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Challenges to meeting the HIV care needs of older adults in the rural South

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Abstract

People living with HIV in rural parts of the Southern United States face poor outcomes along the HIV care continuum. Additionally, over half of people with diagnosed HIV are age 50 and older. Older adults living with HIV in the rural South often have complex health and social needs associated with HIV, aging, and the rural environment. Research is needed to understand what support organizations and clinics need in providing care to this population. This qualitative study examines the challenges health and social service providers face in caring for older patients living with HIV. In 2020–2021, we interviewed 27 key informants who work in organizations that provide care to older adults with HIV in the seven states with high rural HIV burden: Alabama, Arkansas, Kentucky, Mississippi, Missouri, Oklahoma, and South Carolina. Our findings highlight how racism and poverty; culture, politics, and religion; and a lack of healthcare infrastructure collectively shape access to HIV care for older adults in the South. Rural health and social service providers need structural-level changes to improve their care and services.

Keywords

HIV; Rural; Aging; Older adults; Qualitative; Providers

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Ethics

All policies and procedures were reviewed and approved by the Institutional Review Board at the Medical College of Wisconsin. All participants consented to participate prior to their interviews.

Declaration of competing interest

The authors have no conflicts of interest to disclose.

1. Introduction

In 2019, the U.S. Department of Health and Human Services put forth a plan to end the HIV epidemic in the next ten years. This plan includes a prioritization of states that have a disproportionate burden of HIV in rural counties, concentrated in the rural South (Fauci et al., 2019). Nonurban regions of the United States (US), particularly in the southeast, are the only areas of the country with increasing AIDS diagnoses (Centers for Disease Control and Prevention, 2016), and rural areas in the Southern US are more likely to have high HIV prevalence than rural areas in other parts of the country (Sullivan et al., 2021). People living with HIV (PLH) in rural areas experience significant barriers to HIV care, including limited transportation options and long distances to care, provider stigma and discrimination, and concerns about confidentiality (Pellowski, 2013). In addition, rates of HIV testing are lower in rural areas compared to urban areas, contributing to delays in HIV diagnosis and engagement in care (Lopes et al., 2017; Pitasi et al., 2019). Consequently, rural PLH show a more rapid progression to AIDS (Weissman et al., 2015) and have higher mortality rates than their urban counterparts, even when rural patients receive comparable care (Lahey et al., 2007). Additionally, rural residents experience lower levels of retention in care and viral suppression compared to urban residents (Nelson et al., 2018), and those who live farther from their HIV clinic are more likely to disengage in care (Kalichman et al., 2020).

There are significant challenges to providing HIV care in rural settings. Research has documented significant urban-rural disparities in care, including a lack of HIV-experienced clinicians in rural counties (Bono et al., 2021) and limited geographic accessibility to HIV care (Masiano et al., 2019). Additionally, social workers in rural HIV care have described how structural barriers, such as shortages in service providers and conservative policies, negatively influence their ability to meet the needs of rural HIV patients (Owens et al., 2021). In addition to a shortage of health and service providers with expertise in HIV, rural areas face a scarcity of funding for widespread testing and treatment and programs to address root causes of HIV (e.g., poverty, trauma), insufficient community awareness and knowledge around HIV, and limited leadership and political support for HIV prevention and treatment efforts (Schafer et al., 2017).

The population of PLH is aging; in 2018, over half (51%) of people in the United States with diagnosed HIV were aged 50 and older (Centers for Disease Control and Prevention, 2019). Some estimates indicate nearly 70% of PLH will be aged 50 or older by 2030 (Gilead Sciences, 2018). Between 2012 and 2016, the largest percent increase in HIV prevalence was among people aged 65 and older because of advancements in HIV treatment, allowing individuals to live long, healthy lives with proper HIV care engagement (Centers for Disease Control and Prevention, 2019). Although older PLH generally have higher levels of medication adherence than their younger counterparts (Ghidei et al., 2013; Nachega et al., 2012) only about 57% of older PLH are retained in care and 64% are virally suppressed (Centers for Disease Control and Prevention, 2019). Older adults with HIV also have an increased risk of medical comorbidities, including depression, diabetes, chronic kidney disease, and other health challenges, compared to those without HIV, further compounding the importance of health care engagement (Turrini et al., 2020).

The challenges faced by older PLH may be intensified for those who live in rural areas. The share of adults aged 65 and older living in rural areas has consistently grown since the 1980s, and currently more than 1 in 5 older adults live in rural areas (Smith & Trevelyan, 2019, p. 41). Additionally, almost half (45.9%) of the older rural population in the U.S. live in the South, in many of the same states that experience a higher burden of HIV in rural areas (Fauci et al., 2019). Although some research has explored challenges faced by agencies serving rural PLH, little research has specifically addressed the challenges of older rural PLH from the perspective of health and service providers.

