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A Qualitative Study of Barriers to the Utilization of HIV Testing Services Among Rural African American Cocaine Users

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Abstract

This qualitative study is about barriers to the utilization of HIV testing as perceived by African Americans who have recently used cocaine and who live in the rural Delta region of Arkansas. Affordability, physical accessibility, and geographic availability were not perceived as barriers to HIV testing in this sample, yet acceptability was still perceived as poor. Acceptability due to social mores and norms was a major barrier. Many said testing was unacceptable because of fear of social costs. Many were confident of being HIV-negative based on risky assumptions about testing and the notification process. Small-town social and sexual networks added to concerns about reputation and risk. System approaches may fail if they focus solely on improving access to HIV services but do not take into consideration deeply internalized experiences of rural African Americans as well as involvement of the community in developing programs and services.

Keywords

HIV testing, African American, rural, barriers, cocaine

The impact of drug use on the spread of HIV in the United States is not limited to the estimated 9.4% of adults in the United States diagnosed with a substance-use disorder (Brown et al., 2006). Drug use directly and indirectly accounts for about 30% of AIDS cases each year (Centers for Disease Control and Prevention [CDC], 2002) and 40% of AIDS deaths in the United States (National Institute on Drug Abuse [NIDA], 2012). Anyone under the influence of drugs or alcohol is at increased risk of contracting or transmitting HIV/AIDS through the risk behaviors it engenders (NIDA, 2006). Substance use affects judgment and is associated with unsafe sex behaviors such as inconsistent condom use and trading sex for drugs or money, as well as unsafe drug injection practices such as sharing used needles and equipment (NIDA, 2006).

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Rural African American cocaine users are a medically underserved and difficult-to-reach population with limited access to HIV testing and prevention services. This study is about barriers to the utilization of HIV testing and other HIV services as perceived by African Americans who have recently used cocaine and who live in the rural Delta lands of Arkansas. Although there are many definitions of rural, the definition used in this study is the Office of Management and Budget (OMB) definition, which refers to all counties outside metropolitan areas with at least 10,000 but no more than 50,000 people as rural nonmetropolitan counties (U.S. Department of Agriculture, Economic Research Service [USDA, ERS], 2007). This study is designed to provide critically needed information about personal, social, and organizational/system factors that influence HIV testing utilization among rural African American substance users.

Background

HIV/AIDS has had a greater impact on African Americans in the South than any other area of the country. The South, as compared with other regions of the country, has led the nation in overall number of persons living with AIDS since 1993, and reported incidence cases or new cases per year since 2001 (Qian, Taylor, Fawal, & Vermund, 2006). According to the CDC (2011a), African Americans account for 50.1% of HIV diagnoses among adolescent and adult men in the South as compared with 42.1% among men in the Northeast. African Americans account for 70.9% of HIV diagnoses among women in the South as compared with 60.0% in the Northeast (CDC, 2011a). In the South, HIV/AIDS disproportionately affects more heterosexuals and those who live in rural areas (CDC, 2008; Southern AIDS Coalition, 2008). Heterosexual transmission accounted for more than 85% of HIV among African American women in the South, and injection drug use for only 14% (CDC, 2011a).

Drug use has been recognized as one of the driving forces in spread of the epidemic as well as a major barrier to service utilization (Brown et al., 2006; U.S. Government Accountability Office, 2009). Substance use, especially noninjecting cocaine use, is prevalent among African Americans in the rural South, putting rural African American substance users at even greater risk (Booth, Leukefeld, Falck, Wang, & Carlson, 2006; Chu & Selwyn, 2008; Farley, 2006; Fleming, Lansky, Lee, & Nakashima, 2006; Wright et al., 2007). HIV risk behaviors associated with cocaine use include having unprotected sex, using condoms inconsistently, having multiple concurrent sexual partners, having sex when using drugs, and trading sex for drugs or for survival needs (Adimora, Schoenbach, & Doherty, 2006; Fleming et al., 2006; Reif, Geonnotti, & Whetten, 2006; Stratford, Ellerbrock, & Chamblee, 2007; Wright et al., 2007).

Draus and Carlson (2009) describe the combination of small social circles, limited scope of acquaintances and economic opportunities, inadequate drug treatment, and abundant drug supplies as a "vortex" effect that can magnify drug use in rural areas. For example, if there is a great deal of overlap of drug-using networks with other networks such as work, family, and neighborhood, then a person's access to non-drug users would be much more limited, making it much more difficult to escape the "vortex." The same factors can create a sexual-risk vortex in small towns that magnifies the spread of HIV. Chronic drug use is often driven by associations with other users (Draus & Carlson, 2009). Rural drug users are often marginalized within their small-town environments similar to urban crack users. This makes it even more difficult to avoid drugs and access alternative social networks. The closeness of social relationships and unavoidable proximity in rural areas can severely restrict individual behavior. Essentially, rural drug users, particularly African American rural drug users, belong to what Sabar (2002) describes as a "paradoxical social network," one that gives the individual a strong sense of identity and yet actively confines the individual.

Another driving force in the HIV epidemic is lack of HIV testing. The CDC estimates that approximately 21% of persons living with HIV/AIDS in the United States are unaware of their

status (CDC, 2009). This presents a major public health threat for two reasons: (a) The majority of new HIV infections is transmitted by persons who are unaware they are infected and (b) effective treatment is available and reduces infectivity, but persons who are unaware of being infected do not receive the benefits of treatment (CDC, 2006). HIV testing is a key strategy for reducing HIV rates as testing is the entry point for both prevention and treatment (Arya et al., 2010; Branson, 2010). HIV infection meets the criteria that justify routine screening: (a) It is a serious health problem that can be diagnosed before symptoms develop; (b) reliable, inexpensive, non-invasive screening tests can detect it; (c) time and quality of life can be extended by early detection and initiation of treatment; and (d) anticipated benefits outweigh screening costs (Torres, Reiter, & Wright, 2007). HIV counseling and testing is a well-documented effective prevention intervention (Holtgrave & McGuire, 2007; Marks, Crepaz, & Janssen, 2006; Rotheram-Borus, Swendeman, & Chovnick, 2009).

