HIV in the Rural American South

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Abstract

Currently, the federal government is launching an initiative to end America’s HIV epidemic. However, in the rural American South, HIV is a deeply entrenched problem. Several factors contribute to its prevalence, including limited access to healthcare. Many Southern states, especially those who have not expanded Medicaid, have weak health insurance systems that fail to sufficiently provide the public with medication to prevent and treat HIV. Healthcare facilities are also difficult for many rural Americans to reach, as transportation may not be affordable. Furthermore, the conservative culture of the South contributes to the epidemic. Men who have sex with men (MSM) and intravenous drug users face stigma that robs them of support and discourages them from seeking medical attention. African Americans, the poor, and people with mental illness also face struggles that leave them vulnerable to HIV. Ultimately, to truly end HIV transmission, the federal government must commit more fully to the effort. Additionally, Southern states must expand Medicaid and work to promote acceptance of homosexuality within their communities.

Introduction

After years of progress in decreasing the HIV infection rate, public health officials have met a roadblock (1). Despite their efforts, the number of new HIV infections has remained relatively constant since 2013. Consequently, President Trump’s 2019 State of the Union Address called for a 90% reduction in the American HIV infection rate by 2030 (2). To achieve this goal, the federal government will try to increase access to two essential medications: pre-exposure prophylaxis (PrEP), which prevents HIV infection, and antiretroviral (ARV) drugs,
which infected people can take to lower the viral load in their blood and reduce the likelihood that they will infect others.

However, the federal government will not apply its efforts to the whole country; instead, it will target the states with the highest rates of rural HIV transmission, including Alabama, Mississippi, and South Carolina (Figure 1). The inclusion of Southern states is no coincidence: in 2017, 52% of new HIV diagnoses took place in the South, while in 2016, 47% of HIV deaths took place in the South—the most of any region (3). This paper describes the factors contributing to the HIV epidemic in the rural American South, including limited access to healthcare, a conservative culture, and lack of support for vulnerable populations.

**Limited access to healthcare**

Not all Americans have equal access to health insurance (4). While many receive health insurance from their employers, others do not or are unemployed (5). Consequently, many people rely on Medicaid, a government program that provides free health insurance for the poor (6). However, Medicaid coverage varies by state (4). After the passage of the 2010 Affordable Care Act (ACA), states were granted the ability to offer Medicaid to people earning less than 138% of the federal poverty line (7). Nevertheless, fourteen states, most of which are in the South, still refuse to expand Medicaid (Figure 2).

As a result, many Americans lack coverage. According to data from the 2017 American Community Survey, 10.5% of the general US population is uninsured (Table 1). Insurance rates are even lower in the South, where 13.5% of the population is uninsured. Geography is not the only factor influencing insurance status; race also plays a role. Though 73.5% of the American population is white alone, only 65.2% of the uninsured population is white alone. Accordingly, a disproportionate number of uninsured people belong to minority groups.
When states do expand Medicaid, they not only allow more people to receive health insurance but also directly affect the spread of HIV (7). A study analyzing data from the nationwide Behavioral Risk Factor Surveillance System survey found that when states expanded Medicaid, HIV testing rates rose among African Americans and people living in rural areas. Similarly, a 2019 review article found a positive correlation between Medicaid expansion and increasing rates of consistent ARV use (4).

In fact, ARV use is closely tied to the wider health insurance system (10). The ARVs people living with HIV (PLWH) need to survive are extremely expensive, costing roughly $30,000 a year. To put this in perspective, in 2018 the median household income was $61,937, barely twice as much (11). As a consequence, most people rely on their insurance company to cover the cost (10). However, since many plans still require co-pays, ARVs remain prohibitively expensive for some PLWH. These people, as well as the uninsured, often receive free medication through government-run AIDS Drug Assistance Programs (ADAP). However, ADAP is far from perfect. A study of PLWH in North Carolina found that 21% of those using ADAP had been forced at some point to pause ARV treatment, often due to problems renewing program membership. From a public health perspective, such pauses are concerning: ARVs not only help PWLH but prevent them from spreading HIV to others (2).

