Positive Influences: Keeping Black Women Living with HIV in Care

by

Kenja Hassan

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Graduate Supervisory Committee:

David Coon, Chair
Marianne McCarthy
Johannah Uriri-Glover

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ABSTRACT

This manuscript option dissertation elucidates the role of patient-provider interactions in keeping HIV positive Black women in medical care. Since 2012, the Arizona State Department of Health has acknowledged that women of African descent are disproportionately affected by HIV and die at higher rates from AIDS-related complications than other women. The dissertation includes three manuscripts covering a feature of this topic. The first paper is a scoping review of literature on what is known about the influence of patient-provider relationships on adherence and viral suppression among Black women living with HIV in Arizona. The second is an empirical study built upon interviews with Black women living with HIV analyzed through constructivist grounded theory to understand women's perspectives of provider actions that keep them in care. The third offers practice recommendations based on the interviews with Black women living with HIV, dialog with HIV advocates, and proceedings of the Phoenix Fast Track Cities ad hoc committee to end HIV as an epidemic. Together, the three manuscripts integrate the voices of women, advocates, and past research to support best practices and future steps for HIV retention strategies.

Keywords: Black women living with HIV, antiretroviral adherence, patient-provider interactions, retention in care, Fast Track Cities.

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CHAPTER 1

INTRODUCTION

Positive Influences: Keeping Black Women Living with HIV in Care

This manuscript option dissertation elucidates the role of patient-provider interactions in keeping HIV positive Black women in medical care so that more of them may achieve viral suppression and lead healthy, productive lives. The research draws threads among local, regional and national contexts. African American women bear a disproportionate burden of HIV (Kaiser Family Foundation, 2020). Arizona is no exception. Although the proportion of HIV cases is smaller for African Americans in Arizona, the rates of incidence, prevalence, and mortality are exponentially greater than any other racial or ethnic group in the state. For example, national HIV prevalence for Blacks is 725.9 per 100,000 compared to 220.2 for non-Hispanic whites (ADHS, 2020). For Black women in Arizona, the prevalence rate is 434.1 per 100,000, almost ten times the rate for white women at 46.9 (ADHS, 2021.) HIV related stigma remains a concern in Arizona, impacting testing, concepts of risk, and care seeking behaviors for African American men and women (SANTY, 2018). In addition to stigma, a number of other barriers contribute to attrition from care and lack of adherence for Black women living with HIV (WLWH) across the country, such as lack of access to high quality healthcare, lack of transportation, lack of child care, little sick leave from work, stigma, depression, low self-worth and more (Edwards, 2006; Sankar et al., 2002; Warren-Jeanpiere et al., 2014, Whiteside et al., 2014). Less information has been documented on provider actions that encourage women to stay in care once they have overcome hurdles to get to care.

This dissertation is concerned with uncovering beneficial patient-provider relationships from the perspective of Black women living with HIV.

This dissertation includes three manuscripts each covering the patient-provider relationship and the importance of provider actions from a different vantage point. The first manuscript is a scoping review of literature on what is known about the influence of patient-provider relationships and provider actions on adherence and viral suppression among Black women nationally. The second manuscript is an empirical qualitative study of Black women living with HIV in the Phoenix metro area guided by constructivist grounded theory aimed at understanding women's perspectives of provider actions that keep them in care. The third manuscript includes practice recommendations for providers in the context of rapid antiretroviral therapy (ART) initiation, based on the empirical study, dialog with Phoenix area HIV advocates, and meeting minutes of the Phoenix Fast Track Cities ad hoc committee to end HIV as an epidemic. Together, the three manuscripts integrate the voices of women, advocates, and past research to support best practices for patient-provider interactions that enhance HIV retention strategies for this population. While other research has been conducted on Black women living with HIV, literature searches found no published work for the Southwest region or for other regions in which African Americans are a super minority.

The focus of this research is on HIV positive Black women who have been able to maintain viral suppression with its beneficial attributes. This work specifically examines provider actions that enhance or detract from the patient's relationship in order to help more women stay in care and ultimately in control of the virus. The overarching research question for this manuscript option dissertation is: What patient-provider interactions lead to adherence and viral suppression among HIV positive Black women? Each manuscript has a subsequent related question listed in table 1.

Table 1. Research Questions

Overarching question:
What patient-provider interactions lead to adherence and viral suppression among HIV positive Black women?

Manu-script	Research question	Methodology	Prospective Journal
1	What provider actions help keep HIV positive Black women in care?	Integrative review of literature	AIDS and Behavior
2	Why are some patient-provider interactions more successful at keeping HIV positive women in care and virally suppressed?	Constructivist Grounded Theory	AIDS Care
3	What can local providers do to help retain Black women in care and ensure they achieve viral suppression?	Policy / practice analysis and recommendations	Journal of the Association of Nurses in AIDS Care

The Problem

Keeping HIV positive people in care and virally suppressed is and has been a national challenge (Giordano et al., 2007; Horstmann et al., 2010; Tobias et al., 2007). At the time of this writing, 86% of people suspected of having HIV have been diagnosed, 64% of those diagnosed have received care (at least one CD4 test within one year), 49% are retained in care (having at least two CD4 tests three or more months apart within one year), and 53% are virally suppressed (having test results that show less than 200 copies of HIV RNA per millimeter of blood) (CDC, 2020). African Americans fare worse than whites on this continuum of care: among Blacks living with HIV in 2013, 48.5% had achieved viral suppression compared with 62.0% of whites (Dailey, 2017).

Lambert et al. (2018) help clarify the terms ***retention in HIV care*** as opposed to ***engagement in care***, which is important for this study. Retention in care is measured through appointments kept or missed and consistency or gaps in care, while engagement means entering into care at any point in the care continuum (Lambert et al., 2018).

Background and Significance. These three papers focus on African American women who are a narrow sub-set of people living with HIV, but a population that exhibits a pronounced disparity in HIV risk, morbidity, and mortality. Focusing on this one group is also important because Black women's roles as supporters and caregivers to family result in their burden of HIV weighing heavily on whole communities when they become ill and are not able to sustain employment or their usual functions. Nationally, African American women and girls represent 58% of all females with HIV, as identified by sex at birth (CDC, 2020). In 2015, African Americans comprised 52% of all people who died of HIV disease in the US, higher than any other group (CDC, 2018). In 2015, 64% of children diagnosed with perinatal HIV, that is HIV acquired from their mothers, were African American (CDC, 2018). Yet, the CDC (2017) is clear that the risk of transmission is reduced by 99% when women take antiretroviral medications properly during pregnancy and delivery, and provide antiretrovirals to their infants for the first six weeks of life. These numbers indicate that many Black women living with HIV are not receiving a level of care sufficient to prevent transmission to infants.

In Arizona, data from recent years indicate that the disparity is similar to national data. In 2014, the rate of HIV emergence among Blacks was 424% higher than that of non-Hispanic whites (Arizona Department of Health Services, 2014). In 2019, the incidence rate for non-Hispanic Black women and girls in Arizona was 21.4 per 100,000 as compared to 1.8 per 100,000 for non-Hispanic white females and 2.7 for Hispanic females of any race (ADHS, 2020). The mortality rate for Black women living with HIV was twice that of white women in 2019 (ADHS, 2020).

Consistency with antiretroviral treatment is the path toward individual survivability and ending the HIV epidemic; taking antiretroviral therapy as prescribed can lead to an "undetectable" status (NIAID, 2017). A person is considered to have a "durably undetectable" viral load if their viral load remains undetectable for at least six months after their first undetectable test result (NIAID, 2017). When someone is durably undetectable, the virus is untransmittable (NIAID, 2017). Therefore, patients must adhere to an antiretroviral regimen; any lapse can result in the virus becoming resistant to the medication and potentially lead to mortality (Gonzalez et al., 2011; Johnson et al., 2003).

Inconsistent participation in HIV care reduces the likelihood of viral suppression and increases the risk of progression to AIDS or transmission of the virus, or death (Palma et al., 2015). The CDC (2018) has observed that lower quality health care could have a direct role in leading to worse outcomes for African Americans along all stages of the HIV continuum of care, from being less likely to be linked to care to being less likely to achieve viral suppression. In contrast, strong patient-provider relationships are beneficial for helping HIV patients adhere to antiretroviral medications (Christopoulos et al., 2015).

Literature

Overall, the research and clinical practice literature suggests that providers need to consider more than just the physical complications of the virus when it comes to African American women, they must also consider how to build relationships that transcend psychological and emotional barriers and anticipate potential life barriers such as employment, housing, transportation, and food security. Psychological stress is a common problem for many Black women with HIV (Warren-Jeanpiere et al., 2014). Zimlich (2016) argues that the psychological impact of an HIV diagnosis comes with the fear of rejection by others and self-stigmatization, which can make it harder for HIV patients to develop trusting relationships with providers, thus providers must be attentive to patients' psychological state from the very outset of an HIV diagnosis.

Trust in providers is positively associated with adherence. Sankar et al. (2002) found that patients who had a stronger relationship with their providers were more likely to comply with an antiretroviral regimen. Moreover, those who saw their physicians as motivators were more likely to be adherent than those who were indifferent to their physicians (Sankar et al., 2002). Stone (2005) suggests that racial concordance could smooth over some of the communication challenges that happen between minority patients and providers, but that there are so few minority providers that racial concordance is unlikely to happen. In order to overcome racial disparities amid the lack of Black providers, Saha et al. (2010, 2011, 2013) make a case for providers understanding the importance of cultural competence in developing trusting relationships with HIV patients. These are all important considerations for the Arizona context where

Black women are a smaller minority than the national population average and providers may not be accustomed to interacting with African Americans.

Trust can also be gained through good communication (Zimlich, 2016) and some understanding of how patients like to receive information (Mulder et al., 2014). Mulder et al.'s (2014) qualitative analysis revealed that patients have greater trust when they have some sense of control in the decision-making process which lends itself to a sense of control over the disease.

In addition to trust, HIV patients' perceptions of how well their provider knows them as individuals can change health outcomes. Beach et al. (2006) found that HIV patients who reported that their provider knows them "as a person" were more likely to be prescribed highly active antiretroviral therapy, they were more likely to adhere, and they were more likely to have an undetectable viral load. Corwin & Springer (2013) offer an easy to use reference document for providers working with HIV patients that encourage retention in care, such as statements to use when patients are inconsistent with appointments, are not adherent to medication, or don't understand how the virus operates in the human body. Implicit in all of their recommendations is patient centered communication that gives individualized attention. The information herein is targeted at newly diagnosed patients in general, and may be enhanced through fine-tuning for more culturally and ethnically distinct populations. Beach et al. (2015) found that non-adherent HIV patients of providers trained in motivational interviewing had increased discussion about adherence, problem solving, and emotions post intervention without changing the length of the appointment.

Authors cited in this research reveal that the patient-provider relationship can be a positive influence, but the overall dearth of research leaves room to uncover what positive patient-provider communication and interactions lead toward adherence and why.

Conceptual Framework

Patient centered communication has risen in visibility as an important strategy for more effective care of people with chronic conditions (Finney Rutten et al., 2016). With access to proper care and good provider relationships, HIV can now be a chronic condition for most patients rather than a death sentence (Deeks et al., 2013). Due to comorbidities and other factors in a patient's life, HIV can be a complicated illness to treat. Comorbidities combined with the social stigma HIV brings can make care as complex as some cancer scenarios. Epstein and Street (2007) have developed a multifaceted framework for Patient Centered Care in Cancer Settings (PCC). Epstein and Street (2007) draw inspiration from earlier authors of patient centered care, citing Rogers (1961), McWhinney (1985), Balint (1957) and Entralgo (1969). That combined work was "…based on deep respect for patients as unique living beings, and the obligation to care for them on their terms…. patients are known as persons in context of their own social worlds, listened to, informed, respected, and involved in their care…" (Epstein & Street, 2011 p.1). Their argument goes beyond the fact that patient centered behaviors can and do lead to better health outcomes; patient centeredness should be undertaken because it is morally appropriate (Epstein & Street, 2011).

Epstein and Street's (2007) framework is based upon six key communication functions that are as relevant in an HIV setting: 1) Fostering healing relationships, 2) Exchanging information, 3) Responding to emotions, 4) Managing uncertainty, 5) Making decisions, and 6) Enabling patient self-management (Epstein & Street, 2007).

The first function of the Patient Centered Care in Cancer Settings (PCC) is **fostering healing relationships** by developing trust and rapport. Family members and everyone involved in supporting the patient should come to an understanding of each person's role and responsibility in the care-taking process (Epstein & Street, 2007). Trust and rapport, they explain is earned verbally, through body language, by showing interest in the patient and family, and by demonstrating technical competence. When rapport is strong, patients and their family should feel fully involved (Epstein & Street, 2007). African American women living with HIV may or may not have family support in a way that is helpful (Owens et al., 2003). Therefore, it is important for providers to work on earning the trust of the individual patient and potentially helping the patient consider other social supports outside of the immediate family.

Exchanging information increases patient satisfaction, reduces anxiety, and helps the patient cope since seeking information tends to give patients hope (Epstein & Street, 2007). The information exchange includes paying attention to the patients' "opinions, needs, beliefs, values, and preferences" (Epstein & Street, 2007, p. 21). With medical information widely available through online media, clinicians have to be prepared to help patients distinguish useful resources from potentially harmful sites.

Clinicians must check to see if patients understand the information they find or are given, as patients may be too reticent to ask for clarification (Epstein & Street, 2007).

According to local community members actively working in HIV care, many Black women patients can recount lifetime experiences in which they feel authority figures don't hear them or ignore their input. As a result, they often feel medical providers do not listen to them. Consequently, some women resort to assertive language, tone, and gestures that providers interpret as aggressive, or even angry. Therefore, **responding to emotion** becomes an important skill for HIV providers. Epstein and Street (2007, 2011) argue that a patient's anxiety levels during an appointment must be even-keeled enough for them to digest the clinician's information. Responding to emotions is an important part of the framework because it helps providers build rapport with patients (Epstein & Street, 2007). People can respond to an HIV diagnosis with similar emotions described in the cancer framework, including fear, worry, sadness and fatalism (Epstein & Street, 2007). The PCC recommends that providers be aware of patients' emotional state in order to help identify depression, anxiety or other forms of distress and either prescribe medicines, refer them to a psychotherapist, or help them think of other avenues for coping and social support (Epstein & Street, 2007).

Managing uncertainty in cancer settings may not be equivalent for HIV settings. Much of the uncertainty that comes with HIV care has to do with access to medical care and to providers in the first place (Crepaz et al., 2018). For many low socio-economic status (SES) patients, there are fewer options for high quality care. Moreover, higher virologic loads throughout social networks in low SES communities makes HIV a disease that disproportionately impacts urban and rural poor, especially people living at or below the poverty line (Pellowski et al., 2013). With HIV, uncertainty may have to do more with housing, transportation, employment, and food than with getting a prognosis (Park et al, 2020). Therefore, providers should understand that when Black women make it to the clinic they may be dealing with a host of other uncertainties that impact their relationship with the provider and with their illness.

The PCC notes that patients want to participate in **making decisions** at essentially three different levels. Some patients take a paternalistic view allowing the providers to make the decisions, some want to be given all of the information and be left to make the decision on their own, while still others would like to participate in a shared decision-making process (Epstein & Street, 2007). The PCC suggests that quality decisions will have resulted from an exchange between the clinician and patient in which both of their perspectives were made clear, differences were reconciled, and the path forward, which should be supported by clinical evidence, was agreed upon (Epstein & Street, 2007). Based on the PCC's description of how a decision should be made, patient-provider rapport and communication are essential. Epstein and Street (2007) indicate strong support for a shared decision making (SDM) process. Local case managers and nurses have observed that many Black women HIV patients want to be involved in decision making for their health care.

The last function of the PCC rests upon the idea that when patients are engaged in managing their own care, they feel more confident and less anxious (Epstein & Street, 2011). According to the PCC, **enabling patient self-management** involves making recommendations, giving instructions, and giving encouragement (Epstein & Street, 2007). The PCC supposes that if patients feel enabled to manage their condition, they can find information that helps them cope and seek care that they need (Epstein & Street, 2007). The PCC explains that clinicians should encourage patient self-management through advocacy, by supporting the patients' autonomy and by offering guidance and access to resources (Epstein & Street, 2007). Ideally, clinicians would enable patient self-management by helping patients navigate the medical system. If the physicians and nurses cannot do this, a medical case manager should be added to the team, and the patients should be guided to reliable internet sources or to health educators and community organizations (Epstein & Street, 2007).

Although the PCC is intended for complicated cancer settings, it provides a useful way to frame questions for this population because it uses established principles in patient-provider relationships and it has a moral and ethical grounding rather than a strictly outcome-based strategy. Epstein and Street consider patient centered communication, as described in the PCC, to be a central component of patient centered care which, as they proclaim upfront, ultimately aims to reduce suffering and promote healing (Epstein & Street, 2007). They follow a tradition of scholars dating back to the late 1960's who seek to shift patient-provider interaction from being physician dominated to being partnership driven (Epstein & Street, 2011). Their philosophical position is that patient centered care is "the right thing to do," and corresponding actions, "such as respecting patients' preferences" are morally justifiable out of respect for patients' humanity, regardless of health outcomes (Epstein & Street, 2011 p.101). They argue that training physicians from a standpoint that embraces each patient as an individual human being with their own unique life context will encourage providers to move from an authoritative role to one that is collaborative and empathetic (Epstein & Street, 2011). The authors observe that providers who approach communication as part of forming a relationship, rather than just transmitting information, are more inclined to value "caring and sharing" as a function of their role (Epstein & Street, 2007 p. 3).

This moral grounding and emphasis on partnership building turns out to be critical to Black women living with HIV in their assessment of providers and interest in working with them. The women interviewed for this research and in studies that were reviewed for this project had a strong leaning toward providers who demonstrated a sincere interest in their health and wariness of providers who appeared to be concerned about patients primarily as revenue generators. Women discerned the difference between the two through the kinds of communication styles and actions identified by Epstein and Street (2007). Echoing the words of Epstein and Street (2007), these women described relationships with favorable providers as being characterized by acts of caring and sharing.

Chapter 2 (Manuscript One)

The Provider's Role in Retaining HIV Positive Black Women in Care: A Scoping Review

Manuscript one is a scoping review of literate that examines the relationships between Black women living with HIV and their providers and describes the role that this relationship plays in retention and adherence. This method was chosen to determine whether there is a sufficient body of work to conduct a systematic review and follows a set of prescribed steps like other reviews (Munn et al., 2018; Pham et al., 2014; Tricco 2018). Research studies eligible for this type of review may be quantitative and qualitative; they may also be experimental and non-experimental (Whittemore & Knafl, 2005).

Problem and research question.

Since working with a physician is essential for maintaining viral suppression (HIV.gov, 2021), it is helpful for providers to know what actions, behaviors, and communication styles are effective for encouraging Black WLWH to return for appointments. The targeted sub-question for this study is: What provider actions help keep HIV positive Black women in care?

Literature

Preliminary searches yielded little information on the nature of patient-provider relationships for this population independent of other people living with HIV. Initially, a single qualitative study emerged. Based on in-depth interviews by Okoro and Odedina (2017), this study found that Black women living with HIV who felt like their provider knew them as a person were more confident about treatment and care. The personalized relationship Okoro and Odedina (2017) described appears similar to Beach et al.'s (2006) findings that patients who feel their providers know them personally have greater control over HIV as indicated in their viral load test results.

Due to the scant returns on preliminary searches, a scoping review was determined to be the best type of systematic review. Munn et al. (2018, p. 7) state that "scoping reviews are an ideal tool to determine the scope or coverage of a body of literature on a given topic and give clear indication of the volume of literature and studies available as well as an overview (broad or detailed) of its focus." As per Munn et al (2018) this review provides an overview of the evidence related to this question and still follows the guidelines that are standard for systematic reviews.

Methodology

This scoping review employs tracking methods that have become standard for integrative and systematic reviews, including developing an appropriate research question, setting inclusion and exclusion criteria for studies, determining which kinds of results should be presented and how the results should be interpreted (Wardlaw, 2010). A PRISMA flow diagram (Moher et al., 2009; PRISMA, 2018) tracks the numbers of articles identified, screened, excluded and finally included in the analysis and reason for discarding papers. Searches were conducted in CINHAL, PubMed, Cochrane, Medline, and Scopus data bases with hand searches of any articles meeting selection criteria. Keywords included: African American women or Black women with HIV positive; patient and provider with communication, interaction, relationship or engagement.

Tracking of results. A data extraction sheet was used to organize information from each study for comparison. The data included categories recommended by Wardlaw (2010) as well as items pertinent to this study: year of publication, primary purpose of study, whether or not the study described results for African American women specifically, theory or framework, design, setting, sample (available demographic information, such as age, ethnicity, and socioeconomic status, time since diagnosis), number and size of control groups and treatment groups, protocol, survey instruments, findings, summary of their analysis, any recommendations developed from the study and any provider actions described.

Data comparison and presentation of results. Guidance offered by Whittemore and Knafl (2005) was used to manage and analyze the data. Multiple matrices were created in Excel to allow for comparisons between studies and the relationships across data sources. Similarities were noted and used to synthesize both provider actions and recommendations.

A condensed evidence table displays the final selection. This table includes the year of the publication, the theory or framework underlying the study, the study design, the setting, sample characteristics, numbers of participants, the protocol, survey instruments, and findings.

