Patient Work as a Maturing Approach Within HF/E: Moving Beyond Traditional Self-Management Applications

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Over the last five years, human factors and ergonomics (HF/E) applications in healthcare have expanded beyond the institution to encompass the homes and communities of patients. The patient work approach has been developed as a means of formalizing the theoretical and methodological foundations of applying HF/E within this new domain. Early applications of the patient work approach were confined to studies of relatively straightforward self-management tasks. As the patient work approach matures, however, its application is spreading to more complex subdomains of health management in home and community settings. This panel will focus on cutting edge application and methodological areas of patient work. Each panelist will introduce their work, present challenges related to expanding the patient work approach in a new direction, and engage with audience members to address these challenges and brainstorm ways in which the patient work approach can be further adapted to more intricate healthcare challenges.

SUMMARY

The roles and responsibilities of patients are transforming, as healthcare continues to transition from institutional to home and community based settings. Concepts such as "patient engagement," "patient activation," and "shared decision making" are increasingly used within the healthcare domain to express patients' growing participation in decisions and actions surrounding their health. Although the field of human factors and ergonomics (HF/E) has a long history of healthcare applications, the majority of these contributions have concentrated on institutional settings. It is only recently that our field has begun to achieve critical mass in terms of healthcare applications within patients' homes and communities.

Patient work has been one means of formalizing a theoretical and methodological approach at the intersection of HF/E and healthcare within the home and community. The foundation of an extended conceptualization of work is found in Hal Hendrick's definition of work as "any form of human effort or activity, including recreation and leisure pursuits" (Hendrick, 2002, p.1). With this broader conceptualization in mind, the activities that patients engage in to maintain and improve their health (e.g. managing a diet, tracking blood glucose levels, communicating to family and friends about health) may be considered a form of work.

Recently, macroergonomics professionals have begun to formalize the theory of patient work. Both the National Academies of Science (National Research Council, 2011) and researchers tied to the University of Wisconsin—Madison (Holden et al., 2013) have formulated conceptual models of the patient work system. These models have been synthesized with models from the social sciences to further develop the theoretical underpinnings of patient work (Valdez et al., 2015).

Formal application of the patient work approach is now visible within the HF/E literature. Originally, these applications focused almost exclusively on systematic understanding of the ways in which patients and their informal caregivers approached a specific self-care or self-management task. For example, Holden and colleagues studied the self-care management practices of individuals living or caring for someone with heart failure (Holden & Mickelson, 2013; Holden et al., 2015a). Valdez (2012) studied how patients approached health information communication and Zayas Cabán (2012) studied how patients approach health information storage. Thompson and colleagues (2015) focused on asthma patients' approach to managing their condition with a novel mHealth technology.

Methodologically, effort has been concentrated on adapting formal HF/E methods to the study of patient work and determining how to apply these methods within the field sites of patients' homes and communities. Thus,

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progress has been made in terms of the scientific and practical aspects of data collection and analysis. In particular, several HF/E researchers have created data collection instruments that enable formal application of a patient work system theory. Additionally, Nathan-Roberts and colleagues (2015) have begun to explore how measures of workload may be applied within a patient work context. Holden and Valdez, along with additional colleagues (2015), have initiated a discussion on how HF/E professionals should approach interaction with patients and others in home and community settings. They have also begun to codify these recommendations (Valdez and Holden, forthcoming).

This panel builds directly on this previous work and on panels presented in 2014 and 2015 at the HFES Annual Meetings. The first panel (Valdez et al., 2014) introduced the patient work approach and early applications focused on patient self-management. The second panel (Holden et al., 2015b) focused on the methodological challenges of conducting patient work research and practice in patients' homes and communities. Both panels were well attended and generated significant discussion. The proposed panel for 2016 focuses on new frontiers in patient work. In particular, panelists will explore more sophisticated applications both in terms of domain complexity (e.g., health IT privacy and security, transitions of care from institutional to community settings, and medication adherence) and in terms of methodological complexity (e.g., combination with experimental design, combination with applied anthropology). The majority of panelists are new (different from those in 2014 and 2015), both to avoid any repeated discussion and to demonstrate the growing relevance and innovative directions associated with the patient work approach.

The panel will begin with an introduction of the panel's purpose and scope. The chairs will also provide a brief synopsis of the 2014 and 2015 discussions to frame the panel. Afterward, each panelist will present a short overview of how they have applied a patient work approach within the context of a cutting edge application or methodological area. In addition to introducing their work, panelists will also present challenges faced in applying the patient work approach within these domains. Following these brief individual presentations, the session chairs will lead the panelists and audience in an interactive discussion. The purpose of the discussion will be to brainstorm potential solutions to the general challenges represented by panelists' specific experiences. Additionally, the discussion will serve as a means of collectively exploring future directions for the patient work approach.

