Online HIV Awareness and Technology Affordance Benefits for Black Female Collegians – Maybe Not: The Case of Stigma

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ABSTRACT

Objective – We investigate the technology affordances associated with and anticipated from an online HIV prevention awareness platform, myHealthImpactNetwork, intended to reach Black female college students. This population is at increased risk for HIV transmission, but is not often studied. In addition, this population regularly uses digital tools, including websites and social media platforms, to engage in health information seeking.

Materials and Methods – We conducted 11 focus groups with 60 Black female college students attending 2 universities in the US. Focus groups were recorded, transcribed and analyzed using content analyses.

Results: Contrary to our proposition, the participants' information needs did not align with the anticipated benefits associated with the technology affordances of the prevention awareness platform. Concerns about personal online social capital, reputation management and stigma limited participants' willingness to engage with the HIV prevention content on the website.

Discussion - Although the participants' use digital tools as a primary means of becoming informed about health, concerns about friends, family and others in their social network assuming that they were HIV infected limited their willingness to engage with myHealthImpactNetwork. Print media and conversations with healthcare professionals were preferred channels for HIV prevention information.

Conclusions - Perceptions of stigma associated with HIV negatively impact health information seeking and sharing online in the social networks in which Black college

students engage. However, by understanding the unanticipated consequences, researchers can effectively design for cultures and sub-cultures infected and affected by health disparities.

INTRODUCTION

Our study is informed by Fox's commentary on health, race and technology. In a Pew Research Center Internet and American Life commentary at the Federal HIV/AIDS Web Council meeting, numerous opportunities to harness the power of social media and mobile technologies in the context of health and wellbeing were described by Fox[1]. According to Fox[1], one central theme is prominent; in seeking health information, people are connecting to humans using social media applications on mobile devices. Although mediated by information and communication technology (ICT), it is these human connections that influence health seeking. Given that the ICT affords the cultivation of cultures associated with openness of thought, voice and interaction, *we propose that the same is true of those affected and infected by stigmatized diseases, such as HIV. Further, young Black women would be active participants in the use, influence and development of the health discourse[2,3]*. We note that being affected by a health condition means that a person may not be infected, but is impacted by the lives of those infected family, friends and other members of their trusted social networks and associated norms[3,4].

ICTs provide a range of opportunities to engage young Black women with health information seeking and content creation[1-4]. To leverage this opportunity and to bring potentially life-saving health information to vulnerable populations, we need to create culturally relevant ICT artifacts that harness the affordances associated with new

technologies. Affordance theory[5] offers a conceptual framework to understand, design and foster a human-to-human interaction design experience for culturally diverse populations.

Consequently, our research uses affordance theory to inform the design of myHealthImpactNetwork, a web-based platform to promote HIV prevention awareness among Black female college students. In this paper, we describe the affordances that emerged among users – particularly Black female college students – as they searched for information, and created and shared content related to HIV prevention. We conclude that technology affordance is not equally gained by among the Black females, and stigma plays a critical role in how the population perceives online engagement and information-seeking of HIV prevention content.

BACKGROUND AND SIGNIFICANCE

HIV continues to be a serious health threat for Black women[1,3,6,7]. While much of the prior research on HIV prevention focuses on "at-risk" Black women in economically challenged urban communities [8,9,10], our study focuses on Black female college students as a community with unique information and communication needs. Also, we focus on social media and web-based information resources rather than traditional information sources because the digital information channels are heavily accessed and used by this group [1, 3,11-13].

Sum, Matthews, Pourghasem and Hughes [14] examined online social channels in the context of technology affordances. According to Putnam, affordances of technology are the ways in which ICT offers and supports information accessibility, tasks automation, knowledge representation, and communication and collaboration with peers

and experts[15]. Research scholars [14-15] used social capital theory to explain how these channels impart technology affordances to users. Social capital is defined as follows: *Whereas physical capital refers to physical objects and human capital refers to the properties of individuals, social capital refers to connections among individuals – social networks and the norms of reciprocity and trustworthiness that arise from them[15]*. Online social channels are mechanisms that afford information seeking, entertainment, commerce, communication, and creation of social networks with new people. These findings suggest that increases in social capital afforded by technology, in particular higher feelings of trust, are likely to result in a higher level of personal wellbeing among users [3,4,14].

