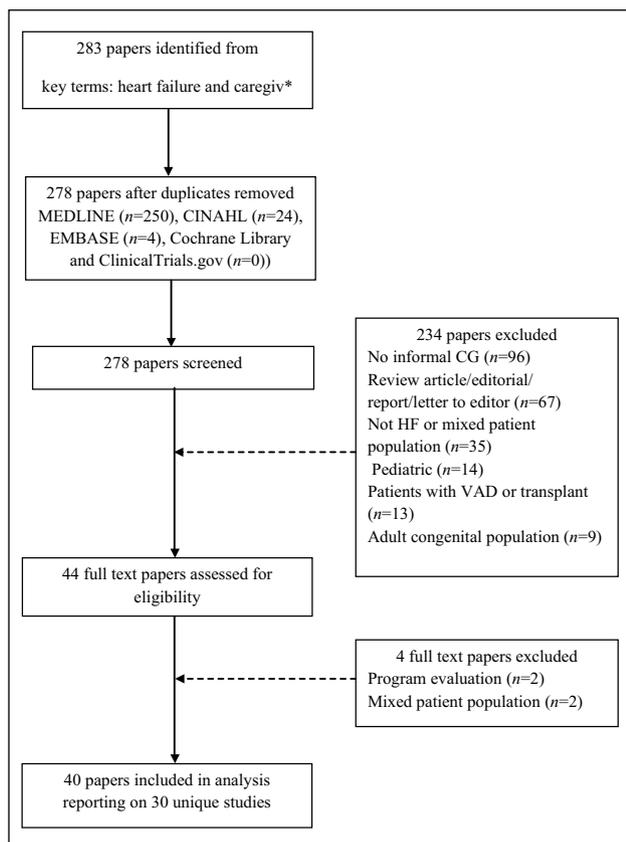


Figure 1. Search strategy. CG: caregiver; HF: heart failure; VAD: ventricular assist device.

Closer examination of the instruments in the quantitative studies ($n=6$) found that items from the Oberst Caregiving Burden Scale,^{35,37,38} or items from a measure created to indicate social support in HF self-care³⁶ were used to identify activities related to self-care such as 'watching for and reporting patient's symptoms'³⁸. In the studies measuring shared care,^{42,43} an item analysis of the reciprocity sub-scale of the instrument revealed that CGs were asked to indicate agreement or disagreement about whether they contributed to symptom evaluation, treatment implementation, and treatment evaluation—all part of self-care.

Specific examples of CG support for self-care activities (Table 1) included medication management;^{35,39-41,44-52} blood pressure monitoring;^{44,52} following dietary recommendations;^{35,41,45,47,50-52} information management;^{35,44,45,50,53} arranging resources (e.g. scheduling appointments, equipment, and services);^{35,45,50} data entry into telemanagement;⁵² encouraging/facilitating exercise;^{39-41,45,50,51,54} regular weighing;^{45,50-52} caring for a cardiac device;⁵⁵ monitoring for extremity edema;^{40,51} monitoring for shortness of breath;^{40,49,51} monitoring and helping to improve fatigue;⁵¹ motivational care;⁵⁶ assessing the need for and give extra diuretics;⁴⁰ and contacting healthcare providers for help.^{39,40,44,45,47,49-51} CG quotes provided in the qualitative studies ($n=3$) indicated that CGs note and respond to specific symptoms by calling the clinician,^{39,40} adjusting medication doses,⁴⁰ and facilitating clinic appointments.⁴¹

