

Extending HIV Prevention: People Living with HIV/AIDS (PLWHA) Strategize to Reduce Stigma and Promote HIV Testing

Tiffany M. Cummings Aholou
Student, College of Family & consumer
Sciences
University of Georgia

ⁱ Su-I Hou
College of Public Health
University of Georgia

Tanisha S. Grimes
College of Public Health
University of Georgia

Acknowledgement: This study was supported by Ryan White federal-flow through funds from the Clarke County Board of Health, Northeastern Georgia Health District, Georgia. The PI is in debt to all staffs and PLWHA participants for their time and support to this comprehensive needs assessment project. Special thanks to Mrs. Deborah Swinford and her staff at the Specialty Care Clinic and all committee members from the HIV/AIDS consortium of NE Georgia for their support, encouragement, and assistance of this project. This research was conducted with the approval of the Institution Review Board for the Protection of Human Subjects at The University of Georgia.

ABSTRACT

Strategies to reduce acquired immunodeficiency syndrome (AIDS)-related stigma are paramount to promoting effective HIV prevention. As in the case of HIV antibody testing, despite the benefits of early detection, links to care, and risk behavior modification, nearly 250,000 people are unaware of their HIV status. AIDS-related stigma has impeded such efforts due to discrimination, ignorance and other forms of stigma. These issues related to stigma and HIV testing are magnified when placed in the context of the rural Deep South region of the United States, where the incidence of HIV/AIDS are growing at alarming rates. The purpose of this paper was to examine strategies to reduce AIDS-related stigma that in turn promotes HIV testing as proposed by people living with HIV/AIDS (PLWHA) who reside in the Deep South. An exploratory descriptive qualitative research design was utilized. The sample consisted of 18 PLWHA. Data was collected using a focus group and individual, semi-structured interviews. The analysis revealed the importance of ongoing education as a mediator between reducing stigma and promoting HIV testing. Other salient findings were related to reframing HIV/AIDS-related health messages to reflect a sense of empowerment; the need to normalize testing; the use of less stigmatizing testing sites; and the continuance of anonymous HIV testing. This article is significant because it illuminates the challenges of HIV prevention in the Deep South, while also generating culturally-sensitive strategies to counter these barriers.

INTRODUCTION

For over two decades, HIV antibody testing has been considered one of the most essential HIV prevention strategies available (Branson et al., 2006). With the advent of new technologies such as rapid blood and oral fluid HIV antibody tests, individuals who seek an HIV test can obtain their preliminary results in less than an hour (Grusky et al., 2005). Early detection of one's HIV status allows for more effective treatment. Medical intervention during this critical, early period can help prolong lives and reduce the spread of the virus (Branson et al., 2006). Furthermore, when coupled with voluntary counseling and testing (VCT), the HIV testing process serves as an opportunity to educate test takers on ways to reduce their risks and to practice healthier behaviors, regardless of the outcome of the test (Myers, Worthington, Haubrich, Ryder, & Calzavara, 2005).

The benefits of HIV antibody testing are often impeded by HIV-related stigma (Brown, Macintyre, & Trujillo, 2003). In Brown et al. (2003) they cite Goffman's definition of stigma as "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society" (p.50). An extant body of literature has shown that HIV-related stigma is often aimed at marginalized groups such as gays and lesbians or intravenous drug users (Chesney & Smith, 1999; Devine, Plant, & Harrison, 1999; Fullilove & Fullilove, 1999; Herek, Capitano, & Widaman, 2002). Several researchers have used the distinctions of *felt* stigma and *enacted* stigma to illuminate the experience of stigmatizing diseases (Brown et al., 2003; Lichtenstein, Hook, & Sharma, 2005; Lichtenstein, Neal, & Brodsky, 2008). In the context of sexually transmitted infections (STI), Lichtenstein et al. (2008) describes *felt* stigma as "perceptions of being stigmatized," whereas *enacted* stigma is "discriminating attitudes or actions toward so-called deviants in society" (p.28). For example, PLWHA who encounter *felt* stigma may begin to internalize the stigma directed toward them, which could result in shame (Chesney & Smith, 1999), fears of disclosure, and leading to further social isolation (Greene & Banerjee, 2006). In contrast, *enacted* stigma may be manifested as overt discrimination, anger, ignorance, pity, ostracism, or physical violence (Chesney & Smith, 1999; Greene & Banerjee, 2006).

Due to the negative connotations created by HIV-related stigma, many people are unaware of their HIV status either due to never been tested, not having a recent test, or failure to return for test results (Bond, Lauby, & Batson, 2005; Kaiser Family Foundation [KFF], 2007). This leaves those who are unknowingly infected without needed care. Furthermore, studies have found that people unaware of their HIV status are less likely to modify their risk behaviors, thus inadvertently placing others at risk (KFF, 2007; Lichtenstein et al., 2005).