Conclusions. The searches yielded seven papers that specifically describe provider actions in relation to this population, yet only two of seven had this goal in mind at the outset. Other studies were more exploratory or sought information for a more generalized audience. The small number of articles offer a fairly consistent message: that personalized relationships are important for this population. The combined articles also offer some suggestions on how providers can create that relationship which resonate with the PCC selected as a framework for this study.

CHAPTER 3 (Manuscript Two)

Positive Influences:

How Provider Actions Affect Retention in HIV care for Black Women

The **problem** discussed in this chapter reflects the overall problem regarding patient-provider relationships. A qualitative approach was pursued to explore this issue so that HIV positive women could offer their own interpretations of provider actions that have been favorable to their retention in care. Grounded theory according to Charmaz (2014) was selected as the methodological approach because it emphasizes a focus on the social interactions between patients and providers while acknowledging that the two individuals may experience a different reality in their daily lives and during the appointments. Due to differences in race, education, socio-economic status, and perceptions of the medical system, patients and providers come with potentially very different assumptions about each other and how to achieve the best health outcomes. This method also encouraged an understanding that data and theories are constructed by the researchers as well as the participants. The methodology developed for this study purposely built in opportunities for multiple individuals to scaffold and inform these data: HIV advocates who were interviewed for context and recommendations on how to ask questions of HIV patients, HIV patients themselves who offered input regarding the questions during focus groups, clarifications on their answers during interviews, and ideas to consider when discussing this information with other participants.

Literature

Qualitative and quantitative studies as well as systematic reviews indicate that African Americans' perception of the medical system, and their relationships with providers factor into whether or not they remain in care and maintain viral suppression (Brincks et al., 2019; Dang et al., 2013). Gaston and Greene (2013) conducted a systematic review of studies on HIV positive African Americans' perceptions of the health care system which affirmed that relationships with providers was a determining factor in whether or not HIV positive women kept appointments and stayed adherent. Qualitative studies corroborate the importance of patient-provider relationships to keeping appointments, including whether or not the provider was seen as a motivator to adherence (Kempf et al., 2010; Sankar et al., 2002).

Using the Roter Interaction Analysis System (RIAS), Beach et al (2011) determined that white providers were more verbally dominant with Black patients than they were with white patients. Their research showed that Black patients spoke less during appointments than white patients, but did not explore why this happens from the patient's perspective. Another study showed that Black patients have greater trust in providers when they perceive cultural similarities with them and when they have trust in the institution where they are being treated (Earl et al., 2013). Again, the authors did not explore *why* this is the case from the patient's point of view. Both studies could be enhanced through discussions and focus groups with patients on why they may or may not feel comfortable speaking with providers and why they may or may not feel confident candidly expressing their medical needs.

Laws et al. (2012) discovered that while Black patients often had shorter office visits with providers, longer encounters were not necessarily patient centered. They concluded that longer visits may not result in patent centeredness and that the goal should be in improving dialog between patients and providers (Laws et al., 2012).

Corroborating the CDC's perspective, Stoskopf et al. (2001) found HIV patients with private insurance were five times as likely to be satisfied with their care than those who had public or no insurance at all. This indicates that patients' perception of care also correlated with their ability to access providers who perhaps have greater availability and patience with them as individuals.

Each of these studies indicate *that* quality relationships with providers are important but not *why*. For example, the Beach et al. (2006) and Saha et al. (2011, 2013) report that Black patients speak less than whites, but don't help us understand why, nor the consequences of speaking less. The Laws et al. (2012) study describes that dialog between patients and providers needs improvement, but does not include how it can be improved from the patients' perspectives.

Purpose

This study sought to gain insight from women who are confident about their control of HIV as to why some provider actions help them and others do not. As a grounded theory project, this study welcomed the possibility that women might describe motivators other than provider relationships. The aim of this study is to understand how patients develop a relationship with providers; it is not intended to illicit an objective truth (Charmaz in Denzin & Lincoln, 2000).

Research Question

Why are some patient-provider interactions more successful at keeping HIV positive women in care and virally suppressed?

Method

Constructivist Grounded Theory (CGT), as described by Kathy Charmaz (2008, 2014), is used as the guide for this study. CGT is based on the notion that people construct their reality and sense of self through interactions with others, and thus CGT methodology acknowledges the complexity of social interactions (Charmaz, 2008, 2014). Constructivism, Charmaz writes, "assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects' meaning" (Charmaz in Denzin & Lincoln, 2000, p.510). To this end, a CGT approach encourages the researcher to recognize that the patients' and the providers' views in this study are subjective and they may experience different realities in the same interaction. These patients are influenced by social markers of race, gender, and socioeconomic status that may or may not be held in common by the person caring for them. CGT also encourages the researcher to recognize his/her own role in co-constructing interpretation of data. In this case, the data was constructed through multiple layers of interactions between the researcher, HIV advocates, women living with HIV, with the influence of the framework selected for this study, the PCC.

Setting and sample. This study included 11 Black women living with HIV from the Phoenix metro area. This is a purposeful sample intended to uncover in-depth perspectives for a specific population (Sandelowski, 1995). It is similar in size to that of studies for Black women living with HIV in other regions (Berkley-Patton et al., 2009; DeMoss et al., 2014; Njie-Carr et al., 2016; Okoro & Odedina, 2016). Participants were recruited through flyers placed at local AIDS service organizations, by way of presentations by the researcher at women's support groups and through word of mouth from HIV advocates. The 11 participants volunteered as a result of these combined recruitment efforts. Participants were English speaking women over the age of 21 who identify as Black or of African descent. The study criteria required that they had been diagnosed with HIV for at least one year and had visited their HIV provider within the last six months. All of the volunteers had over 10 years since diagnosis which allowed ample time for them to have experiences with multiple providers and time for reflective perspectives (Sandelowski, 1996).

Data collection and management. This study was informed by three data collection modes: contextual interviews with HIV advocates, two focus groups with HIV positive women, and individual interviews with HIV positive women. The purpose of the preliminary interviews with HIV advocates was to understand the context in which this population seeks medical care; to gain advice on recruitment; and gather the appropriate kinds of questions for this population. HIV advocates also contributed interview questions for the women.

HIV advocates recommended focus groups as a means to generate conversation among women that might elicit more insight. The researcher held two focus groups with two women in each that centered on discussion about the potential interview questions. Both groups discussed how the questions were worded and how they would answer the questions themselves which helped the researcher hone the questions as the women contributed to data.

The most pertinent data emerged as a result of the individual face-to-face interviews. Throughout both the individual interviews and the focus groups, the underlying intent of the questions was to pursue ‘what matters to you?’ rather than ‘what is the matter?’ (Boyd & Lucas, 2014). For the individual interviews, women were offered their choice of location, a place they felt was neutral, safe, convenient, and comfortable. Interviews were digitally recorded and transcribed using a professional service. Field notes were kept on interactions with interviewees including sidebar conversations and the ambiance of the identified location and were used to inform comparisons among interviews as well as form the basis of some analytical memos.

Participants were screened by phone, during which time demographic information was collected including age, ethnic heritage, years with HIV, education level, years in care, and self-described levels of HIV management.

Data analysis and interpretation. Charmaz does not advocate an exact process, but instead provides guidelines for researchers to determine the best course for the phenomenon as it emerges (Charmaz in Denzin & Lincoln, 2000; Charmaz, 2008; Charmaz, 2014). Analysis occurred immediately after interviews and continued as the transcripts were being cleaned. This was followed by open coding of the first interviews to identify themes that would likely transcend a particular person or instance (Charmaz, 2014). These initial codes were considered provisional and compared to others as coding continued, eliminating some and condensing others. Codes were focused on actions using gerunds to avoid categorizing the people themselves (Charmaz, 2014).

The interview questions had been pre-arranged according to the six dimensions of the PCC framework plus a seventh dimension which was added to cover what the women believe they contribute to the relationship. Initial codes were placed within this framework and these major dimensions were considered provisional analytic categories (Charmaz, 2014). Some grounded theorists recommend axial coding which involves analyzing, comparing and contrasting the dimensions of each category (Strauss and Corbin, 1998) and Charmaz (2014) allows this if the researcher finds it helpful. In this case, the codes aligned very well with the pre-established dimensions of the PCC so those were retained as categories. The next step involved Charmaz's (2014) method of ongoing comparison relying on analytic memos. Charmaz (2014) advocates using memos immediately after data collection and during analysis. The main purpose of analytic memos is to move toward increasing abstraction. Memos can record comparisons between and among codes and categories, and by asking deeper questions of those comparisons (Charmaz, 2014). The memos for this study frequently confirmed the appropriateness of the existing PCC framework and so abstraction was less of a concern than accurately synthesizing the women's responses so as to answer "*why?*" in the research question.

Drawing conclusions. Constructivist grounded theory hinges upon constant comparison between individual cases, between codes, between categories, between incidents and more (Charmaz in Denzin & Lincoln, 2000; Charmaz, 2014). Analysis involved comparing similarities and differences among women in this study and comparing their remarks to other qualitative studies with similar samples. Analytic memos and notes from the researcher's field journal on similar answers in the interviews allowed the researcher to examine the social processes at work and understand with greater clarity why some provider actions are helpful and others are not, based on comparisons across cases rather than descriptions of isolated events (Charmaz in Denzin & Lincoln, 2000; Charmaz, 2014).

Quality and legitimacy were increased through member checks and observer checks. Constructivist grounded theory dictates that research is and should be co-constructed (Charmaz, 2014). To acknowledge that research is constructed and adhere to the underlying principle of co-constructing data, the researcher verified interpretations of participant's statements during the interviews; the researcher also had occasion to verify a summary of her findings with one participant and one advocate.

Use of the Framework. Initially, the Framework for Patient-Centered Communication in Cancer Care by Epstein and Street (2007) was intended simply to provide sensitizing concepts as per Charmaz's (2014) recommendation that novice researchers not attempt to start their work with a completely blank slate. The PCC was used as a guide to organize and refine the questions that advocates provided.

Outcomes. The outcome of this study indicated that the PCC is highly adaptive and appropriate for this population with this health condition, albeit with a few additional considerations. Those considerations include the specificity of the stigma related to HIV, past mistrust of the medical system, and the skewed impact HIV and HIV related stigma have on low SES patients. Providers must be attentive to the strategies outlined in the PCC as a baseline, but add a layer of sensitivity and personalization.

CHAPTER 4 (Manuscript Three)

Positive STARTs:

Encouraging Black Women to Stay in HIV Care in the Era of Rapid ART initiation

This paper focuses on practice recommendations for providers as Arizona clinics begin to shift toward rapid antiretroviral therapy (ART) initiation and away from the previous method of a long consultation process with patients before starting antiretroviral therapy. This approach is inspired by the work of the 90/90/90 Fast Track Cities Campaign that the City of Phoenix joined to improve outcomes for people living with HIV throughout the Phoenix metro area. In October of 2016, the City of Phoenix joined on with cities around the world to develop a plan to end HIV as a public health threat by 2030. Roughly 30 citizens who are involved in HIV reduction, voluntarily or through employment, were sworn in and committed to actualizing a plan that fills gaps in the HIV continuum of care. The continuum of care follows diagnosis through to viral suppression. The goals are to have 90% of people who are suspected of having HIV know their status; 90% of people who are diagnosed with HIV linked to care; and 90% of people who are in care become virally suppressed. Nationally, those numbers are currently 86%, 80%, and 56% (HIV.gov, 2021).

“Linked to care” refers to the numbers or percentages of people diagnosed with HIV and getting at least one CD4 test within 30 days in a given year. In contrast, “retained in care” and “virally suppressed” numbers are based on the *total* numbers of people living with HIV in a given year (HHS, 2020). By the CDC’s definition, retained in care means having had two or more CD4 or viral load tests at least 3 months apart in a given year, while viral suppression is defined as having less than 200 copies/mL at the most recent viral load test in a given year (HHS, 2020)

As a result of the momentum galvanized by the City initiative, a collaboration among public and private clinics with community-based organizations, pharmaceutical companies, and ASU researchers developed unlike any that had taken place in this region previously. Thanks to having two dedicated city staff, this ad hoc committee has been able to meet regularly and hash out myriad challenges in the local HIV care continuum. This committee, for example, has tackled problems with data tracking among entities for the care of newly diagnosed patients, developed new materials to ensure clinics know how to help a person who is newly diagnosed, find providers, coverage, and other needs, and increased public dialog about the need for regular testing.

Problem

Like elsewhere in the nation, Arizona has challenges keeping HIV positive people in care and virally suppressed. In 2019, 78% of people diagnosed with HIV had received care, 60% were retained in care and 65% were virally suppressed (ADHS, 2020). The numbers indicate that Arizona providers are effective once people get into care. Similarly, physicians who participate in the Fast Track Cities initiative remark that roughly 80% of their patients who are in regular care are virally suppressed. The state's challenge lies in keeping more of those who have been diagnosed with HIV in care and adherent. This may change with rapid ART initiation, which is why the Arizona Department of Health Services (ADHS) is piloting the State of Arizona Rapid Treatment (START) program with the Fast Track Cities Initiative. It is possible that some of the actions taken to keep Black women in care may also apply to the 13% of patients who are linked to care but don’t achieve viral suppression.

Research over the past several years has indicated that delayed start of antiretroviral therapy, which had long been the practice, too often results in patient attrition and/or transmission of the virus. In contrast, initiating ART as early as possible leads to longer lives and reduced transmission by reducing the time to undetectable status (Cohen et al., 2011; Zhao et al., 2018). In a study of over 1,700 serodiscordant couples, Cohen et al. (2011) observed 28 transmissions during a three-year period with only one linked to a patient who started ART upon enrollment in the study. Delayed start patients in this study began treatment when CD4 counts dropped to 250 copies per millimeter or developed an AIDS related illness (Cohen et al., 2011). Mugavero et al. (2007) found that longer wait times for appointments was associated with “failure to establish care” more commonly among minority, female patients and those without private insurance, characteristics shared by the population of focus for this study. So, closing the gap between diagnosis and ensuring someone returns for their early appointments has become increasingly relevant. This is especially important for many African Americans who receive a positive diagnosis when the virus has already progressed (Ransome et al., 2016; Ulett et al., 2009).

Purpose

The purpose of this paper is to offer insight into how providers can more successfully engage Black women in a way that encourages them to feel comfortable starting antiretroviral therapy immediately and to stay in care for the long term.

Literature

Aziz and Smith (2011) identified some of the challenges of linking women to care. They underscore the importance of having case managers help women navigate the complexities of an HIV diagnosis. Their review of literature revealed that “one third of women with HIV infection in the United States present with AIDS at the time of their diagnosis or progress to AIDS within 12 months” (Aziz & Smith, 2011). In a large cohort study, they found that 28% of Black women who met the criteria for antiretroviral therapy (with regard to low CD4 Cell count and high viral load) were not prescribed ART (Aziz & Smith, 2011). About 55% of women in this same study were not offered a case manager, who could help them make linkages to care (Aziz & Smith, 2011). Providers on the Fast Track Cities committee have often discussed the critical role of case managers in HIV care and have recently noted that this is a challenge in piloting the START program (City of Phoenix meeting, February 4, 2021).

Literature indicates that effective communication is very important in developing trust, particularly in culturally incongruent relationships and clinicians’ style can be interpreted very differently by patients of different ethnic backgrounds (Doescher et al., 2000; Martin et al., 2013). There are very few physicians of African descent working on HIV/AIDS in the Phoenix metro area, therefore understanding what kinds of communication strategies have kept members of this population in care and adherent while in culturally incongruent situations may help providers close the retention gap.

Research Question

What can local providers do to help retain HIV positive Black women in care?

Method

The recommendations in this paper are derived from the HIV network interviews, recommendations offered by Black WLWH during their interviews for the empirical study, and from discussions in the Fast Track Cities Committee meeting minutes. Recruitment strategies laid out for participants in the empirical study are the same for this paper regarding Black women living with HIV. The HIV advocates were asked to be interviewed based on their name recognition in the field, due to the positions they hold, or through recommendations of other advocates.

Analysis. Constructivist grounded theory per Charmaz (2014) also informed these results due to the emphasis on social interactions and on staying close to the data. Advocates and patients' recommendations were compared with one another and combined when appropriate.

Presentation of results. Recommendations are described as actions for providers to undertake with an explanation of positive impact.

CHAPTER 5. Drawing Conclusions

All three chapters build upon one another by design. The literature from the scoping review informs the grounded theory research project in the subsequent chapter. Both papers inform the practice recommendations in chapter three. The HIV network interviews are shaped by questions for the empirical study and foundational concepts for the practice recommendations paper. When combined, these papers propose an opportunity for local providers to adjust some approaches for their interactions with a vulnerable population and move the county one step closer to ending the HIV epidemic.

Epstein and Street's PCC (2007) offers a substantial and nuanced framework as a starting point for effective communication strategies, but the nature of the social stigma surrounding HIV as well as differences in race and class status call for a few additional adjustments on the part of providers. Women in this study underscore the need for a few more specific steps that remove stigma and judgment, allowing women like them to be fully transparent in their health care needs. Examples of these steps include taking time with the patient and interacting with her personably. Patients may not need this kind of interaction with every kind of provider if HIV does not need to be disclosed, but it is a necessity when providers know of the woman's status because of her anticipation of stigma or judgment. Women in this study revealed that providers who approach their patients as if they are building a partnership earn the women's trust much more so than those who interact with patients in a more transactional manner.

Human Subjects

Two of the three manuscripts required work with ASU's Institutional Review Board. Protocol was approved for three data collection phases for this study: interviews with HIV advocates, interviews with people living with HIV, and review of public minutes from the City of Phoenix Fast Track Cities ad hoc committee to end HIV. HIV advocates are people who work in various capacities in support or treatment of people living with HIV including case managers, physicians, nurses, non-profit and government administrators, and volunteers. Patient privacy is a sensitive concern overall, especially for people living with HIV. De-identified electronic transcripts for this study are kept in a password protected university server and consent forms are kept in a locked drawer in a private ASU office.

CHAPTER 2

THE PROVIDER'S ROLE IN RETAINING HIV POSITIVE BLACK WOMEN IN CARE: A SCOPING REVIEW

Rationale

According to the CDC (2020) African Americans/Blacks continue to bear the highest burden of HIV compared with other races in the United States. In 2018, African Americans made up 13% of the population yet account for 42% of new HIV cases (CDC, 2020). The disparity is even more acute for women as African American/Black women comprise 57% of new cases among all women followed by white women and Latinas at 21% and 18% respectively (CDC, 2020).

Currently, the CDC estimates that, for every 100 persons with HIV, 66 have received some care, 51 are retained in care and 53 are virally suppressed (CDC, 2020). Importantly, 80% of those 51 retained in care are virally suppressed which indicates the efficacy of maintaining regular testing and medical appointments (CDC, 2020). The CDC defines being retained in care as having had two viral load or CD4 tests within one year, at least three months apart. HIV positive patients who are not retained in care regularly are less likely to remain undetectable and more likely to see greater disease progression and mortality (Mugavero et al., 2009). For this reason, retaining as many people in care as possible becomes critical to saving lives, reducing transmission, and ultimately ending HIV as an epidemic.

Previous quantitative and qualitative research has found that HIV patient satisfaction with the overall clinic environment, including relationships with providers, influences patients staying in care and adhering to an antiretroviral regimen (Dang et al., 2013; Laws et al., 2012; Schneider et al., 2004; Vyavaharkar et al., 2008).

Research suggests that patient satisfaction, however, is directly influenced by the quality of patent provider interactions (Oetzel et al., 2015). Oetzel et al.'s (2015) study of 344 people living with HIV suggests that improving patient satisfaction is a matter of improving patient-provider interaction and showed that patient-provider interaction for people living with HIV actually leads to patient satisfaction with overall services as well as adherence. They recommend that research and interventions be aimed at bettering this relationship (Oetzel et al., 2015).

Beach et al. (2006) also found a significant relationship between the quality of the patient-provider relationship and patients' willingness to stay in care and achieve viral suppression. Specifically, this study examined the extent to which patients' perception that the provider knows them "as a person" influences their receptivity toward being prescribed highly active antiretroviral drugs (HAART), their willingness to adhere to a HAART regimen, and likelihood of having an undetectable viral load (Beach et al., 2006). They found a strong positive correlation between patient perception when the provider knows them "as a person" and each of these. Moreover, patients who felt their provider knew them as a person missed fewer appointments, had greater confidence that antiretroviral medicine was beneficial to them, and reported a higher quality of life (Beach et al., 2006).

An integrative review of qualitative and quantitative research to identify the specific actions providers take to facilitate a strong interpersonal relationship could help other providers know with greater certainty what they can do to keep more patients returning to appointments and adhering to their regimen. Preliminary Google Scholar searches, however, yielded little information on the nature of patient-provider relationships for Black HIV positive women within the past 10 years. One qualitative study based on in depth interviews by Okoro and Odedina (2017), found that women who felt that their provider knew them as a person were more confident about treatment and care, echoing Beach et al.'s (2006) findings. As a precursor to an integrative review, scoping reviews are conducted to determine the breadth of literature on a subject and to determine the appropriateness of a research question (Munn et al., 2018; Pham et al., 2014; PRISMA, 2018).

Objectives

This scoping review was conducted in order to gather corroborating research that identifies specific provider actions that encourage HIV positive Black women to stay in care and adherent to medical recommendations. This review also sought to determine if there would be enough studies to develop an integrative or systematic review on this subject. The following research question guided the queries: What provider actions help keep HIV positive Black women in care?

