

Self-Implemented HIV Testing: Perspectives on Improving Dissemination Among Urban African American Youths

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We examined the potential for increasing the reach of HIV testing to African American youths through the dissemination of oral-HIV testing. From 2012 through 2013 we examined the perceptions of alternatives to pharmacy dissemination of SITs in African American youths (5 focus groups) and service providers (4 focus groups), and conducted an ethnographic study of pharmacies (n = 10). Participants perceived significant advantages to delivering SITs through community health and services for adolescents (e.g., increased confidentiality, reduced stigma) over pharmacy dissemination. Given proper attention to fit, SIT dissemination could be facilitated through distribution by health and social service sites, and by improving elements of pharmacy dissemination. (*Am J Public Health*. 2015;105:S449–S452. doi:10.2105/AJPH.2014.302531)

HIV testing is a linchpin in the Centers for Disease Control and Prevention Comprehensive HIV Prevention Strategy (CHPS).^{1–6} CHPS has a national goal of testing 90% of HIV-positive persons by 2015.⁷ In the United States, HIV testing relies heavily on clinic-based testing.⁸ However, clinic-based testing poses significant barriers for adolescents and young adults, including inconvenience (time, location, transportation), privacy concerns, and fears of being socially stigmatized.^{9–14} In particular,

clinic-based testing has limited reach among underserved high-risk populations (e.g., African American adolescents and young adults^{15–26}). Approximately 61% of HIV-positive African American youths do not know their HIV status,²⁰ creating delays in diagnosis and treatment that, in turn, produce poor prevention and survival outcomes. Self-implemented HIV testing (SIT) addresses these problems by increasing privacy and convenience.²⁷

Oral method SIT (OraQuick; OraSure Technologies, Bethlehem, PA) is approved in the United States for sale by retail pharmacies (\$40+/kit) to those aged 17 years and older.^{28,29} Oral SIT requires no special storage, and is preferred over finger stick technology.²⁷ Oral SITs may provide an important supplement to clinic-based testing. However, purchasing oral SITs requires a verbal request of a pharmacist in a relatively public situation that may be uncomfortable for many youths. Moreover, use of neighborhood pharmacies may heighten embarrassment and social stigma if youths are worried that neighbors may observe their kit purchases. Extending the reach of SITs may require innovative dissemination strategies through nontraditional sites.⁵ In this regard, youth-focused, community-based organizations (CBOs) and social or health services may offer greater familiarity, comfort, and privacy from the larger community. We conducted a series of qualitative studies that examined the dissemination of oral SITs with African American adolescents, service providers, and pharmacies.

METHODS

Our study, which took place from 2012 through 2013, stems from a larger community-based investigation that examined ecological factors and socio-sexual development among African American youths from low-income neighborhoods in Chicago, Illinois, and San Francisco, California.^{30,31} Additional details on procedures and measures are available from J. A. Catania.

Procedures, Samples, and Measures

Adolescent focus groups. Youth focus groups were conducted in Chicago using trained, experienced African American facilitators (n = 5 groups: 1 mixed gender group, 2 male-only groups, and 2 female-only groups; there were 6–9 participants per group; total n = 29; 48% males, 52% females; ages 16–19

years). Sexually experienced heterosexual youths with a history of sexually transmitted infections, pregnancy, pregnancy scares, sexual concurrency, or multiple sexual partners (past year) were recruited from CBOs in the study neighborhoods. Participants were provided graphic materials on the oral SIT kit and information on pharmacy dissemination and costs. We queried participants' opinions on purchasing kits through pharmacies, kit costs, and alternative dissemination venues.

Provider focus groups. To capture variation in provider perspectives across urban areas, we conducted focus groups with providers of sexual health and social services for adolescents in San Francisco and Chicago (n = 4 groups; 2 groups per city; 4–7 participants per group; total n = 22; 32% males, 68% females; age range = 19–73 years; 50% African American, 32% White, 18% other). Providers represented various settings (e.g., school-based sex education, health clinics, adolescent or pediatric medical clinics, sexually transmitted infection clinics, after school sports and education programs, programs for homeless youths, child protective services). Participants were provided graphic materials on oral SIT kits and information on pharmacy dissemination and costs. We queried participants' opinions on purchasing kits through pharmacies, kit costs, and alternative dissemination venues.

Rapid Ethnographic Study

We conducted a rapid ethnographic study of Chicago pharmacies (n = 10) in our adolescent participants' neighborhoods that belonged to national chains advertising that they provided the kits to explore the experience of purchasing SIT kits. This work occurred shortly after OraQuick was marketed. An investigator approached each pharmacist, and a request was made to purchase the OraQuick SIT.