On the topic of transmission, PrEP use is also influenced by the availability of health insurance (12). Just like ARVs, PrEP is costly (13). Though generic versions are sold for about $60 a year overseas, in the United States the drug company Gilead still holds the patent. Its drug, Truvada, costs about $20,000 a year. Consequently, many people find PrEP unaffordable, including those with insurance, who sometimes struggle with expensive deductibles and other related costs (14). These people, as well as the uninsured, often use government programs to
access the medication. However, because of the price, even state governments struggle to provide sufficient quantities. The Trump administration has attempted to provide a solution; it negotiated with Gilead to provide 200,000 people with over a decade’s worth of free PrEP (13). However, roughly 730,000 need PrEP but are not taking it, leaving over half a million people unprotected. Ultimately, the uninsured remain vulnerable (12). A study of patients in Missouri, Mississippi, and Rhode Island found that those without insurance were several times less likely than those with insurance to be taking PrEP three months after receiving a prescription.

Paying for healthcare is not the only barrier to HIV prevention and treatment; patients must also be able to access medical facilities (15). This can be difficult, as clinics providing necessary medication are relatively few (16). Researchers analyzing information from the National Survey on HIV in the Black Community, taken by African Americans across the US in 2016, found that only 62% of those surveyed lived within an hour of a clinic providing PrEP. In fact, reaching any medical care can be difficult, as physicians increasingly avoid moving to rural areas (17). Consequently, the cost of transportation to a doctor’s office or clinic is more than many can afford (10). For example, over a quarter of participants in the North Carolina ARV study struggled to pay for HIV-related transportation.

While the problem exists on a local level, its origins are partly political (15). When researchers interviewed eleven government workers caring for HIV patients in rural areas, including the South, interviewees mentioned that due to government budget cuts, programs to assist HIV patients in reaching care had ended. As a result, some of their patients were simply unable to receive medical attention.

**Conservative culture**
The HIV epidemic most impacts MSM; as of 2016, 16.7% of MSM were projected to contract HIV at some point in their lives (18). However, homosexuality is often stigmatized in the American South (19). According to data from the Pew Research Center, 37% of Southern adults disapprove of homosexuality. These attitudes are more pronounced in rural areas (20). Compared to urban MSM, rural MSM are significantly less likely to feel accepted by their communities.

The stigma around homosexuality is particularly important when viewed through the lens of the African American church (21). African American MSM are the group most at risk for HIV; the CDC predicts that half will someday become infected (18). Furthermore, African American MSM are not necessarily supported by their communities (21). In general, African Americans are highly religious, and the church has played a powerful role in shaping African American cultural identity. However, many African American churches condemn homosexuality, which not only creates a hostile climate for MSM but affects their self-esteem. In a study of African American MSM from the South, researchers found that more religious MSM were more likely to view homosexuality negatively.

The stigmatization of homosexuality directly impacts the HIV epidemic, in part because it hampers HIV testing (22). Because MSM belong to an at-risk population, they have a greater need to be tested. However, doctors only learn about their patients’ sexual behavior if patients feel comfortable enough to share it. Just as rural MSM feel less accepted by their communities, they are also less likely than urban MSM to tell medical professionals about their male sex partners (20, 22). Consequently, rural MSM have lower HIV testing rates than urban MSM (23). Stigma also affects PrEP use (24). Many MSM are hesitant to use PrEP because they are concerned their communities will find out and make assumptions about their sexuality. HIV-
positive MSM often behave similarly, concealing both their homosexuality and their HIV infection out of fear they will be mistreated (25). Internalized stigma also contributes to the spread of HIV (21). A study of African American MSM found that those who viewed homosexuality negatively were less diligent about condom use.