Indeed, the geographical disparity noted in HIV/AIDS may be due in part to differences in access to and use of HIV testing (Qian et al., 2006). Timeliness of diagnosis and treatment are important factors in restricting HIV transmission, and an important determinant of prevalence and incidence in the population (CDC, 2010). Deficits in knowledge and/or lack of resources contribute to late diagnoses and entry into care for rural African Americans in the South (Chu & Selwyn, 2008). Late diagnosis and delayed entry into care result in higher morbidity and mortality, and allow those unaware of their infection to continue infecting others for many years, adding to the prevalence and incidence among rural African Americans (Fenton, 2007). Unfortunately, current counseling and testing strategies in the United States may not be culturally or contextually appropriate for rural African American substance users (Purcell & McCree, 2009). We know little about their perceptions or preferences concerning HIV testing or messages promoting testing.

Setting

Two contiguous rural counties in eastern Arkansas are the focus of our study. Both counties are part of the Delta region of the Mississippi River, where the highly fertile flood plain makes it the primary agricultural part of Arkansas.

The total population of Arkansas is 2.6 million, of which 15.8% are African American as compared with 13% of the overall U.S. population (Maulden, Goodell, & Phillips, 2012). According to the OMB definition of rural, 48% of the population of Arkansas live in rural areas (University of Wisconsin Population Health Institute [UWPHI], 2011). Farming/agriculture is a major component of the Arkansas economy, accounting for one out of six jobs and 15% of state labor income (University of Arkansas Cooperative Extension Service [UAEX], 2011). Arkansas is the largest producer of rice in the nation, the second largest producer of poultry, and the third largest producer of cotton and cottonseed (UAEX, 2011). The individual poverty rate for Arkansas is 18.5%; in rural Arkansas, the poverty rate is 21.2% as compared with 16.7% in urban areas (USDA, ERS, 2011). There are larger discrepancies in the poverty levels between White and African American Arkansans. The poverty rate for African Americans in Arkansas is 44% compared with 35% among African Americans in the United States, and 16% among Whites in Arkansas and 13% among Whites in the United States (USDA, ERS, 2011). Per capita income in Arkansas in 2009 is US\$32,315; in rural Arkansas it is US\$28,584, and in urban areas it is US\$34,764 (USDA, ERS, 2011). The unemployment rate is 9.0% in rural Arkansas compared with 7.2% in urban Arkansas (USDA, ERS, 2011). A total of 23% of Arkansans have no health insurance compared with 15% in the United States (UWPHI, 2011).

According to estimates from the 2006 Behavioral Risk Factor Surveillance System (BRFSS), only 31.3% of adults ages 18 to 64 years in Arkansas reported ever being tested for

HIV (Arkansas Department of Health [ADH], 2006). A late diagnosis of HIV is defined as a person who develops AIDS within 12 months of first being diagnosed with HIV (CDC, 2003). In Arkansas, 70% of persons newly diagnosed with HIV were tested late, developing AIDS within 12 months (ADH, 2010). The age-adjusted death rate for HIV in Arkansas is considerably higher among African Americans (13.6 per 100,000) than among Whites (1.4 per 100,000; Maulden et al., 2012). Free HIV testing is available on request at all ADH public health units as required by state law (Arkansas Code Annotated, 2012). Arkansas law does not require substance-abuse treatment programs to offer HIV testing to clients. In 2009, HIV testing was provided by 17 (31%) of the 53 substance-abuse treatment facilities in Arkansas (National Survey of Substance Abuse Treatment Services [Office of Applied Studies], 2009). Routine opt-out testing, recommended by CDC guidelines to detect infection in individuals who are not aware of being infected, is not practiced at public health units or community substance-abuse treatment facilities in Arkansas.

Parent Project

This study was funded by a competitive supplement to a sexual-risk-reduction intervention trial we are conducting among rural African American cocaine users residing in two underresourced, predominantly African American counties in the Mississippi Delta region of Arkansas. The purpose of the parent project is to test the efficacy of a culturally appropriate, theory-based sexual-risk intervention for rural African American cocaine users. HIV testing was not offered as part of the intervention. The study included intervention participants from the local communities as well as community members who served leadership and other roles in the study. A total of 251 participants were recruited from the community to participate in the intervention using respondent-driven sampling (RDS; Heckathorn, 1997). At baseline, 74% of intervention participants had a history of incarceration, 40% had ever engaged in transactional sex, 33% had engaged in unprotected sex the past 30 days, and 30% had more than one sex partner the past 30 days. The parent study also included 10 community advisory board (CAB) members and 16 peer leaders. The CAB was composed of active drug users who provided community-based guidance throughout the project. Peer leaders assisted with delivery of the intervention and served as role models for intervention participants.

Method

Analytic Approach

Given the dearth of information regarding testing/help-seeking for HIV among rural African American cocaine users, we used qualitative methods to increase our understanding of the related personal, social, and organizational/system factors. This approach allowed us to develop a rich multidimensional view of help-seeking specifically from the users' perspectives and to perform an in-depth, detailed analysis of the complexities surrounding this important decision. More specifically, our data collection and analysis techniques combined inductive and deductive approaches (Charmaz, 2005; Marshall & Rossman, 1995; Strauss & Corbin, 1990). Our interview guides were informed by the literature on help-seeking, and some of our questions and probes inquired about specific potential barriers (see appendix). However, we did begin each interview with very open-ended and nonspecific questions concerning their opinions about help-seeking and the nature of any experiences they had with HIV testing. Coding was predominantly inductive and driven by themes emerging from the participants' perspective.

Sampling Strategy

Current Study. Purposive sampling was used to recruit participants (African American current or former cocaine users) from intervention participants, CAB members, and peer leaders enrolled in the parent study. Each group offered a different perspective to deepen our understanding of service utilization among this understudied and underserved population. *Intervention participants* provided information from the perspective of a representative group of rural African Americans actively using cocaine. *CAB members* provided information from the perspective of a group of rural African American cocaine users who were opinion leaders within the drug community. *Peer leaders* provided information from the perspective of a group of rural African American cocaine users with some experience of recovery.

