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### Title

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### Permalink

<https://escholarship.org/uc/item/1hx4w95r>

### Journal

Western Journal of Nursing Research, 42(1)

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### Publication Date

2020

### DOI

10.1177/0193945919842874

Peer reviewed



# HHS Public Access

Author manuscript

*West J Nurs Res.* Author manuscript; available in PMC 2021 January 01.

Published in final edited form as:

*West J Nurs Res.* 2020 January ; 42(1): 4–13. doi:10.1177/0193945919842874.

## The Relationships among Social Capital, HIV Self-management and Substance Use in Women

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### Abstract

Women living with HIV (WLHIV) face unique challenges to successfully self-manage HIV including substance use and limited social capital. We conducted a 6-month mixed-methods study to describe how social capital influences HIV self-management and substance use among WLHIV. Participants completed a self-report survey and in-depth interview at baseline, 3 and 6 months. Descriptive statistics, *t*-tests, and generalized estimating equations were used to examine quantitative relationships. Qualitative data were analyzed using qualitative description. Current substance users reported lower social capital compared with past substance users (2.63 vs 2.80;  $p=0.34$ ). Over time, substance use and social capital were associated with HIV self-management (Wald  $\chi^2=28.43$ ;  $p<0.001$ ). Qualitative data suggest that HIV self-management is influenced by overlapping experiences with social capital, including influential trust, community, and value of self can be complicated by ongoing substance use. Social capital can facilitate improved HIV self-management; however, substance use and trauma can weaken this relationship.

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**Conflicts of Interest:** The authors have no relevant conflicts of interest do declare.

## Keywords

Substance Use; Women; HIV; Mixed-Methods; Self-Management

Women account for approximately 24% of people living with HIV (PLHIV) in the United States, and 19% of new infections (Centers for Disease Control and Prevention [CDC], 2018a). African American women continue to be disproportionately affected by HIV, and account for the largest proportion of women infected with HIV in the US (61%) (CDC, 2018a). Women may also face unique challenges that increase their risk of acquiring HIV including low perceived risk of HIV infection (United States Department of Health and Human Services [USDHHS] Office on Women's Health, 2018b); low perceived power in relationships and fear of rejection that may decrease self-protection (Berenson et al., 2015); and barriers to regular screening for HIV infection such as poverty, stigma, and fear of discrimination (CDC, 2018a).

## Social Capital, HIV, and Substance Use

Substance use among women living with HIV is a major public health concern that is both an independent and aggravating risk factor for HIV transmission (CDC, 2018b). Although fewer women than men use drugs, women are more likely to experience detrimental health effects from drug use, and may become addicted to substances more quickly (National Institute on Drug Abuse, 2016; USDHHS Office on Women's Health, 2018a). Compared to men, women may have unique reasons for initiating drug use, including the use of substances to lose weight, to cope with anxiety and exhaustion, and to deal with higher rates of chronic pain that has been treated with prescription drugs (National Institute on Drug Abuse, 2016; USDHHS Office on Women's Health, 2018a). In one study 37% of WLHIV had substance-use problems, which was significantly higher than men (30.2%,  $p<0.001$ ). Substance use increases the risk of HIV infection while diminishing the ability of PLHIV to adhere to their medications and self-manage their illness (USDHHS, 2018b; Zhang et al., 2018). However, few investigations have examined substance use among women living with HIV (WLHIV). Illicit substance use negatively impacts HIV self-management tasks, including HIV medication adherence and initiation and retention in HIV primary care (Vidot, Lerner, & Gonzalez, 2017; Lake et al., 2017). Recently, data from the Women's Interagency HIV Study reinforced that women who use illicit substances encounter suboptimal medication adherence, despite simplification of HIV drug regimens (Zhang et al., 2018).

Social capital is the aggregation of potential resources, linked to a durable network of relationships of mutual acquaintance or recognition. While debated (Derose & Varda, 2009; Lochner, Kawachi, & Kennedy, 1999), components of social capital include reciprocity, trust, safety, social agency, social networks, value of life, and employment connections (Onyx & Bullen, 2000). Research on social capital and HIV has predominantly focused on preventing HIV transmission with increased social capital being associated with decreased HIV transmission (Campbell, Williams, & Gilgen, 2002). High social capital was the

strongest predictor of HIV self-management in WLHIV and specifically on HIV medication adherence (Phillips et al., 2013; Webel, Phillips, et al., 2012).

Social capital has also been negatively associated with substance use among youth (McPherson et al., 2013; Winstanley et al., 2008) and African-Americans (Green, Doherty, Reisinger, Chilcoat, & Ensminger, 2010). Discrimination was associated with illicit drug use in African American women and aspects of social capital protected women against its effects (Stevens-Watkins, Perry, Harp, & Oser, 2012). However, in rural Appalachia illicit drug use was associated with greater social capital (Jonas, Young, Oser, Leukefeld, & Havens, 2012), highlighting the need to carefully assess social capital and its relationship to substance use behaviors. Given that most examinations of social capital among PLHIV are quantitative and cross-sectional, there is a need to gather more qualitative and mixed methods data to better understand its relationship to health outcomes (Ransome, Thurber, Swen, Crawford, German & Dean, 2018).

## Purpose

The purpose of our concurrent mixed methods pilot study was to examine if and how social capital influences HIV self-management (measured by HIV medication adherence and the HIV self-management scale) and substance use patterns over time among WLHIV by converging both quantitative and qualitative interview data.

