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# Online HIV prevention information

## How black female college students are seeking and perceiving

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### Abstract

**Purpose** – Two research questions are addressed: what are black female college students' perceptions of current messages present on web sites about HIV/AIDS awareness and prevention?; and what messages do black female college students find culturally relevant to them, and why? Results indicate that these women perceive several communication barriers including lack of trust and unfamiliarity with information sources, stigma ascribed to HIV, as well as misconceptions and traditional values held by some in the black community and health institutions. HIV prevention messages are perceived as relevant if they exhibit qualities including interactive features. The paper aims to discuss these issues.

**Design/methodology/approach** – To understand black collegiate women as health information seekers, it is important to engage paradigms that allow researchers to make sense of how group members construct their content needs, what helps shape this construction, and the meaning derived from the consumption of the information, focus groups are an effective qualitative method for enabling collective discussion and interaction between research participants that facilitates the exploration of under-researched topics like HIV prevention as well as the language commonly used by respondents to describe HIV from a socio-cultural perspective. The research team conducted three focus groups to appraise current black female college students' attitudes and perceptions of messages presented on HIV/AIDS prevention and awareness web sites

**Findings** – HIV prevention messages are perceived as relevant if they exhibit qualities including interactive features, practical advice using non-technical vocabulary, content authored and disseminated by familiar and trustworthy individuals and institutions, and risk related to individual behaviors rather than the demographic group. Implications of the findings and suggestions for future research on the design of health information systems are provided.

**Research limitations/implications** – This research is based on a small sample size based on one region of the USA.

**Practical implications** – Health communication materials should also provide strategies for dispelling myths, and combating feelings of stigma, and mistrust. In addition, practical advice such as questions to ask physicians may help to produce positive and desirable outcomes as black women seek services from the healthcare system. The message itself must take into account a number of factors include short and simple messages, clean web pages, navigation structures that make information



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easy to find, comprehensive information all found in a single web site, and interactive features to facilitate discussion and sharing. In particular, with social media, women can also play a role in the creation and dissemination of health messages in multiple modalities including text, spoken word, still and moving images, and music.

**Social implications** – “A major component of preventive health practice is the availability and provision of information regarding risks to health and promotional measures for enhancing the health status among this population” (Gollop, 1997, p. 142). However, as Dervin (2005) cautions, while information is necessary, it is insufficient to encourage behavior change. To combat the health disparities that differentially impact African-American women requires expertise and understanding from multiple perspectives. By providing insight into how black collegiate women perceive HIV prevention information needs, the women in the focus groups lend a necessary voice in the effort toward healthy equity through the creation of effective health interventions that will appeal to them.

**Originality/value** – The author seeks to create an online and socially connected experience characteristic of ongoing user input and active engagement in content development which targets the population. From a human-computer interaction viewpoint, the authors are seeking to avoid design divorced from context and meaning. In developing such an experience, the authors will need to triangulate the roles of culture, context, and design to reduce the content divide, yet amplify the notion of participatory web. Participatory web embodies a social justice movement to build web content from voices typically dampened in the discourse. It (re)shapes meaning, identity, and ecologies in the process of foci on particular social, health, and political causes (e.g. HIV/AIDS). Giving black women ownership over the creation of health information on the internet may improve the ability to provide targeted HIV prevention content that is culturally salient and more effective in reducing HIV infections in this community.

**Keywords** Information needs, Health information, Black women, ICT design, Information-seeking, HIV Prevention

**Paper type** Research paper

## Introduction

In this paper, we examine the online information needs of black female college students in the context of HIV prevention. Collectively, prior studies have found that the use of culturally compelling and relevant HIV prevention messages targeted to black women is an effective means of improving risk-reduction behaviors and skills, such as proper condom use, HIV testing, and sexual assertiveness and communication. For instance, DiClemente and Wingood (1995) conducted a randomized control trial of an HIV sexual risk reduction intervention, and found that community-based HIV risk-reduction programs that are gender relevant and culturally sensitive, and provide social skills training can effectively enhance consistent condom use among young black women. In a more recent study, DiClemente *et al.* (2004) recruited black adolescent girls at high risk for HIV to participate in four group sessions emphasizing ethnic and gender pride, HIV knowledge, communication, condom use skills, and healthy relationships. These researchers found that interventions that are gender tailored and culturally congruent can enhance HIV-preventive behaviors and skills. In a study of black women from a low-income housing project in Chicago, Kalichman *et al.* (1993) found that participants who viewed public health tapes on HIV prevention presented by African-American women were significantly more sensitized to HIV/AIDS and were more likely to have discussed the disease with friends, to be tested for HIV antibodies during the follow-up interval, and to request condoms at follow-up.

In our study, we focus on young black women and HIV prevention because blacks are the racial/ethnic group most affected by HIV. According to the Centers for Disease Control (CDC) (2012), in 2009 blacks comprised 14 percent of the US population but accounted for 44 percent of all new HIV infections (21,200 estimated infections). They also account for 44 percent (an estimated 510,600 persons) of people living with

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HIV in the USA. Black women, most (85 percent) of whom were infected through sex with a male partner, accounted for 30 percent of the estimated new HIV infections among all blacks and 57 percent of all new HIV infections among women in the USA (CDC, 2012). The estimated rate of new HIV infections for black women are more than 15 times as high as the rate for white women, and more than three times as high as that of Latina women (CDC, 2012). Perhaps most disturbingly, the CDC (2012) estimates that one in every 32 black women will be diagnosed with HIV during their lifetime.

Although epidemiologic data are informative with respect to monitoring and quantifying HIV infection rates among black women, they provide little insight into the influence of the diverse cultural, gender, and psychosocial determinants of HIV (Wingood *et al.*, 1993). The CDC (2012), for instance, notes a number of unique challenges faced by black women. These factors include choice of sexual partners, structural inequalities, socio-economic factors, lack of awareness of HIV status, distrust of institutions, and stigma about HIV. Blacks tend to have sex with partners of the same race/ethnicity and the greater HIV prevalence in black communities means that black women face a greater risk of HIV infection with each new sexual encounter. Structural issues, such as racial discrimination and higher rates of incarceration, which disrupts social and sexual networks, directly and indirectly increase black women's risk for HIV infection. Socio-economic issues associated with poverty, including limited access to high-quality healthcare, substance abuse, and food insecurity, directly and indirectly increase the risk for HIV infection. Lack of awareness of HIV status can negatively impact healthcare and outcomes. Deep-seated mistrust of government and healthcare institutions fosters conspiracy theories including the belief that AIDS was created in a government lab to control the black population and HIV/AIDS constitute genocide carried out against black people. While these beliefs may be understandable based on persistent health disparities and the looming historical impact associated with the Tuskegee Study and other issues of medical ethics, they factor negatively into high-risk behavioral decisions (Washington, 2007). Stigma, fear, discrimination, and negative perceptions about HIV from critical institutions in the black community may also lead black women to avoid counseling and testing when high-risk behaviors are enacted. Such factors can result in the avoidance of care and only stand to perpetuate those affected and infected by HIV/AIDS in the black community.

