HIV/AIDS Stigma: Discussions from Black Female College Students on the Role of Family, Religious Organizations, and Health Institutions in Promoting Dialogue and Dissipating Shame

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HIV/AIDS Stigma

Discussions from Black Female College Students on the Role of Family, Religious Organizations, and Health Institutions in Promoting Dialogue and Dissipating Shame

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ABSTRACT—The research used focus groups to analyze the perceptions of Black female college students about HIV/AIDS stigma and prevention efforts. Our findings indicate that study participants perceived family, religious organizations and health care institutions as significantly impacting the promotion or dissipation of HIV/AIDS stigma. Awareness and understanding of students' opinions and perceptions about stigma can assist health care personnel and religious leaders in developing prevention programs and services for individuals and their families within this particular group. This research is funded by National Science Foundation grant # IIS-1144327.

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Introduction

According to Centers for Disease Control and Prevention (2016a) it is estimated that about 1,200,000 individuals are living with HIV/AIDS in the United States (Centers for Disease Control and Prevention, 2016). Another report indicates that in 2014, an estimated 44% (19,540) of newly diagnosed HIV cases in the country were African Americans yet they comprise only 12% of the total population (CDC, 2016b). On the other hand in 2013 an estimated 61% of all women who were living with HIV in the country were African Americans (Centers for Disease Control and Prevention, 2016c). Furthermore, the HIV rate for Black women remains twenty times as high as that of white women, and almost five times that of Hispanic women and AIDS is among the top five leading causes of death among women ages 25–44 in the United States. Thomas et al. (2008) argue that the South is particularly vulnerable and is described as at "increased risk of HIV infections" (p. 116).

With such high rates of HIV infection among Black females, it seems necessary to explore their perspective on the disease prevention and care. Research has found that in addition to their already marginalized status as Black women, the stigma they face as a result of their HIV-positive status further alienates them from their support networks (Melton, 2011). While HIV/AIDS stigma has been exhaustively researched, (Brown, Macintyre & Trujilo, 2003; Derose, Bogart, Kanouse, Felton, Collins, Mata, Oden, Dominguez, Florez, Hawes-Dawson, & Williams, 2014; Carr & Gramling, 2014; Derose, Griffin, Bogart, Kanouse, Williams, Haas, Florez, Collins, Hawes-Dawson, Mata, Oden, & Stucky, 2016; Ironson, Balbin & Stuetzle, 2005; Michels, Hofman & Keusch, 2006; Stuber, Meyer & Link, 2006; Valencia-Garcia, Rao, Strick, & Simoni, 2016) few studies have investigated the role that family, churches and medical institutions play in the process for Black female college students. Researchers have studied college students' attitudes toward HIV/AIDS (Khosrovani, Desai & Sanders, 2011; Taylor & Jones, 2007). However, to our knowledge no studies have analyzed the perceptions of HIV/AIDS and its related stigma among Black female college students. The purpose of this research is to analyze the perceptions of HIV/AIDS among Black female college students and the roles played by the family, churches and medical institutions in addressing stigma. Knowledge about the experiences of Black female college students could help us to understand and redress the social determinants of health disparities.

The subsequent sections review relevant research on HIV/AIDS-related stigma, present the research questions and methodology, summarize the collected data and analysis, and provide practical consequences of the results.

Literature Review

Stigma and uncertainty management

Some scholars argue that HIV/AIDS is the most stigmatizing disease globally (Simbay, Kalichman, Strebel, Colete, Henda, & Mqeto, 2007). These scholars further argue that research shows that people living with HIV/AIDS are viewed by society negatively and are seen as having been contaminated. In addition, these scholars suggest that people living with HIV/AIDS are responsible for their infection since they contract the disease through avoidable behaviors such as unprotected sex and drug abuse. Other scholars argue that HIV/AID stigma can lead to prejudice and actions against people living with the disease from government, health professionals, family, and friends (Brown et al., 2003). It is suggested that HIV/AIDS stigma is deemed as major deterrent to prevention efforts since it leads to fear and death among entire society. Furthermore, HIV/AIDS stigma is not only associated with negative self-perception, inferiority, less employment opportunities, and rejection by society (Fife, & Wright, 2000) but inhibits HIV testing, disclosure, and seeking for help as well as counseling of the infected individuals (Brown, et al., 2003; Genberg, Surinda, Chingomo, Sendah, Chariyalertsak, Konda, & Celentan, 2008). Moreover, the social construction of HIV/AIDS stigma leads to internalized emotions, distress, and lack of seeking for treatment and care (Simbay et al., 2007).