## Method

### Design

We conducted a 6-month, mixed methods longitudinal study with 29 WLHIV who were either current or previous illicit substance users. The use of a concurrent mixed methods longitudinal design was necessary because while numerous studies document a relationship between social capital and HIV health outcomes (Ransome et al., 2018), little is known about how the dimensions of social capital are developed and used to improve those outcomes over time. Integrating concurrent qualitative and quantitative data to examine social capital in this population will allow a more in-depth understanding of how social capital influences HIV self-management and substance use patterns among WLHIV. Social capital cannot be fully captured by psychometric scales, but by integrating qualitative data with quantitative measures we can more comprehensively describe its dimensions.

### Sample

To be included in this study eligible participants had to be (1) Biologically female at birth, (2) adult (aged 18 years), (3) diagnosed with HIV (HIV+ ELISA with confirmatory Western blot or positive HIV-1 RNA level, based on chart review), and (4) currently prescribed HIV antiretroviral therapy medication. Potential participants were excluded if they were either unable to understand spoken English or if they had plans to move out of the area in the next 12 months. This descriptive study was designed as a pilot study to examine if and how social capital influences HIV self-management in this population and if a relationship was observed, we planned to conduct future, fully powered studies to examine

these relationships across multiple sites. As such, our anticipated sample size was approximately 40 WLHIV at a single site.

## Procedures

Potential subjects were from an existing HIV-research registry of approximately 300 adults living with HIV in Northeast Ohio. All registry participants had contacted the study team about previous research opportunities and had given written consent to be included in the registry. All women in the registry were sent an IRB-approved letter explaining the study and asking them to contact the study team via telephone if they were interested in participating. Those who responded were screened via telephone for illicit drug use using the Drug Abuse Screening Test-10 (DAST) (Yudko, Lozhkina, & Fouts, 2007). Subjects scoring  $> 1$  were included in the current illicit drug use strata and those scoring a 0 were included in the not using illicit drugs strata. If we found out during the qualitative interview that the participant has used illicit substances within the past 12 months, she was given a DAST score  $> 1$  regardless of the screening form or the surveys. If a woman met eligibility criteria, she was scheduled for a research visit. At the first research visit, a research assistant explained the study and obtained written informed consent. Next, she completed a battery of surveys in REDCap and an open-ended social capital interview. Interviews were guided by a semi-structured interview guide and audio-recorded. Quantitative surveys were completed prior to interviews to introduce the concepts that were to be discussed and to standardize the data collection. At the conclusion of the visit, participants were compensated with \$20 cash for their time and travel. Data were collected between July, 2015 and June, 2016. All procedures were approved by the Institutional Review Board at the Medical Center.

## Data Collection Measures.

To quantitatively describe how social capital influences HIV self-management and substance use patterns over time among WLHIV we assessed the following variables, based on the literature described above: social capital, HIV self-management, substance use, and potential confounding variables. Participants completed study assessments at baseline and then approximately three and six months later.

Social capital was measured using the 36-item *Social Capital Scale*. This widely-used and psychometrically validated instrument generates a total social capital score and measures eight subscales including: participation in the local community, social agency, feelings of trust and safety, neighborhood connections, friends and family connections, tolerance of diversity, value of life, and workplace connections (Onyx & Bullen, 2000; Webel, Phillips, et al., 2012). Participants rated each item on a 1–4 Likert-type scale. Higher mean scores indicate more social capital. Cronbach's alpha reliability for the social capital scale in adults living with HIV is 0.88 (Webel, Phillips, et al., 2012).

We examined two aspects of HIV self-management, HIV medication adherence and a global measure of HIV self-management. HIV antiretroviral medication adherence was assessed with a 30-day adherence visual analog scale (Lu et al., 2008; Walsh, Mandalia & Gazzard, 2002). To measure HIV self-management more globally, participants also completed the 20-item *HIV Self-Management Scale*, which generates a total score from items measured on a

0–3 scale and measures three domains of HIV self-management (daily health practices including physical activity, diet, etc; social support; and managing HIV as a chronic disease). This scale has been previously examined and was found to be psychometrically valid for use among WLHIV (Webel, Asher, et al., 2012).

Substance use was assessed with the valid and reliable 11-item self-report *Drug Use Disorders Identification Test (DUDIT)* developed to screen individuals for drug problems (Voluse, Sobell, Dum, Sobell, & Simco, 2012). Total scores range from 0 to 44, with higher scores being suggestive of a more severe drug use problem.

Descriptive and potential confounding variables included demographic and medical characteristics, traumatic events and experiences of discrimination and were selected based on previous literature reviewed above. Demographic characteristics were self-reported and included, race, education level, family composition, employment, sexuality and housing status. Medical characteristics, abstracted from the participant's electronic medical record, included year diagnosed with HIV, current CD4+ T cell count, HIV Viral Load, HIV medication history, and retention in HIV primary care. Recent traumatic events were assessed with the 20-item *List of Threatening Experiences Scale*, which lists the experience of traumatic events (e.g., injury, death of a relative, loss of a job or housing, rejected because she had HIV) in the past month. Each of these 20-items are summed and higher scores indicate more traumatic experiences (Corless et al., 2013). Experiences with discrimination were assessed with the widely-used, and valid 9-item *Everyday Discrimination Scale* (Krieger, Smith, Naishadham, Hartman, & Barbeau, 2005; Taylor, Karmack, & Shiffman, 2004). Participants noted how often (never to almost every day) they experienced acts of discrimination. All items are summed (range of 0–45) and higher scores indicate more discrimination.

