

Original Research

Exploring the Everyday Lived Experience of African American People Living with HIV/AIDS (PLWH) in the Rural South

Jill E. Rowe, PhD, MPH*

Western Michigan University, College of Health & Human Services, School of Interdisciplinary Health Programs, Kalamazoo, MI 49008, USA

*Corresponding author

Jill E. Rowe, PhD, MPH

Assistant Professor, Western Michigan University, College of Health & Human Services, School of Interdisciplinary Health Programs, 1903 W. Michigan Avenue, Kalamazoo, MI 49008, USA; Tel. 269-387-2049; E-mail: jill.rowe@wmich.edu

Article information

Received: June 12th, 2019; Revised: July 4th, 2019; Accepted: July 8th, 2019; Published: July 12th, 2019

Cite this article

Rowe JE. Exploring the everyday lived experience of african american people living with HIV/AIDS (PLWH) in the Rural South. *HIV/AIDS Res Treat Open J.* 2019; 6(1): 1-9. doi: [10.17140/HARTOJ-6-129](https://doi.org/10.17140/HARTOJ-6-129)

ABSTRACT

Aims/Objectives

Despite previous findings attesting to the syndemic nature of human immunodeficiency virus (HIV), chronic disease and mental illness coordination of these issues remains a significant barrier to initiating and maintaining the delivery of mental and physical health care to persons living with HIV (PLWH). These inequities are even greater when applied to rural settings, particularly in areas that are medically underserved. To date, there is scarce research regarding the lived experiences of African American PLWH in rural settings. Constructivist grounded theory was used to analyze this qualitative data set. These discourses provide a rich narrative regarding effective systems of care, the context in which these processes take place and related constraints or limitations of the current systems.

Methods

In-depth interviews with 24 African American PLWH both inside (N=20) and outside (N=4) of care in rural Northwestern Virginia were conducted. Rural African American PLWH were queried about their perceptions of the provision of HIV health care services, barriers to linkages to care, retention of PLWH in care, and recommendations for improving HIV health care services for rural PLWH.

Results

Participants offered insights on the linkages to health and mental health care consistent with the pattern recommended by the cascade of care (i.e. pre-screening, testing, refer to treatment, treatment and sustain treatment). Participants identified contextual factors, including traumatic events, medication (side effects), other chronic health issues, issues with the current health and mental health system, stigma, and lack of social support. We highlight PLWH's recommendations for linking rural PLWH into care and sustaining that care.

Conclusion

We discuss the implications of these findings for programmatic development in the rural context.

Keywords

Rural African Americans living with HIV; Barriers to HIV health care; Rural South; HIV lived experience.

INTRODUCTION

In the United States, an estimated 1.1 million people were living with HIV (PLWH) infection at the end of 2016, the most recent year for which this information is available.¹ Of those people,

about 15%, or 1 in 7, did not know they were infected.² Among that group, African Americans continue to be disproportionately affected. Though African Americans only represent 13% of the United States population, they account for 43% (16,694) of PLWH.³ Unless the course of the epidemic changes, at some point

in their lifetime an estimated 1 in 16 African American men and 1 in 32 African American women will be diagnosed with human immunodeficiency virus (HIV) infection.³

Recent data from the US centers for disease control and prevention (CDC) show that the HIV diagnoses were not evenly distributed across states and regions. Furthermore, southern states accounted for more than half of the 38,739 new HIV diagnosis in 2017.⁴ Furthermore, in the southern United States, 23% of new HIV diagnosis are in suburban and rural areas.^{4,5} In the last decade, a shift in the HIV epidemic to the rural South has been noted.⁶⁻⁸ Since the 1990s, a consistent rate of new rural acquired immune deficiency syndrome (AIDS) cases was reported. In 2017, 52% (19,968) of all new AIDS cases were located in the South and there were more deaths from AIDS there than in any other area of the country.⁸

Mental and Physical Health Unmet Needs for PLWH in Virginia

According to the Virginia HIV Epidemiology Profile, as of December 31, 2015 there were 24,853 persons, or about one in 336 Virginia residents who are living with HIV disease.⁹ From 2006 to 2015, the number of PLWH in Virginia increased by about 35%.⁹ Approximately 47% of the HIV-positive population had an AIDS-defining condition.⁹ By the end of 2015; there were 18,423 males and 6,430 females in Virginia who were living with HIV disease, with males representing 74% of the total HIV population.⁹ African American, non-Hispanic males had the highest rate of PLWH at 1,259 cases per 100,000 of the population living with HIV.⁹ African American, non-Hispanic females were 15 times more likely to be living with HIV than European American, non-Hispanic females.⁹ As of December 31, 2015 the transmission risks for all living cases of HIV in Virginia were attributed to: Men who have sex with men/same gender loving men (MSM/SGLM) (47%); heterosexual contact (19%); injection drug use (IDU) (9%) and no reported risk (20%).⁹