Given the recent prioritization of rural HIV care, and the growing population of individuals aged 50 and older living with HIV, we conducted this study to understand the challenges organizations and clinics face in meeting the needs of rural older adults living with HIV in the seven states with the highest rural HIV burden. A better understanding of these challenges may help inform intervention efforts and policies with unique situational context. Through in-depth interviews, we explore how the historical legacy of the South, coupled with contemporary politics and stigma, have created an environment that makes it difficult for PLH to access HIV care. These challenges are further compounded for older PLH, many of whom face multi-level age-related barriers to care. Our goal is to shed light on these challenges and identify potential opportunities for intervention.

2. Methods

From November 2020 through April 2021, we conducted in-depth, semi-structured interviews by phone or Zoom with key informants in the seven states identified by the Ending the HIV Epidemic (EHE) plan (Fauci et al., 2019) as having a significant burden of rural HIV (at least 10% of HIV cases in rural areas with less than 50,000 people): Alabama, Arkansas, Kentucky, Mississippi, Missouri, Oklahoma, and South Carolina (Fauci et al., 2019). Although the eligible states were identified based on EHE parameters of rural HIV (Fauci et al., 2019), in our discussions with providers in those states, we deferred to their conceptualizations of rural. As such, individuals we interviewed may have had different definitions of what areas of their state they considered to be rural. Individuals were eligible to participate if they were 18 years of age or older and working in an HIV service organization, clinic, or other setting serving individuals living with HIV in one of the seven identified states.

The primary aim of these interviews was to examine the barriers to HIV care facing older adults in rural communities and barriers of organizations and their staff to support improved health outcomes among older PLH in rural communities. We used two primary approaches for recruitment: direct outreach and participant referrals. First, we did direct outreach to leaders of AIDS service organizations and HIV clinics in eligible states. Building on partnerships from our team's prior research, we emailed key contacts to explain the study and invite individuals to complete a phone interview. Interested individuals were emailed a pdf of our informed consent (in the form of an informational letter) and a link to a brief demographic survey to complete prior to the interview. The interviews were conducted by a team of three interviewers, trained in qualitative interviewing and with experience conducting interviews around HIV prevention and care. Prior to the start of the interview, the

interviewer reviewed the consent form with the individual, described the study, and received verbal consent from the participant. Interviews lasted an average of 40 min (range 20–75 min) and were audio recorded. Upon completion of the interview, participants were asked to identify other individuals in their organization, or other organizations in their state, who provided services to rural and/or older adults living with HIV. The research team followed up by phone or email to invite these individuals to participate. The study protocol was approved by the Medical College of Wisconsin.

Using a semi-structured guide, we discussed 1) challenges organizations and clinics faced meeting the needs of older adults with HIV; 2) challenges addressing HIV in their state's rural communities; and 3) potential intervention strategies to improve health outcomes for rural older adults living with HIV.

2.1. Data analysis

Interviews were transcribed verbatim. We analyzed data using reflexive thematic analysis (Braun & Clarke, 2006) and incorporated several strategies to ensure a credible, robust analysis. First, we used a team-based approach to coding. In the initial round of coding, all transcripts were coded with basic demographics (e.g., state, participant's role, type of organization). We then used an inductive coding strategy to generate an initial codebook. To do so, four members of the research team (including two of the interviewers) independently read two randomly selected transcripts and generated a list of potential codes. We met to discuss discrepancies, identify initial connections among codes, and develop a single codebook. The revised codebook was then applied to two additional transcripts for refinement and fit assessment by all four members of the analysis team. This process occurred two additional times as the team used interview data to develop and finalize codes, code definitions, and code hierarchy. Our codebook was then supplemented with deductive codes drawn from the literature and our prior work to capture known barriers to HIV care for rural older adults (Quinn et al., 2017, 2020). Upon reaching consensus on the final codebook and code definitions, we used MAXQDA qualitative analysis software to apply the final codebook to all transcripts. All interviews were coded twice, by two different members of the study team, to ensure consistency in the application of the codebook. Throughout the coding process we used memoing to begin to generate initial themes (Saldana, 2016). Memos consisted of initial concepts, thoughts, and ideas about the data, provided space for researchers' reflexivity, and created an 'audit trail' of our analysis and theme development processes (Nowell et al., 2017).

Coded data were examined to begin to identify patterns and potential themes. Specifically, we examined the data to understand the challenges organizations faced in meeting the needs of older adults living with HIV in rural areas. We explored variation and patterns by state to identify potential geographic influences. Potential themes were explored, checked against the data, revised, and finalized to represent a central concept or idea. We selected relevant quotes that represented these themes, narrowing to include representative quotes. Our results were organized around four primary themes that shed light on the challenges to meeting the needs of older, rural-dwelling people living with HIV: 1) Racism and poverty in the rural South; 2) Culture, politics, and religion; 3) Patient-level barriers to care; and 4)

Lack of infrastructure to meet the needs of rural older adults with HIV. These themes are summarized in Table 1.

