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How Women Living with HIV (WLWH) Respond to and Manage HIV-Related Stigma

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California State University, East Bay
2017

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A thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of

Master of Public Health in Hubert Department of Global Health

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Abstract

How Women Living with HIV (WLWH) Respond to and Manage HIV-Related Stigma

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Background. HIV-related stigma interventions for people living with HIV in the United States focus largely on coping, disclosure, social support, and adherence self-management skills. Women are disproportionately impacted by HIV-related and intersectional stigma. Few interventions focus on effective stigma response and management strategies currently used by women living with HIV (WLWH).

Objective. To understand how WLWH respond to and manage HIV-related stigma in order to inform intervention development.

Methods. Between June and December 2015, 76 qualitative interviews focusing on HIV-stigma were conducted among WLWH in San Francisco, CA, Atlanta, GA, Jackson, MS, and Birmingham, AL. Interviews were recorded, transcribed, and coded thematically to elucidate and categorize strategies for responding to stigma.

Results. We identified four strategies: (1) HIV education: women provided information about HIV transmission and living with HIV to family members, friends, and the community, to dispel misconceptions; (2) Selecting Relationships: women built relationships with people who provided non-judgmental, affirming support, and physically removed themselves from people they identified as negative, including those who perpetuate HIV-related stigma; (3) Resistance: women advocated for themselves or other WLWH by responding to experienced stigma with assertive language or behavior; and (4) Disclosure: some women avoided HIV-related stigma by choosing to not inform others of their HIV status.

Conclusion. Further research should examine the relative utility of these, and other strategies used by WLWH for responding to and managing HIV-stigma. These approaches to addressing stigma may be leveraged in stigma reduction interventions to achieve greater equity and better health outcomes for WLWH.

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Chapter 1: Review of Literature

Background and Significance of Stigma:

Stigma and Health

Stigma has previously been defined as the "social process [in which] individuals with socially undesirable attributes or identities are seen as having lower social value than others and as a consequence face prejudice and discrimination" (B. Turan et al., 2017). There are several types of stigma including enacted stigma (experiences of discrimination and prejudice from others), perceived stigma (individual perceptions of stigma within a community), internalized stigma (having negative beliefs of themselves as a result of experienced feelings like blame and shame), and anticipated stigma (belief that others will treat them differently because of disease status) (B. Turan et al., 2017). In recent stigma research the concept of intersectional stigma, stigma based on other aspects of identity like gender, race, class, and sexual orientation, has been identified as another form of stigma that can function in the presence of other types of stigma (B. Turan et al., 2017). Intersectional stigma considers how these factors function together, as a form of oppression, opposed to separately in relation to health conditions (Logie, James, Tharao, & Loutfy, 2011). Addressing stigma from this lens provides a comprehensive perspective in addressing health disparities that disproportionately impact underserved and marginalized communities (Logie et al., 2011; J. M. Turan et al., 2019).

Additionally, stigma impacts health at multiple socio-ecological levels, specifically at the individual, interpersonal, community, and structural levels. Individual level factors include personal attitudes, thoughts and beliefs that impact health outcomes (Fletcher et al., 2016). Interpersonal factors can function within relationships as social support and social dynamics that impact health behavior (B. Turan et al., 2017). An example of this could be non-disclosure of one's disease status to others to avoid anticipated or perceived stigma (B. Turan et al., 2017). Social networks at the community level and discriminatory policies, programs and laws at the structural level can impact health behavior and facilitate stigma (Fletcher et al., 2016; Moloney, Brown, Ciciurkaite, & Foley, 2019). At the macro level, structural stigma can impact marginalized communities through unequal and inequitable access to services, resources, and opportunities (B. Turan et al., 2017).

Frameworks have since been developed to address the role and function of health-related stigma at these various levels. Stangl et al. (2019) developed *The Health Stigma and Discrimination Framework* addressing the health and social impacts of stigmatization across the socio-ecological model while considering both health-related and other intersecting stigmas such as those based on race, gender, class, sexual orientation and poverty. The framework is broken down into three main areas: (1) drivers and facilitators, factors that can be viewed as negative or positive depending on circumstance; (2) stigma marking, the application of stigma on specific groups based on disease status or other differences such as gender, race, class, etc.; and (3) stigma manifestation, resulting in experienced stigma and discrimination (Stangl et al., 2019). All of these categories lead to health outcomes that directly impact marginalized communities. The authors note that this framework ideally should be utilized prior to stigmatizing experiences as a prevention strategy, however, once stigma has been enacted the focus needs to shift to mitigating and reducing stigma (Stangl et al., 2019). In the context of HIV-related stigma, this framework could be applied in addressing drivers such as perceived risky behavior and fear of transmission that are reinforced by current laws and criminalization of HIV among different groups such as men who have sex with men (MSM) and people who inject drugs (PWID) (Stangl et al., 2019).

