2009

Barriers, control and identity in health information seeking among African American women

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Abstract

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Keywords

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ABSTRACT

Qualitative research methods were used to examine the role of racial, cultural, and socio-economic group (i.e., communal) identities on perceptions of barriers and control related to traditional and internet resources for seeking health information. Eighteen lower income, African American women participated in training workshops on using the internet for health, followed by two focus groups. Transcripts were analyzed using standardized coding methods. Results demonstrated that participants perceived the internet as a tool for seeking health information, which they believed would empower them within formal healthcare settings. Participants invoked racial, cultural, and socio-economic identities when discussing barriers to seeking health information within healthcare systems and the internet. The findings indicate that the internet may be a valuable tool for accessing health information among lower income African American women if barriers are reduced. Recommendations are made that may assist health providers in improving health information seeking outcomes of African American women.

Key Words: health information, internet, identity, African American women

INTRODUCTION

Health information is integral to making informed health decisions and practicing healthy behaviors (Nelson et al., 2004). However, racial, cultural, and socio-economic inequities exist in access to health information (Ford & Yep, 2003; Ramanadhan & Viswanath, 2006) that contribute to the well-documented disparities in health outcomes (Smedley, Stith, & Nelson, 2002; Williams & Collins, 2004). Scholars have suggested that the internet has the potential to decrease inequality by making information more accessible to underserved populations (Martin & Robinson, 2007; Neuhauser & Kreps, 2003).

Several studies have examined the efficacy of online programs designed to increase healthy behaviors among underserved audiences (Gustafson & Wyatt, 2004; Masi et al., 2003; Schinke, Schwinn, Di Noia, & Cole, 2004). The results of these studies demonstrate that, while members of these groups often are not considered audiences for this medium, the internet can be a valuable health information tool for disadvantaged populations. However, despite the growing numbers of underserved populations using the internet for health, there continues to be significant racial and socio-economic gaps in utilization of online health information between majority and minority populations, even among those who have access to the internet (Brodie et al., 2000).

To understand the potential of the internet as a resource for seeking health information for underserved groups, it is critical to consider the socio-cultural context within which these groups seek health information (Dutta-Bergman, 2005a; Kvasny, 2006). This context includes the impact of both social (e.g., race, class) and cultural (e.g., African American) group memberships in shaping information seeking experiences as well as perceptions of the internet as a tool for seeking health information (Kvasny & Warren, 2006). However, scholars (Mossberger, Tolbert, & Gilbert, 2006; Tolbert, Mossberger, King, & Miller, 2007) argue that research on the affects of socio-cultural context on internet use has paid little attention to the unique experiences of African Americans. This is particularly true of African American women despite the fact that among African Americans, 61% of newcomers to the internet are women who outpace African American men online (Spooner & Rainie, 2000).

To address this gap, this study examined the roles of racial, cultural, and socio-economic group (i.e., communal) identities in shaping lower income African American women's perceptions of barriers and control related to traditional and internet resources for seeking health information. Obtaining perceptions of health information seeking is important because, according to Fox and Rainie (2002), this online search practice is appealing to individuals regardless of race or income status. However, the digital divide affects access to health information, as more information is provided through online sources (Brodie et al., 2000).

Health Information Seeking

Greater use of health information resources is associated with better overall health status (Thompson, Dorsey, Miller & Parrot, 2003). The motivation to seek health information evolves from prior health information seeking experiences, perceptions about sources of the information, and access to health information (Witte, Meyer, & Martell, 2001). In addition, individuals who actively seek information about a particular health condition from multiple sources may be more motivated about their health than others who obtain health information only through their interaction with physicians (Dutta-Bergman, 2005b). The internet is a popular source for obtaining health information. Motivated individuals may use this resource to enhance their capacity to play a more active role in health decision-making and prevention.

Health Information Seeking Online

There are more than 70,000 health websites and social support platforms covering a multitude of health topics that are utilized by over 77 million people accessing the internet for health-related purposes (Fox & Fallows, 2003). On a typical day, about 6 million Americans go online for medical advice. This exceeds the number of Americans who actually visit health professionals (Fox & Fallows, 2003).

While these statistics describe the general US population, there is also evidence that 36% of African American adults (n=7.5 million) across socio-economic levels are actively using or have intentions to use (46%) the web to seek information (Pew Research Center, 2005; Spooner & Rainie, 2000), with some studies showing higher rates of use among African Americans related to Whites (Gustafson et al., 1999; Jackson, Ervin, Gardner, & Schmitt, 2001). For instance, a study among 787 university students found that African Americans used the internet more than Whites when information was personally relevant (Jackson et al., 2001). Gustafson et al. (1999) found that lower income African American women were more active in a web-based cancer intervention than higher income White women. In a study of 457 urban African Americans (78% women) with diabetes, 89% reported they would use a web-based diabetes prevention program to manage their illness if the internet was offered free of charge (Jackson et al., 2005). Further, while lower-income individuals are less likely to use the internet in general, Zarcadoolas et al. (2002) found that health information to be the highest priority search category for lower income African Americans if they were to access the internet.

