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Interactive systems for patient-centered care to enhance patient engagement

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EDITORIAL

In today's society, most people are both consumers of information technology and of health care. Virtually every person has consumed health care and will consume more as one ages. Moreover, 84% of US households own a computer,[1] and 64% of adults own a smartphone.[2] We carry pocket-sized devices that connect us to people around the world and vast stores of information. With these technologies, we manage our lives from mundane activities like reading, checking the weather, making to-do lists, and buying books and clothes, to more complex tasks such as learning, managing finances, shopping for houses, and maintaining ties with friends and family around the world. With such diverse and powerful technologies at our fingertips and myriad societal-level health care challenges in cost, quality, and outcome, it is tantalizing to imagine all of the ways that health information technologies (health IT) can be used to enhance people's health and societies' health care delivery.

Patient-centered care respects and responds to individual differences in patient preferences, needs, and values.[3] To respond to such differences and achieve patient-centered care, patients and health care professionals must engage in constant communication. In recent years, researchers have examined a number of ostensibly patient-oriented technologies that could enhance such communication, including patient portals, personal health records (PHRs), and mobile health (mHealth) applications. Furthermore, it is not difficult to conceptualize pathways through which such information systems might improve communication between patients and clinicians, create more patient-centered care, and help achieve the triple aim of better experiences of care, better population health, and lower health care costs.[3] Yet, practically, these enticing tools and outcomes are far from reality.

There is scant evidence that patients frequently or effectively access and use information systems that engage them and improve patient-centered care delivery. For example, patients generally have positive attitudes toward using patient portals, but studies have not shown portals to have positive impacts on patient empowerment,[4,5] health outcomes, or costs.[6,7] Also, racial and ethnic differences may impede widespread portal adoption and use,[6] and this threatens to compound already-existing disparities in health care access and communication. Another often-studied system type, the PHR, has been shown to infrequently contain patient-oriented features, which is also likely to limit patient-clinician communication.[6] Next, as smartphone adoption has increased, mHealth technologies have emerged as another set of tools that may enhance patient-clinician communication. Yet despite the existence of many applications, including hundreds for cancer alone,[8] we lack strong research evidence on how to design and use mHealth applications to consistently achieve patient-centered care.[3] Finally, the study of patient-facing systems to improve patient-centered care cannot be disentangled from the study of electronic health records (EHRs). EHRs are nearing ubiquity in the US health care system, meaning that patient engagement, communication, and attainment of patient-centered care is also inexorably tied to the design and use of EHRs.

This special focus issue follows from the 2014 annual Workshop on Interactive Systems in Healthcare (WISH). The WISH workshop aims to promote deeper and more profound connections among the biomedical informatics, human-computer interaction, medical sociology, and anthropology communities. WISH 2014 focused on the challenge that information systems often fall short in adequately engaging patients and ensuring that clinical decisions are patient-centered. This may be attributed to a disconnect between system designers' understanding of clinical work and care processes, a lack of clear protocols defining how patient-engaged technologies should be adopted and used, or an insufficient understanding of people's information needs, preferences, and values. Therefore, the articles in this special focus issue reflect discipline-spanning research teams, methodologies, and perspectives while highlighting new approaches to designing, developing, and evaluating interactive information systems to support patient-centered care and patient engagement.

We have organized the articles in this special focus issue into four themes: health IT for patient-centered heath care delivery and management, patient–provider interactions mediated by health IT, pervasive and mobile technologies to promote patient engagement, and designing for underserved patient populations.

