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Views of Young, Rural African Americans of the Role of Community Social Institutions' in HIV Prevention

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Abstract

Background—We explored rural African American youths' perceptions about the role of community social institutions in addressing HIV.

Methods—We conducted four focus groups with African Americans aged 16 to 24 years in two rural counties in North Carolina. Groups were stratified by gender and risk status. We used a grounded theory approach to content analysis.

Results—Participants identified four social institutions as primary providers of HIV-related health promotion efforts: faith organizations, schools, politicians, and health agencies. They reported perceiving a lack of involvement in HIV prevention by faith-based organizations, constraints of abstinence-based sex education policies, politicians' lack of interest in addressing broader HIV determinants, and inadequacies in health agency services, and viewed all of these as being counter-productive to HIV prevention efforts.

Conclusions—youth have important insights about local social institutions that should be considered when designing HIV prevention interventions that partner with local organizations.

Keywords

Adolescents; HIV; rural; community-institutional relations; African Americans

A complex set of behavioral, historical, social, and environmental factors act synergistically to create disproportionately high rates of HIV infection among African Americans compared with other racial groups.¹ Despite the recognition that numerous factors affect HIV risk, most interventions to date have targeted individual-level determinants such as knowledge, risk perception, and risk behaviors. Interventions that seek to engage community social institutions in HIV prevention have been advocated because of their potential to maximize use of existing community resources while developing sustainability.²⁻⁴ Such interventions have shown promise in addressing diverse public health problems such as heart disease,⁵ high-risk pregnancies,⁶ and asthma prevention.⁷ However, few HIV prevention interventions that collaboratively engage social institutions have been developed,⁸⁻¹² particularly in the South which is disproportionately affected by HIV. Although the South accounts for only 36% of the U.S. population, it contains more than half the people living with HIV and 40% of new infections.¹³ African Americans in the South are disproportionately affected. More than half (52%) of African Americans living with HIV and 58% of new AIDS cases reported among African Americans occur in this region.¹³

Project Growing, Reaching, Advocating for Change and Empowerment (Project GRACE) is an academic-community partnership created to develop multi-level interventions that address the disproportionately high rates of HIV among African Americans in rural, eastern North Carolina. (Corbie-Smith G, Adimora AA, Youmans S, et al. Project GRACE: Building community- academic partnerships to address HIV disparities in rural African American communities. Under Review) In our target counties, 85% of HIV/AIDS cases are among African Americans.¹⁴⁻¹⁶ In 2006, we conducted a community needs and asset assessment to better understand community members' perceptions of local determinants of HIV and to identify community resources available for HIV prevention efforts. The needs assessment included 11 focus groups (n=94) and 37 key informant interviews. The Project and its community partners, which included concerned citizens as well as representatives from the

government, faith, education, health and community non-profit sectors are described in detail elsewhere. (Corbie-Smith G, Adimora AA, Youmans S, et al. Project GRACE: Building community- academic partnerships to address HIV disparities in rural African American communities. Under Review) For the focus groups, we purposefully sampled three populations that our community partners identified as those at greatest risk for HIV infection: youth aged 16-24, formerly incarcerated individuals, and adults over age 25. Key informant interviews were conducted with community leaders from business, government, non-profit, arts, education and faith sectors. Although themes regarding the role of social institutions in HIV prevention among youth were similar across all focus groups and key informant interviews, we present only the data from youth for two reasons. First, few HIV prevention interventions have been developed for youth in rural communities.^{9-12, 17} Second, youth have the highest local rates of infection and were identified by our community partners as the first target for prevention efforts. In this analysis, we were specifically interested in exploring what local social institutions youth identify as influential, what they perceive to be the positive and negative effects of these institutions' policies and activities on community HIV rates, and youths' suggestions for how social institutions can facilitate HIV prevention interventions.

Methods

We analyzed data from the four focus groups (n=38) with youth aged 16-24 years. Focus groups were stratified by gender and risk status with high-risk defined as having dropped out of school, or a history of contact with the juvenile justice system or incarceration. Thus, two focus groups were conducted with low risk youth and two with high risk youth, with one male and one female group held for each risk type. Youth were recruited by local community-based organizations (CBO) who partnered with the Project. Individuals aged 18 and older provided verbal informed consent; for those under age 18, parents provided written informed consent and youth provided verbal assent.