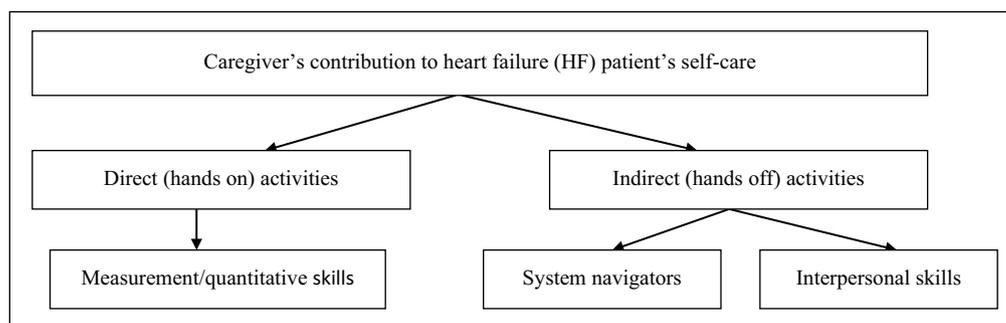
While the analysis of these studies resulted in a rich description of the activities that CGs contributed in each study, we then conducted a deeper analysis to explore the nature and relationships between the individual activities to aid in interpretation of our findings. CGs contributions could be categorized as falling into three distinct domains. CGs contribute activities to patient's self-care that involve measurement or quantitative skills such as monitoring patient blood pressure,^{44,52} arranging the patient's diet to meet recommendations³⁵ or weighing the patient.⁴⁵ This

Table 2. Demographics of the studies.

	Qualitative	Quantitative
Number of studies	17 (39-41, 44, 48, 50-53, 55, 60, 68, 72-76)	21 (35-38, 42, 45-47, 50, 54, 56, 58, 61, 64, 65, 70, 71, 77-82)
Publication years	2005-2012	1994-2012
Journal type	Cardiac (49, 60, 72, 76) Nursing (40, 44, 48, 51-53, 55, 68, 75) Palliative care (74) Patient education (41) Pharmaceutical Science (39) 	Cardiac (36, 37, 42, 45, 47, 50, 54, 58, 64, 65, 77-79) Critical care (35, 56) Geriatric (80) Nursing (38, 46, 61, 70, 71)
Author discipline	Nursing only (44, 49, 51-53, 55, 60, 73) Nursing/medicine (40, 48, 68, 72) Medicine only (41) Other (39, 74-76)	Nursing only (35-38, 42, 46, 47, 50, 56, 64, 65, 71, 80) Nursing/medicine (45) Medicine only Other (54, 58, 61, 70, 77-79)

Table 3. Examples from the analysis of caregiver (CG) activities.

First order findings (main concepts from Table 1) resulting in a detailed description of the activities of the CGs	Second order interpretations (nature and relationships between first order concepts) resulting in interpretation of common/reoccurring concepts	Higher order abstractions (main concepts reinterpreted in light of all other findings on CGs activities) resulting in a synthesis of the activities
Blood pressure monitoring or weighing the patient	Measurement/quantitative skills	Direct activities
Arranging resources (e.g. scheduling appointments, equipment, and services)	System navigators	Indirect activities
Encouraging/facilitating exercise	Interpersonal skills	Indirect activities

**Figure 2.** Activities contributed by caregivers.

was the largest category of activities found in these studies ($n=13$ discrete activities). Each of the activities in this category required that the CG has the ability and/or motivation to assess the patient for deviations from what might be considered the patient's normal state, understand and implement the plan of care, or adjust the plan of care in response to changes in the patient's status (e.g. adjusting medication doses). The second category of activities involves serving as 'system navigators' in the interface with the health care system; for example, assisting the patient in managing information to provide to a clinician⁵⁰ or arranging clinic appointments.⁴¹ This was a smaller category ($n=6$). The third, smallest, category of activities ($n=2$) involved the CGs using their interpersonal skills to motivate the patient to perform better self-care⁵⁶ or to encourage the patient in general. When these three domains are synthesized further one could categorize the domains as involving either 'direct activities' (e.g. measurement or quantitative skills) defined as activities which directly impact the patient (they do something to the patient) or 'indirect activities' (e.g. system navigators or interpersonal skills) defined as activities in which the CG indirectly effects the patient by marshaling other resources (for example, clinicians, durable medical equipment, or social support) to contribute to the patient's self-care.