People struggling with drug addiction likewise face stigma (15). Like MSM, intravenous drug users face an increased risk of HIV, as the infection can spread through shared needles. However, conservative state and local governments often hesitate to fund needle-exchange programs aimed at reducing HIV transmission, as they believe the policy condones drug use (26). Needle-exchange programs are nevertheless proven to work, and when lawmakers refuse to allow them, they give up a key tool for combatting HIV (15). Furthermore, drug users’ behavior is often shaped by stigma (27). In a West Virginia study, intravenous drug users described hesitation in visiting a needle-exchange clinic where workers appeared judgmental. Similarly, a study of African American cocaine users in Arkansas asked people in rural and urban areas to state how willing they would be to take an HIV test in various locations, such as a doctor’s office (28). Rural cocaine users were less willing to take a test at three quarters of the sites, possibly because people living in rural areas were more concerned about others learning their HIV status.

The conservative Southern culture does not just promote stigma; it also fosters ignorance about sexual health, which contributes to the epidemic (29). In states like Mississippi, sex education is incomplete, leaving many people unaware of how to use condoms to protect themselves from sexually transmitted diseases. Similarly, knowledge of PrEP is not widespread; according to a CDC survey, only two thirds of health care providers throughout the country knew about PrEP in 2015 (30). Public knowledge in the South is even lower (31). In a study of 863 mostly African American women in the South, only 10.7% knew about PrEP, though 76.9%
were interested in using it after being informed. Likewise, in South Carolina, researchers tested 171 pregnant Latinas on basic facts about HIV prevention and treatment (32). Less than a quarter scored 73% or above, and 107 of the women did not know that mother-to-child transmission could be avoided with ARV drugs.

**Lack of support for vulnerable populations**

African Americans bear the brunt of the HIV burden, accounting for 53% percent of new HIV diagnoses in the South (3). In part, the prevalence of HIV among African Americans stems from distrust of medical authorities (33). A study of African American MSM in Georgia found that almost half believed that doctors often hid malpractice, while over half believed African Americans received worse care than whites. This distrust was correlated with a lower likelihood of attending medical appointments. Distrust also affects PrEP use (34). When researchers interviewed African American men in Mississippi, they found that many doubted PrEP’s safety and efficacy.

However, African Americans’ distrust of medical practitioners is not baseless. In the same Mississippi study, African American participants reported experiencing racism in medical settings; one woman described being forced to wait at the doctor’s office while a white patient who had arrived later was seen first. Furthermore, a 2016 study of American medical residents and students found that many of them believed myths founded in racism (35). For example, a quarter of residents agreed with the statement “Blacks’ skin is thicker than whites.’” As a consequence, some of the study subjects also believed African Americans feel less pain and should be prescribed lower levels of pain medication. Thus, the country’s history of racism continues to negatively impact the medical care African Americans receive today.
HIV is also tied to poverty in ways beyond a patient’s ability to afford medication (36). This is significant as, according to data from the US Census Bureau, the South has the highest rural poverty rate in the country (37). Homelessness in particular contributes to the epidemic (38). While the public and government often overlook homelessness in rural areas, it nonetheless exists and is often exacerbated by drug use (39). Perhaps because of the inherent instability of life without housing, the homeless are less likely to consistently take ARVs and achieve viral suppression (38). Hunger is also a concern; many Southern states, such as Louisiana, Alabama, and Mississippi, have high rates of food insecurity, which is linked to inconsistent ARV use and worsened ARV side effects (40, 41). Lastly, merely being poor may prevent people from guarding against HIV, as those in dire financial straits have more immediate concerns (42). In a 2019 study of African Americans in Mississippi, some stated that they were more worried about providing for their families than preventing HIV.

Additionally, HIV is connected to mental illness (43). When researchers assessed data from the 2016 Behavioral Risk Factor Surveillance system, a survey of over 33,000 people, they discovered that people with mental health problems were far more likely to participate in behavior that increases risk of HIV, including unprotected sex. In men, this dangerous behavior was mitigated by the presence of social support, but men were less likely than women to feel socially supported. Mental health also influences the behavior of PLWH, which is meaningful as HIV patients are at an increased risk of depression (44). A study of HIV patients at a Michigan clinic did not track depression or anxiety diagnoses but found that patients taking antidepressants or anti-anxiety medication were more likely to consistently take ARVs. However, mental health support is yet another service that many people receive through their insurance company or Medicaid (45).
Conclusion

HIV in the rural American South cannot be controlled without an intensive effort to change the political conditions contributing to the problem (46). In particular, the federal government must commit more deeply to Trump’s plan if it is to work. In 2019, Trump requested $291 million for HIV reduction, but roughly $25 billion are needed. Funding must be increased for any progress to be made.