3. Results

We interviewed 27 key informants in Alabama (4), Missouri (3), South Carolina (3), Oklahoma (5), Arkansas (4), Kentucky (3), and Mississippi (4), plus one participant who represented a regional organization that had expertise in rural HIV care within these states. Importantly, we recruited a diverse sample of key informants who worked in a variety of settings, including AIDS Service Organizations (ASO), academic institutions, and government. Key informants were also diverse in age (range: 32–72), gender (63% female), race (63% white, 31% Black), and education level (30% had a college degree). Additional participant and organizational characteristics are included in Table 2.

3.1. The legacy of racism, poverty, and neglect in the rural South

The seven states included in this study are clustered in the Southeast region of the United States and have a shared legacy of slavery, racism, and limited economic opportunity. While this history has influenced the HIV epidemic and HIV care for all people living with HIV in these states, it provides important context to understanding the experiences of older adults and explains the landscape of HIV care. Many key informants emphasized the importance of understanding the historical context and current culture and political climate of their state. In Alabama, for example, one participant described how the “plantation mentality” contributed to poverty and health disparities:

We’re in a poor area, to be honest with you. The bulk of the area we serve would have been in the 1860s where a lot of the plantations in the United States were located. And the legacy of that is that it led to massive poverty that, to this day, still impacts a lot of these counties. And if you looked at Alabama in healthcare disparities, we’re in the heart of that. Out of our 67 counties, 60 plus of those counties are below the poverty level of the United States. We have so much more poverty. We have health provider shortage areas. Out of our 67 counties, we have only four that are not considered health professional shortage areas. We just don’t have doctors, nurse practitioners. Our hospitals are closing. So, we really are dealing with historic poverty; we’re dealing with historic disparities. We are in a state, like much of the rural South, where a lot of our legislators wanted to keep what I call the plantation mentality. They wanted a population that was poor and undereducated because that made for a cheap workforce ... And so, we do a lot with little, and the best thing is we just cooperate a lot with a lot with other people within and do our best to make sure our people are okay.

– Alabama Academic Institution

Similar sentiments were echoed by participants in Mississippi, who described the intensity of generational and rural poverty:

Now, there are also communities in the state that have persistent poverty. Mainly the base of the Mississippi Delta where people have literally generations of poverty.

So, there are people who were born in poverty, their children were born in poverty, and now their children still are being born in that same level of poverty.

– Mississippi AIDS Service Provider

Generational poverty in the rural South was described as more severe, persistent, and isolating than in urban areas. Conversations about poverty were also often intertwined with discussions about racism.

Our patients are primarily Black. Alabama has one of the biggest gaps when it comes to the rich and the poor, and we have highly densely populated areas that are impoverished that have 75% African Americans within most locations, and those are also some of the locations where we also have the highest HIV rates. So, from – just overall sheer number, Birmingham and Montgomery as well as Mobile kind of go back and forth between who has the highest rates. If you're looking at incidence, we have several rural counties, most of which are located in our Black Belt, that have very high rates of HIV. And it's primarily African American. We're a non-Medicaid expanded state, which also makes it a lot harder for people who are impoverished.

– Alabama Academic Institution

Several key informants described the significant racial disparities in poverty and HIV in their state, with many also citing their state's failure to expand Medicaid as part of the Affordable Care Act. Participants described how unaffordable health care and high rates of poverty contributed to health inequities and racial disparities in HIV in those states.

There were also notable tensions between urban and rural areas within states, and several individuals expressed frustration over the prioritization of and funding availability for urban areas. One participant described the challenge getting funding and services to address the needs in rural states.

You just have the prejudice against rural communities, nobody cared about what's going on out there; they're quiet. "Let's focus on the cities, that's where the votes are, that's where all our money is, let's focus there." And so, rural communities felt left out, and so, therefore, we've left all these issues. So, you just have all of these things coming together in poor states, especially poor states with large rural communities that we're fighting a battle and that alone with just the cultural rural communities to be very independent and not wanna ask for help. It'll wear you out.

– Alabama Community Service Provider

3.2. Culture, politics, and religion

Related to historical and structural challenges, rural culture, politics, and religion seemed to influence the availability and quality of HIV services and were frequently cited as contributors to HIV stigma. For example, in several states, participants described anti-LGBTQ and HIV discrimination policies that contributed to homophobia and HIV stigma. A participant in Missouri described how antiquated HIV laws contribute to stigma:

We still have those terrible HIV laws that are archaic, and they've tried to update them, and it's never passed. So, we still have laws against biting – which doesn't transmit HIV. And spitting on people; that doesn't transmit HIV. It's still in the laws. And I think that contributes a lot to the stigma. It doesn't take into account any kind of intent.

– Missouri Government Agency

Due to the prevalence of this stigma, HIV was simply not discussed privately or publicly, hindering education and prevention efforts. Stigma was seen as a particular challenge facing older adults. In Arkansas, one of the key informants described the stigma experienced by some older individuals who were initially diagnosed with HIV in the '80s and '90s.

Here in Arkansas, in general, it is a big stigma. As far as the older population, I mean they live through the '80s and '90s when there was so much ignorance about HIV and a lot of the hatred and the stigma that goes with that, and so a lot of them don't want to tell anybody at all, especially the older population, because of that stigma, and so they've had a harder time repressing it. They've probably had less support. They can't talk about it freely. Especially the older HIV patients, they can't talk about that.

