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Title: HIV-positive African American women's perspectives on engaging communities in the response to HIV/AIDS in Washington, D.C.

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Anne Sanicki 6015 24th Ave Northwest, #208 Seattle, WA 98107 asanicki@gmail.com +1.360.932.7097 **Title:** HIV-positive African American women's perspectives on engaging communities in the response to HIV/AIDS in Washington, D.C.

Abstract

The number of African American women infected with HIV in Washington, D.C. is growing at an alarming rate. However, the perspectives of these women on engaging communities in the response to HIV/AIDS have been lacking in the literature. To fill this gap, in-depth interviews with 18 HIV-positive African American women living in D.C. were conducted and analyzed using thematic network analysis. Three key themes emerged from these interview: (1) the importance of the church in building HIV/AIDS community competence; (2) women's interest in HIV/AIDS advocacy; and, (3) the negative effects of stigma and limited social bonds on community engagement. We conclude by suggesting that more research is needed on the role of African American women in community capacity building, as well as greater involvement of churches in HIV/AIDS responses.

Key words: 'AIDS competent community', African American women, HIV/AIDS, Washington, D.C., community coping strategies, church, stigma, social bonding

Introduction

Washington, D.C. (D.C) has one of the highest rates of HIV/AIDS in the world with 3% of the population infected, and African Americans account for 75% of the total HIV infections in the city (District of Columbia Department of Health, 2010). Rates of HIV/AIDS for African American women in D.C. doubled from 2010 to 2012, reaching 12.1% (District of Columbia Department of Health, 2012). This paper intends to build understanding on how African American communities cope with HIV/AIDS in D.C. with the aim of improving the delivery of relevant community services. It does this by exploring African American women's perspectives on engaging communities in addressing the needs of those living with HIV/AIDS.

The importance of addressing HIV/AIDS at the community level, rather than an individual level, has been repeatedly demonstrated (Aveling, 2010; Campbell & MacPhail, 2002; Kippax et al., 2013). Grassroots interventions in marginalized communities began at the beginning of the AIDS epidemic in the early 1980s (Arno, 1986; Shilts, 2007; Wyatt et al., 2013). Many community-level responses to HIV/AIDS in African American communities implemented by the government and community agencies have lacked adequate cultural competency, not taking into account how centuries of oppression still affect social systems (Hecht, 2003). African Americans have reported a lack of trust in the government. Their social identities, patterns of communication, and sexual norms have been and are being formed in an environment of mistrust (Parsons & Simmons, 1999; Wyatt, 2009). This structural oppression has not been adequately addressed by government strategies, which are often applied with little regard to population context (Wolde-Yohannes, 2012).

Strategies that do target African American communities include prevention, testing, behavioral interventions, schemes linking diagnosed people to care, and peer advocacy (Harmon et al., 2013; Latkin et al., 2003; Sapiano et al., 2013; "Strategy in Action," 2013). Group-level, cognitive-based, active coping strategies that emphasize self-efficacy have been shown to be effective in decreasing depression in HIV-positive African Americans (Cruess et al., 2002; Jones et al., 2010). Church-based interventions have also been implemented with mixed results. Churches can be supportive, empowering spaces for HIV-positive people; alternatively, they can increase HIV/AIDS stigma (Griffith et al., 2010; Hickman, 2012; Nunn et al., 2012; Wilson, 2000; Wilson et al., 2011).

Perspectives of African American women are key to understanding efforts to engage communities in the response to HIV/AIDS in D.C. for two main reasons. First, high incarceration rates of African American men mean that women are more likely to consistently be present in communities. Nearly 75% of African American men in D.C. will be imprisoned during their lifetime (Alexander, 2011). It is estimated that in certain D.C. neighborhoods there are almost 40% less men than women living there at any given time (Harawa & Adimora, 2008). Second, African American women living with HIV are at the apex of overlapping social inequalities, including race, class, and gender. There has been a lack of recognition of these intersecting forces in HIV/AIDS strategies targeting African American women (El-Bassel et al., 2009). With the aim of informing and improving delivery of community services, this study asks the following question: what can be drawn from HIV-positive African American women's perspectives on community engagement to inform the development of more 'AIDS competent communities' in D.C.?

