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Can we engage caregiver spouses of patients with heart failure with a low-intensity, symptom-guided intervention?

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ABSTRACT

Objective: Evaluate a pilot intervention to engage caregivers in management of heart failure (HF) patient symptoms.
Background: HF impairs quality of life; caregivers provide an important role in HF management.
Methods: We developed modules to help patients report and caregivers alleviate symptoms of depression, pain, dyspnea, and fatigue. Semi-structured interviews followed by a mixed inductive and deductive, team-based analysis were used to evaluate acceptability and feasibility in patients with HF and their caregivers.
Results: Participants ($n = 22$) expressed significant interest but few used the modules in follow-up. We identified three barriers to acceptability and feasibility: the quality of dyadic relationship, the timing and structure of the intervention, and the patient's perceived control over their illness.
Conclusions: Future interventions should evaluate dyadic relationship dynamics, match the timing and content of the intervention to the patient population, and enroll patients with perceived control over their illness to maximize intervention acceptability and feasibility.

Introduction

Heart failure (HF) remains the single diagnosis most commonly associated with hospital admission[1] and readmission[2,3] in the United States, and is a leading cause of disability and impaired quality of life (QOL).[4–6] Attempts to reduce hospital admissions and improve QOL through physician and nurse-directed disease management protocols,[7] telemonitoring,[8] readmission prevention interventions,[9] and heart failure self-management programs[10] have had limited success.[11,12] As a result, novel avenues are being explored. Two innovative areas of particular promise include: 1) targeting symptom management as a complement to disease management; and 2) engaging family caregivers to promote the health of patients with HF.

Traditional disease management interventions focus on fluid and salt intake, daily weights, and vital signs for HF. However, they do not measure or improve the large number of symptoms HF patients experience.[10,13–15] Symptoms in HF prompt health care utilization,[16–19] independently predict hospitalization and mortality,[20] and reduce quality of life.[4,21] Supplementing disease-specific approaches with symptom-based and palliative approaches may provide additional benefit, and are patient-centered.[22] Initial results of a pilot nurse-led symptom-based intervention in HF patients using nurse phone visits, counseling, and an interdisciplinary approach to symptoms suggests such an intervention is acceptable and feasible.[23]

Importantly, symptom-based approaches may lend themselves more strongly to caregiver engagement. Many caregivers desire to be involved in managing symptoms,[24,25] and their involvement may reduce symptoms and augment home management of HF.[26–28] Incorporating caregiver support in other chronic disease

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states, including depression and diabetes, also results in significant improvements in symptom relief and home management.[29,30]

However, none of these studies has assessed how best to engage caregivers in symptom management, nor what both patients and caregivers may find acceptable and feasible in terms of caregiver involvement. Understanding these perspectives is crucial to maximize the efficacy of an intervention prior to implementation.[31] For example, how many clinical contacts are made with the patient and what is required at each contact may be important for both efficacy and engagement with the intervention. Interventions that require significant regular input from the patient in the post-discharge period have not improved outcomes.[8,32] Interventions in stable outpatients have demonstrated benefit in terms of medication adherence and symptoms of depression, but require weekly phone calls in which patients report symptoms, frequent clinician intervention, and engagement of the caregiver by email or the internet.[33] A lower-intensity intervention may be more acceptable to sicker or recently-discharged patients, and be less resource-intensive, but this approach has not been explored. In this study, we evaluated patient and caregiver responses to a low-intensity pilot intervention designed to engage caregivers in symptom management, and report "lessons learned" from this experience to inform future interventions.

Methods

Intervention content

We adapted the content of the intervention from a previously-described intervention for cancer caregivers.[34] In the cancer caregivers intervention, interactive voice response was used to assess patient symptoms at weekly intervals; these were reported to caregivers via the Internet. Caregivers and patients were then directed to materials to support them in managing these symptoms at home.