Alongside social and structural stigma, HIV/AIDS patients often have to contend with high levels of uncertainty as they process information regarding their ailment, medical care, social roles, interpersonal relationships and the future. As some scholars stipulate, pervasive uncertainty is one of the causes of distress for people living with HIV/AIDS (Brashers, Neidig, Reynolds, & Haas, 1998). The authors further state that persons living with HIV/AIDS, a goal may be to reduce uncertainty and establish psychological well-being given the likelihood of distress and negative emotions.

According to Mishel (1988), uncertainty can be defined as a condition when the individual cannot comprehend the meaning of a disease that is unpredictable and complicated. Uncertainty is often viewed by researchers as a negative state—successful reduction of uncertainty leads to increased ability to predict and explain a target's interactional behavior and leads to a subsequent reduction in information-seeking behavior (Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000). The author further states that for persons living with HIV or AIDS, a goal may be to reduce uncertainty and establish psychological well-being given the likelihood of distress and negative emotions.

Uncertainty management and disclosure

Apart from managing their own uncertainty regarding their illness, people living with HIV infections also have to manage sharing information with others. Individuals weigh the risk of disclosing highly intimate information about themselves to significant others, against the benefits of doing so. They face dialectical dilemmas and attempt to resolve these conflicting needs by weighing decision processes (Greene, 2009).

As the Disclosure Decision-Making Model (Greene, 2009) elaborates, people evaluate information for disclosure to various targets, which is cycled through the disease process as newer information is revealed. Five components of information that are weighed are: stigma, preparation, prognosis, symptoms and relevance to others (Greene, 2009). Each of these constructs may be evaluated in a different order, or not at all. For example, a person who is HIV positive may evaluate the social stigma attached to his/her status. If the risk of disclosure is not too great, he/she may consider the specific recipient of the information. He/she may choose to not disclose his/her status or wait for some other cue to emerge before sharing sensitive information.

Stigma and Family

American sociologist Erving Goffman (1963) described stigma as "an attribute that is deeply discrediting" whereby those who are stigmatized become "reduced in our minds from a whole and usual person to a tainted, discounted one" (p. 3). Pequegnat and Bell (2012) describe HIV/AIDS as a family-related disease. They suggest that families may have a supportive or hampering role in the lives of persons living with the disease. According to Goffman (1963) there are three different types of stigma: the first stems from body deformities or marked differences in our corporal structure; the second is related the character of the individual such as alcoholism and drug dependent; and the third, is related to broader factors such as nationality, race, and religion.

In a study of older African Americans, Foster & Gaskins (2009) determined that participants first disclosed their HIV/AIDS status to mothers and sisters because they perceived them to be supportive and understanding. Another study about HIV/AIDS stigma and women showed that the women were more concerned about the psychosocial consequences of disclosure of the disease than about death or physical changes of their bodies (Carr & Gramling, 2004). As a consequence, women were more likely to control the number of people whom they disclosed their diagnosis of the disease. We argue that some HIV positive African American women experience a social stigma based upon their seropositive status.

In a study of predominantly African American women, perceived family support correlated with mental health and suggested that perceived family support, even more so than support from friends, was conducive to less risky behaviors in both men and women (Serovich, Kimberly, Mosack, & Lewis, 2001). Similarly, a study of low-income, HIV-positive Black women (Jones, Beach, Forehead, & Foster, 2003) identified family stressors as a salient predictor in the decline of self-reported health. Support from family and friends can impact the outlook that stigmatized individuals have about life and the choices they make about HIV/AIDS prevention, treatment and care. Furthermore, HIV/AIDS prevention studies have indicated that the family unit is significant when it comes to disease prevention (Pequenat & Bell, 2012).

Stigma and Religious Organizations

The role of faith-based and religious organizations in dissipating stigma has been ambivalent. Some believe that religious organizations have the ability to mitigate HIV/AIDS stigma (Beadle-Holder, 2011; Derose et al., 2014; Derose et al., 2016) while others believe they are more likely to provoke it (Muturi & An, 2010). Extant literature indicates that stigmatized individuals and their families seek religious organizations for coping, social support and information. The Black community, for instance, has traditionally sought religious institutions for various types of support, including health education (Moore, Onsomu, Timmons, Abuya, & Moore, 2012). Prado, Feaster, Schwartz, Pratt, Smith, and Szapocznik (2004) who studied HIV-positive African American mothers, suggested that involvement in religious organizations may result in added social support, which in turn may decrease "avoidant" coping. The authors warned, however, that religion may have both positive and negative effects. On the other hand studies by Derose, et al. (2014) and Derose, et al. (2016) designed interventions to address the issues such as stigma that prevent the promotion of HIV/AIDS programs among the congregations in African American and Latino churches.