To qualitatively describe how social capital influenced HIV self-management and substance use patterns, we developed a *semi-structured qualitative interview guide* based on existing literature to guide in-person interviews. Prior to using it with participants, experts in substance use and women and in WLHIV assessed the interview guide for clarity, relevance, and appropriateness. The *baseline interview guide* initially focused on early substance use, current health practices, past and current social networks, and social capital dimensions (e.g., trust, reciprocity, community resources, community resilience). After several interviews, based on new themes spontaneously emerging from the interviews, it was revised to include more probes related to how trust influences health behaviors and the specific role of faith and its influence on health behaviors. In other words, in the first few interviews WLHIV discussed the role of trust and faith on their health behaviors and we deemed it so important that we wanted to give all respondents a chance to discuss these topics. The *three- and six-month interview guides* were shorter and focused on changes in life situations, health practices, social capital, substance use and resilience that were observed in their quantitative measures. These guides were designed to help us understand any changes in our variables of interest and how they influenced self-management behaviors.

## Data Analysis

Data analysis of the qualitative and quantitative data occurred at the same time, but were not integrated until both types of data were analyzed. In analyzing the quantitative data, we first assessed the distribution of all quantitative variables (demographic and medical characteristics, social capital scores, HIV self-management and substance use behaviors, and potential confounding variables). We summarized baseline characteristics by using means, standard deviations, medians, interquartile ranges, counts and percentages of women by substance use group (current or previous substance user), depending on the variable's distribution. We used generalized estimating equations (GEE) with an identity link function and an unstructured correlation structure to describe how social capital and substance use influences HIV self-management across the three time points. Separate models were fit for each HIV self-management outcome. In addition to the effect of social capital and substance use, we examined independent effects of age, discrimination and traumatic events by adding these covariates to GEE models. All statistical analyses were conducted using Stata 14.0 (College Station, Texas) with  $p$ -values  $< 0.05$  considered statistically significant.

Qualitative data were managed using the qualitative data analysis program Dedoose and was analyzed by the research team using qualitative description methodology (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000, 2010). Data were transcribed and examined by two research team members (C.S. and A.W.) who coded the data using the constant comparative method, identifying patterns and themes (Corbin & Strauss, 2008; Curry, Nembhard, & Bradley, 2009). These team members met regularly during coding to discuss consistencies and inconsistencies in the data. *A priori* codes related to social capital, substance use, and self-management based on our literature review, were initially applied then inductive codes were applied. Transcripts were revisited in a series of iterative steps (C.S. and A.W.) to confirm coding classification and that theoretical saturation was reached. Variations on the themes and negative cases were identified to help understand the full range of data within codes. A final codebook of themes, definitions, and exemplar codes was created to aid analysis. Data were coded, and analyzed using Dedoose version 8.0.42 (SocioCultural Research Consultants, 2016). Study procedures are presented consistent with the Good Reporting of a Mixed Methods Study (GRAMMS) standards (O' Cathain, Murphy, & Nicholl, 2008).

## Results

WLHIV ( $n = 29$ ) were enrolled, 22 completed the 3-month assessment and 19 completed the 6-month assessment (66% retention). On average participants were 50.9 ( $\pm 6.9$ ) years old, African American ( $n = 27$ , 93%), single or divorced ( $n = 23$ , 79%), and unemployed or disabled ( $n = 20$ , 69%). They had been living with HIV approximately 16 ( $\pm 6.8$ ) years, had been on HIV antiretroviral therapy for 15 ( $\pm 5.1$ ) years, had an average CD4+ T cell count of 1020 (614)  $\text{mm}^3$ , and were virally suppressed ( $n = 28$ , 95%). There were no demographic, HIV, or medical characteristic differences between WLHIV currently using illicit substances and those who previously used illicit substances (Table 1).

Participants reported moderate social capital scores at baseline ( $2.71 \pm 0.46$ ), with no differences between WLHIV who currently use illicit substances and those who previously



used illicit substances ( $p = 0.32$ ). Women experienced approximately three traumatic events in the past month and low levels of discrimination. Women who previously used illicit substances had better daily HIV self-management, compared to those who currently use illicit substances (53.4 vs. 45.3,  $p = 0.005$ ). There were no differences in HIV medication adherence between groups (Table 2).

Substance use negatively impacted daily HIV self-management ( $p = 0.01$ ), but did not significantly reduce HIV medication adherence ( $p = 0.19$ ), controlling for age, traumatic events and discrimination over time. A higher social capital score was associated with better HIV self-management and HIV medication adherence, perhaps offsetting the negative effects of substance use over time (Tables 3 and 4).

To understand how social capital exerted this positive effect, qualitative data were searched for codes related to social capital or its dimensions. Several key interrelated themes emerged including trust, community, and value of self.

### **Trust is powerful, but scarce, and has to be earned**

An overarching theme was the power of trust to improve self-management, which was summed up by one woman as follows, if “ladies or addicts ... that could have someone they could trust ... confide in whatever is on their mind or what they are going through ... I think the alcohol and the drugs would be gone.” While this indicates that trust is a powerful tool, it also reveals just how scarce trust is among this population. Who WLHIV trusted varied and included themselves, their family and friends (including faith leaders), and even their healthcare workers. One woman said, “I trust myself, my best friend, and my son.” WLHIV recognized the importance of trusting relationships and some started most relationships with a presumptive trust, but described trust as a two-way street. For example, one woman said, “I don’t have a distrust with too many people. Basically I’ll give you a first chance... I’ll give you a chance. If you mess up that chance ... there’s no trust there.” For another participant: “[My friends] are indeed trustworthy but I don’t trust them with my deepest, innermost because they are not trained counselors and psychiatrists... When I’m talking about what has my head messed up, I need real answers and real solutions.” One participant explicitly described trust in her healthcare workers. She said:

When it comes to my medical team. I have an HIV doctor, a cancer doctor, and an Ob/GYN. I trust these ladies wholeheartedly when it comes to my well-being. I do. Not only are they good with the medical part, they’re good dealing with me and my psychological issues and you know can keep me calm and make me understand why, when, how and what.