One mechanism for reducing new incidents of HIV among black women is to provide culturally compelling information that fosters ongoing and open discussions about testing, myths, and risk behaviors. Black women, however, are not a monolithic group so there is a need to distinguish among various subcommunities. While much of the prior research on HIV prevention focusses on "at-risk" black women in economically challenged urban communities, our study focusses on black female college students as a particular community with unique information needs. Also, we focus on social media and web-based information resources rather than traditional information sources because the digital information channels are more frequently accessed and used by this group (Payton and Kiwanuka-Tondo, 2009; Payton *et al.*, 2012).

To understand information needs, we conducted focus groups with 45 black female college students. The focus groups were guided by two research questions: what are black female college students' perceptions of current messages present on web sites about HIV/AIDS awareness and prevention? And what messages do black

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female college students find culturally relevant to them? In this paper, we report our findings and discuss implications for the design of internet-based information tools and resources that seek to educate, equip, and mobilize this community. As Paek *et al.* (2011) report in their content analysis of anti-smoking web sites, our perception of susceptibility, seriousness, benefits, and barriers shape our understanding of health behaviors and non-compliance with recommended health actions. By uncovering black women's perceptions of HIV, our research can contribute valuable insight for those interested in designing internet-based resources that meet the information needs and reduce barriers to information seeking and use caused by cultural differences.

### Literature review

#### *Black collegiate women and HIV*

While statistics on HIV infection rates for black college students are limited, the Kaiser Family Foundation (2007) reports that black teens (ages 13-19) represented only 16 percent of US teenagers, yet they accounted for 69 percent of new AIDS cases reported among teens in 2005. In 2009, black youths accounted for 65 percent (5,404) of diagnoses of HIV infection reported among persons aged 13-24 years ((CDC, 2011) making them the largest single group of young people affected by HIV. Research has also shown that a large proportion of young people (regardless of ethnicity or demographic) are not concerned about becoming infected with HIV (Centers for Disease Control (CDC), 2008). This lack of awareness and concern can translate into the avoidance of protective health measures.

Our study focusses on collegiate young black women, ages 18-24, because they are at heightened risk for sexually transmitted infections, including HIV. There are several reasons for this higher risk. For purely biological reasons, a woman is about twice as likely as a man to contract HIV infection during unprotected vaginal intercourse with an infected partner (CDC, 2004). In particular, a young woman is more vulnerable to infection due to her less mature reproductive tract (Eng and Butler, 1997). Socio-economic factors that heighten young women's vulnerability include those found in the broader black community – racial discrimination, inadequate access to healthcare and substance treatment, disproportionate rates of incarceration, distrust in government, and poverty. Poverty and lack of opportunity may lead people to have multiple sex partners, sequentially or concurrently (Tuan, 2006). These structural forces may also lead young women to have intercourse with older men and engaging in sexual activities at an earlier age. Sex with older men increases young women's risk of contracting HIV because, compared to adolescent males, older male partners are more likely to: have had multiple partners and varied sexual and drug use experience; have concurrent sexual partners; and/or already be infected with sexually transmitted infections (Begley *et al.*, 2003).

Young black women are impacted by both racial issues, such as discrimination, and gender issues, such as unequal power status in sexual relations. These intersecting racial and gender identities can result in unique barriers to black women's access to health information (Warren *et al.*, 2010). Consequently, there is a need for interventions that help women to enhance self-esteem and self-efficacy, build sisterly connections with peers, and gain skills in negotiation and assertiveness with their male sexual partners. Understanding information needs is the first step in the creation of a digitally connected community of black women creating culturally sensitive HIV prevention messages.

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*Black women and traditional health information channels*

While the internet may be emerging as a viable channel for health information (Pew Internet and American Life, 2011), it is instructive to examine black women's health information needs when using traditional media as well. It is our contention that basic information needs will persist and extend to the newer digital information channels. For example, in a study of black and white college students help-seeking strategies, Ayalon and Young (2005) found that religious belief plays a central role in blacks' help-seeking behaviors. Relative to white college students, black college students used psychological or social services less frequently but used religious services more frequently. The authors explain these group differences in help-seeking behaviors as blacks' beliefs in the power of God. This deeply set religious belief in God's higher power may extend to information on HIV risk reduction and practical strategies for mitigating these risks.

Even with the growth in online information resources of all kinds, traditional channels will remain highly important to black women. In a study of the information needs and information-seeking behavior of professional black women as leisure tourists, Fairer-Wessels (2004) found that these women heavily used traditional information sources including word-of-mouth sources and were less likely to adopt information technology as part of their information-seeking strategies. Nicholson *et al.* (2003) report that a higher percentage of black women report the use of passive information sources, such as broadcast media and organized health events, compared to whites. Similarly, prior research on health information seeking among older black women (Gollop, 1997) found that these women prefer to receive health information from their physicians, the mass media such as television and magazines, and members of their social networks. Factors that positively influence such activity include age, education, self-perceived literacy, and access to health information. Although few used the public library, respondents held a highly positive perception of this access venue. In total, 84 percent reported that there was no health information that they needed or wanted that they could not get from the traditional sources available to them.

For young black women college students, we speculate that they will also desire content from traditional channels, but the internet will be an important source for supplementing this information. Bruce (1999, p. 198) observes that "in this age of digital information environments, users are looking for reality anchors based on non-digital models. When they search for information, they want to 'feel' like they are engaged in the familiar 'down to Earth' practice of visiting a library, looking for references in an index, selecting a resource from a shelf, evaluating the service that is provided, communicating with a human intermediary or librarian, browsing shelves and so on." The virtual and real converge as people attempt to re-establish a connection to the tangible when selecting and evaluating information that they access through the internet.