Focus groups were held at local community organizations. Each lasted approximately two hours. The semi-structured discussion guide was developed by the study investigators in collaboration with our community partners. Twelve open-ended questions inquired about participants' perceptions of factors affecting the communities' HIV risk, community needs and resources for addressing the high rates of HIV and solicited ideas about the types of interventions needed. Questions regarding factors affecting community HIV risk were initially broad (e.g., "Why do you think rates are higher among African Americans than Whites in this community?") and were followed by structured probes to ensure that all focus groups addressed individual, interpersonal, social, cultural and institutional factors identified in the literature as important determinants of HIV risk.¹⁸ Probes regarding social institutions were also initially broad (e.g., What role do you think local institutions or organizations play in the higher rates among Blacks?) but specific probes asked about the role of faith-based organizations, schools, government, health agencies, and CBOs in HIV prevention. Thus, participants initially defined what they perceived to be important social institutions but were asked their opinions about specific social institutions identified as important from the HIV literature¹⁸ if these were not addressed. Discussions were led by two experienced moderators; one facilitated the discussions while the other took detailed notes about the discussion. Participants completed a brief demographic questionnaire. All participants received a cash incentive of \$20. The study was approved by the Institutional Review Board at the University of North Carolina.

Analysis

Focus groups were audio-recorded, transcribed, and coded using Atlas.Ti,¹⁹ a qualitative data management program. We used a modified grounded theory approach.²⁰ Insight gained from each focus group informed revisions to the questions and probes used for subsequent groups.

Analysis proceeded in two steps. First, all passages in each focus group relevant to social institutions were independently coded by two coders with training in public health and qualitative analysis methods. Coders met to compare their coded passages and resolved discrepancies via consensus with a third research staff with similar training. Analysis then proceeded inductively with the initial identification of sub-themes related to the role of social institutions arising from close, line-by-line reading of the coded passages. Sub-themes were then synthesized into a relational outline, referred to as a codebook, that depicted how individual themes related to one another. The transcripts were then recoded using this codebook by a fourth coder trained in public health and community-based participatory research. Data were sorted into matrices to compare responses across focus groups, gender and risk groups. This allowed us to identify themes that were specific to individual focus groups as well as to identify themes salient across all focus groups, indicating thematic saturation. Reported results represent consensus across all focus groups, genders and risk type unless otherwise noted.

Results

Sample Characteristics

Approximately half the sample was female (47%) with a mean age of 18.1±2.0 years. More than two-thirds had completed some high school (71%) and 8% had post-secondary education. Most (78%) had never been married although 11% were currently married. Almost a quarter (21%) were receiving public assistance.

Thematic Overview

Participants spontaneously identified formal sector social institutions as primary or potentially influential social structures affecting HIV risk in their community. They mentioned faith-based organizations (e.g., churches, mosques), schools, government, and health agencies as the main institutions providing HIV prevention and treatment services. Relatively few comments were made about local community-based organizations (CBOs) without prompting from moderators. In general, youth did not perceive local community social institutions as providing active leadership around HIV prevention. They felt that sexual health services in general, and HIV services specifically were targeted towards older youth age ≥18 and adults despite a perceived obvious need for youth prevention and outreach services. Youth expressed a desire for more community programs, events and health promotion efforts traditionally sponsored by voluntary sector social institutions, like community-based youth service organizations, as a tool for increasing adolescent's recreational opportunities. They felt such services would reduce youth engagement in sexual risk behaviors by providing greater structure for their free time.

Grassroots community-based organizations

Most participants were unaware of local CBO programs and services, except those sponsored by organizations that recruited them into the study. Participants who were able to name local voluntary organizations commonly mentioned national or international coalition groups such as the Boys & Girls Club of America, Masons, Salvation Army, Lion's Club, and Red Cross. However, none mentioned being actively involved in programs sponsored by these organizations. Despite limited knowledge about local CBOs, participants recognized the importance of increasing community members' awareness and utilization of these local resources when planning community-based HIV prevention programs. One young man said, "That's where we need to start first, making people aware so you can start from there."

Participants provided a number of insights into how local social institutions could increase their involvement in HIV prevention efforts. They overwhelmingly agreed that CBOs could be most effective at reducing adolescents' HIV risk by increasing availability of positive youth programming. They wanted safer recreational spaces and more positive leisure time options,

particularly for adolescents aged 11-17. One young woman said, "I would just like to see our community centers improve...At the community center, you can dance, you can do your art or whatever it is that you want to do. You can do that there at the community center. So, if you could just get that cleaned up and get someone to basically take care of it and keep the wrong people out of the neighborhood as far as there, I would like to see that." Youth also expressed a desire for life-skills training, job referrals for those with criminal records, educational services for school drop-outs, and general health education. Such efforts were seen as a means of reducing widespread boredom, getting youth off the streets, and preventing engagement in high-risk activities, such as gang activity, substance use, or sexual behaviors.

