

FY 2024 How to Best Meet the Need

Special Workgroup #1 - HIV & Aging

10:30 a.m., Monday April 17, 2023

Join the Zoom meeting: bit.ly/2023HTBMN-Specialwgl

Meeting ID: 881 4413 3557

Passcode: 578354

Or, use your cell phone to participate: 346-248-7799 (same Meeting ID/Passcode)

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**2020 Houston HIV Care
Services Needs Assessment:
Profile of Youth and Aging PLWH**

PROFILE OF YOUTH AND AGING WITH HIV

While HIV may affect people of all ages, the impact of HIV varies across age groups. The Centers for Disease Control and Prevention (**CDC**) report that youth aged 12 to 24 accounted for 21% of new HIV diagnoses in 2018 with 92% of youth new diagnoses occurring among young men who have sex with men (**MSM**).¹ Locally, the HIV diagnosis rate for youth aged 12 to 24 in the Houston Eligible Metropolitan Area (**EMA**) was 32.6 new diagnoses per 100,000 population, 20% higher than the population as a whole.²

People Living with HIV (**PLWH**) ages 45 to 54 within the Houston EMA in 2019 had a prevalence rate of 386.2 diagnosed cases per 100,000 population. Data about the needs and experiences of youth and those aging with HIV in the greater Houston area are of particular importance to local HIV planning as this information equips communities to tailor HIV prevention and care services to meet the markedly different yet equally critical needs of these age groups.

Proactive efforts were made to gather a representative sample of all PLWH in the 2020 Houston HIV Care

Services Needs Assessment as well as focus targeted sampling among key populations (See: *Methodology*, full document), and results presented throughout the full document include participants who were recently released. This profile highlights results *only* for participants who were youth or aging at the time of survey, as well as comparisons to the entire needs assessment sample.

Notes: “Youth” and “aging” are defined in this analysis as PLWH who indicated at survey that they were between 18 and 24 years of age for youth, and age 50 or over for aging. Data presented in this in the Demographics and Socio-Economic Characteristics section of this Profile represent the *actual* survey sample, rather than the *weighted* sample presented throughout the remainder of the Profile (See: *Methodology*, full document). Proportions are not calculated with a denominator of the total number of surveys for every variable due to missing or “check-all” responses.

¹ <https://www.cdc.gov/hiv/group/age/youth/index.html>

² Texas Department of State Health Services

DEMOGRAPHICS AND SOCIO-ECONOMIC CHARACTERISTICS

(Table 1) In total, 17 participants in the 2020 Houston HIV Care Services Needs Assessment were between the ages of 18 to 24 at the time of survey, while 353 were ages 50 and over. Youth comprised 3% of the total sample, while aging participants comprised 60%. This reflects the increasing number of aging PLLWH in the Houston area.

Eighty-nine percent (89%) of youth participants and 94% of aging participants were residing in Houston/Harris County at the time of data collection. As all needs assessment participants, the majority of youth and aging participants were male (84% and 66%) and African American/Black (53% and 62%). Among youth needs assessment participants, 19% reported not being retained in HIV care at the time of data collection. Among aging needs assessment participants, 13% reported not being retained in HIV medical care at the time of data collection.

Several differences were observed between these populations and the total sample. A greater proportion of youth participant's gender identities were reported as transgender/gender non-conforming (17% vs 4%), identified as multiracial (21% vs 4.7%), identified as gay/lesbian/bisexual/aseexual (75% vs 39%). Compared to the total sample, a greater proportion of aging participants identified as heterosexual (61% vs 57%).

Several socio-economic characteristics of youth and aging participants were also different from all

participants. No youth participants reported having private health insurance, and a smaller proportion reported utilizing Ryan White Program services to pay for medical care compared to the total sample (50% vs 24%). Youth needs assessment participants also showed a large proportion of having no insurance compared to the total sample (13% vs 2%). The average annual income among those reporting income for the total sample was \$13,493, compared to \$9,513 among youth participants and \$12,011 among aging participants.

Characteristics of *youth* participants (as compared to all participants) can be summarized as follows:

- Residing in Houston/Harris County
- Male
- African American/Black
- Gay/lesbian/bisexual/aseexual
- Transgender/gender non-conforming
- With higher occurrences of no health insurance coverage, and lower average annual income.

Characteristics of *aging* participants (as compared to all participants) can be summarized as follows:

- Residing in Houston/Harris County
- Male
- African American/Black
- Heterosexual
- With lower occurrences of no health insurance coverage, and slightly lower average annual income.

TABLE 1-Select Participant Characteristics among Youth (18-24) and Aging (50+) participants, Houston Area HIV Needs Assessment, 2016

	Youth %	Aging %	Total %		Youth %	Aging %	Total %		Youth %	Aging %	Total %
County of residence				Sex at birth				Primary race/ethnicity			
Harris	89%	94%	95%	Male	84%	66%	66%	White	11%	17%	14%
Montgomery	5%	1%	1%	Female	16%	34%	34%	African American/Black	53%	62%	60%
Walker	5%	0%	1%	Intesex	0%	0%	0%	Hispanic/Latino	5%	14%	21%
Fort Bend	0%	2%	2%	Other	0%	0%	0%	Asian American	5%	1%	1%
Other	0%	3%	1.6%	Transgender/Gender Non-Conforming	17%	2%	4%	Native American or Native Alaskan	0%	1%	1%
				Currently pregnant	0%	0%	2%				
Sexual orientation				Health insurance (multiple response)				Immigration status			
Heterosexual	22%	61%	57%	Private insurance	0%	7%	9%	Born in the U.S.	100%	89%	88%
Gay/Lesbian	44%	28%	30%	Medicaid/Medicare	21%	56%	67%	Citizen > 5 years	0%	10%	10%
Bisexual/Pansexual	28%	9%	9%	Harris Health System	17%	21%	29%	Citizen < 5 years	0%	1%	1%
Other	6%	2%	3.8%	Ryan White Only	50%	10%	24%	Visa (student, work, tourist, etc.)	0%	0%	0.2%
				VA	0%	3%	3%	Prefer not to answer	0%	3%	0.7%
MSM	77%	37%	43%								
Yearly income (average: \$9,380)											
Yearly income – Youth (average: \$12,017)											
Yearly income – Aging (average: \$9,581)											
Federal Poverty Level (FPL)											
Below 100%	100%	64%	67%								
100%	0%	19%	19%								
150%	0%	5%	6%								
200%	0%	4%	5%								
250%	0%	0%	0.7%								
≥300%	0%	8%	2%								

BARRIERS TO RETENTION IN CARE

As in the methodology for all needs assessment participants, results presented in the remaining sections of this Profile were statistically weighed using current HIV prevalence for the Houston EMA (2018) in order to produce proportional results (see: *Methodology*, full document).

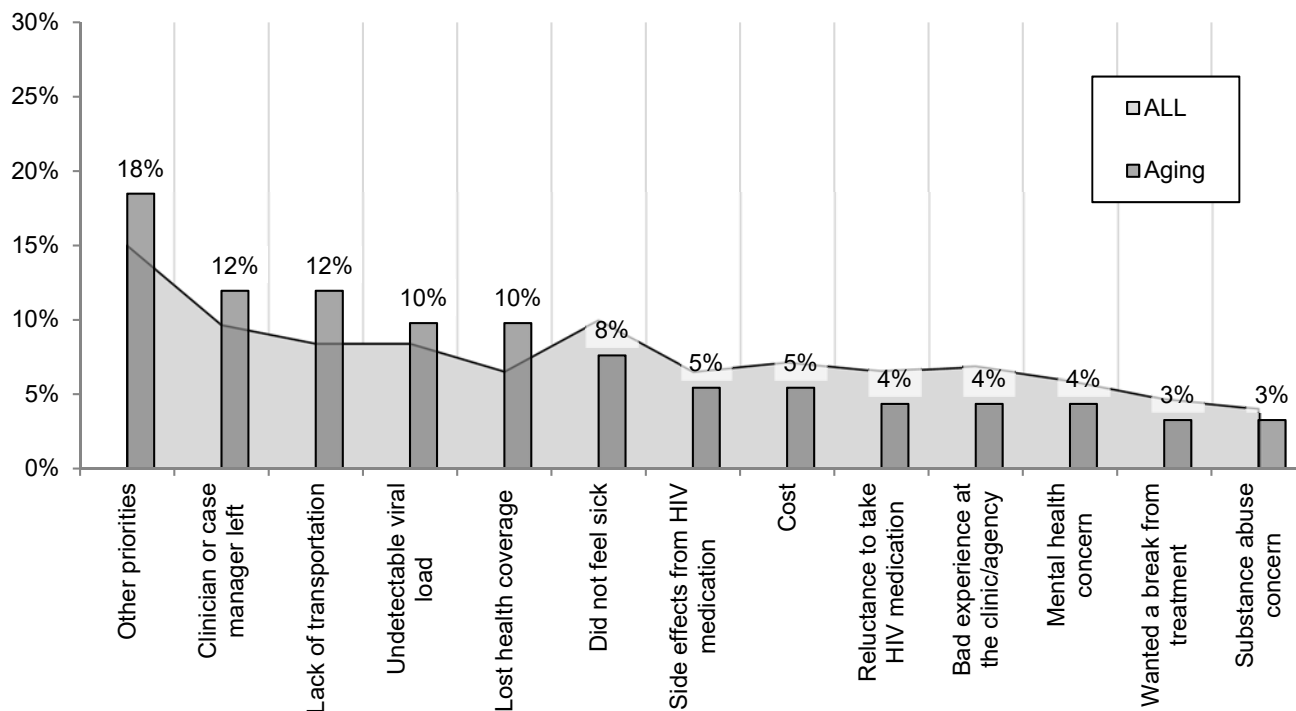
While 67% of all needs assessment participants reported no interruptions in their HIV care for 12 months or more since their diagnosis, 81% of youth and 70% of aging needs assessment participants reported no interruption in care. Those who reported a break in HIV care for 12 months or more since first entering care were asked to identify the reasons for falling out of care. Thirteen commonly reported reasons were included as options in the consumer survey. Participants also had the option to write in their reasons as well.

(**Graph 1**) The sample of youth participants with a history of interruption in care was too small to compare to the aging participants and the total sample and therefore are not reported on in this section. Among aging participants, other priorities were the most cited reason for a break in HIV medical care (18%). Other reasons for a break in HIV medical care were the clinician or case manager left the clinic/agency (12%), lack of transportation (12%), and having an undetectable viral load (10%).

Compared to the total sample, a greater proportion of aging needs assessment participants reported falling of care due to lack of transportation (12% vs 8%), other priorities (18% vs 15%), and loss of health coverage (10% vs 7%). Write-in responses that were provided by participants included being incarcerated, not wanting or being ready to start HIV medical care, it was hard to find a clinic or provider, and loss of loved ones as reported barriers to retention in HIV medical care.

GRAPH 1-Reasons for Falling Out of HIV Care among Aging PLWH in the Houston Area, 2020

Definition: Percent of times each item was reported by aging needs assessment participants as the reason they stopped their HIV care for 12 months or more since first entering care.



