# The Development of Cultural-Specific Caregiver Telephone Coaching Program to Improve Heart Failure (HF) Home Care

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## Background

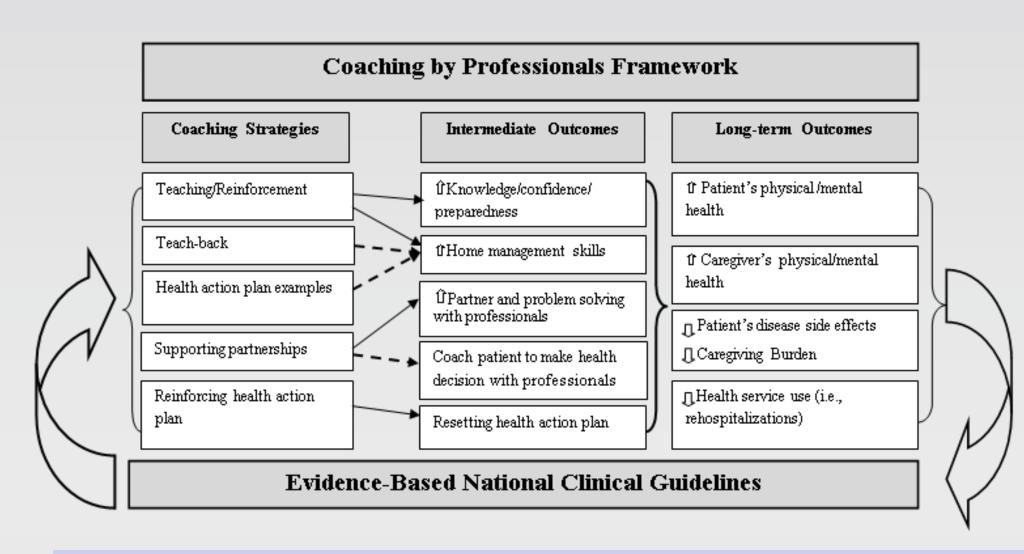
- The significance of this study is related to the prevalence of HF in African Americans at younger ages, with earlier severe complications and mortality. In addition, the economic burden of HF affects these populations greatly.<sup>1</sup>
- Ethnic-specific needs must be identified to help patients and family caregivers. Thus, a program to provide African American caregivers with skills to improve HF home care, reduce patient rehospitalization costs, and prevent caregiver burden is critically needed.<sup>2,3</sup>
- ➤ HF rehospitalization is often precipitated by excess dietary sodium, fluid weight gain, and poor medication adherence related to exacerbations of patient's HF symptoms. Family caregivers can help patients avoid such problems if they learn and practice daily HF care skills including monitoring and timely reporting of symptoms. <sup>4,5,6</sup>
- Due to escalating morbidity and mortality and high costs of HF, interventions with the potential for improving HF home care, reducing caregiving burden and HF rehospitalizations must be tested.<sup>7</sup>

## **Purposes**

Qualitative data from patients, family caregivers, and professionals experienced in HF care and national clinical guidelines were used to guide the development of cultural-specific caregiver telephone coaching program (FamHFcare). Coaching and teach-back strategies were used throughout.

#### **Theoretical Framework**

Figure 1. Coaching Framework for Improving Outcomes in Complex Chronic Care<sup>10</sup>



Coaching by professionals is an ongoing process (top horizontal box) underscored by using evidence-based national clinical guidelines (bottom horizontal box) for supporting health care self-management and with multiple feedback loops (curved arrows). Solid line arrows represent the published empirically verified relationships between coaching strategies and intermediate outcomes. The dashed lines indicate the relationships tested in

This study. The bold bracket represents the testing of all intermediate outcome data on each of the long-term outcomes in future quantitative studies. Curved arrows illustrate feedback loops linking the coaching by professionals based on national clinical guidelines (left arrow) to long-term outcomes, which link back (right arrow).