– Arkansas Social Service Provider

The stigma facing older adults was also mentioned as a barrier to engaging in social support activities and events in Alabama: “Our elders will probably never be as actively involved [in social support events] because the topic is still too private for them.”

Conservative political environments, discriminatory HIV and LGBTQ policies, and the inability to openly discuss HIV were seen as mounting barriers to meeting the needs of rural residents living with HIV. The “Bible Belt” and conservative religious values created further barriers, particularly for older adults who had stronger connections to their churches than younger individuals.

We have to bring in the point of religion. With being in the Bible Belt, being one of the buckles in the belt, often times stigma is related to religion. And religious beliefs and religious practices and religious social circles. So, if you're concerned that it may come out that you're HIV positive, how would the people in your church treat you? And will they treat you differently? Will you not have that space anymore to go to? So, that is a huge driver for stigma around all populations but really around the older population.

– Mississippi AIDS Service Organization

Religion, and the role of the Church, was seen as a particularly important driver of stigma and isolation for older adults. This informant went on to say:

I think there's a generational thing that happens when it comes to religion, where the younger generations seem to be less inclined to hold those religious beliefs. With the aging population, they're more likely to be in the church, doing work in the church, which means they're less likely to get that type of support for their HIV

status because so many churches are still not in a place where they're comfortable with having those discussions.

-Mississippi AIDS Service Provider

3.3. Patient-level barriers to care

As detailed above, the structural challenges faced by patients posed significant barriers to care. Our data also highlight how these factors have contributed to individual-level challenges, including poverty and concerns about stigma and HIV status disclosure. One participant described how poverty influenced the health and HIV care of older patients.

South Carolina is not a very rich state. We have a high index of medically underserved communities, meaning that poverty is high as well. And we know that living with HIV, especially when you can't afford the necessities of life, can just only make the condition worse. But so often our patients living with HIV, they suffer from other comorbidities that makes it hard for them to work. So, with little income, you really don't have the access to the food, shelter, clothing, transportation, the things that you just kinda need in order to be well. And so [the challenge] just builds and builds and builds for many of our older patients, especially those in rural communities.

– South Carolina Social Service Provider

Several interviewees similarly described the challenges individuals living with HIV faced in affording adequate food and housing, noting that individuals often prioritized these basic needs over HIV medication adherence and medical appointments.

The conservative and religious environments described earlier contributed to HIV stigma and homophobia, which key informants noted were among the most prominent barriers to HIV care facing their patients. Interviewees described how fears of HIV and sexual identity disclosure, distrust of medical privacy, and ostracization from family and friends created barriers to HIV treatment and social support. This was particularly true among older patients.

In order for you to have social support, typically you have to disclose your status. So, I do know that one thing that's great about some of our younger patients is that they have a greater ability to have social support through social media. I don't think older adults necessarily have that ability to have these networks and these contacts that they've built through social media. ... when you're older your need for that support to help you get to appointments, help you remember to take your medication and deal with all the other comorbidities that you have is even greater. So, unfortunately, I think for older adults the need for social support is probably much, much greater, and the impact that it has on their health outcome is probably greater as well.

– Alabama Social Service Provider

As a result of stigma and lacking social support, loneliness was common among older adults living with HIV. When asked about the challenges older adults living with HIV in Kentucky faced, this service provider stated:

Loneliness. I'm really hearing that. Over 50% of our patients are over the age of 50. Lonely, comorbidities. I believe the people in the more urban areas would have more access to support groups and community. If you're a gay man in Lexington, you're gonna find a community. But in these rural areas, there's not gay bars. There's not ways for them to connect with other people like them.

– Kentucky HIV Service Provider

Although stigma was described as pervasive in these rural communities, affecting all individuals living with HIV, younger individuals were often able to connect with LGBTQ and HIV communities through social media to garner social support. This avenue was less readily available to older adults, for whom technology access was limited.

So, in South Carolina, again, highly rural, we certainly do have those pockets, those internet deserts, where you do not have access to the internet. It's not even an option for you. Or even if it is an option, you have to pay for it. And most of our seniors are on fixed incomes, you know? They don't have the additional funds to pay for internet. And then once you get access to it, navigating the internet can be something very challenging for seniors, especially because it requires so many clicks, passcodes, passwords, emails, getting in, logging out. There are so many things.

– South Carolina Social Service Provider

The technology barriers facing older rural patients were twofold: not only was affordable and reliable internet access hard to come by, but many older adults did not have the skills needed to identify and access telehealth, social media, or other online health and social support resources.

3.4. Lack of infrastructure to meet the needs of rural older adults with HIV

Key informants interviewed for this study were intimately familiar with the challenges facing rural PLH and older rural PLH, in particular. Yet they expressed frustration and exasperation over their inability to meet the needs of these communities. As the following excerpt from one informant reveals, even when organizations are able to offer a wide range of social services, the marginalization and needs of their patients create seemingly insurmountable barriers.

