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Transportation-related barriers to care among African American women living with HIV/AIDS: “What you getting out of the cab for?”

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Abstract

Transportation-related problems have been consistently reported as barriers to accessing and remaining in HIV medical care, particularly among African American women living in under-resourced areas. With emphasis on the Southern region of the United States, this commentary presents a brief overview of the HIV/AIDS epidemic among African Americans, barriers to remaining in HIV care, and pilot data from a study conducted among African American women living in Mississippi. A small focus group study was conducted to examine the relative influence of transportation-related barriers on attendance and motivation to attend HIV medical care appointments. Eight African American women (mean age of 43.50, $SD = 10.82$) who were engaged in medical care participated in one focus group session. Time since diagnosis ranged from 6 to 17 years. Participants reported transportation-related barriers that were generally consistent with previous research, including lack of personal transportation, limited financial resources to pay family and friends for transportation or gasoline, and inconveniences associated with sharing van services with other patients. Participants appeared to have learned how to successfully navigate these barriers in order to remain in care. Interestingly, participants reported significant fear of disclosure related to use of transportation services provided by insurance providers and community organizations. Specifically, many of the women indicated that family, friends, and neighbors questioned them about where they were going and why they used taxis. These types of encounters might influence whether individuals utilize available transportation services. Participants provided several recommendations for improving the transportation system. Additional research is warranted to obtain a more representative sampling of opinions among African American women living in under-resourced areas.

Introduction

African Americans living in the United States are disproportionately affected by the human immunodeficiency virus (HIV) and, the life-threatening stage of infection, acquired immune deficiency syndrome (AIDS) (Centers for Disease Control and Prevention [CDC], 2012a). Comprising only 12% to 14% of the U.S. population, African Americans are significantly

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more likely to contract HIV, receive a diagnosis of AIDS, and experience HIV/AIDS-related death (CDC, 2012a; Levine et al., 2007). Moreover, African American women accounted for 29% of new HIV diagnoses in 2010 (CDC, 2012a). African Americans are less likely to be in care, less likely to achieve viral suppression, and more likely to be nonadherent to their medication regimen, which increases the likelihood of developing drug resistance, poorer immune functioning, higher levels of the virus in the blood, and risk of HIV transmission to others (Klimas, Koneru, & Fletcher, 2008; Singh et al., 1996; Heckman et al., 1998; Singh et al., 1999). Although there have been significant medical advances since the approval of powerful anti-HIV medications in 1996, such as overall reduction in HIV/AIDS-related deaths, mortality rates among African Americans have worsened. More specifically, mortality incident rate-ratios between African Americans and Whites have increased since treatment became available, and African American women of all ages were at least 13-times more likely to die from HIV compared to same-aged White women (Levine et al., 2007). In other words, more African Americans have died after the introduction of life-saving treatments available than before anti-HIV medications existed.

Additionally, there are notable regional distinctions in the U.S. epidemic. In 2010, African Americans living in the South accounted for 45% of new AIDS diagnoses in the U.S. (South: AL, AR, DE, DC, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, WV; CDC, 2012b). The health, social, and economic disparities that have historically affected African Americans living in the South contributes to barriers related to accessing healthcare in general, and HIV medical care, in particular (Pence et al., 2007). Lack of relevant services (e.g., medical care; mental, substance, and spiritual counseling; housing, financial resources and transportation) has been documented as a significant barrier to accessing and maintaining proper HIV medical care in the South (Reif, Whetten, Lowe, & Osterman, 2006). Furthermore, any one or combination of these barriers may directly and/or indirectly impact the management of HIV disease.

Vulnerable populations, such as ethnic minority women living in under-resourced areas, face significant challenges that influence engagement and utilization of HIV medical care services. Transportation is often identified as a barrier to care. Many patients in both rural and urban areas do not have personal transportation and rely on public transportation, community organizations, or insurance providers. A sample of women living with HIV in Alabama reported the following transportation barriers to accessing HIV medical care: distance from care, lack of personal transportation, limited financial resources for bus or taxi fare, gasoline for personal vehicles, or payments to family and friends for a ride, not wanting to disturb or inconvenience others by asking for transportation, and long travel times when transportation is provided for multiple persons using van services (Moneyham et al., 2010). Konkle-Parker, Amico, and Henderson (2011) assessed barriers to care among 130 HIV-infected persons (62% males and 81% African American) at an infectious disease clinic in Mississippi. They found that 20% of the sample reported an inability to get transportation as a barrier to remaining in HIV medical care, and 13% reported it as the main reason for dropping out of care.

Method

To gain more insight into African American women's experiences with transportation-related barriers to care, we conducted a small pilot study with African American women receiving HIV medical care in Jackson, Mississippi. Supported by a grant from the Institute of Multimodal Transportation, we conducted a focus group study in order to learn more about the relative effect of transportation-related barriers on motivation and utilization of available HIV medical services. The group consisted of 8 African American women diagnosed with HIV. The mean age was 43.50 ($SD = 10.82$). All of the participants earned at least a high school diploma or GED, and six reported having some college/graduated college. Most were unemployed, dating or married, and earned less than \$10,000. Time since diagnosis of HIV infection ranged from 6 to 17 years; seven were prescribed anti-HIV medications. Participants completed a socio-demographic questionnaire and a focus group questionnaire, developed based on review of the literature and consultation with Drs. Bryman Williams (Jackson State University) and Debbie Konkle-Parker (University of Mississippi Medical Center), who have expertise in the area of HIV research and conducting qualitative research. Participants received \$25 reimbursement for their time and transportation. The study was approved by the Jackson State University Institutional Review Board.