Methods

Eligibility criteria

Papers met eligibility criteria if they discussed a qualitative, mixed methods, quantitative experimental or non-experimental study on HIV positive patient-provider relationships that included self-identified African American or Black women. Papers must have been peer reviewed journal articles published between January, 2009 and December, 2019, written in English, focused on women in the United States, specifically discussed the experiences of Black women with providers, and identified provider actions that helped women stay in care.

The researcher sought articles that discussed Black women independent of other HIV positive patients because (a) African Americans have a historical relationship with the medical establishment that creates a potential for friction, discomfort, and sometimes reluctance to engage in care (Ball et al., 2013; Jacobs et al, 2006 ; Saha et al., 2010; Vyavaharkar et al., 2008); (b) since the virus predominately affects men in the United States, it follows that more studies have been directed at men; and (c) studies that combine the experiences of all HIV patients together may not be able to disentangle the concerns of Black women who may experience internalized racism combined with the needs and pressures of family care, and the emotional burden of acquiring HIV most likely through heterosexual contact.

A long date range was chosen due to low results from preliminary searches, but the date needed to be within the post HAART era after which medications were much more tolerable. Studies were limited to the United States because numerous studies focus on Black women in other parts of the world that have very different health care systems and social contexts.

The researcher conducted searches throughout 2019 with a follow up search in each database during March 2020.

Information sources

The following databases were searched: CINHAL, PubMed, Cochrane, Medline, and Scopus. Hand searches were conducted in each of the documents meeting selection criteria. Keywords included: African American women, Black women, HIV positive, patient, provider and communication, or interaction, or relationship or engagement. Limitations on searches varied according to database availability but all included English language, peer reviewed, and the publication date range. For those that made additional limiters possible, the United States was set as the geographic location, journal article as type of source, and female sex or gender. For one search, the limiter patient-provider interaction was available; for another search, “women’s health issues” was available.

The following is a search example: PubMed searched on February 2, 2019 and March 29, 2020 with the keywords, African American Women + HIV Positive + Provider and a limitation of ten years. Both searches yielded 23 results.

Selection of sources of evidence

The researcher read each title and abstract from the search outcomes, discarding immediately those that were not relevant and those that were repeated from other searches. Reasons for immediate discard were a focus on men exclusively, a focus on women outside of the United States, a focus on HIV prevention, a focus on an illness other than HIV, or the article being a type systematic review itself. After immediately discarding those that were not relevant, 42 articles were kept to be read in detail. Of those 42, 14 studies indicated that patient-provider interaction was a facilitator to care for HIV positive Black women. Those 14 were kept for an initial data charting phase and then reexamined for relevance to the research questions.

Data charting process

Data charting occurred in two major phases. First, data from the set of 14 potentially relevant articles was charted as part of the examination process. Data typically sought for systematic reviews was charted on an excel spreadsheet along with additional variables that would help answer the research question and provide recommendations. That data was further distilled in order display just information pertinent to the research question.

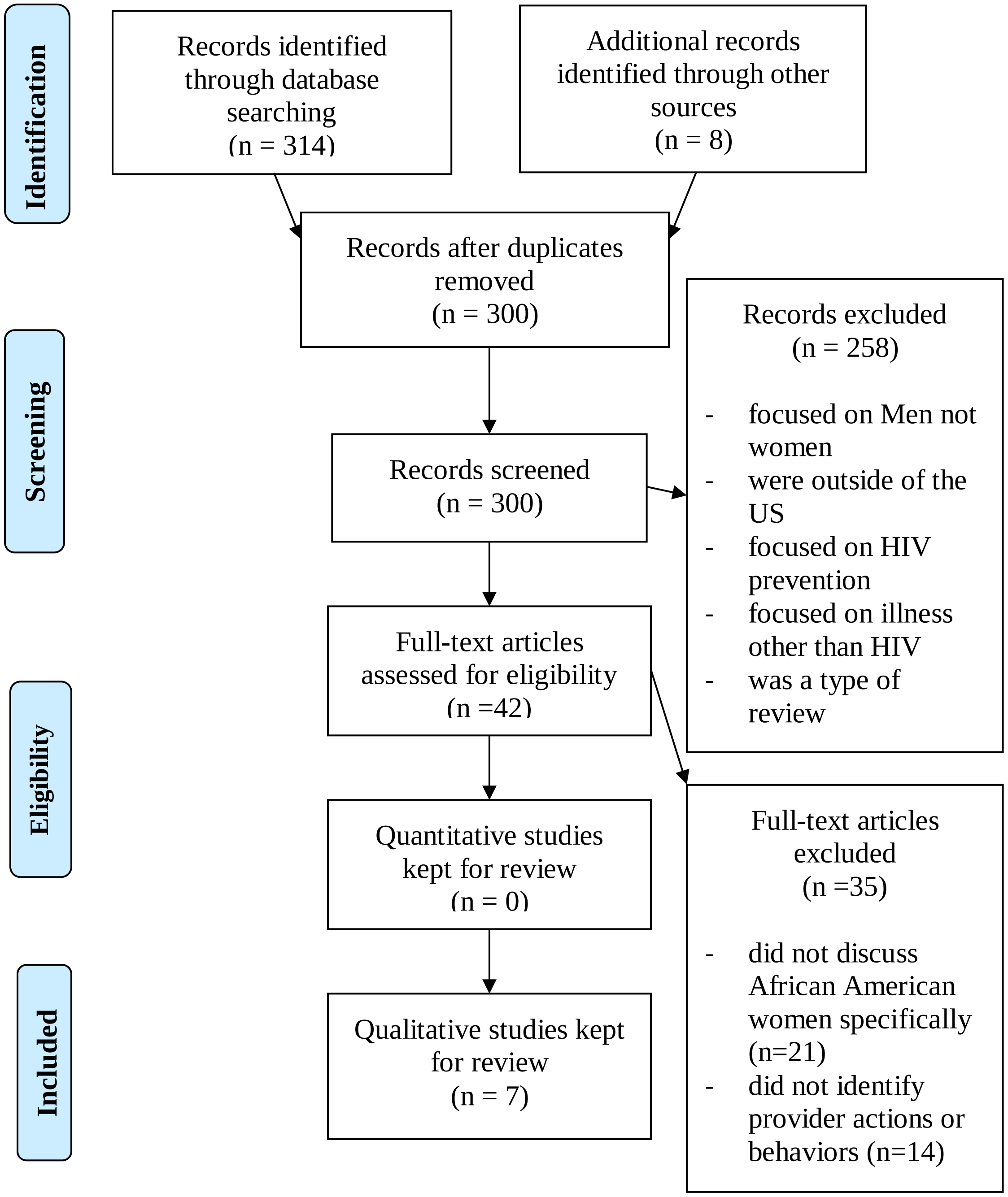
Data variables

The following data were extracted from 14 potentially relevant articles: publication information, primary purpose of the study, theory or framework (if any), study design, setting, sample, number of groups, protocol, instruments used, analytical method, findings, provider actions discussed, other unique findings, and recommendations. The primary purpose of the study was charted in order to understand how many and which studies set out to examine patient-provider relationships or if discussion on patient-provider relationships emerged out of a different purpose. A yes/no notation was made to indicate whether the study made specific reference to African American women. Instruments, analytical methods, recommendations, and other concepts were charted in order to look for commonalities and differences among the studies such as adjectives participants used to describe providers and emotions they tied to the office visit.

After data were charted for information relevant to the study question, those 14 articles were reviewed again to verify that they answered the research question. Those that did not provide answers to the research question were removed from further review. Articles were kept for the final scoping review if the results included specific references to African American or Black women and if the authors described provider actions to help keep women in care based on these data. The final evidence table was reduced to those data that contributed to answering the research question. Seven articles were retained for the final review. See figure 1: “PRISMA flow chart” for inclusion and exclusion process (PRISMA, 2018).

Figure 1

PRISMA Flow Chart



Synthesis of results

The researcher grouped the studies according to those that were exploratory and those focused on an intervention. This allowed for collective knowledge on how often exploration into practices that help this population are evaluated and enacted. The researcher also looked for commonalities among the sample, settings, findings, provider actions, and recommendations. Participant information from the seven final studies was synthesized in order to understand overall sample characteristics including the average age and the range of years since diagnosis.

Characteristics of sources

Table One summarizes each source including the citation, study purpose, design and theoretical framework used (if any), data collection method and setting, sample size, and provider actions identified.

Types of Studies and Appraisal

All seven of the studies that met criteria were qualitative. Each study was read for its contribution to the research question as well as its overall quality based on concepts offered by Malterud (2001). Malterud (2001) makes the case for the value of qualitative studies to medical research by arguing some questions simply cannot be answered through controlled experiments, because, as human beings, both patient and practitioner behaviors are informed by opinions and experiences. Understanding the communications and interactions involved in health outcomes requires the kind of contextualized observation and inquiry that can be accomplished through qualitative studies (Malterud, 2001). Malterud (2001) offers guidelines to help readers of qualitative studies ascertain their usefulness for the topic at hand by encouraging them to assess three major factors: reflexivity, transferability, and interpretation and analysis. Reflexivity refers to the authors' self-disclosure of their own knowledge, professional role, motivation and position in relation to the topic so that readers can accurately discern study results from the author's preconceived views (Malterud, 2001). To understand the degree to which a study is transferable, Malterud (2001) asks readers to examine the study design and description of the sample. Regarding interpretation and analysis, Malterud (2001) directs readers to examine the detail with which authors describe the process of extracting findings from raw data.

All of the studies met most of her criteria for rigor. If the researchers fell short of Malterud's (2001) criteria, it was in documenting reflexivity. Only authors of two papers explicitly described their personal positions and background in relation to the research topic. The others discussed academic knowledge to frame the topic but not their personal positions and motivations. The two that did so were African American women, perhaps motivated to explain their proximity to the community they were researching.

Nevertheless, the studies in aggregate were clear about their aims, rational for the design and choice of theory, sample selection, the characteristic of their samples, and analytical methods. They all made appropriate and informative use of quotes to illustrate key points and present the participants' voice distinctly from their own. Overall the contribution of these studies to medical research is that they allow a window into what this population needs, wants and values in their care.

Study purposes

Each of the studies described provider actions that help keep African American women in care and identified responses tied specifically to this population. Yet, only two of the seven set out to understand patient-provider relationships. The other five studies sought to ascertain general barriers and facilitators to care for women in a particular service area and learned that a good patient-provider relationship was an important motivator to staying in care. Conversely, the studies collectively revealed that negative interactions with providers can be a deterrent to staying in care. Two of the studies were aimed at evaluation and quality improvement for interventions, while the rest were exploratory.

Theoretical frameworks and study design

Three of the studies used focus groups, four used in-depth interviews, and one included interviews with providers as well as patients. Most used a qualitative phenomenological type study design. To guide the analysis, three used grounded theory methodology, one used the transtheoretical model of change, and another used an intersectional theory framework.

Samples and settings

In total, these studies included 147 women who identified as African American or Black, ranging in age from 21 to 69. The average age across studies ranged from 42 to 57. Participants were recruited from HIV or infectious disease clinics in urban centers on the east coast from Massachusetts to Florida. One study focused on rural women in Alabama. None covered mid-western or western locales.

Table 2.

Evidence Table

Author & year	Study purpose	Design & theoretical framework	Data collection and setting	Sample	Findings	Positive provider actions identified
Amutah-Onukagha et al. (2018)	Improve an intervention to empower women substance abusers	Qualitative phenomenological using grounded theory	Focus groups at three agencies in New Jersey using private rooms	N=31. All AA women. Age 21-67, average 50. Most less than college educated.	Participants understood that following doctor's orders must be a priority to maintain good health; many attributed relationships with clinicians to medical adherence and control over health condition.	Not rushing, educating patient, demonstrating "buy-in" to helping patient with overall health. Lack of other social support made provider relationship more important

Kempf et al. (2010)	Determine barriers / facilitators to care for women in the rural southeast United States	Qualitative descriptive based on focus groups	Focus groups held in or near outpatient clinics serving rural patients in Alabama	N=40. 37 AA women, 3 white. Age 29-69, average 46. Low income / low education.	Relationship with HIV care provider a critical facilitator to care. Other facilitators: transportation, clinic organization, hours, and location (not necessarily in their same neighborhood).	Staff being friendly and encouraging. Demonstrating compassion through hugs, talking and laughing, giving full attention, showing respect. Calls for appointment reminders. Comprehensive visits. Limiting time in waiting room.
McDoom et al. (2015)	Understand older black women's' perception of stigma and its impact on seeking care	Semi-structured interviews using grounded theory	Interviews in a private room at an HIV clinic in Boston	N=20. All AA women. Age 56 - 63, average 56. 75% disabled or unable to work	Stigmatizing experiences with some providers led to reluctance to stay in care. Clinics identified with HIV or other communicable diseases were stigmatizing.	Showing compassion, being non-judgmental, not looking down on patients. Avoiding any amount of stigmatizing actions

Njie-Carr et al. (2016)	Understand facilitators to retention in care	Interpretive phenomenological approach using transtheoretical model for change	Interviews with women recruited from a large metropolitan HIV clinic in Baltimore	N=14. 5 AA women, 1 American Indian woman; 7 AA men. Average age of women, 42	The clinic became a "safe haven." Patients felt loved, supported, cared for. Challenges with mental illness and substance abuse were common deterrents to care.	Exhibiting supportive and caring behaviors and opportunity to build genuine friendships with staff. Offering personal attention
Okoro and Odedina (2016)	Improve medication adherence among African American women through patient-provider relationship	Interview patients first then providers, using grounded theory	Interviews with women recruited from an HIV clinic in north central Florida	N=31. 10 AA women; 21 providers. Age not provided.	Patients reported that the patient-provider relationship was critical to adherence; patients need providers to know them personally. Having a consistent provider is important. Provider’s flexibility and willingness to tailor care helps.	Using holistic, patient centered care models. Investing time in relationship getting to know the patient personally; adapting the regimen to individual patient lives, listening to HIV patient panels; offering good HIV education while avoiding overload; preparing patients for side effects; creating linkages through stories, through support groups or referrals to others PLWH

Sullivan et al. (2015)	Assess the effectiveness of a nurse navigator program at increasing adherence	Interview participants and use thematic analysis for interpretation	Telephone interviews with women recruited from UNC clinic in Chapel Hill, North Carolina	N=21 AA women. Age 27 – 62, average 45. All low income.	Patients reported positive relationships with the nurse guide. Many discussed her kindness, heartfelt concern, and availability; participants felt cared for. Nurse Guide became main reason for participants to continue seeking care interactions increased hope	Clarifying information; calling to check in with patients, discussing side effects, offering kindness, availability, genuine concern, hugs, seeking solutions.
Warren-Jeanpiere et al (2017)	Understand social support needs of women aging with HIV	Focus Groups using an intersectional theoretical framework	Focus groups with women at the D.C. Women’s Interagency HIV Study	N=23. All AA women. Age 52-65, average 57	Patients expressed a desire for emotional support from therapists; emotional and informational support from physicians. Patients need to be open with providers. Also need transportation support when family/others cannot assist.	Providing both medical support, information and as emotional support. For some women, providers were the only source of emotional support. Reliance on providers for emotional support is not common with other illnesses.

Discussion

This review sought to determine the scope of existing literature that identifies provider actions that help keep HIV positive Black women in care. All study types were under consideration, however only seven qualitative studies addressed the research question. Although there were not enough studies to lead to a systematic review or meta-synthesis, these seven studies offer very helpful insights through participant direct quotes on what works for them individually and through the authors' aggregation and analysis of all participant input.

Of the studies that met criteria, five were exploratory examining the barriers and facilitators to care, and two were conducted to test or demonstrate the efficacy of an intervention. All revealed important themes for this population.

Exploratory Studies

Provider relationship and staff attitudes

Among the studies that offered the most specific examples of provider actions pertinent to Black women was conducted by Kempf et al. (2010). This study set out to determine barriers and facilitators to care for women in the rural southeastern United States. Although not exclusively focused on Black women, the vast majority of participants in this study were Black (36 out of 39 total participants), thus the findings were highly relevant to the research question. For this study, researchers conducted focus groups using a descriptive inquiry approach in order to allow the women to discuss what was significant to them (Kempf et al., 2010, pg. 516). Participants in the Kempf et al. (2010) focus groups named two "strong incentives" to maintain regular appointments at their clinic: their relationship with their provider and being made to feel welcome by other staff (pg. 517). When participants in this study were met with friendliness, encouragement, understanding, caring, and respect by providers and clinic staff, they enjoyed their visits and missed fewer appointments (Kempf et al., 2010).

Structural and organizational factors

In the Kempf (2010) study, participants' desire or ability to return to a clinic was influenced by how well the clinic operated. For these participants, additional provider actions that helped them stay in care were: more comprehensive visits, such as getting blood work done on the same day, shorter time in the waiting room so they wouldn't have to risk being seen by people who may not know their HIV status, appointment reminder calls the day before each appointment and providers encouraging the importance of keeping appointments in a compassionate manner (Kempf et al. 2010).

Clinics as safe spaces

Njie-Carr et al. (2016) learned that their participants viewed their HIV clinic as a "safe haven" and described behaviors among clinic staff that were "supportive and caring" (Njie-Carr et al., 2016). The staff commitment to the women's health was a motivating factor in kept appointments (Njie-Carr et al., 2016). Most of the patients in this study were newly diagnosed and those who were not newly diagnosed had recently returned to care. The clinic staff were an important part of patients' social support system along with family and friends (Njie-Carr et al., 2016). A limitation on this study for this purpose is that it focused on newly diagnosed. The responses of the newly diagnosed, however, are so similar to those that motivate people who have been in care for many years that this may point to the strength in the findings rather than a limitation.

Patient-centered partnerships

Okoro and Odedina (2016) determined that patient centered care was critical to adherence and kept appointments. They used the definition of patient centered care as a partnership between the provider, the patient, and that patient's close social support individuals (Okoro & Odedina, 2016). This was the only study in the review that also sought providers' input. The Okoro and Odedina (2016) study included interviews with a range of health care professionals: nurse practitioners, registered nurses, a pharmacist, physicians, social workers, community health workers, and a public health professional. It was important for the provider to "know the patient as a person," be able to educate her on benefits and potential side effects of certain medications, and take time to understand the woman's life overall (Okoro & Odedina, 2016). The providers Okoro and Odedina (2016) interviewed were in alignment with the patients, stating they needed to do extra work to earn this population's trust.

Providers in the Okoro and Odedina (2016) study acknowledged the importance of figuring out how to create a partnership with each new patient and that rushing appointments lead to negative perceptions among patients. Providers sought ways to meet individual patient needs such as flexible appointment schedules and mailing medications to rural patients (Okoro & Odedina, 2016). Providers understood the benefits of finding a point of motivation for their patients to stay in care, such as children, and use that as a way to encourage women to stay healthy (Okoro & Odedina, 2016). Patients wanted a consistent provider, even postponing appointments if the doctor with whom they had a relationship was away, so as to avoid having to re-start a relationship with a new provider (Okoro & Odedina, 2016).

Perceived judgement by providers

Two of the exploratory studies focused on the evolving needs of HIV positive women over 50: McDoom et al. (2015) and Warren-Jeanpiere et al. (2017). Older HIV positive women who experienced the stigma from providers in the early days of diagnosis became mistrustful of providers and reluctant to continue seeking care (McDoom et al., 2015). The stigma they experienced were related to stereotypes associated with HIV such as intravenous drug use or promiscuity but they acknowledged that provider compassion and understanding has improved over time (McDoom et al., 2015). For women in this study, the women's perceptions of what the doctor thought about them affected their interest in staying in care. Despite what the provider might intend to convey, women did not want to engage in care if they thought the doctor "looked down on them," was not truly interested in their health, or had an otherwise "negative attitude" toward them (McDoom 2015 pg. 99).

Formal supports to counteract stigma and emotional isolation

Both studies on older women argued that formal supports, such as providers, clinic staff, AIDS service organization staff, became an increasingly important source of social support as HIV positive women age (McDoom et al., 2015; Warren-Jeanpiere et al., 2017). Ageism combined with HIV related stigma made it difficult for older women to find support among informal sources such as family, friends, churches, or social groups compared with other chronic illnesses that disproportionately affect black women (Warren-Jeanpiere et al., 2017). Warren et al. (2017) noted that providers and HIV advocates sometimes became the only consistent and trustworthy support for some women.

Studies designed to evaluate an intervention

Taking time and demonstrating buy-in

Of the two studies that examined an intervention, one was conducted to gain participant feedback on Project THANKS, an intervention for HIV positive substance abusers. (Amutah-Onukagha et al., 2018). Through focus groups, women in this study explained that a good relationship with their providers lent to their adherence and regular appointments. Women noted that the providers they liked did not rush, answered questions, provided education on HIV, and showed they “bought in” to help the women be healthy (Amutah-Onukagha, p. 123).

Professional health navigators and their authenticity

The other intervention related study was developed to evaluate patient experiences with nurse guides in a program created to help HIV positive women of color navigate medical and other resources (Sullivan et al., 2015). Most participants were newly diagnosed, had not previously engaged in care or were returning to care. For the newly diagnosed patients, education from the nurse guides on the survivability of HIV was critical. It was important to have someone to discuss the side effects of medication. The nurse guide showed genuine, not artificial or “phony” concern, was friendly, actively found solutions, was easily accessible by phone, and called the patients to check-in on them (Sullivan, et al., 2015, p.52). Participants felt as though they could talk candidly to the nurse guide, who then supplemented the lack of social support in other areas of their lives, (Sullivan et al., 2015). The nurse gave them instruction on how to ask questions during appointments and cleared up confusion about information offered by physicians and other providers (Sullivan et al., 2015).

Limitations

This review has limitations in both the process and outcomes. The researcher used the keyword "provider" in order cover a broad range of healthcare professionals, but a future search might yield different results if multiple words were used such as nurse, physician, case manager, or doctor. Articles that surfaced during hand searches did not appear in the database searches which may point to inadequate selection of keywords.

Hand searches were limited to those that met final criteria, but could have been more exhaustive had the researcher scanned articles that did not meet criteria. Searches did not include other illnesses that disproportionately burden Black women which might augment the information found in this paper. The reason for limiting the search to HIV, however, is that the social stigmas historically tied to this virus make it potentially dangerous for people to be open about their status, lending to suspicion of some providers.

An important limitation on the total body of evidence is that the average age for participants were older, even when studies were not intentionally seeking older women. This could be the result of self-selection among participants indicating that older women are more comfortable discussing HIV and perhaps there is greater internalized stigma among younger women. Conversely, it could mean there is less stigma among younger generations and therefore less of a need to gain social support from providers. This conundrum is unaddressed by this body of work and calls out for new research.

These studies were also limited to the East coast. Lastly, since there is only qualitative evidence, the pool lacks the scale and objectivity on provider actions that can be analyzed through quantitative methods.

Four of the seven articles were published by *AIDS Patient Care and STDs* indicating a strong interest in this population by this journal. One was published in *AIDS Care*. The others were published in *Journal of the Poor and Underserved* and the *Journal of Ethnographic and Qualitative Research*. It is notable that journals targeting wider public health audiences, those looking at range of ailments, are not among the pool of publications.

Strengths

Although the final pool of articles was small, they offered answers to the research question “What provider actions help keep HIV positive Black women in care?” Many other articles acknowledge *that* the patient-provider relationship is important to women, but do not describe what it is providers actually *do* to create a strong relationship. The database searches were conducted and repeated over a period of months, but this did not increase the numbers of eligible documents indicating an exhaustive search.

Conclusions

This review sought to answer the question: “What provider actions help keep HIV positive Black women in care?” The resulting articles show that a combination of provider interpersonal skills and functions of the clinic (such as appointment reminders and connections to other resources) help women stay in care. They suggest that whole patient care is important to this population because some women may not find social support needed to manage HIV and associated comorbidities elsewhere.

These studies reveal that many HIV positive black women are motivated by an emotional connection to their providers and/or clinic staff. Authors acknowledge that emotional support from providers was an important motivator for return appointments to the women they interviewed (Njie-Carr et al., 2016; Sullivan et al., 2015; Warren-Jeanpiere et al., 2017). Women in these studies used terms like “love,” (Amutah-Onukagha et al., 2018; Kempf et al., 2010; Njie-Carr et al., 2016) and “spiritual connection” in relation to their providers (Amutah-Onukagha et al., 2018). Some expressed genuine sadness when a provider relationship ended (Sullivan et al., 2015). It was also important that they perceived clinics as emotionally safe places. They described supportive clinics as places where they saw “friendly faces,” felt encouragement, and concern, love, caring, genuine friendship from the staff and where they could be at peace (Kempf et al., 2010; Njie-Carr et al., 2016). Women seemed to rely on providers as emotional support to make up for lack of social support elsewhere because of the stigma associated with HIV (Amutah-Onukagha et al., 2018; Warren-Jeanpiere et al., 2017). Supportive clinics also need to be places that were non-judgmental about patients’ sexuality (Njie-Carr et al., 2016). These studies point to a conclusion that provider relationships for this population cannot be simply transactional and that being a technically competent provider is insufficient for building trust and keeping patients returning.

Aside from the actions enumerated in the results section, these studies offer recommendations on how HIV providers can collectively improve care for Black women. Addressing mental health concerns and substance abuse challenges helps keep patients adherent to medication (Amutah-Onukagha et al., 2018; Njie-Carr et al., 2016). Comorbidities are often challenging for women to manage even when HIV is under control, therefore Amutah-Onukagha et al. (2018) and Warren Jeanpiere et al. (2017) suggest providers be prepared to discuss these. Okoro and Odedina (2016) developed multiple recommendations including: training HIV positive women to help other women, patient advisory panels to keep providers mindful of women's views, educating patients with careful timing to avoid overload, and finding something that motivates the patient and helps earn her trust. McDoom et al. (2015) admonish providers to understand women's struggles with stigma, including changing practice or clinic names to avoid the use of HIV and AIDS (McDoom et al., 2015).

Together, the articles suggest that providers are successful when they are attentive to the whole patient rather than just her HIV concerns. They should be able to discuss or consider care coordination with patients' other providers, offer functional mechanisms for staying in care such as appointment reminders, foster medication self-management related to HIV management, and remain keenly aware that they provide an important source of emotional support for a population that may not get that support elsewhere. The fact only two studies set out to understand patient-provider relationships Okoro and

Odedina (2016) and Sullivan et al. (2015) suggests there is room for research that hones in on this important social phenomenon.

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CHAPTER 3

POSITIVE INFLUENCES: HOW PROVIDER ACTIONS AFFECT RETENTION IN HIV CARE FOR BLACK WOMEN

African American/Black women continue to bear the highest HIV burden among all women. As of 2017, HIV was still a top ten cause of death for Black women ages 20-44 despite medical advancements that have made HIV a treatable condition (CDC, 2019). Notably, HIV is not a top 10 cause of death for any other group of women. Retention in care is still a challenge for women nationally with 51% retained in care and 53% virally suppressed (CDC, 2020). The CDC notes that people who are more likely to drop out of or be inconsistent with care are female, minority, and of lower socioeconomic status (CDC, 2019). Closing gaps in retention is linked to reduced mortality rates (Mugavero et al., 2009). With consistent antiretroviral therapy, people living with HIV now have the potential to live four decades or more post diagnosis, ten years more than estimated in similar analyses conducted in the 1990s (Teeraananchai et al., 2017).

In response to these gaps in retention, the CDC exhorts clinicians to use supportive communication and other active engagement strategies as a means of encouraging adherence to care (CDC, 2019). This research study sought to ascertain which provider attributes and actions, inclusive of communication styles, contribute to successful retention in care from the perspective of HIV positive Black women. Per the CDC's recommendations, retention in continuous medical care is defined as taking at least 2 tests (CD4 or Viral Load) at least 3 months apart per year. Women in this study express that providers who engage them as co-creators in enhancing good health are more likely to retain them. Concurrently, when women are attuned to their own health care and interpersonal needs, they will discern which providers are equally committed to their health based upon observed provider actions. These provider actions, such as listening attentively, taking time, and paying attention to the whole person, in conjunction with women's motivation and active involvement, create a reciprocal dynamic that increases the likelihood these women will remain virally suppressed. The ideal relationship is one in which the provider empowers and champions the women as drivers in their own care.

Literature

Qualitative and quantitative studies on HIV patient-provider relationships found that trust in providers increases the likelihood of retention in care and adherence to antiretroviral medication, especially for African Americans (Blackstock et al., 2012; Dang et al., 2013; Eaton et al., 2015; Gaston & Greene, 2013; Oetzel et al., 2015; Saha et al., 2010). Studies in other parts of the United States have shown that relationships with providers are a facilitator to staying in care, especially when patients view their clinics as safe spaces and have a sense of emotional support from providers and clinic staff (Kempf et al., 2010; Njie-Carr et al., 2016; Okoro & Odedina, 2017; Sankar et al., 2002; Sullivan et al., 2015; Warren-Jeanpiere et al., 2017). Women are particularly responsive to providers who demonstrate knowledge of them as individual persons (Beach et al., 2006).

Sensitizing concepts

Epstein and Street's (2007) Patient Centered Care in Cancer Settings (PCC) provides a comprehensive, morally grounded framework for effective provider attributes and communication skills rooted in valuing each patient's unique life context (Epstein &

Street, 2007 p.1). Epstein and Street's (2007) framework organizes six key communication functions that are equally as relevant in the socially and medically complicated context of HIV care: 1) fostering healing relationships, 2) exchanging information, 3) responding to emotions, 4) managing uncertainty, 5) making decisions, and 6) enabling patient self- management. This framework for provider communication forms one third of a three-way system that Epstein and Street (2007) say leads to effective health outcomes. The other two components are a high functioning health system and what they describe as an "activated" and engaged patient. The researcher in this study also added a 7th section to Epstein and Street's (2007) framework: patient contribution to the relationship. While this study probed most deeply into women's perceptions of and responses to provider actions, participant responses revealed that their internal motivation is essential along with what they observe to be effective teamwork in the clinical environment. In other words, these women agreed that supportive provider actions are essential, but true success happens when the patient herself is motivated and true confidence in her care happens when she sees the clinic staff working as a team among themselves and with other providers.

Methods

This study occurred in a large metropolitan area in the Southwestern United States. As no previous studies have been published on this topic in this region, the researcher undertook a lengthy process of understanding the local context by interviewing HIV advocates familiar with both the population and services available before approaching potential study participants. HIV advocates included medical doctors, case managers, HIV program administrators, non-profit employees, and volunteers who advocate for the care of people living with HIV.

Each interview with HIV advocates concluded with the advocate offering a list of questions that would help uncover important patient-provider relationship dynamics. These questions were then organized according to the six major themes identified in the PCC as critical to patient centered communication along with a 7th section on patient contributions. The kinds of questions that the advocates recommended fell most into the category of "fostering healing relationships" as they centered around how providers build trust and rapport. Another area of emphasis was "responding to emotions" because of the social stigmas tied with HIV and social status tied with being a Black woman.

Black women living with HIV (WLWH) were recruited to give their perspective as patients through flyers posted at local HIV clinics, AIDS service organizations (ASOs), and by referral from HIV advocates. Recruitment flyers described all participant criteria as well as privacy and consent related information. Criteria included being over age 21, sufficient English to read and understand the consent form, self-identify as female and Black or African American, be HIV positive for more than one year, have a self-rated adherence of good or excellent regarding engagement in care.

Interested participants contacted the researcher by phone and were screened. The researcher logged participant data on screening forms. Two focus groups comprised of four participants who met study criteria reviewed, offered edits, and approved of the appropriateness and usefulness of the interview questions. Questions were open ended and follow-up questions were asked for clarification. Focus groups were held in a private conference room at an ASO familiar to participants. Individual participants were interviewed in a location of their choice, most often their homes or a private office at the university. Consent occurred in-person prior to the focus group or interview. Participants received a $15 gift card for participation in focus groups and interviews, totaling $30 if they participated in both.

Example interview questions

1. Think of the best provider you ever had in HIV care. How did that provider treat you?
2. Think about times when you have felt uncertain or fearful about your healthcare needs. What might make you fearful to have a conversation with your provider?
3. How much of your life aside from HIV do you share with your provider?
4. What do you think you bring to the relationship with your provider that gets you what you need?

Data Analysis

Interviews were digitally recorded and transcribed using an automated service. The transcripts were reviewed and verified by the researcher. Constructionist grounded theory methods as prescribed by Charmaz (2008, 2014) were used to analyze the data. This approach was selected because it orients the researcher toward the ongoing social processes involved in human interaction while acknowledging that there is no singular objective reality. For this study, it was important to be cognizant that gender, income, race and educational differences would impact the social interactions of this patient-provider population and that some provider actions might carry different meaning to some patients over others. Consistent with Charmaz's (2008) recommendations, analysis was concurrent with data collection in that participants were asked to verify the researcher's understanding of their comments during interviews or focus groups and analysis occurred while a researcher verified each transcript for accuracy. Line by-line coding was used to generate initial themes and to develop a code book. Once all interviews were coded, themes were then compared among the interviews and coalesced into larger themes. The researcher drafted analytic and theoretical memos which were shared and discussed with supervising faculty to determine salient themes. Larger themes were also compared to existing themes in the PCC for fit with this current population.

Author reflexivity

Charmaz (2008, 2014) emphasizes that authors be open about their intent and positionality because they are constructing data and theories rather than claiming or attempting to witness data objectively. The researcher for this study is Black woman who believes her position as a visible community member obliges her to advocate on behalf of PLWH. The researcher views this work as an opportunity to document steps that may help this population achieve parity with other PLWH. The researcher acknowledges that she has more formal education than most of the participants and must be aware that this educational difference may influence how participants respond to her. She is also aware that her education may bias her expectations of participants' knowledge.

As the person conducting the interviews, the researcher sought to engage participants without conveying judgment, inadvertently using stigmatizing language, or conveying a notion of social hierarchy.

Human Subjects

This study was approved by Arizona State University's Institutional Review Board.

Findings

Sample

Thirteen women met criteria. Two participated in the focus groups only, nine completed interviews, and two were not able to participate due to travel and life changes. This sample size is slightly smaller than other studies looking at HIV positive Black women which average 12 participants. Those studies, however, are in locales with larger African American populations (Berkley Patton et al., 2009; DeMoss et al., 2014; Njie-Carr et al., 2016; Okoro & Odedina, 2016). All participants self-identified as Black and female. None identified as Hispanic. They ranged in age from 40 to 69 and had been diagnosed an average of 19.4 years with a range in care of 10 to 25 years and an average of 16.5 years. All had worked with HIV case managers for some period of time indicating a willingness to seek and utilize potential resources available to PLWH. Eight of eleven participants had children, most of whom are now adults.

Table 3. Sample Characteristics

Total number of participants	11
focus group	4
Interviews	9
Race and ethnicity	
Black	11

Hispanic or Latina	0
Age	
Range	40 to 69
Mean	55.7
Gender identity	
Female	11
Years diagnosed with HIV	
Range	11 to 35
Mean	19.4
Years in care	
Range	10 to 25
Mean	16.5
Provider visits per year (average)	2.4
Self-rated adherence on a scale of 1 (poor) to 6 (excellent)	5.2
Highest level of education	
middle school	1
high school or GED	2
some college	3
associate’s degree	4
graduate or professional degree	1

Number of participants with children	8
Number who have worked with an HIV case manager?	11
range in years	1 to 16
Mean	7.5

Predominant Themes

Most of the participant responses paralleled communication strategies and provider actions recommended in Epstein and Street's (2007) handbook on Patient Centered Communication in Cancer Settings but with added recognition of their own role. Epstein and Street acknowledge that an "activated" cancer patient will have greater success than one who is disconnected. Meanwhile, women in this study made it clear that the ability to combat HIV is seeded by self-motivation and fostered by a dedicated provider. Thus, two major areas emerged as fundamental to successful retention in care: provider actions that engender trust and woman's active participation in her care.

Provider actions that generate trust

The lengthiest segment of all interviews was the section related to "fostering healing relationships." Most of the advocate-recommended questions aligned with this concept and several women relished the opportunity to describe their best HIV provider. Participants identified the following actions as those that motivated them to return: listening, taking time, paying attention to other parts of the patient's life, showing respect, relating and being relatable, being understanding and nonjudgmental, being thorough and diligent, being truthful and straightforward, making physical contact, working cooperatively with other providers, asking the patient questions and not assuming the patient knows what to tell the provider, being knowledgeable of HIV and potential resources, and taking action when a patient is in crisis.

Listening was cited nearly as often to describe a good provider relationship as its absence was to describe a bad provider relationship. Women said their best providers authentically heard the specifics of her situation. “They’re willing to listen, hear me and I mean really hear me, because some people don't hear; ‘cause we're all different and this disease is different in all of us,” one participant explained.

A provider that ***takes time*** instills confidence: “I know that if I have an issue or whatever that my provider will sit down and take time. She will take the time if I have an issue and we’ll discuss it. I don't feel rushed,” said one woman. In contrast, rushing was the top issue that generated fear about talking openly with providers.

Participants indicated that good providers ***show an interest in a full understanding of the patient’s life***. This made them feel important and, they noted, helped the provider discern what other medical or life issues may impede retention in care.

Showing respect comes in many forms. It is evident when providers discuss disagreements rather than dismissing patients’ views that don't align with theirs; when they don’t “talk down” to patients; and when they demonstrate to other providers that they are committed to their patients’ well-being. It is also evident when they can make the patients feel like they are human beings, as one interviewee stated: "They did that by taking the time to see what was going on with me. They didn't see a color or race or anything like that, they saw an individual." Closely tied to showing respect is ***not showing judgement***. Women in this group did not want to be cast as promiscuous or as drug abusers and recognize that providers who work in HIV must understand the social taboos PLWH must navigate. One woman explained that providers should be aware that HIV is a "mentally painful disease," sometimes more emotionally than it is physically painful.

Relating to the patient and being relatable themselves could be interpreted merely as good bedside manner and friendliness, but these women looked for something deeper. They looked for how the provider related to them as an indicator of whether or not the provider is in the job for the health of their patients or "to collect a paycheck" as one said. For some, this meant the providers sharing some information about themselves. For two, this included an apparent awareness of the African American historical context and its impact on health.

Women were impressed and comforted by providers who were ***thorough and diligent.*** Such providers were willing to: order more tests, do more research, look deeper into the woman's health challenges, and explore medicines for them. The hallmarks of a thorough provider were ensuring that all of the tests are up to date, knowledge of the patient's specialists, asking about side effects of medications, and familiarity with the patient's chart before she comes into the room.

Women were attentive to how well their providers work with other providers and identified ***teamwork*** as a critical attribute. Participants noticed if providers are willing to give referrals and if they called other providers when situations were uncertain. They were impressed and felt confident when providers inside a clinical setting worked well together, but especially when they worked well across systems.

These women valued providers who were ***knowledgeable about the basics* of *HIV*** and were willing to keep up with new developments, such as new medications and U=U (Undetectable = Untransmittable, the recent data that shows people who have an undetectable viral load cannot transmit the virus, as per the CDC, 2021). Giving thorough explanations about the virus helped people feel comfortable and they knew enough to know the difference. As one woman explained, "I've only been to two who really know and keep on top of their information." She, like almost all of the participants saw, an HIV specialist.

In tense situations, how a provider ***responds to emotions*** while under pressure is especially important to maintaining a productive relationship. These women identified several ways in which a provider can calm a situation gone awry. They can ease women's fear by talking with them and providing information, or they can request the assistance of social workers, but they must show concern, take action, and be available to answer questions or have staff who can do so. One woman explained that her provider approached her with compassion when she was depressed. Instead of brushing off her depression, "He sat down with me and talked to me and calmed my fears." About half of the women are able to describe crisis situations when providers did not take action and compare that to a provider who did take action.

Inherent provider attributes. In general, inherent attributes (race and gender) were less important than how the provider behaved. Most participants said that they did not have a preference regarding the race or gender of the provider, so long as they were treated with dignity and respect**.** None had preference based on race, but many said they would like to see a Black provider if one were available. Those who preferred female providers said this was because of their ability to relate to them emotionally and have a deeper understanding of their challenges. When describing their "best" provider, seven indicated that person was female and four indicated male either outright or through the pronouns they used.

Patient attributes that contribute to good health

Relationship with self. Women remarked that an HIV positive person must "go through an internal process," in order to "come to grips" with their diagnosis. Several described needing to get over denial or depression. These women recognize that this is a serious illness and their desire to be healthy overrides any fear of stigma or other challenges that might arise. One participant cautioned, "staying in denial will kill."

Having self-assurance increases the effectiveness of relationships with providers. This self-assurance may come from religious views, spirituality or a deep sense of self-respect. Women often said that what matters most in managing HIV is how they take care of themselves and what they think about themselves, as this woman illustrates, "It's up to you, it's how you care for yourself, and how you treat yourself, and how you love yourself.” This is not easy or automatic. They say that they have to encourage themselves and not waste time on self-pity. Some find consolation in their church with a pastor or a faith community. Some see that having this virus gives them meaning and purpose to learn how to face challenges and then offer guidance and assurance to others.

Knowing that they are more in control of their lives gives them power over the virus, “I realized that my attitude was paramount in this disease, my own self attitude,” one said. Another explicitly acknowledges her power: “This disease is not in control of me. As long as I know I have the power over this disease that gives me the leverage to do whatever I need to do.”

Most of the women stated clearly that they “knew” their bodies and that physical awareness was an important part of their self-assurance when working with providers. Being very familiar with one's body and how it feels when it is healthy enables the women to know when something is very wrong. Four of the women had experiences with life threatening or excruciating symptoms that providers dismissed. In each case, the women pressed ahead to find a provider who believed them. In addition to their physical health, many also realized that they had to pay close attention to their mental and emotional health.

Understanding the dangers of HIV motivated some women to stay in care. Some of them had seen others suffer and die from HIV related complications. They know that their lives are under threat if they are not virally suppressed as one woman points out, “something simple like the common cold could kill you.” They are committed to regular testing and understanding their target numbers. Keeping up with new information and being educated about the virus gives strength: “When I'm educated I'm empowered,” one explained.

Interaction with providers. While they recognize that they are in control of their health, they know that they would eventually die from complications due to this virus without professional help. Therefore, they are conscientious about their interactions with providers. Moreover, women in this study recognized that the providers are motivated to help them more when they can show their provider that they are following through on recommendations. Two women explained that providers can see that they are serious about their care when they are organized and consistent, for example, “Coming in with questions and being prepared lets the provider know you are taking charge of the virus and your health.”

“When you raise the bar, they raise the bar,” one interviewee said. Many of the participants prepare in advance for appointments with providers. Some of them have kept notebooks, one uses the MyChart app, another writes down what she hears from the provider during the appointment and then repeats back to the provider what she heard in order for them to clarify her interpretation of their words. Another brings a copy of the lab work with her every time and does not leave the appointment until she understands the readings.

