

CONSIDERING CULTURE IN THE DESIGN AND EVALUATION OF HEALTH IT FOR PATIENTS

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In the context of health care, culture can influence the way a patient understands health information, what they consider a health problem, how they express symptoms, who should provide them treatment, and what type of treatment they should be provided. This panel will discuss why human factors professionals should consider the patient's culture when designing and evaluating health information technology and approaches to developing culturally informed technologies. The discussion will begin by highlighting work from a general cultural group: racial and ethnic minorities. It will then become more specific by looking at cultural groups within a certain disease: Black female college students and HIV/AIDS, Hispanic and African American diabetes patients, and lesbians during pregnancy and childbirth. The panelists will focus on lessons learned from previous research within each of these cultural groups that can be applied to the overall design of culturally-informed health IT.

PANEL OVERVIEW

Macroergonomics is a perspective and methodology related to the analysis, design, and evaluation of work systems (H. W. Hendrick, 2002). While macroergonomics recognizes the importance of attending to the cultural context of the work system, much is still unknown about this cultural context (Valdez, 2012). Hendrick's (1987) ground breaking work on macroergonomics coupled with the rising concern for industrially developing countries, enlarged the scope of ergonomics and encouraged attention be paid to ergonomically relevant human-human concerns such as cultural concerns (Kaplan, Morgan Jr, & Kring, 2006). Today, cultural ergonomics pushes researchers to look beyond the typical human-components in HF work (e.g. visibility, sensation, perception, communications cognition and design, motor control, and muscular strength (Wickens, Lee, Liu, & Gordon Becker, 2004)) and begin to look at cultural variables as well. Cultural ergonomics focuses on the identifying users needs that are related to situation and trait-based variation between cultures (Smith-Jackson & Wogalter, 2000).

Culture defines the way a person believes, thinks, cherishes, and honors (Hyde, 2000). The U.S. Department of Health Human Services' Office of Minority Health defines culture as "the thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups" (Office of Minority Health, 2001, p. 4). A patient's culture cannot be narrowly defined to their race, ethnic background, or country of origin as patients belong to more than one single culture (Betancourt, 2004). Culture includes language, communication style, practices, customs, and views of both roles and relationships (Betancourt, 2004). A patient's culture can shape how health information is received, what is

considered a health problem, how symptoms are expressed, who should provide treatment, and what treatment should be provided (Office of Minority Health, 2001). While cross-cultural problems may not manifest overtly in patients or their families, these issues may lead to the misinterpretation of medical information, noncompliance with treatment (Trill & Kovalcik, 1997), missed screening opportunities, or diagnostic errors due to miscommunication (Brach & Fraserirector, 2000).

The implementation of health technology is a national priority (Baig et al., 2010) and widely discussed in the literature. Health technology is defined as a "collective term for procedures and methods for examination, treatment, care and rehabilitation of patients, including instruments, drugs, and preventative procedures" (Kristensen & Sigmund, 2008, p.89). Health information technology (health IT) refers to the implementation of information processing with regards to the storage, retrieval, sharing, and use of healthcare information, data, and knowledge to facilitate both decision making and communication (Thompson & Brailer, 2004).

Despite the national focus on implementing health IT, the concept of culturally-informed health technology is rarely discussed in the literature (Montague & Perchonok, 2012). Health care is a cultural construct, as it stems from beliefs regarding the nature of disease and the human body; therefore cultural issues are central in the delivery of health services (Office of Minority Health, 2001). Designers of health technology must understand, value, and incorporate the cultural differences of America's diverse population in order to serve the needs of populations whose cultures differ from the majority culture (Office of Minority Health, 2001).

The purpose of this panel is to highlight how culture is being considered and gaps in knowledge in the design and evaluation of health IT. Currently the methods, processes and approaches for integrating the patient's culture into the design of health IT are not readily discussed in the literature (Montague & Perchonok, 2012). The panelists will discuss lessons learned from previous research that can be applied to the design of culturally-informed health technology. The discussion will begin by highlighting work from a general cultural group: racial and ethnic minorities. It will then become more specific by looking at cultural groups within a certain disease: Black female college students and HIV/AIDS, Hispanic and African American diabetes patients, and lesbians during pregnancy and childbirth. Each panelist will discuss their research creating or evaluating culturally-informed health IT for the given cultural group.

Culturally Informed Design of Consumer Health IT: Approaches to Needs Assessment

Dr. Rupa Valdez

This work seeks to address the challenge of addressing persistent racial and ethnic health care disparities that can remain even when income, access, insurance status, and diagnosis have been taken into account (Smedley, Stith, & Nelson, 2003). A recent report published by the Agency for Healthcare Research and Quality (AHRQ) indicates that the majority of these disparities remain (AHRQ, 2011). As with any complex problem it is unlikely that a panacea exists; however, it is likely that some of these disparities arise from cultural variation that must be addressed in our interventions. Indeed, a basic premise of macroergonomic theory is that better physical and psychological outcomes (Carayon & Smith, 2000; Norman, 1988) and reduced unintended consequences (Ash, Sittig, Dykstra, Campbell, & Guappone, 2009; Moray, 2000) are achieved when alignment exists within an individual's work system, of which the cultural context is a part (Moray, 2000). Recognizing the potential of culturally informed approaches to health care delivery to reduce racial and ethnic health care disparities, organizations such as the Institute of Medicine (IOM), AHRQ and the National Library of Medicine (NLM) have called for initiatives to augment existing health care systems by making them responsive to the cultural component of patients racial and ethnic identities (e.g., Brach & Frasierirector, 2000; Siegel et al., 2005; Smedley, et al., 2003). Recent scholarship has advanced the concept of culturally informed health care to include the design of culturally informed consumer health IT (Valdez, Gibbons, Siegel, Kukafka, & Brennan, 2012).

