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“HIV is not going to kill me, old age is!”: The intersection of aging and HIV for older HIV-infected adults in rural communities

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Abstract

Older adults with HIV/AIDS living in rural areas face unique challenges to accessing HIV care and medications, and suffer greater mortality than non-rural HIV-infected individuals. This qualitative study examined the intersection of aging and HIV to identify factors that affect overall health, engagement in care, and medication adherence among this understudied population. Qualitative interviews were conducted by phone with 29 HIV-positive adults over the age of 50 living in US rural counties and analyzed using thematic content analysis. Individuals reported complex medical needs in addition to their HIV and noted difficulty discerning whether symptoms were associated with HIV or aging. Although reported medication adherence rates were high, participants also cited several barriers to maintaining adherence. Given the increase in rural individuals living with HIV coupled with an aging population of HIV-infected individuals, interventions are needed to address the complex intersection of aging and HIV, especially for those in rural environments.

Keywords

Engagement in care; Older adults; Rural; Aging

The prevalence of HIV among older adults in the United States (US) is increasing due to both an increase in survival for HIV-positive individuals and a steady rise in HIV diagnoses in this age group (Prejean et al., 2011; White House Office of National AIDS Policy, 2015). Advances in clinical care and antiretroviral therapy (ARV) have significantly decreased morbidity and mortality among HIV-infected individuals (Krentz, Cosman, Lee, Ming, & Gill, 2012; Palella Jr et al., 1998) and transformed HIV from a terminal illness into a chronic disease requiring self-management and long-term care. As a result, by the end of 2013, more than 42% of persons in the United States living with HIV were 50 years or older (Centers for Disease Control and Prevention, November 2015) and approximately 5% of all new infections were among adults age 55 and older (Centers for Disease Control and Prevention,

2013). By 2020 it is estimated that more than half of people living with HIV (PLH) in the United States will be over the age of 50 (Brooks, Buchacz, Gebo, & Mermin, 2012). Simultaneously, the prevalence of HIV/AIDS in rural areas of the United States is increasing (Centers for Disease Control and Prevention, 2015), complicating HIV treatment and health outcomes. Rural patients tend to present for care later, with more advanced HIV infection (Ohl et al., 2010), making them more likely to face comorbidities and need more complex medical care. Consequently, rural patients with HIV infection have higher mortality rates than their urban counterparts, even when rural patients receive comparable care (Lahey et al., 2007). The intersection of aging and HIV for older, rural-dwelling adults in the US requires detailed examination to better inform interventions to meet the needs of this unique population.

Older persons living with HIV face complex health and psychosocial challenges. With increasing age, comorbidities such as cardiovascular disease, diabetes, non-AIDS-defining cancers, and declines in renal and hepatic function become highly prevalent among HIV-infected patients (Buchacz et al., 2013; Hasse et al., 2011). Untreated comorbidities commonly associated with aging (e.g. diabetes, hypertension) may exacerbate cognitive deficits in individuals with HIV (Mateen & Mills, 2012). Type 2 diabetes, HIV, and aging are all independently associated with increased risk of mild to moderate cognitive impairments. Recent research suggests that as PLH age, the combination of HIV and diabetes may increase cognitive decline and interfere with daily functioning. (Vance et al., 2014) Furthermore, aging individuals with HIV may be at risk for HIV-related cognitive disorders including HIV dementia and mild neurocognitive impairment, which become more difficult to treat with increasing age (Mateen & Mills, 2012). Although neurocognitive disorders associated with HIV can be reduced with antiretroviral adherence, such disorders remain common in antiretroviral therapy-treated patients, even among those with longstanding viral suppression (Mateen & Mills, 2012; Simioni et al., 2010).