The issues related to HIV antibody testing and stigmas are magnified when placed in the context of the rural Deep South region of the United States (US), where the incidence of HIV/AIDS is growing at alarming rates (Bowen, Gambrell, & DeCarlo, 2006; Whetten & Reif, 2006). The Deep South is made up of six states: Alabama, Georgia, Louisiana, Mississippi, North Carolina and South Carolina. In 2003, this region accounted for 36% of the newly reported AIDS cases in the south, compared to 4% in other southern states and 5% nationally (Reif, Geonnotti, & Whetton, 2005). One particular state where there has been a consistent increase in HIV/AIDS cases is Georgia. In 2006, Georgia ranked seventh in the number of reported AIDS cases, and eighth in the number of cumulative AIDS cases in the US (Georgia Department of

Human Resources [DHR], 2008; KFF, 2008). According to recent trends, the epidemic in Georgia is increasing amongst rural populations as well as small cities and towns (KFF, 2008).

Several contextual factors may explain the growth of the AIDS epidemic in the rural Deep South. Some of these factors include limited access to healthcare due to the higher concentration of impoverished residents in this region who are unemployed and uninsured (Reif et al., 2005). This is particularly significant given that recent national HIV testing data states that the majority of HIV tests are conducted in private doctor's office (KFF, 2008); and those who test positive were more likely to be tested in hospital settings, community clinics, or among private doctors (Bowen et al., 2006; Whetten & Reif, 2006; KFF, 2008). Also, despite the small, yet steady increase (5-8%) of HIV cases in rural populations (Bowen et al., 2006), funding is typically allocated to metropolitan areas with higher prevalence of HIV (Whetten & Reif, 2006). This results in insufficient human and financial resources available to properly provide education and prevention (Bowen et al., 2006). Additionally, people residing in rural populations have unique geographical challenges. They are widely dispersed (DHR, 2008) and geographically isolated which not only presents transportation challenges that hinders access to treatment (Bowen et al., 2006) but also gives them limited resource options (Lichtenstein, 2005). Lastly, yet most pervasive, this region is centered in the Bible Belt, which represents social and religious conservatism. This conservative ethos of the Bible Belt (i.e. negative views on homosexuality; Lichtenstein, 2005), particularly in rural communities, that may leads to the proliferation of HIV-related stigma.

In a review of 22 existing interventions to reduce HIV/AIDS stigma conducted in various countries (Brown et al., 2003), 13 (59%) were conducted in the U.S. Of the four types of interventions—information-based, skill building, counseling, and contact with affected groups—eight out of 13 of the interventions conducted in the US (62%) utilized information-based approaches, with five interventions combining information-based with another type of modality. Contact with an affected person combined with information-based approaches had the greatest impact than any one modality alone for short-term impact (Brown et al., 2003). Nevertheless, the review suggests there is still much to learn about approaches that effectively reduce HIV/AIDS stigma long-term. Also, though there is endorsement for the use of mass media campaigns to reduce stigma and HIV prevention, in general (Brown et al., 2003; Noar, 2007), there were no documented mass media campaigns conducted for inclusion in the review.

Due to the importance of early detection of HIV, it is imperative that strategies to reduce HIV-related stigma remain in the forefront of HIV prevention efforts. The issues of the rural Deep South illuminate the challenges as well as the need to further explore culturally responsive approaches to combat the AIDS epidemic in this region. The purpose of this article is to examine proposed strategies to reduce stigma and promote HIV testing as suggested by PLWHA, who reside in rural and small town Georgia.

Engaging in a dialogue with participants residing in cities of rural and smaller cities and who are PLWHA is important for multiple reasons. First, although there is a growing body of literature pertaining to the AIDS epidemic in the Deep South, this article fills a gap about the epidemic in rural and smaller cities Georgia. For example, while there has been research conducted in other Deep South states (i.e. NC), there appears to be a paucity of research available that specifically targets PLWHA living in rural Georgia. Therefore, this study helps to give voice to this diverse and growing population. Second, the researchers acknowledge

PLWHA as a great resource because of their first-hand experience coping with the illness. Finally, as public health officials continue to modify recommendations and employ different approaches to combat HIV/AIDS, the inclusion of strategies presented by members of the rural and small town HIV community can reinforce current efforts while simultaneously offer a different perspective to the ongoing concern of prevention in the rural Deep South.

METHODS

Design

An exploratory descriptive qualitative research design was utilized for the present article. Data was collected as part of a 2007-2008 comprehensive HIV/AIDS needs assessment in a non-urban, mid-size city serving 10 surrounding rural counties. The needs assessment collected both quantitative and qualitative data among PLWHA and providers to assess the needs of HIV/AIDS patients and provided recommendations to reduce the barriers to HIV/AIDS services. This paper analyzed the focus group and interview qualitative data collected from PLWHA.