PANEL PRESENTATIONS

Applying Patient Work to the Study of Health IT Privacy and Security

Kelly Caine, Clemson University, USA

One value of applying a patient work perspective is that it gives a voice to patients in the doctor-patient relationship and in their own care. Some of my colleagues have argued that should patients decide to exercise their right to privacy over their health information, they would not provide care for them (Caine & Tierney, 2015). However, if we conceptualize providers and patients as partners, both working together toward the goal of the best possible care, perhaps health IT can be designed to simultaneously both stakeholders' needs.

One unique insight gained from applying a patient work approach in privacy and security of health information technology (IT) is the distinction between *data* and *information*. Currently, what is collected, stored and displayed in Electronic Health Records is data - discrete elements not combined into a useful recommendation, warning or advice. On the other hand, patients, especially those considered contributing partners in their own care, can provide *information*. Doctors have known for a long time to "listen to your patient, he is telling you the diagnosis"(William Osler). Unfortunately, recently, it seems computers may have caused complexity in applying this philosophy.

The future of applying a patient work approach in privacy and security in health IT is multifaceted. As more information is collected about humans, their environments and behavior, patients will be called upon to make more privacy and security related decisions about their health information. All information about individuals, from where they live to what they ate last night, can impact health. Consequently, health information at its best and most useful must be comprehensive. However, a comprehensive view of the person that includes the most intimate details of daily life requires extensive and meaningful privacy protection. This notion of privacy must be aligned with the everyday experiences and expectations of patients as well as with legal requirements. Additionally, because providers are already overburdened by the amount of data they must process during a clinical encounter, decisions about data and information sharing must also account for clinician needs. A patient work approach can help elicit the privacy and security perspectives of patients and determine how these perspectives can be reconciled with legal requirements and clinician needs.

Combining Patient Work and Experimental Design Approaches for Health Information Presentation

Kapil Madathil, Clemson University, USA

Recent studies have found that consumers are increasingly using Internet-based resources (Atkinson, Saperstein, & Pleis, 2009; Hesse et al., 2005). Past studies have suggested consumers use search engines to obtain this information from sources such as research literature published in the media, reports provided by governmental agencies, resources provided by such entities as the Mayo Clinic and the National Institutes of Health (NIH), online social networks, and websites run by individuals (Madathil, Rivera-Rodriguez, Greenstein, & Gramopadhye, 2015). Federal agencies have begun providing data comparing the quality of healthcare systems/providers to enable consumers to make informed choices about their healthcare needs, revealing the variability among providers (Sinaiko, Eastman, & Rosenthal, 2012). These data, referred to as public reports or consumer reports, are an effort to compare providers in a specific specialty within a certain geographic region. The past decade has seen a proliferation of such systems providing summaries of quality-of-care data. However, recent studies suggest that such reports are seldom used by consumers (Kolstad & Chernew, 2009). Rather, these studies suggest that consumers primarily rely on recommendations from friends, relatives and physicians as their sources of information when selecting a provider (Gibbs, Sangl, & Burrus, 1996; Madathil, Greenstein, & Koikkara, 2014). Although numerous surveys and focus groups have suggested that consumers highly value information provided in public reports, very few use it when making a decision (Madathil et al., 2015; Sinaiko et al., 2012).

Public report presentation formats are based on the faulty assumption that consumers know the factors important to them and how each measure influences their specific condition (Hibbard & Peters, 2003). As a majority of healthcare consumers are novices in terms of the health information they are seeking, there is a need to develop interface designs to support their sensemaking needs. Since informed decisions are critical to both individual health and effective operation of the healthcare system, it is imperative to identify approaches to the design of effective public report presentation and dissemination mechanisms. This research investigates the effect of narratives and active engagement on the comprehension of public report data and the decision making process. A patient work approach layered with an experimental design approach was used as reported below.

Using 200 participants, we employed a 2 (public report information presented in the standard format, in a narrative) * 2 (engagement with each quality metric: none, active) between-subjects experimental design. After being randomly assigned to one of four scenarios involving researching dialysis facilities, the participants indicated their preference of facility and their level of confidence in their choice, followed by a knowledge quiz evaluating how they interpreted the information presented, the NASA-TLX, and a usability questionnaire. This narrative format resulted in higher comprehension scores and higher mental demand, with the latter scoring higher with no engagement than with active. Participants felt that the usability was higher with the narrative, perhaps because visualizing themselves in the scenario increased the perceived relevance of the quality measures. The high comprehension score suggests that they both focused on and comprehended the quality measures with the narrative while active engagement with individual measures indicates decision-making based on one alone as well as integrating it with the others resulted in lower mental demand.

