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Social Actors Fight the Rising Tide of HIV in U.S. Southern Poor

“The greatest number of persons living with HIV in the United States are now living in the South, and they face poorer health outcomes and increased AIDS-related deaths as compared to the rest of the country.”

The greatest number of persons living with HIV in the United States are now living in the South, and they face poorer health outcomes and increased AIDS-related deaths as compared to the rest of the country. The southern United States has a disproportionate share of low-income individuals, with many lacking access to health care and health insurance. Health facilities are also comparatively fewer and more difficult to reach than in other areas of the United States. The impacts of this already poor health infrastructure on low-income people living with HIV in the South can be life-threatening.

Background

This policy brief summarizes key findings and recommendations based on qualitative research carried out in 2012 by HIV researchers at the University of Massachusetts Boston, Associate Professor Courtenay Sprague and Senior Fellow Sara E. Simon, to understand in-depth experiences of low-income persons living with HIV (PLHIV) in two locations in the southern state of Alabama. Semi-structured interviews were carried out with 25 PLHIV on the AIDS Drug Assistance Program (ADAP), as well as 25 health and social service providers from the same clinics and AIDS service organizations where clients obtained services. The research invited PLHIV in Alabama to discuss their experiences in obtaining and maintaining HIV care. Low-income individuals who were part of the Ryan White AIDS Drug Assistance Program were recruited; their characteristics are summarized here:

Table 1. Characteristics of study population: age, education, employment, race, sexual orientation, and gender

Age: 20-52		Education range: 7th grade to associate’s degree				Unemployed: 14		
Gender		Race				Sexual orientation		
		African-American	White	Multiracial	Hispanic/Latino	Heterosexual	Bisexual	MSM
Male	18	13	4	1	-	6	4	8
Female	7	3	3	-	1	7	-	-
Total	25	16	7	1	1	13	4	8

Findings

HIV has a disproportionate impact on individuals in the southern United States as compared to the rest of the country

The U.S. South—comprising 17 states—now has the greatest number of adults and adolescents with HIV (PLHIV) in the nation. More than 60% of PLHIV are not in HIV care in Alabama and Mississippi, contrasted with a national figure of 25%. Individuals in the South have poorer HIV outcomes, with 48% of AIDS-related deaths in the South. Support to these individuals should come via two key U.S. policies: the National AIDS Strategy and the Affordable Care Act (ACA).

Box 1—U.S. National HIV/AIDS Strategy Goals:

- 1) reducing the number of people who become infected with HIV;
- 2) increasing access to care and improving health outcomes for PLHIV; and
- 3) reducing HIV-related health disparities

“Half of respondents mentioned housing as an essential part of what they need to be healthy; one-third mentioned transport challenges; and 19 of 25 mentioned challenges accessing adequate food.”

Delays in obtaining HIV care were attributed to multiple factors

Most respondents reported delayed HIV care, describing concentric factors such as psychological distress, fear, lack of information, substance use, incarceration, lack of food, transport, and housing. Respondents reported these issues when discussing difficulties in entering into HIV care at the time of diagnosis. Many did not initiate antiretroviral therapy until after becoming extremely ill, leading to HIV care delays, which can result in declining health and premature mortality.

Respondents were dependent on federally funded social services to enter into and maintain care, including mental health support, housing, food, and transport

The federally funded Ryan White Program includes ADAP, which allows individuals with low incomes or lack of health insurance to access antiretroviral medications. Importantly, Ryan White includes social services programs that were found to be essential for these southern PLHIV in accessing care. Half of respondents mentioned housing as an essential part of what they need to be healthy; one-third mentioned transport challenges; and 19 of 25 mentioned challenges accessing adequate food.

Table 2. Years living with HIV, mental health, substance use, food, housing, transportation challenges, previous incarceration

Years living with HIV (as of November 2012): <1 to 24 years

Number reporting mental health challenges, substance use, food, housing and transportation challenges, and previous incarceration, of 25 people total

	Mental Health Challenges (including anxiety, depression, bipolar disorder, and suicidal thoughts)	Previous or current users of substances (some currently in rehabilitation programs)	Actively using food stamps or expressed challenges accessing food	Difficulty with housing and homelessness	Previous incarceration	Use ASO transportation vouchers, food, and/or rehab programs
Number self-reporting	16	9	19	5	7	25

Informed social workers who work hand in hand with medical services and social support services are the key “enablers”

Alabama’s “social infrastructure” has enabled low-income PLHIV to access care. AIDS service organization (ASOs) are the community-based organizations that provide social services and also link individuals to medical care. This “twinning” of medical with social services is critical, as are the social workers in ASOs and clinics who actively link PLHIV to care and enable them to engage, re-engage, and remain in HIV care. These individuals are social “enablers” who prove vital to ensuring long-term retention in continuous HIV care.

Recommendations

Based on the key findings, the following recommendations were made:

1. At key moment of diagnosis, follow up with PLHIV using text messaging, phone calls, community liaisons, or peer support to break isolation and establish care linkage
2. Provide better support to enable social workers to get individuals into HIV care more easily and effectively by reducing ADAP bureaucracy
3. Secure continued ADAP and Ryan White Program funding in southern states during health care transition
4. Increase public awareness of HIV in Alabama in order to tackle HIV stigma and offer HIV-prevention messaging
5. Reach incarcerated populations with HIV services and remove punitive measures that impact former inmates' access to social programs, such as food stamps and housing

Next Steps: Research and Policy

Additional analysis by Simon and Sprague is under way that draws out the central policy implications under the U.S. health care transition for the health of PLHIV in this population. Additional research in the southern United States—a comparison between Alabama and Mississippi—is forthcoming (with Konkle-Parker, Brown and Kempf).

To read the full article, see <http://www.equityhealthj.com/content/13/1/28>.

About the Authors



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