R: There's more and more for like the young community, like for people like you know that's younger than us 'cause I guess we're growing up.

M: So, that's for like maybe 12 and under?

R: No, I'd say 15.

R: Yeah, about 15, 16. Something like that.

M: So once you get over that threshold, that kind of little limit, then you guys are kind of like stuck. You've got to make your own fun?

R: Till you hit 21.

R: And that's how everybody got HIV and AIDS because what we consider fun is trying to get some.

R: A girl...that's the only thing you can do around here if you ain't working or nothing.
(Exchange among males)

Participants felt local business establishments where youth spend significant amounts of free time represented the best partners for youth-targeted HIV prevention efforts. Commonly cited locations included Wal-mart, local dance clubs, barbershops, and beauty and nail salons. Participants cited HIV prevention approaches that allowed dissemination of information and raising youth's consciousness about HIV while maintaining confidentiality as acceptable, effective ways to reach them. Two examples include door-to-door HIV education campaigns led by community leaders and posting eye-catching HIV prevention messages containing details about whom to contact to obtain confidential information or counseling services.

Role of faith-based organizations

Although faith-based organizations were described as historically functioning to promote social good, participants felt these organizations were now motivated more by financial self-interest than social justice. One young woman commented, "There's some churches that's out there that's all about money. Every time you turn around you have to bring two dollars." They noted that social programs such as food outreach and youth programs have disappeared. One young man remarked, "When I was little, the church used to give out food. They don't even do that anymore." A young woman commented, "The church doesn't even come out and take the kids like they used to do." Moreover, participants expressed the view that HIV prevention was not a priority for faith-based organizations. One young woman said, "We don't think that churches really focus on AIDS and STDs." When asked if faith-based organizations were an appropriate venue for HIV prevention interventions, there was concern that organizations' members would not be receptive. Participants felt congregants would not be comfortable having church representatives discussing HIV-related topics such as condom use, homosexuality, or drug use with youth. A young woman said, "The people are not trying to let their little ones hear that."

Reaching high-risk youth through faith-based organizations was thought to be especially problematic. Although leaders of faith-based organizations may reach out to them, high-risk participants felt congregants look down on those who have engaged in behaviors not generally sanctioned by faith-based organizations (e.g., intravenous drug users, people who engage in homosexual or bisexual behavior). One young man commented, “Cause when you go to church, people ain't gonna do nothing but talk about you. Talking about your past, what you was. And you're trying to change your life.” High-risk participants felt this stigmatization makes it difficult for them to be reintegrated into faith-based organizations or participate in their programs.

School-based sex education

Participants described marked variations in the availability, scope, and content of sex education curricula. For example, one female youth said, “They didn't even teach me one year” while another said, “In my school, 6th, 7th, 8th and 9th grade I got sexual education”. Most reported receiving either abstinence-only or no sex education. Overall, school sex education curricula were perceived as ineffective in a community with high rates of early sexual debut. One young woman said, “They give you a little paper where you sign and say you'll be abstinent but half of them was like ‘I can't sign this. I already had sex.’” High-risk males felt schools were not a place to ask questions and receive frank answers about sexuality: “If we ask them, they will probably get out get off the subject every time it come up.” Despite believing existing school sex education was problematic, schools were seen as an appropriate place for HIV education and prevention interventions. One young woman stated, “It needs to start in school because we spend most of our time in school anyway.” A young man added, “You need to come in elementary school and start teaching them early.”

Government/politicians

Participants perceived politicians as having the power but lacking the will to advance policies and programs to reduce HIV risk within their community. Politicians were viewed as motivated only by self-interest. Once elected, they were not thought to advocate on the community's behalf. “They don't take the time to look at it,” one participant remarked. Another stated bluntly, “They put it in an out box.” Participants felt politicians could help reduce HIV rates by improving the social and economic environment for African Americans. One male said, “Yeah, these things get in the way. The YMCA ain't free. The community is divided by gangs. No place to hold concerts. Nothing downtown. Youth losing parks to gang activity. Hard to get a job because of criminal records, wages or racism.” They recommended bringing better jobs to the community, improving access to safe and affordable recreational opportunities, reducing crime, and reducing urban blight. Participants expressed pessimism about whether these changes would occur, as they believed the needs of African American community members are a low priority for local politicians. As one female said, “Those people, like, the city, right? They're not helping us get... like group discussions about AIDS or nothing... They ain't trying to get no more health departments out here. They just thinking about theirself and if they got it and if they don't. They don't care about us ‘cause we live in the hood.” There was also a general lack of political engagement, particularly by high-risk youth, who were largely unaware of who their local elected officials were or how to reach them. Representative comments include, “We don't know them”, “We don't even see them” and, “They've never been in front of us.”