OVERALL RANKING OF FUNDED SERVICES, BY NEED

In 2020, 16 HIV core medical and support services were funded through the Houston Area Ryan White HIV/AIDS Program, and housing services were provided through the local HOPWA program. Participants of the 2020 Houston HIV Care Services Needs Assessment were asked to indicate which of these funded services they needed in the past 12 months.

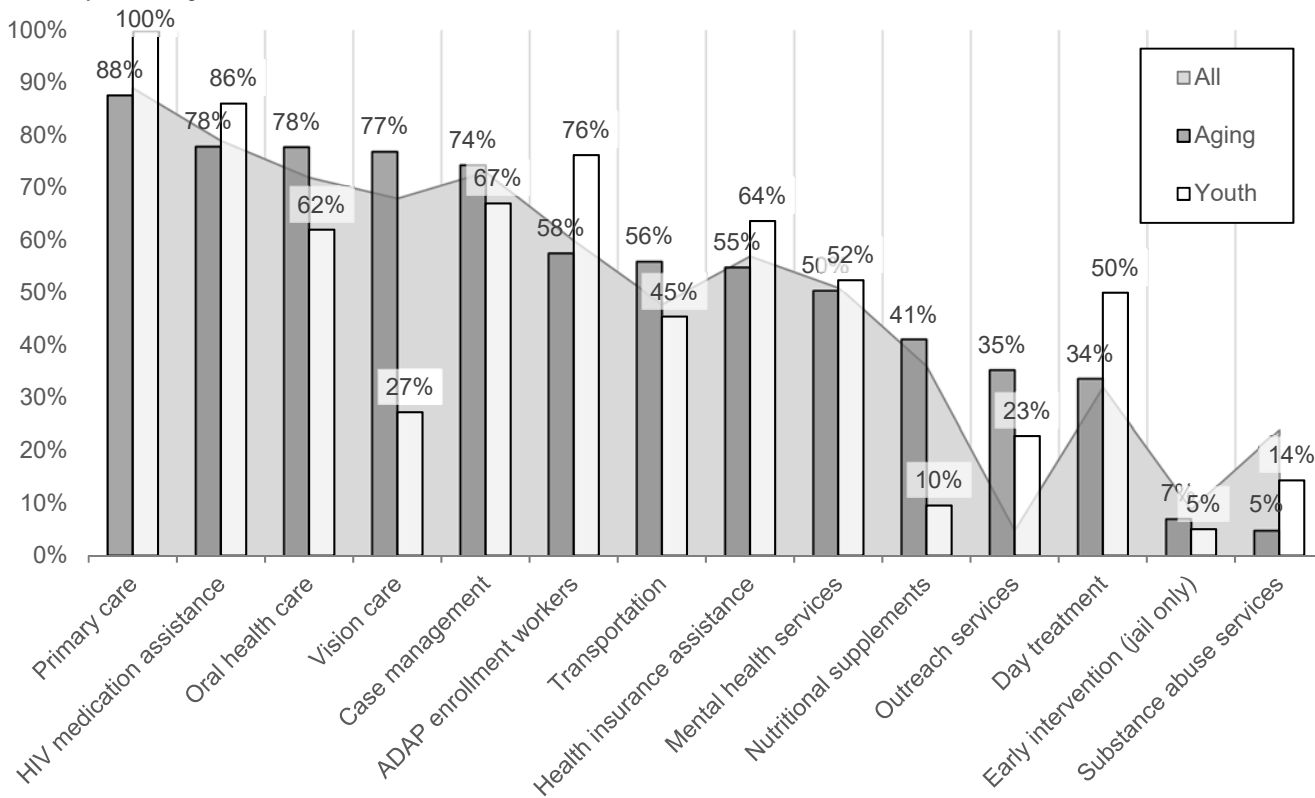
(Graph 2) Like the total sample, youth and aging needs assessment participants identified primary care as the most needed Ryan White funded service (100% of youth and 88% of aging participants). For youth, local HIV medication assistance (86%), ADAP enrollment

workers (76%), and case management (67%) followed in ranking of need. For aging participants, local HIV medication assistance (78%), oral health care (78%), and vision care (78%) followed in ranking of need.

Compared to the total sample, higher proportions of youth participants indicated needing day treatment (50% vs 32%), outreach services (23% vs 5%), ADAP enrollment workers (76% vs 60%), primary care (100% vs 89%). Among aging needs assessment participants, a greater proportion indicated needing outreach services (35% vs 5%), vision care (77% vs 68%), and transportation (56% vs 48%).

GRAPH 2-Ranking of HIV Services among Youth (13-24) and Aging (60+) PLWH in the Houston Area, By Need, 2020

Definition: Percent of youth and aging needs assessment participants stating they needed the service in the past 12 months, regardless of ease or difficulty accessing the service.



Other Identified Needs

In 2020, 10 other/non-Ryan White funded HIV related services were assessed to determine emerging needs for PLWH in the Houston area. Participants of the 2020 Houston HIV Care Services Needs Assessment were asked to indicate which of these other/non-Ryan White funded HIV related services they needed in the past 12 months.

(Graph 3) From the 10 other/non-Ryan White funded HIV related services, the greatest proportion of youth participants reported needing housing (33%), food bank (32%), and health education and risk reduction services (18%). Among the aging needs assessment

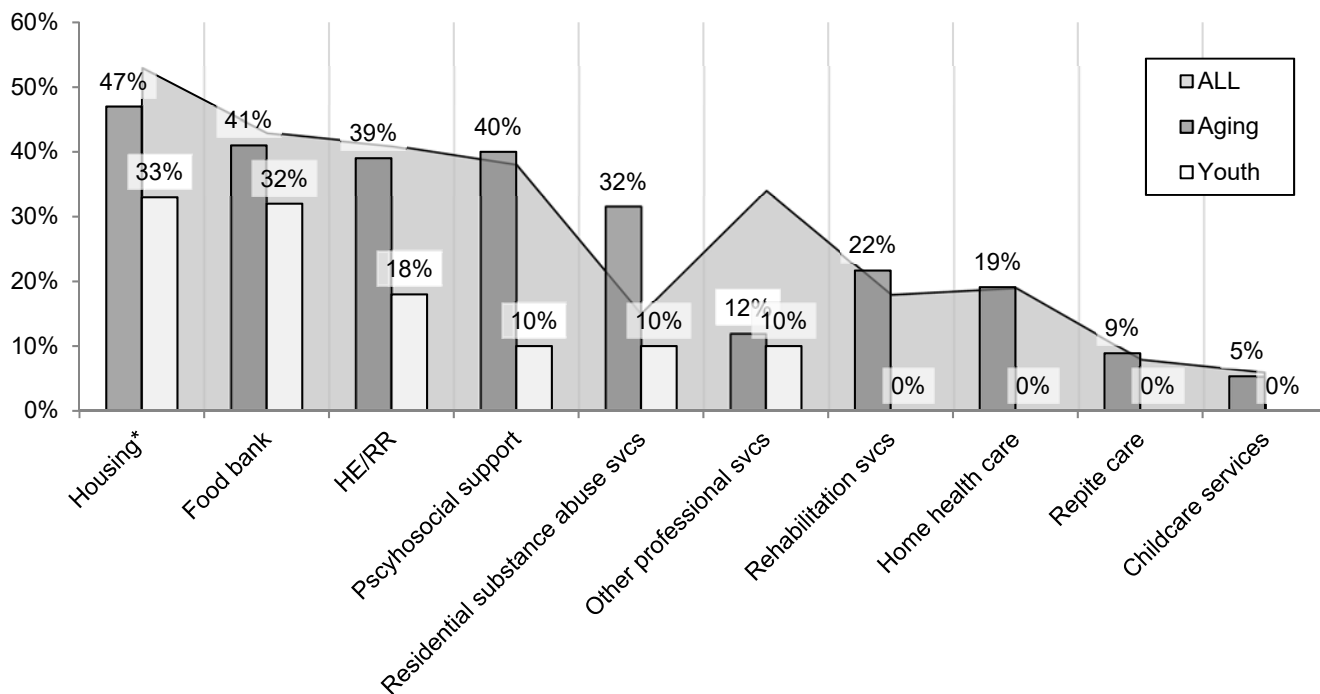
participants, the greatest reported non-Ryan White funded HIV related services were housing (47%), food bank (41%), and psychosocial support services (40%).

Aging participants reported comparable need for other services compared to the total sample, youth needs assessment participants expressed a lower need for other/non-Ryan White funded HIV-related services. Youth needs assessment participants reported a lower proportion of need for health education and risk reduction services (10% vs 41%), other professional services (10% vs 34%), and housing (33% vs 53%) when compared to the total sample.

GRAPH 3-Other Needs for HIV Services among Youth (13-24) and Aging (50+) PLWH in the Houston Area, 2020

Definition: Percent of youth and aging needs assessment participants, who selected each service in response to the survey question, "What other kinds of services do you need to help you get your HIV medical care?"

*These services are not currently funded by the Ryan White program; however, they are available through the Housing Opportunities for People with AIDS (HOPWA) program.



OVERALL BARRIERS TO HIV CARE

The 2020 Houston Area HIV Needs Assessment process continued the practice of reporting difficulty accessing needed services to provide a brief description of the barrier or barriers encountered, rather than select from a list of pre-selected barriers. Staff used recursive abstraction to categorize participant descriptions into 29 distinct barriers. These barriers were then grouped together into 12 nodes, or barrier types.

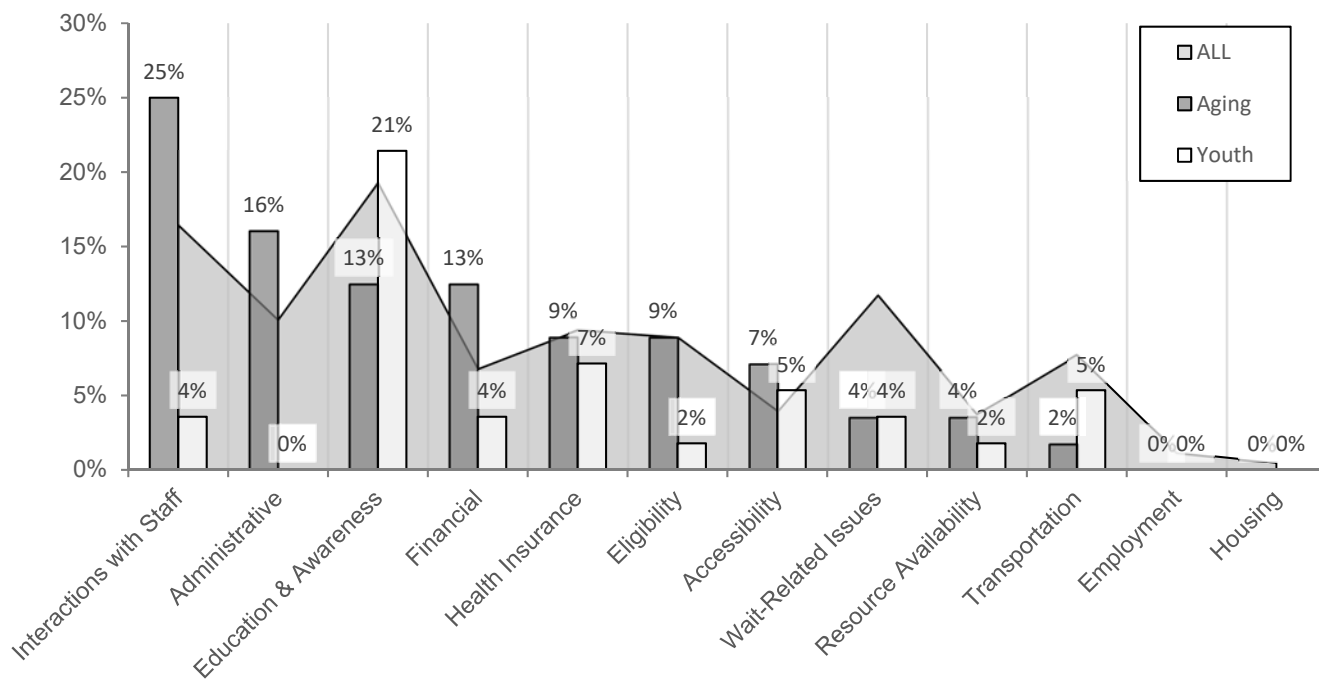
(Graph 4) Youth participants most often cited barriers related to service education and awareness issues (21%), and issues regarding health insurance (7%). Service education and awareness barriers among youth participants pertained mostly to not knowing who to contact for services, as well as not knowing that the service was available. While barriers related to health insurance among youth pertained mostly to health

insurance gaps (certain services/medications not covered by the participants current health insurance) and being uninsured.