There was variation in perceptions of trust in relation to self-management behavior. Some women viewed trust as a positive influence or a mechanism to take better care of themselves.

Trust-knowing that I can go to them and share anything with them without them convicting me is good, or they let me see when I’m wrong or when something is going they can look at me and tell me ‘you ain’t looking good, something on your mind?’ That right there is security within itself?



One woman described how she will “allow my son, if he sees me messing up or doing something I shouldn’t be doing ... to say something to me. But if you don’t know the situation ... and you’re not in my circle, don’t say nothing.” A few participants did not think trust influenced their health behaviors, particularly trust in others. One WLHIV said, “I take care of myself, I don’t care if nobody trusts me or if I don’t trust anybody else. I will still take care of myself.”

### **A woman’s community influences trust, which in turn can affect self-management.**

Foundational to trust was the women’s communities and how the community could support or damage that trust. Many described their community as neighborly, “My neighborhood is a community, a family community. [There are] a lot of animals, people stay to themselves but say ‘hi, how you doing?’ We’re neighborly.” The community offered tangible resources (e.g., hot meals, fresh produce) to help women take care of their health needs. “I go to community meals once a month and see the same people there each time.”

Less tangible but equally important was how community comes together and transmits information that helps WLHIV recover from their addictions. When describing a vigil held by her community to commemorate a tragedy one woman said, “When you riding down the street and see a telephone pole with teddy bears, signs, and balloons, it makes you think ... it [reminds] me of the things I was doing in the past, drugs and stuff.” By helping confer a sense of identity, the provision of resources, and ultimately value, a woman’s community can influence her trust, which can affect her self-management behavior.

But some WLHIV reported detrimental aspects of her community including safety, noise and recently moving into a new neighborhood. For example, a WLHIV was hesitant to access her community resources because of perceived safety threats. “There is a community center but I don’t go there. I’m terrified because it’s a lot of guys who just hang out...” Others did not feel the community helped improve health behaviors and described unhealthy community norms. “[To deal with hard times], my community gets high.” In these cases, community was still influential but in a way that did not promote healthy behaviors.

### **A strong value of self facilitates engagement in self-management behavior.**

The belief that a WLHIV had value was also critical for engaging in self-management behavior. As one woman described, “First you have got to believe in yourself. You have to believe that just because you have a disease, that you’re worth living. You’re worth something and try to live.... You have to find a way to take the good things about yourself and try to make them better.” And “Feeling valued motivates me to do better things for myself today.” However, it was not always easy for WLHIV who use(d) illicit substances to believe they had value.

If you apply for a job and are honest and tell them ‘I used to do drugs’ they’ll discriminate you on that because every drug addict, they get stereotyped as a thief, a liar, which all of us is, but when you go to clean up your life, that’s what keep so many people down.

Despite prejudice, the communities WLHIV belonged to were able to convey a woman's worth through providing resources. One illustrative example was when a local community helped a woman find value by educating her children. As she described,

What I love about my neighborhood is the schooling. The community helped detect my son's ADHD and when I moved here they [screened him] and contacted me and let me know, and then they moved him to another school that might help him. They don't give up on the childrens. They childrens is their future.

However, the benefits of social capital and the ability to access these resources can be inhibited by substance use. When providing advice on how to recover from addiction one woman described it as the need to "Change people friends, and everything." Starting over can help remove triggers for addiction, but rebuilding a social network that provides critical dimensions of social capital can be all-consuming. So that while community, and the social capital built up through engagement with that community, has many benefits that help WLHIV engage in healthy behaviors; for WLHIV who are recovering from addiction or trying to abstain from substance use the loss of the "substance use community" can also be difficult.

## Discussion

In our mixed methods study examining the influence of social capital on HIV self-management among WLHIV, we observed that social capital is important for self-management and we were able to integrate new qualitative data on how social capital does this. Social capital has consistently been linked to improved health outcomes among adults living with HIV, but what has been missing from the literature is how it does that. Our quantitative data are consistent with this literature and clearly demonstrate that better social capital is associated with better self-management in WLHIV. Yet by qualitatively examining the components of social capital in- depth, we describe how three key components of social capital can improve HIV self-management in this population—trust as a powerful yet scarce resource, a WLHIV's community directly influences that trust, and having a strong value of self. Each of these components required that WLHIV actively and positively engage with their social network. However, for women trying to overcome a substance addiction, this can be particularly challenging since aspects of her social network can trigger substance use either directly or via social capital mechanisms we describe. Further, being identified as a current or former substance user may fracture existing social networks or prevent WLHIV from being more connected to their community, which could influence their access to certain types of social capital. Our qualitative data suggest that rebuilding a strong social network, one that enhances trust in others and in oneself, increases engagement with her community, and ultimately helps a WLHIV believe in her value as a person.