Older PLH also face numerous mental health challenges including depression, substance use, and loneliness (Parsons, Starks, Millar, Boonrai, & Marcotte, 2014; Stoff, 2004). Up to half of all older adults with HIV report depressive symptoms (Havlik, Brennan, & Karpiak, 2011), and older adults with HIV are five times more likely to experience depression than their HIV-negative peers (Applebaum & Brennan, 2009). Depression is particularly concerning among PLH, as depression is related to antiretroviral nonadherence (Gonzalez, Batchelder, Psaros, & Safren, 2011; Springer, Dushaj, & Azar, 2012). In persons over 50 with HIV, 39% presented with symptoms of depression frequently associated with loneliness and HIV stigma (Groves, Golub, Parsons, Brennan, & Karpiak, 2010). Older adults in general also tend to have fewer sources of social or institutional support, fewer peers, and HIV may be more stigmatized among older adults (Nokes et al., 2000).

The medical and mental health challenges faced by older PLH are complicated environmental and psychosocial issues including poor nutrition, high rates of poverty, and limited physical and social resources (Grace et al., 2010). Accordingly, the challenges associated with aging among PLH may be exacerbated in individuals with limited resources, including those who reside in rural areas of the United States. In general, rural residents experience worse population health and health care than residents of urban areas (Laditka,

Laditka, Olatosi, & Elder, 2007; McLaughlin, Stokes, & Nonoyama, 2001) and rural counties have consistently had the highest mortality rates (Morton, 2004). Rural counties have higher rates of depression (Probst, Moore, Glover, & Samuels, 2004; Simmons, Braun, Charnigo, Havens, & Wright, 2008), suicide (Hirsch, 2006), and alcohol abuse (Borders & Booth, 2007; Clayton, McBride, Roberts, & Hartsock, 2007), yet fewer drug treatment and prevention programs. Rural residence is also associated with later HIV diagnosis, which can contribute to increased morbidity and mortality and greater HIV transmission risk to others (Weis, Liese, Hussey, Gibson, & Duffus, 2010). Yet, rural residents commonly have less access to primary care, specialists, and health-related technologies (Eberhardt & Pamuk, 2004; Probst et al., 2004). Additionally, given the relatively low prevalence of HIV in rural areas, few providers have adequate training or experience in the care of people with HIV (Grace et al., 2010).

Despite evidence of the health challenges associated with aging for PLH, limited research has qualitatively examined how older, rural-dwelling PLH understand their health and healthcare needs. Surprisingly little research has examined the factors that affect engagement in HIV-related care or health-related quality of life among older, rural PLH. Given the overall increase in the number of PLH over the age of 50, research is needed to better understand the needs of and experiences of older PLH, especially those in resource-limited settings, for whom access to care and services may be especially limited. To address this literature gap, the current study sought to examine the unique experiences of older, rural PLH to inform interventions that will improve the health and wellbeing of this population. The complexity of aging with HIV is complicated by the fact that large cohorts of HIV-infected individuals over the age of 50 are emerging for the first time and as such, we know relatively little about experiences of aging among PLH (Vance, McGuinness, Musgrove, Orel, & Fazeli, 2011). Using qualitative phone interview with 29 individuals in four states, we examined experiences with access and engagement in HIV care among older PLH in rural areas.

Methods

HIV-positive adults, aged 50 and older, living in rural counties were recruited through partnerships with AIDS Service Organizations (ASOs) in Wisconsin, Alabama, Tennessee, and Vermont to obtain geographic diversity. Efforts were made to recruit individuals on the West Coast as well, although we were not able to enroll any eligible participants. We recruited participants from counties defined as non-urban by the US Office of Management and Budget. This designation requires that a county does not contain a Metropolitan Statistical Area (MSA) – defined as a city with a population of 50,000 or more – and does not have social or economic integration with an adjacent county that contains an MSA (US Department of Health and Human Services,).

Case workers and other staff at partner ASOs distributed flyers with information about the study to potentially eligible participants. Interested individuals called the study screening line and were screened for eligibility based on age, HIV status, and county of residence. Eligible individuals were scheduled for a telephone interview with a member of the research

team. All participants verbally consented to participate in the study. All study protocol was approved by the Medical College of Wisconsin Institutional Review Board.