The literature indicates that around the world, religious organizations have been active in both mitigating and fostering HIV/AIDS stigma (Hartwig, Kissioki, & Hartwig , 2006). In the United States, a study of Black churches in North Carolina (Moore et al., 2012), indicated that some churches disseminate HIV/AIDS information among their congregations through a variety of media and church-sponsored support groups. Fulton (2011) argues that the Black church (collective) has been slow in addressing the issue. However, recent initiatives, such as The Black Church and HIV, suggest that there is movement from silence to active engagement to address the issue of HIV/AIDS among the congregation. For instance, studies by Derose, et al. (2014) and Derose, et al. (2016) have designed an intervention with the objective of reducing HIV-related stigma among the congregation in partnership with African American and Latino churches.

Positive efforts by some religious institutions and faith-based organizations towards mitigating stigma have been countered by perceptions that these entities are not using enough of their influence to combat stigma (Keikelame, Murphy, Ringheim, & Woldehanna, 2010). Rather, these entities have been said to perpetuate stereotypes and social isolation associated with the disease. To this end, in a study of Black women affected with HIV/AIDS, Muturi and An (2010) concluded that religious organizations may foster HIV/AIDS stigma through their religious teachings, such as moral penalty, condemnation and damning rhetoric.

Stigma and Health Organizations

Health organizations are not impervious to stigmatization practices, and persons living with AIDS (PLWA) encounter stigmatization from health-care personnel (McCann, 1999; Rintamaki, Scott, Kosenko, & Jensen 2007; Tyer-Viola, 2007). Stigma in health organizations may be experienced by patients as well as HIV-positive health-care staff. In narratives gathered by Newman, Williams, Massaquoi, Brown, and Logie (2008) study participants expressed their disappointment after learning that physicians were not free of stigma and that some doctors refused to treat patients who had an HIV-positive status. Polgar (2000) observed that hospital nurses who were not accustomed to caring for HIV/AIDS patients, and those less knowledgeable about the HIV transmission process, were more likely to fret about contracting the disease. The author further asserts that his concern translated into diminished "willingness to provide care, less continuity of care, and unequal treatment of AIDS patients" (p. 274). Earnshaw and Quinn (2012) argue that "participants living with chronic illnesses who internalized, experienced, and anticipated stigma in healthcare settings were less likely to access care and, in turn, had decreased quality of life" (p. 164).

Healthcare institutions and personnel are, however, still perceived as significant sources of HIV/AIDS information for PLWA (Newman et al., 2008). During interviews with African American women the authors reported that healthcare providers were viewed as important sources of disease and other health-related information for adolescents vulnerable to HIV. Healthcare personnel are also perceived to have an active role in reducing negative connotations concomitant with the disease. According to Kasapoglu, Saillard, Kaya and Turan (2011), physicians, for example, have been instrumental in the introduction of "semantic codes" that help shed some of the negative associations with the infection. The authors further explained, using expressions such as HIV-positive and chronic illness, instead of AIDS, enabled families to perceive the disease as a "curable" illness that can be managed by drugs (p. 1511).

Today, the role of family, religious and faith-based organizations and health-care institutions in reducing stigmatization has a new context. HIV-positive individuals and their families may seek HIV/AIDS information, social support and spiritual counseling online. Digital media technologies can provide individuals with the opportunity to disclose their seropositive status in private without fear of judgment or social repercussions (Baelden, Dorien, Van Audenhove, & Vergnami, 2012). Social media campaigns have proven to be effective in disseminating information about safe sexual practices and family planning in developing countries and in the United States and the global use of technology is influencing the ways in which patients receive and provide information. A study of digital literacy courses intended to provide information on HIV/AIDS to young women in Uganda indicated that participants were looking forward to receiving, crafting and shaping online information and that "global health websites can serve as virtual health-care services" (Norton, Jones, & Ahimbisibwe, 2011, p. 585). Whiteley, Brown and Swenson (2012) suggested that computer-mediated interventions can be helpful in reaching African American adolescents.

Given the significant influence of family, religious organizations and health institutions' impacts on the HIV/AIDS discourse, we seek to address the following research question:

How do Black female college students perceive the roles of the family, faith-based and health care organizations in the HIV/AIDS discourse?