Our data also provide insight into how nurses can help enhance social capital in this population, including having members of the health care team spend the time necessary to earn and keep the trust of WLHIV. Our quantitative data suggest that such efforts may help to improve HIV self-management behavior in this population. Recently, investigators described the importance of building trust in HIV care and engagement over time (Dawson-Rose et al., 2016; Wood et al., 2018). Our data support those findings and highlight that the

long-term trust-building process is critical for those living with chronic HIV infection, and perhaps this process may be even more critical among highly vulnerable populations. However, our qualitative data also reveal other ways to improve social capital, and obtain the benefits derived from it, that are more challenging to implement. We saw clear evidence that physical community can improve a WLHIV's health behaviors. Whether offering tangible goods, information, kindness, or effective use of the school infrastructure, our participants derived much-needed resources from their community, which led to an increased sense of value. This increased sense of value motivated WLHIV to engage in HIV self-management behaviors to help improve their health. These data suggest that continuing to advocate for policies and resources to connect neighbors to one another and emphasizing our similarities can help improve the health of WLHIV.

We also found quantitative evidence that WLHIV face challenges to engaging in HIV self-management that may be influenced by recent traumatic events. While this is consistent with other studies that highlight that levels of trauma exposure influence HIV outcomes, lifetime trauma is also ubiquitous in this population. In high-resource settings, such as ours, trauma and interpersonal violence are estimated to be experienced by 68–95% of WLHIV (Sales, Swartzendruber, & Phillips, 2016). Recognizing the influence of trauma on poor health outcomes in WLHIV and recognizing that trauma can be successfully treated, clinicians and advocates are adopting trauma-informed care models for HIV care. Trauma-informed care models emphasize that both clinician's and individual's recognition and respond to trauma and create an environment that is safe and empowering for WLHIV (Machtinger, Cuca, Khanna, Rose, & Kimberg, 2015). Our quantitative and qualitative data suggest that promoting social capital both within the clinic setting and in the community may temper the negative impact of trauma and provide previously untapped avenues for addressing substance use with WLHIV.

However, we also found differences between our findings and existing literature. A key difference is that we did not find diminished HIV medication adherence between current and previous substance users. Substance use is considered one of the main barriers to achieving higher rates of viral suppression when an HIV diagnosis is established (CDC, 2016). The use of different substances in individuals with HIV is associated with lower antiretroviral therapy adherence, (D'Souza et al., 2012; Rosen et al., 2013; Vidot et al., 2017) increased missed clinic visits, (Kipp et al., 2017; Lake et al., 2017) and decreased knowledge of HIV status (Bruce et al., 2015). This previous research suggests that fundamental resources such as money, time and energy will mainly be used to acquire and use substances with little attention directed to self-care. While we observed a relationship between substance use and global HIV self-management, we did not observe a relationship between substance use and HIV medication adherence. There are several possible explanations for this. First, the field of HIV has done a phenomenal job of teaching all PLHIV of the primary need to take HIV medications every day. As the medications have improved and many PLHIV are taking one HIV medication once a day, it has gotten easier to adhere to these medications. So despite many WLHIV facing personal and structural barriers to HIV medication adherence, the importance of adherence coupled with simplified regimens may help them overcome these barriers. Additionally, our sample of volunteer participants is small and though we saw a

negative effect of substance use on HIV medication adherence, our study may have been underpowered to detect a statistically significant effect.

In addition to our small sample size, there are several other limitations that should be considered. First, all WLHIV were recruited from a single site in the Midwestern United States. The demographics (older, African American) and substance use patterns of our sample limit generalizability of our findings. We also did not use member checking to help enhance the rigor of our findings. However, we tried to overcome these limitations by employing several strategies including triangulating both qualitative and quantitative data, having prolonged engagement between the community of WLHIV and research team, and having multiple team members engaged in our data integration. Integration of quantitative data with our rich qualitative data led to new insights into how social capital can be fostered among WLHIV and how it can be used to overcome challenges faced by them. This would not have been possible without data integration.

In conclusion, social capital was associated with better HIV self-management and HIV medication adherence over time, perhaps offsetting the negative effects of substance use. Social capital increased trust, fostering a strong sense of community, and helped WLHIV feel valued. These findings enhance understanding of how nurses can support WLHIV who are addicted to illicit substances and to help them maintain sobriety and improve their HIV self-management.

### Acknowledgement:

We wish to acknowledge the substantial and invaluable contributions to this study by Jackson Currie and the women who participated in this study.

**Source of Funding:** This project was funded by a seed grant from the Midwest Nursing Research Society and by the National Institutes of Health Grant T32NR014213.

### References

- Berenson KR, Paprocki C, Fishman M, Bhushan D, El-Bassel N, & Downey G (2015). Rejection sensitivity, perceived power, and HIV risk in the relationships of low-income urban women. *Women & Health, 55*(8), 900–920. [PubMed: 26086275]
- Bruce D, Kahana SY, Bauermeister JA, Nichols SL, Hightow-Weidman LB, Heinze JE, ... the Adolescent Medicine Trials Network for HIV/AIDS Interventions (2015). Neighborhood-level and individual-level correlates of cannabis use among young persons living with HIV/AIDS. *Drug and Alcohol Dependence, 151*, 173–180. [PubMed: 25858786]
- Campbell C, Williams B, & Gilgen D (2002). Is social capital a useful conceptual tool for exploring community level influences on HIV infection? An exploratory case study from South Africa. *AIDS Care, 14*(1), 41–54. [PubMed: 11798404]
- Centers for Disease Control and Prevention. (2016). Monitoring selected national HIV prevention and care objectives by using HIV surveillance data-United States and 6 dependent areas-2014. HIV Supplement Report, 1(3).
- Centers for Disease Control and Prevention. (2018a). HIV among women. HIV/AIDS: HIV by group Retrieved from <https://www.cdc.gov/hiv/group/gender/women/index.html>
- Centers for Disease Control and Prevention. (2018b). Statistics overview: HIV surveillance report Retrieved from <https://www.cdc.gov/hiv/statistics/overview/index.html>
- Corbin J, & Strauss A (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: SAGE.