Interviews lasted approximately 60 minutes. We followed a semi-structured interview guide that covered topics including family and social life, stigma and discrimination, history of HIV medical care, medication adherence, and general health. The semi-structured format allowed for flexibility within the interview and participant-guided discussions. Upon interview completion, participants were mailed a \$100 incentive. All interviews were audio recorded, transcribed verbatim, and uploaded into MAXQDA qualitative software for analysis.

Analysis began with four members of the research team reading through two selected interviews to generate an initial list of codes, ideas, and themes. After the team developed an initial coding scheme, each team member applied the coding scheme to two additional interviews. We then discussed discrepancies in coding, clarified code definitions, and repeated this process until we reach consensus and finalized a coding tree. The final coding tree consisted of inductive and a priori codes from the extant literature. Two members of the research team then applied the coding tree to all 29 interviews. Thematic content analysis (Bernard, 2011; Ryan & Bernard, 2003) was used to inductively identify themes that captured individuals' experiences accessing and engaging in care (e.g. ability to receive HIV care within their community, ability to get to regular health care appointments, medication adherence). Specifically, we examined how HIV diagnosis, age, and rural environment created unique barriers for this population. Constant comparative method (Boeije, 2002) was used to examine any differences by race, age, location, and years since diagnosis. With the exception of years since diagnosis, few differences were identified among groups.

Results

We recruited 14 participants from Wisconsin, 8 from Vermont, 6 from Alabama and one from Tennessee. Participants' age ranged from 50 to 73 years old, with an average age of 57.5. Most participants were White (n=21), with the remaining participants identifying as Black (n=5), Native American (n=2) and mixed race (n=1). Two White participants also identified as Hispanic or Latino. The majority of participants were men (n=23) and 16 identified as heterosexual. Participants had been living with HIV for between 2 and 30 years; 17 participants were diagnosed with HIV prior to the year 2000.

I. Multiple morbidities: The intersection of aging and HIV

The intersection of HIV and aging is complex, due to the synergistic effects of physical and mental health issues associated with HIV and aging separately and concomitantly (Onen & Overton, 2009). Although experiences of aging and living with HIV were closely intertwined and difficult to distinguish, individuals were often more concerned about issues they associated with aging rather than HIV. As one participant from Vermont noted, "Put it this way, HIV is not going kill me, old age is!" This sentiment was not unique. While a few individuals reported opportunistic infections and AIDS-related complications, nearly all reported numerous other health conditions and were often taking more than five prescription medications.

Interviewer: How would you describe your general state of health?

Participant: I guess it would be “so-so” you know. I mean I wouldn’t say I’m the best. You know, trouble getting around a lot, I can’t go outside and mow the whole yard in one day. Joints aching, eyesight going bad.

I: We talked about your HIV and diabetes. Do you have any other diagnoses?

P: Cholesterol. They give me some pills for high blood pressure but it’s not really high, they teach me to keep it down. My eyesight. They give me some drops for pressure in my eyes. [58 year-old Black Male; Alabama]

Given their age, it was not surprising that HIV was often just one of many health conditions participants faced. Diabetes, high blood pressure, failing eyesight, and elevated cholesterol were all commonly reported health conditions. Older individuals frequently experience multiple chronic conditions, which can result in poor health outcomes (Fried, Tinetti, & Iannone, 2011), and participants were generally more concerned with health conditions other than HIV.

Interviewer : How big of a concern would you say your HIV is compared to your other health problems?

Participant: Not as much as my heart-related issues... The diabetes concerns me a whole lot because in the last several months it’s become more and more difficult to control. I’m concerned about my circulation problems and my feet and all that kind of stuff. And I’m concerned about the effect of diabetes on your heart, all the other problems associated with it.

I: How long have you been a diabetic?

P: Umm, about 6 years now I think.

I: Ok and you had you mentioned you had heart surgery?

P: Yes, I had a Quadruple bypass. June 2007.

I: And how is your heart and recovery been since then?