Theoretical Framework

We draw on Campbell's (2007) notion of 'AIDS competent communities,' which provides a framework for exploring how the psychosocial dynamics of communities foster HIV/AIDS resilience in marginalized settings. We define communities as groups of individuals that have come together because of a shared cultural understanding or common experience (Campbell et al., 2007). Communities build resilience to HIV/AIDS by providing an opportunity to renegotiate social identities, decrease stigma and discrimination, and collectively address the social inequalities that impact their health and well-being (Campbell et al., 2007). Fostering community competence in the face of HIV/AIDS requires connecting communities to these receptive social spaces, and engaging outside actors with the power to improve health services (Campbell & Scott, 2012; Campbell & Cornish, 2010). This paper examines the enablers and barriers for this type of community engagement from the perspective of African American women living with HIV/AIDS in D.C.

The 'AIDS competent community' framework that we draw on in this paper incorporates six facets of community building that should be generated at the community-level, with partnerships and connections made to outside change agents and receptive social actors with power to affect community health. The framework includes: (1) increasing community HIV/AIDS knowledge; (2) creating safe spaces for dialogue about HIV/AIDS; (3) promoting community ownership of the epidemic, while acknowledging the role of power in appropriating the disease; (4) building confidence in community strengths; (5) generating solidarity within the community; and (6) bridging relationships to outside actors and receptive social spaces, and connecting to partners who have power to affect social change (Campbell et al., 2007, Campbell & Skovdal, 2012, Campbell & Scott, 2012; Putnam, 2000).

Methods

The research design and implementation were grounded in a social constructionist approach (Burr, 1995). A review of the literature informed the creation of the interview topic guide, which contained three subject areas: participation, community, and 'AIDS competent community.'

Semi-structured interviews were conducted with 18 women at a D.C. based social service agency working with African American women living with HIV/AIDS. All participants were HIV-positive African American women and clients of the agency, and their ages ranged from early 20s to late 50s. The interviews averaged 44 minutes in length, and took place in April 2013 at the agency's office. Saturation was reached based on the variety and depth of responses, and the patterns and repetition emerging from the data (Gaskell, 2000).

Interviews were transcribed verbatim and uploaded into Atlas.ti. The transcripts were then coded by blending both inductive and deductive analysis (Braun & Clarke, 2006). The 60 codes that came out of the transcripts were refined and merged multiple times, then used as the building blocks of Attride-Stirling's (2001) thematic network analysis, which tiers codes into basic, organizing, and global themes. The analysis produced 31 basic themes from this data that were then grouped into 13 organizing themes, which then formed three overarching, global themes. This paper will discuss this analysis through the lens of the 'AIDS competent community,' looking at how these themes illustrate African American women's perceptions of HIV/AIDS community competence (Skovdal & Andreouli, 2011).

Findings & Discussion

Three themes about community engagement emerged from the interviews: (1) the importance of the church in building HIV/AIDS community competency; (2) women's interest in advocating for HIV/AIDS; and, (3) the limits of social bonding and a lack of trust in relationships. Each of these themes shows potential for increasing community competency on HIV/AIDS.

The Church's Role in African American Women's Daily Lives

Every participant in the sample mentioned her relationship with her church, and all reportedly attended services regularly. Participants identified the church as a neighborhood presence. As one participant explained, she does not connect churches to being a site for HIV/AIDS services, but does recognize that churches are placed throughout communities. She said:

In order to get the community, you are going to have to branch out and reach the churches (P06).

Participants identified the need for greater church involvement in HIV/AIDS. Churches often take on multiple roles in communities. They have the potential to be spaces for critical dialogue on HIV/AIDS. Churches can be sites to develop competence and act as receptive social spaces because of the power they may already hold in the community (Moore et al., 2012).

Additionally, churches can increase HIV/AIDS community-level knowledge in people that are not traditionally targeted for HIV/AIDS programming. Churches can function as a type of organizational "boundary crosser" to reach a greater cross-section of communities. They may be established community entities, with staff that have an understanding the local context and the trust of their congregations and communities (Kilpatrick et al., 2009). Churches could legitimize and normalize HIV/AIDS knowledge and discourse for parishioners and engage more of the community in mobilizing to combat HIV/AIDS. Some churches were identified by participants as safe spaces for supportive discussions, providing counseling and psychosocial support. Another participant describes one of these churches:

In southeast there is a marvelous church that houses an HIV organization...that's a safe space to talk about that. I think there are a few other churches there that have active HIV ministries, safe spaces there to discuss those issues (P18).