The personal wellbeing and sense of connectedness must be met with culturally relevant content and locations, if we are to reach Black females, in general, and those not engaged in sexual and HIV risk behaviors but wish to have voice in shaping the discourse. For example, Black women are moving online to articulate their vision of Black womanhood and cultural knowledge, and debunk deficit models often associated with minority's use of technology as articulated in the digital divide discourse[16, 17] – thereby disturbing communicative norms and practices on the Internet[16]. Additional research finds that online Black consumers are significantly more connected to others with Twitter being the most popular social media tool. Black women between the ages of 18 and 35 are 72% more likely to generate web content such as authoring a blog on personal products and following members of social networks [13].

In this study, we seek to understand the technology affordances associated with our HIV prevention awareness platform, which is particularly tailored with culturally

compelling content that engages Black females college students. Technology affordance theory provides an opportunity to uncover the results associated with prevention designed to address these issues.

Theoretical framework: Technology Affordance

Norman[18] referred to the material properties of technology as affordances that enable users to meet their objectives – thereby creating a "good" for the users. Often centered in an organizational context, information and communication technologies have been shown to provide both core and tangential affordances. That is, the core affordances are those created intentional by designers of the technology and include textual, audio and face-to-face functionality. Tangential affordances are what users perceive[19], and can be the result of unintended consequences or uses of the technology.

Affordances are outcomes of the complex interaction between multiple actors and the artifacts, not an outcome of the artifact or the actor alone. Zhao and colleagues [5], for example, present an ensemble view of ICT as a socio-technical system that mediates and fosters human communication: *As a technology-mediated or supported socio-technical system enabling participation, communication, and collaboration, social media has a strong [technology] focus, and can be regarded as an [ICT] artifact with two embedded attributes: form and content.*

Research aims and objectives

If ICT will have a significant impact for historically underserved groups, we need to explicitly examine intentional artifacts and their affordances. In this study, we assume an ensemble view of ICT that considers the properties of technology artifacts (HIV

websites) as well as the social practices and context that shape the meaning and use of the artifact. Our objective is to develop a culturally compelling platform that fosters ongoing and open discussions about stigma, myths, and risk behaviors in an effort use ICT to reduce new incidents of HIV among Black women. Our research approach is informed by technology affordance theory, and seeks to uncover how the Black female college students' perceptions of this culturally-relevant and designed artifact aligned with the intended affordances or benefits as articulated in the literature and designed by the researchers.

METHODS

Study participants

To inform the design of our artifact, we conducted six (6) focus groups with 40 Black female college students at two US universities – one in the Northeast and one in the Southeast. The focus groups were conducted from October 2011 through April 2013. The early focus groups focused in participants' perceptions about the existing HIV websites. These perceptions informed the design of the myHealthImpactNetwork platform. In subsequent focus groups women were asked to review the myHealthImpactNetwork, with the intent to observe the alignment between the researchers' core affordances and the participants' tangential affordances. All focus group participates were provided informed content forms which were approved by both universities' institutional review boards (IRB). We use an identical protocol for data collection. Gifts cards were used as participation incentives. Participants ranged in age from 18 to 24 years. Each focus group lasted for 60 to 90 minutes.

Research design

Focus groups were audio recorded and transcribed for this study. Transcripts were analyzed using qualitative thematic analyses[20]. Themes were identified in two phases: design preferences from the initial focus groups followed by technology affordances associated with our ICT artifact. Our intent was to see how well our artifact met the participants' design preferences. The researchers conducted a series of meetings to collaboratively code the transcripts and validate the findings.

Critical to the development of the myHealthImpactNetwork experience was an assessment of how the focus group participants perceived existing HIV online information. This enabled us to gauge the technology affordance associated with existing HIV online platforms. As reported in prior studies,[3, 4, 8, 21] design absent of race, gender, and identity of Black women may encapsulate the assumptions, controls, and potential barriers associated with that of designers. As a consequence, Black women may have a harder time connecting with and making sense of the content found online, or aligning with the ethnic and cultural identities associated with Internet-based platforms [21].

Figures 1 and 2 show the recent screen captures of our ICT artifact, myHealthImpactNetwork. The for-student-by-student spirit (or ethos) communicates the technology affordances of content ownership, design involvement, and trust – as three students were active members of the design team and supervised by the first author. The involvement of undergraduate college students in focus groups **AND** as a part of the design team created and strengthened these affordance as peer-to-peer health education and HIV awareness. In an earlier study focused on Black female college students[12], we learned that the target group desired the following characteristics:

1) Differences between HIV and AIDS without too much clinical language;

2) HIV/AIDS awareness and prevention messages using multimedia and including images of "those who look like me", avoiding the overuse of linear text;

3) Social media presence because "this is what we do";

4) Graphical and other visual depictions of HIV and health statistics.

RESULTS

Intended Consequences : Culturally Relevant and Compelling Design Elements

Accounting for the above list, we migrated from preliminary focus groups to design of the artifact. Figures 1 and 2 depict a Phase 3 implementation of revisions as we continue to engage our audience through student involvement in the social media interaction and website design.

We highlight elements in Figures 1 and 2 to demonstrate how myHealthImpactNetwork evolved in our efforts to create a social media-enabled, culturally relevant experience for our target group. The platform uses a decision tool sponsored by AIDSVu.org in Figure 1 to enable its users to locate HIV resources, and to illustrate risk by providing a graphical heat map to show geographical the disease's prevalence. The arrangement, layout, color scheme and the logo were carefully selected through participatory design methods to convey the desired affordances for the target population. Figure 1 shows infographics as visualization of health data for the users.
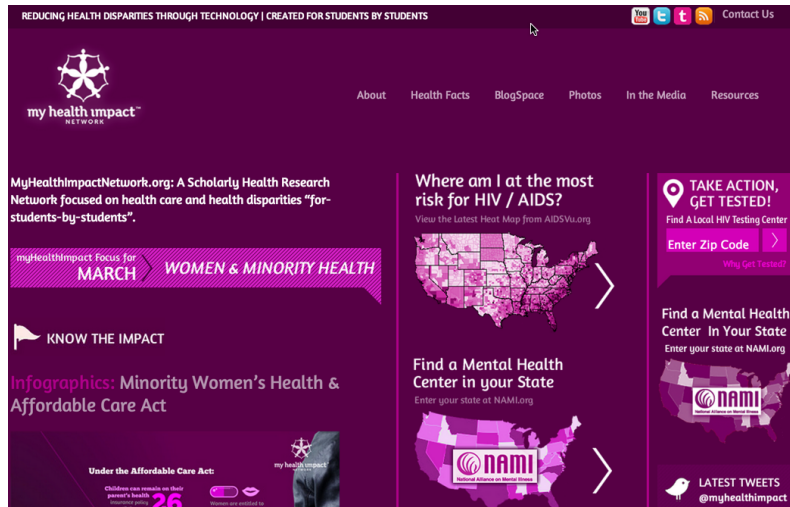
Figure 1 – myHealthImpactNetwork Screen Shot – Taken March 2014

The social media presence includes Tumblr, Twitter and YouTube. In Figure 2, we build on symbolic expressions as we attempt to nurture a user experience of sharing, or a spirit of voice amplification via images, blogging, and affirming Black images. This affirmation concept leads us to the discussion of the dark side of social media, image and the user community.
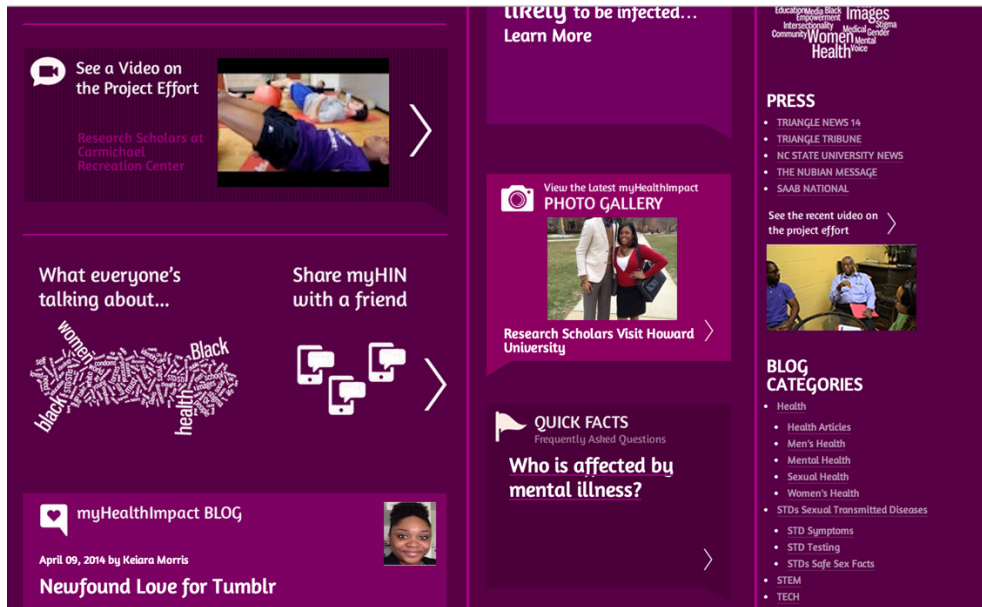
Figure 2 – myHealthImpactNetwork.org Screen Shot – Taken March 2014

