Examining patient work: The who, what, where, and why of chronic illness self-care

Richard J. Holden\textsuperscript{a}, Dan Nathan-Roberts\textsuperscript{b}, Rupa S. Valdez\textsuperscript{c}

\textsuperscript{a}Department of BioHealth Informatics, Indiana University School of Informatics, Indianapolis, Indiana, USA
\textsuperscript{b}Department of Industrial and Systems Engineering, San José State University, San Jose, California, USA
\textsuperscript{c}Department of Public Health Sciences, University of Virginia, Charlottesville, Virginia, USA

1. Introduction

Human factors/ergonomics (HFE) professionals have studied and improved the work of healthcare professionals for over 50 years. The next era of HFE in healthcare must also study and improve the health-related activities of patients and families (Holden et al., 2013). The “patient work” performed by these non-professionals is an underappreciated but critical contributor to health and disease management that can be systematically understood and supported using HFE methods and concepts, including work system analysis and user-centred design (Valdez, Holden, Novak, & Veinot, in press; Zayas-Cabán & Valdez, 2012).

2. Method

Using a work system analysis framework, we analysed data on elderly patients with chronic heart failure. Participants included 62 patients (mean age=73, 45% female, 29% non-White) and 35 family members residing in urban and rural areas of the Southeast US. Participants completed semi-structured interviews and observations at home and during scheduled outpatient clinic visits. A work system framework (Carayon, 2006) was used to collect and analyse data on the persons (Who), tasks (What), contexts (Where), and goals (Why) of self-care (Figure 1). These four elements were identified in transcribed interview and observation data, followed by conventional content analyses to identify themes about each (Hsieh & Shannon, 2005).

![Figure 1. Work system framework for assessing the Who (Persons), Where (Context), What (Tasks), and Why (Goals) of self-care.](image)

3. Results

The study produced 92 interviews, 41 in-clinic observations, and 44 in-home observations.

When examining who was involved in the patients’ chronic illness, we found that the patients themselves had major physical, cognitive, and functional limitations (Holden, Schubert, & Mickelson, 2015). While no one lived in complete isolation, the involvement of others varied from occasional visits from friends to live-in assistance from family members who essentially took over the patient’s care activities. Healthcare professionals were also involved, even outside of clinic visits, and in many cases served as the primary source of information and motivation. Both family and healthcare professionals were generally helpful but at times hindered self-care because they were bad role models, too insistent or intrusive, or provided erroneous information. For some, care was distributed across a broad social network of multiple clinicians, friends and family, and community members.
Examining what was done confirmed that patients and informal caregivers experience a large and varied workload of health- and disease-related activities (Steiner, 2012). The most common and time-consuming activities were daily logging of vitals and health status, procuring food and medications, and attending appointments. Another common set of tasks can be called “articulation work” (Strauss, 1985), or managing logistics such as appointments and health insurance, so that other health-related activities (e.g., taking medications) could be performed. We found that activities directly related to health and illness were inextricable from personal and logistic tasks. For example, taking diuretic medications disrupted patients’ days and nights due to frequent urination; consequently, patients would not take medications when traveling or attending clinical appointments. As another example, food consumption, symptom monitoring, and decisions about social activity (e.g., family meals) formed a highly interconnected control loop.

The contexts where patient work was performed varied, although most activities occurred in the home. Other settings were outdoors, at others’ homes, in the clinic or hospital, at the neighbourhood pharmacy or grocery store, the gym, community meeting places, in transit, and at school or work. Each of these places had physical-spatial, social-cultural, and organizational aspects that promoted or hindered self-care. Homes and restaurants, for example, were settings where food norms were enacted, often to the detriment to patients’ medically restricted diets. Outdoor and community settings often posed difficulties of physical access and ambulation. Homes and work schedules and demands often imposed constraints on the timing and duration of health-related activity.

We found that patient work activity was goal-driven but that why patients acted was variable. For example, even health goals varied from recovery to longevity to quality of life to accelerating the end of life. We observed patients balancing multiple goals, for example, getting enough help while remaining autonomous or enjoying meals while maintaining their diet. Some would disregard or “sacrifice” one of two conflicting goals, rather than attempting to achieve balance. In some, goal-driven behaviours resembled the kind of resilient work performance that has been studied in other work domains, and therefore suggest the possibility that patients can be a source of resilience (Schubert, Wears, Holden, & Hunte, 2015).

4. Discussion

The work of chronically ill patients and their families was amendable to the kind of HFE methods and analyses that have long been applied in professional work domains. Our approach systematically identified relationships, affordances, constraints, and breakdowns that are taken for granted but instrumental to the successful performance of self-care and other health- and disease related behaviours. Based on our findings, we recommend: (1) introducing coordination mechanisms to support the distributed actor network involved in care (Mickelson, Willis, & Holden, forthcoming); (2) systems to represent and communicate patients’ task load and workflow to aid task “assignment” and performance; (3) replicating the support structures in patients’ homes for out-of-home use; and (4) technologies to communicate and manage patients’ goals relative to treatment plans. We also recommend adapting classical research methods to accommodate the unique characteristics of patients’ home and community settings (Holden, McDougald Scott, Hoonakker, Hundt, & Carayon, in press).

Acknowledgements

RJH were sponsored by grants from the National Institute on Aging (NIA) of the US National Institutes of Health (NIH) (K01AG044439) and grants UL1 TR000445 and KL2 TR000446 from the National Center for Advancing Translational Sciences (NCATS/NIH) through the Vanderbilt Institute of Clinical and Translational Research (VICTR). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

References