While these findings are encouraging about the potential use of the internet as a tool to improve the health of lower income African Americans, we argue that the role the internet plays as a tool in managing one's health is likely to differ based upon one's group identity and social position. Our argument is consistent with recent studies that critique the assumption that the internet is a neutral tool that offers a potential solution for overcoming longstanding disparities in health (Gibbons 2008). Kvasny (2005), for instance, argues the digital divide is a political outcome rooted in historical systems of power and privilege, and not simply a gap in access to and use of the internet and computers. Digital divide studies often construct information as an unquestioned good, and those who do not have access to information lack material, social, technical, and cultural capacity (Selwyn, 2004). In this way the information "have-nots" are defined as problem populations (e.g., lower income families, racial/ethnic minorities, inner city residents) who are characterized as outsiders to American culture, and their information needs and seeking behaviors are described as impoverished (Chatman, 1996; Agada, 1999). This scholarly discourse can be implicated as replicating existing cultural beliefs regarding the ways in which minorities' use of information and technology is perceived to be inferior to that of Whites (Brock, 2008). In considering the internet as a tool to reduce health disparities, there is limited acknowledgement of the structural inequities that create the social problems found in inner city environments (Gibbons, 2008).

Therefore, it is important to examine how the internet can serve as a resource among lower income African American women in seeking health information without disadvantaging the group in the process. This can be done by avoiding "essentializing" an individual as a member of a single identity group. In order to accomplish this, the current study applies intersectionality, an approach developed by critical race theorists and feminists to account for the simultaneous influence of multiple social and cultural categories on individuals' experience (Cole, 2009). When examining the internet, we considered the intersectional effects of race, culture, and socio-economic status. In the following section, we discuss factors associated with race, socio-economic status, and culture that are likely to present barriers for lower income African American women seeking health information (National Center on Minority Health and Health Disparities, 2006).

Barriers in Health Information Seeking

Health professionals are important sources of health information (Lambert & Loiselle, 2007). However, these professionals can exhibit biases sharing information based on race, culture, and socio-economic status (van Ryn, 2002). For example, people with fewer material resources have less access to these sources of information, and when they do have access, substantial inequities in provider/client communication often create disparities in access to health information and healthcare services (King & Williams, 1995; Kreps, 2006). Similarly, members of racial and cultural minority groups such as African Americans often have unequal access to information. We start with the intersection of race and culture before moving to a consideration of class.

Race and culture.

Considerable evidence exists that African American patients, both men and women, believe they would receive better care if they belong to a different cultural/racial group, and that they felt they have been judged unfairly by health practitioners based on culture and race (Johnson, Saha, Arbelaez, Beach, & Cooper, 2004). Research finds that African American women are more likely to receive too little information from health care providers due to negative stereotyping among physicians related to race (van Ryn, 2002; van Ryn & Fu, 2003). Additionally, compared with White women, African American women are more likely to report that their health care providers often disregard health-related behaviors and ways of communicating about health that are tied to their cultural group's worldview (Airhihenbuwa & Liburd, 2006). Moreover, differences in language, health literacy, and health practices can result in physicians' unwittingly incorporating racial biases as well as cultural stereotypes into interpretation of clients' symptoms, predictions of patients' behaviors, and medical decision-making (Burgess, van Ryn, Dovidio, & Saha, 2007; van Ryn, Burgess, Malat, & Griffin, 2006).

Socio-economic status.

The disadvantages described above are compounded when socio-economic status is involved (King & Williams, 1995). Stereotypes of lower income African American women negatively influence their quality of health information seeking (Ford & Yep, 2003). Physicians also appear to be less likely to provide in-depth diagnostic data to African American women due to inaccurate beliefs about lower income clients (O'Malley, Sheppard, Schwartz, & Mandelblatt, 2004; van Ryn & Burke, 2000). Inequalities are especially prevalent for individuals receiving public health assistance (McCann & Weinmann, 1996). Health practitioners may be less likely to listen to or accept input from lower income African American women due to perceptions of them not being as rational or intelligent as Whites or higher income patients (van Ryn & Burke, 2000).

The intersection of race, culture and socio-economic status.

Evidence suggests that the intersection of racial, cultural, and class-related identities can result in barriers to African American women's access to health information necessary in making informed health decisions, due to membership in multiple socially disadvantaged groups. Specifically, members of socially disadvantaged groups perceive that they receive inferior or biased treatment within the health care setting (Hobson, 2001). These perceptions have been shown to inhibit the quality of health information by leading members of disadvantaged groups to avoid the health care system (Van Houtven et al., 2005), use it service less frequently (Hobson, 2001), and delay care (Blanchard & Lurie, 2004; Van Houtven et al., 2005). Moreover, higher levels of perceived discrimination within the health care system have been associated with lower rates of participation in several preventive health care services (Trivedi & Ayanian, 2006).

Implications of unequal medical treatment related to membership in stigmatized groups can result in feeling a sense of helplessness or lack of control (Atrash & Hunter, 2006). Research in

stereotype threat suggests that when individuals from stigmatized groups are placed in situations (i.e., medical encounters) where they perceive they are denied access to information because of negative social stereotypes, this may adversely impact their confidence to obtain the information they need, and worse, reduce engagement with health-promoting behaviors, such as seeking health information (Oyserman, Fryberg, & Yoder, 2007; Steele, 1997). In the next section, we discuss perceived control of health information seeking.

Self-Perception of Control in Health Information Seeking

Self-perception of control has been closely identified with empowerment, whereby an individual gains an enhanced awareness and capacity to direct or exert power over his or her personal life (Masi et al., 2003). Self-perception of control also includes perceiving the ability to participate in and influence health decisions.

Oppressive experiences, such as encountering economic, racial, and cultural barriers to health information seeking, have a negative effect on self-perception of control (Atrash & Hunter, 2006). However, in a community-based health initiative that assessed the relationship between increasing access to health information via in-home internet connection and perceptions of control among lower income residents, Masi et al (2003) found that the use of the internet to seek health information had a positive influence on health-related self-perception of control. Amid the challenges many African Americans face in traditional health care settings, the internet may provide a viable supplementary resource for seeking health information.

