



PERGAMON

Social Science & Medicine 58 (2004) 631–643

SOCIAL
SCIENCE
&
MEDICINE

www.elsevier.com/locate/socscimed

A story of maladies, misconceptions and mishaps: effective management of heart failure

Carol R. Horowitz^{a,*}, Stephanie B. Rein^b, Howard Leventhal^c

^a Department of Health Policy, Mount Sinai School of Medicine, Box 1077, One Gustave L. Levy Place, New York, NY 10029, USA

^b Westside Medical Associates, New York, NY 10029, USA

^c Institute for Health, Health Care Policy and Aging Research, Rutgers University, New Brunswick, NJ, USA

Abstract

Congestive heart failure (CHF) is a common chronic disease with effective therapy, yet interventions to improve outcomes have met with limited success. Though problems in self-management are suspected causes for deterioration, few efforts have been made to understand how self-management could be improved to enhance the lives of affected patients. We conducted semi-structured interviews of 19 patients with CHF treated at an urban United States hospital to elucidate their knowledge and beliefs about CHF and to understand what underlies their self-care routines. A comparison of the themes generated from these interviews with the common-sense model for self-management of illness threats, clarifies how patients' perceptions and understanding of CHF affected their behaviors. Patients had an acute model of CHF. They did not connect chronic symptoms with a chronic disease, CHF, and did not recognize that these symptoms worsened over time from their baseline of moderate, chronic distress, to a severe state that required urgent care. As a consequence, they often did not manage symptoms on a routine basis and did not, therefore, prevent or minimize exacerbations. When they worsened, many patients reported barriers to reaching their physicians and most reported seeking care primarily in an emergency room.

These in depth responses elucidate how the interplay between acute and chronic models of a chronic illness effect self-management behaviors. These factors play a previously not understood role in patient's efforts to understand and manage the ever-present but symptomatically variable chronic illness that is CHF. These new concepts illustrate the tools that may be needed to effectively manage this serious and disabling illness, and suggest possible ways to enhance the self-management process and ultimately improve patients' lives.

© 2003 Elsevier Science Ltd. All rights reserved.

Keywords: Heart failure; Self-management; Patient beliefs

Introduction

Nearly 5 million Americans suffer from congestive heart failure (CHF) (American Heart Association, 2002). CHF is expected to double in prevalence by the year 2030 (US Department of Health, 1991), and the number of CHF-related physician visits and hospitalizations are also expected to rise in the coming decades

(Stewart, MacIntyre, Capewell, & McMurray, 2002). It is the most common reason for hospitalization and emergency department, or emergency room (ER) visits by persons over 65 years of age in the US. Hospital discharges for CHF have more than doubled from 1979 to 1999 (American Heart Association, 2002). Despite the myriad studies demonstrating the effectiveness of medications in improving survival and quality of life (Packer et al., 2001; CONSENSUS, 1987; SOLVD, 1991; Hunt et al., 2002), the prognosis for individuals with CHF is grim; 75% of the men and 62% of the women die within 5 years of diagnosis (Ho, Anderson, Kannel, Grossman, & Levy, 1993). In a more recent

*Corresponding author. Tel: +1-212-659-9567; fax: +1-212-423-2998.

E-mail address: carol.horowitz@mountsinai.org (C.R. Horowitz).

European study, median survival of patients hospitalized for CHF increased between 1986 and 1995 (from 1.2 to 1.6 years), but CHF patients' prognosis was still poor (MacIntyre et al., 2000). In fact, in contrast to mortality declines for most heart and blood vessel diseases, CHF deaths in the USA increased 145% from 1979 to 1999 (American Heart Association, 2002).

Recent clinical guidelines highlight the need for patients to have a solid understanding of CHF. Understanding is not confined to abstract, "book" knowledge (ACC/AHA Task Force, 1995). To avoid and/or minimize life-threatening exacerbations and maintain quality of life, persons with heart failure must receive and make regular and appropriate use of recommended treatments and adopt life style changes. US Federal health guidelines suggest that clinicians counsel CHF patients to adhere to drug regimens and a very low sodium diet to avoid fluid retention (Hunt et al., 2002). They should also teach patients to regularly monitor early markers of fluid retention that herald a deterioration, including increases in weight, swelling and shortness of breath, and appropriately respond to these markers. For example, patients should weigh themselves daily, contact their providers if their weight changes by more than 3–5 pounds, and adjust their diuretic dose based on weight changes (Konstam, Dracup, & Baker, 1994).