Data Collection

Two trained qualitative researchers conducted the focus group and individual face-to-face interviews. The same interview guide, which explored barriers towards service utilization including stigma and preventive strategies, was used for both the focus group and the individual interviews. In the focus group, the researchers facilitated a semi-structured conversation with several participants to explore their attitudes and perceptions about the phenomena understudy, whereas the semi-structured face-to-face interviews were used to gain deeper insight into the proposed strategies to reduce stigma and the encourage HIV testing (Patton, 2002). The focus group was approximately 90 minutes in length and the average one-on-one interview time was approximately 45 minutes.

Both the focus group and interview sessions were audio taped, transcribed verbatim and analyzed by two trained researchers. In addition, participants also completed a demographic profile sheet. This study was conducted with the approval of the Institutional Review Board for the Protection of Human Subjects at the researcher's institution.

Participants

Eighteen PLWHA, all residents of rural and small town Georgia, were recruited from a Ryan White CARE funded HIV/AIDS clinic and an AIDS Service Organization (ASO) in Georgia to participate in the focus group or one-on-one interview. Patients were notified via a mailed letter from the service providers about the study. Fliers were also posted at central locations of the aforementioned agencies to recruit participants. As an appreciation for their time, each participant received a goody bag with sample toiletries and a movie ticket.

Data Analysis

An inductive thematic data analysis was utilized to identify strategies to reduce HIV stigma and promote HIV testing. During the analysis process, each transcript was read individually by

two trained researchers, generating semantic codes pertaining to the phenomenon (Braun & Clarke, 2006). Once codes were agreed upon at the individual level, the transcripts were cross analyzed to identify categories and patterns across transcripts (Braun & Clarke, 2006; Patton, 2002). From this process, a set of themes that inductively characterized strategies to reduce HIV-related stigma and promote HIV testing were derived.

RESULTS

Characteristics of the Participants

The mean age of the participants was 41 years (range from 29 to 57 years). Most were single (81%) and 57% self-identified as homosexual. The majority (67%) was African American, and fifty-five were male. Nearly two-thirds-of the participants had been diagnosed with HIV and AIDS concurrently, with over half (61%) learning their status within the last five years. Table 1 provides detailed demographics. A brief description of each participant using pseudonyms is included in Table 2.

Key Themes

A total of seven key themes to reduce stigma and encourage testing were identified: Know Better, You Do Better; The Message Matters; Each One Reach One; Positively Living Positive; It Takes a Village; Break the Barriers; and All in this Together.

Know Better, You Do Better

Ongoing education was the foremost strategy endorsed to reduce stigma. Melissa, an African American female aptly stated, "in the absence of a cure right now, the main thing that we have is education." Several participants reiterated the importance of dispelling the erroneous beliefs about the epidemic, namely how the virus is transmitted or who is likely to be infected.

Some participants actually felt that there is a great deal of information currently available about the epidemic. Consequently, they believed that if people were to take individual responsibility for obtaining the information there would be a reduction in HIV-related stigma, as conveyed by Andre, an African American male "more education, yeah. I think it's up to the individual person to get educated because it's out there...."

In contrast, there was also the belief that people 'choose' to stay misinformed and maintain entrenched, divisive-attitudes and beliefs that perpetuate stigma as suggested by Alston, "A lot of people just don't know about the disease. They don't want to know, because if they knew, they would have to change their mind...cause when you know better you do better."

The Message Matters

The dissemination of balanced messages was also considered a critical strategy to dispel stigma and promote early detection of HIV. The concept of 'death' was heavily discussed by the participants. Many argued against current health messages in the media that attempt to instill

Table 1: Participant Demographics

Characteristic	N	%
Gender		
Male	10	55%
Female	8	44%
Racial/Ethnic Background		
African American/Black	12	67%
Caucasian	6	33%
Age Range		
25-35 years	6	35%
36-45 years	5	29%
46-55 years	5	29%
56-65 years	1	6%
Sexual Orientation		
Heterosexual	7	43%
Homosexual	6	38%
Bisexual	2	13%
Unsure/Questioning	1	6%
Marital Status		
Single	13	81%
Married	1	6%
Divorced	1	6%
Widowed	1	6%
Highest Level of Education		
Some high school or less	5	28%
High School	3	17%
Technical/Vocational	2	11%
Some college or greater	8	44%
Patient HIV/AIDS Status		
Less than 12 months ago	4	22%
1 to 4 years	7	39%
5 to 9 years	3	17%
10 years or more	4	22%
Concurrent HIV/AIDS Diagnosis		
Yes	12	67%
No	6	33%

fear by overemphasizing death. Shawn argued for messages that tell the complete story versus the use of scare tactics

What they see on TV is that people who get it [HIV/AIDS] die. And so I think that goes with statistics that 'this many people die with AIDS.' Well if you communicate how many of these people who didn't take their meds or didn't know they were actually infected, that's going to actually make that list [of deaths] go lower. So if they do it correctly instead of just trying to

scare people...

