Patients with heart failure had inadequate information about the disease and lacked the tools for optimal self care

Horowitz CR, Rein SB, Leventhal H. A story of maladies, misconceptions and mishaps: effective management of heart failure. *Soc Sci Med* 2004;58:631–43.

Q How do patients with congestive heart failure (CHF) perceive and understand the disease and self care?

DESIGN

Grounded theory.

SETTING

An urban, academic, tertiary care hospital in the US.

PATIENTS

19 patients (age range 52–89 y, 53% men) treated for CHF in the hospital, emergency department (ED), or internal medicine or cardiology clinics were identified from a database of inpatient and ambulatory encounters for CHF.

METHODS

Patients participated in audiotaped semistructured interviews (mean duration 50 min), which were transcribed verbatim. Questions focused on patients' illness perspectives, self care, help seeking behaviour, attitudes toward physicians, access to care, definition of and reaction to worsening of their condition, and a detailed description of their most recent critical episode of CHF, if one occurred. Dominant themes were identified by the constant comparative method and compared with the "common sense" model of illness.

MAIN FINDINGS

3 dominant themes emerged. (1) *Inadequate knowledge of the causes, symptoms, and consequences of CHF (gaps in depth and breadth)*. Patients did not connect CHF or a "weak heart" to their symptoms or understand acute and chronic CHF symptoms. Few labelled their illness as heart failure (lack of depth). Many could not provide adequate explanations for the cause of their condition or recent symptoms and did not demonstrate understanding of timelines, causes, and consequences of CHF (lack of breadth). Most did not describe CHF as a chronic illness existing between acute episodes. Patients even did not link severe symptoms to CHF or treating CHF. (2) *Failure to link symptoms with procedures—gaps in coherence*. (a) *Inability to prevent exacerbation*. Because patients did not have a coherent model of CHF as a chronic disease, they did not realise that they could minimise symptoms through self management (eg, diet or medication). Patients seemed unaware that their actions (eg, using high salt substitutes) were negatively related to their goals. (b) *Inability to recognise and address worsening symptoms*. Patients did not connect their symptoms to an illness with a specific name, so they did not react when their condition deteriorated or associate their symptoms with a course of action (lack of breadth). Symptoms were seen as vague sensations that had multiple, but unknown, causes and were not important. Patients believed that physicians were responsible for symptom control. (3) *Barriers to receiving care*. When patients recognised the need to seek medical care, they faced a new set of barriers, which precluded or thwarted development of a clear action plan and led to crisis based responses and inefficient use of care. Patients often didn't know how to obtain care outside of the ED

for worsening symptoms. Many did not know how to call their physicians or thought the ED was the best place to receive care because of the availability of tests, technology and treatment. Patients who did call their physicians often waited hours for a response: "In the time it takes to call them, I'm in good hands in the ER." Other barriers to obtaining timely outpatient care included unwillingness to second guess physicians; inability of physicians to discuss cases over the phone; being too ill for an office visit; and confusion about which of the many doctors who provided their care was in charge.

CONCLUSION

Patients with congestive heart failure had inadequate information about their disease and did not have the tools to prevent, recognise, or act to address exacerbations before their condition deteriorated, which often led to treatment in the ED.

Commentary

Although previous studies have focused on patient and family experiences with CHF, the study by Horowitz *et al* illustrates the very real "disconnect" between the goals and foci of medical and nursing management and the realities of patient perception, interpretation, and action.

The authors used a grounded theory approach, comparing themes generated in participant interviews with tenets of a "common sense" model of illness. Although this strategy may not be considered "true" to the foundational elements of grounded theory, it revealed important themes in CHF self management that provide insight into patient and family experiences and challenge some of the traditions of medical and nursing management of CHF. Themes indicated that patients' inadequate knowledge about their illness, its treatment, and the potential for exacerbations led to dissonance between the models of care provision that are typically seen in cardiac care. Specifically, a lack of interface existed between acute/curative and chronic/palliative approaches to care. Patients seemed to interpret their symptoms from an acute/curative perspective; that is, they did not recognise the chronic nature of their illness and consequently, did not report or manage symptoms in a manner that fit the chronic care model used by practitioners. When symptoms worsened, patients and families sought emergent care rather than viewing the exacerbation in the context of long term illness management in partnership with their primary care providers. Although health professionals often promote self management approaches for chronic conditions such as CHF, patients often lack the prerequisite knowledge and decision making abilities to engage in self management. Indeed, the underlying philosophy of care in the chronic illness model may be at odds with patients' own interpretations of illness, symptoms, and treatment.

The findings of this study clarify the complexities of the CHF trajectory and the importance of clear and regular dialogue with patients. Furthermore, presenting CHF as a chronic illness might orient patients to their role in symptom recognition and prevention of exacerbations. The healthcare system can only be responsive to patients' needs if practitioners and care recipients function from a shared understanding.

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