Patient Education and Counseling 95 (2014) 371–377

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Self Management

Congestive heart failure self-management among US veterans: The role of personal and professional advocates

Eleni Skaperdas [a,*], Anaïs Tuepker [a,b], Christina Nicolaidis [b,c,d], Jessica K. Robb [a], Devan Kansagara [a,b], David H. Hickam [a,e]

[a] Portland VA Medical Center Health Services Research and Development, VISN 20 PACT Demonstration Laboratory, Veterans Health Administration, Portland, USA
[b] Division of General Internal Medicine and Geriatrics, Department of Medicine, Oregon Health and Science University, Portland, USA
[c] School of Social Work, Portland State University, Portland, USA
[d] Department of Public Health and Preventive Medicine, Oregon Health and Science University, Portland, USA
[e] Patient Centered Outcomes Research Institute, Washington, USA

ARTICLE INFO

Article history:
Received 25 September 2013
Received in revised form 15 February 2014
Accepted 2 March 2014

Keywords:
Primary care redesign
Self-management
Qualitative research
Heart failure
Veterans
US

ABSTRACT

Objective: Understand patients' experiences with primary care services for congestive heart failure (CHF) and explore the relationship between health services and self-management.
Methods: We conducted semi-structured interviews with thirty-nine patients with CHF receiving care at one Veterans Affairs Medical Center (VA). We analyzed data using thematic content analysis.
Results: Participants acknowledged the importance of ongoing engagement in the plan of care for CHF. They attributed success in this effort to be greatly influenced by personal advocates. The advocates included both members of the healthcare team with whom they had a continuity relationship and friends or family members who assisted on a daily basis. Participants also identified psychological symptoms as a major barrier to carrying out self-care.
Conclusion: Patients identify relationships with health care workers, help from family and friends, and mental health problems as major influences on the ability to manage their CHF.
Practice implications: Efforts to optimize CHF self-management should attend to health system and psychosocial barriers to care.

Published by Elsevier Ireland Ltd.

1. Introduction

Congestive heart failure (CHF) is a chronic illness associated with substantial morbidity and mortality [1,2]. CHF treatment usually requires both medication management and lifestyle interventions that aim to reduce the frequency of exacerbations. It is widely accepted that self-management, a concept often defined as "patients' active participation in their own treatment", is of crucial importance for achieving better clinical outcomes [3,4]. Patients are expected to self-manage their illness by following potentially complex medication regimens, adhering to dietary restrictions, and vigilantly assessing symptom changes such as weight gain and shortness of breath.

A variety of clinical approaches have been developed in the United States and abroad to engage patients with CHF more effectively, including short targeted programs providing education and practical disease management training. These time-limited programs have shown a limited impact on both measures of self-care and clinical outcomes such as hospitalizations and mortality [5–10]. An alternative approach is to promote systems that provide embedded and continuous self-management support within regular primary care clinic activities [11].

Efforts to improve care of patients with CHF in primary care clinics depend upon understanding patients' needs and crafting approaches that have the best chance of meeting those needs. An emerging literature qualitatively explores the realities and struggles of living with CHF [12]. Multiple studies document the emotional distress and difficulty that often accompany the diagnosis, progressive deterioration, and complex management of CHF [13,14]. However, less is known about patients' views of how healthcare providers encourage or inhibit self-management, particularly within an integrated healthcare system [15–17]. Our

---

[*] Corresponding author at: Portland VA Medical Center, Mailcode R&D63, PO Box 1034, Portland, OR 97207, USA. Tel.: +1 503 220 8262x56787; fax: +1 503 273 5367.
E-mail address: eleni.skaperdas@va.gov (E. Skaperdas).

http://dx.doi.org/10.1016/j.pec.2014.03.002
0738-3991/Published by Elsevier Ireland Ltd.

objective was to explore and understand how patients with CHF engage with health services and perform self-care, with the ultimate goal of using this information to guide patient-centered improvement of current clinical practices.

2. Methods

2.1. Setting

VA is the largest integrated care delivery network in the United States. VA offers subsidized care to a specific population: those who have served in the US military. This study was conducted in a large urban medical center, during the early stages of implementation of a patient-centered medical home (PCMH) model, known within VA as the Patient Aligned Care Team (PACT) initiative. This team-based model of care emphasizes increased access to care, efficiency, coordination, continuity, and expanded preventative services, especially for those with chronic illness [18]. Our Institutional Review Board approved this study.

2.2. Recruitment and sampling

We identified potential participants by searching the VA's electronic medical record system for patients with International Classification of Diseases, Ninth Revision diagnosis codes for CHF. To determine study eligibility, we conducted chart reviews; we excluded patients if they were not community dwelling, had a terminal illness, dementia, drug or alcohol abuse, a history of threatening behavior, major mental illness, were unable to give informed consent, or were not enrolled within VA primary care.

In the initial recruitment stage, we mailed 150 patients a letter describing the study and asking participants to return an opt-out form if they did not wish to receive a phone contact. Twenty declined contact, 44 contacted the research team indicating interest, and 86 did not respond. Our final sample consisted of 5 hospitalized patients who participated in pilot testing of the interview guide, 24 patients who opted in as a result of the recruitment letter, and 10 patients who did not initially respond to the letter but who agreed to participate when contacted in a follow-up phone call. To elicit experiences from patients with different levels of CHF severity, we purposely balanced our sample so that approximately half of the patients had been hospitalized for CHF in the past six months, ending recruitment when this balance was achieved and we had interviewed the majority of interested patients.

2.3. Data collection

A research assistant trained in qualitative interviewing techniques (such as open-ended response elicitation and reflective listening) conducted the interviews. All participants consented to have an audio recording of the interview. We used a semi-structured interview guide with questions and follow-up probes that asked about patients' interactions with the healthcare system and their experiences with self-care (see Appendix A). The interviewer kept field notes of emotional reactions, interactions, and communications not captured by the digital recording. Participants were allowed to include their supporters during the interview, and 11 interviews were conducted with a supporter present. Supporters were wives, other family members, or a close friend. No questions were asked about the supporters' medical problems or other personal information, but the supporters were asked to provide written consent for having their comments recorded and transcribed. Interviews ranged from 25 to 90 min, averaged 40 min, and were recorded and transcribed verbatim.

2.4. Data analysis

We analyzed our data using the technique of thematic analysis [19], a method that accommodates diverse approaches to qualitative data and emphasizes transparency and thoughtfulness about underlying analytic choices. In this study, we used an inductive approach (consistent with grounded theory) in which themes are identified in the process of understanding the data, as opposed to a theoretical approach driven by predominant models or questions in the existing literature. We analyzed data at an explicit rather than latent level, focusing on what participants said, not the constructs or contextual factors that in theory shape what was said. Additionally, we chose to use an essentialist/realist paradigm that draws implications from participants' statements, rather than a constructionist approach that would have theorized about the contextual factors shaping, constraining, or enabling those statements.

The full research team, consisting of VA primary care providers, experienced qualitative researchers, and research assistants, reviewed a subset of transcripts to develop an initial codebook focused on emerging themes. Following techniques of conventional content analysis [20], the codebook was then iteratively refined as two trained research assistants coded texts, identified new themes, and combined overlapping categories using Atlas Ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Differences in coding were discussed and reviewed with an experienced qualitative researcher, who facilitated consensus between the coders. The full research team then met to review and finalize themes.

We used a subjective heuristic to determine significance of themes and inclusion in this paper. A significant theme needed to: (1) be expressed by multiple participants; (2) be expressed as a central concern; and (3) relate to the research topics explored. In response to feedback from peer review, we made a final return to the coded data to clarify themes. Steps in our analytic process are shown in Fig. 1.

3. Results

3.1. Participant characteristics

Between May 2012 and December 2012 we interviewed 39 patients. Participants ranged in age from 53 to 89 years, with a mean age of 69 (SD = 8.8); two were female, two identified as African American, 28 as White, and nine declined to share information about race/ethnicity. Fifteen of the participants were currently married.

3.2. Findings

We identified four common themes describing how participants' experiences of living with and receiving care for CHF affected their ability to participate in self-management.

3.2.1. Good care is personal and responsive

Some patients described having their needs for care consistently met, and spoke enthusiastically of the care that they were receiving. Among these patients, a common refrain was that providers and/or other team members personally knew them and their health problems.

> "...they're aware of my history when I go in [to my primary care clinic]...they call me by first name...The doctors really care, and I mean, they call me at home and they're... just on it. And, I just feel so much more comfortable that uh, I'm gonna be around for a long while, maybe [chuckles]...She'll talk to me for