

## ORIGINAL PAPER

## Improving Heart Failure Self-Management Support by Actively Engaging Out-of-Home Caregivers: Results of a Feasibility Study

Studies described in more than 16 systematic reviews and 1 meta-analysis since 2000 have documented that heart failure (HF) care management can reduce hospitalization and mortality rates.<sup>1–11</sup> Nevertheless, despite effective medical therapies<sup>12,13</sup> and national guidelines for clinical management,<sup>14</sup> wide variations in HF patient care persist, particularly among socioeconomically disadvantaged patients and patients with comorbidities.<sup>15</sup> Most health care systems lack the resources to sustain comprehensive HF care management programs, including the frequent monitoring and behavior-change support calls that many patients need. Home-based automated telemonitoring services are a partial solution to this gap in services, but multiple trials have indicated that, without a capacity to respond to identified problems, such programs have little impact on outcomes.<sup>16,17</sup>

Informal care provided by family members and friends is a low-cost and potentially effective adjunct to HF care management services, improving patients' regimen adherence, quality of life,<sup>18</sup> and mortality risk.<sup>19–25</sup> Informal caregivers can help patients identify early signs of acute illness, encourage appropriate diet and medication use, support lifestyle changes, and assist patients in understanding complex self-care information.<sup>22–24</sup> In one trial, caregiver training resulted in significant improvements in stroke patients' quality of life and health care costs.<sup>26</sup> In another trial of postdischarge home visits, providing caregiver training substantially reduced unplanned readmissions over

*The benefits of heart failure (HF) care management have been demonstrated, yet health systems are often unable to meet patients' needs for support between out-patient visits. Informal care provided by family or friends is a low-cost, and potentially effective, adjunct to care management services. The authors evaluated the feasibility of augmenting HF care management with weekly, automated assessment and behavior change calls to patients, feedback via the Internet to an out-of-home informal caregiver or CarePartner (CP), and faxes to the patient's health care team. The program included 52 HF patient-CP pairs participating for an average of 12 weeks. Patients completed 586 assessments (92% completion rate) and reported problems that might otherwise have gone unidentified. At follow-up, 75% had made changes in their self-care as a result of the intervention. The CP program may extend the impact of HF telemonitoring beyond what care management programs can realistically deliver. (Congest Heart Fail. 2008;14:12–18) ©2008 Le Jacq*

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the subsequent 18 months.<sup>13</sup> Two meta-analyses support the benefits of informal caregivers, particularly among patients with cardiovascular disease.<sup>18,27</sup>

Despite these potential benefits, patients and caregivers often report that their relationships are difficult, stressful, and unhelpful.<sup>18,28</sup> Caregivers often lack the tools and knowledge to monitor patients' health and self-care or to know when and how to respond to identified problems. Increasingly, older patients live alone or at a distance from their adult children and other informal supports.<sup>29,30</sup> Spouses

may be overwhelmed with the responsibility for helping their partners,<sup>31</sup> and outside caregivers often have difficulty maintaining frequent contact with patients because of busy schedules. When informal caregivers communicate with HF patients, their "assessment" of the patient's status is typically unstructured and fails to target key health or self-care problems. Patients may be unwilling to provide others with accurate information about how they are doing,<sup>32</sup> and, accurate or not, most caregivers lack the knowledge of HF self-care to respond effectively.

In summary, family members and other potential caregivers living outside of the household are an important, untapped resource for improving HF self-care. An important challenge is to identify strategies for effectively involving informal caregivers in patients' care management. In this study, we developed and evaluated the feasibility of an automated telemonitoring service with links to the patient's medical home and designed to actively engage an informal caregiver, or "CarePartner" (CP), in support of HF patients' self-care efforts.