All transcribed material was coded using structural and descriptive methods by a team of 4 investigators, and reliability was checked using a consensus approach.^{32–34} Rapid ethnographic field notes were reviewed by 2 investigators.

RESULTS

Adolescents had concerns with over-the-counter pharmacy dissemination, including concerns with losing confidentiality or privacy, and being stigmatized, and concerns over the high retail

Adolescents' and Providers' Perceptions of Pharmacy Dissemination, Self-Implemented HIV Testing (SIT) in African American Youths

Adolescents' Perceptions

Pharmacy dissemination: advantages

Bagging: "A pharmacy counter, 'cause they put it in a little bag and nobody got to see what it is."

Pharmacy dissemination: concerns

Social stigma, less privacy/confidentiality: "Like, that would probably be the biggest problem, like as, you're going to the store trying to buy one. 'Cause I'm not gonna go to a cash register with a AIDS test. It would be kind of embarrassing."

OTC vs on shelf: "Because, maybe, you don't want the pharmacy technician to know." (comment on the idea of point-of-sale being from a store shelf)

Costs: "Dang, \$40.00?"

CBO providers' perceptions of pharmacy dissemination

Pharmacy dissemination: advantages

Consumer education: "The advantage of having a possible reference person, and now that they'll do shots. . . I wouldn't think it would be too much to ask them to do counseling about how to give these (HIV SITs)."

Pharmacy dissemination: concerns

Privacy, social stigma—point of sale: "I think in a pharmacy, if it's kept behind the counter. . . you still have to ask a pharmacist for it. . . I think—that creates a barrier for anybody. . . especially for young people, who people already have judgments around like, 'Well, you shouldn't be having sex anyway.'"

Privacy, social stigma—point of sale: "If that was in that box, and was right next to a pregnancy test, it would likely sit there, because if somebody sees me [provider speaking of adolescents] buying a pregnancy test, I mean you know, I could be pregnant. But if somebody sees me buying this, it could mean that I have something that's deadly."

Privacy, social stigma—dissemination venue location: ". . . and are they going to be forced, because of the privacy issue, to go outside their community? And they still would have—they still have the fear that this information is going to get out."

Privacy, social stigma—dissemination venue location: "What if it's a pharmacy in their neighborhood where they know people who work in the store?"

Venue access problems: "The proximity for these places in communities, I mean there's some communities that don't have some of these resources for miles—a square block radius, or whatever."

OTC vs on shelf: "Yeah, it'd be great if it's sitting on the shelves next to the cold medicine, but I'll be shocked if that's how it is."

Retail costs: "So we have patients that come in every day that can't pay for the bus to get where we are. . . I have a feeling it would be cost-prohibitive for many adolescents."

Note. CBO = community-based organization; OTC = over-the-counter.

costs (see the box on this page). Some concerns could be ameliorated if the pharmacist put the kit in a bag, and off-the-shelf purchasing was available. Providers believed (1) that pharmacies limited confidentiality or privacy, (2) high retail costs might inhibit access, (3) off-the-shelf sales were better, and (4) that pharmacists could serve as a source of SIT education.

Providers believed that their respective settings would have different roles to play in SIT dissemination, including (1) only providing referrals to venues that dispense SITs, (2) only providing education on how to use SITs appropriately, and (3) dispensing SIT kits and education materials (see the box on the next page). Poor organizational, program, and client fit were all mentioned as reasons for not directly dispensing SITs.

Seven of 10 pharmacies had no oral SIT kits available for sale. Reasons for not having the kits were lack of space behind the counter and low consumer requests. Of the 3 pharmacies that had

oral SITs, (1) none offered guidance on using them, and (2) all sold oral SITs from behind the counter.

DISCUSSION

The disproportionately low rates of HIV testing among racial/ethnic minority youths indicated that access to HIV testing remains a significant challenge. Our results suggested that oral SIT presents an opportunity to reach African American youths by reducing barriers presented by clinic-based testing. Point-of-sale costs (\$40/kit) were a barrier to SIT purchasing by low-income youths. Dissemination of SIT through nonprofit organizations would significantly reduce the base cost (\$11.00/kit; Tony Falvo, OraSure, Inc., personal communication, November 20, 2013). We suggested improvements on pharmacy dissemination strategies.