There were others who felt that reframing the health messages in a more normalizing and empowering manner could reduce stigma and promote HIV testing. For example, several participants associated HIV with other chronic illnesses, for example diabetes and cancer. The sense was these diseases could also result in death; however they are *manageable* diseases. This was articulated by Paul, a Caucasian male, “Just making it known that [HIV/AIDS] it’s not a death sentence. That it’s an attainable condition.” Stated similarly by another Caucasian male, Daniel, “there are a lot of diseases that can kill you, don’t let this one take over your life.”

Table 2: Participant Descriptors with Pseudonyms

Pseudonym	Race	Gender	Sexual Orientation	Year living with
HIV				
Alana	African American	Female	Heterosexual	14 years
Carmen	Caucasian	Female	Heterosexual	3 years
Felicia	African American	Female	Heterosexual	4 years
Jamilia	African American	Female	Heterosexual	1 year
Lorraine	African American	Female	Heterosexual	Uncertain
Melissa	African American	Female	Heterosexual	1 year
Rhonda	African American	Female	Heterosexual	1 year
Tamara	African American	Female	Heterosexual	3 years
Andre	African American	Male	Homosexual	10 years
Alston	African American	Male	Homosexual	13 years
Curtis	African American	Male	Bisexual	10 years
Daniel	Caucasian	Male	Homosexual	10 years
Jeffrey	African American	Male	Homosexual	Uncertain
John	African American	Male	Unsure/Questioning	3 years
Lance	Caucasian	Male	Homosexual	20 years
Nicholas	Caucasian	Male	Homosexual	7 years
Paul	Caucasian	Male	Homosexual	5 years
Perry	Caucasian	Male	Homosexual	4 years
Shawn	African American	Male	Unknown	

Each One Reach One

Personal advocacy was another strategy that participants identified as important for rural and smaller cities. There were some participants who felt they could articulate the importance of early detection by sharing their personal experiences or testimonies, so called ‘*testimonial advocacy*.’ Others mentioned how they could reach people within their own sphere of influence, known as ‘*peer education*.’ For example, Alston stated, “I don’t think I can get no heterosexuals over here [to the Ryan White CARE Clinic]. I could probably get gay people to come, but I don’t know about heterosexuals.” Both examples illustrate their willingness to influence their personal network.

Positively Living Positive

In addition to personal advocacy, several participants advocated for a greater visibility of 'positive' campaigns that publically displays PLWHA in a positive light. Several participants adamantly believed that in order to deflate the negative images associated with PLWHA like, "you're either a sexual degenerate, or you're a drug user," there must be a balance as illustrated in the following quote by Nicholas, a Caucasian male:

There can be a positive campaign too. [Instead of] ... giving statistics and pictures of those who died or dying of HIV or AIDS, let's flip it around [and make it] positive. Show the populations of those who had it or have it, like me, for almost seven years...we're functional. We're proactive. We take our treatment seriously. But we're here, we're living.

The sense that the HIV community could aid in dispelling the myths associated with the supposed 'image' of PLWHA was further articulated by Paul:

"...it's nice to see someone living with HIV who appears to be healthy and living. That's one of the things that I want to do, play a positive role model. So I think that having more visible people who are living healthy and positively will be a good thing."

It Takes a Village

Ongoing outreach to the community at multiple levels was considered crucial to combat the stigma and raise awareness. Tamara, an African American woman expressed "I guess, more people that were HIV positive, could come up and speak, like at different organizations, like churches, like schools and stuff, maybe that could motivate 'em a little bit." There were others who spoke of the urgency to reach both the young and the elderly. For example, Curtis, an African American male, felt that if he had the opportunity to get before young people in schools, he could potentially motivate them to get tested, "You can get some people who are really positive who is living the life that we are living... and let them [youth] see us and get that message from the heart. I bet you they'd go get that test for real.

While there were several who supported the efforts to reach the young by going into schools, Alston suggested reaching out to the elderly. He considered this a necessary strategy to break the cycle of stigma that persists in the rural Bible Belt as conveyed in the quote below:

It starts with the older people. They start everything and it trickle down. They tell their children their ideas. Their children latch on to that cause they don't know nothing else, so they just continue that thought process. Then they go to church, not knowing nothing else and continue it. It just spreads.