Being able to ask questions of the provider is very important, these women say, because not all providers offer information. The women indicated that they know to ask about side effects regarding medications, clarity on test results, and non-medical resources.

The majority recognized that they can set the stage for an upbeat and productive conversation with their provider, even when that provider seemed to be not at their best. Many were consciously aware that if they approached providers as if they were people who wanted to have a good workday, they could also have a good appointment. One said she talks with them about normal things like their families their kids. Another was strategic about her role in creating the kind of partnership she wanted to have with the provider in that she planned health related questions and set aside stressors before entering the exam room so she could be fully engaged with the provider. Another recommends that patients start with small things and become more engaging as trust is built. Others say they just walk in with a smile no matter what else is happening.

Discussing problems. These women did not shy away from medical problems. They were ready to talk with their providers, especially as it concerns medication. They were committed to keeping their appointments even when they didn't want to or like going to the doctor. These participants stressed that being honest with providers is essential to getting what they need. One emphasized that “if you provide good information, they can provide good care.” Those who have substance addiction were able to explain when and why they were using to their providers which they believe can help the provider get to the root of a particular challenge.

Social support. Women frequently mentioned reliance on other individuals and groups for social support. These women recognized it was important to not isolate themselves, including those who are not open about their HIV status. Two of the women spoke highly of other HIV positive women who taught them about self-care and securing resources. Social support among these interviewees included family, church members, friends and institutional supports such as employees of AIDS service organizations, support groups, and patient navigators. Some of the women had brought friends or family to appointments when they needed someone to take notes, ask questions they might forget, and when they were dealing with a provider they were not sure about. One spoke of how women from her support group had to go to appointments with a woman who experienced debilitating side effects from medication but was too afraid to talk to her doctor.

Deciding when to leave a provider. Having the fortitude to leave a provider, so long as their insurance allows it, gave these women greater control over their ability to find a provider with whom they can create a partnership. Women in this group advocated for themselves, arguing “It's OK to stand tall, to stand firm on your life…If it's not working for you, move on to the next.” One advises patients to pay attention to the provider, specifically ask oneself, “does he or she take an interest in who you are? Do they take the time to listen, really hear you out?”

When a relationship has gone bad and they cannot leave, they have tried to re-approach providers, but with mixed success. Two have simply stayed with providers out of need, but make it a transactional relationship. This may not be the best outcome for HIV patients who have less stable lives.

Discussion

The purpose of this study was to find out *why* certain provider actions are more effective at retaining women in care. These participants identified actions such as listening, taking time, and showing respect which have been identified in the PCC framework and elsewhere. These findings complement that of other researchers who established that provider relationship were important as an outcome of seeking to understand women's readiness for adherence and facilitators to care (Kempf et al., 2010; Njie-Carr et al., 2016; Warren-Jeanpierre et al., 2017). Using their findings as a starting point, this work sought to learn which actions were critical and why. The simple answer is that the actions described make these women feel like valued human beings. Feeling valued would naturally apply to other patient populations, yet there are actions identified by this group that, once given additional attention, uncover *why* such actions encourage return visits.

The importance of taking time was accentuated when women discussed how rushing made them feel. In other studies, women expressed that preferred providers who did not rush through the appointment (Amutah-Onukagha et al., 2018), but what bothered them about rushing was not described. Women in this study said that rushing made them anticipate that the provider would dismiss their concerns or input. When a provider rushed through the appointment, women felt less important, were more fearful of speaking up, and could forget what they need to ask or tell the provider.

Several women described a preference for genuineness in communication. Being friendly but not "phony" was a trait Sullivan et al. (2015) also found to be important for HIV positive women elsewhere. When probed why too much friendliness was problematic, women said providers who "sugar coated" information, or who tried to sound overly sweet in their delivery or too timid in their directions appeared untrustworthy. One participant stated that providers who sound too sweet or too sugary remind her of a car salesman. On the other hand, some women did not respond well to providers who were gruff, harsh or dictatorial in their approach. One woman described a provider spoke to her “like she was [her] mother.” This style came across as patronizing and not valuing the woman’s abilities.

Thoroughness and diligence gave women confidence that providers were interested in their unique situations and were prepared to go to lengths for them. As for example, when one participant returned to care after a prolonged absence, her new provider “swept her off her feet” with her diligence: “She was thorough. I mean she went through everything from top to bottom. She spent time with me.” This gave the patient a sense of relief and confidence that her return to care would be successful because that provider demonstrated their investment in her.

Teamwork, working cooperatively with other providers, and being willing to make referrals indicates that providers know the limits of their skills. This means they may also be willing to dig deeper and ask questions on behalf of their patients. Both of these show a commitment beyond the paycheck.

Being relatable and non-judgmental carries additional weight with these women because of the stigma associated with HIV, but these traits are also medically important. As McDoom et al. (2015) found, women’s perceptions of what the doctor thought about them influenced their interests in staying with that provider. In agreement with this finding, participants said they had providers at some point who “looked down on them,” which was detrimental to their motivations. Deepening McDoom’s (2015) findings, these women pointed out that not feeling judged gave them a sense that they could ask questions and be open with providers about problems that could affect their health. One woman felt she could tell her provider anything. She said this mattered because it kept her safe from self-harm: “If I couldn't tell her those things, I would probably be in a little trouble because then I would be keeping it to myself and if I keep it to myself then I'm gonna do what I think I should do and that'll be ending up using. And I don't want to use again.” Others, including one who struggles with chronic pain that can sometimes lead to substance abuse, said it is important for women to be able to tell providers when they are drinking or using other pain mitigation strategies.

Providers who update women on their health progress in an encouraging manner provide a unique type of motivation and social support that women could not get elsewhere, especially if they were not open about their status or they had isolated lives: “I was not only dealing with HIV but I was dealing with an abusive husband… So, the encouragement of providers and the support groups were really important.” Having a supportive provider is like having a cheerleader who understands the unique challenges of their life and health goals: “It's really encouraging to have someone that you can be yourself with and know about your situation and not bring you down and be negative about it, but they're there to uplift you and tell you to keep up what you're doing.”

Paying attention to other areas of the woman's life beyond HIV is both motivating to her and has medical practicality for the provider. One participant who volunteered to help women with HIV explained that many of the issues that keep women out of care are not related to the virus itself, therefore providers who ask about the woman's whole life can be better prepared to discern what help she needs to stay in care. The women who had comorbidities felt like HIV was the easier illness to manage once they got their medication on track. Those who knew they had complicated medical histories needed providers who were prepared to help them navigate more than just HIV. One woman who suffers from depression and substance abuse reported that it was very motivating me when her new provider asked about her anti-depressant medications and support needs. This showed her that the provider was concerned and that managing her depression could prevent substance abuse and help her stay in care.

In the course of describing their best provider, several mentioned that providers sat on their bed, held their hand, gave them hugs. For this stigmatizing illness, touch is a demonstration of human kindness, but also shows the providers full confidence in how the virus is transmitted. One of the women told medical students studying to be HIV specialists that they should be willing to hug their patients in order to build trust.

All of the women said it was important or very important that they be involved in decisions regarding their healthcare. Marelich and Murphy’s (2003) quantitative study on patient empowerment found that patients who were involved in the decision-making process also had greater communication with their providers. Using qualitative methods revealed that providers who set the stage for women to be involved in their health decisions through actions that generate trust assures the women that the providers see her as the driver of her health. This provider-supported empowerment reinforces her commitment.

All of these actions lend to the creation of a partnership, which seemed to be the ideal provider relationship for these women. Okoro and Odedina (2016) interviewed both patients and providers on facilitators to HIV care. The providers in their study understood that they needed to figure out how to create a partnership with their patients. This desire for a partnership holds true for Black women in opposite sides of the country. A next step following this study would be to interview providers on what actions they perceive help build a partnership and compare those to what women have said.

Another reason why these actions are so important is because they all lend to the woman's ability to grapple with HIV, become comfortable with medical knowledge, and build confidence with self-care. As noted, most of the participants said it was important for any newly diagnosed person to come to terms with their diagnosis, move past denial, overcome stigma, manage external barriers, and take responsibility for their own health care before they can be successful working with any provider. Providers who can engender self-care and life management are logically the ones these women seek.

Limitations

Despite heavy recruiting efforts among HIV advocates, few women were willing to participate, likely due to fatigue about discussing the topic or a desire to remain anonymous. One participant expressed pleasant surprise when realizing the questions were not about *her* HIV problems, which she said she was no longer interested in discussing. No one with less than 10 years of HIV diagnosis completed interviews. Although women reflected on what would have made it easier for them when they were newly diagnosed, only one could offer experience in the current care environment for newly diagnosed women. This woman described her granddaughter’s experience as bleak compared with her own some 15 years prior in Arizona.

Participants were recruited through referral, self-selection and snowball sampling. Self-selection will skew these data toward women who are more confident and open about their HIV status while referral and snowball sampling will skew these data to women who are linked into social support networks. This does not give us insight into women who are resistant to care or those without HIV related formal support networks.

Strengths

The method for generating interview questions was a collective process involving seasoned researchers and practitioners in the HIV sphere. The questions were edited and approved by participants in the focus groups who felt confident enough in the research to follow-up with an individual interview. The participant responses aligned so closely with the principles described in the PCC that they endorse fundamental provider actions necessary to building patient trust.

As noted above, studies in other parts of the United States demonstrate that relationships with providers are a facilitator to staying in care (Kempf et al., 2010; Njie-Carr et al., 2016; Okoro & Odedina, 2017; Sankar et al., 2002; Sullivan et al., 2015; Warren-Jeanpiere et al., 2017). This study is both unique from and complementary to this earlier research. This study is unique in that it built on previous findings *that* provider relationships were essential to adherence and a facilitator to care. This study then framed questions around discerning which actions women thought were pivotal and how those actions either lent to their motivation or served as de-motivators. This study is complementary to this existing literature in that the participant responses in Arizona aligned with responses given by women in qualitative studies in other regions around the country. This project added validity to previous findings and indicated consistency among Black women regardless of where they reside (Amutah-Onukagha et al., 2018; Kempf et al., 2010; Okoro & Odedina, 2016).

Conclusions

Building on the premise that provider relationships are important to patient retention in HIV care, this study and sought to uncover *which* provider actions supported retention and *why*. The answer as to why some provider actions help retain this population in care lies in how those actions demonstrate the provider's authenticity and connectedness to their patients as individuals. The majority of these participants said the relationship with their provider is an important motivator to staying in care. They are more likely to stay on medication and make healthy choices when the know their provider is paying attention to them and is concerned about them. While concepts like authenticity and connectedness have been discussed in other studies, the notion of paying attention and concern adds depth to the first two traits. As one woman described it, the attention and concern from her provider was similar to the feeling of having a teacher or coach who took pride in the success of those they help. That pride extends to the other person enabling them to have pride in themselves and continue working to maintain good health.

These participants want to be treated as individual human beings with respect, expressing sentiments similar to African American patients in other studies who described historical circumstances as a reason for heightened scrutiny of providers (Jacobs et al., 2006). As is the case with Black women elsewhere, providers become an important source of social support, especially for older patients and for those who may experience intrapersonal or interpersonal stigma (McDoom et al., 2015; Warren-Jeanpiere et al., 2017).

All of the women in this study noted in some way that self-motivation and/or motivation from children, friends or other family was fundamental. Those who did not have a provider who was motivating had to rely on themselves for motivation. In an ideal situation, these women would find a provider who could tap into their self-motivation and become a champion on their journey of health maintenance. Providers who are able to capitalize on the woman's self-motivation and become a champion to that woman in her health care journey will find success at retaining them in care.

This study was unique among HIV literature in that it used a framework for patient communication based on cancer care settings, yet found that the patient's perspective matches that framework's description of ideal patient-provider interactions. The overall alignment between these participants responses and the descriptions offered in the PCC indicates that Epstein and Street's (2007) work catalogs fundamental concepts that are effective for a greater range of patient populations. Using the work of qualitative studies focused on PLWH, an adaptation of Epstein and Street's work could be included as orientation material for providers new to HIV care.

An important area for further research emerges from these interviews regarding the types of training different HIV care providers receive and how more trainings should occur across professions. The women were encouraged to describe their “best” HIV provider, however, to allow for anonymity in this small care environment, the researcher did not ask for profession, only traits and actions. Five women described providers with whom they were enamored. Two of these were physicians and one was unclear. One woman’s top choice was a case manager and another woman’s top choice was a doctor in nursing practice. It would be useful to research and disseminate training for actions and traits across professions so that patient-provider partnership development can occur at multiple levels of HIV care.

On the whole, participants in this study are observant and astute when it comes to their health care providers. They determine early if a provider was a good match for them. If insurance and availability allow for switching providers, most of these women would give a provider one or two chances before deciding to move on. They look for actions that show the provider can view them a someone to be championed, not a reason to collect a paycheck. One woman summarizes this view: “Some people, you know that they are there on your behalf.... and it's not just a job, they want to see you do better, feel better and to be victorious in all areas of your life.”

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CHAPTER 4

POSITIVE STARTS: ENCOURAGING BLACK WOMEN TO STAY IN HIV CARE IN THE ERA OF RAPID ART INITIATION

Through work supported by the City of Phoenix Fast Track Cities committee, public and private entities in the Phoenix, Arizona metro area have collaborated to implement the State of Arizona Antiretroviral Rapid Treatment protocol (START) in effort to curb the spread of HIV (City of Phoenix, 2020; Khalsa, 2019). This new protocol calls for prescribing antiretroviral medication to people diagnosed with HIV as soon as they are confirmed positive based on international guidelines (World Health Organization, 2017). Yet, HIV related stigma and cynical perceptions of the medical system impact care-seeking behaviors for many African Americans (Fletcher et al., 2016; Katz et al., 2013; O'Malley et al., 2004; SANTY, 2018; 2013; Tekeste et al., 2018). As is the case throughout the United States, African American women in Arizona are disproportionately affected by HIV (ADHS, 2019; CDC, 2020). In order to reduce disparities, it is important that African American women living with HIV engage in antiretroviral treatment as soon as possible (Pilcher et al., 2017), especially since they are more likely to receive a late stage diagnosis (Chopel et al., 2015). Given that patient satisfaction with provider relationships has been associated with retention in HIV care (Baker et al., 2014; Beach et al., 2006; Dang et al., 2013), this qualitative study sought to understand what kinds of provider interactions will help inspire adherence in the earliest days of diagnosis. These data can inform providers, clinicians, and case managers as they seek to respond to the goals set forth in state and federal plans, namely the *Integrated HIV Prevention and Care Plan for Arizona* and *Ending the HIV Epidemic: A Plan for America*.

Background and significance

African American men and women continue to bear the highest burden of HIV, representing 42% of new HIV diagnoses, but only 13% of the overall US population (CDC, 2020). The disparity is similar in Arizona where African Americans account for 37% of new HIV diagnoses while they make up only 4.9% of the population and suffer from higher mortality rates (ADHS 2012; ADHS, 2018)

The State of Arizona HIV surveillance report called attention to the stark disparity for African Americans, notably African American women in 2012: “In Arizona, there is a clear and alarming impact of HIV/AIDS in the African American community. African Americans in Arizona experience an epidemic of HIV/AIDS that is almost three times more severe than any other race/ethnic group. This disparity is more pronounced among African American women than among African American men.” (ADHS, 2012, p. 6). Arizona surveillance reports since then indicate that the prevalence rates for Black men tend to be about double that of white men, whereas the prevalence rates for Black women tend to be between nine and ten times greater than that of white women (ADHS 2015).

Since the Arizona Department of Health Services’ (ADHS) pronouncement in 2012, the incidence rate for Black women changed very little. In 2012, the incidence rate for black women was 21.70 per 100,000 as compared to 1.47 for White women (ADHS, 2012). In 2019, the incidence rate for Black women is 21.4, while it is 1.8 for white women, indicating an ongoing disparity (ADHS, 2019). Furthermore, the rate of death for Black women diagnosed with HIV is twice that for white women diagnosed with HIV (ADHS, 2019).

Background

In February, 2019 President Trump introduced *Ending the HIV Epidemic: A Plan for America.* The plan calls for strategically targeting resources at geographic regions with the highest HIV risk. Maricopa County is one of 48 counties, plus Washington, D.C. and San Juan, P.R. which combined accounted for half of all new infections in 2016 and 2017 (HRSA.Gov., 2020). In Maricopa County, the rate of transmission among young African American men has not significantly reduced in recent years (Zetino, 2019), whereas the transmission rate for white men declined gradually but steadily in the years from 1990 to 2018 (ADHS, 2015; ADHS 2019). The rate among young Black men impacts African American women because 85% of transmissions for women occur through heterosexual contact (Aziz & Smith, 2011; CDC, 2020). The Ending the Epidemic plan calls for collaborations between city, county, and state public health departments to implement four treatment goals: diagnose all people with HIV as early as possible; treat people with HIV rapidly; prevent new transmissions by using proven interventions; and respond quickly to potential outbreaks (Fauci et al., 2019; HRSA, 2020).

Arizona’s statewide plan recognizes that regional and cultural differences will require different strategies. The *2017 to 2021 Integrated HIV Prevention and Care Plan for Arizona* calls for “patient centered care and initiatives” intended to shorten the time between diagnosis and linkage to HIV care as a key strategy for the central region. Arizona's central region, encompassing Maricopa County and the Phoenix metro area, includes 70% of HIV prevalence and the highest disparities for African Americans (ADHS, 2017). Thus, the plan for the central region calls for "consumer and provider training related to stigma reduction, cultural competency, and client empowerment" (ADHS, 2016 p. 14).

The City of Phoenix is well poised to work with the national strategy and continue strengthening Arizona's regional strategy as it has already begun its own concerted effort to curb HIV. In October 2016, the City of Phoenix joined the Fast Track Cities Initiative (FTCI), a United Nations effort motivating cities around the world to develop their own plans to end HIV as a public health threat within their cities by 2030. Roughly 30 Phoenix citizens involved in HIV reduction were sworn in and committed to actualizing a plan that fills gaps in the HIV continuum of care in Phoenix and nearby cities. The continuum of care follows diagnosis through to viral suppression. The goal for each Fast Track City is to have 90% of people who are suspected of having HIV know their status; 90% of people who are diagnosed with HIV linked to care; and 90% of people who are in care become virally suppressed (Fast-trackcities.org, 2020).

In Phoenix, the FTCI Committee galvanized regular conversations and data sharing among a voluntary collective of non-profit AIDS service organizations (ASOs), and private and public health agencies. The Committee increased interagency collaboration on tasks and pooled resources in ways that would have been unlikely without ongoing meetings and minutes organized by city staff dedicated to this and other citywide initiatives (Vanig, n.d.). Phoenix's FTCI brought together state and county agencies in the central region of Arizona which has the highest HIV prevalence as per the statewide plan. This collaboration has contributed to the overall state impact to curb HIV. When Phoenix began with FTCI, the Arizona HIV continuum of care numbers were: 63% linked to care, 51% retained in care and 42% virally suppressed (ADHS 2016). In two years, these numbers increased to 74% linked to care, 57% retained and 60% virally suppressed (ADHS 2018). Nationally, the current continuum of care numbers are: 78% linked to care, 49% retained in care, and 53% virally suppressed (HHS, 2020).

In 2018, the City of Phoenix Fast Track Cities Initiative adopted rapid antiretroviral therapy (ART) initiation as a citywide goal. The FTCI and Arizona's Department of Health Services' HIV Prevention Program collaborated to convene private and public clinics to pilot the State of Arizona Antiretroviral Rapid Treatment initiative (START). The START initiative seeks to ensure all newly diagnosed patients in Arizona are prescribed and begin antiretroviral therapy within five days of diagnosis, ideally on the same day (Vanig, n.d). Clinics participating in START have had two years to pilot the protocol. During this time, participating clinics have reduced linkage to care time from 30 to six days and time to viral suppression from 129 to 37 days (City of Phoenix, 2020).

Importance of early linkage to care

It has been recognized that early linkage to care is associated with greater chances of long-term success at achieving and maintaining viral suppression, reducing transmission to others, and reducing mortality (Kitahata et al., 2009; Ulett et al., 2009; Wanyenze et al., 2011). Recent large-scale meta-analyses indicate that starting antiretroviral treatment early, even as soon as the first clinic visit, can improve patient outcomes by reducing patient attrition before they even begin medication (Ford et al., 2018; Rosen et al., 2016). Based on meta-analyses such as these, random controlled trials, and observational studies, the World Health Organization now recommends that initiation of ART begin within seven days of a confirmed diagnosis, regardless of CD4 count (WHO, 2017).

Nationally, linkage to care and subsequent retention in care is more challenging for African American women and men compared with other groups (Aziz & Smith, 2011; Johnson et al., 2003; Sheehan et al., 2017). A CDC published report acknowledges that Black women have lagged behind the national goal to have 85% of newly diagnosed persons linked to care within 90 days, with just about 50% making it to care within that time frame (Stein et al., 2016). A recent study in a Chicago network of clinics with a robust linkage to care program found that African American women were still less likely to be linked to care than other sub-populations in their study, despite higher proportions of African American women coming in for testing than African American men (Almirol et al., 2018). Almirol (2018) found that once women are linked to care, however, they are more likely to stay in care than men, recommending further research into practices that are effective for African American women. Women may still miss appointments, though, and this can often be attributed to caregiving for others (Aziz & Smith, 2011).

