



‘Either You Float or You Drown:’ The Role of Social Ties and Stigma in Lived Experiences of the HIV Care Continuum in HPTN 065

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Abstract

HPTN 065 utilized financial incentives to promote viral suppression among HIV-positive participants. Exit interviews were conducted in a sub-study of participants in Washington, DC and Bronx, NY. The present analyses explored lived experiences of social ties and stigma as individuals navigated the HIV care continuum, including gender differences in lived experiences. Using viral load data and informed by stages-of-change theory, participants were categorized into “Low-Adherers (n = 13)”, “Action (n = 29)” and “Maintenance (n = 31)” stages. Secondary analyses of qualitative data were informed by grounded theory, and instances of social ties and stigma discussed by participants were quantified with descriptive statistics. Participants (N = 73) were mostly male (64%), African American (58%), with yearly income under \$10,000 (52%). Low-adherers identified fewer, and sometimes more combative social ties than those in other adherence stages. Maintainers identified supportive ties as motivation for medication adherence (68%) but relied less on them for motivation than individuals in other adherence stages. Low-adherers described current experiences of stigma related to being diagnosed with HIV more than other adherence stages (23%). Individuals in Action reported stigma related to disclosing their HIV status to others (52%), while individuals in Maintenance mostly stigmatized others engaging in “risky” behaviors (32%). Findings suggest that women may perceive greater HIV stigma than men, perceive less supportive social ties, and were the majority of Low-adherers. Gender-informed approaches can facilitate community de-stigmatization of HIV, as African American women may be at greater risk of negative HIV health outcomes.

Keywords HIV/AIDS · HIV care continuum · Social support · Stigma · African Americans · Health equity

Introduction

Four decades into the HIV epidemic, treatment breakthroughs have changed HIV perceptions from being a death sentence to a chronic disease with which individuals are living full lives. Doing so, however, requires high rates of consistent HIV medication adherence to achieve and maintain viral suppression. Viral suppression is recognized as a critical outcome for all people living with HIV, for its individual-level health benefits as well as a decrease in risk of HIV transmission to others [1–3]. The HIV continuum of care encompasses the process of a person testing positive for

HIV, accessing treatment, and maintaining successful viral suppression [4–7]. Even among individuals with access to HIV treatment, inequities in health outcomes persist among African Americans and low-income populations [2–6]. While African Americans comprise 12% of the U.S. population, they account for 45% of HIV diagnoses [4–6]. Less than 50 percent are retained in HIV care, and only half of African Americans living with HIV achieve sustained viral suppression [5–7]. Challenges navigating the care continuum for African Americans include strained social ties and cultural stigma of HIV [4–7].

Social Ties and Medication Adherence

While social support is generally a facilitator of positive health outcomes, research suggests that individuals living with HIV may have strained social ties due to need for HIV care assistance from loved ones and friends [8–13]. Sensitive interaction systems theory (SIST) has been used to

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describe sources of social strain, such as perceived need for help, availability of support from social ties, and costs of accessing support (whether instrumental, informational, or emotional support) [11–13]. A key construct of SIST is interactive coping, which refers to when HIV supportive care behaviors are not perceived as supportive by their recipient, thereby straining the social relationship [12]. This phenomenon may help to explain gender differences in health outcomes among individuals with HIV, particularly in African American communities. Women in general are more likely to give support than to receive it; further, African American women are more likely to provide care than women of other racial and ethnic groups and are often at higher risk of treatment interruptions and faster HIV disease progression than men [9, 10, 14].

Stigma and Medication Adherence

Individuals living with HIV may also experience stigma, which impedes their ability to access support, remain engaged in care, and/or sustain viral suppression [15–17]. HIV stigma refers to bias and judgment related to living with HIV, and can be experienced within healthcare settings, in personal relationships, or directed towards oneself [15]. Stigmatizing experiences may also occur throughout an individual's HIV care continuum journey [15]. Although social ties are often main sources of HIV stigma, many individuals with HIV consider their social ties as motivation to better manage their illness [15–17]. Nonetheless, activation of social support can strain the relationship, and a greater number of social ties may then increase experiences of HIV stigma [16, 17]. Gender differences may also complicate the relationship between social interactions and HIV outcomes [18, 19]. A review by Florom-Smith et al. found that African American women reported stigma in the form of institutional disregard and feeling that others “defined” them solely by their HIV status [20]. Women with HIV in conservative communities are negatively impacted by stigma, although studies often measure stigma at the individual level and are not contextualized to African American women in regions severely affected by HIV [21, 22].

Purpose

Although major advances have improved the health outcomes of individuals living with HIV, African Americans reap fewer benefits. Research is needed to explore the negative effects of social ties and stigma among African Americans who continue to bear the brunt of HIV diagnoses and challenges in achieving medication adherence and viral suppression. As posited by SIST, understanding processes such as social strain may identify pathways to improving their health outcomes. The present research examined these

factors in a predominantly African American cohort, from a qualitative sub-study of The HIV Prevention Trials Network (HPTN) 065 study, that included a testing, linkage-to-care and viral suppression component in Washington DC and Bronx NY clinics [23, 24]. The present study explored: (a) the role of social ties in HIV medication adherence; (b) experiences of stigma and its impact on adherence outcomes; and (c) gender differences in the roles of social ties and stigma. The present research fills key gaps in the literature related to lived experiences of medication adherence among African Americans with HIV and gender-related differences in these experiences [21, 22, 25].

Methods

Sampling Methodology

This study utilized data from a qualitative sub-study of HPTN 065 study (which was conducted from 2011 to 2015) [23, 24]. HPTN 065, the Test, Link-to-Care Plus Treat (TLC-Plus) study, used a community-focused strategy to ensure that patients adhere to their treatment regimens, and clinic sites in Washington, DC and Bronx, NY were selected due to high prevalence of HIV and existing local efforts in linkage-to-care programs [23, 24]. Qualitative data were from the Financial Incentives to Promote Viral Suppression (FI-VS) arm of the study, where participants were randomized to clinics to receive \$70 gift cards quarterly for maintaining viral suppression compared to standard of care. For the qualitative sub-study, clinic site staff used purposive and non-probability-based sampling quotas to recruit interviewees with diverse socio-demographic characteristics and viral suppression status [26, 27]. Inclusion criteria for the sub-study were: (a) documented HIV-positive status; (b) participation in the parent study for at least 15 of the 24 months' study duration; (c) viral load specimens collected at baseline and throughout the study; and (d) written consent.