I think especially in states where you have highly impoverished communities, structural barriers are just unreal. And the thing is, if we were able to address stigma, improve social support, structural barriers are still there, the access is lacking, it's kinda all for naught. So, a lot of our patients have the benefit of getting some of the services I talked to you about like food boxes and housing. But even with that, I've had several patients – even one of my patients right now who's probably gonna fall outta care and is getting frustrated and overwhelmed because we can't provide housing forever. We can't overcome all of the structural barriers. It's just limited. And, again, I do worry because this is something we have available in Birmingham, but it's not really available in the same degree as other rural counties.

– Alabama Social Service Provider

As noted above, many rural communities simply lacked the resources and services often found in urban areas. Although many urban-based service organizations and clinics had expanded to include rural communities in their catchment areas or incorporated telehealth or transportation support to meet the needs of rural patients, older rural patients remained underserved.

The pie is already not big enough. There's not enough resources, but then, in some of these non-urban pockets, those folks have been even further left behind. Specifically thinking about older populations, some of the emerging fixes around some of these issues, around limited access to providers and anonymity have been these technological fixes of like, "We can do telehealth," and all that. But I also think that there's folks who are like, "telehealth?" I think there's ways to overcome that, but I think that's just an inherent challenge at the confluence of rural and older.

– Southern Region Service Provider

Echoing what was described above, for older adults, the typical interventions that enhanced support for rural patients were often insufficient for rural older patients.

The primary concern expressed by key informants around rural-based HIV services was the lack of infectious disease providers in rural areas.

Fifty-one percent of the state is actually still considered rural. And because of that we have a number of people who have issues around access to healthcare. We have habitually had a shortage of nurses, doctors, providers in this area. Especially for those rural counties. There's no social aspect to being there, so getting a physician to move his family or her family there is a bit of a stretch.

– Mississippi AIDS Service Organization

This was a common sentiment throughout our interviews. The shortage of providers specializing in HIV or able to provide culturally relevant care was a major barrier to HIV care for the most marginalized patients. As explained by a participant in Oklahoma, as a result of a lack of providers, many of their rural patients traveled to Oklahoma City to receive their HIV care.

A lot of them come here because we house, in Oklahoma City, the state health department, as well as OU, the University of Oklahoma, they have their health sciences campus. And that is where our ID doctors are housed. So, a lot of them go either every six months, once a year; drive all the way into Oklahoma City just to see a doctor about their HIV care. There are not a lot of doctors who are specializing in any of that in rural communities ... I know that our South-eastern part of the state, their needs are not being met with a HIV-specific or trained facility, or a doctor, or nurse practitioner in that location. I would say the same for our northwestern part of the panhandle and so forth. It is really difficult in our state to find a doctor who is wanting to go into the infectious disease practice as well as specialize in HIV care.

– Oklahoma AIDS Service Organization

Traveling long distances to see an HIV care provider was particularly challenging for older patients, especially those who were less comfortable driving long distances or unable to drive. Key informants also discussed challenges patients faced in receiving care from an HIV specialist. When asked what the biggest HIV-related challenge facing individuals in rural Kentucky was, this interviewee responded:

I would say the ID docs. There are very few infectious disease doctors, so that's why they have to travel like they do to get an appointment. And then we have had as far as like six weeks before they can see an ID doc before when someone is diagnosed, so that's been a challenge.

– Kentucky Government Agency

While local primary care physicians can manage an individual's HIV care, there were several notable challenges with this. Key informants described primary care providers who were unfamiliar with co-treating HIV and other comorbidities, made outdated treatment recommendations, perpetuated HIV stigma and stereotypes, and did not provide culturally sensitive care to LGBTQ patients.

3.5. The case for comprehensive care

Despite the challenges to meeting the needs of rural, older PLH described by key informants, there was also evidence of innovative, effective, comprehensive programming and efforts that were intended to improve health and social outcomes for older PLH. While the “small town” was often seen as contributing to stigma and privacy concerns, organizations were also able to use this to build trusting relationships with patients.

Listen, over 90% of their people get to their appointments because they go out and get them. They don't worry about 'oh, I can't find them.' They go down the street because somebody else says I just saw her walking down there – they go down there and get her, saying “Miss Johnson, you got an appointment, come on!” “Oh, I forgot about it!” And they get in the car and bring them. Those are the kind of programs we need to support, and they need to be.

– Alabama Social Service Agency

The ability of case managers and other organizational staff to build trust and use that to facilitate engagement in care was a benefit of smaller, more insular communities. Such efforts also helped overcome transportation barriers or other challenges older adults faced.

Comprehensive services were seen as just as central to HIV care as the medical appointments, and organizations worked to try and address all the needs of their clients. Key informants praised the HIV community for prioritizing social determinants of health and understanding how these impact HIV care.

One thing I love about HIV care in general is typically we can do true comprehensive care. So, if you have a substance use disorder, we can get you into rehabilitation. Right? If you have food insecurity, we can get you food boxes in food pantries. We can help with educational programs. We can help with housing.