It is clear that many persons with CHF do not initiate and maintain the self-management strategies needed to avoid rapid deterioration of their condition and the need for emergency assistance. Without self-care, their condition typically deteriorates rapidly and patients then seek help at an ER—not the optimal place to treat patients with complex, chronic diseases—or they may require hospitalization for more intensive treatment. Researchers have begun to uncover the obstacles persons with CHF must overcome so they can manage this illness. While practice guidelines have synthesized best evidence and clinical judgment into specific recommendations for clinicians, many patients receive suboptimal care. Important physician factors that may contribute to CHF exacerbations are under-utilization of established therapy such as ACE inhibitors that can reduce morbidity and mortality, and suboptimal education, including low rates of general and dietary counseling (Smith et al., 1998; CONSENSUS, 1987; SOLVD, 1991; IPRO, 1996). Medication and dietary nonadherence (with sodium restriction), inadequate discharge planning and follow-up, lack of social support and not seeking medical attention promptly when symptoms recur also increase the risk of CHF exacerbations (Ni et al., 1999; Ghali, Kadakia, Cooper, & Ferlinz, 1988; Chin & Goldman, 1997; Vinson, Rich, Sperry, Atul, & McNamara, 1990; Tsuyuki et al., 2001; Michalsen, Konig, & Thimme, 1998).

Although these data suggest great potential to improve the care of CHF patients, a compelling need to do so, and specific areas in which efforts can be made to improve CHF-related function, programs designed to achieve these goals have met with limited success. Many of the programs which have shown improvements in patient outcomes have required substantial investments in multi-disciplinary staff time which may prove to be unsustainable and infeasible in practices with limited resources (Naylor, Brooten, & Jones, 1994; Rich, Beckham, & Wittenberg, 1995; Foranow et al., 1997; Hunt et al., 2002). Newer, less cumbersome programs involving nurse or pharmacist management have shown decreases in hospitalizations and improved quality of life (Blue et al., 2001; Krumholz et al., 2002; Varma, McElnay, Hughes, Passmore, & Varma, 1999; West et al., 1997), but with the exception of one study (Stewart & Horowitz, 2002), there has been no clear improvement in survival. The modest success of interventions points to the need for a fundamental reexamination of how CHF patients understand and manage their physical conditions.

Interventions conducted to date do not benefit from sufficient data on which potentially modifiable factors are responsible for suboptimal treatment, inadequate self-management and adverse CHF outcomes. Specifically, it is important to determine whether patients understanding and perception of CHF capture the features of the disease that are critical for their participation in their own care. For example, do people with CHF know why it is important to take certain medications, check their weights and avoid salt? Do they attend to and perceive the benefits of these protective procedures? Have patients been taught how to monitor the effectiveness of these strategies? Do they know what to do if the strategies do not appear to be working? Can we identify potentially correctable lacunae in their understanding and perceptions that are responsible for less than optimal self-management?

We combined two approaches to answer these questions. Initially, we conducted and analyzed a small set of patient interviews to elucidate patients' knowledge and beliefs about CHF, the strategies they use for self-care, the cues guiding these strategies and barriers they face in trying to maintain their health. We then examined the match between the themes we uncovered, and the factors identified as critical for self-management by the common-sense model of illness (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Diefenbach, & Leventhal, 1992; Brownlee, Leventhal, & Leventhal, 2000). According to this self-regulation model of the mental processes involved in the management of illness threats, self-management reflects how patients' conceptualize their perceptual experience with a disease.

We began with a hypothesis that three aspects of this model, depth, breadth and coherence, will prove critical

متن کامل مقاله

دریافت فوری ←

ISIArticles

مرجع مقالات تخصصی ایران

- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان دانلود رایگان ۲ صفحه اول هر مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات