Online Filipino-Americans' perspectives on informatics-enabled health management

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Abstract

Objectives: The purpose of this study was to understand Filipino-Americans' perceptions of three types of information technology used for health management: personal health records (PHRs), mobile health applications (mHealth), and social networking sites (SNSs).

Methods: An online survey was administered to Filipino-American participants recruited via Facebook during 2013. The survey included open- and closed-ended questions regarding participants' (1) experiences with PHRs, mHealth, and SNSs for health management and (2) preferences regarding technology designed for the Filipino-American community. Data were analyzed using descriptive statistics for participant demographics and usage patterns and qualitative content analysis for perceived advantages and disadvantages of each technology.

Results: Eighty-seven surveys were completed. Participants reported using SNSs (17.6%) and mHealth (10.6%) most frequently for health management, but expressed most interest in using PHRs for future health management (39.0%). Additionally, 61% reported interest in using technology tailored for the Filipino-American community. Reported advantages/disadvantages across the technologies focused on seven themes: accessibility, complementarity, credibility, privacy and security, usability, usefulness, and unspecified.

Conclusions: mHealth usage patterns echoed what has previously been reported in other populations. PHR usage patterns fell between two previously reported extremes and SNS usage patterns were greater than those previously reported. While some perceived advantages and disadvantages reflected those of other patient populations, several were unique to this Filipino-American community. Future policy initiatives should promote design processes that address culture in a nuanced way and educational efforts that increase patient knowledge regarding the potential benefits of informatics-enabled health management.

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Introduction

As the length of patient stay in institutional settings decreases, health care is shifting to home and community settings [1-3]. Achievement of positive patient outcomes will require engagement not only by formal health care providers, but also by patients and their informal caregivers and care partners [4-7]. Patient-facing informatics solutions, or consumer health information technology (IT), will be essential to support patients and members of their social network in meeting the demands of engaging in health management [7,8]. Consumer health IT has been defined as electronic technology specifically designed for use by laypeople to support health management [1,9-11].

Existing governmental policies and the positions of the Healthcare Information Management Systems Society (HIMSS), the National eHealth Collaborative (NeHC), and the American Medical Informatics Association (AMIA) advocate for the acceleration of consumer health IT that more fully supports patient engagement [12-14]. The meaningful use framework, a core component of the HITECH Act of 2009, consists of three stages of increasing patient and family engagement, moving, in stages two and three, to more patient control of data and patient access to health management tools [14]. The patient engagement framework, championed by HIMSS and NeHC, specifies a five-step approach to implementing an interoperable electronic health record (EHR) that evolves from providing patient-specific education to interactively supporting the full team (e.g., caregivers, family, friends, clergy) engaged in a patient's health management [12]. Finally, AMIA recommends movement in four directions: (1) adoption of policies that create a vigorous health information infrastructure, (2) education of health professionals and laypeople about patients' rights to full access of health information and about data sharing benefits, (3) support of research focusing on understanding and addressing patients' experience of generating, accessing, analyzing, and using their health data, particularly patients holding a wide range of cultural identities, and (4) exploration of policy and regulatory incentives maximizing and accelerating the use of innovative health information tools [13].

Aligned with AMIA's third recommendation, this study sought to gain a deeper understanding of individuals' existing experiences with three forms of information technology that may be leveraged by patients for health management. Specifically, this study sought to understand experiences related to the frequency of use, usefulness and ease of use, as well as perceptions related to the advantages and disadvantages of using personal health records (PHRs), mobile health applications (mHealth), and social networking sites (SNSs). It is well acknowledged that understanding individuals' experiences and perceptions is foundational to a rigorous design process (i.e., needs assessment) [15-17]. Moreover, a socio-technical approach recognizes that these experiences and perceptions are not uniform across populations and are shaped by the tasks in which individuals are engaged, the technologies to which they have access, and the larger environments (e.g., political, economic, technological, and cultural) in which they are embedded [18-20]. To meaningfully engage patients through consumer health IT, an iterative design process should be utilized to ensure that technological solutions are aligned with the socio-technical contexts within which patients and their caregivers and care partners are embedded [21-24]. Thus, this paper presents a needs assessment to inform the redesign of existing technological solutions with which patients can engage to support health management.

One aspect of the socio-technical context that requires further understanding as a foundation for the design of consumer health IT interventions is the element of culture [9,13,25-27]. Understanding the experiences of patients holding a wide range of cultural identities (i.e., embedded in diverse cultural contexts) is essential to ensuring that all patients are able to effectively leverage consumer health IT for health management. However, a limited number of studies have focused on consumer health IT use by racial and ethnic minority populations [9,26]. A recent systematic review [26] of use by historically underserved populations found that a majority of such studies focused on African Americans ($n=64$) and Hispanics ($n=51$), followed by Native Americans and Alaskans ($n=4$), and Asian Americans ($n=1$). Asian Americans' needs for and experiences with consumer health IT solutions, therefore, remain largely unarticulated. Consequently, the present study focused on a subpopulation of Asian Americans, specifically, Filipino-Americans.

This study focused on three types of technologies that may be used by patients and their caregivers and care partners for health management: (1) PHRs, (2) mHealth, and (3) SNSs. The first two forms of technology may be considered consumer health IT (designed specifically to support laypeople's health management), while the third is a technology that has been adopted by individuals for health management purposes. PHRs are "an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [28]. Thus far, PHR adoption has been relatively slow; however, PHR satisfaction has been reported among patients with chronic illnesses and unexpected health events [29]. In addition to PHRs, mHealth, consisting of the delivery of "health related services to patients, clinicians, and caregivers through mobile technology platforms on cellular or wireless networks" [30], is expected to be an increasingly vital component of the health care delivery system [31,32]. mHealth has been demonstrated to be effective in long-term health management of chronic diseases, including diabetes, mental health problems, overweight, cancer, and obstructive pulmonary disease [33].

Beyond technologies that are specifically considered consumer health IT, there are also technologies not originally designed to support health management that have been adopted by patients for this purpose. One such technology is SNSs (e.g., Facebook, and Twitter). Several recent studies have demonstrated the communication of health-related information via Facebook profiles [34-37]. Additionally, health-related Facebook groups have become spaces to share information, request information, receive emotional support, and promote awareness and fundraising [38,39]. Consequently, this study focused specifically on understanding Filipino-Americans' experiences and preferences with PHRs, mHealth, and SNSs, as these technologies are increasingly relevant for health management.