

Informing Design through Sociocultural Values: Co-Creation with Low-Income African-American Older Adults

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ABSTRACT

Researchers in HCI and health informatics are often tasked with identifying criteria and content for health technologies based on user demographics, medical conditions, and context of system use. Little work has examined the intersectionality of sociocultural factors (age, ethnicity, socioeconomic status) and whether these factors influence health technologies as a viable or appropriate solution for certain populations based on their perceptions of health. Our work focuses on developing a better understanding of the health-related perceptions and behaviors of low-income African American older adults, as this population often sees a higher incidence of chronic illnesses and disease. Our approach builds off of semi-structured interviews as a way of informing a series of co-creation workshops, which aim to identify this population's concepts of healthy aging and the role of technology in health maintenance.

CCS CONCEPTS

• **Human centered computing** → Interaction design process and methods; Participatory design • **User characteristics** → Race and ethnicity; Seniors

KEYWORDS

Older adults, intersectionality, health technologies, culture

1 INTRODUCTION

Ubiquitous and pervasive health technologies have emerged as a way to encourage self-tracking and management of specific health conditions and general health status. Despite the potential utility of health technologies, reports suggest that usage trajectories of these technologies vary substantially across various user groups (e.g., older people,

resource constrained groups) [16]. Considerations for the design of these technologies as well as the associated health information most often focus on user and system capabilities. Previous studies examining the design of health technologies for older adults have leveraged methods of qualitative inquiry to highlight the perspective of older users based on a particular impairment status or medical condition [2, 8]. There have been few studies within the field of human-computer interaction (HCI) that focus on the design of ubiquitous and pervasive health technologies from the perspective of understanding and leveraging sociocultural dimensions such as age and socioeconomic status [12, 19], and none found that also consider ethnicity or race.

Although much is known about the impact of age-related impairments and needs on the development of health technologies [2, 8], there are additional challenges faced among special populations (low-income, ethnic minorities, rural or inner city residents) in older adulthood. Factors such as health literacy or financial access to health resources may impact design considerations of these technologies. Thus, it is advantageous to consider various intersecting dimensions as they are related to considerations for technology solutions.

The theory of intersectionality [7] asserts that various dimensions of an individual's identity (e.g., ethnicity, age, socioeconomic status, geographic residence) are not discrete dimensions, but rather should be considered together to capture the complexities of identity in a particular context. This theory has been applied in the context of HCI to acknowledge the differences within identity categories to compare the relationships between different social groups [1], and to analyze additional dimensions of identity within a larger target group [20]. Examining various aspects of identity and cultural influence may also highlight the

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ACM 978-1-4503-6450-8/18/05 . . . \$15.00

<https://doi.org/10.1145/3240925.3240966>

potential capabilities of a user group instead of focusing on challenges. Analyzing health technologies through the lens of intersectional sociocultural dimensions can help reveal new approaches to thinking about technology among various user populations and subgroups within those populations.

In order to identify relevant mediums and content of health interventions for individuals who may be marginalized along various dimensions (age, ethnicity, and socioeconomic status), it is important to first understand the ways these populations think about health and thus health management. This presents an opportunity for researchers to directly engage individuals from various communities in design inquiry while integrating factors stemming from cultural influence. Both Parker and Grinter [14] as well as Perchonok and Montague [15] suggest that there is benefit in considering cultural context in the design of health technologies. These studies posit that individuals who identify with various ethnic and economic groups may be influenced by cultural constructs (spirituality, familiarity, literacy and education) in the way they think of health and methods of health intervention. Additionally, Schlesinger's recent analysis of identity representations in HCI research suggests that there is a need to examine the complexities of identity in technology research, as existing work often examines the utility or application of technology along one dimension of identity, focusing on either gender and/or socioeconomic status [18]. Critically analyzing sociocultural influences within a particular minority population presents the advantage of leveraging cultural values of that particular intersectional community to inform the design of appropriate solutions.