# Method

- > The University Medical Center Institutional Review Board approved the study.
- ➤ FamHFcare program was developed from qualitative data, <sup>8,9</sup> feasibility study, <sup>10</sup> and using national clinical guidelines HF home care management contents as a guide. <sup>11,12,13</sup> The project was completed in two interrelated phases: (1) conducted qualitative community based participatory study (n=30) to identify cultural-specific preferences of African American families managing HF at home; <sup>14</sup> and (2) current African American feasibility study funded by Blue Cross Blue Shield (n=20 caregivers, 10 were randomized to intervention group).
- ➤ Inclusion criteria used in other clinical trials and HF meta-analysis research will be used. Subjects are African American family members of patients with HF who had systolic and diastolic dysfunction as both require similar home care management regimens and ejection fractions <40% delineated by the international criteria. All subjects must provide written consent and able to read and write in English.
- Exclusion criteria are patients who have received or are on a waiting list for a heart transplant and patients with another terminal illness or Alzheimer's disease, a condition requiring additional information. Also excluded are those family members with a disability that precludes their ability to use the FamHFcare intervention materials.
- ➤ **Standard (usual) care**, given to all HF patients and their caregivers at KUMC hospital or outpatient clinics is based on JCAHO national core measures<sup>16</sup> (assess left ventricular function, prescribed ACEI or ARB for LVEF < 40%, provide discharge instructions, and smoking cessation counseling), implementation on the next doctor's appointment and then prescribed medications.

## **Culturally-Specific Coaching Intervention**

- FamHFcare intervention (Arm 1) is culturally specific for African Americans. It includes information on all HF core measures discharge and standard care information and also includes 5 weeks of post hospital coaching on specific HF home care skills practice with a teach-back strategy.
- Each FamHFcare coaching session includes information about HF management related to specific cultural strengths and challenges. The nurse coach helps the family coordinates arrangements for transportation, housekeeping, grocery shopping, and supportive telephone contacts.
- The coach also engages local church-based lay parish nurses in HF home support, which is highly accepted in this community. FamHFcare assists caregivers in setting up comprehensive but easy-to-follow daily HF home care.
- ➤ The nurse also facilitates discussions on ways to find low-cost low-sodium foods and use recipes with low fat, salt, and calories that are culturally accepted. The FamHFcare materials on dietary sodium have been modified for cultural preferences in common African American diets.
- Applications for reduced-cost drug programs, are completed to assist with medication expenses. Coaching is given on breathlessness and comorbid symptom recognition, as well as dietary and physical activity instructions per physicians and national core HF measures guides.
- ➤ Visuals for assessing ankle edema, cyanosis, or abdominal swelling in darker skinned individuals are used. Because of African Americans' reluctance to contact physicians, the nurse helps patients and caregivers practice monitoring and timely reporting of HF symptoms to professionals. As a reinforcement for cementing the FamFHcare information each caregiver is asked to "teach back" to the nurse what was learned in each session.
- Referral to mental health specialists is made for participants who are depressed and to social workers for low-income families needing assistance with medication, transportation, and monthly utility bills.

# **Preliminary Results:**

- In the current African American feasibility study, 80% of caregivers completed all four sessions and rated the telephone coaching information as "helpful" in problem-solving HF home care challenges.
- The teach-back data indicates that there was a 45% improvement (measured by monitoring the topics requiring reinforcement) in the HF knowledge, symptom monitoring and reporting from week 1 to week 5.
- ➤ 80% of participants stated that they had not discussed patients' advanced care planning or palliative care which were aligned with literature addressing their cultural challenges among African Americans and the new NINR Palliative Care: Conversations Matter campaign. Therefore, session five was added to FamHFcare to help families plan for palliative care.
- The feasibility study of FamHFcare found intervention costs (RN time, materials, telephone bills) were \$350 per patient.

## **Conclusion and Clinical Implications**

- This project described critical steps in developing cultural-specific caregiver telephone coaching program. The coaching program was evaluated as helpful in problem-solving HF related home care challenges.
- Providing family members with skills to partner with patients and professionals can reduce morbidity and rehospitalizations, lower the costs of care and improve home care and quality of life for African Americans with HF.

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