Overcoming informational health disparities requires paradigms that allow researchers to make sense of how group members construct their informational needs, the processes that shape such construction, and the meanings derived from the consumption of the information (Spink & Cole, 2001). Below, we propose a model that incorporates these considerations.
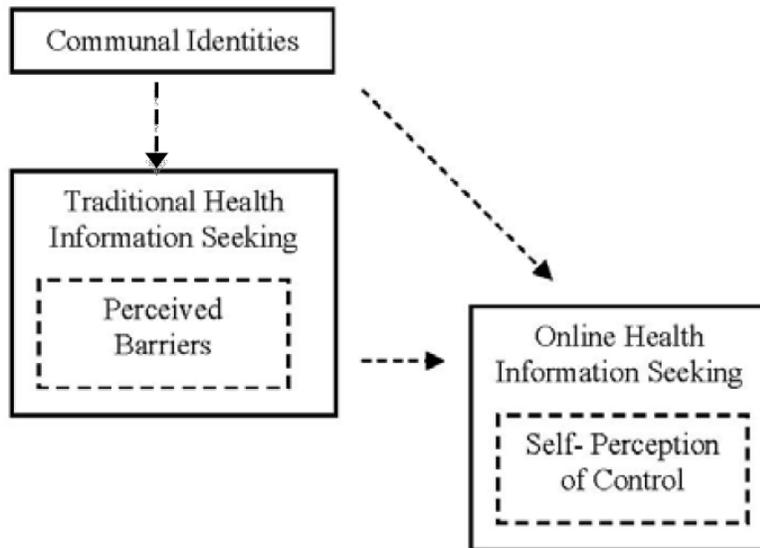
Theoretical Model of Health Information Seeking

Health information seeking is conceptualized and modeled in various ways (Lambert & Loiselle, 2007). Generally, this analysis starts with an understanding of the relationship of discrete variables, such as demographics (e.g., age, ethnic group) to personal factors (e.g., attitudes, behavior). However, little consideration tends to be given to the ways in which individuals identifying with social groups perceive their own abilities to direct health information seeking (King & Williams, 1995), which contributes to positive health outcomes (van der Molen, 1999). Furthermore, personal and contextual factors affecting health information seeking are usually analyzed independent of each other, leading to limitations in predicting health information seeking (Lambert & Loiselle, 2007). Thus, our goal was to develop a theoretical model of health information seeking to include group-based identities, self-perception of control, and barriers in health care to inform the investigation of the potential of online health information seeking among an underserved group.

The theoretical model draws upon the Communication Theory of Identity (CTI) (Hecht, 1993) to provide a broader view of how socially- and culturally-driven phenomena play a role in health information seeking through their influence on health perceptions, decisions, and behaviors. According to CTI, individuals often conceive of themselves as part of multiple and interconnected communities (e.g., racial and socio-economic groups), each of which carries its own sense of identity. In addition, individuals are assigned by others to a particular group. Thus, communal identity is created through how one views himself/herself (i.e., avowed identity) as well as through negotiation of others' views of him/her (i.e., ascribed identity). Stereotypes emerge when images assumed to be characteristics of group members are communicated in rigid and limiting ways (Jackson, Warren, Pitts, & Wilson, 2007).

Communal identities are also important constructs in an individual's understanding of who they are as well as for their interpretation of health experiences and health practices (Hecht, Warren, Jung, & Krieger, 2005). In particular, communal identities may highlight understandings of self-perception of control and perceived barriers in seeking information as well as help us understand the motivations and processes related to information seeking. The ways in which these identities are realized in health communication have important implications for health information seeking and outcomes.

Figure I. Theoretical Model

The theoretical model (Figure I) provides a way of envisioning health information seeking whereby communal identities may be associated with the personal (i.e., self-perception of control) and contextual (i.e., perceived barriers) factors that are involved in health information seeking among underserved groups (Lambert & Loiselle, 2007). Communal identities include racial, cultural, and socio-economic group identification and are inclusive of both self-avowed and perceptions of ascribed identities. As highlighted in the model, communal identities may have an affect on an individual's interpretations of obstacles hindering information seeking in traditional health contexts, which may shape perceptions of the internet as a resource for seeking health information and self-perception of control. Communal identities also may affect perceptions of the internet as a health resource.

While the literature supports the need for the development of a model such as this and the relationships it highlights, a model's potential value is based upon the ability to further understand real world phenomena. Therefore the objective of this study is to explore how and in what ways communal identities influence perceptions of both traditional and online sources of seeking health information by focusing on the processes of information seeking. To that end, we addressed the following research questions:

RQ1: How do lower income African American women perceive their communal identities as affecting health information seeking experiences in traditional (i.e., not on the internet) settings and the internet?

RQ2: How do their traditional health information seeking experiences shape perceptions of the internet as a resource for health information?

METHODS

Overview of Focus Group Methodology

This study consisted of an internet training workshop followed by focus groups. Internet training has been successfully integrated into health-related studies to investigate individuals' perceptions related to quality care and the use of online health information in their own lives (Lesley, Oermann, & Vander, 2004). Internet training workshops provided participants with a common base of information and experiences. In addition, it was a way of ethically providing something to participants in exchange for their involvement in research.

Following the workshops, focus groups were conducted to describe health information seeking. This method brings together purposeful and relative homogenous groups of individual to discuss a particular topic, an important strategy for discovery and generation of hypotheses (Denzin & Lincoln, 2000; Patton, 1990). Due to this mixing of knowledge, the group and not the individual was the unit of analysis; hence the understandings gained are context driven and derived from a known population (Krueger & Casey, 2000).