Additional evidence for our contention about the continued importance of doctors and personal networks can be found in studies that examine the importance of health services professionals (weak ties) and, family and close friends ("strong ties") in information-seeking behaviors of blacks. Morey (2007) examined health information-seeking behavior using Granovetter's strength of weak ties as the theoretical framework. She conducted a telephone survey using 216 (Buffalo, New York) residents. She found that most respondents (97) rely on a health service professional for health information and report having a "somewhat close" relationship with healthcare professionals. Thus, health service professionals serve as a weak tie in

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health information seeking. While respondents reported having “very close” relationships with family members, the quality of the health information from strong ties may be limited because they often lack medical expertise (Courtright, 2005). Gollop (1997) found that older black women saw physicians as the most preferred and believable source of health information on illness prevention, health promotion and treatment of symptoms and disease. However, health information seeking by ethnic minorities is often challenged from receiving too little information from healthcare providers (van Ryn and Fu, 2003) and a lack of ethnically grounded health messages (Airhihenbuwa and Liburd, 2006). Chatman (1999) found that black females in lower-working class communities expressed a number of areas in which they needed information. Nonetheless, they were not active seekers of information outside of their most familiar social milieu of family, friends, and local organizations because they felt that outsiders were not capable of adequately addressing their concerns.

#### *Black women and internet-based information channels*

While recognizing the continued importance of traditional sources, we posit that collegiate black women are proficient users of web-based health information resources and that online sources may enable women to overcome communication barriers. The Pew Internet and American Life Project (2011) reports that 65 percent of women and 47 percent of black Americans go online for health information. “The Internet offers widespread access to health information, and the advantages of interactivity, information tailoring and anonymity” (Cline and Haynes, 2001, p. 671). With regard to black women and other under-presented groups, the internet is viewed as an equalizer in the movement to reduce health disparities (Agency for Healthcare Research and Quality (AHRQ), 2012).

Indeed, in Courtright’s (2005), study web sites were viewed as a major information resource (34 respondents), second only to physicians. For blacks, communication with physicians can be problematic. Prior studies have found, for instance, that health provider bias, stereotyping, prejudice, and clinical uncertainty may contribute to disparities along the lines of gender, class, race, and ethnicity (Balsa and McGuire, 2003). In a study by Bird and Bogart (2001), 63 percent of survey participants indicated that they had experienced discrimination in their interactions with their healthcare provider because of their race or ethnicity. Similarly, black interviewees reported that they perceived discriminatory experiences such as inferior treatment, negative attitudes, being treated as if they were unintelligent, being ignored, inappropriate allegations, and racist remarks when interacting with their healthcare providers (Hobson, 2001).

There is much enthusiasm that the internet can aid in the reduction of long-standing health inequalities (AHRQ, 2012) and the ability of the “Net” to reach those with stigmatized illnesses or those interested in learning more about stigmatized medical conditions (Berger *et al.*, 2005). Scholars, such as Selwyn (2004), Kvasny (2005), Brock (2007) and Kvasny and Payton (2008) caution that normalizing discourses like the “digital divide” present blacks as being deficient in internet access, computer skills, and in the knowledge of how to access and utilize online information in general. Moreover, these discourses rely on the faulty assumption that the wealth of information available online makes internet usage beneficial for everyone.

In a study of black women’s attitudes toward the internet as a health information resource, for instance, Warren *et al.* (2009) found that participants made 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. Nakumara (2002) uses the term “menu-driven identities” to signify the ways in which content providers reproduce inequality through the design of the interface and the personalization of content that fails to accommodate the cultural perspectives of ethnic minorities. Gibbons (2005) found that health information on the internet is not typically tailored to address the realities in which many African-Americans exist, especially those with limited income. Several scholars (Kvasny and Warren 2006; Kolko *et al.*, 2000; Payton and Kiwanuka-Tondo, 2009; Warren *et al.*, 2009, 2010) have reported similar findings in studies of information seeking by minority users. Thus, while the internet offers the potential for information tailoring, a lack of culturally relevant content remains a barrier to health information seeking for black women.

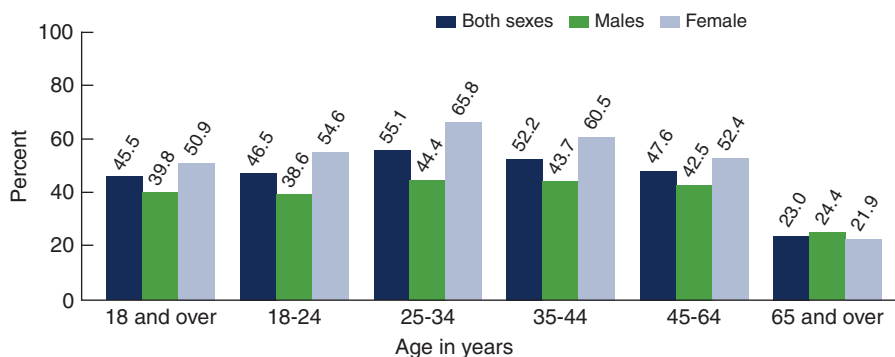
As reported in Payton (2009), health information seekers, according to the Pew Internet and American Life (2006) Project release, are “Internet users who search online for information on health topics” whether they take on the role of consumers, caregivers, or e-patients. Given its ubiquitous nature, the internet continues to be a key source of health information among health seekers. Specifically, the Pew internet data indicates that eight of ten internet users, or roughly 113 million adults, have sought health information online. The question is: what type of health information do these internet users want or need? In 2006, 66 percent of all health seekers searched for information on a specific disease or medical problem for themselves, family members, or friends.

In addition, Figure 1 supports the argument that young college aged women (18-24) are leading consumers and seekers of health information in comparison to males of the same age group, according to the CDC/NCHS National Health Interview Survey (2009).

Similarly and as shown in Figure 2, our target age group for this study leads in online consumption and is actively seeking health information.