This paper focuses on the Northwest Region which consists of the cities of Charlottesville, Winchester, Fredericksburg and the surrounding rural areas. In the Northwestern Region of Virginia 1,944 persons are living with HIV.¹⁰ Among this population, nearly 53% had progressed to AIDS. Seventy-five percent of PLWH in the Northwestern Region were male, and 60% were African American.⁹ The HIV Continuum of Care of PLWH in this region as of December 31, 2015—as measured by care markers defined as CD4 count or viral load lab test, HIV medical care visit or antiretroviral therapy (ART) prescription—indicates that 65% of PLWH established evidence of care (one care marker within a 12-month period); 55% were retained in care (two care markers in a 12-month period or at least 3-months apart); and 55% were virally suppressed (last viral load in the 12-month period that is <200 copies/mL).¹¹ Among 92 persons newly diagnosed in the Northwestern Region, 68% were linked to care within 30 days.¹¹

Historically, many areas in the rural south are impoverished and medically underserved.¹¹⁻¹³ Recent studies found that rural African American PLWH are concentrated in areas lacking

crucial resources necessary for self-sufficiency which may lead to engagement in high-risk behaviors as an escape mechanism.¹⁴⁻¹⁶ Other researchers concluded that there is a great need to assess the conditions of rural PLWH regarding their susceptibility to new infections of HIV and to uncover the barriers to affective delivery of HIV testing, care, and treatment.¹⁷⁻¹⁹ Further, they contend that such efforts can serve a dual role by identifying unmet needs for a wide range of services (i.e. mental health, substance abuse, sexually transmitted infections (STI) screening) for PLWH in the rural south.^{15,20-22}

A number of studies reveal that African Americans who reside in rural southern areas disproportionately face a number of health care challenges, including geographic isolation, poverty, limited employment opportunities, inadequate education, stigma directed toward those who engage in risky behaviors or have been diagnosed with HIV or AIDS, and close-knit social networks which make it difficult both to seek and to disclose confidential HIV testing and attain prevention services.^{15,23-25} Many of these barriers are unique to PLWH in rural areas and can prohibit them from seeking HIV testing, counseling, and care, as well as related services such as drug and alcohol treatment and mental health counseling.^{6,7,26,27}

Demographics and Characteristics of African American PLWH in Northwestern Virginia

In Northwestern Virginia, African American men who have MSM/SGLM accounted for nearly half of all HIV infections and AIDS cases.⁹ Previous research reports that many MSM/SGLM, especially African Americans, do not self-identify as gay, have sexual intercourse with both men and women without disclosing their sexual behavior partners, and are inconsistent in their use of condoms.^{28,29} African American women in rural settings face a number of obstacles as well including higher exposure to drug and alcohol usage, unemployment, limited health care, gender inequality making it difficult [for them] to negotiate condom use with their male partners, socio-economic disadvantages preventing access to medical care, and poor knowledge about HIV/AIDS.³⁰⁻³²

Importantly, the overall findings from previous studies are (1) PLWH consistently single out the difficulty in maintaining appointments with different agencies; (2) repeated provision of specialty services greatly improved the retention in mental and physical health care of PLWH; and (3) frontline service workers play a primary role in coordinating service provision for PLWH among differing service agencies. Strikingly, there is scarce research from the perspectives of PLWH themselves regarding the quality and continuity of HIV/AIDS health care.

Focus of Study

The purpose of this study was to examine the systemic and contextual issues that act as barriers and facilitators to timely treatment of African American PLWH within a medically underserved rural southern area. A constructivist grounded theory research design was employed to explore systematic issues in the everyday lived experience of rural African American people living with HIV.

METHODS

The data reported on in this paper derives from a study of African American people living with HIV in Northwestern Virginia. All research protocols were approved by University Institutional Review Boards (IRB) prior to study initiation. Study participants were chosen from three different organizations that provide health, mental health and community-based services to people living with HIV, specifically providers of (1) community-based services; (2) behavioral and mental health services; and (3) physical health services. The study design involved in-depth interviews with rural African Americans living with HIV who have in the past or are now utilizing services at one of the three organizations that participated in the study.

Recruitment and Participants

Ten directors representing the three types of organizations of interest were contacted and screened. The three study sites that were chosen included: (1) a rural community service board that provides behavioral and mental health services for a seven-county area; (2) an HIV/AIDS medical center located in the infectious disease clinic of a school of medicine, and (3) a community-based organization that provides HIV testing and HIV related support services.

Procedures

Data was collected from June 2013 to May 2014. Each participant was provided an information sheet that explained the intent of the study, and each signed a letter of consent to participate. Participants were informed that they could refuse to answer a particular question and that they could end the interview at any point. Interviewees were compensated \$50 visa gift cards. For the sake of anonymity and confidentiality of sensitive health information, pseudonyms were assigned by the researcher. Each interview lasted ~1-1.5-hours. The interviews were conducted in locations that were convenient for participants (i.e. coffee shops, participants' homes, at local restaurants, at local parks and libraries). A moderately structured interview protocol was developed to place great emphasis on rural African American PLWH's meaning-making process by which they come to understand their experiences linking to HIV care.

Twenty rural African American PLWH in care were interviewed. Of those in care, 13 were men and 7 were women; age range 31-62-years. Four (4) rural African American PLWH not in care were interviewed; age range 22-47-years. Of those not in care, 3 were men and 1 was a woman.