Methods

The research team conducted three focus groups to appraise current black female college students' attitudes and perceptions of HIV/AIDS discourse at home, at church, and in health care organizations. As Berg (1998) stipulates, focus groups allow us to "strive to learn through discussion about conscious, semiconscious and unconscious psychological and socio-cultural characteristics and processes among various groups", (p. 123). The focus group is also known to generate more synergy between participants, therefore providing a richer source of information. In addition, focus groups provide information on the attitudes, practices and perceptions of its participants.

Sampling

This project engaged Black female college students at a large university in the South. Because we were interested in a very specific segment of the population, we used purposive and snowball sampling as suggested by Sandelowski (1995). Purposive sampling allowed us to target a particular group of people, while snowball sampling allowed us to ask prospective participants to recruit other participants for each of the three focus groups—thereby engaging a social network of peers. Forty-one (41) young Black women aged 18 to 24 participated in the study. The participants were diverse in terms of social economic status. Their parents were of different marital status—some had married parents while others were from single parent homes. We should note that participants were not recruited based on their health status, and at the time of recruitment we did not know if the participants were affected or infected by HIV/AIDS. Forty participants identified themselves as Christians and one participant identified herself as non-church goer, and not affiliated with any particular religion. Participants attended a variety of religious organizations, including Baptist, African Methodist Episcopal Zion, and a variety of non-denominational groups.

Procedure

Participants were asked a variety of questions to elicit comments and stimulate conversation about the participants' perceptions on the role of family, church and healthcare institutions on HIV/AIDS stigma. Follow-up questions were also asked to clarify the participants' comments and to corroborate the moderators' interpretations. The sessions began with general questions about HIV/AIDS information and health information sources (e.g., online, family, peers, medical professionals), and moved on to more specific questions. Participants were asked a series of questions that allowed them to express their experiences and opinions on the role of family, religious organizations, and healthcare institutions in disseminating information about HIV/AIDS.

During each focus group session, two moderators facilitated the discussions. Focus group sessions lasted between 60 and 90 minutes each. Sessions were audio-recorded and later transcribed by a member of the research team.

Data Analysis

We used grounded theory as an approach to examine, compare, conceptualize and categorize data (Glasser & Strauss, 1967; Strauss & Corbin, 1990). Independent coders gleaned various themes that emerged in the transcripts from participants' responses. The process was accomplished through the use of qualitative software that allowed us to conduct digital thematic analysis. We uploaded the transcripts onto the software program, examined and compared the information, identified major themes and created nodes for those themes. The nodes provided efficient access to the information. The themes were further conceptualized and categorized. Seven themes emerged from the data: disclosure reactions, cultural perspectives, religious conservatism, leadership schisms, knowledge paucity, communication oversights/trust, and patient initiative as shown in Table 1.

Emergent Themes

Some of the Black female college students shared similar perceptions regarding discussion of HIV/AIDS among the social institutions. Discussions regarding family focused on two emergent themes: disclosure reactions and cultural perspectives. Dialogue about religion centered on three main themes: religious conservatism, leadership schisms and knowledge paucity. Finally, discussion about healthcare institutions revolved around healthcare staff communication oversights/trust and patient initiative. In the following sections, we discuss these themes in detail.

Table 1: Emergent Themes from the Focus Groups

Concept Type	*Description*	*Quotes*
Disclosure reactions	Students' experiences with family disclosures about the disease	*"I didn't really take it seriously until . . . I actually had an uncle that died from it back in 2005 because I was 15 . . . I was like 15–16 . . . 2005–2006 . . . and I guess because we actually saw him go through the process, it didn't hit close to home until then."*
Cultural perspective	Value of privacy within the Black community	*"My family has not talked about it at all. Half of my family doesn't even know he had AIDS. There's only a select few of us who know. And it's something we just don't feel comfortable talking about to other family members, but that's just because of how my family is."*
Religious conservatism	A belief that religious institutions were too conservative to address HIV/AIDS issues	*"Some churches just promote being abstinent period. And they're like, 'if we promote being abstinent, then they is no need to even talk about HIV and AIDS.'"*
Leadership schisms	When one member of the clergy would be willing to discuss the issue, but another would not	*"Before I used to go to my family's church . . . and the pastor . . . he was a little bit older so he didn't really talk about it. But then, once we moved to another church and had a younger pastor, he would kind of address it. So I think it's kind of like a generation thing . . ."*
Knowledge paucity	The belief that church leaders were uninformed about HIV/AIDS issues	*"I think it might be less of them being oblivious, and more of them not being educated on the matter . . . I wouldn't want to discuss something with my congregation if I didn't know what I was talking about . . ."*
Communication oversights/Trust	Student perceptions that health care providers were not fully exercising their role as information disseminators about HIV/AIDS or any other diseases, in general	*"They said that they don't offer the information, and usually when you get birth control they tell you this doesn't prevent HIV, and that's all they told me about it."* *"Because, I also have just a personal thought just that sometimes they [health care community] don't care as far as telling our African-American brothers [especially in small towns] things to help themselves."*
Patient initiative	Participants' need to be personally responsible for seeking information	*"Um, I have asked my health care provider every single time I go to get tested for everything else I get tested for that as well because it's there and I might as well do it."*