The first few medical appointments after diagnosis can be a motivator or deterrence for pursuing treatment for the long term (Christopoulos et al., 2018). Moreover, early appointments may impact and be indicators of long-term survival:

Mugavero et al. (2009) found that patients who missed a visit within the first year after diagnosis had mortality rate more than twice those who did not miss an appointment in the first year. Therefore, implementing recommendations from HIV patients and advocates familiar with this sub-population may increase retention under the new START protocol.

Methods

Data and information for this paper were gathered from three sources: interviews with local HIV advocates, interviews with HIV positive African American women, and public proceedings from the City of Phoenix Fast Track Cities Initiative. The researcher was appointed to the City of Phoenix Ad Hoc Fast Track Cities committee when it was formed in 2016.

In preparation for interviewing HIV positive African American women, the researcher sought context from local HIV advocates. Advocates were approached based on visibility in the field and through word-of-mouth. They were informed that their insights would help shape a research study on provider relationships among this population.

Interview questions for HIV advocates were designed to elicit their perspectives on the overall care environment for Black women, how Black women engage in care as compared to other groups, and what provider actions help them stay in care. Interview questions for women living with HIV (WLWH) were based on questions suggested by the HIV advocates and structured according to a framework of principles for effective patient centered care offered by Epstein and Street (2007) in *Patient Centered*

Communication in Cancer Care (PCC). The PCC was selected because of the depth and breadth of its recommendations for patient centered communication in complicated medical scenarios. Four of the HIV positive participants joined two focus groups to review and approve the usefulness of questions for WLWH, some of which were revised according to their guidance for sensitivity.

Black WLWH were recruited through flyers posted at HIV/AIDS serving clinics and community organizations, recommendations by employees at ASOs, and through presentations at HIV/AIDS support groups. Women met criteria for the study if they were over 21 years of age, self-identified as Black or African American, had been diagnosed with HIV for at least 12 months, and had visited an HIV provider within 12 months. Interested participants called the researcher and were screened by telephone. Eligible participants were consented in person. Interviews occurred in a location identified as safe and comfortable to the woman, most often her home or a private office at the university. Participants were compensated with a $15 grocery gift card for participating in a focus group and/or interview ($30 for both).

Notes on key points during interviews with HIV advocates were typed into a word processor. Interviews with HIV positive women were digitally recorded and transcribed using an automated service and reviewed for accuracy by the researcher.

Based on Grounded Theory methods offered by Charmaz (2008, 2014), analysis of interviews was concurrent with collection. Both the advocates and WLWH were asked for clarification during their interviews to verify the researcher’s interpretation. Charmaz (2008, 2014) recognizes the value of using a theory or framework to sensitize researchers toward the issues. To this end, advocates' comments and their recommendations for questions to ask WLWH were analyzed and organized according to the PCC framework offered by Epstein and Street (2007). Interviews with WLWH were coded line by line initially until larger themes emerged that were then compared with other interviews. Interviews from both groups were compared with each other and overall recommendations were extrapolated.

The Institutional review board of Arizona State University approved all stages of this study.

Results

Sample

A total of 23 HIV advocates and 11 HIV positive Black women patients were interviewed.

Advocates included two physicians, two nurses, two government administrators, two non-medical clinic staff, one volunteer, one medical case manager, three non-medical case managers and 10 current or former employees of community-based organizations that support people living with HIV who took on a variety of roles such as fundraising, administration, prevention advocacy, and testing. Half of the advocates are African American women and the other half include white and Black men, one white woman and one Latina. Five of the advocates are openly HIV positive men and women. Time spent working in some form of HIV care ranged from one to 35 years. Aside from Arizona, the advocates have worked in HIV care in Missouri, Virginia, California, Kansas, Georgia, Maryland, Illinois, and Michigan, bringing a range of exposure to different care scenarios. Two advocates, one white man and one Black woman, currently work in a community clinic in Washington, D.C. The purpose of interviewing advocates in Washington, D.C. was to add current insight based on regional differences or similarities with a locale that has a high concentration of African Americans.

A total of 13 Black women living with HIV volunteered to provide their perspectives as patients. All met criteria but two were lost to attrition. A total of eleven HIV positive African American women participated. Four participated in the focus groups and nine did individual interviews with two doing both. One of the advocates was also a woman living with HIV who chose to join a focus group. She was careful to give an advocacy perspective in one setting and a patient perspective in the other. The WLWH were asked for their personal experiences with providers as patients whereas the HIV advocates were asked for their observations of women's experiences and the overall care scenario for HIV positive Black women. These participants were compensated for their time, as noted above. The HIV advocates were not.

All of the women self-identified as Black or African American; none as Hispanic. The women ranged in age from 44 to 69, with a median age of 55. Eight of eleven women had children, ranging in age from 11 to 44. One woman had a professional/graduate degree, four had associates degrees, five had completed high school or GED, one had completed middle school. The women's average years since diagnosis was 19 with an average of 16 years in care. These women make an average of 2.6 provider visits per year and self-rate their management of HIV an average of 5.2 on a scale of one to six, with six being excellent. All of the women have worked with case managers at some point, ranging from one to 16 years with an average of five years. Of the four women who rated their adherence as excellent (six on a scale of one to six) three worked with case managers for 10 years or more, suggesting that working with case managers long-term may play a valuable role in adherence.

Combined recommendations

Overall comments from WLWH and advocates point to a need for authentic concern at all stages of the HIV journey. Women in this study who did not receive such concern upon initial diagnosis were able to rebound, but not without toil.

Collectively, advocates offered anecdotal impressions of how different populations fared with HIV in terms of access to care, finding non-medical resources, managing stigma, and willingness to talk about sexual health. Many observed that, as a group, Black women fared poorly in each of these areas compared to gay men of all races, but especially compared with white men. The Black advocates in particular felt this distinction was important for providers to recognize: Black women don’t talk about HIV or sexual health as freely as white gay men and are less comfortable in HIV support settings. Thus, when HIV providers encounter Black, women they must be prepared for a different kind of psychological response than with white men who represent a larger proportion and the most vocal group of HIV patients. Moreover, Black advocates expressed that it is important for providers to recognize the unique historical context of African American women and how that shapes their participation in medical engagement overall. They suggested cultural competency was important, but this did not mean that providers need to be experts in Black history and culture, but that they understand

African Americans’ relationship to the medical system has led to mistrust and cynicism about whether or not they will be cared for properly.

Key Information

The WLWH in this study remarked that three key pieces of information were import to hear at the very beginning of a positive diagnosis: long-term survivability; basic medical information about how the virus works and how to interpret test results; and resources for overall life support.

Survivability. It was important to all of the WLWH to hear reassurance from the provider upon diagnosis. About half of the women said that they felt like their life was over when they heard news of their HIV status. It was critical that the provider let her know that life goes on: “I had a provider tell me ‘it don't stop nothing, sugar. Don't let nobody say it's going to stop your life. It's not.’” It was equally important to these women that providers made clear that the choice to survive is up to the patient. This same woman’s provider went on to tell her, the “truth” of her situation which made it easier for her to accept. The provider told her: “it’s up to you if you want to live and it’s up to you if you want to die…. When I came to know and accept it, I said, ‘okay I got you, I want to keep living.” She went on to say, “It makes it easier just to have someone in the beginning to talk to you, kind of like help you.” Another woman had been diagnosed but not prescribed medication for more than two years. Once she started ART her provider had to explain the importance of staying consistent because she had gone so long without medication and didn’t understand the potential consequences.

Medical basics. After reassurance and a stern reminder for self-care, women felt it was important to know in simple terms how to interpret test results on T Cell levels and viral load, and for a provider to take time to answer her medical questions. The women felt it important for providers to explain potential side effects of medications. They liked to know about different medications as they become available - it may be helpful for newly diagnosed patients to know something about the different medications that might become available to them. Women were disappointed when new medications became available and providers didn't tell them. Only one participant reported having learned about HIV in school, and as a result she was not overwhelmed by the medical information. Most others had little in-depth knowledge prior to diagnosis. One woman likes that her doctor shared new discoveries, such as the concept of U=U (Undetectable = Untransmittable), which is based on recent evidence that a person who is undetectable cannot transmit the virus (Eisinger et al., 2019).

Women living with HIV indicated a mix of media including pamphlets, books, and electronic resources may be helpful because different people respond to different tools. Providing a lot of information at the beginning may be overwhelming, but the alternative may be worse. When asked, “what do you think when providers don't give you enough information?” one woman summarized the views of several: “I think that I'm just another number and, you know, I think that they do just enough to get their paycheck.” In an effort to meet this need for information to be presented in a clear, yet kind manner, The FTCI collaboration developed simple and encouraging brochures for newly diagnosed patients to assure them that they can manage the virus and that people are available locally to help.

Non-medical resources. Every woman living with HIV and most of the advocates said that information about non-medical resources is important for retention in care and to share this information early on. As one advocate explained, many adherence problems are not related to HIV directly, but to challenges like food, housing insecurity, transportation, and child care. WLWH corroborated that the following information is important, even if the person appears to not be in need: sources of food, clothing and hygiene products, how to locate CNA's and HIV case managers, support groups, alternative and holistic medicine options, mental health supports, and nutritionists.

Participants in the FTCI meetings emphasize that people who may not have insurance should be informed of coverage options under the Ryan White Act and that an introduction to central eligibility should be made personally, not just through a handout. To address this concern, the FTCI collaboration also set a plan to promote an existing phone line for non-HIV providers so that they could call the local HIV navigating agency when they have a newly diagnosed patient in their presence. The agency can then describe resources for those eligible for Ryan White Part A services and assign a case manager. This gives the newly diagnosed person a chance to create a relationship with the agency while they are still in the presence of the testing clinic or organization.

An additional outcome of the FTCI collaboration is a virtual navigator, a case manager who can be available on-line, to join providers and patients immediately rather than giving the woman a number to call later. During meetings, it was noted that more navigators are needed to meet the demands of people with challenging medical histories or unstable life circumstances.

Women noted that local providers should consider how information sharing has changed over time. One participant was very distressed when a granddaughter was diagnosed and did not receive the level of help, guidance and compassion that was available to the woman herself when she was first diagnosed more than 15 years before. Because this participant felt supported in Phoenix at the beginning of her HIV journey, she urged her granddaughter to come live with her to get help. As it turned out, the support situation had reversed since the woman's initial days. She felt as if local area providers are dealing with burn out. She also blames a generalized loss of urgency about the virus. She felt such despair at the lack of support, she recommended that her granddaughter go back home to Chicago. She also said that lack of information here could be devastating for a newly diagnosed Black people because "there are so few of us" and seeing white physicians will actually be "scary" for some. Others have also seen a shift and explained they have learned to ask for information: "Now, yeah, I don't think they really provide as much information. They provide as much information as you ask for." Since sharing of information is not as robust as it once was, a collaboration like FTCI can help alleviate this through its coordinated communication strategies.

Key actions

Mitigate stigma. Advocates and women noted that stigma is real in the African American community and it is important for providers to recognize that stigma will impact women's engagement in care from the moment of diagnosis forward: "women fear being seen as ‘dirty’ and ‘promiscuous’,” as one advocate stated. Some case managers noted that some women do not want to be seen walking into clinics that are identified with HIV and they also do not want to spend a long time in the waiting room because someone else from the community might recognize them.

Women living with HIV themselves said that it is important for individuals to overcome their own personal stigma challenges and they said that their best providers treated them as if they were normal people not sick or diseased. A nonjudgmental demeanor would be very important for the provider delivering confirmation of diagnosis and persuading a woman to start treatment immediately.

Destigmatize forms and paperwork. One advocate noted that filling out forms and paperwork over again can become tiresome. Strategies to simplify and reduce paperwork may help patients feel less intimidated and more welcome. One woman living with HIV noted that intake forms and questionnaires about how the virus was acquired should be non-judgmental. The way questions are presented can make the patient feel as though they are being judged for being “risqué,” and that their infection is the fault of their own promiscuity.

Personalize the relationship. Advocates noted that many provider relationships are impersonal and that women living with HIV want someone who can recognize them and call them by name. The advocates noted that women “need to feel like they are being respected, not talked down to, that they are being heard.” HIV case management workers in particular and WHLW recognized that women needed someone who would be understanding of the emotional, psychological side of this virus.

Women repeatedly noted that good providers recognize them as an individual. In order to build trust, it is important that the women feel the provider is working with them as human being, not “a number” or “for the paycheck.”

Validate self-care and self-worth. When asked the difference between women living with HIV who have been exemplary in managing their HIV care versus those who fall away from care, advocates observed that the difference is usually a woman’s recognition of her own value as a human being. One advocate remarked, “it’s not about the HIV, it’s about the journey to find self-worth and come to some acceptance of what it is.” He went on to say, “The ones that are exemplary [in management of HIV] are the ones that have gone through all of the underlying stuff and gotten to see their self-worth.” Another advocate stated that women may need providers to point out the value of staying in care which may mean “placing value upon herself” over others who need or expect her care.

Emphasize existing social supports and be a source of social support. Advocates and WLWH note that social networks are important to survival, especially in the early days. Providers should inform women of support groups and or help them think of people they can rely on for different kinds of support.

Anticipate strong emotions. The person who delivers a positive result notification as well as providers in the first meetings should anticipate that this will be an emotional challenge for the patient: not just the news about the virus, but also recognizing that her partner had been unfaithful or untruthful and she may have to contend with pregnancy or other STI’s.

Advocates and WLWH emphasized that providers need to understand that Black women are often characterized as being aggressive when they are actually being emotive. Participants in both groups shared stories of specific instances when women's emotions were misunderstood, used as a reason to provide inadequate treatment or yielded a response that appeared disrespectful to the woman. Providers should be prepared to adjust to highly emotional responses.

Ask about mental health. Advocates raised the importance of being attentive to how a woman reacts to a positive diagnosis because her immediate reaction can foretell the woman's overall coping skills. Some are dealing with abusive relationships or abuse in the past. Mental health questions may help shed light on the woman's current state of mind and how much psychological and emotional support she'll need to continue with care. A few of the WLWH remarked that providers who understand their psychological and psychiatric needs work better with them overall.

Offer flexibility in scheduling. Whenever possible, greater flexibility with scheduling would be helpful for many women. One clinic in Washington DC, which purposefully focuses on women, allows for more flexibility in scheduling after hours and on weekends because they recognize the difficulty their clients have with dependent care, and with time off from work. This may be helpful in Phoenix until funding for child care facilities return.

Take time with the patient and listen. Both patients and advocates are emphatic that women work better with providers who take the time to listen. Rushing through appointments is akin to showing disinterest in the woman's health. One advocate stated that WLWH need providers who will allow time for them to ask all of their questions and "not leave the appointment confused." For WHLIH in this study, not listening and rushing through the appointment were enough reasons to leave a provider if they could.

Demonstrate concern, personally and medically. One advocate quoted Theodore Roosevelt in saying, "People don't care how much you know until they know how much you care." Women interviewed for this study were very clear about this sentiment. Once they could establish that the provider cared about them, it was *very* important that the provider demonstrate competence. One advocate stated, "women are impressed with providers who are thorough." Women living with HIV made this clear throughout their interviews. The providers who demonstrably understood or specialized in HIV made them the most comfortable for this aspect of their healthcare.

Discussion

The World Health Organization states that within this new context of rapid ART initiation, providers should use a human centered approach that takes into consideration the specific context of different populations: "People-centred care should be focused and organized around the health needs, preferences and expectations of people and communities, upholding individual dignity and respect, especially for vulnerable populations, and should promote engaging and supporting people and families to play an active role in their own care by informed decision-making" (WHO, 2017 p. 19). This is this kind of approach that HIV advocates recommend and the kind of support women living with HIV interviewed for this study describe, which includes supplying key information (most importantly that the disease is survivable and where to find life-supporting resources) and implementing key actions (most importantly actions that uphold the patient’s dignity and reduce stigma)

With rapid start protocols now becoming standard of care for new HIV cases, it is important to consider steps providers can take to assure more Black women start ART right away and stay in care. This study sought to gather insights on what provider actions encourage newly diagnosed women in the Phoenix metro area, a location with a small population of African Americans, but the same disparity plaguing Black women nationwide.

The three sources of data (HIV advocates, Black women living with HIV, and public proceedings from the Fast Track Cities Initiative committee) provide overlapping recommendations on information and actions that can help newly diagnosed Black women stay in care. Advocates emphasized that providers can’t rely on approaches that work with white gay men, noting that Black women don’t necessarily have equivalent public empathy, social support, or personal comfort regarding HIV as the white gay male population which comprises the largest proportion of people living with HIV in Arizona. An interpersonal approach that displays competence and sincerity is necessary to develop trust. Black women living with HIV themselves described a personalized approach that would help newly diagnosed women tap into their own sense of self-care and a desire to be healthy for the long term. Both of these groups emphasized that providers needed to actively destigmatize HIV during interactions. FTCI participants are working on structural steps to strengthen the stage from newly diagnosed to adherent within the existing system of care. Steps in the START protocol will alleviate some of the structural concerns noted by both advocates and women living with HIV if the protocol is adopted regionally as the standard of care. In addition to starting medication immediately, these steps included a warm hand-off post diagnosis, sharing of non-medical resources, and immediate linkage to a case manager, unambiguous information on the virus, insight into coverage options, and active follow-up from care providers when people miss appointments. They are also implementing an online data management system (CareWare) to help clinics coordinate patient information more seamlessly. WLWH noted that coordination among care teams and individual providers was important to their sense of confidence in their providers.

The FTCI participants have discussed a need for training non-HIV providers about the resources available to newly diagnosed patients. An important addition to that training would be the distinct nuances among vulnerable populations and how the diagnosis will impact people differently. This additional training on vulnerable populations, including Black women, should also become a regular feature in HIV centered clinics and among the offices of infectious disease specialists who treat HIV. Insight that could be included in such a training are described here. Many of the views expressed by advocates, especially the case managers, aligned closely with the WLWH participants. They reinforced insight from the women living with HIV into the kind of interactions that would help this population stay in care and set the stage for many newly diagnosed patients. Based on their experiences from early diagnosis, WLWH in this study made it evident that providers should be careful with their interactions with newly diagnosed patents because of how those interactions can influence long term care seeking. A provider’s personal demeanor is important as well as indicating knowledge of HIV; WLWH are more comfortable with people who take time to explain things to them. For women to want to start treatment immediately, respect as a person will be important to demonstrate in the initial appointments.

Among African American in Arizona, mistrust of the medical system and stigma still impact perceptions of HIV and care-seeking behaviors (Santy, 2018). Women newly diagnosed with HIV or returning to care may carry reluctance with them as a result. For this reason, personalizing the relationship is important; women need to know that providers are there to genuinely help people. Indicators that a provider is not interested in her as a human being lead to her departure from that provider. For at least one woman, negative first encounters lead to her giving up on HIV care until she was severely ill and her children had to intervene.

How providers deliver information needs to be strong and supportive but not pushy or aggressive. Women living with HIV explained that when information sounds tentative or patronizing, it seems as if the provider is not sincere or invested. If the delivery is pushy it may come across as if the provider doesn’t trust the woman to act in her own best interests. For the first appointment, this may influence whether or not the women will decide to go on ART immediately.

Both advocates and women living with HIV acknowledge that many Black women put their care-providing role ahead of their own needs. A newly diagnosed woman may need a provider to affirm that putting herself first is necessary to so that she can take care of others. Because of stigma, some women hide their HIV status from family and social circles so care providers can become important sources of social support. Both groups interviewed wish for clinics to be places where WLHH can experience judgment free atmospheres.

Providers should understand that their encouragement may be a more significant source of social support than a mere business transaction. Black women who have done this successfully for many years see their best providers as having been champions who act like cheerleaders on their path of good health. Providers delivering news of a positive diagnosis have to be the first persons to help a woman through her own destigmatizing process. Women noted that when providers are really paying attention and commenting on their test results, they are more motivated to continue with care. Allowing time for the appointment is critical. The goal may be rapid initiation, but the provider's interactions with the woman should not be rapid. Clinics should institutionalize a time buffer for appointments with newly diagnosed patients so that they have time to digest information, ask questions, maybe even sit in silence to gather their thoughts and ask more questions.

Limitations

The intent of this study was to understand a local perspective from Black women and so not all of the recommendations will be applicable to the groups with the highest proportion of HIV: men who have sex with men of all races. Self-selection is a limitation for this study; all of the women living with HIV who volunteered for this study have been diagnosed for many years, have developed a level of confidence in their management of the virus, and are open about their status. Further input should be gathered through anonymous means, such as surveys, from newly diagnosed women.

Conclusions

Current national goals to eradicate HIV call for treatment as prevention (HHS, February 2020). Recent research shows that when people living with HIV achieve viral suppression, the virus is untransmittable (Eisinger et al., 2019). Therefore, starting people living with HIV on ART not only benefits the individual but offers an opportunity to bring the HIV epidemic to a close.

Localized information about populations affected by HIV are important to achieving national goals. In Arizona, the vast majority of PLWH reside in Maricopa County with roughly 11,350 of the 18,500 cases (ADHS, 2016). Phoenix is the largest City in Maricopa County containing half of the zip codes that have the highest rates of reported STDs including HIV (Cody, 2019). Providers serving this region can benefit by knowing what helps people in this community return to care after the initial appointment.