MEASURES

Semi-structured interview guides were developed to allow flexibility in the line of questioning while maintaining the in-depth interviews of rural African Americans living with HIV who utilized services at one or more of the three agencies. In-depth interviews were conducted with participants who were receiving or had received services at each location both in care (N=20) and out of

care (N=4). Example questions included the following: (1) What are the current health and mental health services that you use? (2) Thinking about the current services that you use, are there any that do not meet your personal health and mental health needs? (3) Do you have any suggestions or recommendations of ways that would improve the quality of these services? (4) In your opinion, how well do the different organizations work together? (5) What is your experiences with providers?

Data Analysis

The interview data, and fieldnotes were analyzed using open coding, axial coding and selective coding.³³ NVivo—a qualitative data management program was used to store the data. Throughout the entire research process, fieldnotes were kept and documented before and after every interview. Once the data were transcribed, a constructivist grounded theory analysis of the data was conducted with the goal of understanding health services from a localized cultural lens.

The data analysis commenced with open coding to identify concepts that could be easily labeled and sorted. Chunks of data were selected as the unit of analysis (groups of sentences or, at times, isolated ones that appeared to speak to distinct categories). Relationships were then formulated within and among the categories through axial coding. Fieldnotes were referenced to enhance theoretical sensitivity of the analysis and connect analytical frames to the ongoing in-depth interviews.³⁴ Finally, through selective coding, emergent theoretical concepts were tied together to achieve theoretical integration.^{35,36} Based on the goals of the constructive grounded theory approach, the researcher later revisited the themes with the participants to ensure the trustworthiness of the analysis.³⁷

RESULTS

Participants offered insights on systematic and contextual issues that act as barriers and facilitators to timely treatment of African American people living with HIV in Northwestern Virginia. Participants identified contextual factors, including traumatic events, re-education about AIDS, other chronic health issues, stigma, and breeches in confidentiality. We highlight three of the most prominent key themes of PLWH recommendations for linking rural African American PLWH into care and sustaining that care. These themes included: (1) Perceptions of the provision of HIV health care services; (2) Barriers to linkages to care; (3) recommendations for improving health care services for rural African American PLWH.

Perceptions of the Provision of HIV Health Care Services

All of the study participants (N=24) were asked to list the current and past HIV health services that they have used. From this list they were instructed to prioritize their list in the order of the most to the least used services. This list was analyzed as "List Serve" and provides insight into the participant's perception of the quality of HIV health care services each received. An analysis of these

list serves revealed: the lists of mental and physical health services used by the women who were in care (N=7) were much longer than men who were in care (N=13). For PLWH in care (N=20) and PLWH out of care (N=4) there was consistency in the ranking of mental health services as the least effective services that they used.

Almost all PLWH in care 20 (100%) and the PLWH out of care 3 (75%) listed the HIV/AIDS Academic Center as the health service most frequently used. This was tied to their satisfaction with their primary HIV physician. Of those in care, 17 (85%) were very satisfied with the medication services they received and the assistance with transportation *via* taxicab, minibus or the chauffeured car services provided by the participating community-based organization (CBO). This was a crucial issue as 9 (45%) of participants in care (N=20) were not indigenous to the area but had been relocated to the rural area by the housing opportunities for persons living with HIV and AIDS (HOPWA).

Men participants (N=16)—both in care and out of care listed one-to-three items. The primary HIV physician consistently received the highest rankings among this group. Fourteen of participants in care (70%) listed outpatient ambulatory health services and pharmaceutical assistance as other services frequently utilized. Significantly two of the participants currently not in care (50%) ranked medical case management services as the lowest ranking. A frequent issue reported was their failure to adequately assist them in qualifying for social security disability insurance (SSDI). This item was also ranked the lowest by 25% of PLWH participants currently in care.

Women participants (N=8)—both in care and out of care—provided longer lists (five-to 13 items) and were more detailed in their perception of services received. Six women participants currently in care elaborated on their satisfaction with their current HIV provider as the number one reason for utilizing the HIV/AIDS Medical Center. The single woman participant not in care listed dissatisfaction with her primary HIV provider as the main reason she is no longer in care.

Barriers to Linkages to Care

Study participants' supplied responses regarding the high number of people living with HIV who are not in care. Top theories according to the participants currently in care (N=20) included lack of transportation, financial issues and changing living situations that often resulted in homelessness. Other reasons involved contextual and structural issues (i.e. bad experience with supportive services, stigma around the place where they should be receiving services, health conditions attributed to HIV); dislike of clinic or support services personnel (i.e. case manager, physician, psychiatrist); lack of childcare; and differing priorities. A discussion of the issue regarding differing priorities sheds some light on the importance of context and structurally enhanced differences in status.

The respondent is a 42-year-old African American woman living with HIV who is in care. She first received notification of

her current HIV-status when she was living in a homeless shelter with her 2 children. Throughout her life she has experienced numerous bouts of homelessness due to domestic abuse from her partner. At the time of this interview she was no longer homeless and working a minimum wage job in her community in rural Northwestern Virginia. She is currently receiving HIV healthcare from 2 of the agencies that participated in this study. In the passage below she reflects on the difficulties inherent in the struggles of her everyday life that make it difficult to remain in care.