Health agencies and health-related services

Multiple barriers to the utilization of existing HIV education and prevention services by health facilities or were described. First, few participants, particularly young men, were aware of local HIV services and resources: “We ain't got no agencies.” Young women knew about public and

private clinics or CBOs with reproductive health services tailored for youth while young men were mainly familiar only with health department services. Second, participants believed the number of local health clinics and HIV testing sites was insufficient to adequately affect local HIV rates. As one young woman said, “They need to have more clinics.” Third, some perceived health agency services as inadequate or of poor quality. Male participants complained that free condoms provided by health departments were too small, of poor quality, inconsistently available, or lacked variety. One young man commented, “the health department gives defective condoms. Condoms cost too much.” High-risk males reported skepticism about using reproductive health services designed to circumvent access barriers, such as mobile health vans. As one young man explained, “They think it's the police sitting in this van. That's why they don't go to it.” Echoing complaints about the schools, some participants expressed the view that educational services provided by health organizations were out of touch with their sexual health needs. Again, they felt sexual health education messages targeted older youth, ignoring the reality that many younger adolescents are sexually active. As one young man explained, “They don't really talk about it sex. They'll focus on older people, like 18 or 19.” Finally, high-risk participants cited the cost of clinic visits and long waiting times for appointments as barriers. When asked what barriers exist for getting health agencies to help reduce the high HIV rates, one young woman said, “I think getting the agencies to talk to those under 15. Some girls 12 and 13 years old are getting pregnant.”

Multiple health system barriers were noted. High risk youth cited the cost of clinic visits and long wait times for appointments as salient barriers. One participant noted, “It's like they don't even care. They're talking about us walking around with STDs and stuff but I remember one point in time where you could just go to the health department, walk up there and get STD/ AIDS tests and all that. ” Another participant noted, “They ought to let it go back the way it used to be. You could just walk in and get tested. But now you've got to wait. Ain't nobody gonna feel like waiting. They might be burning.” There was the perception that health providers are indifferent to the fate of community members and are unwilling to get actively involved in reducing the high HIV rates. One participant commented, “I think why it is hard to get people from like the Health Department and doctors and stuff out here because they're doing their job just to make money.”

Discussion

In this study, youth did not perceive social institutions – whether in the formal or informal sectors - as providing active leadership roles around HIV prevention. The primary social institutions discussed were formal sector entities including faith-based organizations, schools, government, and health organizations. This is understandable given that these are the social structures through which health services and health promotion efforts often occur. Despite youth's perception that formal sector social organizations hold a prominent position as the primary arbitrators of health promotion activities, they felt that the philosophical orientation of these organizations' programs were often at odds with and prevented them from meeting the needs of youth. They felt there was a general lack of sustained discourse and collective action regarding HIV prevention by social institutions or programs, particularly those intended to serve youth. Youth perceived existing programs as out of touch with their sexual health and educational needs. These perceived limitations of the community's major social institutions in addressing HIV is concerning, given that the institutions described are those traditionally considered the main sources of sex education and HIV prevention programming.

The general absence of discourse about the role of grass-roots organizations in HIV prevention was surprising given the large number of local CBOs involved in our CBPR process and in recruitment. Many of these CBOs provide HIV-related prevention and education programming or offer youth-targeted programs that deal with HIV-related issues such as teen abstinence,

sexual responsibility, pregnancy and STD prevention. There are several possible reasons for participants' limited discussions about the role of local CBOs. First, CBOs' work may not be perceived as directly related to HIV prevention. Second, youth may view these organizations as part of the social fabric of their community, not as separate entities to be categorized with formal sector institutions when conceiving of social sector responses to HIV. Third, participants may have simply been unaware of CBO services and therefore were unable to consider them playing a significant role in HIV prevention efforts. Finally, it may have been a mental stretch to ask community youth to envision voluntary organizations with their often informal social networks and operating structures, limited human and financial resources, and narrow constituent base as playing a significant role within a large-scale community response to HIV when formal sector institutions have been trying, with limited success, to make a major impact for decades.