Data Collection and Research Ethics

The qualitative sub-study was explained to participants as a means of providing individual-level feedback on the HPTN 065 study, which only collected community-level and clinic-level quantitative data [23, 24, 26–28]. Interviews asked how participants learned about HPTN 065; their views on financial incentives; HIV medication adherence; and perceptions of community awareness of HPTN 065. The sub-study was approved by central or local site-dependent Institutional Review Boards (IRBs) prior to data collection [26–28]. The present study was fully approved by the FHI 360 IRB.

Primary Sub-study Analyses

In the original sub-study analyses, participants were categorized using stages-of-change theory (i.e., Low-adherers, Action, Maintenance) [26, 27, 29]. Participants who were virally suppressed in fewer than half of viral load tests were categorized as Low-adherers. In order to meaningfully distinguish individuals beyond simply virally suppressed versus not, those who maintained viral suppression were classified as Maintenance and all others were classified as Action [26–28]. Three individuals had insufficient viral load data to be categorized in any of the three groups; therefore, 73 of the 76 participants were included [26]. Five team members independently coded their assigned transcripts, intermittently double-coding each transcript and meeting to resolve discrepancies and ensure adequate intercoder reliability through consensus coding [26–28]. Two members re-read transcripts to identify sub-themes related to medication adherence (e.g., adherence patterns, barriers to adherence, medication motivations), revised the coding structure and applied additional sub-codes to transcripts [26–28]. Analyses were conducted using NVivo Version 11.0 [30]. Specific codes from the primary sub-study analysis, described below, were used to conduct secondary analyses.

Secondary Sub-study Analyses

Secondary qualitative analyses were informed by grounded theory, which has been previously used in other secondary qualitative analyses to derive data-driven theories that characterize social phenomena [31]. Its coding stages are: (a) open: tentative coding based solely on the data; (b) axial: identifying themes between open codes; and (c) selective: meaningfully synthesizing data by one central variable (i.e., grounded theory) [31]. Open coding was conducted with 38 (half of) transcripts without prior review of existing coding data [31]. Open coding was also conducted to ensure that the original codebook had relevance to our research questions. Because the original interview questions did not specifically ask participants about social ties and stigma, open coding was also conducted to ensure that these constructs were discussed frequently enough by participants to merit secondary analyses. Sufficient data were identified to conduct the present analyses, and the primary analyses codebook included all of the codes that were generated by open coding in the present analyses [26–28, 31]. Upon reviewing instances where participants discussed their social interactions, it became evident that these interactions were not necessarily supportive—therefore, the term ‘social ties’ is used in the present study and analyses rather than ‘social support.’ After open coding, axial coding consisted of queries

of coded data using the following specific codes (*italicized*) and sub-codes (in parentheses) based on theoretical importance:

- (1) Adherence motivation: *Medication adherence* (duration, motivation, feelings, regimens), *HIV impact on patient* (other behaviors, adherence)
- (2) Social ties: *Medication adherence* (religion, partner-community support, provider-clinic support), *Impact on clinic* (patient-provider relationship)
- (3) Stigma: *HIV impact on patient* (theoretical impact on others), *Opinions of HPTN 065* (other people’s opinions), *Medication adherence* (stigma, other’s patterns, risk behaviors), *Community awareness*, *Viral load* (HIV transmission), *Impact on patient* (theoretical impact on others)

Analytic memos noted insights related to these constructs throughout axial coding. Selective coding was used to distill the grounded theory of navigating across the HIV care continuum, by further reviewing each coded instance of the constructs of interest, along with the raw data [29–31].

During selective coding, the following constructs were quantified using the raw data to look for patterns across the three stages of adherence: (1) motivation for adherence (yes/no); (2) social ties as motivation for adherence (yes/no); (3) number of social ties and relationship to participant; (4) description of the supportiveness of ties (supportive, neutral, contentious); (5) HIV-related stigma related to the diagnosis of HIV, or having to disclose HIV status to others; (6) stigmatizing others’ risky behaviors despite having HIV; and (7) perceived community awareness of HPTN 065 (none, unsure, high). After reaching consensus, salient quotes were extracted from the data. Analyses were conducted using NVivo Version 11.0 [31]. Due to the qualitative nature of the data, only descriptive statistics (means and frequencies) were calculated by gender and adherence stage. Quantitative analyses were conducted in Microsoft Excel.

Results

Descriptive Characteristics

As shown in Table 1, participants were mostly men (64.4%), African American (57.5%), and non-Hispanic (76.7%). Nearly 50% of participants identified as heterosexual, over half had a yearly income under \$10,000, and 60% had a high school diploma equivalent or less. Mean age was 44 years (standard deviation: 14.5 years). While women were less than one-third of the total sample, they represented over 60% of Low-adherers.

Table 1 Participants demographics (HPTN065 qualitative sub-study; N = 73)