Family

For some of the students, family played a central role in their knowledge and perceptions about HIV/AIDS and the stigma associated with it. Dialogue about the role of family in fomenting or dissipating stigma centered on students' experiences with family disclosures about the disease, and on the value of privacy within the black community. Several of the participants, for example, vicariously experienced social stigma as they observed relatives who suffered from the disease. Students detected dichotomized stigma: limited or no emotional and moral support for or from relatives infected and affected, and shunning behaviors often due to moral questions or simple ignorance about the disease. One of the students expressed deep emotion as she credited her mother and aunt with teaching her the importance of compassion while they cared for their brother who was dying of AIDS:

> . . . my aunt that's the RN . . . years before they said that he had full-blown AIDS she was like, 'Ma, I think Lenny has AIDS.' My grandma got so upset she didn't talk to my aunt for like six months. And she was like, 'No he does not have AIDS. How dare you say that? . . . ' And I was like, 'she's [aunt] been an RN for 25 years. I think she knows what he's starting to look like.' Then my mom intervened and said, 'You know ma, you just need to relax. I think you need to look at it; think about his lifestyle.' And even until the funeral my grandma just would not accept it. My mom is the one that sat there and helped the hospice nurse . . . help them aid to his bedsores and bathe him.

Although the student was able to observe a supportive disposition by her mother and aunt toward her uncle, she was also able to experience the enacted stigma by her grandmother and other family members. As she noted,

> He wanted to make sure he went away nicely and my grandmother was just so oblivious and in denial about the whole thing and my family just . . . they just sat there and acted like it was nothing . . .

Another student observed the stigma dichotomy after her great uncle disclosed his HIV status:

> My great uncle actually is still living with it, but it's been for a while . . . since I was in ninth grade, but he's just coming back around the family slightly, like to family reunions. But it's still the distant family members who are still acting far from him. They act like, "Oh, I'm gonna catch it

> if I give him a hug type thing." But I feel like this also goes to . . . once you learn about it, learn how you can catch it, prevent yourself from it.

Some of the students believed that knowledge about the disease could reduce HIV/AIDS stigma among family members. A prevailing tendency for privacy in black families prevented them from openly discussing the subject. One student remarked:

> I didn't necessarily feel comfortable sitting in a room with a lot of people I don't know and discussing my family issues or how we handle stuff like that. So I think we're kind of private people. We don't want to let everybody know.

Another student concurred:

> I don't know if this would go for the entire African American community, but I know in my family it's the notion of don't . . . we don't want everybody knowing our business. Kind of like don't dishonor the family. Like a hidden don't dishonor the family notion. So, 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, ya know?

Participants believed that family could also play a central role in disseminating awareness about disease prevention. For example, one of the students spoke of her role in making sure her younger brother learned about HIV/AIDS and about safe sex practices:

> I take my younger brother as being that, that vessel, cause . . . you know, I pass so much information to him. I know . . . it might not have stuck . . . so I'm like these are things that you need to make sure that you are careful of; these are things that you haven't been told. Because, I also have just a personal thought just that sometimes they don't care as far as telling our African-American brothers things to help themselves.

Although the participants' narratives contained examples of family as both a fomenter and a dissipater of stigma, Black female college students in this study seemed annoyed at family members who are prone to propagating stigmatizing behaviors.

Religious Organizations

Leadership schisms, religious conservatism and knowledge paucity were the main themes surrounding the role of religious organizations in increasing or decreasing HIV/AIDS stigma. While study participants belonged to a wide range of faith-based organizations, a majority believed that their religious institutions were too conservative while addressing HIV/AIDS issues. Overwhelmingly, students expressed the idea that they would not feel comfortable discussing the health concerns with members of their respective congregations. One student described how she would be scrutinized and offered the following:

> For me it wouldn't be comfortable just because a lot of people associate contracting AIDS with sex and with my age group, I mean, I'm not married. Sex before marriage is a sin . . .

One student agreed:

> If you bring up the topic of something like that, that has to do with health—even though you can contract it different ways—then it's going to come up, "Are you fornicating? You don't need to be doing that."