Inclusion/Exclusion Criteria. During the consent process for the parent study, intervention participants, CAB members, and peer leaders were asked to sign an authorization-to-release-health-information form if they were willing to be contacted by project staff for future studies. More than 95% of parent project participants and 100% of CAB members and peer leaders had given such permission to be contacted. Intervention participants, CAB members, and peer leaders who had signed the release form were eligible to participate in this study. Incarceration at the time of the interview or focus group was an exclusion criterion.

Procedures

All individual interviews and focus groups took place in local study offices and were conducted by the first author, another investigator, or a well-trained interviewer. Demographic data for intervention participants and CAB members were obtained from baseline assessment data collected by the parent study. Peer leaders did not complete baseline assessments for the parent study, and therefore, demographic information was not available for this study.

Individual Interviews. Only participants in the intervention subcategory participated in face-to-face semistructured individual interviews. As new participants were enrolled in the parent study intervention trial, the data manager added them to a participant list, and the list of eligible participants was re-randomized to ensure all potential participants had an equal chance to be contacted. Potential individual interview participants were then called and invited to participate until all cells in a 2 (gender) × 2 (county) × 2 (age) matrix were filled. The sample was divided by age using a cutoff of 30 years; this was determined based on observations that significant differences exist between African American cocaine users above and below 30 years of age (Wright et al., 2007). Each interview lasted approximately 1 hr, and participants who completed the interview were compensated US\$25 for their time and US\$5 for travel. Data collection efforts continued until no new themes emerged from the interviews. To assure that saturation (Rubin & Rubin, 2012; Strauss & Corbin, 1990) had occurred, interviews with new participants continued until no new themes had emerged in four consecutive interviews.

Focus Groups. Focus groups were conducted after all individual interviews with intervention participants. Focus group participants were recruited from intervention participants who had not completed individual interviews, CAB members, and peer leaders to validate and extend the themes identified in the individual interviews, and to offer a potentially different perspective. The CAB and peer leader focus groups were of mixed gender to add yet another potentially different perspective than that of the intervention participant focus groups, which were composed of either all men or all women. Potential focus group participants were called in random order,

to ensure all potential participants had an equal chance to be called. Those persons contacted were invited to join the scheduled focus group that was appropriate for their role in the parent study (CAB member, peer leader, or intervention participant) and (for intervention participants) the focus group that was appropriate for that person's gender, age, and county of residence. Invitation calls were made until each focus group was full. All focus groups were facilitated by one or more of the study investigators. After purpose and ground rules for the focus groups were explained, participants were asked to respond one at a time to open-ended questions about their perception of and experiences with HIV testing. All focus groups were digitally recorded. Each focus group lasted from 1.5 to 2 hr. Pizza and beverages were served to participants following each focus group. Participants who completed the focus group were compensated US\$25 for their time and US\$5 for travel.

Data Integrity. Based on recommendations by Lincoln and Guba (1985), we took several steps to maximize the trustworthiness of our qualitative data. An interview guide was used in conducting all interviews and focus groups to ensure consistent inquiries without precluding the possibility of discovery of other relevant issues. The interview guides were developed based on the literature and on data collected from baseline interviews in the parent project's intervention trial. All participants were told that, with their permission, the interviews and focus groups would be digitally recorded and notes taken. Personal identifiers were removed from all notes and recordings. Names were kept separately from interview transcripts and stored in a different place under lock and key. The interviews were transcribed verbatim, verified for accuracy, and then entered into ATLAS.ti software for data management (ATLAS.ti Scientific Software Development, 2003-2009).

Data Analysis

As is typical of qualitative studies, data collection and data analysis for this project occurred concurrently. This allowed questions to be revised and/or addition of new topics to increase understanding of how rural African American substance users perceive HIV testing and testing barriers. The data were first read without coding for overall understanding of "What is going on here? What are people doing?" (Charmaz, 2005). Constant comparison and content analysis techniques (Hsieh & Shannon, 2005) were then used to identify, code, categorize, classify, and label primary patterns in the data (Bradley, Curry, & Devers, 2007). A codebook with definitions was developed by the research team based on the first 10 interviews. Two team members then used the codebook to code the data independently. To ensure coding reliability and consistency, they reviewed each other's work, and then discussed and resolved any differences. We approached the coding of the individual interviews and focus groups in the same manner.

Findings

Characteristics of Sample

The total sample ($N = 69$) for this study was composed of three subcategories of participants from the parent study: 54 intervention participants, 7 CAB members, and 8 peer leaders. A total of 41 individual interviews were conducted with intervention participants (female = 20). The response rate for intervention participants, CAB members, and peer leaders invited to participate in focus groups or individual interviews for this study was 100%. Five focus groups were conducted. Two of the focus groups were gender specific with 13 intervention participants participating (female = 7). Another focus group was mixed gender with 7 CAB members (female = 5). There were also two mixed-gender focus groups with peer leaders, one per county consisting of

Table 1. Characteristics of Sample.

Description	Number	%
Female	32	52
Age range (years)	19-54	
Age median (years)	37	
Education		
<high school graduation	30	49
High school graduation or equivalent	25	41
Some college	5	8
College graduation	1	2
Employment		
Unemployed	27	44
Disabled	11	18
Homemaker or retired	6	10
Annual income <US\$5,000	43	71
Never tested for HIV	12	20
Perceived HIV risk		
No risk	30	50
Low (25%) risk	21	35

Note: Table includes respondents from individual interviews ($n = 41$), focus groups ($n = 13$), community advisory board ($n = 7$); peer leaders ($n = 8$) not included.