Stigma Impact on Population Health

Stigma has been identified as a barrier to seeking out health care services and social support. Link and Phelan (2006) identify five ways in which stigma functions within public health including: identifying differences between groups of people, stereotyping, creating separation between groups, discrimination, and exerting power over others. They also note that when each of these domains function together there is an impact on an individual's overall well-being (Link & Phelan, 2006). Additionally, once a disease has been identified as undesirable, the impact of disease-associated stigma in conjunction with other factors like race, age and socioeconomic status can be detrimental at both the individual and communal levels (Link & Phelan, 2006).

Stigma Impact on Women Living with HIV (WLWH)

HIV-related stigma impacts women living with HIV (WLWH) at the individual, interpersonal, communal and structural levels, often manifesting in forms of oppression and discrimination. The psychological impact of social stigma can be detrimental to mental health, self-esteem, and overall well-being for WLWH (W. S. Rice et al., 2018). Mental health conditions like depression have been identified as mediators to HIV-related stigma with disengagement and isolation from others as a means to cope with stigma (Rueda et al., 2016). Lack of social support has been identified as facilitator of HIV-related stigma for women; and women experiencing lack of social agency and feeling unvalued by society may experience more perceived and internalized HIV-related stigma (Cuca et al., 2017). Social stigma directly impacts

WLWH in which they are sometimes rejected by family and friends after disclosing their HIV status (Kontomanolis, Michalopoulos, Gkasdaris, & Fasoulakis, 2017).

For women of color, HIV-related stigma can manifest in forms of microaggression and stereotypes, especially for women who come from underrepresented and marginalized backgrounds. Women are often blamed for their HIV diagnoses due to misconceptions (about HIV transmission and community perceptions of HIV), resulting in discrimination in both health care and personal settings (Sangaramoorthy, Jamison, & Dyer, 2017). Literature suggests that factors like age, race and ethnicity, and built environment impact women's perceptions of stigma and discrimination (Sangaramoorthy et al., 2017). For Black women living with HIV, existing stereotypes about promiscuity and excessive substance use and addiction reinforce these manifestations and have a direct impact on health care seeking behavior and finding support from others (Sangaramoorthy et al., 2017).

Approaches to Addressing HIV-Related Stigma:

There has been significant progress in assessing and addressing HIV-related stigma globally, however, gaps still exist. Stangl, Lloyd, Brady, Holland, and Baral (2013) conducted a systematic literature review of various strategies and approaches to address HIV-related stigma, finding that the majority of studies focus on stigma reduction (removing or relieving socio-ecological factors that impact health outcomes) rather than stigma management (acknowledging and regulating stigma perceptions from others and oneself). Target populations often include health care workers, students, and community members (Stangl et al., 2013). Few interventions focus on key populations for fighting the HIV epidemic such as WLWH. Most interventions utilize skill and information-based strategies to reduce HIV-related stigma targeting primarily at individual and interpersonal levels while community-based interventions focus on understanding perceptions (Mannell, Cornish, & Russell, 2014; Stangl et al., 2013). Although many studies reported seeing a reduction in stigma post-intervention, the majority of the scales that were utilized to measure change in stigma over time are un-validated. Additionally, current validated HIV-related stigma scales focus primarily on one domain such as drivers of stigma (ex: fear of infection) rather than assessing stigma from a multifaceted, intersectional lens (Stangl et al., 2013). Although interventions focus on removing drivers and facilitators of stigma, there are additional factors that cannot always be accounted for such as structural components. As a result, there has been a push to look at various stigma domains at the same time. To fully understand how stigma impacts individual and population-level health, intersectional stigma must be incorporated into interventions and stigma reduction strategies (W. S. Rice et al., 2018; Stangl et al., 2019).

Existing Stigma Interventions for WLWH:

Current HIV-related stigma interventions for women globally and in the United States offer strategies on reducing stigma at individual and community levels. One intervention conducted in Southeast Nigeria assessed whether creating peer support groups for PLWH (majority women) within a health care setting would aid in reducing self-stigma and increasing social support. Study activities took place over the course of one month and compared people who participated in support groups to those who did not. They found that there were minimal differences in self-stigma and disclosure patterns between persons in the non-peer and peer support groups, however, socioeconomic status differed greatly in which individuals of a lower status experienced greater stigmatization compared to those of a higher status (Chime, Arinze-Onyia, & Ossai, 2019). This suggests that future HIV-related stigma interventions may need to address structural factors in conjunction with individual and interpersonal factors.

