Understanding and Designing to Support Patient Work
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ABSTRACT
Within the domain of health care, research related to the concept of work has focused primarily on the activities performed by health care providers. However, the concept of work has been extended in both the human factors and social science literatures to include nonpaid activity, such as that engaged in by patients for self-care and self-management. As patients’ responsibilities increase, there is a pressing need to better understand their experiences of health care work and to use this knowledge as a foundation for relevant HIT design. The purpose of this panel is to present a multidisciplinary discussion of the work patients engage in for self-care and self-management and the implications of this work for HIT design. This panel will consist of experts in the fields of human factors engineering, medical anthropology, and information science. The panel will have two parts: 1) a presentation of four frameworks that can be used to address the methodological challenges of studying patient work and examples of their application within the domain of health IT design and, 2) a mapping of future research directions at the intersection of patient work and health IT design.

Work practice research in health care has almost exclusively focused on those employed by the health care system, rather than those served by it. Yet the concept of work has been extended in both the human factors and social science literatures to include nonpaid activity1,2, such as that engaged in by patients for self-care and self-management. There is a need to better understand patients’ experiences of health care work as the burden of work being assigned to patients is increasing in both volume and complexity. Understanding how patients integrate such tasks into everyday life can provide valuable information to designers of informatics tools and other supportive technologies. The purpose of this panel is to present a multidisciplinary discussion of the methodological challenges and benefits of studying patient work. Panelists will be experts in human factors engineering, medical anthropology, and information science. The panel will consist of two parts: 1) a discussion of frameworks for studying patient work and a presentation of research projects employing these frameworks within the domain of health IT design, and 2) a mapping of future directions at the intersection of patient work and health IT design. The panel will be interactive and involve substantial discussions with the audience.

Part One
With heavy reliance on observational data collection methods, attempting to characterize patients’ work outside the boundaries of the institution presents methodological and analytical challenges. These challenges include how to capture the range of work tasks with fidelity to context, and how to characterize relationships among actors, tasks, artifacts and context in a way that is useful for the research and design audiences. Several frameworks from the fields of human factors engineering and the social sciences make studying patient work tractable by providing a structure for conceptualizing patient work. Panelists will present these frameworks, including their similarities and differences, and present the application of these frameworks to specific research projects. These frameworks and research projects are described below.

1. Framework: SEIPS 2.0, is a macroergonomic framework of the structures, processes, and outcomes of the work of health care professionals, patients, and families3. The work structure depicted in SEIPS 2.0 is a sociotechnical work system of six interacting components: person(s), tasks, tools and technologies, organization, internal environment, and external environment. SEIPS 2.0 specifies three types of work process or activity: professional work (agent = professional(s)), non-professional work (agent = patient(s), family, and other non-professionals), and collaborative professional-patient work (co-agency). These processes result in patient, professional, and organizational outcomes.

Project: SEIPS 2.0 is being used in an ongoing project to design patient-facing health information technology (HIT) called “Flight Plan,” which is intended to support self-care information and behavior for elderly heart failure patients and their informal caregivers. Initial work process analyses produced several key findings, including: the intertwining of patients’ “clinical,” “logistical,” and “personal” work; the multiplicity and great burden of self-care tasks; and the distribution of activity and information across
people, artifacts, environments, and time.

2. Framework: The Human Factors of Health Care in the Home Model is a model grounded in sociotechnical systems theory. This model conceptualizes the patient, the tasks in which a patient is engaged, and the technologies employed by the patient as a triad embedded in four contextual environments: the physical, social, community, and health policy domains. The degree of fit between these model components influences outcomes such as system safety, efficiency, and effectiveness.

Project: The Human Factors of Health Care in the Home Model is being used to study patients’ experiences of using an asthma management mHealth application. The findings focus on both the perceived benefits and challenges related to each component of the model as regards integrating the mHealth application into patients’ daily lives with asthma.

3. Framework: Corbin and Strauss’ framework for patient work in managing chronic illness posits three “lines of work,” including medical tasks referred to as “illness work” and the continuation of household and occupational management or “everyday life work.” These two categories of work are dynamic, involving frequently changing contexts and relationships as life and illness progress. The third line of work, “biographical work” involves strategic adjustments to occupation, identity or other life circumstances as a result of the illness. These lines of work are interwoven along a path that Corbin and Strauss referred to as the chronic illness trajectory, and they are reflected in patterns of activity and information seeking.

Project: The chronic illness trajectory is currently being used to explore the social and technological structures involved in implementing newly prescribed therapies among patients with cardiovascular disease as they transition from inpatient care to managing the chronic illness at home. In another project, information needs are being assessed among pregnant women with prenatal diagnoses over the period from diagnosis into early parenthood.

4. Framework: Strauss and colleagues posit unacknowledged forms of work engaged in by patients. These include “articulation work,” which coordinates efforts, resources, and projects to enable other forms of work. For patients, articulation work responds to internal “contingencies” arising from illness care as well as external ones related to the acquisition, allocation, and use of resources. Such work may be “visible or invisible” in the sense that it may or may not be recognized by health care providers.

Project: Strauss and colleagues concept of “invisible work” was used to investigate the adherence work of African-American individuals with comorbidities. Findings revealed five types of adherence work that commonly arose for patients that may be supported by HIT: 1) constantly searching for better care, 2) stretching medications, 3) eating what I know, 4) keeping myself alive, and 5) trying to make it right.

Part Two

To conclude the panel discussion, we will engage audience members in a discussion of future directions for understanding and designing HIT to support patient work. Future directions that will be discussed include assessing the workload or cognitive demands of patient-engaged work, studying patient and family resilience or adaptations under challenging circumstances, developing work evaluation methods suited to the physical and social contexts where patient-engaged work is performed, and research on patient and family expertise as well as related interventions. Other exciting opportunities include theoretical development of the concept of “routines,” examining the structures that enable the construction and maintenance of routines, and characterizing disruptions of effective routines and how they are overcome. Finally, research efforts are needed that focus on effectively and efficiently translating knowledge about patient work into design guidance for patient-facing HIT.

All panelists have agreed to take part in the panel if accepted for presentation.

References