Characteristic	Low Adherers (n = 13) n (%)	Action stage (n = 29) n (%)	Maintenance Stage (n = 31) n (%)	Total (N = 73) N (%) or Mean (SD)
Gender				
Men	4 (30.8)	18 (62.1)	25 (80.6)	47 (64.4)
Women	8 (61.5)	10 (34.5)	6 (19.4)	24 (32.9)
Transgender	1 (7.7)	1 (3.4)	0 (0.0)	2 (2.7)
Hispanic ethnicity				
No	10 (76.9)	23 (79.3)	23 (74.2)	56 (76.7)
Yes	3 (23.1)	6 (20.7)	8 (25.8)	17 (23.3)
Sexual orientation				
Heterosexual	11 (84.6)	15 (51.7)	10 (32.3)	36 (49.3)
Homosexual	1 (7.7)	10 (34.5)	18 (58.1)	29 (39.7)
Bisexual	1 (7.7)	0 (0.0)	2 (6.5)	7 (9.6)
Other/unidentified	0 (0.0)	4 (13.7)	1 (3.2)	1 (1.4)
Race				
African American	9 (69.2)	18 (62.1)	15 (48.5)	42 (57.5)
White	0 (0.0)	5 (17.2)	7 (22.5)	12 (16.4)
Other/unidentified	4 (30.8)	6 (20.7)	9 (29.0)	19 (26.0)
Education				
8th grade or less/some high school	7 (53.8)	11 (37.9)	5 (16.1)	23 (31.5)
High school diploma/GED	3 (23.1)	6 (20.7)	9 (29.0)	18 (24.7)
Some college/bachelor/graduate	3 (23.1)	12 (41.4)	17 (54.7)	32 (43.8)
Yearly income				
≤\$10,000	10 (76.9)	17 (58.6)	11 (35.5)	38 (52.1)
\$10,000–\$39,999	3 (23.1)	10 (34.5)	8 (25.8)	21 (28.8)
\$40,000+	0 (0.0)	1 (3.4)	12 (38.7)	13 (17.8)
Approximate time since HIV diagnosis				
1 to 5 years	2 (15.4)	5 (17.2)	4 (12.9)	11 (15.1)
6 to 9 years	4 (30.8)	2 (6.9)	1 (3.2)	7 (9.6)
10 to 19 years	2 (15.4)	6 (20.7)	6 (19.4)	14 (19.2)
20+ years	2 (15.4)	4 (13.7)	5 (16.1)	11 (15.1)
Undisclosed	3 (23.1)	12 (41.4)	15 (48.5)	30 (41.1)
Age [Mean years & (SD)]	45 (15.6)	41 (14.3)	46 (14.2)	44 (14.5)

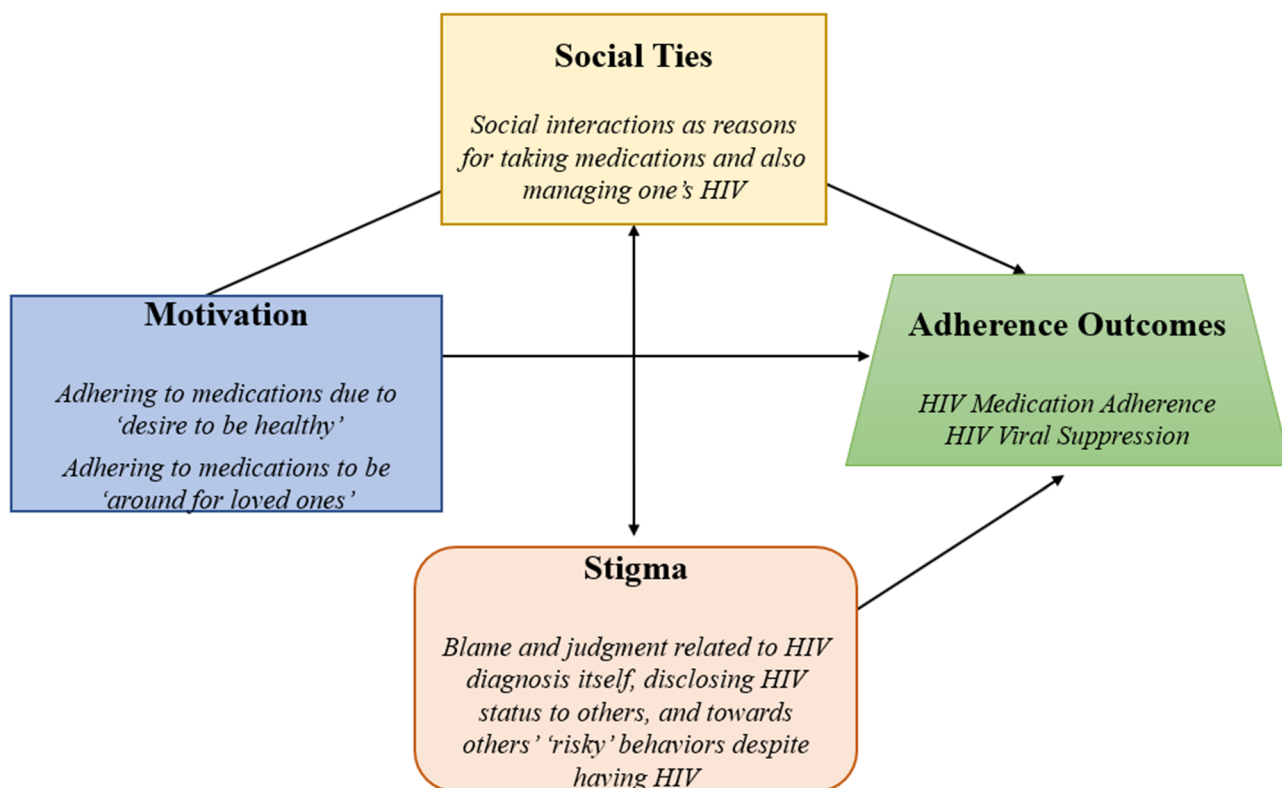
Thematic Framework

Figure 1 depicts the thematic constructs related to the grounded theory of navigating the HIV care continuum to achieve viral suppression, based on thematic saturation from data analyses. Constructs are represented with brief description of how they appeared in raw and coded data, along with lines showing whether they were discussed in relation to other constructs (with bidirectional lines rather than arrows). Constructs which were not directly discussed together are not joined by lines in the figure, and experiences that differed by gender are noted within each theme.

Theme 1 explores overall motivation related to HIV medication adherence. Theme 2 explores social ties related to HIV care and medication adherence experiences across the

adherence stages. Theme 3 focuses on HIV stigma. Three stigma-related processes are described: (1) stigma due to feeling ‘undeserving’ or in denial about HIV diagnosis itself; (2) stigma due to challenges of disclosing one’s HIV status to others; and (3) stigmatizing others who were engaging in ‘risky’ behaviors despite their HIV diagnosis, such as using drugs or not taking their medications.

Taken together, the grounded theory suggests that stigma, interaction with one’s social ties, and seeking motivation for medication adherence are key lived experiences of navigating the HIV care continuum. The unique contribution of this theory is that regardless of gender, individuals may begin directing HIV stigma from inward to outward as they begin to better manage their HIV. As shown in Tables 1 and 2, this process may consist of first stigmatizing themselves at



Grounded theory: Stigma, social ties, and adherence motivation are key lived experiences of navigating the HIV care continuum, and strained social ties and stigma may disproportionately affect women. Regardless of gender, individuals may begin directing HIV stigma from inward to outward (i.e., first stigmatizing themselves at diagnosis, then stigmatizing others once their HIV is well controlled). Women may do this more than men.