Another student said:

> I feel like the church tries to ax sex or diseases. 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.

Participants expressed their fear of being judged or perceived negatively by others. As one student 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 . . .

A few students, however, spoke of church leadership's proactive stance on disseminating health information, in general, and HIV/AIDS information, in particular. For instance, one participant explained how her reluctance to broach the subject of HIV/AIDS at church would not preclude her from benefiting from the message. One student indicated:

> I'm a Christian and I went to [church name] on Sunday and his whole message was about AIDS in the black community, so I think that's a

> good place to start. And it was very educational . . . things that I have never took the time to think about, but he hit home with the message and everything. So, I wouldn't bring that topic up, but I would love to listen to what's going on and . . .

Similarly, another student stated:

> . . . I'm a Baptist, and we have a health ministry and they actually do that. They do AIDS, HIV as well as other health concerns.

The students also spoke about leadership schisms between younger and older pastors within the same congregation, conveying that oftentimes one member of the clergy would be willing to discuss the issue, but another would not. A student explained how she had experienced the difference in leadership styles:

> . . . when I was younger, we had two pastors in that church. So the first pastor, he probably wouldn't even acknowledge it; he would just preach about being abstinent . . . fornication and all that kind of stuff . . . But the second pastor we had, he kind of looked a little bit more youthful and he was aware that the things were going on. Cause people are going do what they wanna do. So, he kinda was more proactive about it.

Leadership differences were echoed by a different participant who credited a change in pastors with a more progressive discussion about HIV/AIDS and other health issues at her congregation. She noted:

> At my church . . . we had two different pastors growing up. So the first one stuck to the book of order. But the second one, I guess, he was more in tune with the issues going on in our community. So I think we actually had an HIV testing day for members of the community to come in and get tested . . . . And I think it kind of just opened up the dialogue between the youth and the pastor and the members of the church to let them know like, no we don't condone teenage pregnancy or teenage sex or what have you, but if you are going to do this, these are the precautions that you should take so . . . it just made it easier.

Besides authority schisms and conservatism, many participants believed their church leaders were uninformed about HIV/AIDS issues. This apparent paucity of knowledge was perceived as a barrier to information dissemination. As one participant noted,

> I think it might be less of them being oblivious, and more of them not being educated on the matter . . . . I wouldn't want to discuss something with my congregation if I didn't know what I was talking about . . . .

The role of religious organizations in fostering or dissipating HIV/AIDS stigma was perceived as being limited by a variety of issues, including lack of knowledge about the disease, conservative views and values by the church leadership as well as the congregation, and fluctuations in leadership that resulted in mixed messages about the disease.

Health Institutions

As with religious organizations, healthcare institutions were also perceived by the students as having a mostly adverse impact on HIV/AIDS stigma. Their perception stemmed from communication oversights by healthcare personnel that restricted the flow of information about HIV/AIDS and health in general, as well as the presence of stigmatizing behaviors that discouraged the young women from seeking information or services. In addition, participants perceived their own initiative as a significant factor in counteracting information and communication oversights. Some even questioned the willingness of the medical community to share appropriate and timely information with those in the Black community. Issues of trust (or the lack thereof) and communication seemingly posed a challenge in the patient-physician relationship.

Many participants described a lack of interest in healthcare providers to offer information or testing for HIV/AIDS or any other disease. One student stated:

> I have a very strong history of diabetes, high blood pressure, hypertension, aneurysms . . . a lot of things. And you go to these people and you tell them this and they just keep on, and you're like, but these are things you should be probing me for as a medical physician'. . . . I feel like they don't, with our community, present us with the information unless we really, really seek it. Unless you go into the office and you're like, "Can I ask you about this?"

Another student expressed her disappointment at the lack of information offered. As she noted, "Usually when you get birth control they tell you this doesn't prevent HIV, and that's all they told me about it." One participant reflected on a possible reason why healthcare personnel may be reluctant to offer HIV/AIDS information to students,

> . . . maybe, I mean, they don't want to come off as if they're stereotyping me or anything like that. I could maybe see that as the only reason why a doctor wouldn't ask.

Another student believed that the lack of information may stem from lack of perceived need by their physician:

> My doctor has a survey . . . and, I guess, if I am not experiencing the symptoms . . . associated with I guess HIV and AIDS then she's not going to raise that issue. So, I mean that just how I take it, because it's never brought up anytime I go to the doctor.