## Methods

### Intervention Description. Overview.

The study was approved by the University of Michigan and Ann Arbor Veterans Affairs (VA) human participants review boards. The CarePartner Program includes an automated telephonic HF assessment and behavior change service with follow-up reports to CPs via e-mail and a patient-specific Web site (Figure 1). Patients received weekly calls from the system and reported information about their health and self-care using their touch-tone telephone. Automated calling attempts were made to the patient's designated telephone number at days and times identified as convenient. Up to 3 attempts were generated for each of 3 preferred calling times per week. Patients did not need computers or specialized hardware, nor did they have to initiate calls. Care managers (typically nurses) received an e-mail, page, or fax when a patient reported an urgent medical condition. Urgent conditions were identified with predefined thresholds pertaining to changes in the patient's breathing or weight. The CP was encouraged to refer the patient to the care manager or primary care provider as needed and to keep in-home caregivers (eg, spouses) involved.

**Call Contents.** Self-care calls to patients included recorded statements and queries, and patients responded to requests for information using their touch-tone

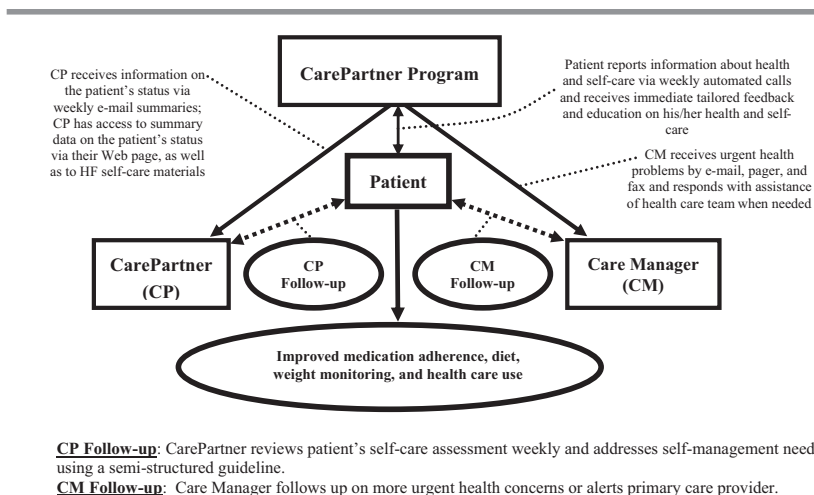


Figure 1. CarePartner Program mechanisms of action.

CHARACTERISTIC (MEAN OR %)	PATIENT (N=52)	CAREPARTNER (N=52)
<b>Demographics</b>		
Mean age (SD), y	65.9 (10.8)	42.3 (9.8)
Male	89	42
White	90	85
Married	62	–
Education <12 y	39	27
<b>Relationship to patient</b>		
Daughter	–	40
Son	–	35
Other relative	–	15
Friend	–	10
<b>Health status</b>		
Self-reported poor health	12	–
Self-reported fair health	49	4
EF <35% or NYHA class III heart failure	50	–

Abbreviations: EF, ejection fraction; NYHA, New York Heart Association.

telephone keypad. The core set of assessment items was defined with input from a cardiologist (PC) and an internist (MH). Assessment domains were those common to standard telephone care management protocols for HF patients, including (1) overall perceived health status; (2) breathing problems and associated issues such as intake of salt and fluids; (3) weight monitoring; and (4) medication availability and adherence.

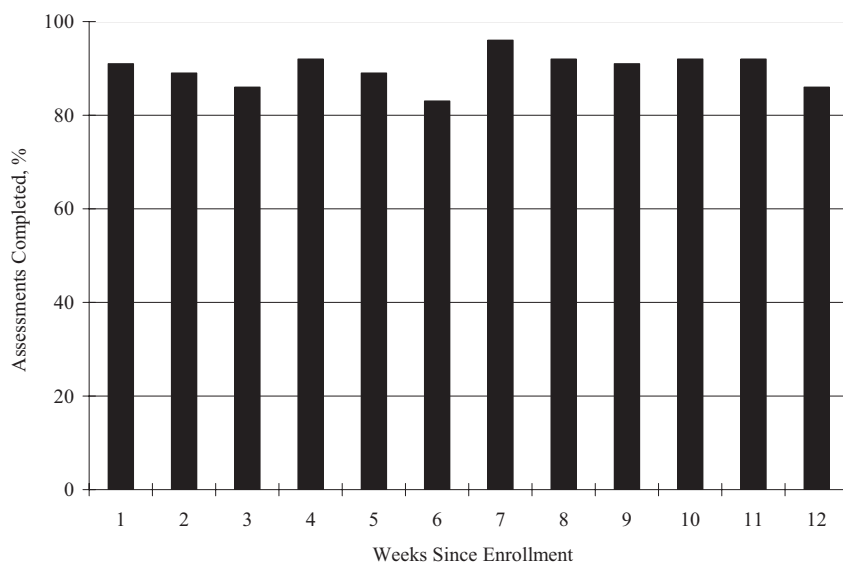
Patients received immediate recorded feedback customized to their responses. Feedback messages were designed to alert the patient about worrisome symptoms or behaviors and