Study Participants

This study took place in Harrisburg, PA in collaboration with Pfizer Pharmaceuticals, the Harrisburg Health Center, and the local YWCA. A sample of African American women were recruited who (a) self-identified as an African American woman, (b) had little to no experience with the internet, (c) lived in the city of Harrisburg, (d) were between the ages of 19 and 60, and (e) had income at or below $30,000. A family of four in Pennsylvania whose income is $30,000, which is twice the federal poverty level, will still have a hard time making ends meet (Dinan, Cauthen, & Fass, 2004).

Recruitment and Procedures

This study was approved by the Office of Regulatory Compliance at the Pennsylvania State University. Primary recruitment strategies involved the distribution of flyers and on site recruiting at a community medical center and through the YWCA. Recruitment efforts continued until an adequate number of participants enrolled in the study. Thirty-five women were screened, found eligible, and confirmed their participation. Twenty women attended the first workshop with a final sample of eighteen actually completing the training (and subsequent focus groups) that included workshops conducted on four consecutive Saturdays. Two workshops were conducted each day in order to keep them small (7 participants 9:30am-11:30am and 11 participants; 12:30pm-2:30pm). The first author facilitated the workshops at a local YWCA's computer lab equipped with 14 computers. Food and beverages were provided at each workshop and, upon completion, each woman received a certificate of completion and gift bag at a dinner celebration.

Workshops

The workshops were designed to introduce the participants to computers and the World Wide Web and then provided them with skills searching for health information. The content of each is described below.

Day One. Participants were introduced to the computer (i.e., hardware, software) and the World Wide Web (e.g., browser home page, menu bars, etc). The skills were reinforced through online activities (i.e. a scavenger hunt to locate health resources) and discussions.

Day Two. Participants were introduced to standard criteria to evaluate the credibility of health information, the basics of building a personal health webpage, and opened web-based email accounts.

Day Three. Participants continued to explore seeking health information on the Web and worked on building their personal health web pages.

Day Four. Participants continued to explore seeking health information. Personal Web pages were completed and presented to the other participants through a discussion of why the participant chose their health topic, and what sites they used to learn more about the health area to build their health Web page.

Data Collection

A standard demographic questionnaire was completed on the first day of the workshop (e.g., age, income, education, computer use location, and internet use). Following the workshops, two audio-taped focus groups were conducted, lasting two hours in length. The first focus group had 7 participants and the second had 11. In conducting exploratory research, a total number of participants across focus groups is usually 20-40 (Morse, 2000). While utilizing established focus group procedures (Krueger & Casey, 2000), the moderator integrated an action interview format, whereby the participants were verbally encouraged to draw upon a complexity of meanings and understandings in addressing relevant issues (Holstein & Gubrium, 1995). The moderator utilized an interview guide that addressed the following content areas: sources of health information; experiences seeking health information, limited income and information access; race and information access; culture and information access; perceptions of technology; using the internet to get health information; and health topics searched for online.

Data Analysis

Data analysis drew upon a constructivist methodology (Guba & Lincoln, 1989; Lincoln & Guba, 1985). Central to constructivism is the understanding that experience (e.g., patterns of relationships, interactions, behaviors, cognitions and belief) is contextualized, socio-culturally constructed, and based on individual perception (Goodman, 1978). The existence of each of these factors is contingent upon the others, serving, in part, as the shared basis for knowledge and understanding. While constructivist analytical techniques enable the investigation of broad categories (i.e., communal identities), this analytical technique often starts with the voice of the participants and, through their unique perspectives, can generate conceptual understandings of predetermined categories (Denzin & Lincoln, 2000). The goal of constructivist methodology is to provide an in-depth description of any socially-driven phenomena through a detailed reading of collected materials.

The focus group interviews were transcribed verbatim and uploaded by the first author into QSR NVivo, qualitative data management software (version 8.0; QSR International). NVivo was chosen because it allows for easier management of detailed analysis, including the coding of transcripts. Through the process of computer-aided free coding using NVivo, the first author rendered a close reading of the transcripts identifying a 'unit' of data that was either a word, sentence, part of a paragraph (Lincoln & Guba, 1985). This technique enabled these units to be labeled using the language of the participants (also called an in vivo code or a theoretically derived label) (Miller-Day, 2004). In vivo codes maintain the most authentic depiction of the participants' thoughts.

Analysis of the transcripts identified 153 units of data based on words, phrases, sentences, and paragraphs across focus groups. These units or codes were compared and contrasted, and then grouped conceptually using NVivo software (Miles & Huberman, 1994). Conceptual domains were further compared and contrasted with other units in the same domains in a constant review of logical relationships and contradictions (Miller-Day, 2004). Lack of consistency in a conceptual grouping led to the re-examination of data. Within conceptual domains, subcategories were then analyzed and critically discussed among the first, second, and third authors for consistency (i.e., an

audit check was conducted) and conceptual links with relationships before being collapsed into larger thematic groupings (Strauss & Corbin, 1998). Based on these discussions findings were agreed upon and finalized. Inter-rater reliability was not formally assessed.

RESULTS
Quantitative Findings
Demographic characteristics. Table I reports demographic characteristics of the sample. There were 18 African American women. The median age was 48.5 (range 26-60 years). Participants tended to be single (50%; n=9), and have a high school education or GED (50%, n=9). Thirty-nine percent (n=7) had an income of $8,000-$13,000 and 29% (n=5) maintained an income of $14,000-$23,000. Over half of the participants had 0-1 year (61%, n=11) experience in using a computer. The median length of time for internet use was 1 year (range 1-4 years). Thirty percent (n=5) of the participants used the internet from home. Forty percent (n=7) utilized the internet from 2 or more locations.