Aging needs assessment participants most often cited barriers related to interactions with staff (25%), administrative issues (16%), service education and awareness issues and issues related to finances (both 13%). Aging participants reported that issues relating to interactions with staff mainly pertained to poor treatment, staff having limited or no knowledge of services, and poor correspondence or follow-up from staff. Issues related to administrative issues reported by aging participants were complex processes at the clinic/agency, and understaffing. Education and awareness issues reported by aging participants were related to not knowing that a service was available.

GRAPH 4-Ranking of Types of Barriers to HIV Services among Youth (13-24) and Aging (50+) PLWH in the Houston Area, 2020

Definition: Percent of times each barrier type was reported by youth and aging needs assessment participants, regardless of service, when difficulty accessing needed services was reported.



**For more information or a copy of the full 2020 Houston
HIV Care Services Needs Assessment contact:**

Houston Area Ryan White Planning Council

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Houston, TX 77027

Tel: (832) 927-7926

Fax: (713) 572-3740

Web: rwpchouston.org

Quality of Life VISION for PLHIV

All people living with HIV will have unfettered and ‘hassle-free,’ access to a full range of life-extending high quality culturally sensitive, gender affirming care and social support free from all stigma and discrimination that prioritizes our mental, emotional, and spiritual health as well as our financial wellbeing. People living with HIV are “people first” and our quality of life is not defined by our race, gender identity, sexual orientation, HIV status or measured solely by viral suppression.

Quality of Life THEMES

1. Intersectional stigma, discrimination, racial and social justice, human rights and dignity
2. Overall wellbeing, mental, emotional and spiritual health
3. Aging, comorbidities and life span (can include functionality, cognitive ability, geriatrics)
4. Healthcare services access, care and support
5. Economic justice, employment, stable and safe housing, food security
6. Policy and research

Quality of Life DEFINITION

We demand a quality of life that achieves the following:

1. Ensures that all people living with HIV thrive and live long healthy dignified lives.
2. Recognizes that HIV is a racial and social justice issue and works to dismantle the structural barriers that marginalize and diminish our quality of life.
3. Uplifts our humanity and dignity as human beings; we are people living with HIV and not a public health threat.
4. Values our emotional labor and personal stories as worthy of compensation and meaningfully involves people living with HIV as subject matter experts in all decisions that impact our lives as paid staff and consultants and not just as volunteers.
5. Recognizes that because we have a large number of people aging with HIV that include those born with HIV, long term survivors and people over the age of 50, we need for accessible services, support and care to ensure that we age with dignity
6. Understands that safe and stable housing, healthcare and financial security are basic human rights. We should not have to live in poverty to be eligible for services.
7. Recognizes that we are human beings entitled to live full rich pleasurable sexually active lives without fear of prosecution and understands the importance of social support networks to our overall well being.
8. Embraces our rich diversity in race, age, gender identity or expression, language, sexual orientation, income, ethnicity, country of origin or where we live and tells the full story of our resilience and not just our diagnosis.

THEME #1: Intersectional stigma, discrimination, racial and social justice, human rights and dignity

Strategy	Actions/Activities	Responsible Party	Year 1, 2, 3, 4 or 5
Reduce the impact of intersectional stigma for PLHIV and communities vulnerable to HIV	Implement new research tool developed by the Global Network of PLHIV called stigma index		
Ensure that all funding, policies, programs and decisions use an intersectional racial/social justice lens approach	Develop & apply racial/social justice lens to all decision making		
Implement/Operationalize MIPA throughout all service delivery	Integrate MIPA into RW planning councils		

THEME #2: Overall well-being, mental, emotional and spiritual health

Strategy	Actions/Activities	Responsible Party	Year 1, 2, 3, 4 or 5
Focus on “people first” rather than just treating HIV	Re-evaluate rapid start and other programs to ensure that services are person centered		
Eliminate use of stigmatizing language by organizations, services and throughout the workforce	Include people first language training requirement in all contracts and pay PLHIV to deliver trainings		
Increase the availability of social support services	<p>Require all Part A providers to provide support groups led by PLHIV</p> <p>Develop at least 3 support groups by December 2023 for high priority populations</p> <p>Develop list of peer/PLHIV willing to lead support groups and be compensated</p>		

THEME #3: Aging, comorbidities and life span (can include functionality, cognitive ability, geriatrics)

Strategy	Actions/Activities	Responsible Party	Year 1, 2, 3, 4 or 5
Reduce mortality rates for PLHIV	Develop data that more adequately reflects mortality and comorbidities of PLHIV		
Address aging needs of PLHIV	<p>Develop aging related services for PLHIV at all health care providers</p> <p>Ensure that all demographics are represented in research</p> <p>Create a research CAB focused on aging issues</p> <p>Develop needs assessment to gather data to address the special needs of verticals</p>		

Older Adult Clients:

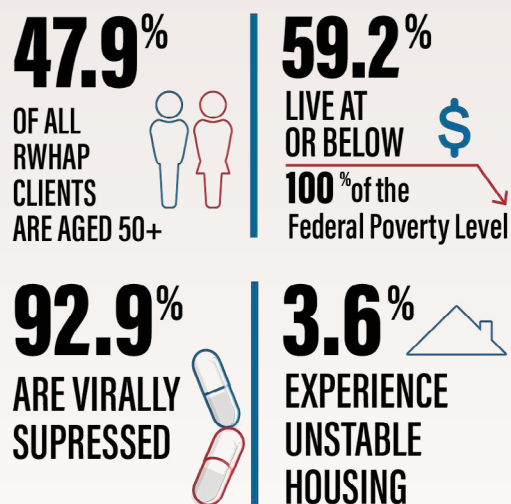
HRSA's Ryan White HIV/AIDS Program, 2020



Population Fact Sheet | July 2022

The Health Resources and Services Administration's Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people with HIV. More than half the people with diagnosed HIV in the United States—nearly 562,000 people in 2020—receive services through RWHAP each year. The RWHAP funds grants to states, cities, counties, and local community-based organizations to provide care and treatment services to people with HIV to improve health outcomes and reduce HIV transmission. For more than three decades, RWHAP has worked to increase health equity, stop HIV stigma, and reduce health disparities by caring for the whole person and addressing their social determinants of health.

Ryan White HIV/AIDS Program Fast Facts: Older Adult Clients



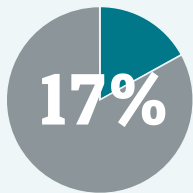
RWHAP clients are aging. Of the more than half a million clients served by RWHAP, 47.9 percent are people aged 50 years and older. Learn more about these clients served by the RWHAP:

- **The majority of RWHAP clients aged 50 years and older are from diverse populations.** Among RWHAP clients aged 50 years and older, 68.0 percent are people from racial and ethnic minorities; 44.2 percent of RWHAP clients in this age group are Black/African American people, which is slightly lower than the national RWHAP average (46.6 percent). Additionally, 21.2 percent of RWHAP clients in this age group are Hispanic/Latino people, which is slightly lower than the national RWHAP average (23.6 percent).
- **The majority of RWHAP clients aged 50 years and older are male.** Data show approximately 70.8 percent of clients aged 50 years and older are male, 28.1 percent are female, and 1.1 percent are transgender.
- **The majority of RWHAP clients aged 50 years and older are people with lower incomes.** Among RWHAP clients aged 50 years and older, 59.2 percent are living at or below 100 percent of the federal poverty level, which is lower than the national RWHAP average (60.9 percent).
- **Data show 3.6 percent of RWHAP clients aged 50 years and older experience unstable housing.** This percentage is lower than the national RWHAP average (4.8 percent).

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission. People with HIV who take HIV medication as prescribed and reach and maintain viral suppression cannot sexually transmit the virus to their partner. In 2020, 92.9 percent of clients aged 50 years and older receiving RWHAP HIV medical care are virally suppressed,* which is higher than the national RWHAP average (89.4 percent).

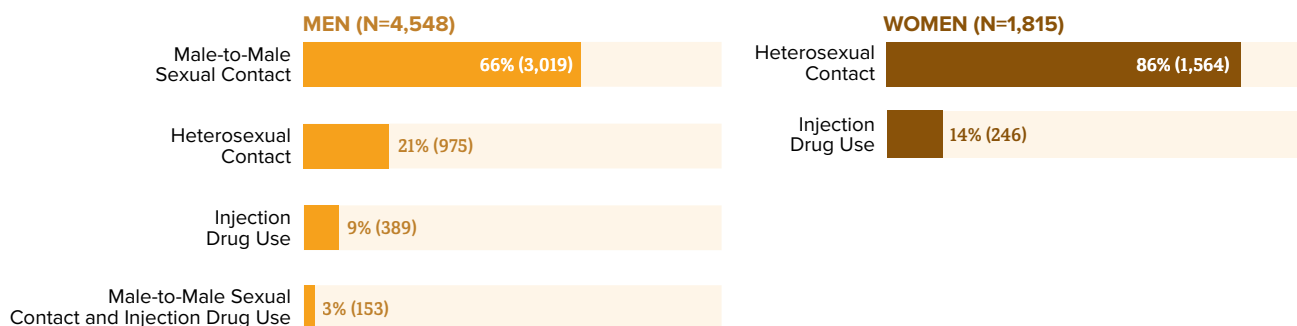
*Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among people with HIV who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

HIV and Older Americans



Of the **37,968 NEW HIV DIAGNOSES** in the US and dependent areas* in 2018, 17% were among people aged 50 and older.

Among people aged 50 and older, most new HIV diagnoses were among men.†

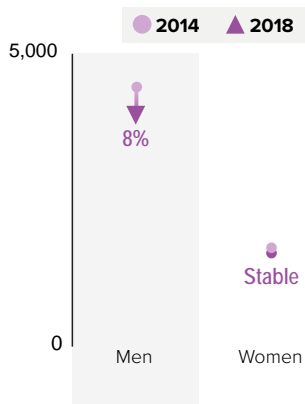


Totals may not equal 100% due to rounding.