4 members each (female = 2 each county). Two additional gender-specific groups had been planned but were not conducted because saturation was reached and further data collection would have been repetitive and unproductive. As shown in Table 1, the sample was evenly distributed among men and women, and most (75%) were poor, having less than US\$5,000 annual income. Nearly 50% were unemployed. Almost one half (49%) of the sample had not completed high school, and few had any education beyond high school. Although 80% reported they had been tested at least once for HIV, 50% did not consider themselves to have any risk for acquiring HIV. As noted, Table 2 does not include peer leaders.

Testing History of Sample

Due to privacy issues, we did not ask focus group members to reveal during the group session whether they had been tested. During individual semistructured interviews, intervention participants ($n = 41$) were asked whether they had ever been tested, and then asked to explain their reasons for either getting or not getting a test. Their answers were listed, and then categories were constructed for similar reasons. Table 2 shows the reasons given for getting tested.

Reasons for Getting an HIV Test. The most common ($n = 18$) reason given by men younger than 30 years of age was *self-care* or *wanting to know*. As one young man said, "I want to know so I can fix the problem." The most common reason for testing given by all women and older men was the assumption they had been *tested with other health services*. The assumption of being tested is important because most who gave this reason had not asked for an HIV test, had not been told by the health care provider that an HIV test was conducted, and had never received test results. Many women assumed an HIV test was included with a routine Pap test. Some men assumed they were tested every time they went to the health clinic or whenever blood was drawn. One

Table 2. Reasons for Getting HIV Test.

Reason for HIV Test	Men		Women		Total
	<30 years	≥30 years	> 30 years	≥ 30 years	
Self-care/want to know	10	2	3	3	18
Tested with other health services	0	5	6	5	16
Risk behavior (self)	3	2	0	2	7
Risk behavior (partner)	0	0	3	4	7
Asked by partner or group event	3	0	1	0	4
Prison	0	2	0	0	2
Symptoms	0	0	1	0	1
Death of friend/relative with AIDS	0	1	0	0	1
Total	16	12	14	14	56

Note: Some participants tested more than once, so reasons given are greater than number of participants tested.

older man told us, “I am tested every year when I go to my eye doctor in Memphis.” Another older man said, “Patients are tested for HIV anytime they go to the community health center for any reason.” Women who assumed HIV testing was included with their annual Pap smear thought they were being tested for HIV every year, for example, “I get tested every year with my annual check-up.” Interestingly, no younger men assumed they had been tested with other health services. Both younger and older men as well as older women said they were tested due to concern about their *own risk behaviors* such as having unprotected sex or having more than one sex partner. No younger women gave their own risk behavior as a reason for getting tested. Only women, both younger and older, were tested because of concern about their *partners’ risk behaviors*. As one older woman said, “I get tested because I don’t trust him (my husband).” A few younger men and one younger woman said they were tested as part of a *group event* or because their *partner asked them to be tested*. Two older men said they were tested in prison. One of these men said he found out he had HIV when tested in prison. One young woman said she got tested every time she had “symptoms down there [genital area].” Only one person, an older man, said he was tested because he had a *friend who died from AIDS*.

Reasons for Not Getting an HIV Test. Of the 41, 12.5% said they had never been tested. This included two older men, two older women, and one younger woman. All of those who said they had never been tested said there was no need for them to be tested. However, the reasons given for not needing a test varied. One of the older men said he had no need to be tested because he did not have a partner, and the other older man said he did not need a test because he and his wife had been in a monogamous relationship for 30 years. One of the older women and the younger woman said they had no symptoms and therefore did not need a test. The other older woman said she did not think that she needed a test now but would consider being tested in the future.

Testing Site. There were clear age and gender differences in choice of testing sites. The majority of younger men were tested at the state health department’s local health unit, while the majority of older men were tested at their doctor’s office, community health center, or in the emergency room. A few women, both older and younger, were tested in either a local women’s clinic or their primary care physician’s office, but the majority were tested at the local health unit. Only men reported being tested in prison. A total of 82% of women reported being tested at the local health unit, compared with 55% of the *men*.

Themes Around Help-Seeking and Access in HIV Testing

After all interviews were coded and major barriers to HIV testing identified, we constructed one table of overarching themes for all groups rather than a separate table of themes for each distinct group of participants (intervention participants, peer leaders, CAB members, female-only focus groups, male-only focus groups). The investigative team felt this provided a richer, more complete understanding of decision making about HIV testing among African American cocaine users living in small, rural communities. Our analysis of interview and focus group data revealed the following prominent themes and subthemes, which can help explain the help-seeking behaviors of rural African American substance users and the factors that influence their engagement in HIV testing: (a) Risky Assumptions About Testing; (b) Distrust of Providers, Medicines, and Social System; (c) Perceived Self-Efficacy; (d) Pride/Shame; (e) Small-Town Social Networks; and (f) Drug-Related Lifestyle. Clear gender differences were evident within each theme and are discussed in detail below (see Table 3).

Risky Assumptions About Testing. Two assumptions about HIV testing were commonly expressed. The first assumption was the belief that an HIV test had been administered as part of routine health care even though one did not ask for an HIV test or was not told he or she was receiving an HIV test. The second assumption was the belief that if one does not receive results for an HIV test, his or her test is negative.

Men in particular had a passive approach to testing. Several older men expressed confidence that they had been tested because blood had been drawn when they had a doctor's appointment. According to these men, any doctor or hospital visit that involved blood being taken or given automatically included an HIV test, "I think they automatically test you." For example, a 43-year-old man told us, "I know I get tested because I go to the doctor all the time to get my blood taken." Another older man said he thought he was tested when he received treatment in the emergency room for a gunshot wound although "nobody never said nothing to me about it." A couple of young men thought they had been tested as children, one as part of routine foster care and the other because he had been hospitalized for severe burns. The second assumption was held almost universally by both men and women in the study. Whether they sought testing or simply assumed they had been tested, most said "no news is good news" regarding HIV test results. This was stated very clearly by a 36-year-old man: "You don't have nothing to worry about if they don't call you or come looking for you; they will get with you if you got a problem, they will tell you if you are positive."