... I think the barrier comes when you're in those rural communities, you don't always get access to those same types of services because most of our community-based organizations are still located within areas that are more populated.

– Alabama HIV Clinic

As this key informant noted, despite the recognition of the importance of these services, their availability was often more limited in rural areas, where organizations tended to be smaller and provided fewer services. That said, there were some organizations that did provide holistic care and worked to meet the specific needs of rural, older PLH.

We were providing transportation to all medical appointments, follow-up appointments with the social workers. There are a few who have housing issues. A housing specialist works with them on how to pay housing in those rural areas, which of course is limited compared to the other areas. We provide food assistance, food vouchers, but the only grocery store that's taking that is here in our area, so we do transport from their home in the rural areas closer to the shopping and take them back home from there. And of course communication, because a lot of them, they have cell phones, but the reception in rural areas is kind of poor, so communication is another issue. We're having a lot of use of our transportation coordinator, a lot of correspondence, so that's the biggest thing for them.

– Alabama AIDS Service Agency

Importantly, several key informants talked about the need for case managers and other frontline providers who have expertise in working with older adults. Participants noted that older adults were generally not seen as a “priority” population within HIV or broader society. As an Alabama key informant stated, “I think we have to go back to a culture of respecting the elders... We've got to have true good case management for our elders.” For example, a few key informants noted that case managers and providers often lacked knowledge of aging-specific needs and resources.

Every agency doesn't have someone well versed in Medicare to talk about your Medicare plan. This is what is covered because you'll need these. These are the medications you use. We do come into contact with a lot of insured clients whose Medicare coverage plan doesn't cover their HIV meds. That's an issue as well.

– Mississippi AIDS Service Organization

Intensive case management programs, with staff skilled in working with older adults, that were able to build long-term relationships between case management staff and patients were able to provide a needed bridge between patients and HIV and other medical care. However, the primary challenge in being able to provide these services was the lack of available funding. As described earlier, key informants expressed frustration over feeling like both rural areas and older adults were not priority areas for HIV funding. That, coupled with the smaller scope of many rural organizations (and therefore more limited staff and personnel resources), made obtaining consistent funding for these services difficult.

4. Discussion

This qualitative study highlights several key challenges that health and social service providers face in meeting the complex needs of older PLH in rural areas. Results from this study indicate that historical, cultural, and political factors, including slavery, conservative social norms and politics, religion, historic and contemporary racism, poverty, and stigma collectively shape HIV care in rural communities in the South. While different regions and states have their own distinct amalgam of social norms and resources, it is notable that informants from nearly every state referenced their state's history of racism, current conservative politics, or cultural norms associated with being in “the Bible Belt.” Participants pointed to state-level policies that influenced the narrative around sexual health and HIV and determined availability of funding for HIV prevention and treatment. While the Southern political and cultural landscape influences HIV care for all PLH in these rural communities, this is an important context to understand the challenges to meeting the needs of older PLH in these communities. In describing the landscape of HIV care for older PLH in the rural South, key informants primarily focused on social and structural factors that shape access to care. These factors were amplified for older adults, many of whom faced additional burdens and barriers to care. For example, stigma, rooted in historical cultural, political, and religious tradition and contemporary politics, was identified as a significant barrier to HIV care in the South. Stigma thrives and perpetuates health disparities in environments with historically shaped power inequities and can negatively influence efforts to address HIV (Bonett et al., 2020). HIV criminalization laws, cited by participants in Oklahoma as being particularly troublesome, criminalize intentional HIV transmission to an individual unaware of their partner's status. However, many of the behaviors detailed in these policies (e.g., spitting) are unrelated to HIV transmission (Yang & Underhill, 2018). Such laws offer little or no public health benefit (Adam et al., 2014), inhibit HIV prevention efforts, and contribute to HIV stigma (Baugher et al., 2021; Bonett et al., 2020). Researchers have identified high levels of structural stigma related to sexual orientation (measured by public policies and opinion toward sexual minorities) and HIV criminalization enforcement in six of the seven states included in this study (with Missouri being the only exception; Tran et al., 2019). Stigma was seen as particularly pervasive among older patients, stemming from their greater involvement in conservative religious communities, their history living through the HIV epidemic of the 1980s, and their social isolation.

Similarly, key informants highlighted the impact of loneliness and isolation facing older adults. Lack of social engagement is a significant unmet need among older PLH (Burchett et al., 2020) and is associated with functional impairment and poor health-related quality of life among older PLH (Greene et al., 2017). Older PLH have expressed interest in opportunities to socialize with other older PLH to combat isolation and help cope with HIV stigma (Burchett et al., 2020). However, key informants noted that while online platforms provide numerous opportunities for connection to LGBTQ communities and other PLH, many older adults are less comfortable with using the internet and social network sites, or struggle with slow internet services and outdated technology at home.