Fig. 1 Grounded theory (Key experiences related to successful navigating the HIV care continuum). Each of these four constructs depicted were discussed by participants in relation to managing their HIV. Lines represent theorized relationships and arrows represent theorized directions of relationships

Table 2 Instances of social ties and stigma discussed, presented by adherence stage (N = 73)

Experience	Number of individuals who mentioned this experience (by adherence stage)			
	Low-adherers (n = 13)	Action (n = 29)	Maintenance (n = 31)	Total (N = 73)
'Being healthy' as main motivation for adherence	11 (85%)	28 (97%)	29 (94%)	68 (93%)
HIV stigma related having been diagnosed with HIV (past or present)	8 (62%)	14 (48%)	17 (55%)	39 (53%)
Recent experiences of HIV stigma related to being diagnosed ^a	7 (88%)	8 (57%)	6 (35%)	21 (54%)
Stigma related to disclosing HIV status to others	5 (38%)	15 (52%)	10 (32%)	30 (41%)
Stigmatization of others' 'risky' behaviors despite having HIV	2 (15%)	3 (10%)	9 (29%)	14 (19%)
Social ties as main motivation for adherence	8 (62%)	19 (66%)	21 (68%)	48 (66%)
Mean number of social ties identified (range 1–5)	2.2	3.0	2.3	2.5
Mean supportiveness of ties mentioned (range 0–3) ^b	2.0	2.2	2.2	2.2

^aOnly among individuals who identified HIV stigma related to HIV diagnosis

^bTies designated as supportive, contentious, or neutral and scored 0 (no supportive ties) to 3 (all supportive ties)

diagnosis, experiencing stigma from others as they disclose their HIV status, and then stigmatizing others once their HIV is well controlled. Our grounded theory also suggests that women may stigmatize themselves and others more than men as they progress along the care continuum. Results presented below further convey these relationships.

Theme 1: Motivation

Most participants across all three stages identified health-related motivation for medication adherence, i.e., wanting *‘to live as long as possible’* (Table 2). Even among Low-adherers who were not virally suppressed, external forms of motivation (financial incentives) was described as *‘nice but unnecessary’* to promote medication adherence. As described by one Low-adherer, the gift cards *‘come and go.’* Another Low-adherer felt that while gift cards were unnecessary, they were a nice *‘self-esteem boost’* which helped her cope with her HIV diagnosis. Another individual described them a *‘win’* for individuals living with HIV because *‘you get tired of losing.’* This was mentioned within the context of describing the mental health challenges faced by individuals living with HIV:

...It shouldn't be just about the gift because, see, that comes and goes, but it should just be about you. I got to take care of myself. If you don't get nothing else out of it. That encourages you to make that first step to take care of yourself...And take your medicine every day. – (Low-adherer/Woman/50 years old/African American/1-5 years since diagnosis)

[Gift cards are not needed but are] a really good thing because just sometimes my self-esteem can go a little low because of my condition...as long as my viral load was undetectable that I would receive a gift card for \$70. I thought that was really [nice] because I could pamper myself with it and I did just that. – (Low-adherer/Woman/48 years old/African American/6-9 years since diagnosis)

...As a matter of fact, they should bring it back. They should ... they should bring it back, I mean because it's just Like ... you know? It gives somebody something ... something to look forward to every 90 days or the case may be. You know what I'm saying? An incentive way to keep their ... to keep their T-cells and viral load tight. Something like that there, you know? And to keep things moving in the right direction for them, man. Instead of playing little silly games with yourself, because you're the one that loses. You know what I'm saying? You get tired of losing, man, whatcha going to do? Commit suicide? That's the next

move. Forget that. – (Low adherer/Man/26 years old/African American/1-5 years since diagnosis)

Individuals in Action and Maintenance also identified *‘wanting to be healthy’* as their main motivation for adherence to medication. Roughly two-thirds of participants in each of these groups also mentioned at least one social tie who supported them and for whom they wanted *‘to be around.’* Typical social ties included children, grandchildren, and main partners for both men and women.

...I want to be here for my grandkids. And my daughter, my two daughters. I want to live. I don't want to go nowhere. I just want to stay here, you know, with them. – (Action/ Woman/57 years old/Other Race/6-9 years since diagnosis)

No, because ... I have seven kids, and I have to worry about that, so I have to take my medication. I still want to be there for them. My situation is my situation, but that don't have nothing to do with me trying to be there for them, so I've got to take my medication. So I don't really look at it like no problems, or I try my best to remember to make sure to take my medication. – (Action/Man/54 years old/African American/20+ years since diagnosis)

Many of the participants who identified social ties as motivation for adherence mentioned having friends who supported their HIV medication adherence and were living with HIV themselves. As shown in Table 3, no differences in adherence motivation were found by gender.

Theme 2: Social Ties

Individuals across all adherence stages discussed social ties related to their HIV diagnosis, treatment, and management. Many of the individuals mentioned were in their social networks but were not those with whom they identified a close relationship. Examples include acquaintances they knew from participating in the HPTN 065 study and acquaintances they knew through their friends. Additionally, social interactions were not consistently described as supportive of medication adherence or viral suppression. Therefore, the individuals mentioned are referred to as *‘social ties,’* rather than sources of *‘social support.’* Regardless of gender, Low-adherers generally named fewer social ties, and reported lower perceived supportiveness from their social ties compared to those in other stages. When discussing a contentious relationship with loved ones, one Low-adherer described frustration because loved ones did not *‘understand what living with HIV was like.’*

I try to keep myself busy so much to not think about it...My cousins ask me about it, my friends ask me about it, my mom asks me about it, and it's like -- it

Table 3 Instances of social ties and stigma discussed, presented by gender (N=68)

Experience	Number of individuals who mentioned this experience (by gender)	
	Men (n=44)	Women (n=24)
Low-adherers	6 (14%)	5 (22%)
Action	15 (34%)	12 (52%)
Maintenance	23 (52%)	6 (26%)
'Being healthy' as main motivation for adherence	40 (92%)	23 (96%)
HIV stigma related having been diagnosed with HIV (past or present)	22 (50%)	16 (65%)
Recent experiences of HIV stigma related to being diagnosed ^a	22 (50%)	16 (67%)
Stigma related to disclosing HIV status to others	18 (41%)	11 (48%)
Stigmatization of others' 'risky' behaviors despite having HIV	29 (66%)	17 (70%)
Social ties as main motivation for adherence	7 (16%)	7 (30%)
Mean number of social ties identified (range 1–5)	2.5	2.6
Mean supportiveness of ties mentioned (range 0–3) ^b	2.3	1.9