A mixed-methods study was conducted to assess the impact of community centered hubs in health care facilities for HIV stigma reduction among adults in North West Province, South Africa (Prinsloo, Greeff, Kruger, & Khumalo, 2017). The intervention lasted five months during which study participants were exposed to HIV stigma theory, how stigma functions and manifests and how to cope when experiencing HIV-related stigma (Prinsloo et al., 2017). At the close of the study they found there was a slight decrease in HIV-related stigma at the interpersonal and community levels, however, these findings were not significant (Prinsloo et al., 2017).

A study by (Barroso et al., 2014) found that sharing common experiences among Black WLWH living in the Deep South an advantageous strategy in reducing stigma and building resiliency among women. Women were given iPods and were expected to listen to stories and reflections of other WLWH including experiences surrounding disclosure, acceptance of their status and engaging with health care providers and other clinical staff over the course of 90 days. After the intervention, they found that women felt a personal connection with the stories and improved their self-efficacy including disclosing their HIV status to family and friends for the first time (Barroso et al., 2014).

Importance of Stigma Management:

Stigma management has been described as “a proactive and intentional [way of] controlling others’ understanding of a stigmatized condition” (Moloney et al., 2019). Meisenbach (2010) proposes the Stigma Management Communication (SMC) theory focusing on the acceptance and denial of existing stigma based on an individual’s identity. SMC theory has three propositions: (1) forms of stigma exist based on perceptions of people who both enact and experience stigma, (2) stigmas can change over time, and (3) stigma severity can vary based on circumstance (Meisenbach, 2010).

The SMC typology also introduces stigma management strategies including: acceptance, stigmatized persons acknowledging and accepting the existence of stigma and how it may apply to them; avoidance, passively distancing oneself from stigmatizing experiences; evading responsibility, deflecting or changing public opinion of stigma; reducing offensiveness, wanting to change stigma perceptions of others though sub-strategies like refocusing or minimizing stigma; and denial, ignoring stigma's applicability to oneself (Meisenbach, 2010). A study conducted in Boston and Washington, D.C. focusing on disclosure stigma management of women with disabilities in the workplace found management of identity (related to disability and other factors like age and ethnicity) as a way to counteract stereotyping played an integral role in self-preservation when experiencing stigma (Moloney et al., 2019). Additionally, a study from New York assessed how heterosexual, serodiscorant couples manage HIV-related stigma. They found that anticipated and experienced stigma exists for both the partner living with HIV and the HIV-negative partner (Siegel, Meunier, & Lekas, 2018). The identified stigma management strategies identified were educating family and friends about HIV transmission misconceptions, seeking support outside of their immediate social networks, avoiding people who they believed would invoke stigmatizing language about their HIV positive partner and not disclosing the HIV status of their partner (Siegel et al., 2018).

Problem Statement:

HIV-related stigma interventions for people living with HIV in the United States focus largely on coping, disclosure, social support, and adherence self-management skills. Women are disproportionately impacted by HIV-related and intersectional stigma. Few interventions focus on effective stigma response and management strategies currently used by WLWH.

Purpose Statement:

The purpose of this project is to understand how WLWH respond to and manage HIV-related stigma in order to inform intervention development.

Chapter 2: Manuscript

How Women Living with HIV (WLWH) Respond to and Manage HIV-Related Stigma

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STUDENT CONTRIBUTION

All data collection and initial thematic analysis for the Women's Adherence and Visit Engagement (WAVE) sub-study was completed prior to beginning this thesis. Several papers have already been published using this dataset. My contribution to this project focused on understanding the ways women living with HIV (WLWH) respond to and manage HIV-related stigma using sub-codes for the main stigma and discrimination code. A secondary analysis of sub-codes of the original STIGMA/DISCRIMINATION code (i.e. INFORM, ISLOATE, RETALIATATION, and NOT EXPERIENCED) was performed. Segments from each sub-code were retrieved, reviewed, categorized into topics, and finally developed into themes. The emerged themes from those codes included education, support and relationships, assertiveness, and non-disclosure that were related to women's experienced HIV-related stigma and discrimination.