“One of the things that providers need to truly understand is that their priority is not my priority. My priority is how I’m going to keep my lights on, how am I going to get food in the house for my children, that I might be being abused whether I’m a male or female or transgendered in a relationship. So how will I get past those things first, you talking about me staying in care? Care is back here on 33rd Street because it’s the last thing I’m thinking about right now. And if you’re working with me, understand those things. Understand those things so that when I come to you don’t judge me. If you can help me, help me. And if you cannot then point me in the direction of somebody who can?”.

Pre-existing mental health issues was another item frequently mentioned by participants currently in care. An example of how this issue was brought out in interviews is from a 56-year-old African American man who is currently in care. He first found out his HIV status when he was involved in a major automobile accident in which he was hospitalized. Since his diagnosis he has been in and out of care. Most recently he has been experiencing bouts of depression that he attributes to a family history of mental health. His explanation involves the context around behaviors that often get labeled as noncompliance by medical establishment.

“I think with the mental health piece, because we have had a history of mental health throughout our families that we don’t talk about. It’s when we begin to see signs and symptoms in people that we so much dismiss them then to understand this person is going through some things. That it’s just not behavioral stuff, it may be genetic stuff that’s going on. This person really does need to talk to somebody to find out some more family history of what’s going on to be able to help them. There may be a reason why he’s not going to take medication the way you want him to. He’s not going to stay in care because he can only comprehend staying in care but so much?”.

Study participants out of care (N=4) report experiences with personal traumas as having a large impact on why they are not currently in care. The examples below illustrate the type of everyday traumas experienced by respondents in this study not in care and provide the context of the lived experiences of traumatic events. The respondent is a 45-year-old African American male who first learned of his diagnosis when he was incarcerated. After serving a 7-year sentence he returned to his rural community and began working at the community-based HIV organization. He is currently living with a roommate that he suspects has mental health issues. His description illustrates the resilience and normalization of trauma in the everyday lives of many of the respondents.

“My roommate committed suicide under the bridge. Some other people were there, and they called me, instead of calling the damn ambulance. They called me. I had to leave work and come over there to clean the blood and

stuff up. I went down there and tied him off and got the rescue squad down there to get him out. I am always called out to handle these kinds of things. It makes it hard for me to keep up my appointments.”

Breaches in Confidentiality

Participants not in care discussed breaches in confidentiality regarding their HIV status as a reason they were not currently in care. They explained that this is an exceptionally sensitive issue due to the rural context of service locations. One participant explained that such breaches in confidentiality undermine efforts to connect people living with HIV to multiple services and uphold the stigma around HIV through oral communication channels. A poignant example from the interviews reveals how such breaches can occur. The respondent is a 39-year-old African American woman who is currently in care. She utilizes all of the HIV-related services available but provides insight into how important confidentiality is in the rural context.

“There was a counselor at the community-based organization (CBO) that was a neighbor of mine. I was in shock when I walked into the CBO and she was sitting there. I discovered later that she had disclosed my HIV status to a mutual friend. I reported this to the director of the CBO and she was fired. Unfortunately, this was too late as she had already spread the word. This is one of the reasons I advocate for the CBO using exclusively people living with HIV to staff the facility”.

There was agreement between participants in care and out of care that the issues of other chronic health problems and stigma prohibited rural African American people living with HIV from linking to care. Respondents thoughts on how these issues contribute to the out of care status are discussed in the next sections of this paper. The issue of stigma has been identified in a number of previous studies.^{5,6,12,23,32,38}

Other Chronic Health Issues

Chronic health issues emerged as a contextual reason for a rural person living with HIV to be out of care by respondents in care and out of care in this study. Participants in care expressed this as health conditions attributed to HIV. For example, loss of vision due to HIV status and loss of memory. Respondents out of care described this as other chronic health conditions. They did not elaborate regarding what those conditions could be. A study participant in care describes how his multiple chronic health issues impact his HIV diagnoses and posits that this may be a factor in others not obtaining care for their HIV due to prioritization of other health conditions. He is a 54-year-old African American man who has known of his HIV-status for twenty years. He was first diagnosed when he was living in Arizona. He moved to Virginia to be close to his family of origin ten year ago. Since returning home he has experienced a number of health issues that complicate living with HIV.

“Not only do I have my HIV problem; I have degenerate joint disease and I’ve been treated for high blood pressure. I’ve been treated for depression. So, I’ve got all these things that are going on with me, and on top of that, I only have a seventh-grade education”.

Stigma

HIV stigma was an indirect factor that respondents in care and out of care described as an issue that prevents a rural African American person from linking to care. In this study, respondent’s descriptions of stigma emerged in different ways. Some participants recounted stigma around the actual HIV/AIDS clinic. Their accounts noted barriers related to the stigma of obtaining services from a building known to provide services to people living with HIV or disclosing HIV status to service providers, family and other members of the community. The example comes from a 37-year-old African American woman who is currently in care. She first found out of her HIV status when her partner—and father of her child—died of complications from HIV. Prior to her partner’s death she was living in an urban environment. After his death, she was not financially able to take care of their daughter by herself and moved back to her family home in rural Virginia. Since arriving there she has not been able to find a job. She attributes this to her HIV status and the stigma of HIV in her rural setting.