Table I. Demographic Characteristics*

Study Variable	
Age Median	48.5 (range 26-60 years)

Marital Status, % (n)
   Married
   Single
   Divorced
	
	33% (6)
	50% (9)
	17% (3)

Number of Children, % (n)
   0
   1-3
   4-6
	
	22% (4)
	50% (9)
	28% (5)

Salary, % (n)
   > 13,000
    13,000-23,00
   < 23,000
   Prefer not to answer
	
	39% (7)
	28% (5)
	6% (1)
	27% (5)

Education, % (n)
   Some high school
   High school/GED
   Community college/trade school
   Some college
	
	11% (2)
	50% (9)
	22% (4)
	17% (3)

Length of computer use, % (n)
   0-1 year
   2-4 year
   5> years
	
	61% (11)
	11% (2)
	28% (5)

Length of internet use Median	 1 year (range 1-4 years)

Location of internet use
   Home
   2 or more sites (home, work, relative, community)
	
	30% (5)
	40% (7)

*Percentages and frequencies reported except where median is noted.

Table II shows the frequency of online searches for specific health topics online across participants. The participants tended to search for information related high blood pressure (10 searches), diabetes (11 searches), and heart disease (11 searches).

Table II *Searches for specific health topics online

Health Area	Percent (n)	Health Area	Percent (n)
Diabetes	61% (11)	Fibromyalgia	6% (1)
Heart Disease	61% (11)	Sickle Cell Anemia	6% (1)
High Blood Pressure	56% (10)	Cholesterol	6% (1)
HIV/AIDS	33% (6)	Menopause	6% (1)
Cancer	28% (5)	Pituitary Health	6% (1)
Depression	22% (4)	Keyloids	6% (1)
Asthma	22% (4)	Vision	6% (1)
*Participants visited more than one health area.			

Qualitative Findings

Key qualitative findings are organized according to the model. Accordingly, two major domains include Traditional Health Information Seeking (Perceived Barriers) and Online Health Information Seeking (Self-Perceptions of Control) (see Table III). Qualitative analyses resulted in the identification of six factors within these two overarching domains, including secondhand healthcare, withholding health information, tension in access, embrace technological change, seek more health information, and access to technology. Table IV outlines the communal identities that are salient for each factor. The findings are described below.

Traditional Health Information Seeking (Perceived Barriers)

Three factors, secondhand healthcare, withholding health information, and tensions in access describe perceptions of barriers to traditional health information seeking. These involve substandard care and information related to cultural, racial, and socio-economic communal identities.

Secondhand healthcare.

This factor reveals participants' beliefs that they receive inferior health care due to racial discrimination by health professionals. The metaphor of "secondhand," as in secondhand clothes, emerged to describe the substandard nature of care they believe they receive due to a shared racial identity. This compromises their ability to obtain the information they need for themselves and their families. The following quote provides insight into what these women deem as secondhand medical care:

> *You [African Americans] get secondhand education . . . You get secondhand medical care. And the thing that I'm saying is if we don't come out and if we don't say we want this you're [the health system] gonna continue to do this. You gonna continue to keep us subservient.*

There is a strong tendency to perceive the medical industry as treating African Americans "*any ole way*," as one woman adamantly asserted. A big concern is that doctors placate them by telling the women that nothing was wrong, they do not need treatment, or that over-the-counter medicine would work.

The perception that they are mollified rather than given the required treatment is also evident in the women's attitudes that doctors prescribe medicine they do not need or the same medicine for every illness. One woman notices that "[Y]*ou get the same medicine for every sickness. Went to doctor* [he] *gave same medicine to kids. Refrigerator* [is] *full with it. [I] began to notice it over time."* Drawing attention to what the medicine is, another woman provides, *"Anything you name an African American person got, Amoxicillin can cure."*

Additionally, a common perception is that doctors experiment new products on African American women. One woman declares in regards to her doctor prescribing a new medicine for her reoccurring ailment, *"They want me to start taking this medication. But I don't feel comfortable. I really don't feel that I need it."* In response, other women chimed in with such statements that doctors *"try out new products on you"* and that *"African American people are especially guinea pigs."*

Table III Summary I of Qualitative Findings

Domain: Traditional Health Information Seeking (Perceived Barriers)
1. Secondhand healthcare
a. Distrust of health providers
b. Substandard treatment
c. Misinformation regarding treatment
d. Questionable prescribing of medicine
2. Withholding health information
a. Do not want to hear health concerns
b. Generalization of African Americans
c. African American providers give better health information
3. Tension in access
a. Health resources available
b. Limited/no insurance barrier to receiving health services
Domain: The Internet in Health Information Seeking (Self-Perception of Control)
1. Embrace technological change
a. Access to vast health information
b. Help to overcome obstacles
c. Facilitate personal empowerment
d. Use technology with caution
e. Reification of social hierarchies and inequalities
2. Seek more health information
a. Support information from health providers
b. Second opinion
c. Facilitates client and health provider's communication
3. Access to technology
a. Computers are available in the community
b. Need motivation/willingness to use
c. Negative self-perceptions barrier to use

Table IV Summary II of Qualitative Findings

Domain: Traditional Health Information Seeking (Perceived Barriers)
1. Cultural identity
2. Racial identity in health information seeking
a.   Secondhand healthcare
b.   Withholding health information
3. Socio-economic identity in health information seeking
a.   Tensions in access
Domain: The Internet in Health Information Seeking (Self-Perceptions of Control)
1. Cultural identity in health information seeking
a. Embrace technological change
b. Seek more health information
2. Racial identity in health information seeking
a.   Technology reifies social hierarchies and inequalities
3. Socio-economic identity in health information seeking
a.   Access to technology
b. Technology reifies social hierarchies and inequalities