ABSTRACT

Background. HIV-related stigma interventions for people living with HIV in the United States focus largely on coping, disclosure, social support, and adherence self-management skills. Women are disproportionately impacted by HIV-related and intersectional stigma. Few interventions focus on effective stigma response and management strategies currently used by women living with HIV (WLWH). **Objective.** To understand how WLWH respond to and manage HIV-related stigma in order to inform intervention development. **Methods.** Between June and December 2015, 76 qualitative interviews focusing on HIV-stigma were conducted among WLWH in San Francisco, CA, Atlanta, GA, Jackson, MS, and Birmingham, AL. Interviews were recorded, transcribed, and coded thematically to elucidate and categorize strategies for responding to stigma. **Results.** We identified four strategies: (1) <u>HIV education</u>: women provided information about HIV transmission and living with HIV to family members, friends, and the community, to dispel misconceptions; (2) <u>Selecting Relationships:</u> women built relationships with people who provided non-judgmental, affirming support, and physically removed themselves from people they identified as negative, including those who perpetuate HIV-related stigma; (3) <u>Resistance:</u> women advocated for themselves or other WLWH by responding to experienced stigma with assertive language or behavior; and (4) <u>Disclosure:</u> some women avoided HIV-related stigma by choosing to not inform others of their HIV status. **Conclusion.** Further research should examine the relative utility of these, and other strategies used by WLWH for responding to and managing HIV-stigma. These approaches to addressing stigma may be leveraged in stigma reduction interventions to achieve greater equity and better health outcomes for WLWH.

INTRODUCTION

Women are disproportionately impacted by HIV, especially in the US South ((CDC), 2016), likely in part due to the stigma faced by women at risk for and living with HIV (WLWH) at individual, interpersonal, communal and structural levels, often manifesting in forms of oppression and discrimination (Fletcher et al., 2016). Stigma has previously been defined as the "social process [in which] individuals with socially undesirable attributes or identities are seen as having lower social value than others and as a consequence face prejudice and discrimination" (B. Turan et al., 2017). Stigma can be categorized into experienced (enacted) stigma (experiences of discrimination and prejudice from others), perceived stigma (perceptions of stigma within a community), internalized stigma (having negative beliefs toward oneself as a result of experienced feelings like blame and shame), anticipated stigma (expectation that others will treat them differently because of disease status), and intersectional stigma (based on other aspects of identity like gender, race, class, and sexual orientation) (B. Turan et al., 2017). Intersectional stigma, specifically, considers how these different identities can function together, as a form of oppression, opposed to independently in relation to health conditions (Logie et al., 2011). For WLWH, intersectional stigma addresses and acknowledges the co-existence of HIV status, gender, and race which affects women of color living with HIV and associated health outcomes.

For women of color, HIV-related stigma can manifest in forms of microaggression and stereotypes, especially for women who come from underrepresented and marginalized backgrounds. Women are often blamed for their HIV diagnoses due to misconceptions (about HIV transmission and community perceptions of HIV), resulting in discrimination in both health care and personal settings (Sangaramoorthy et al., 2017). Literature suggests that factors like age, race and ethnicity, and built environment impact women's perceptions of stigma and discrimination (Sangaramoorthy et al., 2017). For Black women living with HIV, existing stereotypes about promiscuity and excessive substance use and addiction reinforce these manifestations and have a direct impact on health care seeking behavior and finding support from others (Sangaramoorthy et al., 2017).

The psychological impact of social stigma can be detrimental to mental health, self-esteem, and overall well-being for WLWH (W. S. Rice et al., 2018). Mental health conditions like depression have been identified as mediators to HIV-related stigma with disengagement and isolation from others as a means to cope with stigma (Rueda et al., 2016). Lack of social support has been identified as a facilitator of HIV-related stigma for women; and women experiencing lack of social agency and feeling unvalued by society may experience more perceived and internalized HIV-related stigma (Cuca et al., 2017). Social stigma directly impacts WLWH in which they are sometimes rejected by family and friends after disclosing their HIV status (Kontomanolis et al., 2017).

Furthermore, stigma impacts WLWH at multiple socio-ecological levels, specifically at the individual, interpersonal, community, and structural levels. Frameworks including The Health Stigma and Discrimination framework were developed to inform stigma reduction research and efforts. This framework, in particular, depicts the health and social impacts of stigmatization across the socio-ecological levels while acknowledging health-related and intersectional stigma (stigma based on race, gender, class, sexual orientation and poverty) (Stangl et al., 2019). The theory behind this framework can be utilized when addressing HIV-related stigma for women.

The majority of studies regarding approaches to address HIV-related stigma focus on stigma reduction (measuring the decrease in stigma over time) rather than stigma management (the acceptance or rejection of public stigma as it related to oneself) (Rao et al., 2018; Smith & Bishop, 2019). Very few of these studies focus on WLWH (Stangl et al., 2013).