Creating alignment with the cultural component of patients' racial and ethnic identities is challenging. The sheer number of racial ethnic groups makes creating health IT for each group of questionable feasibility. Furthermore, patients may identify with more than one racial and ethnic identity, identify with a

given identity in a multitude of ways and strengths, and change the ways in which they identify with the cultural component of a given racial or ethnic identity based on their life experiences (Valdez, 2012). One approach to addressing this complexity is to first gain an understanding of the in breath of the design space across individuals holding diverse racial and ethnic identities. This study sought to explicate the design space across individuals holding diverse racial and ethnic identities for the task of health information communication with members of the social network for the purpose of informing the design of culturally informed consumer health IT built to support this task. This task has been shown to be burdensome for patients (Pratt, Unruh, Civan, & Skeels, 2006), and performed differently across cultures (Blackhall et al., 1999; Janzen, 1987). Findings demonstrate that designers must account for a larger design space and is currently addressed to meet the needs of a culturally diverse group of users. For example, existing technologies to support health information communication with members of the social network is primarily oriented to facilitating communication with close family members and, to a lesser extent, with friends and colleagues. This study, however, showed that consumer health IT built to support this task must account for a wider range of individuals to whom information is communicated including divinities, faith based community members, and extended familial networks.

Beyond the conceptual challenges related to creating culturally informed consumer health IT are the methodological challenges of gaining access to relevant populations and gaining systematic yet rich data from patient participants. This study sought to address the former challenge by establishing a long-term relationship with two Federally Qualified Health Centers and by building rapport with individual participants through prolonged engagement. This study sought to address the latter challenge by merging methods from engineering design with methods from cultural anthropology (Valdez, 2010). Pasmore's (1988) conceptualization of the work system was used to systematically explore the design space. This framework was paired with methods drawn from cultural anthropology to ensure that a rich understanding of patients work systems was obtained.

“For-Us-By-Us”: Towards Culturally Centric Approaches to Health IT Design

Dr. Woodrow Winchester

My Health Impact Network (myHIN) is a nonprofit organization funded by a two-year research grant from the National Science Foundation (NSF) to study the use of social media networks in promoting HIV and AIDS prevention among black female college students. The goal is to use social media to attract African-American college women and provide them with information about HIV/AIDS prevention.

While demonstrating how health IT can be more responsively designed in helping individuals make better decisions about their health and wellness, myHIN also offers a research test bed for explorations in understanding and discerning that elusive yet vital contextual consideration in the design of health IT, culture. In evolving myHIN as a platform, we are exploring a more active engagement of our constituents in the design process – “for-students-by-students” (FSBS) as an approach for both uncovering and translating relevant cultural considerations in design. As detailed by Shen, Woolley, and Prior (2006), “the closer the similarity in socio-cultural background between the user and the designer, the stronger the assurance of a successful human-computer interaction”. In this panel, we will discuss our formative evaluation work of myHIN through the lens of offering insights on the potential efficacy of FSBS as a design approach. We hope that the offered evidence could also prove vital in advancing the development of more culturally-centric approaches to health IT design (Hill et al., 2011; Winchester, 2010).

Designing Usable and Culturally Informed Glucometers

Dr. Monifa Vaughn-Cooke

Facilitating treatment adherence (diet, exercise, medication, self-management technology use) among patients with chronic conditions poses a significant challenge to health care providers. Diabetes is a highly prevalent chronic condition with a treatment that is confounded by high levels of treatment non-adherence. It is widely accepted in the literature that minorities (African Americans and Hispanics in particular) have lower diabetes patient adherence rates (Egede et al., 2011; Gebregziabher et al., 2011) and significant differences in glycemic control compared to the Caucasian majority (Harris, Eastman, Cowie, Flegal, & Eberhardt, 1999). Although studies have clearly established that both the quantity and quality of health care are inferior for minorities (Natale-Pereira, Enard, Nevarez, & Jones, 2011; Smedley, Stith, Colburn, & Evans, 2001), the causes of these disparities and their impact on self-management, are not fully understood.