“Basically, there’s no life out here for us because everywhere we go, if you tell people that you have it, we’re shut down. People fire us. People don’t have nothing to do with us. People want to, you know, stay away from you like you’re gonna, if you cough on them, you’re gonna give it to them. You know it’s a harsh feeling the things that people say about people with HIV and AIDS”.

Recommendations for Improving Health and Mental Health Care Services

Participants were asked what their recommendations were for improving health and mental health care services for rural African American people living with HIV. Recommendations included; (a) more community education outreach that involves both people living with HIV and family members. One respondent in care suggested, *“We could bring people who don’t have it so that where they can learn the decisions on how we feel about it and then they could learn more about the disease. Maybe that will bring us out more.”* Other suggestions involved providing ‘real world’ solutions to their complex lives that would benefit them in other aspects of their lives; passing out health education materials that stresses self-preservation and making those materials available in locations that are convenient to parks and community centers frequented by the target population; avoiding making judgments or overarching stereotypes about individual’s sex lives and that mental and physical health professionals should take time to build trusting relationships with the target community. Participants added that mental and physical health professions should also be prepared to give rural people living with HIV referrals to community resources that help with alcohol abuse, drug abuse, battered women’s shelters and financial assistance.

DISCUSSION

An analysis of the list serve reveals that support services (i.e. substance abuse outpatient services, mental health services) are the lowest ranked services utilized by participants not in care. This finding is consistent with recent studies of rural southern areas in the United States (US) that report inadequacies in the delivery of HIV health care services to PLWH in rural southern areas as an

issue.^{14,26,38-40} Table 1 details the responses from study participants.

Table 1. List Serve—Mental and Physical Health Services Used

List Serve Item (from most used to least)	Percentage of Participants in Care (N=20)	Percentage of Participants Not in Care (N=4)
HIV/AIDS Center	20 (100%)	3 (75%)
Outpatient Ambulatory Health Services	14(70%)	3(75%)
Pharmaceutical Assistance	14(70%)	3(75%)
Substance Abuse Outpatient Services	13(65%)	1(25%)
Oral Health	12(60%)	1(25%)
Medical Nutrition Therapy	11(55%)	0
Health Insurance Premium Assistance	11(55%)	0
Home Health Care	10(50%)	0
Hospice Services	8(40%)	0
Mental Health Services	8(40%)	1(25%)
Early Intervention Services	6(30%)	0
Medical Case Management including Treatment Adherence Services	5(25%)	2(50%)

This continues to be a problem on a national level. This is a significant concern as research suggests that the era of prevention is dependent on the continuum of care model.⁴¹ In 2012 the CDC found that of the 1,178,350 PLWH in the US as of 2012 approximately: (1) 80% are diagnosed; (2) 62% are linked to care; (3) 41% are retained in care; (4) 36% are on antiretroviral therapy and (5) 28% have a suppressed viral load of less than or equal to 200 copies/ML.^{41,42} Rural persons with HIV are more likely than their urban counterparts to be diagnosed and enter care at advanced stages of infection.⁴³ Later diagnosis is associated with both worse outcomes and increased HIV transmission. Later HIV diagnosis in rural areas suggests that rural persons are less likely to have an HIV test during the early, generally asymptomatic years of infection, and indicates a need for strategies to increase HIV testing in rural populations.⁴¹⁻⁴⁴

One barrier to linking to care that was elaborated on by participants in care and out of care involved what was perceived as stringent requirements of disability qualifications. Two programs utilized extensively by PLWH are SSDI and supplemental security income (SSI). SSDI is only available to people who have paid Social Security taxes while working and have become disabled. To qualify for SSDI, a person must have earned approximately twenty work credits in the ten years prior to the year of disability onset, but the number of work credits needed depends on the age when an individual becomes disabled; that is, younger workers can qualify with fewer credits. A work credit depends on the number of earnings and increases as nationwide wage levels increase. Only four work credits can be earned per year. For Social Security purposes, a person who cannot work as she previously did for at least one year is considered disabled. For those who do not have consistent work histories, such as many of those representing the new HIV epidemic, these requirements may be difficult to meet.

There are policies and procedures in place regarding qualification for disability. The largest barrier, according to study participants, concerns adequate work credits—earned twenty years prior to the occurrence of the disability. This was a constant theme as participants’ in care and out of care discussed how previous years incarcerated, homelessness or the status of wards of the state prohibited them from acquiring work histories. The lack of work histories were barriers to qualification in the current SSDI system. This finding is crucial since many participants had a host of other chronic medical conditions, mental health diagnosis, and critical health conditions (i.e. vision loss) brought on by the advancing stages of their HIV diagnosis.