To adapt the content, the primary author identified four "modules" (Depression, Pain, Breathlessness, and Fatigue) that are the most commonly experienced symptoms in HF patients, and developed HF-specific modules for patients and for caregivers.[4] This draft of each module was then edited by a diverse group of clinicians including an HF and a pulmonary nurse practitioner, a palliative care physician, psychologist, social worker, and an expert in health literacy and communications until consensus was reached on content and design.

Each module consisted of several pages of type-written text written for a layperson (sample depression module is available in the Appendix). The modules were specific to the patient or caregiver. Each module provided background information about the symptom, such as, "How do I know if I am depressed?" and "What causes depression?" The module then suggested methods for management of the symptom in a variety of domains (e.g. activity, diet, and medications) and strategies for communicating about the symptom with loved ones and health care professionals. We provided the modules in paper format to patients and caregivers, then conducted our interviews a mean of 4 weeks after receipt of the modules. We provided the modules in paper format to patients and caregivers, then conducted our interviews a mean of 4 weeks after receipt of the modules. If the patient or caregiver had not evaluated the module prior to our call, we gave them time during the scheduled call to review the module, then subsequently interviewed them.

Participant recruitment

To be eligible for inclusion, patients had to have a hospital admission with heart failure as the primary discharge diagnosis in the last six months. Patients with preserved or reduced ejection fraction were eligible. They also had to have at least one unrelieved symptom addressed by the modules (pain, fatigue, dyspnea, depression) despite treatment for heart failure by a primary care physician or cardiologist. This was assessed by asking potential subjects whether they had pain; fatigue, tiredness, or lack of energy; shortness of breath, feeling winded, or feeling like they did not get enough air; or feeling sad, blue, or not interested in things they typically enjoy. Patients also had to have a support person or caregiver, a functioning telephone, and adequate health literacy. A support person or caregiver was identified by asking patients, "Can you think of the one person besides a health care provider who helps you most with your heart condition?" Health literacy was assessed using the validated question, "How confident do you feel filling out medical forms for yourself?"[35] Patients who responded they were not confident or a little confident were excluded. Patients who permanently resided in a nursing home (where substantial care would be provided by someone other than the caregiver) or who were receiving hospice care were also excluded.

Informed consent was obtained from all participants. The study was approved by the Colorado Multiple IRB.

Study procedures

Patients and caregivers each chose one of the four modules to review that was most applicable to the patients' symptoms (caregivers could choose a different module from patients). In this way, every enrolled participant viewed a module, and all modules were viewed by at least one participant in each group. After participants reviewed the study materials, study staff experienced in qualitative methods conducted a semi-structured interview. We interviewed patients first, and subsequently interviewed their caregivers separately. The study staff explained the proposed intervention and asked for participants' feedback on the intervention framework, timing, content, and design. After one month, we conducted a follow-up interview to assess patient and caregiver use of the module. All interviews were digitally recorded and detailed notes were taken during the interviews. An example module and our question guide are contained in the Appendix.

Qualitative analysis

In order to consider the acceptability, feasibility, and determine the contextual nuances in the setting of HF patient and caregiver roles, we designed an emergent qualitative descriptive study[36] framed by naturalistic inquiry and social constructionist epistemology. These frameworks emphasize that a patient and caregiver's situational knowledge, experiences, and values influence their interactions with their environment and contribute to their perspective of value and truth.[37,38] We used utilization-focused evaluation principles to help derive themes.[37] This paradigm emphasizes the importance of engaging intended users of an intervention (patients and caregivers) in the evaluation of the intervention up-front.

Thus, when conducting our analysis, our group focused on the needs and interests of these intended users. For example, we asked patients, "On a scale of 1–10 (with 1 being "not at all" and 10 being "totally") how interested would you be in having your support person be informed about your symptoms (by either a telephone call or a website)?" We also asked both patients and caregivers after they had reviewed the module, "On a scale of 1–10, with 1 being "not at all likely" and 10 being "extremely likely," how likely is it you would use this type of handout to help with your symptoms? What would need to happen to make it a 10?" We were also interested in the influence of the patient and caregiver's context (such as duration of illness, severity of