Increasing dissemination beyond pharmacies to other venues was generally acceptable if

attention was paid to achieving appropriate fit between agency conditions or mission and HIV testing. Because of the purposive sampling strategy, our findings could not be generalized to other settings. Moreover, we did not examine online sale sites that offered point-of-sale privacy, but had a loss of confidentiality with mail delivery. Research is needed to examine oral SIT in the context of innovative dissemination strategies (e.g., vending machines) that will increase reach. Overall, SIT might provide an alternative for those averse to seeking clinic testing. ■

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Providers' Perceptions of Alternative Dissemination Venues Self-Implemented HIV Testing (SIT) in African American Youths

Client/Program/Organizational Fit

Program-client fit

"We have youth who've aged-out of the . . . system, so they're living in the building but they've aged out so it's not really—they're not really youth anymore, they can make their own choices now that they're 18, 19. But then with the juveniles who work with the juvenile system, maybe we can make it available to them." (Context: Agency provides care for both younger and older adolescents, but those over 18 years make their own health care decisions so they could seek testing outside of the system.)

"I think parts of the organization can because like, okay, one part we're working with grandparents raising grandchildren so I'm not—I don't think they'll be open about their grandkids being tested for HIV." (Context: Agency works with grandparents who are raising their grandchildren and believe grandparents would want more control over the decision to be tested.)

Program fit

"[We are] a youth community center in the community, [youths should] be able to get it there, you know, because of the time they [providers] work with youth services, things like that, like sexual awareness and things."

". . . almost definitely would not offer this as a service just because we don't offer health [services]."

Organizational fit

". . . definitely not [provide SIT] as like something we would do at our office because that's just—yeah, we're not the type of agency that does services." (Context: Agency provides no direct services.)

". . . but there would certainly be pushback for HIV rapid testing to happen in schools and that just wouldn't happen."

"I think my agency would never give it because we bill for the services."

Agency Dissemination Roles

Direct provider role

"We would probably just present it as an option among many options..."

"The way that we would incorporate this into our center would be to have our facilitators present this as an option with a very, very clear caveat of, you know, we want you to talk with an adult that you trust about this test, about the result of the test."

Referral role

"We've had some students who've been reluctant to go to a clinic for a pregnancy test. And are like I'm just gonna go buy one at Walgreens and then I'll let you know. And they do for the most part. So I'm hoping that we would be able to encourage the same with this as well."

Education role

[participant A to participant B] "Okay, but you'd be willing to educate youth about it? And to educate other youth to educate other youth about it?" [Participant B responds] "Absolutely. And we would as well. Yeah, absolutely. . . we would certainly do that. We certainly provide the education and we'd even talk about a video or how it works and what it looks like; absolutely."

"I could see us integrating information on how the testing is done and kind of the steps that go along with the testing into our education because we talk about what getting tested for. . . sexually transmitted infection."

Education and referral

"When we do health education. . . we talk about HIV or this is a place you can go to get tested. . . you can go to Walgreen's and get this. . . . We want to offer all options to adolescents."

"Schools could have it [education and referral] through a classroom. It could happen through small group discussions that are facilitated by certified counselors. . . then that is. . . a referral process to community based organizations that may offer the opportunity."

"I think it would have to be integrated as part of our health classes."

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Contributors

All authors reviewed and contributed to the conceptualization and writing of the article. L. G. Dolcini was the principal investigator of the grant supporting this work (HD061027), and G. W. Harper and J. A. Catania were co-investigators. D. H. Tyler, A. Timmons, and D. Motley were involved in primary data collection and data

coding. E. R. Orellana, S. L. Towner, and L. G. Dolcini-Catania were involved in data coding and analysis.

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Human Participant Protection

The study was approved by the institutional review boards at Oregon State University and De Paul University, Chicago. We complied with the "Principles of the Ethical Practice of Public Health."

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The Medicaid Expansion Gap and Racial and Ethnic Minorities With Substance Use Disorders

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We compared the race and ethnicity of individuals residing in states that did and did not expand Medicaid in 2014. Findings indicated that African Americans and Native Americans with substance use disorders who met new federal eligibility criteria for Medicaid were less likely than those of other racial and ethnic groups to live in states that expanded Medicaid. These findings suggest that the uneven expansion of Medicaid may exacerbate racial and ethnic disparities in insurance coverage for substance use disorder treatment. (*Am J Public Health*. 2015;105:S452–S454. doi: 10.2105/AJPH.2015.302560)

The Patient Protection and Affordable Care Act’s¹ Medicaid expansion has the potential to connect many Americans in need of substance use disorder (SUD) treatment with insurance coverage. However, some racial and ethnic groups may be underrepresented in the Medicaid expansion population because they are more likely to live in states that have not expanded Medicaid.^{2,3} Although racial and ethnic minority groups constitute 37% of the US population, they constitute 47% of individuals who meet new federal eligibility criteria for Medicaid.² The estimated percentage of individuals who meet the new Medicaid criteria and live in an expansion state is 34% among African Americans, 45% among Whites, 53% among Latinos, and 69% among Asians.

Yet, how Medicaid expansion may affect long-standing racial and ethnic disparities in