As pointed out by previous quotes, the schools and the church were the most frequently mentioned venues to penetrate with accurate information about HIV/AIDS awareness and HIV testing in rural communities. It was apparent that some participants seemed to be aware of the significance of engaging the church in terms of reaching a wide range of people with information. On the other hand, others were cognizant of how some people, including the

church, especially in the Bible Belt have attempted to ignore the severity of the epidemic with silence. Jamilia, an African American female expressed the following:

Getting the word out, stressing it more. It really needs to be in the church... People they try to sweep it under the rug, but this is something we really do need to express more in the church I think.... in order for us to help one another, it got to be put out there and constantly talked about so people can know its serious, its no joke.

Break the Barriers

Eliminating as many of the barriers related to cost, confidentiality, and availability of testing sites was also considered imperative. Access to free HIV testing was regarded as important, in addition, Michelle and Andre, both African American participants, also recommended a door-to-door HIV testing approach. Andre, placed great emphasis on confidentiality, "...individual testing door-to-door where you think HIV high levels might be...it's still confidential. That's the one thing you gotta let people know that it's confidential. And for people who is giving out the result, it has to be confidential."

Paul and Carmen, both Caucasian participants recommended free testing in sites that are more inconspicuous, thus being less stigmatizing. For example, Paul shared:

...maybe offer testing in an environment that...Like with [Local AIDS Service Organization (ASO)], even though it is a pretty anonymous looking building, people still know it's [Local ASO]. Maybe if it were some kind of facility that didn't have a stigma that people could test at.

The health department was also mentioned as a location where HIV testing takes place. However, like the ASO scenario, Paul and Carmen advocated for more generalized locations. Carmen suggested an "open clinic" where people could come to the health department and get tested on a particular day of the month, in a general health 'open clinic' setting. Paul echoed this as suggested in the following:

I think...the hospitals or the general care facility where people won't always think...even the health department, if you go in there you got gonorrhea or something. But if it was something a little more general ..., then by going in there people don't feel as if their being judged...

All in this Together

| _There were a number of participants who believed that even with increased educational resources, advocacy, increased community engagement, and fewer barriers that many people would still remain fearful about learning their HIV status because of the perpetual stigma associated with being HIV positive. Shawn summarized this in the following except:

It's hard to reach people, because for one a lot of people don't want to know, because like I said they think that their life is going to come to an end. And another reason is that they think they are invincible or that if you're not gay you're not going to get it.

In response to the need to eliminate stereotypes and reduce barriers, a few participants considered the normalization of HIV testing for everyone as paramount to combat stigma, thus increasing the number of people who learn their HIV status. There were also a couple of participants who suggested for mandatory testing's as best way to ensure testing. Two participants addressed their concern with messages that overemphasize certain populations as 'at risk'. For example, Curtis, an African America male stated, "We talking about the black community. A lot of races got it, but they stress on us like we really carrying the load. Similarly, Nicholas, a Caucasian male concurred by stating, "at risk populations, of course those demographics change almost weekly..."

Finally, there were a couple of participants who felt that mandatory testing would be the best way as suggested by John, an African American male, "the only way I know definitely is to have it mandatory by law. That's the only way somebody would get tested and to know because it's a health risk and I take my health seriously." Nicholas also offered specific points of entry where the government could intervene in order to de-stigmatize HIV testing in the general population:

...have the government say one of the prerequisite in getting a work permit or a driver's license is to get an HIV test. Before you can get a marriage license, you got to have a HIV test. If one partner is positive and the other one isn't, it has to be disclosed...go into counseling and get medicine started immediately. You know these are areas the government can control definitely.

DISCUSSION

This article sought to explore strategies to reduce HIV-related stigma and promote HIV testing as suggested by PLWHA who reside in rural and small town Georgia. The findings revealed the cultural and contextual barriers that have stifled HIV prevention efforts in this region. It was evident that many of the participants understood the plight of living with HIV in the Deep South. Even with their understanding of the deep-rooted stigma of southern culture as well as their personal experiences coping with stigma, they provided an array of strategies that parallel with current efforts; yet at the same time expose the paradoxes between strategies proposed by the HIV community versus those endorsed by the public health community.

Like the public health community, the findings revealed a strong endorsement for education as the foremost strategy needed to reduce stigma and promote HIV testing. Providing factual information has been a central component of the CDC since the beginning of the epidemic. Yet many people still maintain stigmatizing attitudes and beliefs about the AIDS epidemic (Herek et al., 2002; Lichtenstein, 2005). Consistent with the finding of Herek and colleagues (2002), the PLWHA in this study argued that there must be a greater emphasis on HIV/AIDS education to explicitly debunk erroneous myths about HIV transmission, testing and diagnoses as well as perceptions of people living with the illness to curb AIDS-related stigma.