One approach to centering these populations as the focus of design processes is participatory design. With the premise of democratizing the design process, researchers often leverage participatory design as a method that centers the ideas and feedback of the intended end user through collaborative activities with researchers and designers. This collaborative method provides a viable platform to advocate the needs of marginalized individuals, affording better insight into the needs of these users for future product development. Various advocates of this method posit that the structure and approach to collaborative design practices are best served when informed by an understanding of the community of interest [11, 14, 17].

Building off of related work in HCI, health informatics, and public health, our current research seeks to understand the perceptions of health and wellness as expressed by low-income African-American older adults, and to identify their approaches to health tracking and health management. Our work focuses explicitly on identifying the perspectives of health and technology interventions among low-income African-American older adults in the Chicagoland area, as this population often experiences a disproportionate prevalence of health issues, and various barriers to

technology interventions that could address these issues. As a secondary focus of this work, we aim to advance the concept of participatory design among communities of individuals who are considered marginalized, by exploring relevant tools and methods which amplify the ways these communities frame health and wellness.

2 BACKGROUND & RELATED WORK

We provide a brief discussion of related work in public health and social sciences which suggest the association of cultural influences and values on health amongst marginalized communities. We then discuss how sociocultural context has been shown to have an impact on the design of health technologies, including an overview of research efforts in HCI and pervasive health that have examined and implemented this approach.

2.1 Understanding Cultural Influences and Impact on Health

Reports indicate that marginalized populations in the US such as African-Americans experience chronic illnesses (diabetes, hypertension, obesity) at a disproportionate rate when compared to other ethnic groups [4]. Among low-income African-Americans, this prevalence increases, often due to lack of health-related resources such as access to medical care, or healthier food supplies [4]. When compounded with natural age-related impairments, there exist significant challenges for this population, creating additional barriers (restricted incomes, lack of transportation access, lower health literacy) to health resources [6]. Many of these systemic and environmental challenges place a burden on managing health in later life, and therefore must be considered when identifying any relevant health intervention.

In addition to these factors, cultural beliefs and values play a significant role in the way health behaviors are approached. When identifying constructs of health and wellbeing among African-American older adults with Type-2 diabetes, researchers found that the concept of healthy aging was associated with independence, spirituality, adaptation and overcoming adversity [5]. These constructs shape how individuals approached the management of their diabetes, and adherence or nonadherence to medication due to skepticism and a lack of trust of medical institutions. These findings suggest that sociocultural dimensions may be critical considerations for both medical providers and resulting health interventions.

2.2 Cultural Context and Health Technology Design

Previous research suggests that an individual's sociocultural background may be a major influence in the ways they think about health and thus should be considered in the way health technologies are designed [15]. Approaches to healthcare or acceptance of health technology use may be directly tied to

beliefs that stem from religion, family, or community. Similarly, perceptions of one's individual capabilities in regard to health can be based on one's class, gender, age, or socioeconomic status. Studies have examined the impact of sociocultural values or beliefs in the design of health technologies, most typically addressing common dyads of dimensions of user identities.

Leveraging the dimensions of gender and ethnicity, researchers found that Latin-American women held unique beliefs about how they could develop breast cancer, which directly affected their breast screening practices [3]. Participants believed that diseases such as breast cancer are predestined by God, and thus felt that there is nothing they can do to prevent or treat it. Researchers leveraged this insight into the development of a prototype for an awareness video, as this would directly affect how promotional health messaging might be received by this community. This application supports the foundation that cultural beliefs should be an important consideration in the design of technology interventions.

In a qualitative examination of nutrition and diet behaviors among low-income African-Americans, Parker and Grinter examine the dimensions of ethnicity and socioeconomic status. This study asserts that a positive shift in eating practices is best supported by a collectivist approach, as this has significant cultural meaning to the community [14]. This proposed approach is informed by findings that the nutrition behaviors of low-income African-Americans are most notably influenced by community resources and practices among the community.