The glucometer is a diabetes self-management technology to aid in self-monitoring of blood glucose (SMBG) adherence. However, the form, functions, and information architecture of the glucometer may actually impede SMBG adherence due to low glucometer usability resulting from the lack of consideration of the patient and their individual differences. An individual difference that has not been adequately addressed in glucometer design is the socio-cultural context, which impacts health beliefs, health literacy, and the ability of diabetes patients to effectively interact with the glucometer. Given existing racial/ethnic differences in glycemic control, we sought to explore how culturally-influenced views on self-management (specifically, SMBG) may contribute to technologically supported diabetes treatment outcomes. Insights into culturally-specific perspectives may inform

intervention strategies (Norris, Engelgau, & Narayan, 2001), such as SMBG patient adherence risk mitigation. Adherence performance shaping factors can be categorized in Social, Personal, Organizational, and Technological (SPOT) levels: 1) Personal - individuals' personality and capabilities; 2) Social - roles, relationships and conditions within the family; 3) Organization - the workplace, school, healthcare organization, economic conditions, and cultural norms and expectations; and 4) Technology –tools to facilitate social interaction and monitor the patient health condition (Vaughn-Cooke, Nembhard, & Ulbrecht, 2010).

We are interested in understanding how the social, personal, and organizational levels of the SPOT Model interact with the technological level (glucometer usability). This information will inform the design of a usable glucometer that supports SMBG patient adherence. We performed a usability study with one of the goals being to understand glucometer cultural competency within African American and Hispanic populations. Expert (usability heuristics) and patient usability testing (originally constructed surveys, observation, and think-aloud protocol) were performed for the top glucometer models to determine the features and functions that contribute to low usability and user error. For the patient usability tests, we sought to capture a wide range of illness experiences representing a variety of age, gender, health literacy, IT literacy, stage and severity of diabetes, level of family support and socio-economic status. We also recruited patients from a range of settings including support groups and suburban and urban endocrinology clinics. Study results include the identification of significant SPOT Model factors (insurance support, interpersonal relationships, support from family/friends, age, highest level of education, urban/suburban effects, language, etc.) on SMBG adherence for specific glucometer model features and functions. In addition, the relationship between glucometer usability, user errors, SPOT model factors, and SMBG adherence will be explored to determine future focus areas for clinical support and technological design interventions.

This research will serve as a platform to model SMBG adherence and glucometer cultural competency disparities due to biologic factors, sociodemographic factors, access and quality of care, and self-management behaviors and attitudes. In summary, being aware of the impact of race and ethnicity is important, however, it should be noted that these factors have a limited direct role in patient adherence. The factors that can have greater impact on adherence are the ones most amendable to change (Fincham, 2007). Patient demographic factors are typically correlated with other socio-cultural and behavioral factors (SPOT Model) that can be addressed to enable more effective diabetes treatment interventions and outcomes.

Effects of Culturally Uninformed Design: Case Study of Lesbians'

Experiences with the Health Care System During Pregnancy and Birth

Jennifer Perchonok, MS

Healthy people 2010, a federal interagency workgroup that provides 10-year national objectives for improving the health of the United States, recognizes Lesbian, Gay, Bisexual, and Transgender (LGBT) individuals as a priority population. However, despite this recent push to improve the health of the LGBT population, lesbians still experience health disparities. Lesbians face health disparities with regards to breast cancer (Committee on Lesbian Gay Bisexual and Transgender Health Issues and Research Gaps and Opportunities, 2011), cervical cancer (Tessaro, 1998), ovarian cancer (Dibble, Roberts, Robertson, & Paul, 2002), and lung cancer (Brown & Tracy, 2008) and in their Body Mass Index (BMI) (Aaron, Markovic, & Danielson, 2001; Cochran et al., 2001). Furthermore the lesbian population faces high rates of substance abuse, alcoholism, and tobacco use, which has been attributed to the stress associated with experiencing discrimination and stigma on a daily basis along with the lack of culturally competent health care services (Hunt & Byrd, 2012).

A women's experience during pregnancy and childbirth is a personal one, one that is both physical and emotional (Crowe & Von Baeyer, 1989). Research suggests that the attitudes, expectations, and beliefs of an expectant couple may prove the most important determinants of their experience during childbirth, regardless of physiologic factors such as the length of labor and the baby's position (Genest, 1981). The heteronormative aspect of society, or the assumption that every citizen is heterosexual (Chambers, 2003), creates a daunting experience for lesbians during pregnancy and childbirth. In addition to the normal anxiety of a pregnant couple, lesbians must overcome potential homophobia and discrimination along with health care professionals who are not well versed in lesbian-specific health care needs during pregnancy and birth.

Little research exists on the experiences of lesbians during pregnancy and childbirth. Therefore this study, which consisted of 13 semi-structured interviews with lesbian birth mothers and coparents (the lesbian partner who did not carry the baby), examined the lesbian experience during pregnancy and childbirth. The study found that no lesbian-specific technology exists even though some of the participants wished for lesbian-specific technologies, such as websites to track ovulation cycles. Additionally, the women were often disappointed by the health care system's use of heteronormative language. If culturally-informed technology was created for lesbians during pregnancy and birth, it would be imperative for it to include the correct jargon. Just as Hispanic communities wish for technology to use the Spanish language, lesbians wish for technology that uses terms like "partner" instead of "husband" and "coparent" instead of "father". It is clear that the lesbian culture creates a unique

experience for these women and that cultural aspects need to be examined when designing technology for the population.

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