P: it’s been pretty good I mean I’ve had few issues every now and then and my medications have changed a little bit but I’ve had good reports. I did have one of my bypasses close up completely but it is in a section of my heart that does not affect the performance of my heart. But so far the other arteries remain pretty good. [57 year-old White male; Tennessee]

The lack of concern about the health effects associated with HIV may be attributable to the fact that many participants had been living with HIV for over two decades and at the time of the interview, they had few HIV-related complications. Thus, their more recent diagnoses and acute symptoms were often more troubling. The participant above, for example, reported high levels of HIV medication adherence and regular engagement in HIV care since his diagnosis and as such, he had few concerns associated with his HIV diagnosis.

Although participants who had been living with HIV since the '80s and '90s had fewer HIV-related health concerns, they frequently discussed challenges associated with the intersection of aging and HIV and difficulty not knowing whether symptoms were associated with aging, HIV, or something else.

Interviewer: Are you experiencing any symptoms related to your HIV and or medications?

Participant: I'm having digestive issues with certain kinds of food. Other than the HIV or age or a combination of it, so it's really hard telling the doctors the same thing, I couldn't tell you. What is age and what is HIV? I'm at the front of this one because I'm getting older with this.

I: Do you have any other medical conditions, including anything like depression or memory problems?

P: Memory problems for sure and that well could be HIV. This is something that creeps into it particularly when you are a survivor; how much of it is related to age and how much of it is related to decades of some pretty severe drugs that we don't know long term what the medications are ... we don't know what 20 years of taking has done to us. So it's worth a gamble. [50 year-old White male; Wisconsin]

Even when individuals did not report acute HIV symptoms or complications, several individuals who were diagnosed with HIV in the late 1980's and early 1990s noted concerns about the long-term health effects associated with the various HIV medications they had taken. Yet, many of these individuals also noted that they never expected to live more than a few years following their diagnosis, and thus, being able to discuss aging and HIV was a relief. One participant reported frequently calling her doctor to ask about concerning symptoms.

When you're feeling aches and pains and you don't know whether it's just because you're getting older, or if it's something you should be real concerned about because of HIV. You sit back and wonder if it's normal or not normal. So, I find myself questioning my doctor all the time ... and usually she'll say, 'Well, you know you're getting older' and I say, 'I know, but that's a good thing.' [52 year-old White female; Vermont]

II. Barriers to engagement in HIV care

All participants in this study were engaged in HIV care at the time of their interview, and the vast majority had been regularly engaged in care for many years. Yet, participants reported numerous challenges to maintaining care, most notably, a lack of local providers and the travel required to access care. Many participants were seeing a primary care physician in addition to their HIV provider and other healthcare specialists, and they often traveled long distances to receive care. The following participant was being treated for skin cancer in addition to HIV:

Interviewer: Is there anything that makes it difficult for you to get to your doctor's office?

Participant: It's actually 67 miles from my house to the parking lot. If I had to drive that sick, that's horrible. And, depending on how sick you are, it is dangerous. I go at least once a month in between head surgeries and seeing my doctor there, biopsies, yeah, I'm down there for me at least once a month. I have 3 trips there this week and then I have to go next week for my HIV doctor, so this gets expensive.... I was at the pawn shop yesterday to get \$60 so we can make these trips happen. [50 year-old White male; Wisconsin]

The lack of patient-centered and coordinated scheduling was a barrier for many participants who saw multiple physicians. Even when participants had a medical home and their physicians were co-located, they faced challenges accessing and affording all of their appointments. Multiple appointments in a given month or week were challenging to schedule and adhere to and the additional cost and time for rural residents created an added burden.

While traveling long distances to receive care was the most frequently cited barrier to care, a few individuals did have local access to HIV and primary care physicians. Yet, even in these situations, individuals faced unique barriers to access and engagement in care.

Participant: My doctor only comes once a month. That's my HIV doctor. I can call, but I might not always get her.

Interviewer: So she travels to your town once a month to see patients?

P: Yeah. There is a nurse that's here 3 days a week, mostly only in the afternoon. So if I want to get a message to my doctor I have to use her, but she's not always available. If I have a real emergency, the local hospital is not equipped to handle HIV cases. That would be about a 2 hour drive. [55 year-old White male; Vermont]

The use of traveling physicians can be useful in addressing physician shortages and transportation barriers for rural residents. Yet, as the participant above highlighted, these physicians are not readily available to address urgent needs and patients still may still be forced to travel long distances or deal with restricted scheduling and access. Only a few individuals had access to a local physician but even then, several voluntarily traveled to see physicians outside their town because of privacy concerns and the stigma associated with HIV.