In terms of socioeconomic status and age, White et al. examines the ways in which low-socioeconomic status older adults think about their health and the coping mechanisms they employ to address health challenges [19]. They suggest that the perceptions and coping mechanisms of this population are influenced by current financial status, perception of social class, and environment. Findings suggest a needed shift in the way monitoring technologies are developed to better consider these coping mechanisms and adaptive strategies, from highlighting limitations and challenges to a more positive perspective of acknowledging comparisons with peers. Similarly, Chaundry et al [6] also supports this notion of shifting to a positive consideration of coping strategies and mechanisms, highlighting that integrating spiritual methods of coping in health data might provide a more meaningful experience for low-income older adults. Findings from their qualitative analysis also highlight that perception of control in making health choices may alleviate feelings of marginalization and struggle among low-income older adults.

2.3 Structuring Participatory Design for Various User Populations

Participatory design is leveraged as a way to enable end users to have more influence on the products and technologies that are designed for them. Prior work in this area proposes that this design method is a viable approach to highlighting the needs and voices of underrepresented individuals that may otherwise not have buy-in in the design process [8, 9]. Despite this precedence, there is a need to understand the appropriateness of co-creation materials and session structure in creating meaningful co-creation experiences for these populations.

The selection and use of appropriate materials may be best supported by understanding sociocultural dimensions of the users engaging in co-creation activities [10, 13, 14, 17]. It is important to acknowledge that there are certain cultural connotations that may be associated with certain materials. Researchers could create either an inviting or ostracizing experience for individuals who may hold adverse beliefs regarding materials selected. There is a need to consider factors such as financial access, historical association, or even religious beliefs in the potential synergy between participant and material [13]. Previous studies also suggest that there are factors of relationship rapport and trust that play into the ability to truly engage various populations in co-creation. Both Hussain et al [10] and Lazar et al [13] employ approaches of familiarizing researchers in the culture of the intended user group at some level prior to initiating co-creation activities. Understanding the cultural values and beliefs of the target population may help researchers to better foster a welcoming environment while also being aware of topics that may be considered taboo or offensive.

Our approach to exploring health needs from a sociocultural perspective and leveraging this perspective in co-creation activities builds upon this related work. Most research to date examining health technology needs has focused on the intersection of socioeconomic status and age, or socioeconomic status and ethnicity. However, as evident by previous public health research, there are unique health challenges that may be experienced for low-income minority populations in older adulthood. We focus explicitly on identifying the perspectives of health and technology interventions among low-income African-American older adults in the Chicagoland area.

3 FIELDWORK METHODS

Our study takes a two-phase approach where we aim to fully understand the influence of sociocultural dimensions on health-related perspectives and behaviors among low-income African-American older adults. Additionally, we are designing participatory design workshops where we intend to identify how health tracking and management is imagined among this population, and the most relevant ways that

technology can be integrated into those processes. The design of this study leverages the assertion that to successfully conduct participatory design with a new community, researchers must revise tools and methods to be considered relevant and understood by the intended community.

3.1 In-depth Interviews

To gain insight into how low-income African American older adults think of health and wellness, we are conducting in-depth semi-structured interviews with older adults in local community and residential centers in the Chicagoland area. Participants have been recruited through flyers as well as by word-of-mouth. Additionally, the first author attended meetings at local community centers and living facilities that are primarily patronized by the target population to make announcements about the study.

Through these interviews we are exploring participants' concepts of what it means to be healthy and "age well", in addition to their current health-related practices and whether those practices involve technology in any way. Participants are being asked to share their perceptions of healthy aging, influences on health (family dynamic, past experiences, community influence), prior and current experiences with keeping track of their health, and to what extent they consider health technologies relevant to the concept of health maintenance. From these interviews we are exploring the tensions between the desire to remain healthy and knowledgeable of one's own health, and the barriers of trust associated with technology in the dissemination of health information.