Key informants also described limited access to quality HIV care and related social services for older PLH in their communities. Research on HIV clinical workforce capacity has

shown that HIV-experienced clinicians are more likely to practice in urban areas, and rural counties tend to have fewer HIV-experienced clinicians per 1000 diagnosed HIV cases (Bono et al., 2021). However, key informants noted that even if local providers are available, the small-town isolated environment meant some patients worried about confidentiality and unwanted disclosure of HIV status. In a recent study of the Ryan White HIV/AIDS Program, researchers found that although 5.9% of diagnosed PLH live in rural areas, less than half received care from rural providers (Klein et al., 2020). This is likely due to a combination of choice (Quinn et al., 2017), and limited availability of care in rural areas. However, telehealth has the potential to improve access to and retention in HIV care in some nonurban areas (Ohl et al., 2013). App-based interventions have also shown promise in health promotion, building supportive relationships (Hightow-Weidman et al., 2015), and increasing access to HIV pre-exposure prophylaxis (PrEP) in rural areas (Siegler et al., 2019). These interventions can help overcome stigma (Kalichman et al., 2020), allow patients to access care without leaving their homes, and may be similarly effective at improving access to HIV care. However, as noted above, this may not be feasible for older patients with lower technology literacy and comfort (Quinn et al., 2020). Thus, many of the interventions that have demonstrated success in improving rural health care (e.g., telehealth, strengthening of the rural workforce, and ridesharing), may not be as effective or easily accessible for older PLH (Dandachi et al., 2019; Touger & Wood, 2019; Wood et al., 2021).

Our results highlight several opportunities for future research and public health practice and point to the need for structural and policy-level interventions, specifically designed with older PLH and rural communities in mind. Research has consistently demonstrated the significant HIV burden in rural communities, yet federal HIV prevention and Ryan White treatment funding has historically prioritized allocation of funds to urban areas (Masiano et al., 2019), which has contributed to a lack of available resources in rural communities. Related, several key informants noted that their states did not expand Medicaid, referring to the nationwide expansion of Medicaid to individuals with incomes below 138% of the Federal Poverty Level under the Affordable Care Act (ACA). Only two of the seven states with rural HIV epidemics, Kentucky and Arkansas, initially expanded Medicaid in 2014; Missouri and Oklahoma opted to expand Medicaid in late 2021 (Kaiser Family Foundation, 2021). Medicaid expansion increased health insurance coverage among newly-eligible individuals by approximately 14% (Freaun et al., 2017), and had a particular impact on increasing coverage among rural populations (Soni et al., 2017), and improving access to HIV care (Kates et al., 2020). Importantly, although their eligibility was not directly affected by the ACA expansion, data examining poverty rates found that adults aged 65 and older benefited, by extension, from the expansion of Medicaid, which contributed to reductions in poverty among older adults (Zewde & Wimer, 2019).

The lack of providers was identified as one of the most significant barriers to HIV care. Key informants stressed the importance of community-based infectious disease physicians who could provide culturally sensitive HIV care, while also managing age-related comorbidities. There is a need for training HIV providers and case managers on the intersecting issues of HIV and aging, including the comorbidities that often accompany aging. Interventions that incorporate geriatric assessments and consultation into specialty care have demonstrated success in other subspecialties and may help HIV providers identify age-related challenges

and make appropriate referrals (Singh et al., 2017). The shortage of HIV providers reflects a larger challenge for rural health care; over 60% of Health Professional Shortage Areas are located in rural parts of the country (Bureau of Health Workforce, 2021). Even more troubling, the rural physician workforce is forecasted to decrease more than 20% by 2030, as aging rural physicians retire and the number of younger physicians entering rural practice declines (Skinner et al., 2019). Provider-level consultation and support models may improve access to HIV care in rural areas, particularly for older adults. Extension for Community Health Outcomes (ECHO), for example, combines didactic sessions with case-based learning to increase the capacity of rural primary care providers to deliver specialized care (Scott et al., 2012).

The ECHO approach has successfully trained primary care providers in geriatrics (Bennett et al., 2018) and contributed to increased provider comfort and confidence in their skills (Furlan et al., 2019). This model may help address shortages in HIV specialists and gerontologists in rural communities by providing consultation services to primary care providers, helping them to address clinical challenges associated with aging, comorbidities, or managing multiple medications (Harris et al., 2020). Additionally, engaging and training more advanced practice providers (APPs) in HIV care has shown promise. In one study, quality of HIV care provided by APPs was on par with HIV physicians and better than non-HIV specialists (Wilson et al., 2005). Nurse practitioners are one of the fastest growing non-physician health providers, particularly in rural and low-income areas (Xue et al., 2019). Although there has been limited research on engagement of nurse practitioners in HIV treatment, recent research has shown favorable outcomes in PrEP delivery care among nurse practitioners (Nelson et al., 2019; Zhang et al., 2020). Research on the feasibility and effectiveness of such programs for rural older PLH is needed.