Participant: To the doctor I have to drive an hour, hour and a half... I don't want the local people to know about my condition and they can access my records. If I do get a primary doctor, it will not be around me, you know. I live in a small town. [55 year-old Black male; Wisconsin]

Concerns about HIV-related stigma were strong and most participants reported that only a handful of individuals in their communities knew their HIV status. As such, some participants felt it was necessary to seek providers and pharmacies outside their communities.

Despite the barriers to access and engagement in care, a few participants described assistance programs in place designed to help overcome some of the barriers. For example,

Medicare patients were often eligible for free transportation to and from doctor's visits and several social service agencies provided assistance with money for gas or provided buses and shuttles to clinics and hospitals.

Participant: Ok, this is the way it goes with mine. It's awesome what happens there. My social worker, they have this system that if you are in a rural area that they have this transportation thing that they can send out and I think it's just the most awesome thing that I can call and get if I can't get there. That's what they do, just to make sure that I get there. It's 75 miles one way and then 75 miles back, so that's pretty good. I pray that the funding never runs out because if it does, there's going to be some people in bad shape. [62 year-old White female; Alabama]

Another woman who lived on a Native American reservation in Wisconsin had a case manager at her local tribal clinic who not only hand-delivered medications on a weekly basis, but also picked her up to take her to medical and mental health appointments to ensure she was retained in care. Yet, these programs were not widespread and individuals under the age of 60 were not eligible for Medicare transportation programs.

III. Barriers to medication access and adherence

Recent efforts have focused on improving antiretroviral medication adherence among older adults living with HIV (High et al., 2012; Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011), and despite barriers, older adults are more likely to be adherent than younger adults (Barclay et al., 2007; Hinkin et al., 2004), except when other health problems interfere (Wutoh et al., 2001). As evidenced above, participants in this study were contending with numerous co-morbidities, which could not only threaten their ability to adhere to HIV medications, but also make it difficult for participants to keep track of all of their medications.

Interviewer: Besides HIV, can you tell me what other health conditions you have?

Participant: Bronchitis, COPD, that's about it.

I: Ok, and you said you're on 21 different medications? Do you know any of the medications off hand that you could tell them to me?

P: Oh, honey, I can't even pronounce them. [59 year-old White male; Alabama]

Not surprisingly, several participants could not recall all of their medications and a few individuals were not sure which medications were treating which illnesses or symptoms. Although the majority of participants reported high levels of adherence to their HIV-medications, many noted difficulty keeping track of various medications, their refill dates, and their purposes, not uncommon for older adults with chronic conditions. Furthermore, the financial burden associated with medication costs was significant for several participants.

Participant: [Prescription costs] takes probably an extra \$125 or \$150 a month out of my monthly income, cause I'm on a long list of medications.

Interviewer: Can you tell me what medications you are taking right now?

P: How much time do you have (laughter). I have a very long list. Let's see I'm on medications called Intelence, a medication called Prezista, a medication called Norvir, and Isentress... I'm taking medications for blood pressure, for cholesterol, I'm taking medications for diabetes, I'm taking medications for depression, and I take medication for my prostate. And then I have like ointments for skin, you know. I get little breakouts on my skin and in my ears and that kind of thing. I think it's a fungus a lot of people get when then get older. Oh, and I take a medication for chronic fatigue. I take a stimulant. [57 year-old White male; Tennessee]

Many participants in this study received Medicare, which covered the full cost of prescriptions once a patient met their yearly deductible, which was frequently met within the first three months of the year. Consequently, the beginning of the year was often financially challenging. For individuals in Wisconsin and Vermont, this also coincided with the high heating bills associated with winter, making affording medication co-pays particularly challenging. Participants reported sacrificing food and basic utilities to afford medications or selected only some of their medications to purchase at the beginning of the year.