Distrust of Providers, Medicines, and Social System. Distrust of providers, medicines, and the social system appeared to underlie the belief among many in our sample that they received substandard health care and treatment. The *Symbolic Effect of Magic Johnson* was a subtheme of the distrust theme.

Several men were especially critical of local providers. A man in one of the focus groups stated, "Local doctors will kill you. You won't get the 'real' stuff you're supposed to get here. They'll give you cheap generic meds that don't work good." Several men and one woman expressed distrust of the rapid test. Women did not talk as much as men about distrust of providers or health services in interviews or in focus groups. However, not all women had confidence in the skills of local health department providers. One of the women participating in a focus group said she would go to her doctor to double check test results from the health department because "I'm not comfortable with their [local health department's] practice. They don't know what they are talking about." This woman said her distrust of the health department was based

Table 3. Barriers to HIV Testing.

Themes	Subthemes
Risky assumptions	Routine care includes HIV testing If you are not contacted, your results are negative I don't have HIV unless I am sick
Distrust of the health care system/treatment	You will receive substandard care You will receive cheap substitute meds, no real meds You cannot trust the diagnosis given by local providers HIV/AIDS medicine will kill you The government/system is trying to kill you Symbolism of Magic Johnson Disbelief that he has AIDS Money gives him access to effective treatment Money/fame did not protect him from stigma
Perceived self-efficacy	Stress Fear Denial Fatalism
Pride/shame	Gender differences Self-respect Respect for race and family
Small-town social networks	Stigma Confidentiality
Drug lifestyle	Don't care about anything but drugs Peer influence Need for drug greater than other needs

on personal experience with misdiagnosis. She went on to say “the health department was okay for getting condoms,” but she did not trust them for providing health care services.

The only person in the study who said he had AIDS was a 36 year-old man who was first diagnosed with HIV in 1996 while in prison. He said he now has AIDS and that his CD4 cell count was 235. This man said he would not take his antiretroviral medicine because “I know it will kill me; I tried it once and could hardly walk. I'm not going to take it because the medicine killed my friends; they killed all my friends. I seen how it killed them.”

Distrust among men extended beyond testing and treatment for HIV. In focus groups, men talked about their distrust of the government. For example,

I might be wrong for saying this here, and I could be wrong, but I don't trust the government because I think they actually put some of this mess out here to kill off some of us people around here.

Symbolic Effect of Magic Johnson. Magic Johnson appears to be an important example to men as someone who has HIV, but he is clearly not someone they perceive as similar to them. His name was mentioned by several men as someone they admire or envy. Some of the older men said they did not believe he really had HIV because he appeared to have no physical effects. One of these men said, “Magic don't look like anything wrong with him,” and another went on to say, “As long as he done had it, I don't care how much medicine he's taking, some effect would have

come on his body by now.” Others in the group said they did not think Magic really had AIDS, that it was just a publicity stunt for commercials and endorsements or to scare young people. Some of the women, too, expressed doubts about Magic Johnson. One older woman said she did not believe he had HIV because he “doesn’t look sick.” A woman in the women’s focus group who had recently attended a local HIV education and testing event featuring a local woman living with AIDS said,

She shows you before and after pictures of herself. There’s no way you can’t believe it. Not like Magic Johnson. Like they say he has it; I don’t never believe it. He may does, he may do, but I don’t believe it.

Young men admired Magic and were more likely than older participants to accept that he had HIV. The difference in Magic Johnson’s having HIV and a member of this community having it was summarized by a 48-year-old man: “If I’m HIV positive and I’m poor, my risk of living would not be as high as a person like Magic Johnson who has got a lot of money.” However, although Magic Johnson’s success and wealth meant that he had access to the best drugs money can buy, and so could “beat” HIV, one of the men in a focus group commented that “it cost him his career, he was shunned.”

Perceived Self-Efficacy. According to Bandura (1982), perceptions of self-efficacy determine what activities people undertake or avoid. People tend to undertake activities they feel capable of managing and avoid those that exceed their perceived ability to manage. Most participants in this study demonstrated self-efficacy for getting tested but not for coping with awareness of being infected, obtaining treatment and services, responsibility for telling others, or social isolation. Younger men and women appeared more confident in their ability to deal with the possibility of a positive test than older participants, and gave “wanting to know” as a reason for getting tested. Both younger men and women made statements such as, “I want to know so I can fix the problem” and “I’d rather know and be able to do something about it than not know and be dead.” Younger men and women also referred to getting tested for HIV because they wanted to know they were “safe.” In one young man’s opinion, “if you don’t want to get tested, it’s something that you’re not confident with yourself about.” Nested within the broad theme of Perceived Self-Efficacy were four distinct subthemes: (a) *Stress*, (b) *Fear*, (c) *Denial*, and (d) *Fatalism*.

Stress. Most of the participants spoke of the stress caused by HIV testing whether or not they had ever been tested. Several older men said they could not handle it if they tested positive: “I’d be done lost my mind to tell you the truth, because I was on the edge with my first test. I was on the edge.” Some men in interviews and in focus groups said they did not like rapid HIV tests (tests that can provide results in 20-30 min rather than a week or more) because they felt people needed time to prepare themselves for results. They said it caused too much stress to cope in a short period of time with making the decision to get tested, getting the test, anticipating results, getting results, facing being positive, facing mortality, considering what to do next, learning how to get drugs and treatment, and contemplating disclosure to others. As one man told a focus group, “I would not know what to do next or how to manage, how to get meds.” Another older man explained, “You can’t give them a test today and tell them in the next 10 minutes that you’re dying or you’re not dying. Give them a day or two because it’s something to think about.” One man said even 2 weeks (the typical wait for standard HIV test results) was not long enough to prepare for results.