This study has limitations. First, it is important to reiterate that these data are from key informants, healthcare providers, and social service providers, and their perspectives may differ from those of older, rural-dwelling PLH. Nevertheless, their experiences are critical to understanding the barriers faced by rural healthcare systems that are trying to meet the needs of this population; these interviews also provide important insights into rural HIV care. Similarly, given that these were interviews with health and service providers, their perspectives may come from their experiences working with PLH who are engaged in care. The challenges faced by individuals not engaged in care or accessing related services may not be represented here. Second, these data focused exclusively on seven states with a high rural burden of HIV. The experiences of providers in these states may differ from providers in the rural Midwest or northeast regions of the U.S. Additionally, while there were some experiences shared across states, there were also notable differences by state and, in some cases, even some variation by region within a state. This highlights the importance of taking local context into account and partnering with local organizations and leaders when developing and implementing interventions. Third, our data do not allow us to examine how the barriers described here influence HIV care outcomes or services for older PLH. Nonetheless, this highlights important issues to continue to investigate and address. Finally, data were collected during the COVID-19 pandemic, which may have shaped key informants' perspectives, particularly around engagement in care, isolation of older PLH, social service needs, and use of telehealth services.

This study adds to two important bodies of literature related to the rural HIV epidemic and to older adults living with HIV. While typically examined independently, this study demonstrates the importance of considering the rural environment for the growing population of older adults with HIV. The political, social, and structural barriers to rural HIV care in these seven states must be addressed if we are to end the HIV epidemic by 2030. Furthermore, prioritizing the needs of older PLH and addressing the intersection of infectious disease and gerontology will be essential as this population continues to grow.

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Table 1

Demographics characteristics of key informants and their organizations (n = 27).

Continuous Variables	<i>M</i>	<i>SD</i>
Informant age (<i>n</i> = 20; range: 32–72)	50.0	11.0
Informant years at agency (<i>n</i> = 22; range: 1–31)	11.8	9.9
Percent of clients: 50+ years old (<i>n</i> = 16; range: 10–75)	40.0	16.3
Percent of clients: Rural (<i>n</i> = 18; range: 15–100)	49.7	28.9
Categorical Variables	<i>n</i>	%
Gender identity		
Female	17	63.0
Male	10	37.0
Race/ethnicity		
White	12	63.2
Black	6	31.6
Multiracial	1	5.3
Missing	8	
Education		
Some College	2	8.7
College Degree	7	30.4
Masters	8	34.8
PhD/MD	6	26.1
Missing	4	
Agency Type		
AIDS Service Organization	13	48.2
Governmental Institution	5	18.5
Academic Institution	4	14.8
Hospital	2	7.4
FQHC	2	7.4
Other	1	3.7
State		
Oklahoma	5	18.5
Alabama	4	14.8
Arkansas	4	14.8
Mississippi	4	14.8
Missouri	3	11.1
South Carolina	3	11.1
Kentucky	3	11.1
Southern Region	1	3.7

Note: Percentages represent the number of people that responded to each question. Percentages may not add to 100 due to rounding.

Table 2

Qualitative Themes.

Qualitative Theme	Supporting Interview Excerpts
The legacy of racism, poverty, and neglect in the rural South	Rural poor is very different from city poor. When I think of city poor, I think of people who live in the middle of a city, but you still have access to things. You can get to it if you need to, right? Rural poor, you're usually in an isolated space where you don't even have access to things. Even if you did have money, you still can't get there, right? Even if you had a few coins, you couldn't get there. And so I feel like it's just a different level of poverty when we look at our rural communities versus those in the heart of the city. – South Carolina Social Service Provider
Culture, politics, and religion	Stigma is a very big issue in Oklahoma... There are some programs here in Oklahoma City that have tried to address [HIV stigma], but it goes back to that Bible Belt where you don't talk about it. We had the Oklahoma AIDS care fund. They were always fundraising for HIV clinics and different services and raising money for them and through grants and so forth. One of their biggest fundraisers was called Red Tie Night. Even then, at the event solely supporting HIV and AIDS, you didn't talk about it. It wasn't mentioned. – Oklahoma AIDS Service organization
Patient-level barriers to care	Many times, we're the only ones they can come to about their issues and concerns because they don't want anyone else to know. They're afraid of being ostracized from their friends and family and from their job. – Kentucky service provider
Lack of infrastructure	Most of them are seeing regular primary care physicians, which that can be great and also can be limiting as far as the specialty care that they need, and just the kind of cultural competency around treating somebody who's LGBT or living with HIV. I don't think they necessarily get the caliber of care that some of our urban clients do. – Oklahoma AIDS Service Organization
The role of comprehensive case management	Poverty is a major challenge. The lack of economic independence and lack of consistent earnings from our clients causes the other issues to be more prevalent. Food insecurity is real. It is very real for us. We are building a program with the local grocery store to provide our clients who have food insecurity with food vouchers. We're trying to marry that food voucher program to our nutrition education, so they know healthy eating. These are the things you need to get. Because food insecurity is an issue but then those who can get their own food, they may not have enough money to eat healthier. Food insecurity, we're trying address that at the ground level by first providing folks the means to be able to go get food and then educating them on what they need. – Mississippi AIDS Service Organization and clinic

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