For some participants both in care and out of care, the largest gap in services happened after diagnosis and the first occurrence of a major health issue that resulted in a hospital stay. One informant currently in care revealed that he did not take the virus as seriously as he should have when he was younger. Another informant currently not in care stated that he did not find out he was infected until a major trauma happened in his life. Still another participant in care described how he found out his HIV diagnosis after he was hospitalized after a major car accident. Another participant in currently in care did not find out her HIV diagnosis until she had been homeless for a number of years and got reconnected to health services when relocated to housing in a rural area. Lastly, a participant in care only found out her HIV diagnosis after her partner died of AIDS related complications. She was living in an urban area but moved back with her family in her rural home once her partner died.

These examples point to the need to expand HIV prevention programs in rural areas. This could be accomplished by promoting the early identification of HIV through voluntary, routine testing as a matter of routine clinical practice. The CDC has recommended that every American aged 13-64, regardless of the presence of known risk factors be offered HIV testing.⁴⁴ Studies in the US show that rural persons living with HIV are more likely than their urban counterparts to be diagnosed at a late stage of infection, suggesting missed opportunities for HIV testing in rural areas.^{42,43,45,46}

The intersection between the stigmatization of race, poverty and HIV diagnosis can result in marginalization, stress and trauma.^{41,43} Study participants both in and out of care report having experienced personal traumas, which can result from the cumulative stress of historical or cultural discrimination, homelessness, living in poverty and financial distress, divorce or separation, caregiver stress, incarceration, sudden unemployment, stigma or oppression. Cumulative traumas, which are the effect of trauma accumulated across the life course, can cause high levels of subjective stress.^{15,26,32}

CONCLUSION

To address the growing inequities in HIV/AIDS prevention and treatment among rural populations, the CDC recommends the following steps to reduce HIV infections: (1) intensifying HIV pre-

vention efforts in communities with high prevalence, (2) increasing education efforts for all Americans, and (3) increasing the numbers of PLWH in care and treatment.⁴² Further, the Division of HIV/AIDS Prevention (DHAP) identifies the development of strategies to increase HIV-testing and improving linkages to care and timely treatment as an area of high priority.⁴⁴

Re-education of HIV was a prominent theme in this study population. This may indicate a knowledge gap. Acquiring knowledge is a critical first step for stopping the spread of HIV in the rural context. Culturally relevant HIV prevention education programs are needed to help rural African American PLWH protect themselves and their partners. While proper safeguards must be in place to ensure that HIV testing is always voluntary, efforts to expand HIV testing in rural areas will help greater numbers of people learn their HIV status, allow those who test positive to seek early treatment and reduce their risk of transmitting HIV.

An important implication of this pilot study is that it contributes to a broader understanding of the contextual component of barriers that prohibit rural African American people living with HIV/AIDS (PLH) from seeking and accessing physical and mental health care. Program and policy implications are to develop greater access to specialty health and mental health services in rural areas. It also indicates that the prevalence of stigma and re-education on AIDS signals a greater need for culturally specific health education campaigns targeted in rural areas.

The incidence and prevalence rates of HIV in the rural South of the United States represents a critical shift in the HIV North American HIV infection trends.^{2,4} Profound HIV-related health disparities persist due to stigma, gaps in health services ad trauma, particularly in southern rural communities of color.^{7,12,14} Moreover, racial minorities represent the disproportionate nature of HIV infections in the southern United States, particularly in rural areas where high rates of poverty, racism, drug use, and poor access to care may be more profound than in urban locales.^{4,5,40} Future research should focus on understanding the challenges in rural settings and implementing novel interventions that could rapidly make a difference. Evidence-based and novel best practices should be funded urgently and disseminated to rural southern communities. Lastly, an indication of this qualitative study and the broader literature asserts that funding agencies increase support for research that seeks to understand unique barriers that exist across the HIV care continuum in rural settings, and the interventions required to overcome these barriers.

LIMITATIONS

One of the chief limitations of this pilot study was the difficulty in locating rural African American people living with HIV who are out of care. Another is the small sample size, which is typical of qualitative research.⁴⁶ Because all of the participants in this study were residents of Northwestern Virginia, the findings may not be generalizable to rural settings in other areas. Another potential limitation of the study is some of the selected locations for interviews. Though participants were able to select a location for per-

sonal convenience, several participants chose public places, such as the local McDonald's. Such selections may have limited participants' candidness in discussing sensitive topics due to the potential loss of confidentiality. In addition, public spaces may have added distractions that could not be avoided. Finally, the data for this study were collected in 2013 to 2014. The system or the perception of the PLWHs could have changed in the interm period.

FUNDING

This study was funded by the National Institute of Mental Health Supported by [R25-MH087217]. The author would like to extend appreciation to the participants for their time and for sharing their experiences with the mental and physical health systems.

COMPLIANCE WITH ETHICAL STANDARDS

All research protocols were approved by local institutional review boards prior to the initiation of the study.

ACKNOWLEDGEMENTS

- Supported by NIH-NIMH 5R25-MH087217-03
- Research Education Institute for Diverse Scholars (REIDS)
- Center for Interdisciplinary Research on AIDS (CIRA).