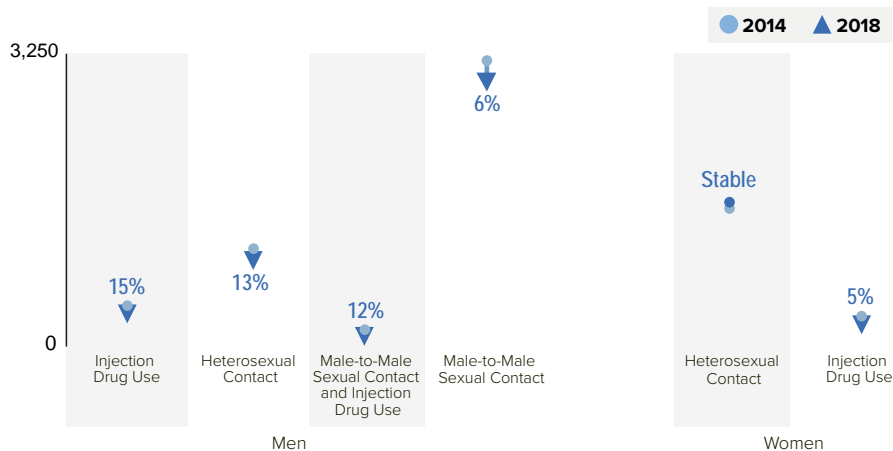
HIV diagnoses decreased 6% overall among people aged 50 and older from 2014 to 2018.



Trends by Sex†



Trends by Transmission Category†



* American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the US Virgin Islands.

† Based on sex at birth and includes transgender people.

‡ In 50 states and the District of Columbia.



People aged 50 and older who don't know they have HIV can't get the care and treatment they need to stay healthy.



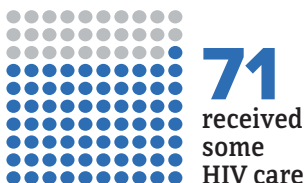
At the end of 2018, an estimated **1.2 MILLION AMERICANS** had HIV.† Of those, 379,000 were aged 55 and older.

9 in 10 people aged 55 and older knew they had the virus.



It is important for people aged 50 and older to know their HIV status so they can take medicine to treat HIV if they have the virus. Taking HIV medicine every day can make the viral load undetectable. People who get and keep an undetectable viral load (or stay virally suppressed) can live a long and healthy life. They also have effectively no risk of transmitting HIV to HIV-negative sex partners.

Compared to all people with HIV, people aged 55 and older have higher viral suppression rates. In 2018, for every **100 people aged 55 and older with HIV**: ‡



For comparison, for every **100 people overall** with HIV, **65 received some HIV care**, **50 were retained in care**, and **56 were virally suppressed**.

There are several challenges that place some people aged 50 and older at higher risk for HIV.

Fewer Discussions with Doctors



Although they visit their doctors more frequently, older people and their health care providers are less likely to discuss HIV testing and sexual or drug use behaviors.

Knowledge of HIV Prevention



Older people may not be as knowledgeable about HIV prevention and sexual risk and may be less likely to use a condom or other prevention options.

Delayed Treatment



Older people are more likely to have late-stage HIV at the time of diagnosis, may start treatment late, and suffer more immune system damage.

Stigma



Older people may have additional challenges getting into care due to stigma, isolation, and loss of support from their family, friends, and community.

How is CDC making a difference for people aged 50 and older?



Collecting and analyzing data and monitoring HIV trends.



Supporting community organizations that increase access to HIV testing and care.



Conducting prevention research and providing guidance to those working in HIV prevention.



Promoting testing, prevention, and treatment through the *Let's Stop HIV Together* campaign.



Supporting health departments and community-based organizations by funding HIV prevention work and providing technical assistance.



Strengthening successful HIV prevention programs and supporting new efforts funded through the *Ending the HIV Epidemic* initiative.

For more information about HIV surveillance data and how it is used, read the "Technical Notes" in the HIV surveillance reports at www.cdc.gov/hiv/library/reports/hiv-surveillance.html.

For more information visit www.cdc.gov/hiv

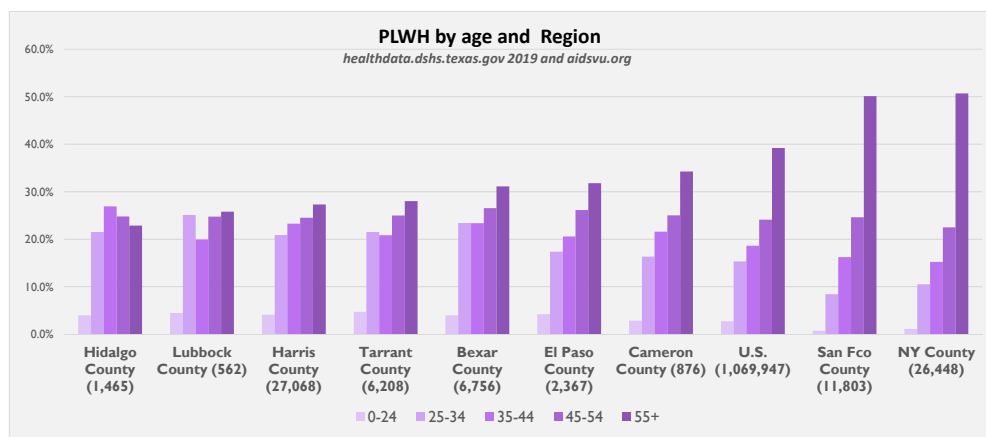


Institutional capacity to address the health & social needs of older Texan Hispanics/Latinxs living with HIV

Daniel Castellanos, DrPH
*VP of Research & Innovation
 Latino Commission on AIDS
 2/28/23*



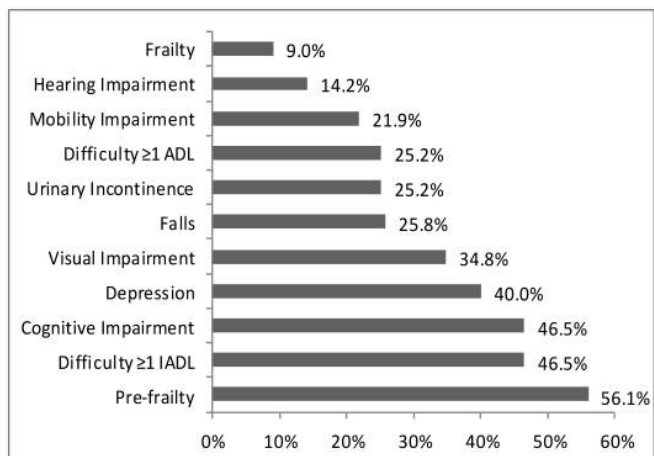
PLWH BY AGE GROUP



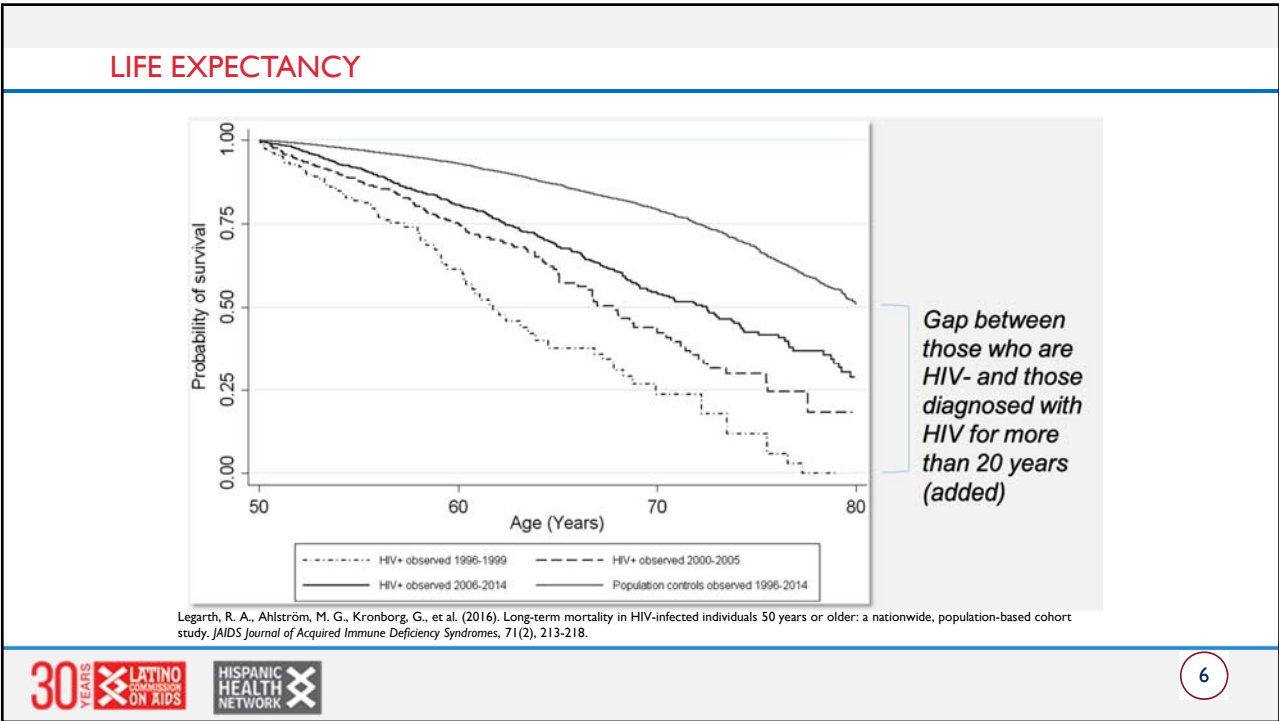
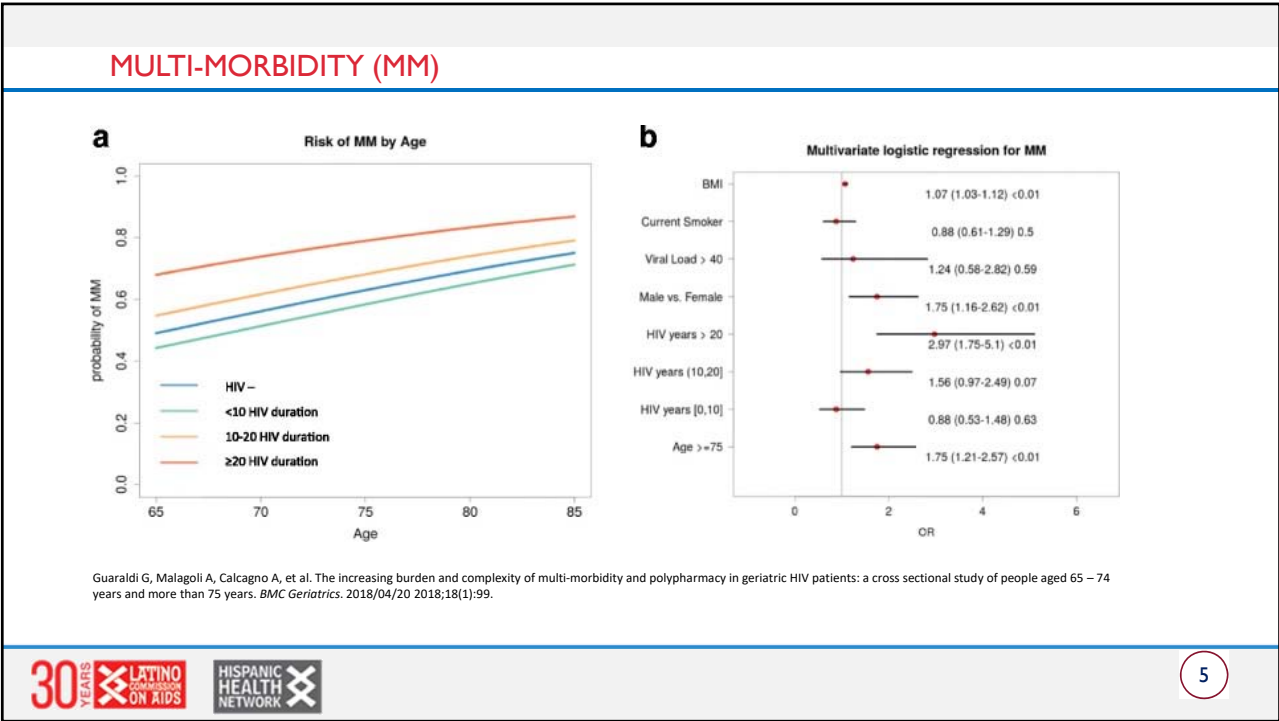
KEY CONCERNS