Participant: I get my medicine from you know, the Medicare and Medicaid, and right now it's in the catastrophic, you know, my medicines are. But when it goes back to the first of the year, I will have to pay my co-pay. It's not real high, but it will be somewhat high. It would be like, well, I will have to choose my water or my medicines. I would have to make the right choice, I would choose my medicine because then I would go and seek help from somebody to get my water turned back on, I would. [62 year-old White female; Alabama]

In addition to affordability, access to pharmacies was a common barrier. Although some participants reported receiving medications by mail and having few problems with this system, several others noted significant challenges to getting their medications every month. Individuals who had to pick their prescriptions up at the pharmacy often discussed being strategic about running multiple errands at the same time to save on gas money.

Participant: I've been restricted on my ability to go places because of the cost of gasoline. I would schedule my trips to town and do two or three things at the same day ... for some reason, my prescriptions come staggered, I don't get them all at the same time every month. And because of Part D, I can't change my refill date to make them fall on the same day. That was probably one of the biggest issues that required me to go into town more often. [57 year-old White male; Tennessee]

The inability to pick up all prescriptions once a month was a notable challenge, especially given that many participants were taking multiple medications to manage various illnesses and symptoms. In addition, several participants reported at least one instance when challenges with their pharmacy or insurance coverage caused them to miss a few days of their medications. Participants reported their pharmacists were not familiar with their HIV medications and did not regularly carry their prescriptions. One participant in Wisconsin described the challenges he faced accessing medication, including the need to pick up medications at two pharmacies, located in different cities outside his own.

Interviewer: Do you have a pharmacy that is nearby?

Participant: I do, but it's kind of hard to access, just because of the hours. It's a small town and it's not open on Sundays and they aren't open after 5:00, so if I need something, I go to the ER. And then there's the issue of [AIDS Drug Assistance Program]. This pharmacy has no idea how to deal with it and has never heard of it, which I understand. They don't have many people who have HIV, so we got some growing pains with that. And then because some other medications aren't on the ADAP formulary, I'm having to go through a different pharmacy to get medicines that aren't on the formulary.... The pharmacist has no clue about this, he never sold an HIV-specific drug ever. So that was new to him. [50 year-old White male; Wisconsin]

Although mail-order prescriptions could alleviate some of these barriers, participants receiving medications by mail still reported delays and incomplete prescription delivery, among other challenges.

Participant: I have to time them just right because they only come 3 days a week. I have to time it just right for it to fall on one of those. I have to remember to call the pharmacy and say, "I'm almost out of this medication, can you deliver it?" They only deliver on Monday, Wednesday, and Friday. [55 year-old White male; Vermont]

While some experienced restrictions on delivery services offered by local pharmacies, others reported challenges with billing and prescription coverage of mail-order prescriptions.

Participant: At one point they did mail them, but then they wouldn't get a co-pay from the state. Their computer and the state computer wouldn't match up and they would never understand I have this other insurance on top of Medicare D... In trying to call to tell [pharmacy] I needed meds, I always had to call my regular doctor. The whole situation was kind of like, 'how many people do I have to call just to get another refill on a med?' And I have to take 5 of them a day. So to manage all of that, it's enough to take the freaking things and to manage how to get them is another whole thing. I mean, it's supposed to be easy if it's mail order and it's never been, and I'm wondering why they put so many hurdles on it. [62 year-old White male; Vermont]

Mail-order and prescription delivery services are often seen as an opportunity to circumvent challenges associated with pharmacy access, yet the individuals in this study reported nearly as many barriers with this system. Even more participants were not able to access mail-order pharmacy services altogether.

Discussion

This study provides insight into the unique experiences of older PLH living in rural areas and highlights the complicated health challenges and barriers to HIV care these individuals face. Given the increase in HIV/AIDS prevalence in rural areas (Centers for Disease Control and Prevention, 2015) and an aging cohort of PLH (Centers for Disease Control and Prevention, 2013), there is an increasing need for tailored interventions along the HIV care continuum. Findings from this study demonstrate how the interconnected experiences of

aging, living with HIV, and residing in a rural environment influence the availability and accessibility of care.

