



# The patient work system: An analysis of self-care performance barriers among elderly heart failure patients and their informal caregivers



Richard J. Holden<sup>a, b, \*</sup>, Christiane C. Schubert<sup>c</sup>, Robin S. Mickelson<sup>d</sup>

<sup>a</sup> Department of BioHealth Informatics, Indiana University School of Informatics and Computing, Indianapolis, IN, USA

<sup>b</sup> Center for Health Informatics Research & Innovation (CHIRI), Indianapolis, IN, USA

<sup>c</sup> Department of Medical Education, Loma Linda University School of Medicine, Loma Linda, CA, USA

<sup>d</sup> Vanderbilt University School of Nursing, Nashville, TN, USA

## ARTICLE INFO

### Article history:

Received 15 February 2014

Accepted 8 September 2014

Available online

### Keywords:

Work system

Healthcare

Elderly patients

## ABSTRACT

Human factors and ergonomics approaches have been successfully applied to study and improve the work performance of healthcare professionals. However, there has been relatively little work in “patient-engaged human factors,” or the application of human factors to the health-related work of patients and other nonprofessionals. This study applied a foundational human factors tool, the systems model, to investigate the barriers to self-care performance among chronically ill elderly patients and their informal (family) caregivers. A Patient Work System model was developed to guide the collection and analysis of interviews, surveys, and observations of patients with heart failure ( $n = 30$ ) and their informal caregivers ( $n = 14$ ). Iterative analyses revealed the nature and prevalence of self-care barriers across components of the Patient Work System. Person-related barriers were common and stemmed from patients’ biomedical conditions, limitations, knowledge deficits, preferences, and perceptions as well as the characteristics of informal caregivers and healthcare professionals. Task barriers were also highly prevalent and included task difficulty, timing, complexity, ambiguity, conflict, and undesirable consequences. Tool barriers were related to both availability and access of tools and technologies and their design, usability, and impact. Context barriers were found across three domains—physical—spatial, social—cultural, and organizational—and multiple “spaces” such as “at home,” “on the go,” and “in the community.” Barriers often stemmed not from single factors but from the interaction of several work system components. Study findings suggest the need to further explore multiple actors, contexts, and interactions in the patient work system during research and intervention design, as well as the need to develop new models and measures for studying patient and family work.

© 2014 Elsevier Ltd and The Ergonomics Society. All rights reserved.

“[C]linicians are not the only actors in health care; patients also play an important role in their own care ... the patient’s work must be examined in our efforts to reduce errors.” (Unruh and Pratt, 2007, p. S236)

## 1. Introduction

The healthcare industry undeniably recognizes, even embraces, the human factors/ergonomics (HFE) discipline, its concepts, and

methods (Carayon et al., 2014; Hignett et al., 2013; Russ et al., in press). HFE approaches to safety management, human–computer interaction, teamwork training, and design have become valued tools in international campaigns to improve the safety and quality of healthcare delivery since the turn of the century (Carayon, 2012; Institute of Medicine, 2000; Vincent, 2006; World Health Organization, 2009) and in some cases earlier (Weinger et al., 1994, 1998).

In a recent paper, Holden et al. (2013a) argued that maintaining HFE’s perceived value to an industry depends on the discipline’s ability to support the industry’s evolving practices and priorities. Addressing HFE in healthcare specifically, they and others (Unruh and Pratt, 2007; Vincent and Coulter, 2002) underscored the evolving role of the patient from passive recipient of care to “actor.” The authors accordingly promoted a branch of HFE that they call

\* Corresponding author. Department of BioHealth Informatics, Indiana University School of Informatics and Computing, Walker Plaza – WK319, 719 Indiana Avenue, Indianapolis, IN 46202, USA. Tel.: +1 317 278 5323.

E-mail address: [rjholden@iupui.edu](mailto:rjholden@iupui.edu) (R.J. Holden).

**patient-engaged human factors**, or the application of human factors theories and principles, methods and tools, analyses, and interventions to study and improve *work done by patients and families*, alone or in concert with healthcare professionals (Holden et al., 2013a; Holden and Mickelson, 2013).

### 1.1. Studying the patient work system: toward patient-engaged human factors

A majority of HFE applications in healthcare target “professional work,” or “work in which a healthcare professional or team of professionals are the primary agents, with minimal active involvement of patients, family caregivers and other non-professionals” (Holden et al., 2013a, p. 1676). Nevertheless, there are many good examples of HFE applied to the work of unpaid individuals, including patients (Fisk et al., 2009; Lipka et al., 2008; Morrow et al., 2005; Pak and McLaughlin, 2011). This means that there are already HFE models and tools available to support patient-oriented research and interventions but that they need to be better advertised and more widely applied in the healthcare arena. In this paper, we apply one of HFE’s foundational tools, the systems model (Carayon, 2006), to investigate the factors shaping self-care performance among elderly heart failure patients and their informal caregivers.

#### 1.1.1. Self-care in chronic illness and heart failure

Chronic illness is a controllable, but not curable illness lasting more than one year that often limits activities of daily living and requires continuous medical attention (National Center for Health Statistics, 2013). Chronic illness is globally prevalent, especially among the elderly. In the US, 80% of older adults have at least one chronic disease and 50% have two or more, accounting for 75% of healthcare expenditures (Centers for Disease Control, 2009). Annually over half of all deaths in the US are related to chronic illness (Kung et al., 2008). Controlling and managing the symptoms and progression of chronic illness is hardly a task for clinical professionals alone (Bodenheimer et al., 2002) because it depends critically on the performance of recommended self-care behaviors such as medication taking and nutrition management by patients or their informal (lay) caregivers (for an HFE-oriented review, see Mitzner et al. (2013)).