- Early onset of aging
- Multi-morbidity and polypharmacy
- Mobility impairment and frailty
- Multiple sources of stigmatization
- Long-term trauma
- Isolation

EARLY GERIATRIC SYNDROMES IN PLWH > 50 AND OLDER



Greene, M., Covinsky, K. E., Valcour, V., et al. (2015). Geriatric syndromes in older HIV-infected adults. *Journal of acquired immune deficiency syndromes* (1999), 69(2), 161.



KEY CHALLENGES

- Diverse sociocultural and medical views about what constitutes old age
- OPLWH and staff unclear about the impact of HIV versus the aging process
- OPLWH and staff feeling overwhelmed with multiple conditions and treatments
- Early onset of aging requiring prevention, screening, and treatment
- Balancing primary care versus ID medicine versus geriatric care
- Additional resources, workload, and training among non-clinical and clinical staff
- Insurance coverage limitations for specialized services and resource



7

PROJECT DESCRIPTION

GOAL: To assess the health and social needs of older Texan Hispanics/Latinxs living with HIV and the institutional capacity needs

POTENTIAL QUESTIONS:

- Core health and social service needs related to aging with HIV among Hispanics/Latinxs
- Sociocultural views on aging and aging care among older Hispanics/Latinxs and HIV service providers
- Effective strategies for addressing the aging-related needs of clients
- Programmatic strategies and resources needed for integrating HIV case management and aging services



8

PROJECT DESCRIPTION

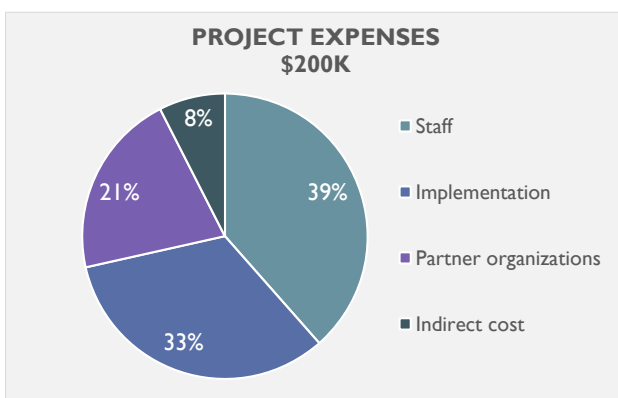
METHODS:

- Interviews with 5 older Texan Hispanic/Latinx individuals living with HIV at each of the 6 organizations
- Interviews with 5 case managers/social workers at each of the 6 organizations
- 300 surveys with older Texan Hispanics/Latinx individuals living with HIV (50 surveys at 6 organizations)



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PROJECT EXPENSES (DRAFT)



PROJECT FUNDED BY GILEAD

- Staff (\$77K)
- Implementation (\$66K)
- Contribution to institutional partners (\$42,000)
- Indirect cost (\$15K)

ADDITIONAL LCOA SUPPORT

- Staff (\$35K)



10

WE WANT TO BUILD AREAS OF CONSENSUS BEFORE WE START THIS PROJECT

- Any reactions? What are your thoughts?
- What do you like?
- What do you dislike?

HOW CAN WE ENHANCE THE COLLABORATION EXPERIENCE?

- What could we do to enhance the project?
- How can we support the implementation process at the local level?

TEXAS BEHAVIORAL HEALTH ASSESSMENT

- Conducted 13 focus groups in Texas
- 120 surveys completed
- Submission of invoice
- 2023 National Latinx Conference:
Community-Led Strategies to Increase Health Equity: Assessing Mental Health and Substance Use Stigmatization and Literacy
Saturday, May 13th, 11:00am – 11:45am



13

Q & A

Daniel Castellanos, DrPH
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Visit <https://ilhe.org/>



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HOUSTON AREA HIV SERVICES RYAN WHITE PLANNING COUNCIL



We envision an educated community where the needs of all persons living with HIV and/or affected individuals are met by accessible, effective, and culturally sensitive health and psychosocial services that are part of a fully coordinated system. The community will continue to intervene responsibly until the end of the epidemic.

The Houston Eligible Metropolitan Area (EMA) Ryan White Planning Council will improve the quality of life and advocate for those living with and/or affected by HIV by taking a leadership role in the planning and assessment of HIV resources.

MINUTES

12 noon, Thursday, June 9, 2022

Meeting Location: St. Philip Presbyterian Church 4807 San Felipe, Houston, Texas 77056
and Zoom teleconference

Reports from Committees

Quality Improvement Committee:

FY 2023 Targeting for FY 2023 Service Categories: See attached. Turner asked if it was discussed to target aging. Williams said this was discussed by the Quality of Life workgroup and last year Dr. Patel said that family practice doctors would be better than gerontologists. Legacy has a gerontologist on staff. Martin added that many elderly receive primary care through Medicaid or Medicare so this cannot be provided through Ryan White if they have other coverage for it. Clinics in Houston have Infectious Disease doctors for HIV but in the rest of the country they have family practice doctors that also take care of HIV. We have an old fashioned model here. **Motion #6:** *Approve the FY 2023 Targeting for Ryan White Part A/MAI, Part B and State Services funded service categories.* **Motion Carried.** Abstention: Aloysius, Castillo, Crawford, Padilla, Shaikh.

Adjournment: The meeting was adjourned at 1:52 p.m.

Legacy Community Health is Now Offering Geriatric Services

By Legacy Staff - Jan 18, 2023

Legacy Community Health is now offering geriatric services to better serve its older-adult patients. Patients age 65 or older can now benefit from a physician trained to handle their unique health needs — a geriatrician.

A geriatrician is a medical doctor who specializes in the diagnosis, treatment and prevention of disease and disability in older adults. As the body ages, its health care needs become more complex. Geriatricians address those unique demands, such as the management of multiple chronic conditions and medications.

According to the [United States Census Bureau](#), the U. S. will experience considerable growth in its older population between 2012 and 2050. And an AARP [bulletin](#) called geriatrics “... a critical role, becoming increasingly important as America ages.”

“Adding geriatric services allows us to better serve the needs of our aging communities,” says Dr. Patricia Hayes, Legacy’s Director of [Family Medicine](#). “It’s a pressing need and another way for us to drive healthy change in our communities.”

Older adults should consult a geriatrician if they’re experiencing memory problems, Alzheimer’s disease or dementia, falls or difficulty walking, constipation, depression or anxiety, unexpected weight loss, bladder control problems, or difficulties with personal care, such as bathing, toileting, feeding or getting dressed.

Legacy geriatricians work together with nurses, social workers, pharmacists, dieticians, and behavioral health providers to treat the whole person — physically, emotionally and socially.

Geriatric services are currently offered at Legacy’s [Fifth Ward](#), [Northline](#), and [San Jacinto](#) (coming soon) Clinics.

Senior Care

What you need to know about Alzheimer's & Dementia

Understanding Alzheimer's and Dementia

Thursday, March 9th, 10 AM – 12 PM

10 Warning Signs of Alzheimer's

Thursday, April 13th, 10 AM – 12 PM

Tour our clinic, meet our providers, enjoy refreshments and receive a free gift.

[RSVP to an Upcoming Event](#)

Specializing in health care for senior adults with Medicare, Medicare Advantage and HMO/PPOs.

Our Senior Care team is committed to meeting all the health and wellness needs of seniors—and to helping each patient live a healthier, fuller life. We know health and wellness needs change as we age, and our team works with each patient to provide personalized care and support delivered with compassion and respect. We value our patients and the trust they place in us as part of their health and wellness journey, and we care for all patients as if they're family.

It's Easy to Become a Patient

We know changing doctors isn't always easy. That's why our caring team members are available to answer all your questions and help you every step of the way. Want to learn more? Call us at (832) 548 5000. We can schedule a private tour or an appointment with one of our providers. We can also provide you with the forms you need to transition your medical records if they're with another doctor. It's that easy! New patients welcome! Immediate appointments available!

[Click to Call - become a patient today](#)

A Team Focused on Your Health and wellness

When you become a Legacy Senior Care patient, you gain a team of experts: doctors, nurses, nutritionists, pharmacists, therapists, social services specialists and more! Your team will work together to meet your physical, emotional and social wellness needs. We'll also provide you with the education, support and resources you need to implement your care plan.

comprehensive care with lots of convenience

Comprehensive Care with Lots of Options

We're committed to providing great care with great convenience. Our Senior Care centers offer:

A wide variety of services, including new patient consultations, annual wellness exams, care for chronic conditions, and immediate connection to specialty care

Onsite community rooms where we can provide educational and community activities to further support physical, emotional and social wellness needs

Longer appointment times to allow for plenty of time to address concerns

Senior-friendly spaces to meet the physical needs of seniors, making your time with us more comfortable

New to Medicare? We can Help

If you're about to become (or have recently become) eligible for Medicare, we can help answer your questions and schedule your Medicare Initial Preventive Physical Examination (IPPE). You can learn more about the visit [here](#) – or call us today at (832) 548 5000 to schedule an appointment with one of our caring providers. You can see our updated list of Medicare Advantage Plans [here](#).

What Care Does Legacy Senior Care Provide?

Primary care

Coordinated care for all health and wellness needs

Medicare annual wellness visit and preventive services

Behavioral Health*

Chronic disease management (e.g., arthritis, diabetes, heart disease)

Immediate connection to specialty care

Same- and next-day appointments

Longer appointments with your provider to address all your needs

On-site lab services

Clinical pharmacy services*

Senior care social work consultations

Monthly activities and educational classes

**coming soon*

What Can I Expect During a Senior Care Visit with a Geriatrician?

Since our health care needs typically change as we age, our Senior Care visits allow ample time to address all of a patient's needs – physical, emotional and social. We work with patients to manage chronic illnesses such as arthritis and diabetes, review immunization status and any prescription and over-the-counter drugs, vitamins and supplements a patient is taking, and create a treatment plan. And, if a patient needs a specialist, we will make an immediate connection to care.