Our findings revealed a prominent intersection between HIV and aging. It was aging, rather than HIV, however, that was the primary concern among the majority of participants. This is not surprising given that among HIV-infected individuals with suppressed viral load, HIV often ceases to be the ‘dominant’ comorbidity, but is simply a key element in the overall milieu of multiple morbidities (Justice & Braithwaite, 2012). Individuals experienced numerous chronic conditions typically associated with aging, and with well-managed HIV, these other conditions took precedence. This may, in part, reflect the advances in HIV medical care and the quality of care participants are receiving, despite the barriers in place. Although we did not use laboratory data to assess viral load, self-reported medication adherence rates were also high and accordingly, participants reported few HIV-related complications and opportunistic infections. Yet, some HIV symptoms can mimic age-related conditions and it is often difficult to tease out whether an individual is experiencing HIV complications or general aging ailments. Nevertheless, participants overwhelmingly viewed age as more concerning than their HIV status.

The intersection of aging and HIV has important implications for health care and treatment. First, physicians’ inability to attribute symptoms definitively to HIV or aging was a source of frustration for several individuals. In a few instances, participants believed their experiences were associated with HIV, medication side effects, or the result of long-term HIV medication use, although their doctor attributed the symptoms to aging. Disagreement about the cause of a symptom or health condition can contribute to doubts about the effectiveness of medications, misunderstandings about the progression of their disease (Siegel, Schrimshaw, & Dean, 1999), patient frustration, and poor patient-provider communication. Additionally, the intersection of aging and HIV could present challenges for physicians in accurately diagnosing and treating older PLH. For example, the perception of cognitive decline as normal aging rather than HIV-related, may conceal an emerging disease and contribute to delayed diagnosis including medication toxicities and polypharmacy (Mateen & Mills, 2012). Although HIV-associated neurocognitive impairment can be treated with antiretroviral therapy, it becomes increasingly difficult to treat with age. (Heaton et al., 2010)

Similarly, medication management may become increasingly challenging for older PLH. Polypharmacy, or the concomitant use of multiple medications, has been associated with increasing age, as well as an increased risk of poor outcomes (Holtzman et al., 2013). Among older adults without HIV infection, the risk of adverse drug toxicity, drug-drug interactions, and nonadherence increases with each additional drug beyond five medications (Justice & Braithwaite, 2012). The risk for drug-drug interactions may be particularly high among the aging population of HIV-infected individuals due to treatments for multiple comorbidities (Buchacz et al., 2013; Hasse et al., 2011) and the concomitant use of antiretroviral therapy. The majority of participants in this study reported taking more than five medications, with a few individuals reporting upwards of 15 prescription medications. Greater number of daily medications (not including antiretrovirals (ARV)) can increase the

risk of ARV/non-ARV combinations with potential for clinically significant interactions for individuals with HIV, particularly those 50 years or older (Holtzman et al., 2013).

Receiving effective treatment for HIV is complicated for older PLH living in rural and other resource-constrained communities. Participants' rural environment created numerous barriers to HIV and mental health care, as well as medication access: physical isolation, limited access to local health providers, limited transportation, lack of patient-centered, coordinated scheduling, stigma, and poverty. Individuals generally had to travel more than 60 miles to see HIV specialists and were reluctant to see local providers given the stigma surrounding HIV. More than half of participants in this study also reported seeing primary care physicians as well as other specialists, requiring at least monthly trips to out-of-town clinics and hospitals. The lack of coordinated scheduling contributed to multiple physician visits per month or week to the same hospital or clinic. Efforts are needed to coordinate scheduling across departments and units to minimize time and transportation barriers, especially for older individuals for whom traveling long distances can be difficult. Although a few individuals received all their prescriptions by mail, many others struggled to manage refilling and picking-up prescriptions at several points each month, often at multiple pharmacies in different neighboring towns. Although publicly and privately-funded support programs were available to many individuals overcome some of these barriers, individuals also reported making significant sacrifices (including foregoing food, delaying utility payments, and selling personal belongings) in order to afford and access the care they needed. Future research should examine the effects of poverty on HIV care for older PLH in resource-constrained settings, as our analyses indicate that poverty underlies many of these barriers. Yet, it is important to highlight that despite the barriers cited by participants, all of them were currently receiving HIV care. Future research should similarly examine resources and resilience among this population to identify opportunities to enhance the factors that facilitate engagement in care.