REFERENCES

1. Centers for Disease Control and Prevention (CDC). Estimated HIV incidence and prevalence in the United States. 2010-2015. HIV surveillance report. Web site. <https://www.cdc.gov/hiv/basics/statistics.html>. 2018. Accessed April 7, 2019.
2. Centers for Disease Control and Prevention (CDC). Diagnosis of HIV infection in the United States and dependent areas, 2017. Web site. <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>. 2018. Accessed April 7, 2019.
3. Centers for Disease Control and Prevention (CDC). HIV among African Americans. Web site. <https://www.cdc.gov/hiv/group/racialethnic/africanamericans/>. Accessed April 7, 2019.
4. Centers for Disease Control and Prevention (CDC). HIV and AIDS in the United States by geographic distribution. Web site. <http://www.cdc.gov/hiv/resources/factsheets/geographic.htm>. 2018. Accessed April 7, 2019.
5. Reif S, Whetten K, Wilson E, et al. HIV/AIDS in the Southern USA: A disproportionate epidemic. *AIDS Care*. 2014; 26: 351-359. doi: 10.1080/09540121.2013.824535
6. Hall H, Li J, McKenna M. HIV in predominantly rural areas of the United States. *J Rural Health*. 2005; 21: 245-253. doi: 10.1111/j.1748-0361.2005.tb00090.x

7. Agee B, Funkerhouser E, Roseman J, et al. Migration patterns following HIV diagnosis among adults residing in the nonurban Deep South. *AIDS Care*. 2006; 18 (Suppl 1): S51-S58. doi: 10.1080/09540120600839355
8. Centers for Disease Control and Prevention (CDC). CDC—HIV/AIDS—Surveillance Reports. Web site. <http://www.cdc.gov/hiv/library/reports/surveillance/index.html>. 2017. Accessed April 7, 2019.
9. Virginia HIV Epidemiology Profile. Web site. http://www.vdh.virginia.gov/content/uploads/sites/10/2017/02/HIV_Epi_Profile_2016.pdf. 2016. Accessed April 7, 2019.
10. State Rural Health Plan. “Defining Rural.” Web site. <http://www.va-srhp.org/docs/plan/11-appendix-d.pdf>. 2008. Accessed July 14, 2012.
11. Prejean J, Song R, Hernandez A, et al. Estimated HIV incidence in the United States, 2006-2009. *PLoS One*. 2011; 6(8): e17582. doi: 10.1371/journal.pone.0017502
12. Whetten K, Reif S. Overview: HIV/AIDS in the deep South region of the United States. *AIDS Care*. 2006; 18(Suppl 1): S1-S5. doi: 10.1080/09540120600838480
13. Mainous A, Kohrs F. A comparison of health status between rural and urban adults. *J Community Health*. 1995; 20: 423-431. doi: 10.1007/BF02260438
14. Akers A, Youmans S, Lloyd S, et al. Views of young, rural African Americans of the role of community social institutions in HIV prevention. *J Health Care Poor Underserved*. 2010; 21(Supp): 1-12. doi: 10.1353/hpu.0.0280
15. Cené C, Akers A, Lloyd S, et al. Understanding social capital & HIV risk in rural African American communities. *J Gen Intern Med*. 2011; 26(7): 737-749. doi: 10.1007/s11606-011-1646-4
16. Sutton M, Anthony M, Vila C, et al. HIV testing and HIV/AIDS treatment services in rural counties in 10 southern states: service provider perspectives. *J Rural Health*. 2010; 26: 240-247. doi: 10.1111/j.1748-0361.2010.00284.x
17. Ohl M, Lund B, Belperio P, et al. Rural residence and adoption of a novel HIV therapy in a national, equal-access healthcare system. *AIDS Behav*. 2013; 17: 250-259. doi: 10.1007/s10461-011-0107-8
18. Weis K, Liese A, Hussey J, et al. Associations of rural residence with timing of HIV diagnosis and stage of disease at diagnosis, South Carolina 2001-2005. *J Rural Health*. 2010; 26: 105-112. doi: 10.1111/j.1748-0361.2010.00271.x
19. Cohn S, Berk M, Berry S, et al. The care of HIV-infected adults in rural areas of the United States. *J Acquir Immune Defic Syndr*. 2001; 28: 385-392. doi: 10.1097/00126334-200112010-00013
20. Grossman C, Gordon C. Mental health considerations in secondary HIV prevention. *AIDS Behav*. 2010; 14(2): 263-271. doi: 10.1007/s10461-008-9496-8
21. Zaller N, Gilliani F, Rich J, et al. A model of interpreted primary care for HIV positive patients with underlying substance abuse and mental illness. *AIDS Care*. 2007; 19: 1128-1133. doi: 10.1080/09540120701335196
22. Mugarevo M, Ostermann J, Whetten K, et al. Barriers to antiretroviral adherence: The importance of depression, abuse and other traumatic events. *AIDS Patient Care STDS*. 2006; 20: 418-428. doi: 10.1089/apc.2006.20.418
23. Adimora A, Schoenbach V, Doherty I, et al. HIV and African Americans in the southern United States: Sexual networks and social context. *Sex Transm Dis*. 2006; 33: S39-S45. doi: 10.1097/01.olq.0000228298.07826.68
24. McKinney M. Variations in rural AIDS epidemiology and service delivery models in the United States. *J Rural Health*. 2002; 18: 455-466. doi: 10.1111/j.1748-0361.2002.tb00910.x
25. Heckman T, Somlai A, Peters J, et al. Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*. 1998; 10(3): 365-375. doi: 10.1080/713612410
26. Coker-Appiah D, Akers A, Banks B, et al. In their own voices: rural African American youth speak out about community-based HIV prevention interventions. *Prog Community Health Partnersh*. 2009; 3(4): 301-312. doi: 10.1353/cpr.0.0093
27. Foster P, Frazier E. Rural health issues in HIV/AIDS: Views from two different windows. *J Health Care Poor Underserved*. 2008; 19: 10-15. doi: 10.1353/hpu.2008.0004
28. Wolitski R, Jones K, Wasserman J, et al. Self-identification as “down low” among men who have sex with men (MSM) from 12 U.S. cities. *AIDS Behav*. 2006; 10: 519-529. doi: 10.1007/s10461-006-9095-5
29. Cohen M, Deamant C, Barkan S, et al. Domestic violence & childhood sexual abuse in HIV infected women & women at risk for HIV. *Am J Public Health*. 2000; 90: 560-565. doi: 10.2105/AJPH.90.4.560
30. Vyavaharkar M, Moneyham L, Murdaugh C, et al. Factors associated with quality of life among rural women with HIV disease. *AIDS Behav*. 2012; 16(2): 295-303. doi: 10.1007/s10461-011-9917-y
31. Hodder S, Justman J, Haley D, et al. Challenges of a hidden epidemic: HIV prevention among women in the United States. *J Acquir Immune Defic Syndr*. 2010; 55(S2): S69-S73. doi: 10.1097/