Locations

San Jacinto

4301 Garth Rd.
Ste. 400
Baytown, TX 77521

Phone: 281-420-8400

Fax: 832-548-5460

Hours

Mon - Thurs: 8:00 am - 8:00 pm

Fri: 8:00 am - 6:00 pm

1st & 3rd Sat: 8:00 am - 4:00 pm

2nd, 4th & 5th Sat: Closed

Stafford Fountains

12540 Sugardale Dr.
Stafford, TX 77477

Phone: 713-814-3525

Fax: 713-559-3001

Hours

Mon - Fri: 8:00 am - 5:00 pm

Third Ward - Law Harrington Senior Center

2222 Cleburne St.
Suite 108
Houston, TX 77004

Phone: 832-548-5000

Fax: 713-559-3021

Hours

Mon - Fri: 8:00 am - 4:00 pm

Located inside of the Law Harrington Senior Center

HIV and the Older Person | NIH

Considerations for Antiretroviral Use in Special Patient Populations

HIV and the Older Person

Key Considerations and Recommendations When Caring for Older Persons with HIV

Key Considerations and Recommendations When Caring for Older Persons with HIV

- Antiretroviral therapy (ART) is recommended for all people with HIV regardless of CD4 T lymphocyte cell count **(AI)**. ART is especially important for older individuals because they have a greater risk of serious non-AIDS complications and potentially a blunted immunologic response to ART.
- Given that the burden of aging-related diseases is significantly higher among persons with HIV than in the general population, additional medical and social services may be required to effectively manage both HIV and comorbid conditions.
- Adverse drug events from ART and concomitant drugs may occur more frequently in older persons with HIV than in younger individuals with HIV. Therefore, the bone, kidney, metabolic, cardiovascular, cognitive, and liver health of older individuals with HIV should be monitored closely.
- Polypharmacy is common in older persons with HIV; therefore, there is a greater risk of drug-drug interactions between antiretroviral drugs and concomitant medications. Potential for drug-drug interactions should be assessed regularly, especially when starting or switching ART and concomitant medications.
- The decline in neurocognitive function with aging is faster in people with HIV than in people without HIV. HIV-associated neurocognitive disorder (HAND) is associated with reduced adherence to therapy and poorer health outcomes including increased risk of death. For persons with progressively worsening symptoms of HAND, referral to a neurologist for evaluation and management or a neuropsychologist for formal neurocognitive testing may be warranted **(BIII)**.
- Mental health disorders are a growing concern in aging people with HIV. A heightened risk of mood disorders including anxiety and depression has been observed in this population. Screening for depression and management of mental health issues are critical in caring for persons with HIV.
- HIV experts, primary care providers, and other specialists should work together to optimize the medical care of older persons with HIV and complex comorbidities.
- Early diagnosis of HIV and counseling to prevent secondary transmission of HIV remains an important aspect of the care of older people with HIV.

Rating of Recommendations: A = Strong; B = Moderate; C = Optional

Rating of Evidence: I = Data from randomized controlled trials; II = Data from well-designed nonrandomized trials or observational cohort studies with long-term clinical outcomes; III = Expert opinion

Download Guidelines

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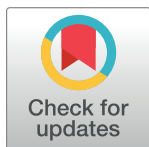
RESEARCH ARTICLE

Assessing the health status and mortality of older people over 65 with HIV

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Antigone Dempsey², Heather Hauck², Laura W. Cheever², Andre R. Chappel¹

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Abstract

Background

Nearly half of people with HIV in the United States are 50 years or older, and this proportion is growing. Between 2012 and 2016, the largest percent increase in the prevalence rate of HIV was among people aged 65 and older, the eligibility age for Medicare coverage for individuals without a disability or other qualifying condition. Previous work suggests that older people with HIV may have higher rates of chronic conditions and develop them more rapidly than older people who do not have HIV. This study compared the health status of older people with HIV with the older US population not living with HIV by comparing: (1) mortality; (2) prevalence of certain conditions, and (3) incidence of these conditions with increasing age.

Methods and findings

We used a sample of Medicare beneficiaries aged 65 and older from the Medicare Master Beneficiary Summary File for the years 2011 to 2016, including 100% of individuals with HIV (N = 43,708), as well as a random 1% sample of individuals without diagnosed HIV (N = 1,029,518). We conducted a survival analysis using a Cox proportional hazards model to assess mortality and to determine the need to adjust for differential mortality in our analyses of the incidence of certain chronic conditions. These results showed that Medicare beneficiaries living with HIV have a significantly higher hazard of mortality compared to older people without diagnosed HIV (3.6 times the hazard). We examined the prevalence of these conditions using logistic regression analysis and found that people with HIV have a statistically significant higher odds of depression, chronic kidney disease, chronic obstructive pulmonary disease (COPD), osteoporosis, hypertension, ischemic heart disease, diabetes, chronic hepatitis, end-stage liver disease, lung cancer, and colorectal cancer. To look at the rate at which older people are diagnosed with conditions as they age, we used a Fine-Gray competing risk model and showed that for individuals without diagnosis of a given condition at age 65, the future incidence of that condition over the remaining study period was higher for people with HIV even after adjusting for differential hazard of mortality and for other

OPEN ACCESS

Citation: Turrini G, Chan SS, Klein PW, Cohen SM, Dempsey A, Hauck H, et al. (2020) Assessing the health status and mortality of older people over 65 with HIV. PLoS ONE 15(11): e0241833. <https://doi.org/10.1371/journal.pone.0241833>

Editor: Kenzie Latham-Mintus, Indiana University Purdue University at Indianapolis, UNITED STATES

Received: January 8, 2020

Accepted: October 21, 2020

Published: November 5, 2020

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Data Availability Statement: Medicare Master Beneficiary Summary File data cannot be shared publicly because of privacy and confidentiality issues. Data can be requested from ResDAC, a CMS contractor, by emailing RESDAC@umn.edu. The process for requesting data is described here: <https://www.resdac.org/research-identifiable-files-rif-requests>.

Funding: The authors received no specific funding for this work.

Competing interests: The authors have declared that no competing interests exist.

demographic characteristics. Many of these results also varied by personal characteristics including Medicaid dual enrollment, sex, and race and ethnicity, as well as by condition.

Conclusions

Increasing access to care and improving health outcomes for people with HIV is a critical goal of the National HIV/AIDS Strategy 2020. It is important for clinicians and policymakers to be aware that despite significant advances in the treatment and care of people with HIV, older people with HIV have a higher odds of having multiple chronic conditions at any point in time, a higher incidence of new diagnoses of these conditions over time, and a higher hazard of mortality than Medicare beneficiaries without HIV.

Introduction

Treatments for HIV have improved significantly over the past 24 years since combination anti-retroviral therapy was first introduced in 1996. HIV is now a manageable, chronic condition and individuals retained on anti-retroviral therapy have much longer life expectancies than in the past, which is contributing to an ongoing shift in the age distribution of people with HIV [1–5]. This trend, seen in the US and elsewhere [6], toward an aging of the population with HIV raises important questions regarding the health care needs of older people with HIV, how they may differ from those of older people without HIV, and how best to address those needs.

While treatments have allowed people with HIV to live longer and have decreased the likelihood of AIDS-defining illnesses, other health conditions such as various non-communicable diseases appear to be becoming more common among older people with HIV. There are a number of potential reasons why older people with HIV may have different baseline health statuses or trajectories than older people without HIV, and the reasons likely differ by condition. First, HIV itself leads to chronic inflammation, which in turn is associated with systemic chronic immune activation and a higher likelihood of a number of diseases [7–10]. Second, the long-term toxicity of antiretroviral therapies (ARTs) may directly affect the body and may also interact with other medications [11]. Although newer treatment regimens cause fewer side effects than those used in the past, long-term use of ART is associated with increased risk of heart disease and heart attack; use of ART in general may lead to a number of health problems, including liver toxicity, pancreatitis, neuropathy, and impaired glucose metabolism [12, 13]. A third issue is that older people who are newly diagnosed with HIV tend to have more advanced disease due to delayed diagnosis, leading to more advanced immunodeficiency and an increased likelihood of blunted immune response to ART due to immune senescence [14]. This may be partly the result of barriers to early testing and diagnosis for older individuals, such as a lack of awareness of how risk factors may be different for older adults compared to younger individuals, as well as an underestimation of the risk of HIV infection at older ages both by patients and providers [14–18]. Delays in HIV diagnosis are associated with negative health outcomes, decreased life expectancy, and increased HIV transmission [19]. Finally, rates of HIV infection are higher in certain populations that tend to have poorer long-term health outcomes generally, including among men who have sex with men, transgender women, racial and ethnic minorities, and people experiencing poverty [20, 21]. Recently, the prevalence of HIV among people living in rural areas has been increasing, and these individuals are more likely to have delayed diagnosis and to face additional barriers to accessing health care, in general, and from providers with experience treating HIV, in particular [22]. In

addition, a range of other adverse health behaviors, such as smoking, are disproportionately common among people with HIV [23, 24].

Previous research and anecdotal evidence from providers have raised concerns that, despite often having high rates of adherence and viral suppression [25, 26], older people with HIV may have a higher prevalence of chronic conditions overall and may develop new conditions at an earlier age. However, currently little is known about the health trajectory of older people with HIV as they age given the limitations of methods and data used in previous studies, particularly the use of cross-sectional data to examine point prevalence of various outcomes and the use of smaller or selected samples of people with HIV (for instance, a limited number of clinics from The HIV Outpatient Study [27], individuals in Medicare from 2006–2009 [28], Medicaid enrollees with HIV are not older adults [29]). Cross-sectional analyses that simply compare the average age of onset of a condition or disease can potentially lead to incorrectly concluding that there is evidence of premature aging if population age structure differences are not accounted for. Given that there are fewer older people with HIV than there are without HIV, the unadjusted mean age of onset may be lower even if the risk or incidence at a given age is actually the same [30]. Cross-sectional analysis also limits the ability to account for possible selection effects from differences in mortality rates. The few studies that try to use cross-sectional data to look at incidence and premature aging have mixed findings [31]. Without following patients over time, it is difficult to distinguish between the effects of “premature” aging, where diagnoses of conditions occur at earlier ages, or “accentuated” aging, where people with HIV have higher prevalence rates of certain conditions than people without diagnosed HIV at every age but there is no change in the average age of onset [32]. The ability to distinguish between premature and accentuated aging can enable health providers and programs serving older people with HIV to better care for and prepare for the needs of this population, especially if the accumulation of health conditions of older people with HIV follow a trajectory that involves more conditions, higher severity, and a faster timeline. Together, these previous studies suggest that even among older people with HIV on antiretroviral therapy, there are higher rates of cardiovascular disease, heart disease, chronic hepatitis, chronic obstructive pulmonary disease (COPD), renal disorders, osteoporosis, and non-AIDS related cancers (e.g. lung and colorectal cancer), among other conditions, compared to those without an HIV diagnosis. Likewise, these patients are more likely to have multiple comorbidities and polypharmacy compared to older people without diagnosed HIV [11, 12, 18, 27–29, 33–42] for a selection of examples].