Participants primarily discussed formal sector institutions such as faith-based organizations, schools, and health agencies as having primary influence on community HIV rates. Faith-based organizations represent a particularly important institution for providing HIV health promotion activities for African American youth.²¹ Faith-based organizations have long served as a center of spiritual, political and civic growth within the African American community^{22, 23} and are often engaged in diverse health promotion activities. The influence of the church may be greatest for African American youth residing in the South, where faith-based organizations are an integral part of the cultural landscape^{22, 24} and where more than half of African Americans reside.²⁵ Similar to previous studies^{23, 26, 27}, youth in our study felt that faith-based organizations had largely failed to mobilize a coordinated effort to address HIV and avoided discourse around key HIV issues affecting youth, such as teen sex, homosexuality, condom use, or substance use. Faith institutions' alienation of high risk African American youth, particularly gay and substance-using youth, robs these institutions of a golden opportunity to reach youth most in need of both social support and prevention services. However, local youth were confident that successful collaborations with faith-based organizations for HIV prevention were possible if the barriers are addressed.^{22, 28}

Participants felt local school and health agency policies represented inadequate HIV prevention tools. At the time of this study, the North Carolina legislature mandated that schools provide abstinence-until-marriage sex education curricula.²⁹ Health agencies' sex education and HIV prevention programs were perceived to target older youth. Both these policy approaches were felt to be inappropriate in communities with early coital debut and high rates of teen pregnancy and STIs. Participants' desire for comprehensive sex education is consistent with national prevention guidelines³⁰⁻³⁴ and the desires of parents and the general public both nationally³⁵ and within the state.³⁶

Finally, youth felt politicians had the potential to address macro-level factors contributing to HIV risk among African Americans but lacked the political will and sense of social responsibility. A growing body of literature has documented that social policies regarding housing, neighborhood blight, unemployment, education, job skills training, incarceration, and drug policies affect HIV and other health risks within the African American community.^{1, 18, 37} Like youth in this study, this literature has advocated for more policies that address broader social issues as part of comprehensive approaches to HIV prevention in African American communities.

Implications

The comments from youth in this study provide multiple lessons for intervention development. The major message is that HIV prevention programs need to more effectively utilize the infrastructure and resources inherent in local social institutions to change the course of the

epidemic. Youth's suggestions for change provide a roadmap for the future. They indicated that social institutions need to be willing to acknowledge the primary factors affecting HIV risk, such as early adolescent sexual behavior, and tackle them head-on, even if they are politically sensitive. Youth suggested that community social institutions confront long-standing political oppositions to providing more comprehensive sex and HIV-related education and age-appropriate sexual health programs in schools and health organizations. Youth's lack of awareness of local CBOs indicated that rather than starting HIV prevention efforts by identifying community organizational partners to house interventions, intervention developers need to raise youth's awareness of local community resources and invest time strengthening existing organizations' capacity to engage youth.¹⁷ For example, mounting media campaigns to educate both parents and youth about existing youth-targeted programming, providing transportation services and repackaging existing programs to appear more youth-friendly may be important first steps. Finally, youth indicated that broad initiatives that address environmental determinants of HIV risk behaviors, such as the creation of more youth targeted social and recreational programs, could reduce local HIV rates by providing positive recreational opportunities and reduced time for engaging in risk behaviors.

Limitations

There are several considerations when interpreting the data from this study. First, these data from two rural communities may not be generalized to populations with different socio-demographic characteristics. Second, social desirability bias may have affected the range of responses provided given the group discussion format. Third, these data reflect youths' *perceptions* but may not be an accurate representation of reality. For example, there may be an adequate number of local health agencies relative to the population size and density. That youth may not be aware of these facts clearly affects their perceptions about their communities' institutional capacity to address the local HIV epidemic. Finally, the perspectives of local HIV positive youth are missing. These individuals have the best perspective on how and why they were infected and may have provided additional insights about the potential of local social institution in primary or secondary HIV prevention.

Conclusion

Our findings indicate that effectively engaging social institutions in HIV prevention efforts will be critically important to altering the course of the epidemic, particularly in rural African American communities in the south. The findings also suggest that HIV prevention messages and the social institutions traditionally used for providing them have not evolved sufficiently to incorporate the challenges faced by today's African American youth. Youth clearly articulated their concerns that the policies, educational and prevention messages provided by major social institutions are out of touch with their needs. Comprehensive HIV prevention programs should understand the role that local social institutions play – both real and perceived – in mediating HIV rates. Identifying which institutions community members believe influence local HIV risk will allow us to identify those institutions that can serve as effective partners in HIV prevention efforts. Identifying community members' perceptions of barriers to HIV prevention efforts presented by local social institutions and perceived barriers to the utilization of HIV services provided by social institutions will help us to develop interventions that incorporate approaches to deal with these challenges.

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