Fear. Perceived inefficacy in coping with adverse events results in fear (Bandura, 1982), and fear was the most common reason given for not getting tested for HIV. Fear of positive results,

fear of knowing, fear of others finding out, fear of never having sex again, fear of being shunned, fear of treatment, and fear of death are some of the fears associated with HIV that were given by participants. The most poignant example of fear was given by a 20-year-old woman who was first tested when she was 16 because she had been exposed to a sex partner with HIV. She told of the relief she felt when her results were negative because "I was afraid that if I would have had anything, my mama wouldn't love me no more." The same woman also related the story of one of her "homegirls" as follows:

She wasn't nothing but like 16 or 17 so I took her to the doctor. Even though you've got to have a parent with you, I was like, "I'm her older sister." And when her results came back, when they told her she had HIV, I felt sorry for her . . . She didn't know how to tell her mama. By me being a friend to her, I told her "that's your mama, she needs to know." She [friend] got mad at me. So 2 days later she killed herself. She hung herself.

Denial. Denial is a coping strategy that protects the person from having to face the fears, consequences, and responsibilities related to receiving a positive HIV test. The untested person can deny the implications of having HIV to self and others as long as he or she has not been tested or does not have symptoms. The person in denial is relieved of making decisions about disclosure or changing risk behaviors or obtaining treatment. Speaking of those who refused to be tested, a 54-year-old man said, "They feel it is good to ignore it; ignorance of it is going to make it go away." This was echoed by several others in individual interviews and focus groups as a reason some people did not get tested, with statements like, "If I don't know, I'm alright," "but once you know, you go down," and "It's better not to know; knowing makes it real, what you don't know can't hurt you."

Fatalism. Fatalism is the belief that events are inevitable and that your actions cannot change things no matter what you do. This was evident in three ways among most participants. First was the belief that HIV/AIDS will always kill you, second was the belief that there is no effective treatment for HIV/AIDS, and third was the belief that even if effective treatment existed, it would not be affordable or available to them. Few participants distinguished between HIV and AIDS—the terms were used interchangeably. A diagnosis of HIV was perceived as a diagnosis of AIDS. Many said they thought the belief that "just hearing you have AIDS will kill you" was a major barrier preventing others from getting tested. One older man explained that, for many, getting a diagnosis of HIV or AIDS was the same as getting a "death certificate . . . you're already dead." Fatalism was common among all participants whether male or female, young or old.

Pride and Shame. Pride was conceptualized by our participants as self-respect and respect of race and family. Gender differences in pride and shame concerning HIV and testing for HIV were apparent. There was agreement among men and women that it is the woman's responsibility to get tested for HIV. For women, it was a matter of pride to take care of themselves and to keep themselves "clean," which included getting tested for HIV. Most women, especially the young ones, made it very clear that they had no shame associated with going to the clinic or their primary care provider and asking to be tested for HIV. Both men and women agreed that men are more "shamed" by seeking testing for HIV than women. Men described their reluctance to be tested as a "macho thing or ego thing," whereas women described men's reluctance to be tested as "a stupidity thing." Several men said that although they would not feel right going alone to be tested, they would go if asked. This was stated very clearly by one of the older men and others in the group agreed: "If a man is not asked, he is not going to seek. He will say yes to a test if asked, but he will not volunteer for it."

Men, unlike women, discussed racial pride and the stigma of homosexuality as barriers to testing as shown in this statement by a male peer leader:

Black peoples are some proud peoples. Black people are proud and the whole thing about it is a Black fag is a disgrace to his race . . . it's the same thing if you tell a person they gay if they have AIDS.

A man in a different focus group echoed the above statement saying that for a Black man, "being gay or having AIDS is a disgrace to family and race."

Small-Town Social Networks. Small-town social networks refer to the characteristics of social relationships in rural communities that are perceived as barriers to HIV testing. *Stigma* and *Confidentiality* were the subthemes of Small-Town Social Networks that emerged as barriers to testing by most participants in individual interviews and focus groups.

Stigma. To rural African American drug users in this study, stigma was considered a major barrier to HIV testing. Peer leaders in one of the focus groups said people with HIV or AIDS in their communities were avoided or were not treated like humans. For example, they reported that people did not want people with HIV to be in their car, did not want to hug them, and would not talk to them. In the women's focus group, it was said that even caregivers for persons with AIDS experience social stigma. One of the women in this group said, "If someone refuses to be tested, it means they already have it, know they have it and don't know how to tell you because of being afraid you will no longer be their friend."

CAB members talked about small-town gossip and how persons with HIV or AIDS were "cast-outs, isolated." In the men's focus group, one man said, "You would be blackballed if you had HIV, you could not get work, nobody would want to be around you; you are ruined and would have to leave here."

In telling how he would treat someone who was HIV positive, a 25-year-old man said that he would treat them the same except he would not eat or drink after them. He said he would throw their cup away when they were not looking because he did not want to hurt their feelings. Some of the women said stigma was a barrier to testing caused by the lack of education programs and knowledge about risk, testing, and treatment.

Confidentiality. One of the most common utterances during this study's interviews and focus groups was, "Everybody knows everybody in a small town." Confidentiality concerns centered around possible provider violation of confidentiality and being seen at known testing sites by others in the community. Several respondents said a relative worked at the local health department or community health center. For some, this was a source of comfort and trust that their privacy would be protected. For others, this was a reason to go out of town for testing. Almost everyone said the health department was convenient and they were treated courteously there, but even so, many recommended getting tested "anywhere besides the health center because a lot of people find out and tell your business." In both counties, many men and women interviewed were convinced that lists were posted in the health department with names or codenames for persons with HIV. One of the men in the men's focus group told us, "The health center's got a big list in one of the rooms back there of everybody that got HIV positive. That list don't supposed to hang on no wall." Young people needed places other than the local health department to go for testing, said a 28-year-old woman, because they were afraid their parents would find out they were sexually active if they were tested there. Just being seen at the health department was enough for some men and women to be concerned that others would automatically determine it was because "they had something." As a 48-year-old man said,

If your hometown is a small town, it's not confidential (testing). Because the town is so small, the population is so small, you ain't really got no privacy. If you had AIDS, the people next door would know. Go out of town. Go to the city to be tested.