We were able to find one set of published analyses of a large, representative cohort, the Veterans Aging Cohort Studies, which followed a large number of veterans with and without HIV over time, but these results may not be generalizable to other populations (the sample was almost entirely male, for instance, and younger on average than our population of interest; see [43, 44] for two examples from the Veterans Aging Cohort Studies). From the Veterans Aging Cohort Study, there was a small but statistically significant increased association between general physical decline and age for older people with HIV compared to older people without HIV [43], and a statistically significantly larger association between age and diabetes, vascular disease, and liver disease for older people with HIV compared to older people without HIV [44]. Another Veterans Aging Cohort Study analysis found that adjusted mean age of myocardial infarction and non-AIDS defining cancer were not significantly different for people with HIV and people without HIV, but HIV-infected adults were diagnosed with end-stage renal disease, on average, 5.5 months younger than people without HIV [33].

This current study builds on the existing evidence base by using longitudinal data from the general population to compare the health status of older people with HIV with the older US population not living with HIV by comparing: (1) mortality; (2) prevalence of several

important, often co-occurring, conditions; and (3) incidence of these conditions as individuals age. This study used the Medicare Master Beneficiary Summary File (MBSF) from 2011 to 2016, which allowed us to track the health status of a large, nationally representative sample of older people with HIV, aged 65 and older, while accounting for individual characteristics and survival trends. This also allowed us to extend our analyses to look at populations that may be differentially affected by aging with HIV, including by urban/rural residence, Medicaid enrollment, sex, and race/ethnicity. As far as we are aware, this is the first study to use a nationally representative cohort of Medicare enrollees over time to look at aging with HIV, and in particular, to account for differential mortality.

Methods

Data and samples

The data for this project came from the Centers for Medicare & Medicaid Services (CMS) Master Beneficiary Summary File (MBSF), which contains data on all individuals enrolled in Medicare in a given calendar year. Citizens and permanent residents of the United States are generally eligible for Medicare at age 65 or if they have end-stage renal disease or have a disability and have accumulated a sufficient amount of work history individually or through a spouse or parent to qualify for Social Security Disability Insurance (SSDI) or Social Security Retirement Benefits or Railroad Retirement benefits or a railroad disability annuity. We used a random 1% sample of beneficiaries who never had an HIV diagnosis and 100% of the individuals who ever had an HIV diagnosis in the MBSF files from 2011 to 2016 and then compared these two groups of individuals as long as they were alive for those years. We chose to limit our analysis to 2011 to 2016 because of concern about a CMS rule change noted in Pub 100-04 Medicare Claims Processing (Transmittal 2028) beginning in January 2011, which increased the number of diagnosis codes that could be recorded on a claim from 9 to 25 (potentially making people artificially appear sicker than they were before the change). Individuals could enter the analytic sample in any year after age 65; we observed beneficiaries annually up to six years (five years on average). For all mortality and incidence analyses, our unit of time was therefore the calendar year. Although we were able to analyze outcomes for the entire population of people with HIV, we used a 1% sample of beneficiaries without a diagnosis of HIV for comparison due to computing limitations and because sensitivity analyses showed very similar results that did not change our findings with a 5% sample. Our sample included 1,073,226 individuals aged 65 and older, of whom 43,708 had an HIV diagnosis. As expected, individuals with an HIV diagnosis (49,561) accounted for a small percentage (0.1%) of the entire population of Medicare fee-for-service beneficiaries (50,360,645) in 2016. We excluded those younger than age 65 who appeared in our data (namely, those who qualified for Medicare coverage based on disability or because they had end-stage renal disease and not because of age). The MBSF files contained beneficiary-year level data on demographic and geographic characteristics, whether an individual was enrolled in Medicaid, diagnosis flags for a number of conditions (including diagnosis of HIV or AIDS), and date of death (if applicable). The diagnosis flags were hierarchical condition category (HCC) codes developed by CMS, which used International Classification of Diseases (ICD) codes from medical claims and mapped them to particular disease groups (for instance, diabetes or chronic kidney disease) [45].

Statistical methods

We conducted three sets of regression analyses to compare: (1) mortality; (2) prevalence of selected chronic conditions; and (3) incidence of these conditions among older people living with and those without an HIV diagnosis. In all models, our primary explanatory variable of

interest was the HIV diagnosis indicator (the comparison group is older adults without an HIV diagnosis ever during the study period). For prevalence and incidence comparisons, we selected a set of health conditions hypothesized to be associated with HIV infection as well as others that are generally associated with older ages (many, such as cardiovascular disease, are associated with both). We analyzed the following 11 conditions as outcome variables in separate regressions: depression, hypertension, chronic kidney disease, chronic obstructive pulmonary disease (COPD), osteoporosis, heart disease, colorectal cancer, lung cancer, diabetes, chronic hepatitis, and end-stage liver disease. For people with HIV, these were comorbid conditions to their HIV, while for people without HIV, these may have been their only chronic condition.

In our first set of models, we used survival analyses to assess whether older people with HIV have a higher hazard of mortality over time than older individuals without HIV. We did this both to analyze mortality as an outcome, and to assess the extent to which selective mortality may be a concern for subsequent chronic condition models, which was the focus of our analysis. To do this, we used a Cox proportional hazards model to compare the mortality hazard between older people with HIV and older people without diagnosed HIV as they age. For this set of models, we further restricted our overall sample for this analysis to individuals we observed at age 65 (between 2011 and 2016) and were observed annually or until they died. This was done because we were interested in comparing the health status of individuals beginning when they first age into Medicare. The Cox proportional hazard models included covariates for sex, race and ethnicity (non-Hispanic Black, non-Hispanic White, non-Hispanic Asian, and Hispanic), dual enrollment in Medicaid and Medicare (a proxy for low-income status), rural (or non-core based statistical area [46]) or urban residence, and indicator variables for the year they turned 65 (to control for temporal changes in factors such as treatment and cohort composition). Additionally, interaction terms with exposure time (years since 65) were included for the indicators for HIV diagnosis and for non-Hispanic Black designation, based on failures of the checks for the proportional hazards assumption for those covariates conducted using Schoenfeld residuals [47]. To look at population subgroups of interest, additional extended models included interactions between HIV diagnosis and individual characteristics including Medicaid dual enrollment, rural or urban location, sex, and race or ethnicity. For all results, hazard ratios (HR) and 95% confidence intervals (CI) were reported.

One potential limitation of this age restriction is that, given our six years of data, we were only looking at the ages of 65 to 71 (among the people with HIV in our sample who were at least 65, approximately 39% of them are older than 71). To address whether the results would be significantly changed if we were to look at a wider age range, we ran several robustness checks (S1 Table). The first robustness check analyzed individuals beginning when they turned 75 (rather than 65). The second robustness check included individuals at all ages but adjusted for age. The results of both of these robustness checks were extremely similar to our primary results. The main specification for our mortality and incidence analyses also removed anyone who was newly diagnosed with HIV after the age of 65 (12,566 Medicare beneficiaries, approximately 1% of our sample). Although this was a small number of individuals, they may be quite different from the vast majority who are diagnosed at younger ages and who have been living with the diagnosis and potentially in treatment for many years. For the third robustness check we ran these analyses with them included and this did not substantially change our results (results in S1 Table). In addition, there may be concern that HIV diagnosis may be associated with health conditions which themselves are associated with mortality (as we will illustrate with the second set of analyses on prevalence). We considered matching or including these conditions as covariates but ultimately chose not to in our preferred specification because of the concern that HIV itself may be a contributing factor for many of those conditions, so

including (or matching) based on them would be capturing some of the effects of HIV as well. However, in the fourth robustness check in [S1 Table](#), we show that there is still a significant, although somewhat attenuated, relationship between HIV diagnosis and mortality even if we include the other conditions as covariates, and also if we use an inverse probability weighted model. We did not use inverse probability weighting or other similar propensity score methods given the limited number of other demographic and personal characteristics available in the data. Another possibility was to match on our small set of demographic characteristics to create a control group that appears more similar in terms of observed characteristics to the population of older people with HIV on those dimensions. However, this would not necessarily reduce confounding from unobserved characteristics compared to using the full sample and adjusting for observed characteristics [48], and therefore we chose not to employ a matching method.

In our second set of models, we investigated whether older people with HIV have a higher prevalence of each of the previously mentioned conditions at any given age, not adjusting for differential mortality. For each outcome, we ran a logistic regression model using 2016 data only in order to understand the prevalence at a given point in time (odds ratios [OR] and 95% CI are reported). The models were also run for other years and the results did not substantially change; for simplicity, only 2016 is presented in the main table although other years are shown in [S2 Table](#). The models also controlled for age, sex, race and ethnicity, dual enrollment in Medicaid, rural or urban residence, as well as state of residence. Whereas the primary set of models include everyone, we were also interested in whether any observed patterns varied by select stratification variables: rural residence, Medicaid dual enrollment, sex, and race and ethnicity. To look at this question, we ran similar models but also included interactions between each covariate and the stratification variable (fully saturated models). The main specification for the prevalence models include everyone age 65 and older and adjusts for age, whereas the survival analysis (and incidence analysis discussed below) uses a more restricted sample of individuals who we observed as they enter Medicare. We tested whether restricting the prevalence sample to individuals who are included in the mortality and incidence regressions changed the results, and the results were very similar ([S2 Table](#)). While some researchers have a preference for risk ratios over ORs, particularly for more common events when ORs and risk ratios are more likely to diverge, we chose to use a logit and report ORs which are informative, even for common outcomes, if interpreted appropriately. In addition, there are some researchers who argue that there are methodological reasons for preferring ORs, and that risk ratios may actually be worse in cases where outcomes are common or the underlying risk in a population may not be homogeneous [49].

Given that we found a higher mortality rate for older people with HIV in the first set of models, for our third set of models, we used a competing risk model based on Fine and Gray [50] to analyze whether the incidence of new conditions occurs more rapidly for people with HIV, but with a competing risk that an individual may die before developing the condition. A standard time to event model analyzing incidence would treat individuals who die as if they would otherwise have the same risk of developing the condition as the people who remain alive. However, this assumption seems unrealistic if individuals who die are less healthy overall. Given their worse health status, it seems reasonable to hypothesize that they would be more likely to develop additional conditions. A competing risk model enables us to account for this situation. Similar to the survival models, we restricted the sample to individuals who we observed when they turned 65. The competing risk models therefore analyzed the time to diagnosis or death for individuals who have not yet been diagnosed with a particular condition of interest as of age 65. Individuals enter the analysis at age 65 and exit because of death or because we reach the end of the observation period. Our basic model included an indicator for

diagnosis of HIV infection as well as the same set of demographic characteristics used in the mortality models. To look at population subgroups of interest in extended models, we included interactions between HIV diagnosis and personal characteristics of interest including Medicaid dual enrollment, rural and urban location, sex, and race and ethnicity (as we did in the mortality analysis). All results are reported as subhazard ratios with 95% CI.

Due to the relatively large number of outcomes of interest in the analyses of prevalence and incidence, the tests of significance for our coefficients of interest in our primary models were corrected for multiple hypothesis testing. In particular, we used a Bonferroni correction on all p-values and CI in our main analyses using an alpha of 5% adjusted to reflect that we run a separate model on each of 11 health conditions. Dataset construction was done in SAS System, Version 9.4 (SAS Institute, Cary, NC, USA) and all statistical analyses were done in Stata/IC 14.2 (StataCorp LP, College Station, TX, USA).