### Methodology

To understand black collegiate women as health information seekers, it is important to engage paradigms that allow researchers to make sense of how group members construct their content needs, what helps shape this construction, and the meaning derived from the consumption of the information (Spink and Cole, 2001,



**Figure 1.** Percentage of adults aged 18 and over who in the past 12 months looked up health information on the internet, by sex and age, USA – 2009

**Notes:** Data are based on household interviews of a sample of the civilian non-institutionalized population

**Source:** CDC/NCHS, National health interview survey, 2009, sample adult component

Activity	Millennials Ages 18-34	Gen X Ages 35-46	Younger Boomers Ages 47-56	Older Boomers Ages 57-65	Silent Gen. Ages 66-74	G.I. Gen. Age 75+	All online adults Age 18+
Go online	95%	86%	81%	76%	58%	30%	79%
For the following activities, the youngest and oldest cohorts may differ, but there is less variation between generations overall:							
E-mail	96	94	91	93	90	88	94
Use search engine	92	97	86	87	82	72	87
Look for health info	78	84	80	83	73	69	80
Get news	76	79	76	76	67	54	75
Buy a product	68	66	64	69	59	57	66

**Sources:** Pew Internet and American Life Project (2011). Findings for individual activities are based on adult internet users. For survey dates of all activities cited, please see the Methodology section at the end of the Generations 2010 report: <http://pewinternet.org/Reports/2010/Generations-2010/Methodology/Note-on-survey-dates.aspx>

**Figure 2.** Internet use by age cohorts

Chatman (1999). According to Frith (2000), focus groups are an effective qualitative method for enabling collective discussion and interaction between research participants that facilitates the exploration of under-researched topics like HIV prevention as well as the language commonly used by respondents to describe HIV from a socio-cultural perspective.

Our research team conducted three focus groups to appraise current African-American female college students' attitudes and perceptions of messages presented on HIV/AIDS prevention and awareness web sites (e.g. NIH, CDC, and WebMD). During the focus group sessions, the participants were shown the NIH web site as it was deemed the leader in the field based on HealthRatings.org (2007), and this strategy extends the prior work of Payton and Kiwanuka-Tondo (2009).

There were six participants in the first focus group, 21 present in the second, and 14 present in the third. Of the 40 female participants, all were black and ranged between 18 and 24 years old. The women reported a mean family size of four (based on parents, themselves, and siblings) and between six and ten years of internet experience. This indicates that they have been "connected" for a significant portion of their lives. In total, 38 of the 40 were undergraduate students with two graduate students. In total, 25 or roughly 63 percent reported studying in science, technology, engineering, and mathematics (STEM) fields, such as computer science and various engineering disciplines. In total, 30 of the participants partake in at least one university-affiliated association while 24 are involved in two student organizations.

Each focus group session lasted approximately an hour to one hour and thirty minutes each. The sessions were audio recorded and later transcribed by a member of the research team. Following this, two teams of coders reviewed the transcript. Specifically, each team was tasked with answering one of the following research questions:

*RQ1.* What are students' perceptions of current messages present on web sites about HIV/AIDS awareness and prevention?

*RQ2.* What messages do African-American female college students find culturally relevant to them?

The use of multiple focus groups enabled us to determine the reliability of our findings, and to determine rather our data collection methods could be repeated to yield the same or similar results (Yin, 1989; Ulin *et al.*, 2005). We also accounted for internal validity to determine if certain conditions are shown to lead to other conditions. Here, we used pattern matching and thematic analyses to assess themes among independent coders. Prior to data collection, this enabled us to examine an expected pattern of the variables in the research questions (Yin, 1989). However, we sought to avoid the hierarchy of credibility which assumes that the perspectives of the powerful (i.e. researchers) is more valid than those of a lesser status (i.e. informants). Rather, we wanted to capture the students' unfiltered perspectives and examine their information needs (Taylor and Bogdan, 1998).

To interpret the answers to these questions, the teams of coders looked for various themes that emerged in the transcript from participants' responses. They did this by agreeing on units of analysis, and then copying these units from the transcript onto note cards. These note cards were used to conduct a thematic analysis through the constant comparison method by grouping similar units together. Ultimately, the coders responsible for the first research question found seven themes that emerged from the data, and the coders investigating the second research question found nine themes. After discovering these themes, the coder teams completed a member check with a participant from each focus group session to confirm that the themes they found were indeed representative of participants' perceptions. Finally, the two teams ran intercoder reliability checks with each other to validate their individual findings. The results of intercoder reliability after coding data from the first two focus groups yielded the following:  $\kappa$  0.812 and 0.710 for *RQ1* and *RQ2*, respectively. The third focus group was coded separately, months after the first intercoder reliability check was run, and it yielded the following results:  $\kappa$  0.750 and 0.715 for *RQ1* and *RQ2*, respectively.

### Portrayal of results

*RQ1*. Perceptions of current messages present on web sites about HIV/AIDS awareness and prevention.

#### *Misconceptions, religious values, and the societal stigma attached to HIV/AIDS*

Participants were unanimous in their belief that there are several impediments preventing the effective diffusion of information and awareness about HIV/AIDS. These barriers include misconceptions, religious values, and the societal stigma attached to HIV/AIDS. For instance, one participant spoke from personal experience about people avoiding a family member who died from AIDS at a funeral stating, "Even at the funeral, it was a closed casket. Nobody wanted to go near it. Everybody was just scared that even though they were dead they were going to somehow catch it or something." Religious values and norms can serve as especially salient barriers that prevent information dissemination. For example, one participant mentioned, "I mean for me, growing up, my dad is a pastor, and he was like, 'Don't have sex, you're gonna have HIV and that's it.'"

#### *Trust/credibility*

This theme dealt with comments pertaining to a need for trust and/or credibility on HIV/AIDS information sources (e.g. web sites, friends, doctors). Participants offered conflicting accounts of this theme. On the one hand, the credibility of the information sources increased the trustworthiness of the content. While talking about where she

would search for information online, one participant mentioned, "I would actually go to that website because it's a government website and I know that the information is reliable [...] unlike Wikipedia where the information can be changed or altered by anybody on that website." Another stated, "I would Google it originally and then maybe even use Wikipedia. But I always go to NIH to clarify because everything is certified." This theme also included perceptions of a lack of trust between participants and these information sources. For instance, when asked how she differentiates a trustworthy site from a less reputable source of information, one participant said, "It depends on who they cite. If they cite a doctor or someone who has actually done research in that field. Yea someone with some credibility as far as degrees or certifications [...] just not like information slapped on a page."