explain opportunities for improving self-management to decrease the risk of adverse outcomes. The goal was to identify self-care problems and symptoms so that acute crises could be prevented. Patients were reminded during each call to dial 911 or call their physician if they experienced serious problems such as increased shortness of breath or chest discomfort, pressure, or pain.

**CP E-Mail Reports and Patients' Summary Web Page.** CPs received weekly structured e-mail reports based on the patients' assessments. These reports included information about

**Table II.** Health and Self-Care Problems Reported During Automated Telephone Assessments

	REPORTS/100 PATIENT-WEEKS OF FOLLOW-UP	% OF ALL PATIENTS (N=52)
Not enough medication to last 2 weeks	8.2	35
Need a refill	6.9	29
Eat too much salty food	5.7	29
Not weighing self every day	15.0	46
Health compared with previous week: fair or poor	5.1	31
Shortness of breath compared with previous week	8.3	50
Drink too many fluids	7.0	29
Increased swelling in legs, feet, ankles, abdomen	3.4	23

**Figure 2.** Proportion of automated telephone assessments completed by pilot study participants.

how the CP could support the patient's HF self-care and help the patient avoid acute exacerbations, including the time frame within which the CP should follow up. Patient responses requiring more urgent attention were emphasized in CP reports. Reports also included educational messages about patients' symptoms as well as more general messages about HF self-management. CPs had access to a patient-specific, password-protected Web page with information about the patient's status in 4 domains: overall health, breathing, weight, and medication use. The Web site also included links to online resources for HF patients and their families.

**Recruitment. Patient Eligibility.** Patients were identified from electronic

medical records in a university-based health care system and the Department of VA health care system. HF patients were eligible if they had New York Heart Association (NYHA) class II or III diastolic or systolic HF. Patients were excluded if they had a serious mental illness or cognitive dysfunction diagnosis; did not speak English fluently; were receiving palliative care; were unable to use a telephone; or had no eligible out-of-home caregiver. Potential participants' physicians gave approval before patient contact.

**CP Eligibility.** Patients with an interest in participating were asked to name up to 4 individuals with whom they were in at least monthly contact either by telephone or in person and who might be willing to serve as their CP.

Each relationship was scored using the Norbeck Social Support Questionnaire (NSSQ),<sup>33</sup> a 9-item scale measuring closeness in relationships. Based on NSSQ scores and further conversation, a research assistant helped the patient identify the most suitable person to serve as the CP.

Potential CPs had to live outside of the patient's home, have access to the Internet, and have the ability to communicate via e-mail. CPs were screened over the telephone and were ineligible if they had a serious mental illness, did not speak English fluently, were younger than 21 years, had no working telephone in their home, or spoke to the patient <1 time/month.

In the baseline survey, patients provided information on their general health, HF knowledge, depressive symptoms, relationship with their CP, and demographic characteristics. HF knowledge was measured using the Dutch Heart Failure Knowledge Scale.<sup>34</sup> Depressive symptoms were measured with the Center for Epidemiologic Studies Short Depression Scale.<sup>35</sup> Patients also were asked about the importance of and difficulty in talking with their CP about their HF (S. L. Brown, PhD, unpublished data, 2007). CPs were asked about their general health, their relationship with their patient-partners, depressive symptoms, and demographics.