This study focuses on those managing heart failure, a chronic illness described in Table 1. Heart failure is a prevalent, costly, progressive illness characterized by impairment of the pumping or filling functions of the heart. This impairs the delivery of oxygen to the body (causing shortness of breath and fatigue) and limits the body’s ability to expel wastes, particularly water, whose accumulation can cause harm. Multiple self-care activities are recommended to heart failure patients. Adherence is limited, despite the designation of self-care as a Class I recommendation—i.e., having the highest benefit-to-risk ratio—in professional guidelines for managing heart failure (Yancy et al., 2013). Non-adherence is estimated at 40–60% for medication taking, 12–92% for dietary and fluid restriction, 25–88% for daily weighing, and 41–58% for exercise (Moser and Watkins, 2008; van der Wal et al., 2005; Wu et al., 2008). This is problematic because excessive fluid congestion can lead to sudden death and non-adherence is associated with increased mortality and hospitalizations, reduced quality of life, and decline in health status (Ditewig et al., 2010; Jovicic et al., 2006; Lee et al., 2009).

Several studies identify barriers to performing recommended heart failure self-care (McEntee et al., 2009; Oosterom-Calo et al., 2012; Siabani et al., 2013; Zaveritnik, 2014). Most of the studied barriers are patient-related factors such as age, lack of knowledge, and low self-efficacy (Oosterom-Calo et al., 2012). Person-level

**Table 1**

Heart failure and heart failure self-care.

<p><i>Summary (Remme and Swedberg, 2001; Rich, 2001; Yancy et al., 2013)</i></p> <ul style="list-style-type: none"> <li>• Heart failure is a group of symptoms (breathlessness, fatigue, and/or ankle swelling) that occur when the ability of the heart to eject or fill with blood is impaired.</li> <li>• Caused by heart attack, prolonged uncontrolled hypertension (high blood pressure), and other chronic cardiovascular diseases that progressively change the physical structure of the heart.</li> <li>• Leading and fastest growing cause of death in the US among all cardiovascular diseases.</li> <li>• Also known as chronic heart failure or congestive heart failure.</li> </ul> <p><i>Prevalence and costs (Chaudhry et al., 2010; Curtis et al., 2008; Go et al., 2014)</i></p> <ul style="list-style-type: none"> <li>• 5.1 million Americans aged <math>\geq 20</math> have heart failure, projected to increase 25% by 2030</li> <li>• 12% prevalence rate in adults aged <math>\geq 65</math>; 80% of heart failure patients are aged <math>\geq 65</math></li> <li>• Projected US costs of heart failure: \$32 billion (2013), \$61.4 billion (2020)</li> </ul> <p><i>Recommended self-care behaviors (Riegel et al., 2009, 2011; Yancy et al., 2013)</i></p> <ul style="list-style-type: none"> <li>• Medication adherence (scheduled and as needed)</li> <li>• Symptom monitoring, including daily weighing (and appropriate response)</li> <li>• Restriction of dietary sodium intake</li> <li>• Restriction of fluid intake</li> <li>• Smoking cessation, alcohol restriction</li> <li>• Regular exercise (for cardiac fitness) of 30 min or more</li> <li>• Weight loss</li> <li>• Keeping regular appointments, communicating with clinicians</li> </ul>
---

characteristics of the informal caregivers who help co-manage the disease are rarely considered and relatively few studies address barriers associated with healthcare professionals (Siabani et al., 2013). Characteristics of self-care tasks (e.g., treatment complexity, regimen side-effects) and tools (e.g., medication packaging, documentation systems) are less commonly studied but quite pertinent to self-care (Wu et al., 2008). Contextual or “environmental” barriers have been studied with variable regularity and often reveal self-care difficulties due to lacking social, financial, and community resources (e.g., transportation, access to care) (Arbaje et al., 2008; McEntee et al., 2009). The emphasis on barriers related to patient characteristics may explain why so many heart failure self-care interventions involve education, intensified contact with clinicians, or both (Ditewig et al., 2010; Molloy et al., 2012). Interventions focused on redesigning the patient’s work and work system (e.g., beyond educating the patient) are rare and could be promoted by considering self-care from a whole-systems human factors perspective.

Another limitation of the literature on heart failure self-care barriers is the relative shortage of studies with elderly patients (Zaveritnik, 2014). Further, quantitative studies have been limited in scope (i.e., measuring fewer barriers, concurrently) and ability to understand how barriers operate in practice. Qualitative studies, in contrast, have used general probes to elicit a broader range of barriers (e.g., Riegel and Carlson, 2002; van der Wal et al., 2010); however, these rarely probed about specific categories of barriers nor provided reliable information about barrier prevalence. Critically, *no single empirical study has used a systems model to elicit barriers to heart failure self-care*. This is problematic because systematic reviews that have used systems frameworks to synthesize the barriers literature clearly demonstrated that self-care performance is shaped by multiple factors at and above the individual level of analysis (McEntee et al., 2009; Wu et al., 2008). Furthermore, conceptual models of geriatric self-care recognize that self-care is shaped by an interaction of patient characteristics, home and community factors, aspects of the healthcare system, and tool design (Murray et al., 2004). Indeed, applying a human factors framework depicting the entire system in a single study has the added benefit of showing how multiple system factors combine and interact to shape self-care performance (Carayon et al., 2014;

Download English Version:

<https://daneshyari.com/en/article/6947967>

Download Persian Version:

<https://daneshyari.com/article/6947967>

[Daneshyari.com](https://daneshyari.com)