This participant described this church as a site of open discussion for people to gather, share, and find comfort. Some churches have the potential to be that kind of safe space for discourse. Mattis' (2002) study of the role of religion and spirituality in African American women's coping strategies found their faith made them feel stronger in confronting the realities of their lives. This strength from faith could be bridged through church involvement to facilitate conversations that connect supportive discussion to critical dialogue (Mattis, 2002).

Conversely, participants did identify barriers to churches facilitating 'AIDS competent communities.' Women identified tensions between church doctrine and supporting people living with HIV/AIDS (PLWHA):

A lot of religions look at it like you were promiscuous, you made your bed you laid in it, so that's what you got, and in a way that's how I see the pastor (P09).

This difficulty comes from some Christian denominations preaching against sex outside of marriage and against homosexuality. Church engagement with HIV/AIDS could generate or

perpetuate existing HIV/AIDS stigma in the community. Treating HIV/AIDS as punishment for people's actions negatively affects the social bonding necessary for building 'AIDS competent communities,' and may be divisive (Nunn et al., 2012).

Clergy attitudes were mentioned by some of the women as a barrier to church involvement in HIV/AIDS:

...I went to the churchwoman, and I said...you're trying to save your church...a good way to do that is through outreach. And I'm saying outreach with anybody. Has no gender or anything. Homosexual, fine, whatever...She ran it by the pastor, and the pastor shut her down. And he shut her down because he heard the three letters came out—HIV (P04).

The pastor suppressed the participant's attempt to introduce HIV/AIDS services to her church. This woman's attempt to help her community was rejected, which has the potential to discourage her from further action.

Perceptions of Participation in Advocacy

Participants reported high levels of HIV/AIDS biomedical knowledge, which fulfills the first element of the 'AIDS competent community' framework. All participants were active clients at the agency and most had been aware of their status for at least ten years. Multiple respondents felt HIV/AIDS knowledge should influence behavior, with one respondent saying:

Once you know something you know something, and you're held accountable for the knowledge that you have (P05).

This focus on individual behavior change misses the effects of community determinants of health (Campbell et al., 2007; Ogden, 2012).

Some respondents identified social oppression based on race, connecting race and class to a lack of affordable housing. Further, participants spoke about the challenges of coming to terms with these lived social realities. Two of these participants observed:

Right now, without a voucher, it would cost \$1200 to live in a twobedroom apartment in my building. Who has that? White people with good pockets (P04).

[Women who participate in advocacy] already understand the reality, but the ones that don't, they not ready to know to understand it ...they aren't ready to understand what is really going on (P13).

This participant suggests that coming to terms with reality and being able to discuss issues is a process (Yang et al., 2007). These connections are demonstrative of Paulo Freire's (1974/2005) conceptualization of the development of critical consciousness, connecting race to access. This connection can fuel the critical dialogue necessary for building 'AIDS competent communities.'

However, participants did cite a lack of community space for these discussions. The agency was identified as one of the only safe spaces for open discussion. One woman said:

Here...you know I'm HIV-positive, and you can feel normal...you can just be yourself (P05).

The agency holds weekly support groups for clients and monthly client advocacy meetings, which half of the sample had or regularly attended. Other participants prioritized their psychosocial well being over engaging in advocacy. With limited time and resources, some chose to attend support groups instead of advocacy meetings.

Building on this support, participants reported confidence that extended into other areas of their lives:

You have a lot more confidence in yourself because of the small community that you're in and how stabilized and how comfortable you feel there, so then you feel more comfortable outside of that realm (P05).

This shows the high value placed on the support gained from being part of the community. Confidence fueled by their participation at the agency could increase overall community HIV/AIDS competence.

Multiple respondents felt a responsibility to advocate as an HIV-positive woman. This participant wanted to say to outside actors:

I need you to hear me...this is what I'm going through, I'm not the only one, but I'm speaking for 20 other women behind me who don't have the guts (P01).

This participant expressed the need to not only have her story be heard, but took responsibility and ownership as a spokeswoman for other HIV-positive African American women who may not have the means to advocate for themselves. Further, participants expressed a desire to build a stronger collective voice, which could be used to reach to influential, outside actors. There was also a sense from those that discussed advocating for social issues that there was:

Not enough critical mass to force these outside agencies who have impact on our lives to make a change (P18).