Unanticipated Consequences - Stigma by Association

We found that Black women are concerned about "stigmatized association". That is, a conflict exists between the ICT artifact bright side affordance (human-to-human interaction, empowerment, knowledge sharing, social justice, etc.) and the connection to a stigmatized condition, particularly in the digital space. This is different than the stigma of being infected with HIV. Rather, this is the stigma of being publicly associated with and participating in the HIV prevention discourse. The participants offered insights about digital participation and the negative assumptions that the broader society, and even some in their own social networks, would have about them personally. These findings fell into three categories: online and offline stigma, HIV and health information, and relatable trust.

Online and Offline Stigma

The women at the northern university were particularly reluctant to follow the project on Twitter. In fact, none of the participants joined even though most had an active Twitter account. When asked why she chose not to follow, one participant stated "*I would not follow the Twitter account, participate in a public service announcement on HIV awareness...people would automatically think that I'm positive.*" This concern about being associated with a highly stigmatized disease was echoed by other northern focus group participants.

The fear of being stigmatized carried over into online information seeking. Participants expressed a need to know more about HIV prevention, but there was a bit of reluctance to do so. As one woman argued, "*Yeah. I wouldn't expect anybody to be looking at what I am looking at. But besides that, even if they did it's like what's wrong with me like looking this up? I need to know information about it. (Someone questions if I have HIV because I am looking up the information).*"

HIV and Health Information

The need for private information seeking was a common refrain among all of the women at both institutions. However, the participants were particularly concerned with how Black women are represented in the HIV discourse. The participants did not see themselves engaging in activities that put them at risk. In fact nearly every woman at the northern university stated that she was not sexually active. However, the women felt that the HIV prevention literature portrays all Black women as vulnerable and sexually promiscuous. "*Well, until closer to my adulthood, I never heard black women are at risk,*

and black women are at a high number, and these cities, and this, that and the third. You were just kind of introduced to...well this exists and it exists if you have unprotected sex or share a needle...All black women...we are not promiscuous or drug users."

The women took responsibility for their lack of knowledge, and argued forcefully that it was incumbent upon them to take responsibility for their health. Some felt that physicians were not forthcoming with information. They had to demand it even from healthcare providers! *"You're like 'but these are things you should be probing me for as a medical physician.' I don't...I feel like they don't, with our community, present us with the information unless we really, really seek it. Unless you go into the office and you're like 'can I ask you about this.'"*

Relatable Trust

The women in the focus groups desired culturally salient information. The trustworthiness of the information was not a given, however. The information had to be verified and deemed credible, but it should also be relatable. *"I wouldn't trust it automatically. I'd still have to read it and stuff, but I think it would be more relatable."* Women in a northern focus group even adopted the term "relatability" and used it throughout the session as a means of conveying the centrality of culturally salience in HIV prevention information. The southern women, likewise, used the term "me-ness" to describe the relatable notion espoused by their northern peers.