The Patient Work Approach Applied to Medication Adherence: A New Approach to an Old Problem

Robin S. Mickelson, Vanderbilt University, USA

Medication non-adherence continues to be a barrier to health in older adults with chronic disease. Research reports 50% of chronically ill older adults do not take their medications as prescribed, increasing healthcare costs and rates of morbidity and mortality in this population (Sabatâe, 2003). Despite the abundance of published research, interventions to improve medication adherence have not proved effective in the long-term (Haynes et al., 2008). Guided by socio-behavioral models of health (Krueger, Berger, & Felkey, 2005), these interventions were primarily directed at individual patient or provider factors and overwhelmingly involved educating the patient (Ruppar, Conn, & Russell, 2008). The process of adhering to medications – medication management – was largely based on researcher assumptions and lacked empirical evidence. We applied a patient work approach (Holden et al., 2013; Valdez et al., 2014) to interview, observation, and survey data from 91 older adults with heart failure. The value of the patient work approach is twofold. First, it shifts the emphasis of solutions from labor intensive, human-delivered interventions to the design of system-focused tools. Second, the design of tools depends on a thorough understanding of the work of medication management, an under-researched area in medication adherence literature.

Using the patient work approach, we gained unique insights into the nature of medication management in heart failure patients. Interacting components of the context (tool, task, environment, community) constrained and enabled medication activities performed individually and collaboratively by patients, families, healthcare providers, and others (Valdez et al., 2015). For example, medication management was interwoven into everyday life (Holden et al., 2015; Mickelson, Willis, & Holden, 2015) and often conflicted with other life goals such as socializing with friends or traveling, forcing patients to choose between medication adherence and other activities. Patients developed “workarounds,” adapting medication schedules to these immediate situations with little consideration to their health and safety. Patients had few tools to guide decisions or assist with medication tasks. Patients used tools that were based on assumptions about patient medication work and designed for or by clinicians (Mickelson, Willis, & Holden, 2015) and adapted these tools to better fit their workflow. In addition, medication management activities were socially distributed (Mickelson & Holden, 2013), and highly collaborative (Holden et al., 2015). For example, refilling a prescription may involve a reminder call from the pharmacist, the patient requesting authorization from the physician, a caregiver transporting the medication to the patient's home, and the patient double-checking the medication for accuracy. These results suggest tools to improve medication management performance must facilitate the dynamic distribution of medication work, adaptive decision making, and the specific workflow of home-based medication activities.

Understanding Patient Work as an Approach at the Intersection of HF/E and Applied Anthropology

Laurie Novak, Vanderbilt University, USA

A goal of many anthropologists is to find ways to characterize situations. How do people act? What do they know? What structures their action? The immediate objective may be to improve the design of a technology, or perhaps to understand the work of chronic illness management in order to educate clinicians about the everyday lives of their patients. Whatever the objective, when we seek to improve situations (i.e., engineer them), we must understand them. This requires that we develop conceptual resources to describe the relationships among actors, artifacts, and the environment. HF/E shares this theoretical and methodological requirement with applied anthropologists.

I will provide an overview of the field of applied anthropology, focusing on design ethnography. I will also explore the synergies between the approaches that applied anthropologists and human factors professionals use to describe patient work, illustrating with data from research among people with diabetes. In a study that is ongoing, we are conducting home interviews using this synergistic approach to capture detailed information about how diabetes management is connected to and shaped by daily routines and spaces. Data include short videos narrated by the participants demonstrating the locations and artifacts in the home that figure into diabetes management. The method, referred to as active video interviewing (AVI), reveals information about the overall trajectory of a day's activities, the sequence of tasks, how space and artifacts are used to trigger actions, and the role of other actors. Preliminary data will be presented, along with a description of the method used and its limitations and its utility in understanding patient work.

A Patient Work Approach to Improving Transitions of Care from the Hospital to Home Healthcare

Nicole Werner, University of Wisconsin-Madison, USA

Care transitions from the hospital to home are vulnerable to adverse events (Coleman & Boult, 2003; Kripalani et al., 2007; Naylor, 2002). Over two decades of research have been focused on improving transitions of care across healthcare settings with mixed results (Phillips et al., 2004; Jack, et al., 2009; Shepperd et al., 2004). Care transitions are characterized by a shift in burden of care from hospital providers to patients and their informal caregivers. However, research on transitions has focused mostly on provider work rather than on developing an understanding of the patient work required for a successful transition.

We employed a patient work approach to identify the barriers to successful care transitions from the hospital to home care from the perspectives of the patients, informal caregivers, and SHHC providers in 3 states and 5 sites (rural and urban). The goal was to leverage these perspectives to broaden our understanding of the patient work required during the transition period, and to better understand barriers to successful transitions. We identified multiple barriers to patients being able to perform the care tasks as instructed. For example, we found that it was a challenge for patients to shift from being dependent on hospital providers for care, to being responsible for the burden of care. This often resulted in inaction or use of emergency services. We also found that discharge instructions did not always match what patients were physically, socially, or emotionally willing and/or able to perform. Examples of this included non-mobile patients being discharged to a home where they needed to use stairs, patients needing medication that they were unable to afford or access, and patients feeling too sick and/or tired to take on self-management tasks. The results generated from this patient work approach can be used to strengthen efforts to improve care transitions by accounting for the full complexity of the care transition process.

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All panelists have agreed to participate in the panel if accepted.