The first theme includes studies that focus on improving EHR and PHR effectiveness and patient-centered care outcome. The studies range from designing a scaffolding system to existing EHR, customizing a commercial EHR system, identifying strategies of using EHR during patient consultation, re-examining the role of EHR in primary clinical workflows, and designing an experiment to determine the PHR impact on patient engagement. For instance, to improve patient engagement and EHR effectiveness, researchers implemented a scaffolding system to include patient-reported outcomes integrated into the existing EHR and identified both facilitators (e.g., high degree of process automation, good interface usability, capability of targeting the right patients at the right time) and barriers (e.g., uncertain clinical benefits and constraints on time, workflows, and efforts).[9] Similarly, researchers from Texas Children's Hospital customized a commercial EHR to include the design of a new work element for a cross-functional team to prioritize the outcome measurement in EHR optimization, which significantly improved the outcome status tracking and number of patients involved.[10] Moreover, researchers continue to investigate workflow issues[11] and the tensions of using EHR while interacting with patients face to face[12] in primary care settings, which helps inform commercial vendors about how to improve the design of EHR for accommodating the dynamic needs of frontline clinicians. Furthermore, an observational study on the use of PHR indicated significant improvement in the HbA1c levels of the active and super user

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groups while no other health outcomes improved. There was also no statistically significant improvement observed in patient engagement during the study. While the research context is limited in coronary artery disease patients, we hope this study could shed light on the current debates of PHR usefulness and effectiveness, and invite additional efforts in examining the effectiveness of patient-centered systems, including patient portals, on improving patient engagement and health outcomes.

The second theme focuses on the design of health IT to improve the quality of patient–provider interaction. Studies included the development of a web-based toolkit to improve patient education and involvement in the care plan during hospitalization,[13] the design of a dashboard to facilitate data collection and efficient use of patient-reported outcomes,[14] and design recommendations for a web-based tool to satisfy the caregivers' information needs in the context of inpatient pediatric hematopoietic stem cell transplant.[15] As there is a paucity of research in designing IT tools to support patients and caregivers in an inpatient setting, we hope that these studies will provide readers with valuable insights and practical design experiences for approaching the problem, including ways to engage patients, caregivers, and providers in the iterative user-centered design process.

The third theme involves the use of pervasive and mobile technologies to promote patient engagement, such as.[16] Many mHealth technologies were found to be useful for patients to manage their care and improve health outcomes. However, certain patient factors must be considered when designing mHealth technologies, as they play a pivotal role in patient engagement. For example, patient factors like ethnicity, health literacy, and age were found to impact the use of mHealth applications for managing medication adherence[17] and service members' background characteristics were reported to impact their engagement with an mHealth application for managing their post-trauma issues.[18] On the other hand, one size does not fit all. It is therefore important to customize mHealth tools for patients with special needs to ensure patient engagement. For instance, an mHealth tool designed for diabetic patients from economically disadvantaged communities and ethnic minorities was found to help patients self-monitor and reflect,[19] and a PHR application customized for post-cardiothoracic surgery patients was useful to support their medication management and tracking in a hospital setting.[20]

The last theme that we identified is centered around designing for underserved patient populations, e.g.[21] It is well-known in the health informatics community that studying underserved patient populations is challenging. Thus, most previous research focused on a single case study. While a single case study offers valuable knowledge, cross-case analysis of diverse case studies offers exceptionally important insights to the success factors, barriers, and common patterns identified across multiple cases.[22] In addition, research targeted at underserved populations offers lessons particularly instrumental in the design of health IT to meet the specific needs of individual underserved populations. For example, a large-scale national program succeeded in promoting health and well-being in older adults using a suite of accessible computing,[23] a longitudinal participatory design approach supported the design of mHealth applications for overcoming perinatal depression of women from vulnerable populations after their pregnancies,[24] and the use of daily questionnaires helped to identify the association between service members' background characteristics and their engagement with an mHealth application for managing their post-trauma issues/conditions.[18]

In conclusion, researchers in this growing, vibrant health informatics community have been diligently exploring a range of relevant topics in the design, implementation, and evaluation of interactive, patient-centered health IT systems for enhancing patient engagement, as evidenced in the sample research included in this special focus issue. While challenges remain and future work abounds, we believe that our effort has led us a step closer to achieving a high level of health care quality and outcomes.

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