Additionally, the federal government should take firm action in regard to Gilead. When Truvada was developed, government money was used to fund its testing. As a result, the Justice Department is currently suing Gilead for a share of the company’s profits (47). However, the government should act even more decisively and remove Gilead’s patent under the Bayh-Dole Act (46). Ending the patent would substantially decrease the price, making PrEP easier to access.

More drastically, Congress should consider redesigning the American healthcare system (48). Candidates in the upcoming 2020 election are discussing new approaches, such as the implementation of a single-payer system in which the government covers all healthcare costs. While this method may make some Americans uncomfortable, it is nonetheless worth considering. The current health care system leaves too many people without the treatment they need and is one of the most influential factors in the perpetuation of the HIV epidemic (7).

If the current system remains in place, states must take increased responsibility for public health. Certainly, all states must expand Medicaid as soon as possible in order to increase HIV testing and ARV adherence rates. However, they should also increase funding for other programs, such as those providing transportation vouchers to help patients reach clinics (15). Sex education must also improve; all young people should be fully informed about PrEP and condom use in school to prevent HIV transmission (29).
Social change is also vital (21). Since the African American church is such an influential presence in the lives of an at-risk population, public health officials should work with the church to spread information about HIV, ideally in ways that would promote testing and reduce stigma. The possibilities of this method have already been proven (49). In a 2015 study, researchers implemented Project FAITHH, which worked with rural African American churches in Alabama to inform the public about HIV in ways specifically adapted to their religion and culture. Not only did the program reduce stigma and increase HIV knowledge, but many participants even enjoyed the associated activities.

Moreover, change must occur within the medical community (34). Even if health care providers do not treat African Americans differently, they should be aware of the skepticism some African Americans harbor toward doctors and take care to treat their patients with respect. Meanwhile, researchers should study the best ways to overcome medical mistrust.

Another potential avenue for improvement is the use of technology as a tool to combat HIV (50). Researchers have developed an algorithm allowing doctors to quickly pinpoint patients most at need of PrEP. This tool has potential, both because doctors often rush through patient visits and because testing is tremendously valuable in managing the HIV epidemic. A Florida study of rural African American men found that many began to use safer sex practices, including regular condom use, after taking their first HIV test, even though their tests were negative (51). Thus, a tool that facilitates testing may have far-reaching ramifications.

The Internet is another potential tool (20). In rural areas, MSM frequently use the Internet to create a sense of community. Consequently, health officials could use the Internet to reach MSM with HIV-related information, perhaps by buying advertisements on websites frequently
used by MSM. The anonymity of the Internet will allow MSM to gain the knowledge they need to protect themselves without exposing their identities to the judgement of those around them.