Results and Discussion

Half of the participants had their own transportation, and the remainder relied primarily on public or insurance-provided transportation. Three women had a history of missed appointments due to lack of money to pay someone for a ride (payments ranged from \$5 to \$25). Two women reported that transportation problems caused them to miss HIV medical appointments *occasionally* in the past 12 months. Half of the sample believed that their motivation to seek HIV medical care was impacted by transportation-related problems *some of the time to often*.

Public Transportation

Among those without personal transportation, participants often used bus or taxi services. Advantages of using public transportation included: cost effectiveness, saving gasoline, bus transportation has more anonymity in terms of where they are going and why, bus has predictable schedule. Disadvantages of using public transportation included: thoughts and feelings of paranoia, taxi drivers may not know where to go, taxi may take too long or not come at all.

Shared Transportation

Community organizations and insurance providers often use vans or small buses to pick up a group of patients at their homes and take them to and from their appointments (i.e., shared transportation). Participants reported several frustrations associated with shared transportation services. Many reported that they don't always use free transportation services due to inconsistency and inconvenience of arrival and departure times (e.g., arrive too early), numerous steps required to contact the driver (e.g., must call a 1-800 number,

call gets transferred, and a dispatcher contacts the driver), and long wait for other van riders to finish their appointments. Participants indicated that it might be more conducive for them to ride the bus because of the predictable schedule, especially when they are not feeling well. Some participants indicated that they would do all they could to take care of themselves (e.g., take over-the-counter pain medicine) in order to prevent calling the ambulance, whereas other participants reported calling the ambulance when they felt ill and they had no other transportation options.

Public or Shared Transportation and Fear of Disclosure

Some expressed fear of disclosure of HIV status if another passenger liked to talk to the bus/taxi driver about where they are going and why, and if they are identified using a particular type of taxi, van, or government vehicle. Participants also noted that other people might ask questions about the taxi, “Where are you going in the cab?” “What you getting out of the cab for?” Some participants stated that they would ignore those questions, whereas others stated that they would tell inquirers to mind their own business. One participant explained that some individuals would “stay at home and die rather than to be identified by a cab or the van or even coming to pick up their medication. They just don’t want to be identified.”

Family, Friends, Neighbors

Participants reported that they would also ask family, friends, or neighbors for a ride to their appointments. This usually required reimbursement to the driver for gas, which has become increasingly difficult with rising gas prices. Participants also reported that payments for a ride were especially difficult because of fixed incomes and the number of appointments they have for various healthcare needs and other obligations. Participants were less likely to ask someone for a ride again if that person asked a lot of questions about where the participant needed to go and why. Furthermore, participants reported difficulty asking someone to take them to their appointment because of the necessity of accounting for both driving and waiting time.

Recommendations

Our study participants made several recommendations when asked, “If you were governor for the day what changes would you make to the transportation system in Mississippi?” Participants reported that they would ensure anonymity of transportation vehicles (i.e., no slogans or company names). They also suggested that insurance providers and community organizations provide individualized transportation since payment is provided on a per-person basis, ensure patients are picked up on time and can depart when they are finished, and give patients the option of waiting on others to finish their appointments, as some women didn’t mind waiting if they were not feeling ill. Participants also recommended that the bus system run 24 hours a day, seven days a week, so they can get to the hospital if they become sick in the middle of the night.

Motivation

Participants expressed motivation to do what is necessary to attend appointments because of their desire to live, stay healthy, and prevent high medical expenses associated with

emergency care, particularly for those without insurance. Participants expressed motivation to take anti-HIV medications. One respondent stated, "...I have seen so many friends and people that I work with just die. So, I know the results of not taking this medication. So, it's not even an option to me. You know it's not *if* [emphasis added] I'm going to take it. I'm going to take it."

In conclusion, this small pilot study is limited by sample size, but provides insight into the lived experience of some African American women living with HIV. Transportation barriers are an important consideration among vulnerable populations in under-resourced areas. Research has shown that directly addressing transportation by providing bus tickets and reimbursement for taxi or personal vehicle mileage can influence service utilization and motivation to remain in care (Whetten et al., 2006). The women in this study appeared to have been relatively successful in managing transportation-related barriers. The transportation-related barriers reported were similar to those reported by women in previous studies, including lack of personal transportation, limited financial resources to pay family and friends for rides or gasoline, and inconveniences associated with sharing van services with other patients. Unlike previous studies, participants endorsed significant fear of disclosure associated with shared transportation services, and were especially concerned about the use of marked vehicles (e.g., company logos). Additional research is warranted to obtain a more representative sampling of opinions. Nonetheless, as the U.S. deals with ever-increasing fiscal uncertainty and budget cuts to existing healthcare programs, African American women living with HIV in under-resourced areas might experience greater challenges related to transportation. Service providers and policy makers must attend to and advocate for the basic needs of our most vulnerable patients in a manner that is sensitive to the myriad of issues, such as those addressed in this commentary, that influence their ability to stay in care.

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