Only two studies reported the impact of CGs activities on HF patients' self-care. Gallagher and colleagues³⁶ used data from the 'Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure' (COACH)⁵⁷ trial to conduct a secondary analysis of the impact of

differing levels of social support on HF patients' self-care. They developed a theoretically-driven composite measure of social support (CG is knowledgeable, vigilant, practically/emotionally supportive, and relationship quality) and categorized patients based on their scores. In this COACH sample ($n=333$; mean age 72 ± 11 ; 66% male) of New York Heart Association class II–IV HF patients, patients who were reporting high levels of CG support also reported significantly better self-care vs those with low support ($p=0.003$).³⁴ When particular self-care activities were analyzed, patients with high levels of CG support were significantly more likely to report adherence to fluid restriction ($p=0.02$); medication ($p=0.04$); flu vaccine ($p=0.01$); exercise ($p=0.01$) and contacting a clinician with weight gain ($p=0.02$) than those with low support.³⁶ Sebern and Riegel⁴² explored the relationship between the construct *shared care* (comprised of interpersonal processes of communication, decision making, and reciprocity) and the patient's self-care. In their sample ($n=75$; mean age 71 ± 10 ; 73% male) of chronic HF patients (no class/stage provided), patient and CG decision making (defined as the capacity to seek information and be involved in decisions) was the only process significantly associated with patient self-care.⁴² In both studies, CGs' contributions resulted in better outcomes for patients.

The maturity of the science

Our second question addressed the development and evolution of the science of self-care in a targeted analysis of

the studies that specifically focused on quantifying or understanding the CGs' contribution to HF self-care: $n=4$ quantitative studies;^{35,36,56,58} $n=3$ qualitative studies.^{40,48,51} As identified earlier, we analyzed the design, methods, and limitations of the studies according to PRISMA criteria and then examined them using the CASP criteria. The majority addressed kinds (particular activities) and amounts (time required for those activities) of care,^{35,36,40,58} while three studies investigated the impact of caring on the CG^{48,56} or CGs' perspectives on their level of preparation to care for HF patients.⁵¹ All of the studies were conducted between 2008–2011. Sample sizes ranged from 30 individuals to 76 dyads (152 individuals).⁵⁶ All of the studies were at the descriptive, exploratory or explanatory level. Only one study involved a longitudinal analysis.³⁵ Two quantitative studies^{35,56} used general linear models to assess relationships between CG person level variables (physical and mental health) and CG outcomes such as health related quality of life and impact of caregiving respectively. Three studies measured CGs activities (not burden) using a caregiver burden instrument (Oberst³⁵ or Dutch Objective Burden Instrument).^{56,58} When the studies were assessed for validity, clinical importance, and applicability using the CASP criteria, studies were found to range from low quality to high quality with the majority of the studies assessed at the moderate quality level. Limitations included small sample sizes, convenience sampling, single site studies, or lack of details about data analysis or recruitment setting of care.

Discussion

Summary of evidence

This systematic review focused on CGs' specific contributions to HF patient self-care in order to provide valuable insight into this under-researched area. This is the first review – to our knowledge – which systematically assesses and describes the specific activities performed by HF CGs. Distinct from knowledge contributed by recent reviews on the HF caregiving experience^{26,59} and global family influences on self-care,²¹ our findings offer unique insight by mapping specific caregiver activities to the middle range Theory of Self-care of Chronic Illness,³ synthesizing the activities to create a higher order understanding of those activities, analyzing linkages to patient outcomes and assessing the strength of the science.

We found that CGs contribute a plethora of caregiving activities, which can be characterized as including activities that require the ability to measure and quantify (weights, fluid intake etc.) as well as those that assist the patient in navigating the health care system, or require the interpersonal skills of patience, understanding and support. These CGs contribute to patient's well-being in both direct, 'hands on' ways and indirect or 'hands off' ways.

We also found that few ($n=2$) studies quantified the impact of CGs' activities on patient self-care. Our analysis also provides evidence for an emerging science related to understanding the CG contribution to HF patients' self-care.