Overall, America has to ability to end the HIV epidemic. The federal government has expressed the desire to combat the problem and is taking initial steps, while research groups continue to study the best ways to increase testing and treatment (2, 49). However, considerable work still needs to be done, and without substantial changes to our society and healthcare system, it is unlikely that HIV transmission will ever be eliminated (21, 4). Ultimately, for true improvement to occur, the public must pressure all levels of government to take action and save lives.
References
1. CDC. CDC data confirm: Progress in prevention has stalled [cited 2019 Nov 10].
2. HIV.gov. What is ‘Ending the HIV epidemic: A plan for America’? [cited 2019 Nov 10].
3. CDC. HIV in the United States by region [cited 2019 Nov 10].
   https://www.cdc.gov/hiv/statistics/overview/geographicdistribution.html
4. Adamson B, Lipira L, Katz A. The impact of ACA and Medicaid expansion on progress
   http://www.bbc.co.uk/newsbeat/article/10067521/how-does-us-healthcare-work
6. Rudowitz R, Gardfield R, Hinton E. 10 things to know about Medicaid: Setting the facts
   straight [cited 2019 Nov 10]. https://www.kff.org/medicaid/issue-brief/10-things-to-
   know-about-medicaid-setting-the-facts-straight/
7. Gai Y, Marthinsen J. Medicaid expansion, HIV testing, and HIV-related risk behaviors in
   Nov 10]. https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-
   decisions-active-map/
9. United States Census Bureau. Selected characteristics of the uninsured in the United
   States [cited 2019 Nov 10].
   https://factfinder.census.gov/faces/tables服务/jsf/pages/productview.xhtml?src=bkmk
    barriers and lapses in treatment and care of HIV-infected adults in a southern state in
    the United States. AIDS Patient Care and STDs. 2017;31(11):463-9. DOI:
    10.1089/apc.2017.0125.
11. Guzman G. New data show income increased in 14 states and 10 of the largest metros
    insurance coverage on utilization of pre-exposure prophylaxis for HIV prevention. PloS
    2019 May 9.
14. Luthra S, Gorman A. Rising cost of PrEP to prevent HIV infection pushes it out of reach
15. Albritton T, Martinez I, Martinez I, Gibson C, Angley M, Grandelski VR. What about
    us? Economic and policy changes affecting rural HIV/AIDS services and care. Social
16. Ojikutu BO, Bogart LM, Mayer KH, Stopka TJ, Sullivan PS, Ransome Y. Spatial access
    and willingness to use pre-exposure prophylaxis among black/African American
    individuals in the United States: Cross-sectional survey. JMIR Public Health Surveill.
23. CDC. HIV testing in 50 local jurisdictions accounting for the majority of new HIV diagnoses and seven states with disproportionate occurrence of HIV in rural areas, 2016-2017 [cited 2019 Dec 1]. https://www.cdc.gov/mmwr/volumes/68/wr/mm6825a2.htm
30. CDC. Daily pill can prevent HIV [cited 2019 Nov 10]. https://www.cdc.gov/vitalsigns/hivprep/


37. USDA. Rural poverty & well-being [cited 2019 Dec 1].
https://www.ers.usda.gov/topics/rural-economy-population/rural-poverty-well-being/#note


40. USDA. Key statistics & graphs [cited 2019 Dec 1].


45. Kaiser Family Foundation. Facilitating access to mental health services: A look at Medicaid, private insurance, and the uninsured [cited 2019 Dec 1].
Figure 1. States, counties, and cities receiving focused federal attention to combat HIV transmission.

The Trump Administration plans to combat HIV transmission in the most affected areas of the country. The blue dots represent 48 counties, Washington DC, and San Juan, Puerto Rico; these locations have extremely high HIV diagnosis rates. The blue shaded regions are seven states with a high burden of rural HIV transmission. All marked regions will receive federal attention.

Taken from HIV.gov, Reference 2
Figure 2. Medicaid expansion status by state, 2019

Under the Affordable Care Act, states can choose to expand Medicaid, allowing those with income up to 138% of the Federal Poverty Line to receive insurance. As of 2019, the majority of states had chosen to do so and had implemented the change; these states are dark blue. The light blue states had expanded Medicaid but not yet put the policy into effect, while the orange states had not expanded Medicaid.

Taken from the Kaiser Family Foundation, Reference 8

Table 1. 2017 census and American Community Survey data concerning uninsured populations in the United States

<table>
<thead>
<tr>
<th>Population</th>
<th>Total population</th>
<th>Total uninsured population</th>
<th>Percent Uninsured</th>
<th>Percentage of people who are white alone</th>
<th>Percentage of uninsured people who are white alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>316,027,641</td>
<td>33,177,146</td>
<td>10.5%</td>
<td>73.1%</td>
<td>65.2%</td>
</tr>
<tr>
<td>South</td>
<td>118,846,282</td>
<td>16,030,157</td>
<td>13.5%</td>
<td>71.2%</td>
<td>65.9%</td>
</tr>
</tbody>
</table>

Minorities are uninsured at disproportionately high rates in both the United States and the South specifically.

Adapted from the United States Census Bureau, Reference 9