Drug-Related Lifestyle. Drug use and a drug-related lifestyle were barriers to HIV testing according to a great many of men and women participants, young and old. HIV was associated with persons who did not "care about themselves enough to keep themselves up or keep themselves clean." Such persons were often described as "nasty" or "dirty," so strung out on drugs they would do anything or have any kind of sex with anybody to get their fix. These were also the people study participants said would be less likely to be tested for HIV. "People on drugs don't care about their health, the drugs have them not caring about anything," said a 26-year-old man, and a 25-year-old man said that drug use is a barrier because "you are not thinking clearly; you need a fix and will do anything to get it." Although recent drug use was an eligibility requirement to be in the parent study from which the sample for this study was recruited, participants spoke of drug users as others and did not refer to themselves as drug users. Drug users were identified with "the street" and looked down on by study participants. Drug users were sometimes described as "party people" who engaged in unsafe sex but did not want to be tested. A 48-year-old man elaborated,

It all depends on peer groups of people. People that don't drink, don't smoke, don't party or nothing. Those are the ones who say you have to go get tested. But the ones that's drinking, smoking, and partying, they don't care. Party people will still have unprotected sex with someone with AIDS because their mind is chemically unbalanced.

Discussion

Participants in this study reported multiple barriers to HIV testing stemming from emotional/intrapersonal issues, interpersonal and social pressures, and perceptions of structural barriers to quality health care. However, participants did not report the usual access barriers, as defined by Pechansky and Thomas (1981), of availability, affordability, accessibility, or accommodation; rather, barriers primarily dealt with acceptability. Intrapersonal barriers included drug use and lifestyle, assumptions about testing, perceived lack of efficacy for coping with a positive test result, and knowledge/attitudes/beliefs about the health care system in general and HIV/AIDS specifically. Social barriers included stigma, racial pride, gender roles and responsibilities, the drug environment and relationships with drug users, lack of male role models with whom they could identify for initiating testing or for living with HIV or AIDS, and the lack of privacy and confidentiality inherent in a small town. Gender roles and responsibilities for testing were clearly drawn regarding HIV testing. Women in all-female focus groups made it clear that they regarded getting tested for HIV their responsibility as women. Testing was the accepted social norm for women. Passive testing or no testing was the social norm reported by men, especially in all-male focus groups. Men were not expected by their peers or partners to seek testing. Men had no problem with passive testing; they were willing to be tested so long as they did not have to ask for it. System barriers included historical, institutional, and experienced racism and discrimination that fostered mistrust and suspicion, a lack of culturally appropriate outreach and educational messages and programs, poor linkage to HIV services and treatment, and the lack of routine opt-out testing.

There are numerous forces at work inhibiting perceived need or demand for HIV testing. Social networks shape the daily social processes of everyday life that make up a person's experiences and opportunities (Pescosolido, 2006). The limited social and sexual networks of drug

users in our study communities exemplify what Draus and Carlson (2009) so aptly described as a “vortex” in his study of drug use in rural Ohio and Lichenstein (2007) referred to as the “tyranny of small places” in her study of illegal drug use and the social context of HIV/AIDS in the rural Black Belt of Alabama. African American cocaine users in this study move between cycles of drug use, irregular employment, and incarceration in their small rural communities where drug use and sexual risk are magnified by easy access to drugs, limited economic opportunities, and limited choices of sexual partners. As one male peer leader described his network,

We use each other for drugs. We use each other for money. We use each other for mobility. We use each other for stability. If you got all the drugs, I ain't gotta go nowhere . . . this is the lifestyle . . . this is the entertainment of the Delta. There's nothing here. Unfortunately, you don't have nowhere to go but to the rehab and to the jail and to the post office.

The social network is thus the primary resource for social and financial support and for transmitting attitudes, values, and norms about help-seeking and HIV testing.

Stigma is alive and well, and indeed pervasive, in this community. Study participants did not identify themselves as drug users, even though they themselves used drugs. Indeed, drug use was the social norm among their small social and sexual networks consisting largely of active drug users. However, clear distinctions were made between average or social drug users and heavy or career drug users. By and large, participants referred to drug users in the third person, and described them as other people who had no control over their drug use or lives and no concern for their own well-being or that of others. Such heavy drug use and heavy drug users were stigmatized within the social network of drug users as well as the larger community. Homosexuality was still very stigmatized in this community, as has been reported by others studying rural African Americans (Dreisbach, 2011; Preston et al., 2004). HIV was stigmatized and associated with drug addicts, street people, and gays. A diagnosis of HIV was equated not only with physical death but perhaps also, more importantly, with social death. The stigma of HIV spoiled not only the individual's identity but also collective identity, in that it brought shame to family and the Black race. Routine HIV testing would help normalize testing and remove the barrier, especially for men, of seeking or asking for an HIV test.

The assumptions about testing among our sample reveal multiple potential points of failure in HIV testing and notification policies and processes. The assumption that HIV tests are conducted automatically anytime a health care provider draws blood is of considerable concern, particularly combined with the belief that “no news is good news” regarding such automatic tests. If this perception is commonplace in other similar populations, estimates of the proportion of a population that has been tested for HIV may be inaccurately high, and many individuals may mistakenly believe that they are definitely HIV-negative. Although a majority of participants self-reported that they had been tested for HIV, the results of this study suggest that many may not have been tested in reality. Several said they thought they had been tested for HIV because they received blood tests at their doctor's office for other conditions or because they had been treated for an injury at the emergency department. They had not asked for an HIV test nor been told by their provider that they were being tested for HIV. They assumed they had been tested and that the results were negative because no one had contacted them to tell them the results were positive. This is consistent with findings that a sizable proportion of people who do actively seek out testing do not return for their results, which underscores the passive testing approach's pervasiveness (CDC, 2011b).

Errors in understanding of the reporting process were also evident. Many assumed they were HIV-negative because of the belief that authorities are required to “track them down” to notify them if they test positive. Although this assumption is correct in some situations, it is not always

accurate (and this assumes that the test was in fact performed, which, based on our results, is a risky assumption itself). Indeed, the legal burden regarding reporting of HIV test results is on the provider to notify the state health authority, not on the state authority to notify the patient, as many in our sample believed.