Although rural communities have scarce funding available to finance educational campaigns

(Whetten & Reif, 2006), efforts could be made at the national level. For example, a lower-cost comprehensive, national prevention strategy employed in the past was mass mailings (i.e. an information-based approach) that provide HIV/AIDS education to all homes in the U.S. (Office of the Surgeon General, 1986). As suggested by the current data, a similar approach could be considered that provides updated information as well as advancements in prevention and treatment (i.e. rapid HIV antibody testing; antiretroviral medications), the changing trends, as well as coupons to encourage people to get tested.

Although over half of the study participants were recent or newly diagnosed within five years; there was a strong sense of advocacy. This is noteworthy because some individuals with HIV may actually resort to social isolation (Myers et al., 2003) or prefer to not discuss the issue. However, several of the study participants were quite vocal about what could be done to stop the spread of HIV in their communities. Like other programs that utilize PLWHA as advocates in the fight against HIV (Palmary, 2000), participants in this study addressed advocacy as a matter of social responsibility (Marks et al., 1999). The discourse regarding advocacy manifested on different levels—testimonial advocacy, peer education, and positive living positively. Each level of advocacy entails educating others about the importance of early detection within their own sphere of influence as well as outreach in the community such as the schools, churches, and even in places of business. Due to the entrenched stigma in rural and small town communities, speaker's bureaus may not be readily available. However, even with the speaker's bureaus provided by ASOs, where PLWHA share their stories with diverse audiences, there is still a lack of social marketing that portrays PLWHA in a positive manner. Research has found that mass media campaigns should be considered in HIV prevention because of the capability to increase knowledge and awareness among large, diverse audiences (Noar, 2007).

Over half of the participants in the study were African American. Although religiosity or church attendance was not measured, it was evident from the responses that many understood the significance of the church in the African American community. Several studies have found that communities with higher levels of religiosity (Lichtenstein et al., 2008) and high church attendance (Lichtenstein, 2005) were more likely to have stigmatizing views toward PLWHA. Interestingly, African Americans who are disproportionately infected with HIV/STI nationally, also have higher church attendance than any other ethnic group (Lichtenstein et al., 2005). These findings are important on two levels. On the one hand, many of the African American participants demonstrated an awareness of the role the church has played in hindering prevention efforts and perpetuating stigma with silence or ostracism (Fullilove & Fullilove, 1999). On the other hand, they did not ignore the pivotal role of the church in terms of its influence on the community, hence strongly recommending the continuous engagement with the church as an important setting and strategy to educate about HIV (Stroman, 2005), reduce stigma, and promote testing (Brown & Hill, 2005). While engaging the clergy and churches in the African American community is not uncommon in urban metropolitan settings, it is imperative that rural African Americans churches become a focal point (Brown & Hill, 2005; Fullilove & Fullilove, 1999; Lichtenstein et al., 2005).

In addition to approaches that are more widely used in HIV prevention efforts, there were also several strategies suggested that may be perceived as paradoxical. Sometimes the health messages intended to promote a behavior can inadvertently be counterproductive. For example, there is a body of research that discusses how fear appeals have been used as a strategy to dissuade certain behaviors (i.e. pictures of sexually transmitted infections) while

other times used to persuade behaviors (i.e. evoke fear of death in hopes of promoting condom use; Devos-Comby & Salovey, 2002; O'Grady, 2006; Slavin, Batrouney, & Murphy, 2007). Similarly, it has been argued that loss-framed messages that may discover a health concern are considered more persuasive compared to gain-messages that are aimed at preventing the onset of a health problem (Apanovitch, McCathy, & Salovey, 2003; Devos-Comby & Salovey, 2002; Rothman, Bartels, Wlaschin, & Salovey, 2006). Despite the empirical literature that endorses the utility of such appeals (Devos-Comby & Salovey, 2002), the general public is less likely to decipher the intended audiences for such messages, thus continuing to perpetuate fear.

In contrast, the participants in this article argued for more visibility of campaigns that actually depict PLWHA in a positive light that is not defined by their status, but by the way they live their life. In fact, the data suggests framing the illness as a chronic condition rather than a fatal disease. As more PLWHA adhere to medication regimens, they are living longer. Studies showed fear-arousing campaigns could actually deter the approximate 42%-59% of PLWHA who are not in care from seeking treatments (KFF, 2007), thus balanced messages that speak of being both preventable yet attainable are more likely to be effective (Devos-Comby & Salovey, 2002).

The results also suggested the use of universal messages that do not foster 'them' versus 'us' binaries (Devine et al., 1999). This is particularly important given the disparity among the races in their HIV testing practices. For example, the KFF (2008) reported that in 2006 approximately 42% of the US population had never been tested. When aggregated by race/ethnicity, 45% versus 24% were Caucasian and African American, respectively. While the results are not to discredit the importance of targeting populations (Devos-Comby & Salovey, 2002) such as African Americans that are disproportionately infected; however, they do suggest that when there is too much emphasis placed on one population, it can inadvertently instill a false sense of security to others (Marks, Burris, & Peterman, 1999).