While the limitations of this bonding and marginalized group cohesion will be discussed in the next section, participants also placed value on these connections in building agency.

Lack of Trust in Relationships

Social bonding is an integral part of building community responses to HIV/AIDS (Campbell & Cornish, 2010). Participants identified both the benefits and limitations on social bonding. They reported that both levels of HIV/AIDS knowledge and social spaces for critical discourse are limited outside the agency, churches, and other social service organizations. Participants also identified contributing issues that deter community discussion such as drug use, violence, and a lack of motivation to engage in community building. These barriers to safe spaces for discussion limit social bonding because direct communication is needed to create social bonds (Campbell et al., 2002; Putnam, 2000).

A lack of trust in relationships was reported. Participants frequently discussed this in terms of intimate partner relationships and gender norms. A few participants cited contracting HIV from having unprotected sex with a partner who knew about his HIV-positive status. Men were described as deceitful with uncontrollable sexual desires and little concern about unprotected sex, no matter either partner's HIV status. A participant said:

Men supposed to be our strength, our somewhat leaders...I had told men I have HIV, they don't care. They don't care. As long as they can get what they want, they don't care. As long as you can look the part, play the part. They don't care (P12).

Describing boundless male sexual desire and lumping all men together as recklessly spreading HIV/AIDS is divisive and does not support community cohesion (Mane & Aggleton, 2001). This could hamper community solidarity and limit community competence on HIV/AIDS.

Interpersonal conflicts and lack of trust in other women at the agency were also reported. While these claims were from a minority of the sample, with the majority citing the 'sisterhood,' these show that simply because they are all African American women with HIV does not mean they will bond together in solidarity. As this participant said:

HIV is the common denominator, but I'm an individual, so you have to treat me and my HIV individually (P01).

Her statement identifies the tension between generating strength through collective voice, while still having her particular needs addressed.

Stigma and denial of the HIV/AIDS epidemic in their communities outside of the agency came up time and again. One participant said:

It's like, you gonna pray that I don't have it, but what would I do if I did come up positive. Communities are afraid to know and I really think that is the issue, they really don't wanna know (P09).

While community-level denial and stigma was mentioned by most of the women, the overwhelming majority of participants said they themselves are open about their HIV status outside of the agency. Overall community-level denial of HIV/AIDS can limit social bonding. Silence can imply shame about HIV/AIDS and fear of discrimination against PLWHA, which can perpetuate internal and external stigma. This community-wide denial is a major barrier to creating more competent communities and stymies all of the strategies in the 'AIDS competent community' framework.

Conclusions

Overall, the findings of this study show that one of the primary challenges to building communities that effectively advocate on HIV/AIDS is generating participation and commitment beyond meeting attendance. The community competency framework used in analyzing these interviews with African American women outlines a key method for confronting this challenge in the D.C. context. A foundation of trust needs to be built through dialogue and the development of the networks of communication and support that build women's confidence in participating in critical discourse and advocacy. Secondly, social bonding within the group needs to be leveraged to engage outside actors with the power to influence community health. The social bonding occurring within agencies and churches provides a potential means of making connections between African American communities and influential community health stakeholders, including government. Moving forward, there needs to be more research on the relationship between churches and HIV/AIDS to tap the potential of these institutions.

However, these efforts only involve a portion of the community. This study only includes those women with access and engagement in services, which is not representative of the African American community in D.C. Additionally, even with limited access to community involvement,

men's perceptions and involvement in this process are necessary to building HIV/AIDS community competency. Focusing on church participation as a means of building community responses to HIV/AIDS may also limit the potential for greater community bonding, excluding those that are not active in these organizations.

The insights gathered in this project can be useful in updating 'AIDS competent community' strategies in D.C. and potentially be adapted into other contexts. The value of the perspectives of the women in this study cannot be overstated. They contextualize the realities of living as an African American woman with HIV/AIDS in D.C. and their insights have revealed potential for increasing community competency through building upon an established collective voice. Moving forward, these viewpoints need to be included and reflected in practice to best facilitate more health-enabling contexts in these communities, and to ultimately lower the rates of HIV/AIDS, improving health and lives. (3,126 WORDS)

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