The Stigma Management Communication (SMC) theory was developed to address stigma through different strategies for managing stigma (Meisenbach, 2010). The SMC is based on three underlying assertions : (1) forms of stigma exist based on perceptions of people who both enact and experience stigma, (2) stigmas can change over time, and (3) stigma severity can vary based on circumstance (Meisenbach, 2010). The SMC typology also introduces stigma management strategies including: acceptance, stigmatized persons acknowledging and accepting the existence of stigma and how it may apply to them; avoidance, distancing oneself from stigmatizing experiences; evading responsibility, deflecting or changing public opinion of stigma; reducing offensiveness, wanting to change stigma perceptions of others though sub-strategies like refocusing or minimizing stigma; and denial, ignoring stigma's applicability to oneself (Meisenbach, 2010). Stigma management studies have previously focused on various sub-populations including persons with workplace disabilities, families impacted by drug use, and children of incarcerated parents (Luther, 2016; Moloney et al., 2019). In these studies, researchers found that the decision to remove oneself from stigmatizing experiences was directly related to coping mechanisms as a stigma management tool (Luther, 2016).

There is a current gap in knowledge of how stigma management strategies can be employed for WLWH. Exploring the ways women employ various strategies when reacting to HIV-related stigma is crucial when developing programs and interventions targeting stigma management. To better understand this gap, this study seeks to recognize the ways WLWH respond to, cope with and manage HIV-related stigma.

METHODS

Study Population

The Women's Adherence and Visit Engagement (WAVE) is a sub-study of the Women's Interagency HIV Study (WIHS), a large prospective cohort study following HIV disease progression among WLWH in the United States (Adimora et al., 2018). WAVE focuses on understanding gaps that exist in HIV-related stigma research for women and examining the impact of stigma on HIV medication adherence and use of health care services. The original WAVE sub-study methodology has been described previously (W. S. Rice et al., 2018; W. S. Rice et al., 2019). This secondary analysis will focus on understanding the ways in which women respond to and manage HIV-related stigma and discrimination.

Sampling and Recruitment Strategies

WIHS staff recruited WLWH for the WAVE sub-study at semi-annual study visits in: San Francisco, CA (University of California, San Francisco); Atlanta, GA (Emory University); Birmingham, AL (University of Alabama at Birmingham) and Jackson, MS (University of Mississippi Medical Center). The original study team established a purposive sampling target of 75 qualitative interviews, to account for the varied social and demographic statuses of WLWH in the United States, with specific attention to representing diversity of geographic location, race, Hispanic/Latinx ethnicity and income level. Women were eligible to participate if they were living with HIV, over the age of 18, spoke English, and were able to provide written informed consent.

Data Collection

Between June and December 2015, trained WAVE staff conducted 76 qualitative in-depth interviews averaging 73 minutes each. The interview guide facilitated conversation about previous stigmatizing experiences using open-ended questions such as: “Can you describe a time when you felt stigmatized or discriminated against?” and “What stereotypes do you hear about women living with HIV?”. Interviewees were also asked to share their perspectives about how HIV-related stigma functions in their everyday life and how they manage any associated stigma. All interviews were audio-recorded and transcribed verbatim post interview. Study participants received a $30 cash incentive for their participation.

Data Analysis

All transcripts were de-identified, coded thematically, and analyzed by the WAVE qualitative analysis team (WSR, TMN, MW, AWB). A secondary analysis of sub-codes of the original STIGMA/DISCRIMINATION code (i.e. INFORM, ISLOATE, RETALIATATION, and NOT EXPERIENCED) was performed (by MRF). Segments from each sub-code were retrieved, reviewed, categorized into topics, and finally developed into themes. The emerged themes from those codes included education, support and relationships, assertiveness, and non-disclosure that were related to women’s experienced HIV-related stigma and discrimination.

Ethics Statement

All WAVE study procedures were carried out with approval of the Institutional Review Boards at the University of California, San Francisco, Emory University, the University of Alabama at Birmingham, and the University of Mississippi Medical Center. Signed written informed consent was obtained from all participants at each site. All study personnel were trained on the HIPAA Privacy Rule and in procedures for maintaining confidentiality, and security regarding the use of computers to access study files, acceptable means of communication with other team members about the study, and regarding reporting and dissemination of study findings.

RESULTS

Participant Characteristics

Among the 76 interviews, 25 were conducted at each of the Atlanta and San Francisco sites, and 13 were conducted each of at the Jackson and Birmingham sites. The majority of participants identified as Black (n=46), were over the age of 45 (n=50) and had attended at least some high school (n=65). Most women had a monthly income below $2000 (n=65) and at least one child (n=52).