On the other hand, some participants mentioned their inability to identify with the information on government web sites which prevented them from engaging with the sites. While the government sources are trustworthy, they lack "a coolness factor" to make them relatable to young black college students. For instance, when speaking about current web sites, one participant mentioned: "[...] If it does look like one of those [government] websites I'm not going to want to go to it. But if it's something more relatable to our generation [...] Like, even if it had cool t-shirts [...] like I remember the Got AIDS? shirts that people wore. But even if it's something more like, you see that celebrity wearing it maybe after you've gone through the training or you look at the video or you can help donate to the cause and you get a cool t-shirt too. Like, [it needs] some way to market it really well."

#### *Ease of recognition*

These comments demonstrated that participants were familiar or comfortable with certain web sites and messages because they recognized them from a media source (e.g. commercials on TV). According to the participants, this ease of recognition helped inform their decision-making processes when seeking an information source for HIV/AIDS. For example, one participant said, "Back home in Maryland, they put Web MD a lot on TV. So if I think anything medically that would be, like what [participant name] said, the first place I would go to look for something." Another person explained how TV helped educate them about HIV/AIDS stating:

[...] I heard about it in class and stuff, but when I watched [...] it was an episode of *Girlfriends* [television show's name] where one of their friends had AIDS [...] yea, and that's where I learned about it a little bit more [...] and how scared people were of it because Joan [character on *Girlfriend*] didn't even want to use the knife that [an infected woman] was using and stuff like that.

#### *Importance of web site content/layout*

The comments that populated this theme centered on a preference for web sites and messages that were easy to use and navigate. Many people mentioned a desire for messages that convey information in a concise manner because they felt that HIV/AIDS information can become overwhelming if it is too detailed/specific or too broad for their search purposes. In speaking about her preference for WebMD, one participant said, "A lot of the information is very detailed [...] It seems like they try to [...] I don't want to say dumb it down, but they try to filter out the concept." The messages they reported as being most effective were typically short and simple.

In addition to this preference for short messages, participants also commented on web sites' esthetic appeal. After viewing the NIH site, one person mentioned, "Um, due

to the colors and all that, it looks more welcoming. And it looks like you can click a lot of different categories to find different things you're searching for." When speaking about website characteristics in general, one person mentioned she did not like the NIH site because information was too hard to find. She stated, "it was so many different choices and nothing was just straight out."

*Identification*

Comments from this theme showed the participants were able to identify with the messages presented on certain web sites in some way. Take the following exchange regarding what participants would prefer to see on future web sites, for example:

Respondent: I think also as African American women we feed off each other's stories, so maybe if there was something focused on a woman who went and got tested, who used condoms with her boyfriend and found out that he had AIDS and she was able to prevent [...] ya know, I was able to prevent contracting AIDS because I did [...] we went and got tested and we used the proper precautions maybe something like that [...]

Researcher: So personal stories?

Respondent: Right.

Researcher: Like a testimony?

Respondent: Right.

Whether through parasocial relationships with TV characters/celebrities or simply seeing a face that looked similar to their own, participants reported being more comfortable with messages with which they could identify. When asked why she preferred a site like *essence.com* to others, one person said, it "[identifies] with African American women. So I was like hmm, let me get more information. Not saying I would go there for AIDS information, I'm just saying as far as targeting African-American/black women they do a good job."

Other participants stated current web sites have irrelevant information and images that immediately cause them to disengage. For instance, one participant responded, "I would want to see an average African American female because when we were talking about would you want people to see if you were looking it up because it's a negative stigma attached to it. If you are showing women who may have been prostitutes or drug addicts, or with a gay man or something like that, you're going to (think) that is not going to be me so I don't have to worry about it. So I would focus on the average women who has a regular boyfriend, a regular, masculine black man that can appeal to everybody else."

This theme also included comments about participants' perceptions about how the framing of messages led to feelings of inclusiveness and exclusiveness. For example, one person suggests that those practicing abstinence often ignore HIV prevention messages because they do not perceive a risk of contracting the virus. "I more feel like if you do [have sex], because your conscious is drawn to that, you'll be like, 'well I'm doing that, I'm having sex so I can actually get HIV.' If I'm not having sex then I'm not going to be really concerned about it."

*Comprehensive web sites*

This theme emerged from comments about why participants preferred certain web sites to others. Many participants mentioned that the prospect of having a comprehensive web site with all the information they need – a one-stop shop essentially – is more appealing than having to search multiple sites for the same information. One participant commented on WebMD, a popular health site in the focus

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groups, stating, “They just seem like they have everything on it. Any time I had to look up anything health related, Web MD would be my go-to place.”

*Content desired/lacking aspect*

This theme was prominent among the participants who offered comments regarding what current web sites lacked. To offer a more alluring user experience, the participants suggested web site design effectiveness would be inclusive of the subthemes noted below:

- (1) The content needs to be engaging/interactive and include personal narratives or videos – One of the participants stated, “I like [participant’s] idea a lot. The whole story because nothing’s more powerful than hearing someone else’s testimony.”
- (2) The content needs to be objective and fact based (e.g. statistics or debunked myths) – For instance, someone in the focus group stated, “But also knowing the other ways that you can get HIV like sharing needles or anything that has to do with sanitary like blood transfusions or anything like that. I think a lot of people don’t know about that, they just think it’s a sexually transmitted disease.”

Another person commented, “[...] I was thinking the statistics as well because a lot of African-American women may know that we are more prone to it, but how much versus white women or other races? So I feel like statistics will kinda put it in perspective.”

- (3) The content needs to focus on preventative measures – One participant said, “I would like to see ways to prevent it, maybe possible scenarios. Because sometimes people are put into certain situations, and are not exactly sure on how to respond so they may make the wrong decision [...] [I want to see] ways to help make certain decisions.” Regarding the desire to see preventative information on web sites, one participant mentioned, “I don’t think people necessarily look up stuff, like even if you have like a cold you’re not going to research your symptoms until you have those symptoms. So I think if it’s more about preventative care, things like videos would help. And then if you infuse those into social media so if you like click on a link, you will be like now let me go see more information about it. I don’t think people will necessarily go look up all that information without having a reason to.”
- (4) The content needs to have a positive spin – for example, one participant made the following comments about what she would like to see added to HIV/AIDS web sites.