- Corless IB, Voss J, Guarino AJ, Wantland D, Holzemer W, Hamilton M, ... Cuca Y (2013). The impact of stressful life events, symptom status, and adherence concerns on quality of life in people living with HIV. *Journal of the Association of Nurses in AIDS Care*, 24(6), 478–490. [PubMed: 23473660]
- Curry LA, Nembhard IM, & Bradley EH (2009). Qualitative and mixed methods provide unique contributions to outcomes research. *Circulation*, 119(10), 1442–1452. [PubMed: 19289649]
- D'Souza G, Matson P, Grady CD, Nahvi S, Merenstein D, Weber K, ... Wilson TE (2012). Medicinal and recreational marijuana use among HIV-infected women in the Women's Interagency HIV Cohort (WIHS), 1994–2010. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 61(5), 618–626. [PubMed: 23011399]
- Dawson-Rose C, Cuca YP, Webel AR, Solís Báez SS, Holzemer WL, Rivero-Méndez M, ... Lindgren T (2016). Building trust and relationships between patients and providers: An essential complement to health literacy in HIV care. *The Journal of the Association of Nurses in AIDS Care*, 27(5), 574–584. [PubMed: 27080926]
- SocioCultural Research Consultants. (2016). Dedoose: Web application for managing, analyzing, and presenting qualitative and mixed method research data [computer software] Available from [www.dedoose.com](http://www.dedoose.com)
- Derose KP, & Varda DM (2009). Social capital and health care access: A systematic review. *Medical Care Research and Review*, 66(3), 272–306. [PubMed: 19174538]
- Green KM, Doherty EE, Reisinger HS, Chilcoat HD, & Ensminger M (2010). Social integration in young adulthood and the subsequent onset of substance use and disorders among a community population of urban African Americans. *Addiction*, 105(3), 484–493. [PubMed: 20402992]
- Jonas AB, Young AM, Oser CB, Leukefeld CG, & Havens JR (2012). OxyContin(R) as currency: OxyContin(R) use and increased social capital among rural Appalachian drug users. *Social Science and Medicine*, 74(10), 1602–1609. [PubMed: 22465379]
- Kipp AM, Rebeiro PF, Shepherd BE, Brinkley-Rubinstein L, Turner M, Bebawy S, ... Hulgian T (2017). Daily marijuana use is associated with missed clinic appointments among HIV-infected persons engaged in HIV care. *AIDS and Behavior*, 21(7), 1996–2004. [PubMed: 28213820]
- Krieger N, Smith K, Naishadham D, Hartman C, & Barbeau EM (2005). Experiences of discrimination: Validity and reliability of a self-report measure for population health research on racism and health. *Social Science and Medicine*, 61(7), 1576–1596. [PubMed: 16005789]
- Lake S, Kerr T, Capler R, Shoveller J, Montaner J, & Milloy MJ (2017). High-intensity cannabis use and HIV clinical outcomes among HIV-positive people who use illicit drugs in Vancouver, Canada. *The International Journal on Drug Policy*, 42, 63–70. [PubMed: 28336000]
- Lochner K, Kawachi I, & Kennedy BP (1999). Social capital: A guide to its measurement. *Health Place*, 5(4), 259–270. [PubMed: 10984580]
- Lu M, Safren SA, Skolnik PR, Rogers WH, Coady W, Hardy H, & Wilson IB (2008). Optimal recall period and response task for self-reported HIV medication adherence. *AIDS and Behavior*, 12(1), 86–94. [PubMed: 17577653]
- Machtinger EL, Cuca YP, Khanna N, Rose CD, & Kimberg LS (2015). From treatment to healing: The promise of trauma-informed primary care. *Womens Health Issues*, 25(3), 193–197. [PubMed: 25965151]
- McPherson KE, Kerr S, Morgan A, McGee E, Cheater FM, McLean J, & Egan J (2013). The association between family and community social capital and health risk behaviours in young people: An integrative review. *BMC Public Health*, 13, 971. doi:10.1186/1471-2458-13-971 [PubMed: 24138680]
- National Institute on Drug Abuse. (2016). Substance use in women and men Retrieved from <https://www.drugabuse.gov/related-topics/trends-statistics/infographics/substance-use-in-women-men>
- Neergaard MA, Olesen F, Andersen RS, & Sondergaard J (2009). Qualitative description - The poor cousin of health research? *BMC Medical Research Methodology*, 9, 52. doi: 10.1186/1471-2288-9-52 [PubMed: 19607668]
- O' Cathain A, Murphy E, & Nicholl J (2008). The quality of mixed methods studies in health services research. *Journal of Health Services Research & Policy*, 13(2), 92–98. doi:10.1258/jhsrp.2007.007074