Individuals who did not identify by a single gender excluded (n=5)

^aOnly among individuals who identified HIV stigma related to HIV diagnosis

^bTies designated as supportive, contentious, or neutral and scored 0 (no supportive ties) to 3 (all supportive ties)

gets frustrating, 'cause sometimes I don't think some people really understand where I'm coming from. They just see that I'm doing pretty well and that if I'm taking my meds then what's the problem?... – (Low-adherer/Man/26 years old/ Hispanic/6-9 years since diagnosis)

Another Low-adherer described mental health challenges and relationship strain because she had to explain to loved ones that '*she didn't give it [HIV] to anyone,*' and contracted HIV from her partner. She described some contentiousness because her social ties did not understand the disease which made it harder to share information with them.

... I was in so much pain, so much heartache. And then I had to share the information with my children and some of my family members because everybody don't understand what this disease is and what's going on, how you contract it and stuff like that. I didn't give it anyone, someone gave it to me... although I'm trying every day to focus, to stay focused and to live and be vibrant cause I have a grandbaby, one grandbaby, and my daughter's about to have a baby... – (Low-adherer/Woman/48 years old/African American/6-9 years since diagnosis)

One individual in Action described the experience of managing her HIV as '*either you float or you drown,*' and that social ties did not prevent the day-to-day challenges she experienced. She stated that although her family was aware of her illness, they did not fully comprehend its effects on her energy level, activity level and mental well-being.

... It's either you float, or you drown...before you were able to like you know like do everything that they do. So, people not understanding that and sometimes like my close family like my sisters they know but they don't understand [what living with HIV is like]. It's like I'm tired, we just walked like 5 blocks but I'm so tired and I feel like I ran a few miles. And I'm just tired. Or you know even now in the summer like my kids like they want to go to the park, they want to go to the beach, sometimes I just like, I, I, I just wanna be home ... – (Action/ Woman/30 years old/Hispanic/1-5 years since diagnosis)

In general, participants in Action identified supportive social ties as a facilitator of their medication adherence (mean number of ties identified in secondary analysis: 3). Often, these social ties did not provide support to the individual or have a close connection. For instance, one participant in Action mentioned knowing an individual who had HIV and served as '*inspiration*' to her because this individual's illness was well-managed and she '*still looks good.*'

[Medication made] my body just started feeling funny, and... I was talking to my best friend and there's another person I know that's been on it for like 26 years...and she's like really my inspiration, yea. since like, I've known her since like '95. But she's been had it from '95 till now and she still looks good. – (Action/Woman/38 years old/ African American/1-5 years since diagnosis)

Most individuals in Maintenance identified social ties of various kinds, including knowing others who were also living with HIV. One individual described that his social ties included others who were *‘doing well’* with managing their illness, which helped him assuage the misconceptions he and others held related to HIV medications and the medication’s effectiveness.

What made it easier [to take medication] is the support I got here through the doctor and --- running the study. And friends, I had a big support team that ...the people who have already been on HIV pills and told me, don’t freak out and stress, you know. There’s always someone out there who’s going to tell you something negative about ... about medications... – (Maintenance/Man/41 years old/White American/10-19 years since diagnosis)

Compared to other stages, participants in Maintenance discussed less reliance on their social ties for adhering to their medication, while Low-adherers identified less perceived supportiveness of their social ties. Regardless of adherence stage, women were slightly more likely than men to identify social ties when they were asked about what motivates them to adhere to their medication (70% versus 66%, respectively). However, women also reported less supportiveness from their social ties when they discussed their HIV care irrespective of adherence stage (mean: 1.9 versus 2.3, respectively).

Theme 3: Stigma

As depicted in Fig. 1, three main forms of stigma were described: (1) stigma related to HIV diagnosis, such as ‘not deserving’ HIV; (2) stigma related to disclosing one’s HIV status to others, and related challenges such as missing medication doses due to fear of being seen with pills; and (3) stigmatization of others’ ‘risky’ behaviors who were jeopardizing their health because they have HIV. Examples of this stigmatization included discussion of people who were not taking their HIV medication consistently, or still engage in drug use despite their HIV diagnosis. Differences emerged in which form of stigma was discussed most, depending on the adherence stage of the individual.

Roughly half of participants reported current and/or past experiences of stigma related to being diagnosed with HIV. As shown in Table 3, most Low-adherers who reported stigma related to being diagnosed with HIV had recently experienced this form of stigma, suggesting that stigma experienced at the initial stage of the care continuum may hinder progression along the continuum. Less than 60% of participants in Action and less than 40% of those in Maintenance who reported stigma of HIV stated

that the experiences were current. Many Low-adherers who described stigma related to HIV diagnosis linked those feelings with being *‘shocked’* by the diagnosis. For example, one transgender individual stated that they should not have HIV because they *‘were not a whore.’* This individual contracted HIV by sharing needles with their friend, while both were using hormones for gender reassignment.

... I shouldn’t have the HIV because it wasn’t like I was a whore or something. My friend passed it on to me through a needle...we shared a hormone shot, so I gave it to her once, not knowing I still had the needle on there, so I stuck myself. So, it was kind of my fault, but it was her fault too, because she’d had it for three years and didn’t tell her only best friend that she called best friend, and then passed it on to me... – (Low-adherer/Transgender/23 years old/Hispanic/Undisclosed years since diagnosis)

Another participant who was a Low-adherer described anger from his HIV diagnosis, which was undeserved because *‘he did not share needles.’* Instead, he described being infected with HIV via unprotected sex.