Patients and CPs completed follow-up surveys via telephone after 6 weeks of automated calls. Patients were asked about their self-care activities using a scale modified from an instrument developed for diabetes patients.<sup>36</sup> Patients also were asked to report their

perceived competence in HF self-care using a chronic disease self-management scale.<sup>37</sup> The follow-up surveys also assessed problems with using the system, patient and CP satisfaction, and problems related to increased CP caregiving burden.

**Analyses.** The automated telephone assessment system collected data on all patient calling attempts (eg, incomplete calls, busy lines, patient hang-ups before call completion, and out-of-service numbers), as well as responses to health and self-care questions. We calculated overall assessment completion rates, evaluated trends in assessment completion over the course of patients' participation, and compared completion rates across subgroups of patients. The prevalence of patient-reported problems was evaluated at the patient-week level (ie, the percentage of problem reports per 100 patients followed for 1 week) as well as at the patient level (the percentage of patients reporting each problem 1 or more times during the course of their 12-week participation). Patient-level reports were compared across subgroups with a  $P < .05$  for chi-square tests considered statistically significant.

## Results

**Recruitment.** A total of 173 HF patients, including 102 VA system patients and 71 university clinic patients, were identified from electronic medical records, approved for participation by their physician, and screened via telephone. Of these, 36 (21%) patients did not meet inclusion criteria, 28 (16%) patients or their CPs did not return their consent form, and 57 patients (33%) declined participation. Only 8 patients (5%) were excluded because they could not identify someone able and willing to serve as their CP. Among eligible patients, one potential CP refused to participate after being contacted. A total of 52 patients (29 VA system and 23 university clinic patients) participated in the study.

**Baseline Characteristics of Patients and CPs.** The average age of the patients was 65.9 years (range, 55–77 years), 38% were unmarried, 10% (5 patients) were racial/ethnic minorities, and 89% were men (Table I). More than one-third (39%) of patients had no more than a high school education. Fifty percent of patients had a left ventricular ejection fraction of  $<35\%$  or an NYHA class of III, and 51% reported fair or poor health during their baseline survey. Patient knowledge of HF at baseline indicated a less than optimal understanding of the importance of exercise (65%), appropriate fluid intake (31%), and recording daily weights (31%).

The average age of the CPs was 42.3 years (range, 33–52 years); 15% (8 CPs) were racial/ethnic minorities and 42% were men (Table I). Three-quarters (75%) of participating CPs were the patients' adult children, with slightly more than half of them being daughters; 15% were other relatives and 10% were friends. Compared with patients, CPs were more likely to have at least some college education (73%).

**Success Rate in Completing Assessments.** Patients received automated assessment calls for 6 to 15 weeks (mean, 12.3 weeks). Forty-four patients (85%) had at least 12 weeks of automated assessment call attempts, with a total of 637 patient-weeks of assessment attempts. Patients completed 586 weekly assessments, representing a successful completion of 92% of all patient-weeks with an assessment attempt. No drop-off in assessment completion rates occurred over time (Figure 2). Patients who had more severe HF (ie, ejection fraction  $<35\%$ ), were older, and were less educated were as likely to complete their assessments regularly as were younger, better educated, and less sick patients.

**Problems Reported During Assessment Calls.** Patients reported a variety of health and self-care problems that otherwise might have gone unnoticed (Table II), including running

out of medications (8.2 reports/100 patient-weeks), increased shortness of breath (8.3 reports/100 patient-weeks), and worsening health (5.1 reports/100 patient-weeks). Approximately 35% of patients reported running out of medications at least once, 50% reported increased shortness of breath, and 29% reported problems with their diet, including too much salty food or excessive fluids. Unmarried patients were more likely to report health and self-care problems, including running out of medication (11% of unmarried patients vs 5% of married patients;  $P = .008$ ), eating salty foods that resulted in increased shortness of breath (11% vs 4%;  $P = .0006$ ), and extremity swelling (7% vs 2%;  $P = .003$ ).