As in most other states, HIV is a reportable disease in Arkansas, which means state health authorities must be notified of persons with confirmed positive tests. State disease investigation specialists (DIS) may aggressively seek out persons who test positive yet still be unsuccessful in finding them due to inadequate resources or incorrect contact information. DIS staff do not have police powers and, so, must operate between what is legally required and what is legally allowed in notification attempts. Thus, individuals relying on DIS may delay receipt of test results far beyond what would occur if tested individuals requested their results directly.

We found a general sense of mistrust and doubt among participants concerning HIV/AIDS information and health services, as well as the common belief that an HIV/AIDS diagnosis was equivalent to a death certificate. Study participants made no distinction between HIV and AIDS, the terms were used interchangeably to refer to a disease that meant certain death. The importance of testing and the effectiveness of early treatment were far removed from the world of rural African American drug users in this study and the health system as they knew it. Few had any knowledge of treatment services for HIV or how to obtain them. Those who were aware of effective treatment did not believe it was available to them. Lack of knowledge about the existence of effective treatment, information about services and resources available to persons with HIV, and assistance in navigating the system was a major barrier to testing. Participants in this study reported feeling stressed and doubtful of their ability to cope with receiving a diagnosis of HIV because they would not know what to do. In addition to providing information about the effectiveness of treatment and about assistance programs that can pay for antiretroviral treatment, such programs should emphasize the availability of treatment from both local providers and providers in nearby towns, to offer options to those who have substantial privacy concerns.

Efforts are being made to reach rural African Americans through community-based programs that have demonstrated success (Dreisbach, 2011; Hall, Li, & McKenna, 2005). If our sample is any indication, there would be little pushback from consumers if the CDC's recommendation for routine opt-out testing of adults in all health care settings was to be implemented (CDC, 2006). Our findings provide rich context and support for existing recommendations for development of HIV/AIDS education programs that are tailored to be relevant and understandable to rural African American drug users about the progression of HIV infection, and why testing and early treatment are important (Barrow et al., 2008; Bogart & Thorburn, 2006; Williams, Wyatt, & Wingood, 2010).

Limitations

The small sample size and unique setting of this study may reduce generalizability. In addition, our findings emerged from interviews with noninjecting cocaine users and may not transfer to rural African Americans who are injectors or use drugs other than cocaine, or to other rural or ethnic groups. Although the open-ended nature of the questions may ensure the participants discussed the most pertinent and meaningful issues from their perspectives, we may not have learned about other aspects of access because we did not ask directly about them.

Conclusion

Our findings provide information that is critically important for developing new strategies to address the growing disparities in HIV and rapid growth of the epidemic among African

Americans in rural areas. Affordability, physical accessibility, and geographic availability were not perceived as barriers to HIV testing in this sample, yet acceptability was still perceived as poor. Most knew where to go for testing in their community and said the location was convenient. Most had no preference for either a blood test or an oral test. Cost was not a factor as testing is free at local public health clinics in Arkansas. Acceptability due to social mores and norms, however, was a major barrier. Many said testing was unacceptable because of fear of social costs. Small-town social and sexual networks added to concerns about reputation and risk. System approaches may fail if they focus solely on improving access to HIV services but do not take into consideration deeply internalized experiences of rural African Americans as well as involvement of the community in developing programs and services.

Appendix

Key Informant Interview Questions

1. What are your concerns about sexual health?
 - a. What steps do you take to stay healthy, sexually?
2. Where do you go for help for your sexual health problems or concerns?
3. Have you ever gotten tested for HIV or had an opportunity to get tested?
 - a. If you have been tested, where did you go *the last time* you were tested, and what was the experience like? What was your best experience with being tested? If you haven't been tested, where would you go to get tested, and what do you imagine it would be like?
 - b. Did you go in and ask to be tested or were you told you were being tested for HIV?
 - c. If you didn't ask to be tested, or weren't told you were being tested, how did you know you *were* being tested for HIV?
 - d. Did you receive a blood test for HIV? Did you receive an oral swab test for HIV?
 - e. How do you know when you get your blood tested that the test will include HIV?
 - f. Did you get back your test results?
 - i. How were your results given to you (i.e., a phone call, letter, return visit)?
 - ii. How long did it take to get your results?
 - g. How were you treated by the staff at the place *where you last got tested* (or, if no one has been tested, how do you expect the staff would treat you if you went to get tested?)
4. What are some reasons a person would get tested for HIV?
5. How do you think people you know would react if they knew you were getting tested for HIV?
6. What would be a good place for people to get tested that might be most comfortable or easy for them?
7. Has anyone ever told you they would not get tested or refuse to be tested?
 - a. What are some reasons a person gives for not getting tested for HIV?
 - b. Has anyone told you they would not be tested because of fear of the results?
 - c. What do you think "scared to know" really means?
8. We have been told by some people that men are less likely to be tested or that women are less likely to be tested, what do you think?
 - a. Do you think there are other groups of people in your community who are less likely to get an HIV test, even though they might be at risk?
 - b. If so, do you know specifically that people in these groups have refused to be tested? If so why?

9. What would make it easier for people in this community to get an HIV test or a STD (sexually transmitted disease) test? What, in your opinion, would be the most convenient way or place to get tested?
10. Have you personally ever known anyone with HIV or who is HIV positive?
 - a. Did you ever talk with them about it?
 - b. What were they doing about it?

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Geoffrey M. Curran received his PhD in sociology from Rutgers University. He is a professor and an associate director, Division on Health Services Research, Department of Psychiatry, and a medical sociologist with significant expertise in systems research, qualitative methods, and the contextual aspects of substance-use treatment delivery.

Brenda M. Booth received her PhD in biostatistics from the University of Iowa and has headed multiple health services research projects in substance abuse and mental health. She is particularly interested in rural populations and has conducted a six-state comparative study of rural and urban at-risk drinkers, and, more recently, a multisite study of rural stimulant users.