...I came out of jail and they sent me to the board of health and went to take an HIV test and I took it there...I got mad. Cause, it wasn’t. I didn’t, I didn’t, I didn’t get it through sharing needles. I got it through sex. That’s one of the things that got me mad. I didn’t share needles with nobody. How the hell [did I get HIV?] – (Low-adherer/Man/57 years old/Hispanic/20+ years since diagnosis)

More than half of participants in Action mentioned HIV stigma related to having to disclose their HIV diagnosis to others, due to *‘not wanting others to know.’* By comparison, less than 40% of participants who were Low-adherers or in Maintenance stage described HIV stigma related to disclosing their HIV status to others. Participants described missing doses of their HIV medications, because they did not want others to see them taking any pills. As explained by one participant in Action, many individuals in her home country had HIV, and HIV stigma resulted in widespread fear in their community. Therefore moving to the US facilitated her HIV medication adherence and willingness to take medication regularly (Table 4).

... You know, in our country, if somebody had that, everybody would be [aware of it]. Yeah. I didn’t want anyone to know I have it. That’s why it (was) making me scared about it [having HIV]. But since I came here in America...it’s no problem, you can take it, you can take your medicine any time...And that would make

Table 4 Qualitative themes related to lived experiences of the HIV continuum of care

Construct	Example quotes
Social ties	<p>Low-adherers (Stage 1)</p> <p>...I try to keep myself busy so much to not think about it...I don't know it's weird 'cause I haven't been in a relationship for six years. And my cousins ask me about it, my friends ask me about it, my mom asks me about it, and it's like – it gets frustrating, 'cause sometimes I don't think some people really understand where I'm coming from. They just see that I'm doing pretty well and that if I'm taking my meds then what's the problem?... – (Man/26 years old/Hispanic/6–9 years since diagnosis)</p> <p>... I was in so much pain, so much heartache. And then I had to share the information with my children and some of my family members because everybody don't understand what this disease is and what's going on, how you contract it and stuff like that. I didn't give it anyone, someone gave it to me... although I'm trying every day to focus, to stay focused and to live and be vibrant cause I have a grandbaby, one grandbaby, and my daughter's about to have a baby so I'll be a grandma a 2nd time... – (Woman/48 years old/African American/6–9 years since diagnosis)</p> <p>Action (Stage 2)</p> <p>...[Medication made] my body just started feeling funny, and... I was talking to my best friend and there's another person I know that's been on it for like 26 years...and she's like really my inspiration, yea. since like, I've known her since like '95. But she's been had it from '95 til now and she still looks good. – (Woman/38 years old/African American/1–5 years since diagnosis)</p> <p>... It's either you float or you drown...before you were able to like you know like do everything that they do. So people not understanding that and sometimes like my close family like my sisters they know but they don't understand. It's like I'm tired, we just walked like 5 blocks but I'm so tired and I feel like I ran a few miles. And I'm just tired. Or you know even now in the summer like my kids like they want to go to the park, they want to go to the beach, sometimes I just like, I, I, I just wanna be home ... – (Woman/30 years old/Hispanic/1–5 years since diagnosis)</p> <p>My kids [help me]. They call me Up,, "Dad, you take your medication?" I say, "Yeah, I did." "All right, we'll be over there." I'm like, "Aw, you ain't coming over here." Not ... not what ... let's see your pill case. You ... what you the ... what you the ... medication police or something? Yeah. – (Man/54 years old/African American/20+ years since diagnosis)</p> <p>Maintenance (Stage 3)</p> <p>...Yeah. I start medication like two years ago... [my friend] had more than 20 years with medication for HIV. He tell me, "Why the doctor tell you that you no need medication now? It's much better for you to start now... and it's more better for you prevent [to] something [from getting worse]." – (Man/46 years old/Other Race/6–9 years since diagnosis)</p> <p>What made it easier [to take medication] is the support I got here through the doctor and -- running the study. And friends, I had a big support team that...have already been on HIV pills and told me, don't freak out and stress, you know. There's always someone out there who's going to tell you something negative about ... about medications. Coming here made it a lot ... this particular office made it a lot easier for me, because I was comfortable here. – (Man/41 years old/White American/10–19 years since diagnosis)</p> <p>...Me and my partner, husband, stay on top of each other...otherwise, if we were both individual, then we'd probably forget. But we're always very ... try to be very vigilant about leaving them out, saying, "Did you take yours? I took mine," whatever... – (Man/55 years old/White American/Undisclosed years since diagnosis)</p>
Stigma	<p>Low-adherers (Stage 1)</p> <p>...I'm only 23 years old. I shouldn't ...have the HIV because it wasn't like I was a whore or something. My friend passed it on to me through a needle. So my life would've been good, but me being a good friend, not listening to my mother, or my grandmother, who is a RN, and had been an RN for a long time, we shared a hormone shot, so I gave it to her one, not knowing I still had the needle on there, so I stuck myself. So it was kind of my fault, but it was her fault too, because she'd had it for three years and didn't tell her only best friend that she called best friend, and then passed it on to me. But I told her she gave it to me. So we sat down and we cried, we talked, and everything else ... – (Transgender/23 years old/Hispanic/Undisclosed years since diagnosis)</p> <p>...I found out I was HIV through the board of health, cause I came out of jail and they sent me to the board of health and went to take an HIV test and I took it there...I got mad. Cause, it wasn't. I didn't, I didn't, I didn't get it through sharing needles. I got it through sex. That's one of the things that got me mad, I didn't share needles with nobody. How the hell [did I get HIV?] – (Man/57 years old/Hispanic/20+ years since diagnosis)</p> <p>I'm still denying I'm [HIV-positive]... I don't focus on it ... on my sickness. You know, and I'm glad like that because I don't be ... I don't be depressed. Matter of fact, I don't think about it, you know... I believe in God, and God said the devil is a liar. I never claimed it when I found out, and I'm still not claiming it. OK. I'm still not claiming I'm not HIV. I'm still not claiming it, you know... – (Woman/50 years old/African American/10–19 years since diagnosis)</p>

Table 4 (continued)