Respondent: “I guess the way it draws in I guess [...] it needs to be vibrant. Not vibrant as in as ooh I got AIDS. But kinda like how to live. Because you know there is always a different mindset between I am dying from something or I’m living with something. So really to have that focus on [...] ok I have it, ok that’s a fact, ok I know I got it, but how do I now go about living from now. I know I have it now so what are the next steps. It needs to be kinda like a living, ya know like a living [...] like a good, I don’t know the word I am looking for like a good feel to it [...]”

Researcher: Positive spin.

Respondent: Yea, not just like you got AIDS and you did this and now you are going to die just something [...] some good feeling from it.

RQ2. What messages do African-American female college students find culturally relevant to them?

Based on the thematic analysis, results may be divided into two major themes, status quo and suggestions for improvements. Status quo describes the current state of the discourse. Under this major theme, there are five subthemes describing the current state of the HIV/AIDS online discussion. Suggestion for improvement follows.

#### *Cultural resonance*

First, focus group participants confirm that the current web content does not resonate with their group. This lack of reverberation includes a myriad of factors including use of celebrity status and figures, such as Magic Johnson, in media campaigns, and overuse of medical jargon which can be difficult to discern – hence, making health decision making complicated. For example, one participant noted that, “NIH and the CDC sites [...] I don’t know, they seem like those are for people who are in [research] realms” instead of being intended for casual browsing. Someone else responded to these government sites stating, “It doesn’t interest me at all. There is nothing on it that grabs my attention. It looks like if I was on here then I would not know what to do.”

#### *Personal responsibility*

In addition, a smaller group of participants reported people need to be active seekers of information, and that individuals must take personal and medical responsibility. Accordingly, personal responsibility includes assurance that one’s sexual partner(s) are healthy, take precautions and take action by getting regularly tested for the disease. For example, one participant mentioned:

[...] that’s why I’m so open about it and everything because I don’t [...] I just don’t understand why people [...] I just really wish people were more comfortable with discussing issues of all kinds, not just HIV and AIDS. Put yourself aside and think about someone else. It’s okay. I feel like you shouldn’t think about other people’s opinions because I feel like your health is that much more important than the person who knows nothing about you.

When speaking about her willingness to discuss HIV/AIDS with her partner, one young woman frankly stated, “I gotta do what I gotta do for myself.” In the focus group, this statement translated to her taking ownership and personal responsibility for her health despite her partner’s individual choices.

Moreover, the focus group discussion revealed that both denial and misconceptions are underlying factors influencing societal attitudes toward HIV/AIDS. On the one hand, living with the unknown is a preferred behavior pattern as long as the disease fails to disrupt life functions and daily activities. Needless to say, this serves to perpetuate risky behavior. On the other hand, various misconceptions remain part of everyday life. Among those noted by the participants were: eating with the same utensil will give you HIV/AIDS. For instance, one participant offered:

[...] A lot has to do with the way we were brought up just as black women. I can’t speak for everyone, but just in general terms looking at how my family has handled their health matters where they might not go and look up something or they might not go to the doctor

until it gets to the point where they need to go to the doctor. So it's kinda that, "Oh I'm not going to deal with it until it affects me to where I have to deal with it."

Regarding how these sentiments affect African-American college females, one participant stated, "I know some people, like when it's HIV/AIDS awareness week, they'll go get tested but then they don't go and get their results." This demonstrates a sense of partial compliance and false confidence in an unknown status.

*Source of information*

Furthermore, participants mentioned the sources of information of HIV/AIDS that played a role in their education including institutions and individuals that help to shape their perceptions of the disease. As earlier scholars have reported that, for black women, these sources are often grounded in religious institutions, physicians, and social networks (Abrums, 2000; Sillence *et al.*, 2007). This aligns with the creation of a "trustworthy" source or artifact that can influence users' decision making as Table I shows these sources and phrases offered by the young women participating in this study.

For instance, a participant responding to where she gets information from stated, "[...] as a female, it depends. It kinda depends on the topic, but I guess since we're talking about HIV, I would probably feel more comfortable talking to another female." Another participant said "[she would] just Google it" when looking for information on HIV/AIDS. She mentioned that going to the doctor would not be a likely first choice because "[she would] probably have to be feeling something in order for [her] to go, but any other time [she] wouldn't." Still others mentioned going to web sites for information. Another young woman indicated that she would most likely visit the Mayo Clinic web site because "[she] was in HOSA, the Health Occupation Students of America, and [she] used that for research a lot." She, however, recognized that she was the exception and not the rule given her healthcare background and training.

*Stigma*

There is a pervasive issue of stigma in connection to HIV/AIDS that prevents the topic from being publicly and openly discussed. The young women expressed concern regarding discussing HIV in the presence of anyone who would have reason to judge them, such as physicians, clergy, and even family members. In particular, families often

HIV/AIDS information source	Respondents' phrases
Primary education	"Learned about HIV via sex education in high school, but it was limited."
Family/friends	"Mom had a friend who died of AIDS." "Aunt has AIDS." "Dad is a pastor who forbids me having sex" "Credible people are my church members, Blacks, pastor, doctor, & people who had experience with HIV/AIDS, female & educated; this is who I am most comfortable with."
Social institutions	"Don't have sex and you won't get AIDS; this is from the church." "Just practice abstinence." "Younger pastors talk about AIDS."
Online health information	"I search the web." "Google, Wikipedia, key matches in browsers, web MD, newspapers are important."
Health care community	"I call and/or visit my doctor"

**Table I.**  
HIV/AIDS information sources and responses from the focus groups

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feel embarrassed when another family member dies of AIDS. For example, one participant mentioned how she felt her church would perceive her if she asked questions about HIV/AIDS stating, “[...] if I had [HIV or AIDS] and went in the church and was like ‘Pastor, I need you to pray for me. I have HIV and full-blown AIDS. I’m AIDS positive and whatever’ he would probably be like stand-offish and then probably talk about me to everybody in the pulpit.” Another person echoed this sentiment stating: “I feel like the church tries to act as if sex or diseases do not exist. They just want to focus on ‘oh, go to Heaven, do right, and if you don’t do right, then these things might happen.’ Churches even shun some people, because I’m sure churches shunned people for having AIDS when AIDS first came out. They’re always gonna have a personal outlook on something. Even regardless of religion or what they should do as Christians or any other religion.” The driving factor here was a fear of being judged or perceived negatively by others. As one person mentioned, “I feel like that would kinda prevent me from talking about it even if I’m around people I can relate to just because I don’t want people to know the business [...]”