Limitations

Certain limitations should be kept in mind while evaluating this or any systematic review. It is possible that studies were not captured by our search, particularly those published in a language other than English. However, our use of the most inclusive terms in well-known databases should improve confidence about the exhaustive nature of the search and retrieval of relevant research. To alleviate concerns about subjectivity in data extraction and analysis, we engaged multiple reviewers at all stages of this project and used both PRISMA and CASP criteria to improve the rigor of our review. A further, potential limitation is the inclusion of multiple papers from one study. For example, five of the studies used data from the COACH^{49,50,58,60,61} multicenter clinical trial. This may have given undue weight to certain findings despite their unique research questions. The choice to include these papers was based on the small number of extant studies. Finally, we acknowledge that the use of other theoretical conceptualizations of HF self-care or self-management might have resulted in different findings. However, the Theory of Self-care of Chronic Illness is in keeping with currently well-known conceptualizations of HF self-care and practice guidelines and its use allowed us to situate our review within the current science.

Conclusions

Three important results merit further discussion. First, examination of the actual activities across studies reveals that there are significant gaps in what is known about CGs' contributions to patient self-care. Specifically, it is unclear what part CGs play in the symptom and treatment evaluation process and how they contribute to patients' self-care confidence (an important mediator and moderator of self-care). Symptom and treatment evaluation have been linked to symptom recognition in patients; whereby those who recognize their symptoms quickly are more likely to score higher when treatment evaluation is measured.⁵ However, the effect of CG vigilance with respect to symptom recognition and treatment evaluation on patient outcomes remains unknown. In other chronic illness populations, patients and CGs are known to work together by pooling knowledge, energy, and activities.⁶² Current evidence does not help us understand (a) whether this occurs in HF, or (b) the mechanisms by which such activities improve patients' health. Further, self-care confidence has been found to moderate the effect of self-care on HF economic outcomes and mediate the relationship between social support and HF self-care management.⁵

However, only one study⁴² explored the relationship between CG variables and patient self-care confidence and the instrument used did not elicit specific information about the CG actions that promoted self-care confidence. Therefore, we are left with a clear signal that CGs contribute to self-care and self-care confidence, but the mechanism by which this occurs requires detailed examination.

Second, few studies linked CGs' contributions (to HF self-care) with patient outcomes. Costs, in particular, have not been examined. Clearly this form of gratis, informal care would be very costly to replace with paid community-based services or long term care. The current focus on 'self'-care in HF may be misleading and camouflages the essential role that CGs contribute. They are, perhaps, unsung heroes in the current disease management and self-care paradigms. The fact that only two out of 40 studies measured the impact of CGs contributions on patient self-care outcomes may speak to the lack of a robust measurement approach to this complex phenomenon. There is a need to develop a psychometrically sound tool designed to capture contributions of CGs to patient self-care. The use of burden and dyadic shared care instruments to measure CG contributions, as was found in this review, supports this contention. While several instruments have been developed to measure similar constructs (i.e. burden and social support), none currently specifically measure the CGs contribution to self-care activities. One instrument designed to measure patient engagement in self-care was recently modified to measure caregiver engagement in self-care using a European sample.⁶³ However, theoretically derived items, while extensively tested in patient populations, may differ for CGs. This difference makes conducting a direct modification of wording without an ensuring solid conceptual basis in CG's experience possibly problematic and may limit validity of the revised instrument. Nevertheless, this may be a necessary first step and its development suggests that other researchers agree there is need for the measurement of this vital construct. A robust instrument measuring the activities that CGs specifically contribute to HF patient's self-care is currently being developed and tested by this group of scientists to address this gap in the science. Instrument items are being derived from the activities identified in this systematic review. In addition, items are also being developed from understudied areas identified in this paper, as for example, CGs contributions to symptom and treatment evaluation.