Construct	Example quotes
	<p>Action (Stage 2):</p> <p>...Because to take it [medication], some people when they see me taking it, they know. I was scared before, but now I can take it no problem. I can take it because I'm alone, I can take it any time. I can take the time they told me... You know, in our country, if somebody had that, everybody would be [aware of it]...Yeah. I didn't want anyone to know I have it. That's why it making me scared about it. But since I came here in America, then [AoW: Inaudible word], they control me.[AoW: Inaudible segment], it's no problem, you can take it, you can take your medicine any time.... And that would make me have courage for it. – (Woman/28 years old/African American/Undisclosed years since diagnosis)</p> <p>...I'm ashamed [of having HIV]. You know, I'm a very private person. Yeah, it's like I hate that I got this, so there's nothing good about it all the way around. There's nothing good about it. Every single day I wake Up,,, I hate myself. I hate ... I don't know how I'm going to feel today. My family would not touch me with a ten-feet pole if they knew. They would not come nowhere near me, nowhere ... my mother told ... tell me she do not want no parts of nobody with no ... with this here. So, to keep the relationship with her, that's my mother, I would not tell her. – (Woman/52 years old/African American/10–19 years since diagnosis)</p> <p>That's what really spoke to me and it speaks to me today because I can remember those dark days when so many of my friends and partners died, the stigma attached to HIV, the adverse side effects, the fear that haunted people, the fear that immobilized people. I was a part of that generation and as a result sometimes I became isolated and angry. – (Man/54 years old/African American/20+ years since diagnosis)</p> <p>Maintenance (Stage 3)</p> <p>Yes [others may not be deserving of gift cards when they are not adherent if they do]...street drugs. You know, they're too high, they forget to take their meds, or they'll sell their meds, you know, to get money to do the drugs...I don't know, because I'm not ... I'm not a drug user like that, so I don't know...for them selling the drugs, they're getting more money, because they don't have to stay on their point on their health, and they can make more money, you know, streetwise...they don't care about their health... – (Man/58 years old/Hispanic/Latino/10–19 years since diagnosis)</p> <p>[What are my] reasons for taking medicine? Because first of all, HIV is your immune system is low okay? And people are like "Oh my God you know HIV. Oooh oooh God Ooh get away from me!" Excuse me you know. The medicine is to keep me from getting sick. Like you have a cold. And you sneeze it on me. Don't sneeze on me, don't be scared. I'm scared of you! If I don't take my medicine then any—any thing I can get sick... – (Woman/56 years old/Other Race/10–19 years since diagnosis)</p> <p>...After I was healthy...I didn't feel like I was a poster child for HIV so I just live the regular life. I took my meds, but that was just it. Now recently because of a community group that I'm involved in who was really strong into the HIV community, HIV awareness. Then you know I am getting this, what we are like 3 or 4 years later now. But just day-to-day, I was never connected with the world. It was just something, you know like, that I was taking a vitamin or something. You know but just to have knowledge or information or education about HIV, I did not. And I definitely did not have education, like I have friends that's not even in the medical industry and they was like "oh yea, I know such and such is HIV positive." I said how? He said "psh, I know the meds." ... – (Man/44 years old/African American/ Undisclosed years since diagnosis)</p>

me have courage for it. – (Action/Woman/28 years old/African American/Undisclosed years since diagnosis)

tell her. – (Action/Woman/52 years old/African American/10-19 years since diagnosis)

Another participant described her unwillingness to disclose her HIV status to loved ones, because HIV made her feel 'ashamed.' She described feeling isolated from her family, and that her mother would not support her if she disclosed her HIV-positive status:

...Well, for me, to have [HIV], I'm not happy with it. I'm ... I'm ashamed. You know, I'm a very private person. Yeah, it's like I hate that I got this, so there's nothing good about it all the way around...My family would not touch me with a ten-feet pole if they knew. They would not come nowhere near me, nowhere ... my mother told ... tell me she do not want no parts of nobody with no ... with this here. So, to keep the relationship with her, that's my mother, I would not

Fewer participants in Maintenance expressed stigma than those in other stages. Instead, these participants were more likely to describe stigma as related to perceptions of others' risk behaviors (Table 4). Participants stated that individuals who engaged in risky behavior such as drug use or selling their HIV medications were 'undeserving' of financial incentives to promote viral suppression. Several participants in Maintenance stated that this was irrespective of whether someone was virally suppressed, because engaging in 'risky' behaviors jeopardized their health:

Yes [others may not be deserving of gift cards when they are not adherent if they do] street drugs. You know, they're too high, they forget to take their meds, or they'll sell their meds, you know, to get money to do the drugs...I don't know, because I'm not ... I'm not a

drug user like that, so I don't know...for them selling the drugs, they're getting more money, because they don't have to stay on their point on their health, and they can make more money, you know, streetwise... they don't care about their health... – (Maintenance/Man/58 years old/Hispanic/ Latino/10-19 years since diagnosis)

Another man in Maintenance discussed that stigma was something he experience in his past. With time and support, however, he had processed his illness and learned how to live a regular life (i.e., navigating the continuum to prolonged viral suppression). This individual described being part of a community group to help raise awareness about HIV, and that he now worked to dispel some of the stigma about living with HIV based on if individuals had HIV medications.

...After I was healthy, if you will, it was never like, I didn't feel like I was a poster child for HIV, so I just live the regular life. I took my meds, but that was just it. Now recently because of a community group that I'm involved in who was really strong into the HIV community, HIV awareness...And I definitely did not have education, like I have friends that's not even in the medical industry and they was like "oh yea, I know such and such is HIV positive." I said how? He said "psh, I know the meds [and I saw them]." ... – (Maintenance/Man/44 years old/African American/Undisclosed years since diagnosis)

Similar to discussion of social ties, raw and coded data were reviewed for all instances where stigma were discussed, and whether discussion referred to stigma of HIV diagnosis, of disclosing HIV status to others, or stigmatizing others with HIV due to 'risky behaviors' such as drug use. As mentioned, women comprised the majority of Low-adherers. Also, a greater proportion of women than men discussed stigma related to their HIV diagnosis (65% versus 50%, respectively). Women also stigmatized others' HIV risk behaviors more than men, and more frequently reported negative perceptions of others who engage in 'risky' behaviors despite their HIV diagnosis (30% versus 16%, respectively). These data support our grounded theory, in that women may be more negatively affected by stigma than men in relation to their ability to successfully navigate the care continuum towards sustained viral suppression.

Discussion

The present research explored social ties and stigma among individuals living with HIV as related their medication adherence, and is the first to focus on the individual-level impact of these factors in HPTN 065. The present study is

also unique in its grounded theory which suggests that individuals may begin directing HIV stigma from inward to outward as they begin to better manage their HIV. This process may consist of first stigmatizing themselves at diagnosis, experiencing stigma from others as they disclose, and then stigmatizing others once their HIV is well controlled. Findings from this HPTN 065 sub-study suggest that social ties and stigma are highly salient aspects of lived experiences as individuals move across the HIV care continuum from diagnosis to long-term viral suppression (Fig. 1). Forms of stigma may differ along this continuum, particularly by gender (Tables 2, 3, 4). Several of our findings are consistent with previous research.