All of the HIV advocates interviewed pointed out that stigma impacts Black women's care seeking behaviors and providers should be keenly aware that simply getting tested and making it to the first appointment demonstrates a woman overcoming a substantial hurdle. All providers, even those who will only be involved in the initial appointments, should understand that women respond better to someone who is invested in them as human beings, not just another medical case file. Making warm hand-offs, as one advocate said, is very important in successful linkage to care process. As the FTCI committee recommends, a city or county wide effort to educate non-HIV providers on ways to help newly diagnosed patients get into HIV care should be pursued by state and county health departments.

Trainings for both non-HIV providers and HIV specialists should include reminders on how to destigmatize the notification process and how to offer support until the patient becomes stably adherent. For example, when sharing news of a positive diagnosis, providers can help this population by behaving as if HIV is a chronic condition, not a mark of shame against the person who acquired the virus. This may include physical contact such as a hug or a hand held. Misunderstandings about Women's emotions can lead to attrition from care, so strong emotions should be viewed for what they are, not acts of aggression. The initial appointment or an appointment shortly thereafter should include conversations about the importance of keeping appointments. Providers should discuss what potential barriers might arise in order to help the woman think through how she will overcome them. Taking time and listening during this initial stage demonstrates respect for the woman as the driver in her own health, clears confusion, and encourages her participation for the long-term.

To reinvigorate HIV providers' active communication skills, Epstein and Street's *Patient Centered Care in Cancer Settings* as well as the Mountain Plains Education Training Center's booklet, *Retention in HIV Care: A Clinicians Guide to Patient-Centered Strategies* should be available as reference material at HIV specialty clinics, if not made mandatory.

In sum, enhancements to rapid ART initiation protocol that will support this population include training that helps providers understand the unique circumstances of

Black women's relationship with the medical system, the barriers to care that many face, and the emotional toll of a positive diagnosis. This training should apply to front desk staff, administrators and all levels of medical care providers. Each stage in the continuum of care should be destigmatizing and approached with a sense of concern for the individual's success, no matter how brief the interaction. Of particular importance, the person who gives notification of a positive diagnosis should anticipate fear and distress, even if this is not expressed by the patient, and offer encouragement through their own demeanor and with information. The FTCI continues to work on anti-stigma campaigns for larger community which will also support this population's care seeking intentions.

Ending the epidemic by 2030 remains a daunting challenge, but voluntary coordination at the local level by dedicated providers, volunteers, and government agencies who have a deep understanding of disproportionately affected populations can turn the tide.

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CHAPTER 5

DISCUSSION

Through an integrative review and an empirical study, the first two manuscripts sought to answer the following questions: first, what provider actions help keep HIV positive Black women in care, and, second, why are some patient-provider interactions more successful at keeping women in care and virally suppressed? The third manuscript offers practice recommendations to answer the question, what can local providers do to keep more HIV positive Black women in care? These recommendations are based on data gathered from the empirical study to answer the second question combined with additional sources from local HIV advocacy efforts that are applied to a pilot program currently underway. Overall, the data gathered offers insight into provider attributes and actions inclusive of communication styles that women say help them stay in care.

The studies screened for the scoping review indicate that Black women living with HIV desire a person-centered relationship with providers in which providers recognize them as individuals with a distinct set of challenges. The empirical study affirmed the outcomes of the scoping review and offered Epstein and Street’s (2007) Patient Centered Care in Cancer Settings (PCC) as a viable resource for guiding effective communication strategies pertinent to this population. That study acknowledged that the social stigmas and socio-economic disparities that affect Black women living with HIV elsewhere are also endemic in the Southwestern U.S. The practice recommendations offered in the third manuscript result directly from women’s statements gathered for the empirical study and insight from HIV advocates invested in the health and well-being of PLWH including Black women. The advocates were interviewed as a precursor to interviewing the women themselves so as to understand the context for the local HIV care environment relative to this population.

Integration of Studies

Combined, this work demonstrates that adherence to medication and medical appointments, which are integral steps towards viral suppression, is an interplay between patients' commitment to their own health and support from a provider who is both competent and willing to champion the women as the drivers of their own health. The effective interactions include steps to create rapport and generate trust through multiple means. An example is allowing time for personable conversation that enable the patient to discern that the provider is genuinely interested in her care and giving indication that the provider believes in the woman's knowledge of her own body, her symptoms, and her medical history.

Women in this study echoed Laws et al.'s (2012) pronouncement that adapting to the challenges of HIV, with its comorbidities and social stigma, "requires a transformation of identity and internalization of motivation to maintain health" (p. 893). It is important for providers to recognize that this step is a critical part of women's self-care process. According to statements offered by participants in the current study, providers who show compassion and help women realize their own responsibility and capability for self-care will have greater success at helping them become and stay adherent. This rapport results from and reinforces a reciprocal dynamic between the woman and her provider and promotes mutual efforts; for example, the woman prepares in advance for appointments and the provider actively listens to woman's concerns and questions. In an ideal partnership, providers will take time to answer all of the women's questions and women will be comfortable offering responses to provider questions, including those of a personal nature such as sexual partners, addictions, and mental health because she knows she will not be judged.

Implications for Education and Training

Providers entering the sphere of HIV at any level, from phlebotomists to physicians, should be prepared for the unique psychological nuances that accompany an HIV diagnosis and be ready for distinctions among sub-populations disparately affected by HIV. Resources that offer insight into specific needs of HIV patients should be included in curricula such as *Retention in HIV Care: A Clinician's Guide to Patient-Centered Strategies Mountain Plains AIDS Education and Training Center* (Corwin & Bradley-Springer, 2013). Resources that detail the nature of effective patient centered communication should also be included such as Epstein and Street's (2007) *Patient Centered Communication in Cancer Care*. Both would need to be accompanied by additional information for this specific population, including sensitivity to the role of stigma and historical mistrust; the potential for providers to misunderstand emotions for aggression or anger; the importance of linkage to social supports and other resources; patients' desire to be heard and respected as knowledgeable about their bodies; and the opportunity to become a champion in support of the patient's journey.

Application of the PCC framework

All of the six areas of the PCC framework resonated with the communication strategies and actions that participants in this study and women in other studies indicate as effective. The empirical study mostly describes methods for developing trust and rapport as this is foundational to a working relationship. The other five areas of the framework are also highly instructive for this population (exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling patient self-management). A strong example of this applicability is Epstein and Street's (2007) endorsement of a "process model of information exchange" (p. 21) rather than a one-way transfer of information from provider to patient. They advocate a "reciprocal effort" between both parties to come to "a shared understanding of the medical and personal issues underlying the patient's health condition" (Epstein and Street, 2007 p. 21). While women in this study identify the types, styles, and timing of information they like to receive, they articulate the importance of sharing their knowledge about their own bodies and symptoms with providers, which lends to both parties' understanding of their unique experience with HIV, comorbidities, and medication side effects.

Additions to the PCC framework for this population. The PCC reminds providers to be prepared for cultural and linguistic differences, but leaves it up to the provider to discern what cultural learning is necessary. In this case, additions to the PCC that would increase providers effectiveness in treating Black women living with HIV would include an understanding that stigma and historical trauma impact women's psychological well-being and care seeking behaviors and skepticism among Black women that providers will take women's understanding of their symptoms as credible information. The women interviewed argued that providers should recognize that their own body language and physical contact, or lack thereof, can increase or reduce the patient's internalized stigma. For example, standing too far away from a patient can be interpreted as discomfort the person's race or HIV status. Both advocates and women explained that providers must have a cursory understanding of African American relationships to the medical system including historical and current challenges to equitable care. Consequently, providers should anticipate that some women may need emotional support with this illness in a way that is not typical with other illnesses because Black WLWH may not have family support due to stigma. Interviewees for this and other studies indicate that women may hide their status from others or feel uncomfortable discussing it. Ongoing courses and required reflections on implicit bias and cultural differences in self-expression should be required of all staff working in HIV clinics, including front desk.

Patient activation

As stated above, sources consulted for this study indicate the importance of motivating women toward self-care. Epstein and Street (2007) noted that "activated" patients communicate more effectively with providers. HIV advocates anecdotally observed that patients who are more engaged in their overall self-care are the ones who keep appointments. Indicators of such engagement include attending support groups, seeking and taking advantage of resources available to people living with HIV.

Participants in this study confirmed that acceptance of the virus, moving out of denial and realizing that they were in control of their health were all important steps to developing a productive provider relationship. Women noted that providers have the ability to motivate them to take charge of their own care if providers chose to do so. Therefore, methods to increase patient engagement, including ways to help women move out of denial, should be highlighted in HIV provider training. Additional steps include paying attention to them by asking follow-up questions from previous visits, remarking on progress and demonstrating enthusiasm for achieving milestones, and including her in decision making by offering options to help her feel engaged in her care. Providers may need to actively dispel the stigma of HIV in order to help the woman move out of denial and into a state of motivation.

Referring patients to support groups proved to be helpful among study participants because they could learn from peers who are successfully managing their overall health. Listening to HIV patient panels should be part of provider training and continuing education curricula for clinic staff.

Implications for Practice

The implications for practice emerging from this study resonate with and reinforce previous research and can be condensed to a single point: that provider actions must continue to move toward a personal rather than a transactional approach to care. Because of lingering stigma surrounding HIV and its prevalence in low socio-economic status communities, providers need to act as social supports more so than with other illnesses. This requires a more humanistic approach.

The scoping review yielded specific actions that encouraged women stay in care which participants restated in their own response to open ended interview questions for this study. These actions include both operational and interactive strategies such as the following truncated list from the seven articles meeting criteria (Amutah-Onukagha et al., 2018; Kempf et al., 2010, McDoom et al., 2015; Njie-Carr et al., 2015; Okoro & Odedina, 2016; Sullivan et al., 2015; Warren et al., 2017):

Operational:

- Allowing time for the appointment (i.e. not rushing)
- Standardizing customer service practices such as knowing patients by name, and friendly and encouraging demeanor among all staff, including front desk
- Calling for appointment reminders
- Using holistic, patient-centred care models
- Adapting the regimen to individual patient lives
- Calling to check in with patients
- Planning for comprehensive visits
- Limiting time in the waiting room
- Providing non-medical information

Interactive:

- Demonstrating "buy-in" to helping patient by investing time and getting to the patient personally
- Educating the patient at a speed that works for them and clarifying information

- Demonstrating compassion through hugs, talking and laughing comfortably, giving full attention, and showing respect
- Avoiding any stigmatizing action and being non-judgmental
- Offering linkages to support groups or referrals to other people living with HIV

These articles offer overlapping information across an eight-year span and a geographic range that includes the major urban centers of Boston, Newark, Baltimore, and Washington DC, as well as smaller urban hubs and rural areas in North Carolina, Florida, and Alabama. The fact that women identify similar and complementary actions in different locales at different points in time underscores the importance of these actions. The patient interviewees want a provider to pay attention to them as a whole person and pay attention to symptoms describe. They seek this because HIV is an immune disorder and because the medications have wide ranging side effects, so they would like the provider to consider if there is a link between what they are experiencing, the treatment, and the virus. Providers must also recognize that a woman in distress does not equate hypochondria.

Key contributions and takeaways from this research

In addition to the operational and interactive recommendations listed above, insight from women and advocates interviewed for this dissertation indicate that providers who take the following actions will have greater success with patients:

- Create a partnership with the patient by valuing her knowledge of her body and taking stock of the symptoms she describes.

- Include the patient in decision making processes and set goals related to frequency of appointments, testing, and other health benchmarks as appropriate.
- Demonstrate authenticity – women are repelled by providers who are in the work for a paycheck more than for the people.
- Be straightforward – women don’t trust providers who come across as artificially friendly or too pushy and domineering.
- Celebrate the patient’s progress – reviewing test results can be a time to commend the patents’ effort and encourage ongoing adherence.
- Empower the patient – no matter how long or short the interaction, help the patient find motivations for staying in care: family, self-love, sense of purpose, or serving others.
- Share information through a variety of mediums - oral, written, and video links. Education in the virus should happen when ready to process the information, for some this may not be at the time of diagnosis.
- Learn about the specific disparities that plague African Americans and their historical context.
- Ask about emotional and mental well-being – women remark that when their mental health changes due to external circumstances, their ability to stay engaged in care may suffer.

Implications for practice in the context of Rapid START protocol

These implications are immediately applicable to the START (State of Arizona Rapid Treatment) program, which began in January, 2018 to curb HIV in Maricopa county. The results from the scoping review, the women interviewed for the empirical study, and the interviews with HIV advocates endorse the importance of a friendly, reassuring, human touch to secure an ongoing commitment from newly diagnosed patients. Starting antiretroviral therapy immediately moves people toward a commitment because it alerts them to the urgency of treating the virus as well as the benefits of limiting transmission to others. Anecdotally, participants describe people who don't understand why they should start ART before they show symptoms, so providers need to prepare to address this with the newly diagnosed.

Some of the participants described the notification process as being impersonal and demeaning: for example, listing sexual partners for contact tracing can feel invasive and embarrassing. Both participants and advocates noted that women do not want to feel like they are being deemed promiscuous or "dirty". No matter their initial experience, participants are clear that the general tone at the time of notification can set the stage for women's long-term engagement. Moreover, if providers take note of women's responses to diagnosis, this information can help inform the potential for long-term mental health challenges. In short, the attentiveness and humanness of the notifiers is as important as the providers who will treat HIV patients afterward.

Implications for Policy

The START pilot described in the third manuscript is a step toward a test and treat policy in Arizona that has been shown to curb HIV elsewhere by reducing patient attrition and slowing transmission (CDC, 2020; Ford et al., 2018). A fundamental premise is to recognize that many people will need emotional, social and practical support in the form of medical navigation during their first year after a diagnosis or longer. Therefore, a key component to ensuring the success of this intervention will be increasing the number of case managers and others who can help women develop their own confidence and commitment to their own care. All of the participants in this study describe working with case managers at some point since diagnosis, most as long as 10 years. This indicates that case managers remain useful guides on the viral suppression journey. For some patients, a person with a role even more involved than basic case management is needed. Having a peer available when people are newly diagnosed to talk about survivability helps people make the initial steps from denial and toward care.

To increase support for patients in ongoing care, revisiting steps that worked in the past and bolstering some existing programs will make it easier for clinics to retain women patients in general. Creative approaches to childcare and flexibility in appointments will enable more women to overcome barriers to appointments. The facilities in Phoenix once had a grant-funded childcare center, this should be part of more stable state or federal funding for clinics serving low-income women. Clinic managers should encourage and fund ongoing training of all staff on communication strategies outlined in this study as well as implicit bias and methods to deescalate patients experiencing distress. Clinical teams should implement strategies that foster teamwork as patients themselves notice improved care when providers work well within and among facilities. Across clinics and insurers, policies that support flexibility in provider choice may allow patients greater ease in finding providers who match their needs more closely. Patient participation in the workshops offered by community-based organizations and public entities remain important and incentivizing Black women to participate remains necessary.

Attention to patients' whole life-needs including mental health are paramount to the stability necessary for adherence and should be afforded attention at all stages of the HIV care continuum. It has been documented that a positive HIV diagnosis can have deleterious effect on women's mental health, especially if they already live in difficult circumstances. A World Health Organization global survey of HIV positive women, including women in the United States, revealed the diagnosis launches or exacerbates mental distress. Respondents experienced 3.5 times as many mental health issues after diagnosis than they did beforehand and reported "experiences of depression (74.0%), shame (70.8%), self-blame (70.0%), feelings of rejection (69.9%) and insomnia (68.4%)" (Orza et al., 2015, p. 4). Participants in this study either explicitly described or alluded to many stressful challenges: addictions, life instability, infidelity and/or abusive partners, incarceration, single parenthood, debilitating illnesses, and employment levels that necessitate reliance on public support systems, including public health insurance. Therefore, non-stigmatizing verbal questions and written questionnaires to help assess mental health should be explored for clinics serving women. Questionnaires about transmission should also be destigmatizing.

Strengths

This study is unique from those found in the literature searches conducted in that it focuses on the Southwestern United States where the population of African Americans is small. Thus, this dissertation highlights current needs and recommendations for women in a region where their burden of HIV is ten times greater than that of white women (ADHS, 2021), yet they have less likelihood of finding a large or varied network of support among other people of African descent.

This study is also unique in that it asked patients to identify provider actions that earn patient trust and lead to retention, not what providers think is best. This step was supported by context offered from people who work with HIV patients on a daily basis and who have a particular concern for this population. An important outcome from this approach is the emphasis on provider authenticity and communication styles that allow for input from the patient rather than authoritative one-way communication, particularly from physicians. While being too authoritative is problematic on one end of the spectrum, being overly “sweet” makes providers seem untrustworthy and being too timid or passive makes the information providers convey seem unimportant.

Another important outcome from this line of questioning is the emphasis these women place on women’s need to understand their control of the situation and their role in driving their own good health. In other words, although the questions were mostly about provider actions, and women welcomed the opportunity to talk about helpful and hurtful interactions, they all acknowledged the importance of their role in managing this aspect of their health. This gives providers an opportunity to consider where and how they can engage patients in finding their own means of control.

The choice to use Grounded Theory methodology lend to the strengths of this research, despite not generating a new middle-range theory. Charmaz’s (2014) recommendation to use an existing framework for sensitizing concepts led to the selection of a viable framework for engaging this population and this illness: Epstein and Street's (2007) PCC. Grounded Theory's emphasis on pursing "why" questions to investigate social processes led to an analysis of the underlying reasons why some providers' attempts at building rapport are successful while others fail. Charmaz's (2014) emphasis on open-ended questions with probing questions for further depth encouraged participants to raise issues and speak freely about their perceptions more so than a survey or more regimented interview styles. Charmaz's (2014) constructivist approach acknowledges multiple realities which is foundational to interpreting social interactions involving people from very different social strata. The constant comparison of data and inductive approach of CGT allowed the researcher to explore the data without being restricted by the theoretical framework which yielded insight into points that are specific to this population.

Lastly, the researcher developed rapport with many people in the HIV community over several years before embarking on independent research. This, combined with serving on the Fast Track Cities Ad Hoc committee, provided for opportunities to gather candid, sincere information as well as offer informed recommendations from the research. Because this dissertation includes a local focus informed by national trends through the literature and through the relationship with the global Fast Track Cities campaign, this work situates these patient-provider interactions in the local, national, and global contexts of HIV.

Limitations

This study focused on a small subset of the HIV positive population which was reflected in the size of the existing body of research for the scoping review and in the number of participants for the empirical study. There was a small body of literature to draw upon that focused specifically on Black women living with HIV, and no other publications for this region or regions with very small African American populations. For the empirical study, only a few women were willing to talk and recruitment involved a high level of self-selection. One participant said she had lost interest in telling others about "her" HIV and she was pleased to find that the interview questions were about the provider not her. Another participant was previously an active and ardent HIV advocate, always willing to talk about HIV in the past, but had taken a substantial step back in recent years due to burn-out. A third expressed exasperation about the lack of interest in HIV among people who are not directly involved in care and advocacy. Their sentiments point to fatigue among this population and its support network.

Participants were also recruited from within a network of people interested in HIV including local community-based organizations who actively educate patients about HIV through support groups. All of the Black WLWH participants had been diagnosed for many years and felt comfortable disclosing their status, so this study may not address the concerns of those who are not comfortable with disclosure. This group of women may know more about HIV than Black WLWH who are more isolated. It is also possible that they are more confident talking with providers due to exposure to other women who are also confident. Some participants were very outspoken about providers who were not helpful but others may have self-censored as the community of providers is small and they may not want to damage relationships.

The women in this study think of themselves as survivors and will find a way to get what they need for their medical care. Other women, however, may not have that internal resolve and ways to reach them may be missing from these recommendations.

Participants for the focus groups were difficult to secure. The initial goal was to have at least four participants in each group and advocates who agreed to help recruit were confident this number would be reached. Three were recruited for each group, but in both cases one person cancelled the day before or the day of.

Contributions to the Literature

The scoping review revealed that there is small body of research dedicated solely to Black women living with HIV despite the extreme nature of the disparity between them and other women. This work contributes to the literature by focusing exclusively on Black women in a region where needs for this population have not been published in peer reviewed journals and where they report feeling overlooked because of their small population size. This work may contribute to other regions where the populations of African Americans are relatively small by informing providers that they have to be prepared to be social supports themselves, help the women patients develop internal resourcefulness, and help women seek external resources for PLWH.

Race and gender congruence. Some literature emphasizes cultural incongruence as a barrier to care-seeking among people living with HIV, particularly African Americans (Brincks et al., 2019; Heslin et al., 2005; Jacobs et al., 2006). Therefore, interview questions were included in this study to explore the importance of race and gender congruence to the participants. These women indicated that race and gender congruence were less important than the provider's authenticity. Women noted that having Black providers would be welcome, but not necessary so long as the provider is authentic. Gender congruence is a little more nuanced. Although only two said they preferred a female provider, when asked to describe the best provider they ever had, seven of eleven said that "best" provider was a woman.

Future Research and Next Steps

START pilot

Future research should seek the perspectives of newly diagnosed women in the START pilot to ascertain how best to help women be comfortable starting ART immediately upon the news of a positive diagnosis.

Effective philosophical underpinnings by profession

This study did not ask participants to distinguish types of providers. Some may have been describing interactions with HIV physicians while others were not. At least one described a doctor in nursing practice while another discussed a case manager. Future research could discern what types of providers offer the best kind of wraparound supports and hence what kind of training or attitudes might be needed according to profession. It may be important to learn which philosophical approaches lend to the most effective relationships and cross-train all HIV providers on this approach.