Other paradoxical strategies suggested were centered on the normalization of HIV testing. While ASO's and health departments often receive funding to promote and provide HIV antibody testing (Grusky et al., 2005), both entities were perceived as stigmatizing institutions (Lichtenstein, 2005). The current data suggests offering HIV testing in a health department within an 'Open Clinic' with trained staff that provides a variety of health services for the general population may be considered less stigmatizing than having to be screened for HIV in an STI clinic. In addition, current data revealed the importance of confidentiality as crucial to promoting HIV testing, and anonymity as the key factor to reduce stigma. While confidential testing is preferred by providers for tracking purposes (Grusky et al., 2005), the findings suggest that rural and small towns residents are more likely to seek testing if they are 1) free, 2) anonymous, 3) offered in inconspicuous locations, and 4) with a strong regard for confidentiality.

Outreach efforts, such as door-to-door individual testing, could be extended to neighborhoods in order to address barriers to confidentiality (Brown & Hill, 2005) as well as access issues. For rural and small towns communities where there is a fear of being 'outed' to friends and family if spotted in certain settings, this approach may be plausible to reduce stigma and promote testing.

The final strategy suggested to advance the normalization of HIV testing was the 'quasi-mandatory' approach, which to some may be perceived as controversial. With all the benefits

of VCT, there are still approximately 250,000 people unaware of their status (KFF, 2008). Although efforts to normalize HIV testing in health-care settings have been put in place (Branson et al., 2006), the need to implement other governmental regulated 'opt-out' testing policies in non-medical facilities is important. While some consider mandatory or government regulated testing policies as 'punitive' (Herek et al., 2002) there are others who suggest making such practices normative. For example, Herek et al. (2002) suggest that the support for 'punitive' testing policies is an infringement on the human rights of PLWHA masked "under the guise of protecting public health" (p.376). Ironically, while the participants in Herek and colleagues' study may have been motivated by stigmatizing attitudes to endorse mandatory testing, a few PLWHA in the present article recognize the benefits in requiring regular HIV testing as a normative practice to 1) reduce HIV-related stigma, 2) help to identify the 25% who are unaware of their HIV status, and 3) decrease the spread of HIV. The premise for such approaches is that it reduces stigma if everyone, regardless of risk level, has to go through the same process at some point.

Although the findings from this study are both informative and provocative, there are a few limitations that should be recognized. Firstly, while this article does acknowledge and empower the voices of PLWHA in a segment of a non-urban, mid-size city in Georgia, it does not fully reflect the diversity of the rural Deep South. For instance, all the participants were clients of one clinic serving low-income patients from surrounding non-metropolitan/rural counties in Georgia. Secondly, the recommendations represent the voices of PLWHA who are currently receiving services. Therefore, additional research is needed to gather the perspectives of PLWHA who are not in care.

In conclusion, the strategies recommended by the PLWHA in this article came out of a place of private anguish and public advocacy. While there was acknowledgement of current efforts that have proven effective in other regions, it was also apparent that the participants wanted to challenge the public health community to find alternative ways to 1) tailor effective urban approaches for rural areas, 2) normalize rather than stigmatize, and 3) convey balanced messages of disease prevention alongside disease management. Seeing that the issues of HIV-related stigma in the Deep South are convoluted and difficult to tackle, it is imperative for the public health community to continue to hear the perspectives from PLWHA and develop culturally responsive strategies to reduce stigma and encourage HIV testing.