First, financial incentives to promote viral suppression were used in HPTN 065 because of their demonstrated effectiveness in previous research. As described in previous qualitative studies of HPTN 065 [26–28], our study found that participants viewed financial incentives as 'nice but unnecessary.' Incentives were described as beneficial, but individuals were more willing to 'wanting to be healthy' as motivational, even when they were Low-adherers and virally unsuppressed. Recent literature suggests that even among individuals with well-controlled HIV, medication adherence motivation fluctuates daily and may directly impact adherence [32–35]. Therefore, financial incentives may be a critical facilitator of adherence, even when individuals express self-motivation to take their HIV medications [32–35].

Many participants mentioned social interactions when describing their experiences living with HIV—however, social ties were not universally described as supportive of medication adherence or HIV management. Low-adherers also described more instances of contentious interactions, such as strain from disclosing HIV status to loved ones. Participants further along in managing their HIV medication adherence generally described more supportive interactions with social ties, compared to those whose HIV medication adherence was less consistent. While the present research is exploratory in nature, previous research has associated negative social interactions as barriers to HIV medication adherence [18, 26, 36–40].

Social ties were not always described as supportive by participants, which is in contrast to much of the literature about social support being protective for individuals living with HIV. Considering the lens of sensitive interaction systems theory, interactive coping may help to contextualize the relationship strain caused when individuals disclose their HIV status to loved ones and are seeking emotional social support that is not being provided [12]. Because many African Americans living with HIV may also be of lower socioeconomic status, they may rely more on their social networks for HIV-related support due to limited access to HIV services. Their social ties may be providing care for which they are unprepared, straining the relationship due

to mismanaged expectations [12, 38–40]. Negative social interactions may subsequently reduce medication adherence and number of social supportive ties overall [41, 42]. It is noteworthy that much of the existing literature on HIV caregivers has been conducted in international contexts where social norms and availability of services are different from domestic settings [43–50]. More research is needed to address the intersection of stigma, emotional attachment, and caregiving roles among African Americans with HIV, and future interventions to promote adherence must include coping skills to manage social interaction related to HIV care [34, 36, 38, 40, 46].

Although participants were not explicitly asked about HIV stigma, various instances emerged depending on an individual's stage of adherence. Low-adherers described recent experiences of HIV stigma related to being '*undeserving*' of HIV diagnosis, while individuals in the Action stage described stigma related to disclosing their HIV status as a reason for missed medication doses. Individuals in Maintenance mostly reported past experiences of HIV stigma, and nearly one-third stated that individuals living with HIV who engaged in '*risky*' behaviors were undeserving of financial incentives even if they were virally suppressed.

While this was not the focus of the present analyses, a handful of individuals across all adherence stages mentioned mental health challenges while coping with their illness. Mental health challenges in managing HIV diagnosis are intertwined with stigma and can lead to contentious social ties, that negatively impact medication adherence and viral suppression [43–47]. More research is needed to contextualize the pathways of HIV-related stigma which may intersect with mental health and poor HIV outcomes in the African American community [40–48]. Additionally, existing interventions to reduce stigma lack high methodological rigor [50], and have not comprehensively addressed current and past experiences of HIV-related stigma as multi-level determinants of long-term viral suppression outcomes among African Americans.

Study findings also reinforce existing research on gender differences in lived experiences of HIV. Low-income African American women also report lower HIV medication adherence and viral suppression than their African American men counterparts [39, 43, 46, 51, 52]. In the present study, participants were not directly asked about gender identity as related to their experiences living with HIV. Nonetheless, women comprised the majority of Low-adherers, articulated the most instances of current stigma, and perceived less supportiveness from their social ties. Given that women tend to begin HIV medication at a later stage of their HIV illness progression, are less likely to achieve viral suppression [51, 52], and are more likely to report elevated depression levels after HIV diagnosis [51–55], interventions are urgently

needed among African American women who are among the populations hardest hit by HIV in the U.S.

Limitations

The present study has several limitations. First, the themes explored related to social ties and stigma were not explicitly examined as part of the primary sub-study and instead arose spontaneously. Similarly, the composition of our sub-study – in terms of gender, geography and other characteristics is likely to differ from other contexts. While our findings suggest that the experience of stigma may vary by gender and adherence stage, these should be further examined in future research. Also, secondary analyses were conducted using grounded theory while primary analyses were thematic in approach. However, axial and selective coding are thematically-driven grounded theory processes that have been previously conducted in secondary analyses [31], and the lead author of the original analyses guided this secondary analysis [26–28]. Next, HPTN 065 study was conducted in DC and NY, however community-level perceptions of HIV-related stigma vary by culture, region and gender. Therefore, study findings must be contextualized with caution among other predominantly African American low-income populations living with HIV. Finally, lesbian, gay, bisexual, or transgender (LGBT) status is often related to experiences of stigma and viral suppression outcomes among individuals living with HIV, irrespective of race or gender. The present analyses did not identify salient differences by sexual orientation, and instead focused on gender differences in HIV-related experiences.

Conclusions

Stigma related to HIV diagnosis and disclosure represent critical barriers to medication adherence and viral suppression among low-income African Americans. Within the context of care provision, programs which target individuals with few supportive ties and greater experiences of HIV stigma are critical. Low adherence is a stage during which these barriers are particularly challenging; therefore, programs must promote skill-building to foster supportive social ties. In the present study, motivation related to medication adherence appeared associated with viral suppression, and often, social ties were critical determinants of adherence motivation and subsequent pathways to promote long-term viral suppression. Future research should further explore the role of gender in social ties, stigma and HIV medication adherence outcomes among low-income, vulnerable patients of color living with HIV. More research is

needed to examine our finding that individuals begin internalizing HIV stigma when they are diagnosed but, as they navigate towards medication adherence, direct stigma outward towards others' risk behaviors. Finally, future interventions to improve health outcomes among African Americans should focus on gender-related norms in addition to social ties and HIV stigma, to target African American women who continue to be at great risk of negative HIV health outcomes.

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