- Onyx J & Bullen P (2000). Measuring social capital in five communities. *Journal of Applied Behavioral Science*, 36(1), 23–42. doi:10.1177/0021886300361002
- Phillips JC, Webel A, Rose CD, Corless IB, Sullivan KM, Voss J, ... Holzemer WL (2013). Associations between the legal context of HIV, perceived social capital, and HIV antiretroviral adherence in North America. *BMC Public Health*, 13, 736. doi:10.1186/1471-2458-13-736 [PubMed: 23924399]
- Ransome Y, Thurber KA, Swen M, Crawford ND, German D, & Dean LT (2018). Social capital and HIV/AIDS in the United States: Knowledge, gaps, and future directions. *SSM Population Health*, 5, 73–85. doi:10.1016/j.ssmph.2018.05.007 [PubMed: 29892697]
- Rosen MI, Black AC, Arnsten JH, Goggin K, Remien RH, Simoni JM, ... Liu H (2013). Association between use of specific drugs and antiretroviral adherence: Findings from MACH 14. *AIDS and Behavior*, 17(1), 142–147. doi:10.1007/s10461-011-0124-7 [PubMed: 22246513]
- Sales JM, Swartzendruber A, & Phillips AL (2016). Trauma-informed HIV prevention and treatment. *Current HIV/AIDS Reports*, 13(6), 374–382. doi:10.1007/s11904-016-0337-5 [PubMed: 27704251]
- Sandelowski M (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334–340. [PubMed: 10940958]
- Sandelowski M (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33(1), 77–84. doi:10.1002/nur.20362 [PubMed: 20014004]
- Stevens-Watkins D, Perry B, Harp KL, & Oser CB (2012). Racism and illicit drug use among African American women: The protective effects of ethnic identity, affirmation, and behavior. *Journal of Black Psychology*, 38(4), 471–496. doi:10.1177/0095798412438395 [PubMed: 24482547]
- Taylor TR, Kamarck TW, & Shiffman S (2004). Validation of the Detroit Area Study Discrimination Scale in a community sample of older African American adults: The Pittsburgh Healthy Heart Project. *International Journal of Behavioral Medicine*, 11(2), 88–94.
- United States Department of Health and Human Services. (2018a). Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents Retrieved from <https://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf>
- United States Department of Health and Human Services. (2018b). HIV and drug and alcohol users. HIV and Specific Populations Retrieved from <https://aidsinfo.nih.gov/understanding-hiv-aids/factsheets/25/84/hiv-and-drug-and-alcohol-users>
- United States Department of Health and Human Services Office on Women's Health. (2018a). Alcohol use disorder, substance use disorder, and addiction. *Mental Health* Retrieved from <https://www.womenshealth.gov/mental-health/mental-health-conditions/alcohol-use-disorder-substance-use-disorder-and-addiction/>
- United States Department of Health and Human Services Office on Women's Health. (2018b). Women and HIV. HIV and AIDS Retrieved from <https://www.womenshealth.gov/hiv-and-aids/women-and-hiv/>
- Vidot DC, Lerner B, & Gonzalez R (2017). Cannabis use, medication management and adherence among persons living with HIV. *AIDS and Behavior*, 21(7), 2005–2013. doi:10.1007/s10461-017-1782-x [PubMed: 28456895]
- Voluse AC, Sobell LC, Dum M, Sobell MB, & Simco ER (2012). Psychometric properties of the Drug Use Disorders Identification Test (DUDIT) with substance abusers in outpatient and residential treatment. *Addictive Behaviors*, 37, 36–41. [PubMed: 21937169]
- Walsh JC, Mandalia S, & Gazzard BG (2002). Responses to a 1 month self-report on adherence to antiretroviral therapy are consistent with electronic data and virological treatment outcome. *AIDS*, 16(2), 269–277. [PubMed: 11807312]
- Webel A, Phillips JC, Rose CD, Holzemer WL, Chen WT, Tyer-Viola L, ... Salata RA (2012). A cross-sectional description of social capital in an international sample of persons living with HIV/AIDS (PLWH). *BMC Public Health*, 12, 188. doi:10.1186/1471-2458-12-188 [PubMed: 22414342]
- Webel A, Asher A, Cuca Y, Okonsky JG, Kaihura A, Dawson Rose C., ... Burant CJ (2012). Measuring HIV self-management in women living with HIV/AIDS: A psychometric evaluation



study of the HIV Self-management Scale. *Journal of the Acquired Immune Deficiency Syndrome*, 60(3), e72–e81.

- Winstanley EL, Steinwachs DM, Ensminger ME, Latkin CA, Stitzer ML, & Olsen Y (2008). The association of self-reported neighborhood disorganization and social capital with adolescent alcohol and drug use, dependence, and access to treatment. *Drug Alcohol Depend*, 92(1–3), 173–182. doi:10.1016/j.drugalcdep.2007.07.012 [PubMed: 17913396]
- Wood TJ, Koester KA, Christopoulos KA, Saucedo JA, Neilands TB, & Johnson MO (2018). If someone cares about you, you are more apt to come around: Improving HIV care engagement by strengthening the patient–provider relationship. *Patient Preference and Adherence*, 12, 919–927. doi:10.2147/PPA.S157003 [PubMed: 29872277]
- Yudko E, Lozhkina O, & Fouts A (2007). A comprehensive review of the psychometric properties of the Drug Abuse Screening Test. *Journal of Substance Abuse Treatment*, 32(2), 189–198. doi: 10.1016/j.jsat.2006.08.002 [PubMed: 17306727]
- Zhang Y, Wilson TE, Adedimeji A, Merenstein D, Milam J, Cohen J, ... Golub ET (2018). The Impact of substance use on adherence to antiretroviral therapy among HIV-infected women in the United States. *AIDS and Behavior*, 22(3), 896–908. [PubMed: 28560499]