#### *Vulnerability*

Participants discussed what would make them vulnerable to HIV/AIDS, with focus on individual behavior. The group offered insight in stereotypes and high-risk behaviors, such as drug use and multiple sexual partners, which are often associated with the black community. One woman discussed the common misconception that having one partner automatically protects you from the disease, and knowing that sexual intercourse is the mode of transmission but not understanding the importance of condoms. In response to condom use, one person mentioned, “[...] also the importance of condoms. You know, whether [...] because I know a lot females feel like they don’t need to carry them, but I definitely think that would be very important.” Another indicated, “If you tell me something I’m doing may cause me to have, you know, HIV, it’s like, ‘Hold on, wait, I need to think about how I’m doing this.’ And if I’m having unprotected sex, maybe I need to [...] let me protect myself.”

#### *Make information easy to find*

The young women offered their feedback on unappealing characteristics of online health information. When asked what was culturally compelling about health web sites, one person noted that she often found that information was “hard to find. It was so many different choices and nothing was just straight out.” Another woman’s comments supported this statement but offered: “Not even that it was hard to find, but even the one that we did click, it wasn’t even in layman’s terms. It was just, like she said, basic information, which kinda seemed irrelevant for anyone who’d be searching the topic in the first place.” One participant responded to web page layout concerns and stated, “it doesn’t interest me at all. There is nothing on it that grabs my attention. It looks like if I was on here then I would not know what to do.”

#### *Debunk stereotypes*

For the second category of suggestions for improvement, we sought to determine what would make web content more culturally compelling for the young women. Interestingly, the women wanted to debunk the stereotypically paradigms associated with black women and HIV. Many of the comments included: “I am not a drug user, promiscuous. In many cases, the content we see assumes I fit into a category of the socially or have done something inappropriate. If I am not a drug abuser, then what? If I am not

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promiscuous, then what? If I am not rich, how do I cure myself? If I am not having sex, then what?" Others mentioned the need to "see" and identify with role models. To this end, the group confirmed the need to see those who are their demographic in terms of age, ethnicity, gender, and station in life (college students). As several women put it, "I want to see language that speaks to me not scientists but simple language to get the messages across. I want to hear from people with experience with HIV/AIDS. I can IM someone to chat but don't talk to me about it in front of my parents and others."

### *Image identification*

This was just as critical as message and content delivery for the participants. Stated succinctly, engaging web content for the target audience is a duality between imagery and messaging. As one young women confirmed, "If you are showing women who may have been prostitutes or drug addicts, or with a gay man or something like that, you're going to be like, 'that is not going to be me so I don't have to worry about it [...]' " Another person responding to this statement commented, "As soon as I seen drugs [on the site], I wouldn't look there anymore."

### *Use layman terms*

Further, participants preferred messages that were easy to understand where the content had been in "layman terms." Among the other descriptions for an engaging web experience offered by the participants were: vivid colors, catchy songs or music, a well-organized page, give-aways (e.g. free t-shirts), brief two- to five-minute messages/videos, funny and/or interactive content, quick facts, unique ideas like a party with HIV tests, and the use of social media. Many people felt the same as one participant who mentioned, "[...] but it has to engage me. It has to be funny, like she said, or 'ohh, that's deep,' or like just something to pull me in."

## **Discussion**

This study provides preliminary understanding of black collegiate women's needs for targeted HIV/AIDS prevention information in online contexts. It adds to the growing body of knowledge that attempts to understand the impact of cultural differences on the ways in which black women seek and acquire health information. Dervin (2005) suggests that to accommodate the information needs and preferences of black women and other historically underserved groups, it is important to understand their situational circumstances and sense-making needs.

For the women in our study, there were several barriers that diminished their ability to find information. For instance, women expressed a mistrust of health information, which is consistent with prior literature (LaViest *et al.*, 2000; Matthews *et al.*, 2002; Sanders Thompson *et al.*, 2009). When trust is absent, social identification and knowledge sharing are compromised (Ho *et al.*, 2012). Traditional and religious values also shape sexual behavior beliefs such as abstinence, condom use, sex before marriage, heterosexuality, and non-normative forms of sexuality. Oftentimes, these traditional and religious beliefs do not afford space for meaningful discussions that give young women guidance that is compatible with the contemporary college milieu where they have to negotiate a complex web of alcohol and drug use, hyper sexuality, and hookup culture. Discourse can also be reduced to catchy slogans and health campaigns without much in the way of engagement.

Denial, misconceptions, and fear of the unknown were raised as potential barriers to health information seeking. Here, the idea is that ignorance can be kind to those who

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may be most at risk for contracting HIV. Some will avoid HIV screening altogether; others will get tested but not go back to receive the results. HIV prevention messages that help women to take personal responsibility for their health, face their fears, and become actively engaged in HIV testing and safer sex practices may help to reduce avoidance behaviors.

Trust also emerges as a central component of black women's sense making. Here, the institutional source of the information makes or breaks both the credibility and the reception of the message. Women in this study looked favorably upon comprehensive web sites, such as WebMD. Like Detlefsen (2004), we found that black women are increasingly using the internet for information searches. However, if the representations of gender and sexuality in the prevention message are in conflict with how women perceive themselves, dissatisfaction, and mistrust may arise, and women may resist the HIV/AIDS information available to them. Content that did not resonate well with women in our study include celebrity spokespersons used in health campaigns, wordy, and cluttered web pages. This theme supports that notion of a staged trust model described in Sillence *et al.*, (2007). This model offers that most internet users engage in an initial rapid screening of a large number of sites primarily found via search engines. This is followed by a user's evaluation of a smaller subset of sites along with the available content to create a trust impression. Our focus group data supports this premise as the young women often stated, "I would just Google it."

Although collegiate black women are increasingly searching for health information online, these women continue to use print media and television. Black women magazines were also looked upon favorably as health communication channels. Television emerged as a passive channel for health information seeking where women were exposed to health information resources, like WebMD, primarily through commercials and advertisements. In addition to the commercials, television offers a multi-modal way of telling stories with rich moving images and voices of black women in situations that the focus group participants could identify. The importance of storytelling in black women's language and image has been discussed in prior studies of HIV prevention in online communities (Kvasny and Igwe, 2008).