Withholding health information

There is a general belief that health professionals and hospitals withheld information based on ascribed racial and lower income (socio-economic) communal identities. Participants state that "doctors may not listen at all" or, "when they do, they prescribe medication to keep clients asleep [e.g., quiet, subdued] so they won't bother them." One woman explains this lack of information through the observation that doctors tend to generalize African Americans:

> *So I said to the doctor can you explain to me how, where glaucoma comes from. Oh he said, "Well, all brown people get it." I said, "No wait minute there's 12.5 million African American people in American . . . But I got it from them? Is this what you're telling me?" He never bothered to say glaucoma can skip a generation and go to the next generation. He never bothered to tell me it may have come from your great great grands [great great grandparents]. It may be on both sides of your family. It may be on one side of your family. He never told me this but I went and found out for myself. I had to. But to have him to generalize me.*

This passage describes how this woman questions the doctor in light of his over generalization, but she also goes out and finds the information she needs herself. This sentiment of withholding information was echoed by the majority of the women. In regards to medical institutions and information gap, it is offered:

> *What hospitals don't tell you is they have a special fund already set up for people that need medical care. They won't tell you that up front or at a desk. It's already put in place.*

Not all doctors, however, were seen as withholding information. Women believe that sharing was more likely if the physician was also African American:

It depends on the doctor, who you are, and how you present yourself. . . . as to the info they will give you . . . You [can] make big money and he might not tell you nothing. . . . Because you're African American and because they see that you are in need they will tell you much more than that White doctor.

Another aspect of withholding includes the belief among participants that physicians are not disclosing enough information about treatment and medications. One woman sums up the sentiment of both groups by sharing that she did not want her doctor, *"giving any ole info or any type of medication. Before you give me anything now I want to know."*

Tensions in access

Participants express tensions in which they perceive they have limited access due to their membership in a lower income community, while at the same time acknowledging that help is available. Many women provide information on services available to people without insurance.

Helick Health Center provides free health visits with prescriptions. Triclinic . . . does it. So there's no excuse. My daughter was six months old without insurance. I needed an inhaler. They paid for everything. You just have to seek out help.

While many women were thankful to have these resources, the general attitude is that having no insurance proved difficult. In response the question, "Does being lower income influence your access to health" one of many women responded:

Yes it does. Because I have worked in the medical field for a long time it's hard to say this. I have the experience of being in the emergency room and they're [patients] ill and they [doctors] give 'em emergency treatment and they might know that they need further treatment and they send them home, which a lot of times they should be admitted into the hospital. But the first thing they ask is your medical insurance and if they don't have any they go out the door. That happens.

Other women describe long wait times at the doctor's office to see the doctor for patients with limited insurance. Also, the general attitude was that without insurance you do not have access to the better doctors.

Online Health Information Seeking (Self-Perception of Control)

We turn, now, to perceptions of the internet as an information source. This overall domain consists of three factors reflecting both positive and negative perceptions of the internet as well as caution about the role of their identities. The factors include embrace technological change, seek more health information, and access to technology.

Embrace technological change

Technology presents a challenge to these women as it does to all novice users. However, after seeing the potential of the internet during training, they conveyed excitement about confronting the challenge, which exemplifies African American cultural characteristics of problem-solving and assertiveness (Hecht, Jackson, & Ribeau, 2003). This is expressed in the three dominant attitudes that emerged across groups: overcome the fear of technology, progress is necessary, and computers overcome boundaries. Related to fear, a woman offers:

There were times I was like. . . I don't want to learn that computer because I had a fear that I couldn't do it. Then when I actually got on there I was "Hey wait a minute you know I can do this."

The idea of progress stemming from racial prejudice finds salience in this woman's words:

I mean when you look around and you see we excel in anything that we do. This is why labels are put on us to keep us down. Technology is a beautiful thing. Technology takes us where we need to go. It is here to stay. It is going to be what tomorrow is all about.

Another woman embraces dissolving demarcations. She provides, *"I know I have more choices now. And when I go to the computer I don't have to stay and wonder. I can go all over."* Tying this point with the idea of power, one participant asserts, *"It makes me feel powerful. Go places I weren't able to go before."*

Although technology is viewed as a tool to access vast resources, transcend obstacles, and offer empowerment, it is also observed with suspicion. This acknowledgement of the benefits tempered by awareness of challenges in technology use exemplifies another distinctly African American characteristic – diunital (both/and) orientation (Hecht et al, 2003). The women referred to lack of privacy, identity theft, credit card fraud, and government control of all computers. The following passage reflects this general perspective:

You know, what you can link up to so far as informational value is good. . . . . You still have to use a grain of salt with things. You know they say believe half of what you see and none of what you hear. I'm always leery . . . .

A sub-factor emerged in which technology is perceived as a site for the 'reification of social hierarchies and inequalities'. The participants express tensions surrounding technology, related to their race and class identities. One woman explains:

I think there are still games that are being played so far as keeping technology away from the African American community. It's not as overt and outward as the discrimination of the past has been but it is a form of discrimination.

Another woman notes the intersection of racial and socio-economic identities:

Now we have to fight as African American people. Systematically they are keeping the computer away from us . . . Monetarily they're away from us [Whites have more money] because most of us are on limited income. And they're keeping that [computers] away from us because we're in poverty.