**Table 1:**  
Demographic Characteristics of Participants

|   |   | Current Substance User (n=16) | Previous Substance User (n=13) | p-value <sup>I</sup> |
|---|---|-------------------------------|--------------------------------|----------------------|
|   |   | Frequency (%)                 | Frequency (%)                  |                      |
| <b>Race</b>   |   |                               |                                |                      |
|   | African American                                    | 15 (94%)                      | 12 (92%)                       | 0.70                 |
|   | Latina  | 1 (6%)                        |                                |                      |
| <b>Marital Status</b>                                   |   |                               |                                |                      |
|   | Married or Domestic Partnership                     | 1 (6%)                        | 3(23%)                         | 0.29                 |
|   | Single  | 6 (38%)                       | 7 (54%)                        |                      |
|   | Separated   | 1 (6%)                        | 1 (8%)                         |                      |
|   | Divorced  | 8 (50%)                       | 2 (15%)                        |                      |
| <b>Education</b>  |   |                               |                                | 0.32                 |
|   | 11 <sup>th</sup> Grade or Less                      | 7 (44%)                       | 6 (50%)                        |                      |
|   | High school Diploma                                 | 2 (13%)                       | 3 (25%)                        |                      |
|   | Some College  | 4 (25%)                       | 0                              |                      |
|   | Two or more years of College                        | 3 (18%)                       | 3 (25%)                        |                      |
| <b>Employment Status</b>                                |   |                               |                                |                      |
|   | Working now   | 0                             | 0                              |                      |
|   | Temporarily laid off, sick leave or maternity leave | 0                             | 2                              |                      |
|   | Looking for work, unemployed                        | 2                             | 1                              |                      |
|   | Retired   | 1                             | 0                              |                      |
|   | Disabled  | 11                            | 6                              |                      |
|   | Keeping House                                       | 1                             | 3                              |                      |
|   | Student   | 1                             | 0                              |                      |
|   | Other   | 0                             | 1                              |                      |
| <b>Permanent Housing</b>                                |   | 15 (94%)                      | 12 (92%)                       | 1.0                  |
| <b>Sexual Identity</b>                                  |   |                               |                                | 0.74                 |
|   | Homosexual  | 1 (6%)                        | 1 (8%)                         |                      |
|   | Bisexual  | 2 (12%)                       | 0                              |                      |
|   | Heterosexual  | 13 (81%)                      | 12 (92%)                       |                      |
| <b>Substances Used at Least Twice in the Past Month</b> |   |                               |                                |                      |
|   | Cannabis  | 4 (25%)                       | 1 (8%)                         |                      |
|   | Cocaine/Crack                                       | 4 (25%)                       | 0                              |                      |
|   | Sleeping Pills                                      | 4 (25%)                       | 5 (39%)                        |                      |
|   | Pain Pills (pain relievers)                         | 8 (50%)                       | 8 (62%)                        |                      |
|   | Tobacco   | 10 (63%)                      | 9 (69%)                        |                      |

<sup>I</sup>: Differences between substance use group calculated using Fisher's Exact Test

**Table 2:**

## Participant Baseline Measures

|                                    | Range and Orientation                      | Current Substance User | Previous Substance User | <i>p</i> -value |
|------------------------------------|--|------------------------|-------------------------|-----------------|
|                                    |  | Mean (SD)              | Mean (SD)               |                 |
| Social Capital Scale               | 1–4; Higher is more Social Capital         | 2.63 (±0.50)           | 2.8 (±0.40)             | 0.323           |
| HIV Self-Management Scale          | 20–60; Higher is more Self-Management      | 45.3 (±8.3)            | 53.4 (±4.9)             | 0.005           |
| Life Events Check List             | 0–20; Higher is more traumatic events      | 3.0 (±2.3)             | 3.7 (±4.1)              | 0.527           |
| Everyday Discrimination Scale      | 0–45; Higher is frequent discrimination    | 10.8 (±7.6)            | 6.5 (±6.8)              | 0.147           |
| Three Day HIV Medication Adherence | 0–100; Higher is more medication adherence | 94.1 (±18.2)           | 97.8 (±6.9)             | 0.485           |
| Monthly HIV Medication Adherence   | 0–100; Higher is more medication adherence | 92.4 (±16.9)           | 98.9 (±4.2)             | 0.195           |

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**Table 3.**Social capital & substance use are associated with HIV Self-Management over time ( $n=28$ )

|                       | $\beta$ | SE   | $p$   | 95% CI |       |
|-----------------------|---------|------|-------|--------|-------|
| Current substance use | -6.30   | 2.18 | 0.00* | -10.58 | -2.02 |
| Social Capital        | 5.73    | 2.05 | 0.01* | 1.72   | 9.75  |
| Traumatic Events      | 1.00    | 0.41 | 0.02* | 0.19   | 1.81  |
| Discrimination        | -0.96   | 0.14 | 0.48  | -0.36  | 0.18  |
| Age (years)           | -0.16   | 0.15 | 0.28  | -0.46  | 0.14  |
| Wald $X^2$            | 28.43   |      | <0.01 |        |       |

SE: Standard Error; CI: Confidence Interval

\* Statistically significant at 0.05  $p$ -value

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**Table 4.**

Social capital & substance use are associated with HIV Medication Adherence over time (*n*=29)

|                       | $\beta$ | SE   | <i>p</i> | 95% CI |       |
|-----------------------|---------|------|----------|--------|-------|
| Current substance use | -4.79   | 3.62 | 0.19     | -11.88 | 2.31  |
| Social Capital        | 9.08    | 3.74 | 0.02*    | 1.75   | 16.41 |
| Traumatic Events      | 0.52    | 0.59 | 0.38     | 0.65   | 1.68  |
| Age (years)           | -0.04   | 0.27 | 0.89     | -0.56  | 0.49  |
| Wald $\chi^2$         | 8.74    |      | 0.07     |        |       |

SE: Standard Error; CI: Confidence Interval

\* Statistically significant at 0.05 *p*-value

Adherence in the past 4 weeks

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