We also found an interesting dichotomy; 30% of the studies ($n=12$) viewed the CG's experience as either burdensome ($n=7$)^{35,37,38,45,56,58,64} generally viewed as negative, or as socially supportive ($n=5$)^{36,41,56,65,66} often viewed as positive. This is supported by Hwang and colleagues⁵⁶ who reported positive and negative effects on HF caregivers. However, what if caregiving is more nuanced than this dichotomous conceptualization? What if the effects would be more correctly understood as occurring across a

spectrum from burdensome to deeply meaningful? An early and uncritical adoption of assumptions that caregiving is burdensome or a form of social support may have shaped the findings of some of these studies. HF caregiving *is* labor intensive and CGs often provide the primary means for the care recipient to connect with the outside world,^{67,68} however, caregiving is often concurrently a reciprocal phenomenon with some CGs finding their caregiving deeply meaningful and feeling supported by their care recipient.⁶⁹ However, everything that we know about the HF CGs may have been shaped by what was measured and the measurement approach—if we measured burden we only perceived burden.

Finally, it is clear that CGs contribution to HF self-care is of increasing interest. In a decade by decade analysis it was found that while five studies were published in the first decade, 31 studies were published in the subsequent decade. The earliest study captured by our search was published in 1994.⁴⁶ In the following nine years only four studies were conducted.^{39,46,68,70} Between 2003–2007 six studies were published, and in the last five years (2008–2012) twenty-five studies were published. This increase in studies is an encouraging finding. Unfortunately, there is a preponderance of small, single site, descriptive studies at this early stage of the science. The result is heterogeneity in the findings which precludes conducting a meta-analysis of the findings. This finding, of an emerging area of inquiry, points to the needed next steps, such as focusing on certain aspects of the caregiving role, standardizing measurement and the need for longitudinal studies linking CG's contributions to patient outcomes. Our review of extant studies suggests that a more theoretically rich and complex understanding of CGs contributions is needed to fully appreciate CGs impact on patient self-care and health in HF. As HF medical management has become increasingly evidence based and guideline driven during this time period, so too, one could hypothesize, the role of the CG has become more complex along with it, but this might be somewhat speculative because there is so little early data. We do not have the evidence to explicitly show how the HF CG role has evolved.

Clinical implications

Few studies contributed evidence-based clinical data for or against engaging CGs in HF patient self-care. However, there is qualitative and theoretical support describing important contributions that CGs make every day to maintaining the HF patient safely in the community. As clinicians, we need to educate and support these co-providers of instrumental HF care. Suggested practice changes may involve encouraging the presence of the CG in the examination room (with the patient's permission) so that they can see and hear what the patient is experiencing, ask questions or make comments, using the 'teach back

method' (asking the patient and CG to repeat in their own words what they need to know or do after they receive new information in the clinic visit) with both patient and CG, assessing for CG burden and in general viewing the patient and CG as a unit of care instead of separating the patient from the CG. In addition, we need to partner with researchers to address the gaps in best practice for supporting and collaborating with HF CGs. There is as much need for 'practice-based' evidence as there is for evidence-based practice. Clinicians and researchers can work together to plan the implementation and study of novel methods of engaging CGs before they are utilized in clinic, facilitating the acquisition of meaningful data.

Theoretical implications

The Theory of Self-care of Chronic Illness is a recent result of a multi-national collaboration between North American and European experts in self-care. As such it reflects the best of what is currently known about self-care in Westernized health care systems. Our use of theory raises the analysis in this review from arbitrary or individualistic into the sphere of coherent and systematic, and strongly supports the inclusion of 'support from others'¹ as a key element of self-care activity. The theory provided a benchmark against which all of the CG activities could be measured and a consistent standard for determining which activities constituted self-care. In using this theory as an organizing framework for the identification and analysis of CGs activities we have provided evidence for the utility of this theory for this task.

Implications for practice

- Informal caregivers are valuable co-providers of community based HF care.
- New collaborative models of care including the informal caregiver are needed.
- More research is needed to measure the impact of caregivers on HF self-care.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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