HIV provider resiliency

Many practice recommendations identified here and in other studies, such as care navigation, have been adopted to varying degrees by HIV serving clinics and community-based organizations nation-wide and locally. Yet, patients and advocates note that provider and worker burn-out play a role in whether or not education, practice and policy recommendations can be followed. Research on how to encourage resilience and optimism among professionals and volunteers who support underrepresented PLWH will have a correlative effect on the patient population.

Research into patient activation for Black women

Women in this study, some of whom never completed high school, corroborate the observations of learned experts Epstein and Street (2007) throughout their framework on patient centered communication, including the need for having an activated patient. Since multiple women in this study said the first step to a healthy life is overcoming denial, further research into what helps newly diagnosed patients move from denial to acceptance quickly may help newly diagnosed patients accept antiretroviral medication within the ideal one-week time frame. Additional research into what helps Black women and women of other ethnicities who may anticipate gender bias from the medical system become engaged is warranted.

Conclusion

Women who participated in this study demonstrated shrewdness in their observations of providers and the clinic environment. For retention to be successful, it is vital that providers believe that these women know their symptoms, the side effects of medications, and their own medical history. The participants' collective insight corroborates the outcome of earlier research by Jacobs et al. (2006) on African Americans' views of the trustworthiness of physicians: trust may never be earned if the patient perceives that providers are in the field for economic gain, if providers lack technical or interpersonal skills, or if there is any hint of racism or judgement.

The overall answer to what provider actions are effective at retaining Black women in HIV care and why point to the authenticity of the provider first and their competence second. Certainly, women want both. Yet, the providers who motivate active patient engagement and returning appointments are with those who are sincerely interested in the women's health and make that interest apparent. Regardless of their medical competency, providers who act in ways counter to this can cause women to leave that provider or give up on care altogether as was the case with one participant in the study. Jacobs et al. (2006) noted the same outcomes of mistrust among African Americans broadly: a patient will walk away from a provider and potentially from care if trust cannot be established. Women in this study described experiences that merit the mistrust common among African Americans nationwide.

Specifically, these patients communicated a desire for a partnership with their healthcare provider, someone who would champion them along the path of good health. This fits the framework of patient centered care as described in Epstein and Street's (2007) PCC and with the encouragement of the World Health Organization as both call for understanding and interacting with patients as if they are the drivers of their own health care. Due to the social circumstances surrounding HIV this population has a unique need to know that their providers genuinely care about them. Providers should invest in the effort to be empathetic enough for their Black women patients to trust them. With that, the U.S. will be able to reach the ambitious objective of a 90% undetectable viral load among all PLWHIV by 2030.

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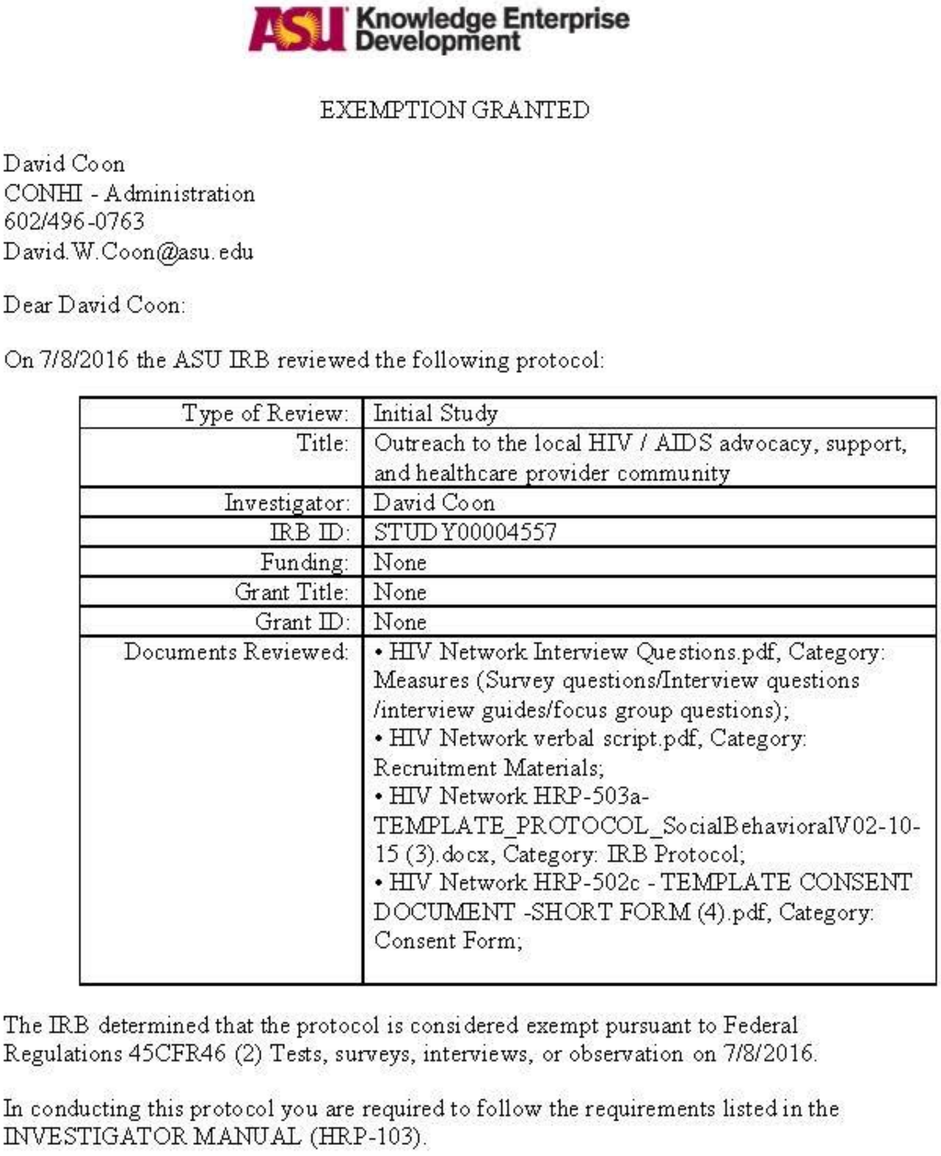
APPENDIX A

HUMAN SUBJECTS APPROVAL DOCUMENTS



ASU Knowledge Enterprise Development

EXEMPTION GRANTED

David Coon
CONHI - Administration
602/496-0763
David.W.Coon@asu.edu

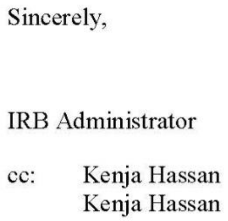
Dear David Coon:

On 7/8/2016 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Outreach to the local HIV / AIDS advocacy, support, and healthcare provider community
Investigator:	David Coon
IRB ID:	STUDY00004557
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• HIV Network Interview Questions.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • HIV Network verbal script.pdf, Category: Recruitment Materials; • HIV Network HRP-503a-TEMPLATE_PROTOCOL_SocialBehavioralV02-10-15 (3).docx, Category: IRB Protocol; • HIV Network HRP-502c - TEMPLATE CONSENT DOCUMENT -SHORT FORM (4).pdf, Category: Consent Form;

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 7/8/2016.

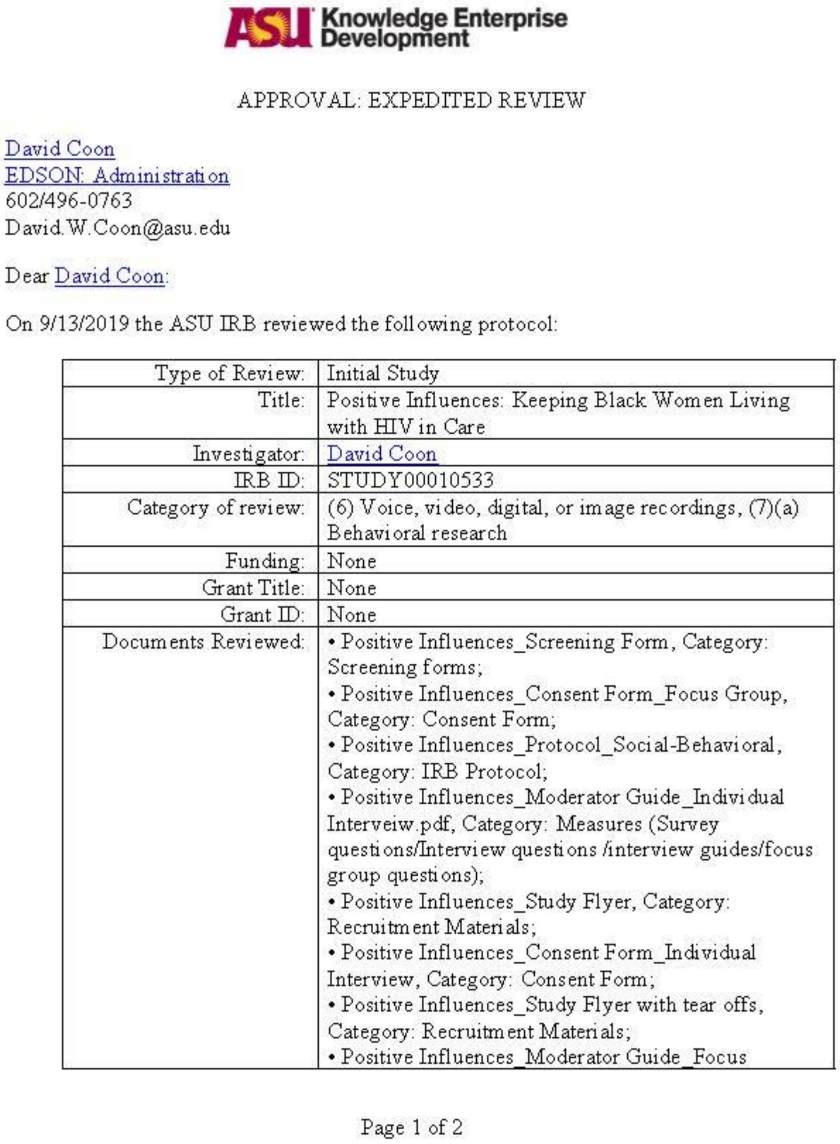
In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).



Sincerely,

IRB Administrator

cc: Kenja Hassan
Kenja Hassan



ASU Knowledge Enterprise Development

APPROVAL: EXPEDITED REVIEW

David Coon
EDSON: Administration
602/496-0763
David.W.Coon@asu.edu

Dear David Coon:

On 9/13/2019 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Positive Influences: Keeping Black Women Living with HIV in Care
Investigator:	David Coon
IRB ID:	STUDY00010533
Category of review:	(6) Voice, video, digital, or image recordings, (7)(a) Behavioral research
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• Positive Influences_Screening Form, Category: Screening forms; • Positive Influences_Consent Form_Focus Group, Category: Consent Form; • Positive Influences_Protocol_Social-Behavioral, Category: IRB Protocol; • Positive Influences_Moderator Guide_Individual Interveiw.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Positive Influences_Study Flyer, Category: Recruitment Materials; • Positive Influences_Consent Form_Individual Interview, Category: Consent Form; • Positive Influences_Study Flyer with tear offs, Category: Recruitment Materials; • Positive Influences_Moderator Guide_Focus

Page 1 of 2

	Group.pdf, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Positive Influences_Verbal Script.pdf, Category: Recruitment materials/advertisements /verbal scripts/phone scripts;

The IRB approved the protocol from 9/13/2019 to 9/12/2024 inclusive. Three weeks before 9/12/2024 you are to submit a completed Continuing Review application and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of 9/12/2024 approval of this protocol expires on that date. When consent is appropriate, you must use final, watermarked versions available under the "Documents" tab in ERA-IRB.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Kenja Hassan
Kenja Hassan

APPENDIX B

CONSENT FORMS – FOCUS GROUP AND INDIVIDUAL

Consent Form

Positive Influences: Keeping HIV Positive Black Women in Care

Focus Group

Title of research study: Positive Influences: Keeping HIV Positive Black Women in Care.

Investigator: Professor David W. Coon & graduate student, Kenja Hassan, from The Edson College of Nursing and Health Innovation at Arizona State University.

Why am I being invited to take part in a research study?

We invite you to take part in a research study because we want to know what you think providers do or can do better to help keep more HIV positive black women in care.

Why is this research being done?

The purpose of this study is to understand what provider actions help keep HIV positive women in care, help them adhere to a medication regimen and achieve viral suppression. This research is being done to help more HIV positive Black women live full, healthy lives.

How long will the research last?

We expect that individuals will spend 2 hours in the focus group.

How many people will be studied?

We expect about 12 people to participate in this study.

What happens if I say yes, I want to be in this research?

You are free to decide whether you wish to participate in this study.

- You will be asked to sign this consent form indicating your willingness to participate.
- Once everyone in the group signs this consent form the focus group will start
- The focus group will be audio taped and later transcribed by a transcription company

You can leave the focus group at any time it will not be held against you.

Is there any way being in this study could be bad for me?

The risks or discomforts from participating in this study are minimal. For some people, talking about past experiences with HIV care can be difficult. If you feel uncomfortable about any of the questions we ask you, you can choose not to answer the question or skip the question. You can also decide to leave the study.

With any study, the risk of breach of confidentiality exists; however, the investigator has steps in place to ensure your confidentiality is protected according to federal regulations and rules of Arizona State University. Participants will be assigned a code and will chose a pseudonym. The key that holds the codes and links to any of your personal contact information will be stored separately.

Since focus groups involve a group conversation with several people, complete confidentiality cannot be guaranteed.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include having a chance to learn from other women what has helped them be successful in managing HIV and an opportunity to share your expertise and let providers know how they can help more women. Participants will be provided with $15 gift card to a local grocery store.

What happens to the information collected for the research?

Efforts will be made to limit the use and disclosure of your personal information, including research study records, to people who have a need to review this information. We cannot promise complete secrecy. The results of this study may be used in reports, presentations or publications but your name will not be used.

We will take the following steps to make sure we protect your personal information and identity.

- The researcher will keep all study materials locked in a secure location.
- All electronic files which contain identifiable information will be password protected.
- Any computer hosting such files will also have password protection to prevent access by
- unauthorized users.
- Only the researchers will have access to your personal information. All information will be saved on an ASU password protected server and in a locked office.
- The typed transcript will not have any of your personal information in it.

Who can I talk to?

If you have questions, concerns, or complaints, call David W. Coon at 602-496-1239 or Kenja Hassan at ***480-965-0695.***

This research has been reviewed and approved by the Social Behavioral IRB. You may talk to them at (480) 965-6788 or by email at research.integrity@asu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.

- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

Signature

Please initial to indicate you agree with efforts to keep this conversation confidential.

____

Please initial to indicate you understand this conversation will be recorded.

____

Please sign below to indicate your permission to take part in this research.

Signature of participant	Date
Printed name of participant	
Signature of person obtaining consent	Date
Printed name of person obtaining consent	

Consent Form

Positive Influences: Keeping HIV Positive Black Women in Care

Individual Interview

Title of research study: Positive Influences: Keeping HIV Positive Black Women in Care.

Investigator: Professor David W. Coon & graduate student, Kenja Hassan, from The Edson College of Nursing and Health Innovation at Arizona State University.

Why am I being invited to take part in a research study?

We invite you to take part in a research study because we want to know what you think providers do or can do better to help keep more HIV positive black women in care.

Why is this research being done?

The purpose of this study is to understand what provider actions help keep HIV positive women in care, help them adhere to a medication regimen and achieve viral suppression. This research is being done to help more HIV positive Black women life full, healthy lives.

How long will the research last?

We expect that individuals will spend 60 - 90 minutes in a one-on-one interview.

How many people will be studied?

We expect about 12 people to participate in this study.

What happens if I say "yes, I want to be in this research?"

You are free to decide whether you wish to participate in this study.

- You will be asked to sign this consent form indicating your willingness to participate.
- Once you sign this consent form the interview will start.
- The interview will be audio taped and later transcribed by a transcription company

You can leave the interview at any time it will not be held against you.

It is possible that your responses will need greater clarification. In this case, the graduate student, Kenja Hassan will contact you to arrange a follow-up interview via phone.

Is there any way being in this study could be bad for me?

The risks or discomforts from participating in this study are minimal. For some people, talking about past experiences with HIV care can be difficult. If you feel uncomfortable about any of the questions we ask you, you can choose not to answer the question or skip the question. You can also decide to stop the interview and leave the study.

With any study, the risk of breach of confidentiality exists; however, the investigator has steps in place to ensure your confidentiality is protected according to federal regulations and rules of Arizona State University. Participants will be assigned a code and will chose a pseudonym. The key that holds the codes and links to any of your personal contact information will be stored separately.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, possible benefits include having a chance to learn from other women what has helped them be successful in managing HIV and an opportunity to share your expertise and let providers know how they can help more women. Participants will be provided with $15 gift card to a local grocery store.

What happens to the information collected for the research?

Efforts will be made to limit the use and disclosure of your personal information, including research study records, to people who have a need to review this information. We cannot promise complete secrecy. The results of this study may be used in reports, presentations or publications but your name will not be used.

We will take the following steps to make sure we protect your personal information and identity.

- The researcher will keep all study materials locked in a secure location.
- All electronic files which contain identifiable information will be password protected.
- Any computer hosting such files will also have password protection to prevent access by unauthorized users.
- Only the researchers will have access to your personal information. All information will be saved on an ASU password protected server and in a locked office.
- The typed interviews will not have any of your personal information in it.

Who can I talk to?

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This research has been reviewed and approved by the Social Behavioral IRB. You may talk to them at (480) 965-6788 or by email at research.integrity@asu.edu if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.

- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

Signatures

Please initial to indicate you understand this conversation will be recorded.

____

Please sign below to indicate your permission to take part in this research.

______________________________	______________
Signature of participant	Date
______________________________	
Printed name of participant	
______________________________	______________
Signature of person obtaining consent	Date
______________________________	______________
Printed name of person obtaining consent	

APPENDIX C

RECUUITMENT FLYERS BACK AND FRONT

Positive Influences:
Keeping Black Women in HIV Care

Everyone has a story to tell.
We would like to hear yours.

Positive Influences is a research study to understand what providers can do to help keep more Black women in HIV care.

- **How?** Focus group and/or individual interview. Participants may join one or both activities.
- **Time expectations:** Focus group - 2 hours | individual interview – 1 to 1.5 hours
- **Topic**: provider actions that motivate Black women to stay in HIV care
- **$15** will be provided for participation in either activity

To participate, you must be:

- An African American or Black woman living with HIV
- Diagnosed HIV positive 12 months or longer
- 21 years or older
- Engaged in care for HIV with medical providers for 12 months or longer

Purpose: This research is being done to help more HIV positive Black women live full, healthy lives.

Where: Focus groups and interviews will be held in locations accessible by public transit.

When: Fall, 2019

Privacy: The results of the study will be shared in reports and presentations, names will not be used and participant privacy will be protected.

To learn more, contact:
Kenja Hassan,
Arizona State University
PhD Student

Phone:
(480) 965-0695

Email:
Kenja.Hassan@asu.edu

See reverse for detail

ASU Knowledge Enterprise Development

ASU IRB IRB # STUDY00010533 | Approval Period 9/13/2019 – 9/12/2024

Positive Influences:
Keeping Black Women in HIV Care

Why we doing this project?

We are interested in helping providers of all types better understand the needs of Black women living with HIV. “Providers” include staff who work to support your physical and psychological health: case managers, receptionists, phlebotomists, nurses, physicians, pharmacists, dentists, etc.

We are inviting you to participate in this project so that you can share your views on “what works” to keep Black women in HIV care based on your own experiences.

What will participation mean for me?

Participants in the focus group will share their views on possible interview questions to ask in the individual interviews.

Participants in the individual interviews will be asked to describe steps providers take that help them stay in care.

Participation in this project is voluntary and you have the right not to answer any question or to stop participating at any time. There will be no penalty if withdraw from the project after starting.

You will receive $15 for participating in the focus group and/or $15 for participating in the interview.

How will this project help Black women in HIV care?

Your participation may help inform programs, services, and research to benefit people living with HIV. There are no foreseeable risks to your participation.

How will my privacy be protected?

To protect confidentiality, you will be asked to use an alias instead of your real name, and all participant responses will be coded to keep you anonymous. The results of this project may be used in reports, presentations, or publications but your name will not be used. We ask that all focus group participants keep anything discussed in the group confidential and not share the information with people outside the group. However, we cannot guarantee that complete confidentiality will be maintained.

We plan to audiotape the focus groups and individual interviews. Tapes will be secured in the College of Nursing and Health Innovation at ASU’s Downtown campus. Upon completion of the project, the tapes will be erased and destroyed.

Who can I talk to for more information?

If you would like to participate or have any questions concerning the project, please contact Kenja Hassan, PhD student, College of Nursing and Health Innovation (CONHI), 480-965-0695.

ASU IRB IRB # STUDY00010533 | Approval Period 9/13/2019 – 9/12/2024

Positive Influences:
Keeping Black Women in HIV Care

Everyone has a story to tell.
We would like to hear yours.

Positive Influences is a research study to understand what providers can do to help keep Black women in HIV care.

- **How?** Focus Group and/or individual interview. Participants may join one or both activities.
- **Time expectations:** focus group - 2 hours | individual interview - 1 to 1.5 hours
- **Topic**: provider actions that motivate Black women to stay in HIV care
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- An African American or Black woman living with HIV
- Diagnosed HIV positive 12 months or longer
- 21 years or older
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Kenja.hassan@asu.edu

Positive Influences Study
(480)965-0695
Kenja.hassan@asu.edu

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