This study highlights several opportunities for interventions. Most significantly, interventions for this unique population must be contextualized by both age and geographic location. It is important to reiterate that the barriers to care faced by older, rural PLH are often interconnected and require a cohesive, collaborative response. Interventions should incorporate needed social and community supports including case management services, food and nutrition support, and financial assistance with rent, utilities, and transportation. Community-based care that incorporates family members, neighbors, or other friends, can provide the psychosocial aspects of treatment support, which are essential in maintaining medication adherence and treatment retention (Mateen & Mills, 2012). Isolated location and transportation barriers were a noted concern. Furthermore, individuals were reluctant to access care within their own communities given the stigma associated with HIV. As such, transportation support should be expanded by either providing shuttles or reimbursement for travel costs to and from medical appointments.

Technological advances may provide a useful mechanism to reach physically isolated individuals. Telemedicine has already been demonstrated to increase adherence to ARVs (Collier et al., 2005; Reynolds et al., 2008), decrease risky sexual behaviors in HIV-infected persons in rural areas (Lovejoy et al., 2011), and reduce depressive symptoms in rural

persons living with HIV.(Ransom et al., 2008) However, the use of technology and telemedicine with older adults needs more study. Although not discussed in this manuscript, about half of the participants noted limited or no internet access, attributable to both the expense of internet services and the lack of exposure to and comfort with computers and technology. Thus, although telemedicine may be useful for some older PLH in rural environments, such interventions should simultaneously seek to increase access and comfort with technology to ensure such interventions are accessible and user-friendly. Finally, there have been programs that have effectively provided HIV medical care to individuals in rural communities. The Vermont Model, for example, established regional HIV specialty clinics in regional hospitals to integrate HIV care into primary and other specialty care. Between visits, care is provided by a Nurse Practitioner at a local clinic and reviewed via telephone consultation with HIV physicians. This program was able to bring experienced HIV providers to rural areas and clinical data demonstrate similar outcomes to patients receiving care in urban areas (Grace et al., 2010). Such evidence-based programs should be emulated in other states and regions, tailored to the unique needs and resources of individual states. Additionally, as individuals with HIV continue to age, they will be more likely to experience additional health consequences and for some, disability, limiting travel to an even greater extent. The provision of ambulatory services needs adequate attention and planning and greater attention should be paid to rural and underserved communities.

There are limitations of this study to note. The sample size for this study is small, geographically limited, and comprised primarily of men. Women may have unique experiences associated with aging and HIV and additional research is needed to fully explore their needs. Access and barriers to care may vary significantly on a state-by-state basis based on state funding, federal program administration, and social services. Thus, the findings from this study cannot be generalized to all older PLH living in rural communities. Participants are residents of four states (Wisconsin, Alabama, Tennessee, and Vermont), which are likely not representative of the country's rural, older adult, PLH population. Similarly, participants in this study were recruited through ASOs, and as such, all were currently engaged in HIV care, which likely biased the sample. There may be additional barriers that are not yet known because they prohibit individuals from accessing care entirely or participating in research. Additional research is needed to better understand PLH in rural communities who are out of care and develop interventions to increase engagement. The next phase of this study will include a national, quantitative study to examine many of these issues in greater depth and provide a more comprehensive look at barriers and access to care for rural older PLH nationwide.

Our findings provide initial insight into the experiences of older PLH living in rural communities. Rural residence and aging are both independently associated with poorer health and HIV outcomes (Parsons et al., 2014; Stoff, 2004)(Weis et al., 2010), and our results highlight how these all intersect to inhibit HIV care. Yet there is a clear need for large-scale, quantitative studies and subsequent interventions that address the intersection of aging and HIV targeting both patients and providers.

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