The participants spoke at length about strategies employed in their lives to manage HIV-related stigma. The key strategies that emerged were: educating others about HIV, selecting relationships, resisting experienced HIV-related stigma through advocacy and assertive language and behavior, and disclosure of HIV status.

HIV-Related Education

Many women reported feeling the need to educate other people in their lives about HIV. Gaps highlighted by these participants included transmission misconceptions and a lack of knowledge around the topic of HIV in general, especially regarding risk perceptions for women. The individuals receiving this education included partners, family, friends, and the communities in which they lived. Within interpersonal relationships, many women talked about family members and friends being hesitant to have them around. Some women attributed this to lack of knowledge and understanding regarding what it means to be living with HIV. In response, women chose to provide additional information to the people in their lives. One participant shared:

> *My family were a little terrified of me. I told them. I said, "You are more harmful to me than I could ever be to you. The whole world is more harmful to me than I could ever be to it. It is an illness like any other illness. I would probably live longer than you because I take better care of myself"...it took them a while to adapt to me and have me around. I waited a long time to…not have to wear gloves at the Christmas dinner and Thanksgiving dinner because I wanted to help, but everybody is afraid…I might put something in blood or something.* (Black Participant, Age 55, Jackson, MS)

Participants also explained the need for education at the community level. Some women described experiences speaking to children at local schools to share their experiences and inform students about HIV and potential risk factors. Women also expressed concern that much of the HIV-related information being received in these communities was inaccurate and coming from unreliable media sources, often prompting the women in the current study to speak on behalf of WLWH to correct misinformation. One woman stated:

> *I mean like I tell a lot of people when I sit back and I hear other people talking sometimes. I say that's why I say there are a lot of HIV classes for you to find out information ... People have this opinion and people have that opinion. Sometimes I try to clear opinions up. I'll be like I took this class and I took that class, so I know. I tell them that I am positive, but they don't know. You watch certain pictures on TV and you don't know what's going on.* (Black Participant, Age 51, Birmingham, AL)

Some women also expressed that women of color are viewed and treated differently as compared to their counterparts in society due to HIV and related intersecting stigma. Black and Latina women discussed community stereotypes that assume monolithic experiences and circumstances around women's acquisition of HIV. As a result, women felt the need to share more about their personal story to dispel these norms. One participant stated:

> *…when I listen to conversations, a lot of time when people talking about AIDS or HIV, it's very negative and they just kind of look at black women as being stupid and careless and reckless and poor, yeah, just sleep around and women are wild, too...I find myself always educating it seems all the time, like almost in every setting that I'm in… I try to bring something in my experience and nine times out of ten, people have, are really being ignorant and non-factual.* (Black Participant, Age 44, Atlanta, GA)

Selecting Relationships

Many participants expressed a desire to distance themselves from other people as a way to avoid stigma. Some women attributed their own tendency toward social distancing to an introverted personality, while other women attributed self-removal to previously experienced stigma. Women indicated that the challenges of adjusting to life with HIV, coupled with introversion and/or previous experiences of stigma, contributed to their cautious outlook on relationships with others. One participant stated:

> *I always want to be very open with friends and family. I really learned that not everybody is your friend. You cannot trust everybody. That everybody is different. Everybody is going to have their own opinion. For me, it kind of makes me—I used to be shy. I have been shy. Like I am not very open person. I don't know. I think it makes me feel a little bit*

> *afraid of opening myself totally to new people and friends, new relationships. Yes, for me, having HIV I think pulls me back for so many things. I am not the woman or the young girl that I used to be before HIV…* (Latina Participant, Age 41, San Francisco, CA)

Women also expressed concern about maintaining distance in relationships to prevent unwanted stress and emotional labor. When they did encounter negativity and insults from people in their lives, they removed themselves and simply stopped engaging in conversation with that individual regarding their HIV status. One participant shared:

> *The negative ways? I don't feel that it has really impacted my life much because …as said, people that are negative about everything. I try not to even speak on a subject such as this with them. I know that I'm living with it…my health as of right now, the way I feel, I'm fine. I don't have anything. I know I have to take the medicine for it in order for it to stay that way. I try to stay away from their negativity. That's why I only told a limited amount of people that I know wouldn't be negative about everything. They would be positive and speak positive things to me.* (Black Participant, Age 46, Jackson, MS)

Resistance

Advocacy

Participants shared the need to speak up on behalf of other WLWH. Some women identified political lobbying and writing to political leaders as one method to support and work towards creating change on a larger scale. In contrast, other women talked about working directly in the community they live in and engaging with local organizations already doing social justice and advocacy work for WLWH. One participant shared:

> *I stand up for every woman. I don't like anyone to mistreat any woman. I don't care who she is. If she's being mistreated, not being treated right, or being fair, that was part of my being an advocate. As an advocate, I had to learn what our rights were, volunteering with [legal organization where participant lives]. They would bring those workshop to us and teach us what our rights were that we could stand up for. I stood up for every woman. I don't play that. You don't mistreat a woman. It'll hurt me if you mistreat another woman, especially if she's HIV positive. I take that personally, yes I do.* (Latina Participant, Age 50, Atlanta, GA)

Assertiveness

Women also explained feeling the need to retaliate against other people when they are on the receiving end of an insult, microaggression, or another offense of some kind. Some participants noted that lashing out either verbally or through their behavior was a way to cope with the experienced event. One participant reflected on an incident with her family and stated:

> *I heard them in the kitchen talking about me. 'What she drunk out of?' 'I don't know but I let her use the bathroom and everything.' I overheard them talking about me and I got real damned stupid for real. Honey…I went touching the walls and said… 'You're going to need to move the fuck out. The walls infected, the sofa infected, all your vehicles and everything'...I said 'y'all need to get up out this damned house you done paid for because it's infected with HIV' and that's what I told them. I laughed so bad up in there...* (Black Participant, Age 48, Birmingham, AL)

Avoid Retaliation

Some participants indicated concern about being condemned for their HIV status. Additionally, women talked about finding seroconcordant partners in order to avoid potential legal ramifications such as jail time if their HIV status was not disclosed prior to a sexual encounter. One participant stated:

> *I just won't want to mess with no one that is HIV negative. That's risky business. Even though you might of told them your status…and then the minute they get infected they can go tell the law…She didn't tell me! Who the law going to believe? That person. And there I go 20 [years]…might be the rest of my life…I think people that are HIV positive and if you're going to be with someone HIV negative…the best place to tell it is in the doctor's office for the doctor to say. Just in case he or she decides they want to get mad with you and say you didn't tell them? They can't go put the law on you and the law is throwing you away forever.* (Black Participant, Age 48, Birmingham, AL)

Disclosure

Some women expressed that they had not experienced any forms of stigma or discrimination related to their HIV status, gender, or race. It was notable that these participants were much less likely to have openly disclosed their HIV status. Women expressed choosing not to disclose their HIV status to people outside of their doctor, other clinic staff, or a couple of close friends or family members. When asked about her experiences related to HIV stigma, one woman said:

> *…nobody really knows my status, obviously, unless I tell them. So I really don't get that stigma because nobody knows..If they knew, they probably would...* (Black Participant, Age 55, Birmingham, AL)

It should be noted that there were other participants who had disclosed to others, and felt supported by the people in their lives that were aware of their HIV status. These women explained that their friends and family had accepted them and did not treat them differently because of their status. One participant stated:

> *My older sister said…it's no different than having cancer or anything else. Somebody has to take medication for everything. It's no different than having high blood pressure, cancer, leukemia. It's all just another disease. It's another name for it…* (Black Participant, Age 43, Atlanta, GA)

DISCUSSION

Current stigma management literature has minimal focus on WLWH. Additionally, current approaches to address HIV-related stigma concentrate on reducing stigmatizing experiences. The key findings from this analysis highlight the ways WLWH respond to and manage HIV-related stigma: namely, through educating others, being selective in relationships, resisting stigma and avoiding disclosure.

The results suggested that women responded to HIV-related stigma through educating peers about misinformation regarding HIV transmission (ex. notions that modes of HIV transmission include non-intimate physical touch, sharing cups and utensils, and touching inanimate objects), regarding HIV risk among women, and regarding stereotypes about women of color living with HIV (ex. women are promiscuous and abuse their bodies). Fear of transmission due to a lack of accurate information has been described previously as a driver of HIV-related stigma, especially towards WLWH (Chambers et al., 2015). In a recent systematic review, Ingram et al. (2019) explained that to help mitigate these drivers further intervention is needed at both the interpersonal and community levels to challenge perceptions regarding risk factors for women and HIV acquisition. These findings emphasis how WLWH may act as agents for interventions focused on changing risk perceptions within communities as a way to address misinformation. Furthermore, these findings also highlight the utility in assisting stigma management and reduction efforts, specifically domains focusing on stigma elimination or evading responsibility (Meisenbach, 2010).

The second finding focused on how WLWH decided when to disengage with others to avoid anticipated stigma and unwarranted stress as a result from previously experienced stigma. This finding is similar to the avoidance management strategy of the SMC theory in which individuals will distance themselves from other to get rid of stigma-related behavior (Meisenbach, 2010). In the context of this study, women chose to disengage with people who perpetuated HIV-related stigma, negativity, were judgmental and not supportive. Current literature suggests that experiencing stressful situations and encounters with other can contribute to poorer health outcomes for people living with HIV such as lack medication adherence and increased substance use (Reif et al., 2011). Although this analysis focused on women's responses to HIV-related stigma, it is important to acknowledge and assess the relationship between stress and self-removal.