Many students believed that the lack of prompting from health-care professionals had motivated them to become custodians of their own health. As one participant explained:

> I see my physician yearly and, usually, if I get something tested, it's because I verbally say I want to get tested. When I personally was tested for HIV, I went on my own accord

Additionally, the same young woman felt it was her personal responsibility to seek health services and stated as follows:

> I actually went to a free clinic. It was not because my provider said this is something that could be affecting you as a college student, it's something that could be affecting you because you are an African-American woman.

Participants in this study believed they had a choice to seek or not to seek information. In fact, many made a conscious choice not to ask for information if they felt they were not engaging in behaviors that would bring about the disease. Although students felt empowered to ask for information, some became discouraged by the stigmatizing practices and limited communication of their healthcare professionals. One participant described feeling uncomfortable with the change in demeanor of the health care staff when she requested to be tested for HIV/AIDS:

> I noticed when I did ask, she was like okay. And then, the nurse came and got me, and the nurse kinda looked down the whole time and was kinda . . . 'hmm is everything ok?' And was asking really weird ques-

> tions. And I'm just like I want to make sure everything's fine. I am confident everything is fine, but I was just double checking. It was really uncomfortable and it made me almost not even want to go back and get tested again because it was like almost she put me in that category of already being diagnosed even though I haven't been . . .

Another participant contrasted her experience with her primary care physician to her experience with health care in the military:

> My healthcare provider actually never mentioned it or brought it up . . . But as far as the military goes, they push it. Every time I have to go . . . they're on top of it. And, we constantly have to get tested for HIV.

Participants in this study had the perception that healthcare providers were not fully exercising their role as information disseminators, especially when it came to HIV/AIDS. The students felt they needed to be personally responsible for seeking information. Patient-provider communication, however, does appear to be a critical factor in patient efficacy and provider delivery. Similarly, this communication best serves the patient when the provider's care delivery is void of assumptions regarding one's HIV status and the stereotypes that often accompany the stigma associated with the disease. Patients, on the other hand, must be empowered by enacting proactive practices relative to their personal health.

Through the various examples provided by the participants, the study points to the continued association of stigma with HIV/AIDS patients and the perpetuation of the stigma by families of the patients, healthcare providers and religious institutions. The primary reasons for the same are a lack of knowledge among the Black community about the disease, its prevention and care; the failure of healthcare personnel to communicate vital information about the disease and its prevention; and the conservative views of religious organizations that prevent their leaders from imparting correct guidance and support to those who seek it. As a result, most of the participants feel discouraged about talking openly about the disease and seek timely guidance, and often have to take proactive steps for information and diagnostic services by overriding stigmatizing behaviors, which can be distressing.

Without the support of vital institutions such as the family, healthcare providers and religious organizations, containment of the disease becomes a challenge, leading to denial and a lack of timely preventative action and/or care for affected individuals.

Discussion

For our study, we analyzed focus group interviews of Black female college students and their perceptions of the role of family, religious organizations, and healthcare institutions in fostering or dissipating HIV/AIDS stigma. Below is an analytical discussion about the emergent themes in our study that includes family, religious organizations, and healthcare institutions.

Family

Our findings indicate that existing stigma in connection to HIV/AIDS prevents the issue from being discussed publicly or openly in private. The literature suggests that people living with HIV/AIDS feel a sense of rejection because the disease is associated with behaviors that are negatively perceived by society which in turn leads to fear of isolation and lack of disclosure (Brashers et al., 1998; Brown et al., 2003; Fife & Wright, 2000). Participants expressed concern while talking about the topic in the company of any person that would have a reason to judge them, such as doctors and pastors. It can be argued that this concern by family members about discussing the disease in the company of doctors and pastors can lead to lack of seeking information as suggested by some scholars (Brashers et al., 2000). Our study also indicated that family plays an important role in both fostering and dissipating stigma associated with HIV/AIDS. This finding is consistent with prior research by scholars such as Pequegnat and Bell (2012) and Varas-Díaz, Serrano-Garcia and Toro-Alfonso (2005). Many of the students interviewed spoke of personal experiences and how family stigma contributed to heightened emotional suffering and reduced coping skills of relatives with the disease. Participants who had HIV/AIDS patients in their family pointed to stigma as primary factor for decreased contact between the infected individual and other affected members of their family. This is consistent with research by Ruiz-torres, Cintron-Bou, & Varas_Diaz (2007) who studied the impact of family among individuals living HIV/AIDS. Interestingly, participants indicated that people living with HIV/AIDS were more likely to disclose to their mothers who played a more supportive role which is line with prior research by Carr & Gramling (2004), Foster & Gaskin (2009), Li et al., (2008). Other studies have shown that partners and family play a major role in pregnant women's decision to accept to test for HIV/AIDS and to disclose their HIV status (Turan, Bukusi, Onono, Holzemer, Miller, & Cohen, 2011).