Seek more health information

Participants view information seeking on the internet as potentially enhancing their capacity in their offline interaction with health professionals, enabling them to behave more assertively and demonstrate their abilities (e.g., to solve problems, to overcome health information seeking challenges). As one woman proclaims regarding her use of the internet for seeking health information, *"Yeah, basically to back up what they [health professionals] say. Like if we went on the African American Women's Health [website] . . . and we found something."* Another woman suggests, in reference to online health information that *"it's sort of like a second opinion."* The following woman takes this notion of a second opinion into practice by bringing a printed copy to share with their physicians.

Yeah and we printed it out. So if they said you know "Well this is what this certain type of thing is" then you go to this paper with them and you're like "Okay well I looked on the web health page and its saying something different."

Informational access for these women is not denied by racial or socio-economic communal identities. However, the participants acknowledge that people must have access to the technology itself and the skills to utilize it effectively.

Access to technology

There was a general attitude that a socio-economic or lower income communal identity has no effect on accessing the internet or finding online health information. Many believe that they do have access as well as the willingness to exert the effort needed to obtain it. One woman points out:

> *By me being low income doesn't have anything to do with me having access to computers. Cafes, neighbors, family, Y[WCA]. There is no reason for me not to be able to pull information from a computer because I'm poor.*

However, these assertions are tempered by the socio-economic realities of these women's lives. The challenges these women express in life and in the health care system often shape understandings of who they are and can inhibit their futures. This socio-economic identity is summed up well in the following quote:

> *A lot of people have low self-esteem and they don't think that they're good enough or whatever or that they can't learn . . . Because we may have been on food stamps when we were children and may not have had what the next door neighborhood had. . . . we don't think we're worthy of it.*

DISCUSSION

This study provides preliminary understanding of how racial, cultural, and socio-economic communal identities intersect to affect lower income African American women's perceptions and experiences of health information seeking in traditional and online contexts (see Tables 3 and 4). Findings provide support for the relationships outlined in the theoretical model (Figure 1).

Perceived Barriers in Health Information Seeking

Race. These women's perceptions of their racial communal identity, which they see as marginalized and devalued within the larger culture, appear to both shape and be shaped by their experiences in the health care system, including their experiences with obtaining information about their health. One key factor is the women's belief that information is withheld from them by health care providers in traditional settings. In some cases, this is perceived as an unconscious oversight, but in other cases, the women feel that information was intentionally withheld. Similarly, many believe that their health concerns are treated differently than those in the dominant culture and that African American doctors provide more trustworthy information than White doctors. Overall, there is a high level of distrust and suspicion of traditional sources of medical care, which supports extensive research (Freimuth et al., 2001; LaVeist, Nickerson, & Bowie, 2000). Many believed that they received 'secondhand medical care' and some described feeling as if they were guinea pigs. In this way, these women's experiences and, perhaps, medical legacy played salient roles in the understanding of their racial identity (Washington, 2007).

Taken together the participants' accounts may, at times, appear inconsistent (e.g., not getting prescription drugs, getting the same prescriptions, and being used by physicians to experiment with new drugs). This seeming inconsistency may be indicative of confusion they experience when interacting with their physician due to a lack of knowledge on their part, not being provided clear reasons for their physician deciding when and what to prescribe for a particular illness/disease,

and/or not taking or being provided an active role in health decision-making with their provider (Nussbaum, Ragan, & Whaley, 2003). Further research is needed to better understand what underlies these experiences.

Socio-economic status. Socio-economic communal identity, for example, appeared to work in combination with racial communal identities in fostering beliefs about receiving inferior medical care. For instance, the women believe that not having medical insurance grouped with racial stereotypes perpetuated negative experiences with health professionals. The perceived lack of credible attention by health care professionals attributable to income and race appears to maintain the climate of suspicion that many African American women in this study harbor about the medical industry.

The intersection of race, culture and socio-economic status. We conceptualized identity as multi-layered or intersectional, which lead to an analysis examining two or three of the identities simultaneously. In this way, racial and socio-economic communal identities appeared to play a greater role affecting obstacles in health seeking experiences. These findings are consistent with research documenting that perceptions of race and lower income status can factor negatively in African Americans women's experiences in seeking and receiving medical care (van Ryn & Burke, 2000). Cultural community identities was not as salient in the perception of barriers.

Self-Perception of Control in Health Information Seeking

In addressing the potential of the internet as a resource for health information, the intersectional nature of racial, socio-economic and cultural identities was even more apparent. Findings indicate racial and socio-economic communal identities may be an integral aspect of how the women perceive technology. These results are consistent with previous research (Kvasny, 2005, 2006).

Race. While participants believe the internet can help them to resist racist and classist injustices, they also believe that Whites maintain ultimate control over technology because they can withhold or distort the information available through the internet. Additionally, there appears to be the attitude that Whites can take technology away from these women whenever they choose. Some have internalized the view that technology was not created for their use.

Socio-economic status. While the effect of socio-economic status and access to technology is well documented, the present study suggests that having little money does not imply an inability to access technology or a lack of desire to access health information online. The women in this study embrace the idea of being able to use the internet to seek health information. Challenges in obtaining insurance coverage for seeking second opinions, and/or the structural constraints (e.g., transportation, childcare) to accessing health care may, by comparison, engender a view of the internet as a readily accessible resource even if travel to the library is necessary. This understanding provides an alternative view that personal and structural constraints may indeed limit internet use in information seeking. However, there is acknowledgement that self-esteem may play a role in the use of the internet as an alternative channel in seeking health information – a psychological challenge potentially related to socio-economic communal identity.