**Urgent Clinician Reports.** Forty urgent faxes were sent for 30 patients (7.5 fax reports/100 patient-weeks of participation). Reports were most commonly for shortness of breath along with at least one other problem, such as excess fluid intake or swelling ( $n = 22$  [47%]). Other reasons were rapid weight gain (16 reports) and shortness of breath without reporting other problems (9 reports). As a result of these issues, care managers and primary care providers actively engaged in conversation with the patients. One patient's dialysis schedule was altered as a result of an urgent fax report about weight gain. One physician noted, "It was useful to have this additional source of patient monitoring and support. The few alerts I received were all appropriate and signaled problems that indeed required immediate attention."

**Patient Feedback.** At 6 weeks post-enrollment, most patients (77%) agreed that it was important for them to talk with their CP about their illness, and only a small proportion (8%) reported that it was difficult to do so (Table III). Seventy-eight percent reported that their CP helped them to stay healthy, and 73% agreed that their CP assisted in solving problems. Ninety-eight percent of patients agreed that they liked the support they

**Table III.** Patients' Follow-up Survey Reports (n=51)

	% SOMEWHAT OR STRONGLY AGREE
It was important for me to talk with my CarePartner about my heart failure.	77
It was difficult for me to talk with my CarePartner about my heart failure.	8
I felt that my CarePartner helped me do things I need to do to stay healthy.	78
My CarePartner assisted me in solving my problems or concerns.	73
I liked the support that I received using the assessment calling system.	98
I would be more satisfied with my care if a system like this were available to patients.	92
I felt comfortable sharing information using the assessment calling system.	100
In general, I felt it was easy to use the assessment calling system.	96
I felt the recorded messages I heard on the system were easy to understand.	96
I found the system helpful for managing my heart failure symptoms.	92
My CarePartner was able to obtain information about my concerns using the system.	88
My CarePartner contacted me because of the assessment calling system.	82
The system helped me learn how to better manage my heart failure.	75
After participating in the CarePartner program, I feel more confident that I can take my heart failure medicine exactly as prescribed by my doctor.	73
I learned something new about how to take care of myself from the system.	65
The information I provided using the system resulted in a change in my heart failure care.	29
I felt like the assessment calls were a hassle.	16

**Table IV.** CarePartners' Follow-up Survey Reports (n=49)

	% AGREE OR STRONGLY AGREE
Provision of self-management support	
It was important for me to talk to my relative <sup>a</sup> about their heart failure.	92
It was rarely or never difficult to talk with my relative about their illness.	84
I found the CarePartner Program helpful for managing my relative's heart failure symptoms.	84
I learned something new about how to take care of my relative from the CarePartner program.	79
I was able to obtain information about my relative's concerns using the e-mail updates and Web site.	76
I contacted my relative because of the CarePartner program.	68
After participating in the CarePartner program, I feel more confident that I can help my relative take their heart failure medicine exactly as prescribed by their doctor.	68
I felt that I helped my relative do things they needed to do to stay healthy, like eat a healthy diet or exercise more.	68
The CarePartner program helped my relative learn how to better manage his/her heart failure.	53
I assisted my relative in solving problems or concerns.	47
Satisfaction with CarePartner program	
In general, I felt it was easy to use the CarePartner system.	97
In general, I was satisfied with the CarePartner program.	95
I felt that the e-mails I received and the Web site were easy to understand.	90
I would be more satisfied with my relative's care if a service like this were available to patients.	87
I felt comfortable obtaining information using the e-mail and Web site.	76
I liked the support that I received using the e-mail and Web site.	66
I felt that receiving the e-mails was a hassle.	3

<sup>a</sup>The relative or friend that the CarePartner provided support to during the pilot study.

received with the assessment calls, and 92% agreed that they would be more satisfied with their health care if such a service were available. Patients with and without a spouse were equally satisfied. Patients' mean depression score was unchanged at follow-up.