Religious institutions

It was interesting that the role of religious institutions was also salient in our findings. Fulton (2011) noted that African American churches have had mixed responses to HIV/AIDS. Furthermore, while Beadle-Holder (2011) argues that religious institutions can play a positive role in dissipating HIV/AIDS stigma Muturi and An (2010) argue that they can play a negative role by exacerbating stigma. Our research supports the argument of mixed feelings about the role of religious institutions in dealing with HIV/AIDS issues in general and HIV/AIDS stigma in particular. For example, study participants indicated that the response to HIV/AIDS would vary depending on individual pastors and institutional leadership. In addition, some scholars suggest that the black community has traditionally sought religious institutions for various types of support, including health education (Moore et al., 2012). Furthermore, Prado et al. (2004) argue that involvement in religious organizations may result in added social support, which in turn may decrease HIV/AIDS stigma.

Interestingly, participants noted the dichotomy between younger and older faith leaders. In general and in comparison to more seasoned clergy, younger ministers were said to confront the HIV/AIDS discourse more openly through active outreach programs, pulpit delivery and imparting a penalty-free "church" which engenders dialogue and experience-sharing with misconceptions and/or preconceptions. Our research showed that the students did not feel comfortable discussing HIV/AIDS issues in their religious community. The students were aware of the stigma associated with the topic, and seemed concerned about being criticized or judged for merely introducing the subject.

Healthcare Institutions

The results of the current study show that participants perceived healthcare institutions as having a negative impact on HIV/AIDS stigma. This is not surprising given the findings by other scholars such as McCann (1999), Rintamaki et al. (2007), and Tyer-Viola (2007). What was surprising was that participants felt that healthcare providers restricted the flow of information about HIV/AIDS and displayed stigmatizing behaviors which discouraged the seeking of information and services. Participants even questioned the willingness by medical professionals to share information about HIV/AIDS among the Black community. Hence, consistent with Rintamaki et al. (2007), our study suggests that healthcare personnel should avoid stigmatizing behaviors that may deter students from seeking information and care. When students request to be tested for HIV/AIDS, medical staff should refrain from any changes in demeanor that may discourage students from requesting future testing. Furthermore, healthcare personnel must be more proactive in developing ways to reach and appeal to Black female college students. These findings hold implications for effective patient-physician communication, as well as improved health literacy for young women.

On the other hand, the study indicated that participants were active seekers of information. Participants expressed an intensive interest in personal responsibility for their health, increasing their health knowledge and sharing information among their social networks, particularly among peers. Participants' discussions revealed that both denial and misconceptions are underlying factors causing people's attitudes towards HIV/AIDS. The participants believed that living with the unknown is a preferred behavior pattern, for as long as the disease permits people to function properly. Similarly, participants noted that various misconceptions, particularly regarding disease transmission, continue to be part of daily life. These misconstructions included myths such as using the same utensils as a person with the disease, or simply being near an HIV-positive person would result in increased risk of contracting the virus. Finally, research should be conducted to monitor the incidence of HIV/AIDS among all college-aged adults. Research has also shown that young people aged 18–24 years have the highest rate of undiagnosed HIV cases, lower rates of HIV testing and condom use, and higher rates of sexually transmitted diseases than any other age group in the United States (Centers for Disease Control and Prevention, 2016d).

Implications

The current study offers information about the attitudes and opinions of college-aged young women regarding the role of family, religious organizations, and healthcare organizations on alleviating the HIV/AIDS crisis. By doing so, the study makes a significant contribution to the understanding of the perceptions of Black Female College students about HIV/AIDS stigma in the US which has been largely neglected in the literature on this epidemic. Awareness and understanding of students' opinions and perceptions about stigma may assist family members, religious leaders, and healthcare providers in developing more effective programs and services for HIV/AIDS prevention and testing within this particular group. The findings also suggest that faith-based and healthcare entities can offer family-based health literacy to diminish emotional stigma associated with those "simply asking for health knowledge" as well as those affected and infected. Study results may also assist in the development of communication practices to better disseminate information about HIV/AIDS to this segment of the population and, in the process, assist in decreasing HIV/AIDS stigma. Healthcare personnel must be more proactive in developing ways to reach and appeal to Black female college students. Finally, communication modalities should account for the voices, herein, and discern how young adults communicate using mixed channels, including digital media, television and print.

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