REFERENCES

- Apanovitch, A., McCathy, D., & Salovey, P. (2003). Using message framing to motivate HIV testing among low-income ethnic minority women. *Health Psychology, 22*, 60-67.
- Bond, L., Lauby, J., & Batson, H. (2005). HIV testing and the role of individual- and structural-level barriers and facilitators. *AIDS Care, 17*, 125-140.
- Bowen, A., Gambrell, A., & DeCarlo, P. (2006). What are rural HIV prevention needs? *Center for AIDS Research Studies*. Retrieved November 21, 2007, from <http://www.caps.ucsf.edu/pubs/FS/pdf/revruralFS.pdf>
- Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W., Lyss, S. B. et al. (2006). Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings. *Morbidity and Mortality Weekly Report, 55*, 1-18.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.
- Brown, E. J., & Hill, M. A. (2005). Perceptions of HIV risks and prevention strategies by rural and small city African American who use cocaine: Views from the inside. *Issues in Mental Health Nursing, 26*, 359-377.
- Brown, L., Macintyre, K., & Trujillo L. (2003). Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention, 15*, 49-69.
- Chesney, M. A., & Smith, A. W. (1999). Critical delays in HIV testing and care: The potential role of stigma. *American Behavioral Scientist, 42*, 1162-1174.
- Devine, P. G., Plant, E. A., & Harrison, K. (1999). The problem of "us" versus "them" and AIDS stigma. *American Behavioral Scientist, 42*, 1212-1228.
- Devos-Comby, L., & Salovey, P. (2002). Applying persuasion strategies to alter HIV-relevant thoughts and behavior. *Review of General Psychology, 6*, 287-304.
- Fullilove, M. T., & Fullilove, R., E. (1999). Stigma as an obstacle to AIDS Action: The case of the African American community. *American Behavioral Scientist, 42*, 1117-1129.
- Georgia Department of Human Resources. (February 2008). AIDS in Georgia: Fact Sheet. Retrieved July 10, 2008 from http://dhr.georgia.gov/DHR/DHR_FactSheets/2008%20AIDS%20in%20GA%20Fact%20Sheet.pdf
- Greene, K., & Banerjee, S. (2006). Disease-related stigma: Comparing predictors of AIDS and cancer stigma. *Journal of Homosexuality, 50*, 185-209.
- Grusky, O., Roberts, K. J., Swanson, A. M., Joniak, E., Leich, J., McEvoy, G., et al. (2005). Anonymous versus Confidential HIV Testing: Client and provider decision making under uncertainty. *AIDS Patient Care and STDs, 19*, 157-166.
- Herek, G., Capitanio, J. P., & Widaman, K. F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. *American Journal of Public Health, 92*, 371-377.
- Kaiser Family Foundation. (June 2007). HIV testing in the United States. Retrieved November 21, 2007, from <http://www.kff.org/hivaids/upload/6094-06.pdf>
- Kaiser Family Foundation. (June 2008). HIV testing in the United States. Retrieved July 10, 2008 from http://www.kff.org/hivaids/upload/6094_07.pdf
- Lichtenstein, B. (2005). Stigma as a barrier to HIV prevention in the rural Deep South: Fact Sheet. *Rural Center for AIDS/STD Prevention, 16*, 1-4.

- Lichtenstein, B., Hook, E. W., & Sharma, A. K. (2005). Public tolerance, private pain: Stigma and sexually transmitted infections in the American Deep South. *Culture, Health & Sexuality*, 7, 43-57.
- Lichtenstein, B., Neal, T. M., & Brodsky, S. L. (2008). The stigma of sexually transmitted infections: Knowledge, attitudes, and an educationally-based intervention. *The Health Education Monographs* 2008; 25:28-33.
- Marks, G., Burris, S., & Peterman, T. A. (1999). Reducing sexual transmission of HIV from those who know they are infected: The need for personal and collective responsibility. *AIDS*, 13, 297-306.
- Myers, T., Worthington, C., Haubrich, D. J., Ryder, K., & Calzavara, L. (2003). HIV testing and counseling: Test providers' experiences of best practices. *AIDS Education and Prevention*, 15, 309-319.
- Noar, S. (2007). HIV/AIDS mass media: Fact Sheet. *Rural Center for AIDS/STD Prevention*. 20, 1-2.
- O'Grady, M. (2006). Just inducing fear of HIV/AIDS is not just. *Journal of Health Communication*, 11, 261-267.
- Office of the Surgeon General. (1986). The surgeon general's report on acquired immune deficiency syndrome. Retrieved March 17, 2008, from <http://http://profiles.nlm.nih.gov/NN/B/B/V/N/>
- Palmary, I. (2000). The beyond awareness campaign's living openly project: A qualitative evaluation. HIV/AIDS and STD Directorate Department of Health, 1-21.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods*, 3rd Edition. Thousand Oaks: Sage, , p.14.
- Reif, S., Geonotti, K., & Whetten, K. (2005). HIV Infection and AIDS in the Deep South. *American Journal of Public Health*, 96, 970-973.
- Rothman, A. J., Bartels, R. D., Wlaschin, J., & Salovey P. The strategic use of gain- and loss-framed messages to promote healthy behavior: How theory can inform practice. *Journal of Communication*, 56, S202-S220.
- Slavin, S., Batrouney, D., & Murphy, D. (2007). Fear appeals and treatment side-effects: An effective combination for HIV prevention? *AIDS Care*, 19, 130-137.
- Stroman, C. (2005). Disseminating HIV/AIDS information to African Americans. *Journal of Health Care for the Poor and Underserved*, 32, 24-37.
- Whetten, K., & Reif, S. (2006). Overview: HIV/AIDS in the Deep South region of the United States. *AIDS Care*, 18, S1-S5.

i CORRESPONDING AUTHOR:

Department of Health Promotion and Behavior, College of Public Health
The University of Georgia
300 River Road, 309 Ramsey Center,
Athens, GA 30602
Email: shou@uga.edu, Phone: 706-542-8206, Fax: 706-542-4956