**CP Feedback.** During their follow-up survey (Table IV), the majority (92%) of CPs reported that it was important to talk to their relative or friend about their illness and that it was rarely or never difficult to do so. Eighty-four percent of CPs found

the program helpful for providing assistance to the patient, 79% agreed that they learned something about HF, and 68% reported that during the first 6 weeks of assessments, they contacted their partner because of the e-mail reports.

**Table V.** CarePartner Burden Reports From the 6-Week Survey (n=49)

	% RARELY OR NEVER
I felt that my health suffered because of my involvement with the care of my relative. <sup>a</sup>	98
I felt that my social life suffered because of my involvement in the care of my relative.	98
I felt my relative made requests of me that were over and above what he/she needed.	96
I felt that my relative expected me to take care of him/her as if I were the only one he/she could depend on.	96
Because of my involvement with my relative, I didn't have enough time for myself.	94
I felt that my relative affected my relationships with other family members in a negative way.	94
I felt that my relative didn't appreciate what I did for him/her as much as I would have liked.	94
I felt embarrassed because of my relative's behavior or condition.	94
I felt stressed trying to give to my relative in addition to carrying out other family responsibilities, my job, etc.	92
I felt resentment toward other relatives who could have helped my relative, but who did not.	82

<sup>a</sup>The relative or friend that the CarePartner provided support to during the pilot study.

Overall, there was almost no indication that the service increased caregiver burden or stress (Table V). Almost all CPs (96%) reported that they rarely or never felt that their partner asked for more help than was needed, 94% rarely or never felt that the service negatively impacted their personal time, and 92% rarely or never felt stressed by giving their partner attention. The mean CP depression score did not increase at follow-up.

## Discussion

Given findings of a recent meta-analysis demonstrating the benefits of HF telemonitoring,<sup>15</sup> health systems need cost-effective ways to provide HF patients with support between medical visits. It is unrealistic to expect telemonitoring for HF to soon become widely available, given that reimbursement is often unavailable for patient education services, nurses are in short supply, and questions have arisen about the cost-effectiveness of telephone care.<sup>38</sup> Rather, clinicians and health systems need to be resourceful in finding efficient new approaches to provide the self-management support their chronically ill patients need.

We found that structured, automated telemonitoring with feedback to patients' health care teams (for urgent and complex problems) and to informal caregivers (for routine support for treatment adherence and lifestyle changes) may be a feasible and effective strategy to increase patients' access to self-management

support. Patients completed automated telephone assessments regularly and reported a number of health and self-care problems that might otherwise not have been addressed. Both patients and their CPs learned new information about HF from the program, felt more confident in managing HF self-care, and worked together to make changes in self-management as a result of the assessments and follow-up CP e-mails.

The CP program links patients more closely with their care teams and informal caregivers. However, the current program does not provide a mechanism for CPs and clinicians to communicate directly. Ultimately, bringing informal caregivers under the umbrella of "care coordination" could be valuable, although several issues remain to be addressed. Perhaps the most serious concern is clinicians' lack of time for additional relationships with informal caregivers. In addition, patient privacy/confidentiality issues and professional ethics about information sharing must be considered when structuring clinicians' communication with informal caregivers. Despite these concerns, patients' family and other social network members often have an enormous impact on the patients' self-care.<sup>39</sup> Accordingly, creative strategies for leveraging these supports under the guidance of the patients' professional caregiving teams merit further attention.

This study had several limitations. It included a clinically diverse sample of HF patients from two health sys-

tems, but the number of patients was small. Longer follow-up is important to determine whether the program increases caregiving burden. The question of whether the increased monitoring and CP involvement unduly increases the burden on the health care team remains unanswered. Of course, one of the most important metrics for evaluating a program such as this is whether it positively improves patients' self-management and clinical outcomes. Those questions remain open, pending the results of a randomized trial currently being planned.

With those caveats, we conclude that automated telephonic monitoring of HF patients with feedback to informal caregivers outside of the patients' household is feasible, is perceived as useful by patients and their informal caregivers, and may increase the effectiveness of HF self-care support. Given the growing epidemic of HF and health care resource constraints, efforts to better utilize informal caregivers to promote HF self-management deserves more rigorous evaluation.

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