Findings from these interviews will be used to derive potential directions for ubiquitous and pervasive health technologies. Additionally, we are using insights from these interviews to inform co-creation activities to visually capture how low-income African-American older adults imagine health, health-information seeking, and health management.

3.2 Participatory Design Workshops

Building on our preliminary analysis of the semi-structured interviews, the second phase of this study has the primary goal of furthering our understanding of how intersectional sociocultural dimensions influence older adults' concepts of health. The secondary goal of these workshops is to identify appropriate methods of co-creation with individuals from these communities.

We are designing a series of participatory design workshops to be conducted in local Chicagoland area community centers which will directly work with low-income African American older adults in co-creation activities. Sessions are being designed to allow researchers to work with groups of 7 or 8 older adults that fit the target population directly in the community spaces that they frequent. Workshops will be conducted weekly where

different aspects of health perceptions, behaviors, and interventions will be addressed. Weekly prompts will focus on the following topics: types of health information considered important to this community; methods of health information sharing; barriers to health maintenance; ideal health resources in the local community; concepts of ideal health; previous experiences and current health behaviors; and ways technology may facilitate these behaviors. These prompts will be facilitated through both individual and collaborative activities such as group collaging, scenario mapping and reflection, artifact analysis, and group discussions.

In addition to the prompts and topics for each workshop, we are placing consideration on material selection and setup of workshops to evaluate the most conducive approaches to participatory design with this population. We seek to outline the ways in which designers can support co-creation among this community, pushing forward an area of research which leverages culturally-informed co-creation in HCI. While previous research suggests the value in including older adults and underrepresented individuals in co-creation processes [8, 9], there is still a need to explore material selection and design of creative spaces when engaging with different user groups through this method. Lazar et al. suggest that varying the materials utilized in co-creation activities may support self-expression with individuals who have varying needs, thus having an impact on the outcomes of resulting designs [13]. We intend to explore what methods of co-creation best support low-income older adults in expressing their perceptions of health and health technology needs.

4 DISCUSSION

A better understanding of intersectional sociocultural influences has the potential to support a more accurate conceptualization of health technologies for marginalized populations. Understanding the complexities of user identities and the values and beliefs associated with these identities plays an important role in working towards inclusive technology solutions for health. Additionally, these complexities influence the ways in which designers approach collaborative design efforts with end users. Research precedence in HCI suggest that including individuals from marginalized communities through community-based participatory design provides direct insight into relevant intervention needs. Thus there should be careful consideration to how this design efforts are structured.

Designing health technologies from a more culturally-informed perspective will help researchers and designers in choosing appropriate mediums for disseminating health information to be culturally relevant to their intended population. Understanding the ways in which individuals approach health maintenance and whether or not that

includes technology may eliminate the gap between available health technologies and those who use them. Culturally-informed health technologies may also contribute to addressing the digital divide often seen among marginalized communities.

Although this has become a convenient approach to health management, the design of health tracking technologies may be several steps down the line in addressing health needs among low-income African-American older adults. There is a need to first gain an in-depth understanding of what is encompassed in this population's thoughts of "health" and "tracking". It may also be advantageous to examine how to promote health literacy and technology proficiency among this population. Cultural competence plays an important part in this understanding, and presents a newer framework for researchers to work from.

Our goal in participating in this workshop is to gain feedback and insight into ways to strengthen the design of our series of co-creation workshops. We also invite a critical discourse concerning ways in which researchers within the pervasive health community can leverage the influences and cultural values of complex identities in the considerations for health technologies. We are interested in identifying what it means to see the complexities of marginalized identities as a positive foundation for innovation as opposed to a methodological challenge, and push forward the approach of designing culturally-informed health technologies.

ACKNOWLEDGMENTS

This work was supported in part by NSF Grant IIS-1551574 and a Delaney Family Foundation grant.

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