[QAL0b013e3181fbbdf9](https://doi.org/10.17140/HARTOJ-6-129)

32. Foster, P. Use of stigma, fear, and denial in development of a framework for prevention of HIV/AIDS in rural African American communities. *Fam Community Health*. 2007; 30: 318-327. doi: [10.1097/01.FCH.0000290544.48576.01](https://doi.org/10.1097/01.FCH.0000290544.48576.01)
33. Miles M, Huberman A. *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, CA, USA: Sage Publications; 1994.
34. Glaser B, Holton J. Remodeling grounded theory. *Forum Qualitative Sozialforschung*. 2004; 5(2): 1-24.
35. Glaser BG. *Doing Grounded Theory: Issues & Discussions*. Mill Valley, CA, USA: Sociology Press; 1998.
36. Charmaz K. *Constructing Grounded Theory*. Thousand Oaks, CA, USA: Sage Publications; 2014.
37. Charmaz K. *Grounded Theory: Objectivist and Constructivist Methods*. In: Denzin NK, Lincoln YS, eds. Thousand Oaks, CA, USA: Sage Publications; 2014: 249-291.
38. Schur C, Berk M, Dunbar J, et al. Where to seek care: An examination of people in rural areas with HIV/AIDS. *J Rural Health*. 2002; 18: 337-347. doi: [10.1111/j.1748-0361.2002.tb00895.x](https://doi.org/10.1111/j.1748-0361.2002.tb00895.x)
39. Krawczyk CS, Funkerhouse E, Kilby JM, Vermund SH. Delayed access to HIV diagnosis and care: Special concerns for the Southern United States. *AIDS Care*. 2006; 18(Suppl 1): S35-S44. doi: [10.1080/09540120600839280](https://doi.org/10.1080/09540120600839280)
40. Reif S, Lowe Geonnotti K, Whetten K. HIV infection and AIDS in the Deep South. *Am J Public Health*. 2006; 96(6) :970-973. doi: [10.2105/AJPH.2005.063149](https://doi.org/10.2105/AJPH.2005.063149)
41. Holtgrave D, Maulsby C, Wehrmeyer L, Hall HI. Behavioral factors in assessing impact of HIV treatment as prevention. *AIDS Behav*. 2012; 16: 1085-1091. doi: [10.1007/s10461-012-0186-1](https://doi.org/10.1007/s10461-012-0186-1)
42. Centera for Disease Control and Prevention. Vital signs: HIV prevention through care and treatment-United States. *MMWR* 2011; 60: 1618-1623.
43. Ohl ME, Perencevich E. Frequency of human immunodeficiency virus (HIV) testing in urban vs. rural areas of the US: results from a nationally representative sample. *BMC Public Health*. 2011; 11: 681. doi: [10.1186/1471-2458-11-681](https://doi.org/10.1186/1471-2458-11-681)
44. Rural Center for HIV/STD Prevention (RCAP). HIV/AIDS in rural America: Challenges & promising strategies. Web site. http://www.indiana.edu/~aids/factsheets/factsheets_23.pdf. Accessed July 14, 2012. 2009.
45. Berry DE, McKinney MM, McClain M. Rural HIV-service networks: Patterns of care and policy issues. *AIDS Public Policy J*. 1996; 11: 36-46.
46. Trotter RT. Qualitative research sample design and sample size: Resolving and unresolved issues and inferential imperatives. *Prev Med*. 2012; 55(5): 398-400. doi: [10.1016/j.yjmed.2012.07.003](https://doi.org/10.1016/j.yjmed.2012.07.003)