Traditional information sources and institutions continue to play an integral role in black women's health information seeking. In our focus groups, women talked about sex education in high school, church, physicians, family members, and female peers. While doctors were seen as the most credible health information providers, the church and school were largely frowned upon for their "abstinence only" messaging. Abstinence education is important, but women felt a need for alternatives as they engaged in health decision making. In particular, the church and family were singled out for perpetuating harmful stigmas related to HIV/AIDS. Women felt that they would be judged negatively even if they sought information, or confessed that they had acquired HIV. Female peers and family served as comfortable sources to communicate with, but the credibility of the information could be suspect. Perhaps this fear of being judged helps to explain why, compared to white women, a higher percentage of black women report the use of passive information sources, such as broadcast media and organized health events (Nicholson *et al.*, 2003). Increased access to active resources like online and print health media might increase healthcare knowledge and improve long-term health for black women (Nicholson *et al.*, 2005).

Together, these traditional and online channels are woven into a continuously evolving health information ecology. Nardi and O'Day (1999) define an information

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ecology as “a system of people, practices, values, and technologies in a particular local environment. In information ecologies, the spotlight is not on technology, but on human activities that are served by technology.” As women use the internet, print, and visual media, and human relationships to gain information and practical advice on how to stop the spread of HIV, they give each medium unique roles and identities through their patterns of use and non-use. They use various sources of health information at different times and for different reasons. Each woman’s information need is shaped by what she sees in the environment and what information she constructs from the environment (Spink and Cole, 2001). Dervin (2005) argues that each woman subjectively constructs her own information needs. She, then, uses these same cognitive constructions to inform her information-seeking strategy as well as the absorption and rejection of the information that she finds. Thus, each woman’s choice of channels is dependent on culture. The collection of these information channels and cognitive constructions shape the women’s interpretation of the information found in each channel and forms the basis of the information ecology.

The women in our study provided several concrete areas in which HIV prevention messaging in their information ecology could be improved. These include engaging and interactive content online, the use of personal narratives, objective and fact-based content, engaging social media channels, and a focus on actionable preventative measures. The health messages needed to have a positive perspective, be written in commonly used “black vernacular,” include images of black women and couples, and not use fear tactics or shaming. In this way, the women could critically examine the information that they encounter passively or through active searches. Perhaps most importantly, women in our study strongly voiced the need and desire to find information for themselves. This confidence in their search abilities through a variety of channels and sources is encouraging.

### **Implications and future research**

The discussion presented in this paper provides several insights for designing culturally compelling and relevant HIV prevention information for black collegiate women. First, health communication materials should provide HIV and AIDS statistics that focus on black women. These statistics should be presented in a non-judgmental and unbiased manner, and in simple language that can be understood by people outside of the medical profession. However, women do not want to be inundated with statistics; they want practical, localized advice. If women are to take personal responsibility for their health, they need tangible information and access to local resources for HIV testing, health screening, condom distribution.

Women desire statistics but these should be paired with culturally compelling HIV prevention messages that include practical strategies such as condom negotiation, abstinence, and talking with your partner about sexual histories, stigma reduction, and signs and symptoms of illness. Culturally compelling health messages for young black women would also address reliance on religion, spirituality, and prayer; and speak in a manner that invokes both black authenticity and emotional intensity. However, caution should be used when using colloquial terms like “THE illness,” “the bug,” “slim” for HIV/AIDS when they reinforce the stigma of the disease (IRIN/PlusNews, 2008). Health communication materials should also provide strategies for dispelling myths, and combating feelings of stigma and mistrust. In addition, practical advice such as questions to ask physicians may help to produce positive and desirable outcomes as black women seek services from the healthcare system.

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The message itself must take into account a number of factors including short and simple messages, clean web pages, navigation structures that make information easy to find, comprehensive information all found in a single web site, and interactive features to facilitate discussion and sharing. In particular, with social media, women can also play a role in the creation and dissemination of health messages in multiple modalities including text, spoken word, still and moving images, and music. However, these interactive features and social interaction were found to be less important than issue involvement for influencing users commitment to online communities (Wang *et al.*, 2012). To facilitate issue involvement, culturally compelling HIV prevention messages would also include testimonials from African-American female role models that address heterosexual romantic relationships and sexuality, positive perceptions of black women to build self-esteem and to promote empowerment, and proactive health attitudes and behaviors.

Prevention materials should be distributed online as well as through local events like community and church health workshops, health and wellness fairs that take place in a broader information ecology of black women's sexual health. Plays and dramatizations could provide effective dissemination strategies for black women. Enrolling black cosmetologists as lay health advisors, disseminating coupons and samples, and disseminating materials on magazine racks in beauty shops provide innovative dissemination mechanisms that speak effectively to black women (Kim *et al.*, 2007; Sadler *et al.*, 2000). In a study of consumer online behavior, Srisuwan and Barnes (2008) found that a mix of offline and online advertising can present a message and reinforce it for consumers in different channels. This same principle of reinforcing messages across channels may be applicable for health information.

Future direction calls for our research team to take this input and construct an organic artifact (web site) that captures the needs and functionality expressed by the young women. We seek to create an online and socially connected experience characteristic of ongoing user input and active engagement in content development which targets the population. From a human-computer interaction viewpoint, we are seeking to avoid design divorced from context and meaning. In developing such an experience, we will need to triangulate the roles of culture, context, and design to reduce the content divide, yet amplify the notion of participatory web. Participatory web embodies a social justice movement to build web content from voices typically dampened in the discourse. It (re)shapes meaning, identity, and ecologies in the process of foci on particular social, health, and political causes (e.g. HIV/AIDS). Giving black women ownership over the creation of health information on the internet may improve our ability to provide targeted HIV prevention content that is culturally salient and more effective in reducing HIV infections in this community.

In conclusion, "a major component of preventive health practice is the availability and provision of information regarding risks to health and promotional measures for enhancing the health status among this population" (Gollop, 1997, p. 142). However, as Dervin (2005) cautions, while information is necessary, it is insufficient to encourage behavior change. To combat the health disparities that differentially impact African-American women requires expertise and understanding from multiple perspectives. By providing insight into how black collegiate women perceive HIV prevention information needs, the women in our focus groups lend a necessary voice in the effort toward healthy equity through the creation of effective health interventions that will appeal to them.

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