Culture. In conceiving the internet as a resource to overcome barriers to health information, the participants reveal a cultural communal identity among many African Americans that values diunital, problem-solving and assertiveness characteristics (Hecht et al., 2003). These cultural aspects serve as a lens through which these women perceive and communicate resilience. The women demonstrate resilience by finding alternative health care services in their local neighborhoods. Since they typically do not trust their physicians, those who maintain a feeling of efficacy and self-confidence utilize their problem-solving skills and assertiveness to seek relevant health information. They describe

their desire to challenge the information by seeking alternative channels. Supporting previous research (Kvasny, 2005; Masi et al., 2003), the internet was perceived as alternative health resources in exercising control over challenges in seeking health information and presents a means to interact with health professionals about their health needs. However, these women maintained an African American characteristic of a diunital orientation toward their use of technology (Hecht et al., 2003). They would use it, but cautiously.

The intersection of race, culture and socioeconomic status. Although we did not include gender as an intersecting social group identity, it is interesting that it did not emerge as particularly salient. This may be due to the fact that the study included only a small sample of women or that it did not contrast the experiences of men and women. It may also be due to racial, cultural, and socio-economic communal identities being the most relevant in these women's health experiences, superseding those related to gender.

LIMITATIONS

It is important to note the limitations of this study. The findings are uniquely tied to the context and community members under investigation in the small sample needed for interpretive research and may not be entirely generalizable or transportable to other populations of lower income women. The small sample size also indicates the theoretical model should be further investigated. Similarly, while the model suggests cause and effect, the methodology employed is not designed to test causality but to highlight perceptions of the relationships among model constructs. Additionally, even though this study draws attention to the health information seeking experiences of a particular group of lower income African American women, these experiences may be similar for others belonging to socially stigmatized groups. Without a comparison group, it is difficult to assert the health information seeking experiences of one group are distinct from those of other groups. As a possible constraint, this study did provide a comprehensive workshop on the use of the internet prior to the focus group that may have biased responses. One strength of this approach is that the discussion was grounded in concrete experiences using the internet. Lastly, this study chose to conceive of an a priori model based upon substantial bodies of literature supporting the integration of the constructs rather than develop the model based upon the study's findings. We recognize that this choice influences our interpretation of results.

APPLICATIONS

Online health information seeking has important benefits not only for individual African American women, but also for their families and their communities with additional potential for other under-served communities. Libraries, faith- and community-based organizations in lower income urban communities across the US provide free computer and internet access and training for those without regular access at home, work or school. Individuals, however, are limited in their ability to attend these programs due to barriers (e.g., social systems/resources, community, content, and literacy) negatively impacting meaningful access to the internet (Warschauer, 2002). Also, individuals who depend on public access sites use the internet less frequently (Mossberger, Tolbert & Stansbury, 2003), which can have adverse effects on growing basic technology skills and skills in searching, assessing, and evaluating online information and the validity of the information source (DiMaggio, Hargittai, & Celeste, 2004). The limitations on programs and challenges in skill development may discourage people from using the internet to seek health information (Hargittai, 2002).

While there are still challenges in access and use of the internet, African American women believe

in the benefits of computers and the internet more strongly than similarly situated Whites (Brodie et al. 2000; Tolbert et al., 2007). These women also believe that the internet has the potential to become a powerful tool for increasing their own and other lower income African American women's capabilities to overcome provider bias and become empowered health information consumers. Patients who are knowledgable about their illness would be better prepared to ask relevant questions and participate more in the care delivery process. (Nussbaum et al., 2003). However, for this potential to have a glimmer of realization, health information providers must carefully attend to the unique information needs and resiliencies of these so called 'non-traditional' users as well as provide groups new to the internet with training in assessing the credibility of web-based resources and how to use the information in relation to their health related issues. In doing so, 'non-traditional' users may gain greater access to health information, as well as access more trustworthy and culturally salient information. This may help to (re)build their trust in healthcare system.

Moreover, the participants drew a critical distinction between access to the internet—which they viewed as under their control—and the content of the internet—which they perceived to be under the control of the dominant White culture. While acknowledging further research is necessary in this area, one challenge may be how to create ownership over the content of health information on the internet. In practice, high quality health information is, by definition, developed by the traditional, biomedical establishment. One potential solution may lie in the distinction that the women in our study made between Black and White physicians. It may be possible to engage national or local organizations of physicians and nurses of color to work with underserved communities to develop online sources of health information that resonate with the social identities of these groups. This distinction also supports our decision to embrace an action research paradigm in which services, here internet training, is combined with data collection.

CONCLUSION

Cultural, racial and socio-economic communal identities appear to play important roles in these women's perceptions of technology, health information seeking experiences, and perceptions of control, while gender played a more secondary role in this study. The theoretical model (Figure 1) provided a useful heuristic that allowed for contextualizing or locating health experiences in communal identities. After engaging the women in our study, we are even more convinced of the need for models that integrate personal and contextual factors affecting health information seeking (Lambert & Loiselle, 2007). With further investigation the model may be able to add to previous approaches to health information seeking. Additionally, findings may be useful as a base for future research focused on choices and behavior in health information seeking. Future studies should draw upon a larger and more diverse sample to implement a comparative investigation focusing on causality suggested in the theoretical model. It is also important that future research examine the experience of lower income, African American women who did not receive such internet training to gain a broader understanding of barriers to internet use. Contextualizing health information seeking choices and behaviors is critical to providing accessible channels and resources that are ideally empowering or that can leverage innate resilience for groups disproportionately impacted by health communication inequities.

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