Keenly aware of the higher incidence of HIV in the Black community, the women interrogated their greater risks from both being Black and being female. This type of intersectional thinking is expressed in the following quote: *"It seems like when they*

bring up statistics, they always break it down by black and white. And since we are like on a higher level of being women and black, it's probably like, not more dedication, but more out there. Better results...because we be the most." Others supported this intersectional view as stated: *"They (doctors) will tell us anything. Being Black, female and from a rural area. They do not see us as informed patients. This is why I go to doc visits with my little brother and Mom. I have to protect them."*

While all of the women described themselves as heavy online users, they also found many online resources to be indifferent and impersonal. In addition, the spirit evoked from handling a tangible book or pamphlet was still salient for these millennials. *Sometimes I think like electronics and all those things are less personal. I mean, how comfortable do you feel going to a library (if you have no computer) and typing in something about ... something personal. I think that's less personal because you have people around you. How often are you, like, in a secluded place where you can say 'let me figure this out' or 'I'm having this type of problem'. No matter how personal the problem is you still wanna have seclusion where you can do it in your own privacy. So I think the Internet, like being able to do things on your phone, like people can look at your history and certain things like that. So when you have things more personalized like reading a book you feel more attached to it, where it's more tangible versus reading it online. Where you can scroll down or skip things, but when things are more tangible they feel more personal to you....On the computer, say like you don't want your parents to know something, but they can backtrack your steps.*

The public nature of one's impression motivated participants to manage their impressions quite carefully. Others[14] have likened this to the notion of social capital in the technology affordance research. Research on social network use and personality likened these findings to impression management, a notion that social media users try to have the right list of friends or associations in order to create the desired image of themselves[22].

Given this and the stigma concerns of the participants, we concluded that some Black female participants failed to engage the platform. These findings led our team to "open" the HIV discourse to include other health conditions and topics (e.g., Affordable Care Act, mental health, fitness & wellbeing) as shown in Figure 1. In addition, expansion of the focus has resulted in health themes that are of interest to the target population and are now inclusive of Black men as well.

DISCUSSION

Intended and Unintended Affordances

Our work examines the affordances associated with a platform initially designed to disseminate HIV prevention information to Black female college students. Data were collected from two large academic institutions: one in the Southeast U.S. and another in the Northeast U.S. While much of our data disclosed intended affordances by the study's participants, there were unintended affordances that emerged from the participants in both locations.

Primarily, the unanticipated affordances emerged as a result of personal reputation management in a social media space where the context focused on stigmatized

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health conditions, such as HIV. Our findings show that participants are concerned about societal perceptions of being socially connected to the HIV discourse, even in instances when the disease does not directly affect them. Hence, despite the empowerment, voice amplification, and openness afforded by ICT, social media can dampen these affordances in the context of broader societal stigmatized conditions. As one focus group participant mentioned, "I just see these stats and say yes, I am Black and female. I do not want to be in the stat or associated anyone that may suggest that I am".

This finding supports much of the previous literature that reports that social network sites primarily support pre-existing social relations. To bridge this online-offline social network, users carefully manage the processes of impression management, self-presentation, and friendship performance online[23]. However, when specifically looking at health information seeking, our findings contradict those reported on quality and accessibility affordances[24]. This scholar found that when a condition was stigmatized, such as herpes, people were more likely to use the web for information. By way of contrast, people tend to turn to family and friends for information before scheduling an appointment with a doctor or seeking information on less stigmatized health concerns. In our study, women were not privately seeking information about HIV; they were publicly seeking information and participating in a discourse. This public-private means of searching for health information has important implications for people's level of online engagement.

CONCLUSION

This research demonstrates some unintended challenges associated with tailoring online platforms for historically underserved populations. We also demonstrate that Black women are thoughtful, engaged consumers and producers of online health information. The information content must be paired with technology affordances as perceived by the intended audience, if unique cultural experiences will be capture in online healthcare platforms. This research also serves as evidence that perceptions of one's social capital in the digital sphere plays a central role in the dissemination of online HIV prevention information. Further, these perceptions extend affordances to include online channels, palatable content and social meaning embedded in the artifact and social uses[25] by the target population.

On a more practical level, our work challenges technology affordances frameworks. We learned that a monolithic definition of affordance among and within a demographic or population group (the Black female college community) limited the design and potential user interactions with the online experience. Designers are encouraged to rethink how they create culturally relevant artifacts that are inclusive of the culture and sub-culture depictions and the social computing world for which we now exist.

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