Chambers et al. (2015) found that self-efficacy and resilience in challenging views and opinions towards WLWH were related to engagement in social advocacy work. The findings from this analysis are similar; our participants actively combated stigma through advocacy work (ex: politically lobbying and volunteering), retaliating against others when experiencing microaggressions related to their HIV status and engaging in sexual relationships with others that are HIV positive to avoid negative ramifications of stigma such as jail time for not disclosing their status. Current media platforms and community organizations focused on activism for people living with HIV utilize their platforms in public settings to create social change (Gillett, 2003). Additionally, non-profit organizations targeting HIV prevention and well-being among Black women like SisterLove and the Black AIDS Institute focus specifically on the intersection of HIV and other factors such as race and gender that drive societal inequities for marginalized communities through their advocacy work, aligning with sentiments expressed by women in this study (Watkins-Hayes, 2014).

The final way women responded to HIV-related stigma was by selective HIV status disclosure. Current literature around disclosure of disease status notes that it is a personal choice and an individual is more likely to disclose their status if they find it to be beneficial (Moloney et al., 2019). This aligns with the findings of this study in which women noted not experiencing HIV-related stigma as a result of: a) non-disclosure (beyond clinic staff) and b) acceptance, love and support from close family members and friends who were non-judgmental after disclosing. Other studies have also noted that social networks impact disclosure patterns for WLWH such that women who have positive social support from the people in their lives are more inclined to share their HIV status (E. Rice, Comulada, Green, Arnold, & Rotheram-Borus, 2009). Disclosing one’s status has also been associated with a decreased mental health conditions such as depressive disorders for WLWH (Vyavaharkar et al., 2011).

This study is not without limitations. The women were sampled from a larger study of women actively engaged in care; therefore, their experiences may be different than women who are not engaged in research (W. S. Rice et al., 2018). For example, women who are not attending regular study and follow-up visits related to their HIV may have different experiences that are not captured. This study also has a couple of key strengths. Participants were diverse in terms of race and ethnicity, income level, and location in terms of women living in urban and rural areas of the United States which provided a detailed and multi-layered perspective into the lived experiences of WLWH. Current HIV stigma management research focuses medication adherence and HIV prevention which is integral in understanding ways to keep women engaged in care (Rintamaki et al., 2019; Siegel et al., 2018). This analysis is novel because the ways women are responding to stigmatizing HIV-related experiences is assessed and can be used to inform future management and reduction research.

Women are disproportionately impacted by HIV in the United States. However, few interventions focus on understanding the ways that women cope with and manage HIV-related stigma as well as strategies for responding to HIV-related and other intersecting stigma. Current research addressing HIV-related stigma for people living with HIV focus primarily on recognizing stigma, reducing stigma, medication adherence and improving self-efficacy (Stangl et al., 2013). Understanding the ways women employ various strategies when reacting to HIV-related stigma is crucial when developing programs and interventions targeting stigma management.

Chapter 3: Conclusions and Recommendations

HIV-related stigma management for WLWH is understudied although women are disproportionately impacted by HIV. Current strategies focus largely on understanding the function and coexistence of multiple stigmas at individual, interpersonal, community, and institutional levels to reduce stigma and build resilience (Stangl et al., 2013). The analysis from this study found that WLWH respond to and manage HIV-related stigma through educating others, being selective in relationships, resisting stigma and avoiding disclosure. WLWH provided information about HIV transmission and living with HIV to family members, friends, and the community, to dispel misconceptions; built relationships with people who provided non-judgmental, affirming support, and physically removed themselves from people they identified as negative, including those who perpetuate HIV-related stigma; advocated for themselves or other WLWH by responding to experienced stigma with assertive language or behavior; and chose to not inform others of their status to avoid anticipated stigma. Future stigma management research should focus on exploring how stigmas are viewed by the public in addition to how individuals view themselves with an emphasis on intersectional stigma (Meisenbach, 2010). It is essential that interventions target the many stigma management and communication strategies to holistically address the multiple forms of stigma that disproportionately impact WLWH (Meisenbach, 2010). Using this approach to address stigma may leveraged in stigma reduction interventions to achieve greater equity and better health outcomes for WLWH. Understanding the ways women employ various strategies when reacting to HIV-related stigma is crucial when developing programs and interventions targeting stigma management.

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