Ethics statement

The current study involved retrospective analysis of existing, de-identified Medicare claims data and no new, primary data from human subjects was collected, so the study fell under one of the exemptions for secondary research under §46.104(d)(4) of the revised Common Rule and IRB approval was not required.

Results

Descriptive characteristics

Descriptive statistics for all Medicare beneficiaries age 65 and above who were observed between 2011 and 2016 are presented in [Table 1](#), which compares demographic and geographic characteristics for people with HIV and people without diagnosed HIV. On average, beneficiaries living with HIV were first observed in our sample when they were slightly older than people without diagnosed HIV (median of 70 years versus 69 years) but were observed for fewer years (potentially reflecting higher mortality), so overall our sample of individuals with HIV was slightly younger. They are also more likely to be male (63% versus 45%), dually enrolled in Medicaid (43% versus 13%), and non-Hispanic Black (34% versus 10%) or Hispanic (13% versus 8%), and less likely to be non-Hispanic White (51% versus 80%) or non-Hispanic Asian (2% versus 3%). Finally, there were geographic differences, with beneficiaries with an HIV diagnosis less likely to reside in rural areas (8% versus 19%), more likely to live in the South (43% versus 37%) or the Northeast (27% versus 19%) and less likely to live in the Midwest (12% versus 22%) or West (19% versus 22%).

Mortality hazard

Of the 321,999 individuals included in the survival analysis (including 6,927 people with HIV), 12,537 of them died (including 1,435 people with HIV) during 1,278,600 person-years of observation. In the Kaplan-Meier plot ([Fig 1](#)), unadjusted survival curves for people with HIV were significantly different than for older people without diagnosed HIV (the p-value for the log-rank test for the overall difference was 0.0000).

After adjusting for other demographic and geographic characteristics in the Cox proportional hazard model, an HIV diagnosis was associated with a hazard ratio (HR) of all-cause mortality that was approximately 3.6 times the HR of older adults without diagnosed HIV (column 1 of [Table 2](#)). The HR was even higher when we included an interaction with exposure time (years since age 65) to address non-proportional hazards (HR = 5.90), although this ratio

Table 1. Demographic and geographic characteristics, (Medicare beneficiaries aged 65 and over between 2011–2016).

Age	People with HIV			People without diagnosed HIV			Significance of difference		
	Median age first observed	Mean number of years observed	Median over pooled observations	Median age first observed	Mean number of years observed	Median over pooled observations	***	***	***
	70	4	70	69	5	73			
Male		63.1%			44.7%				***
Medicaid		43.1%			13.4%				***
White (non-Hispanic)		50.7%			79.6%				***
Black (non-Hispanic)		34.4%			9.5%				***
Hispanic		13.2%			7.5%				***
Asian (non-Hispanic)		1.8%			3.4%				***
Rural		8.0%			19.1%				***
Northeast		26.6%			19.0%				***
Midwest		12.1%			22.2%				***
South		42.6%			37.3%				***
West		18.7%			21.5%				***
N		43,708			1,029,518				

Each individual appears in this table once, for most variables the value when they are first observed is used except for median age observed, which pools observations across all years of the data. Upper age is trimmed at 98 years to avoid the impact of outliers (who predominantly do not have HIV). Statistical significance of differences in medians and binary variables were calculated for each row using a chi-squared test, differences in significance of differences in means were calculated using a t-test. Significance levels are shown with *** p-value < 0.001, ** p-value < 0.01, and * p-value < 0.05.

<https://doi.org/10.1371/journal.pone.0241833.t001>

decreased by approximately 1% for each year of exposure (column 2). Beneficiaries who are male, non-Hispanic Blacks, rural, or dually enrolled in Medicaid all had higher HRs in every specification of the model. The primary result—the mortality hazard was higher for people with HIV than for people without HIV—was robust across all specifications of the model.

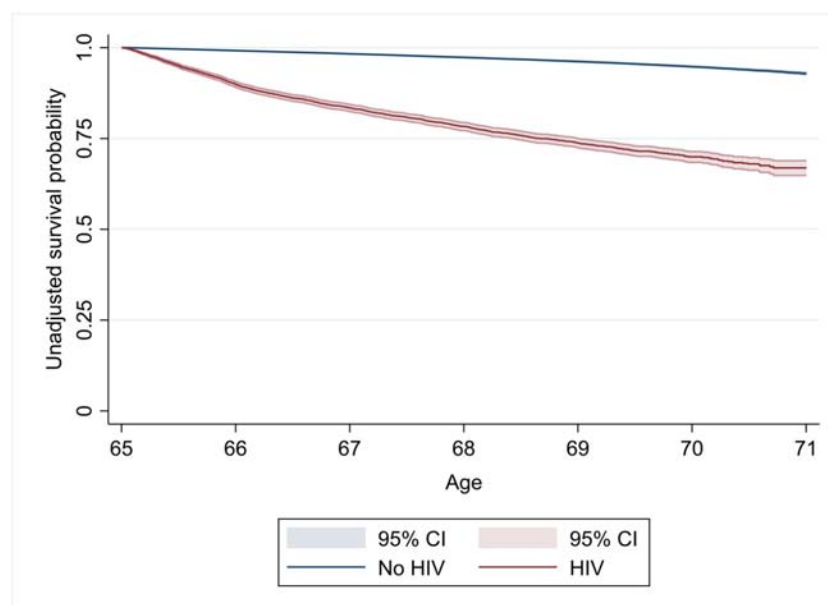


Fig 1. Kaplan-Meier plot of unadjusted survival by HIV status. Years since age 65.

<https://doi.org/10.1371/journal.pone.0241833.g001>

Table 2. Cox proportional model, hazard ratios reported (Medicare beneficiaries observed at age 65 between 2011–2016).

	(1) Basic model	(2) Basic model + time-varying coefficients ^a	(3) Extended model (sex)	(4) Extended model (race/ethnicity)	(5) Extended model (Medicaid dual enrollee)	(6) Extended model (Rural)	(7) Extended model (original entitlement) ^b
HIV	3.59*** [3.38, 3.83]	5.90*** [5.33, 6.53]	3.81*** [3.39, 4.29]	4.02*** [3.69, 4.38]	5.84*** [5.33, 6.45]	3.54*** [3.31, 3.78]	2.21*** [2.08, 2.36]
Male	1.66*** [1.60, 1.72]	1.66*** [1.60, 1.72]	1.66*** [1.60, 1.72]	1.66*** [1.60, 1.72]	1.66*** [1.60, 1.72]	1.66*** [1.60, 1.72]	1.60*** [1.54, 1.66]
Black	1.13*** [1.07, 1.20]	1.26*** [1.14, 1.39]	1.26*** [1.14, 1.39]	1.13*** [1.07, 1.20]	1.13*** [1.07, 1.20]	1.13*** [1.07, 1.20]	1.02 [0.97, 1.08]
Asian	0.39*** [0.34, 0.45]	0.39*** [0.34, 0.45]	0.39*** [0.34, 0.45]	0.39*** [0.34, 0.45]	0.39*** [0.34, 0.45]	0.39*** [0.34, 0.45]	0.47*** [0.41, 0.54]
Hispanic	0.59*** [0.55, 0.64]	0.59*** [0.55, 0.64]	0.59*** [0.55, 0.64]	0.59*** [0.55, 0.64]	0.59*** [0.55, 0.64]	0.59*** [0.55, 0.64]	0.62*** [0.57, 0.67]
Medicaid	3.57*** [3.41, 3.73]	3.57*** [3.41, 3.74]	3.57*** [3.41, 3.74]	3.57*** [3.41, 3.74]	3.57*** [3.41, 3.74]	3.57*** [3.41, 3.74]	2.62*** [2.50, 2.76]
Rural	1.06* [1.01, 1.11]	1.06* [1.01, 1.11]	1.06* [1.01, 1.11]	1.06* [1.01, 1.11]	1.06* [1.01, 1.11]	1.06* [1.01, 1.11]	1.00 [0.95, 1.05]
Interaction of HIV status with years since 65		0.999*** [0.999, 0.999]					
Interaction of HIV status with male sex			0.93 [0.81, 1.05]				
Interaction of HIV status with Black race				0.80*** [0.71, 0.91]			
Interaction of HIV status with Asian race				1.00 [0.51, 1.96]			
Interaction of HIV status with Hispanic ethnicity				0.94 [0.77, 1.14]			
Interaction of HIV status with Medicaid enrollment					0.52*** [0.46, 0.58]		
Interaction of HIV status with rural residence						1.20 [1.00, 1.45]	
Disability							2.71*** [2.59, 2.83]
ESRD							8.84*** [7.35, 10.63]
Disability and ESRD							10.45*** [8.81, 12.40]
Log pseudolikelihood	-18,268,062	-18,254,350	-18,268,062	-18,268,054	-18,267,999	-18,268,060	-18,147,357

Includes robust standard errors clustered by beneficiary and year aged into Medicare fixed effects. The omitted group is non-Hispanic White, urban, non-Medicaid enrolled males. Individuals are weighted using probability weights to reflect differential selection probabilities based on HIV diagnosis. 95% confidence intervals are reported in parentheses. Significance levels are shown with *** p-value < 0.001, ** p-value < 0.01, and * p-value < 0.05.

^a Includes year*exposure time and non-Hispanic black*exposure time interaction terms

^b The omitted group are individuals originally entitled to Medicare because of age.

<https://doi.org/10.1371/journal.pone.0241833.t002>

In Columns 3 through 6 we added interaction terms between HIV diagnosis and various demographic and personal characteristics. The association between mortality hazard and HIV was not significantly different for men compared to women (Column 3), for either Hispanic or non-Hispanic Asian compared to non-Hispanic White beneficiaries (Column 4), or for

rural compared to urban beneficiaries (Column 6). On the other hand, the association between HIV infection and all-cause mortality hazard was smaller for non-Hispanic Black beneficiaries than for non-Hispanic White beneficiaries (HR of 0.80). This is not a surprising result since non-Hispanic Black beneficiaries overall had a higher hazard of all-cause mortality, leaving less room for a differential effect of having HIV. A similar relationship applies to other findings presented in this analysis. For instance, the association between HIV infection and all-cause mortality hazard was smaller for dually-enrolled beneficiaries (OR = 0.52), while the mortality hazard of individuals dually enrolled in Medicaid, overall, was substantially higher. Finally, in Column 7, as a robustness check we added a control for whether the individual originally became eligible for Medicare based on age, end-stage renal disease, or disability (among our sample of people with HIV, 60% originally became eligible for Medicare based on age, 38% originally became eligible because of disability, and the remaining <2% originally became eligible because they had ESRD or ESRD and disability). This attenuated the coefficient on HIV diagnosis but it is still large and significant (HR = 2.2). Beneficiaries who originally became eligible because of a disability or end-stage renal disease have much a higher mortality hazard than those who originally qualified based on aging into the program.

Prevalence

People with HIV had higher overall unadjusted rates for all health conditions compared to those without diagnosed HIV (Columns 1 through 3 in Table 3). The same calculations for

Table 3. Prevalence of health outcomes, unadjusted means and odds ratios reported.

	Medicare beneficiaries at age 65 between 2011–2016, unadjusted			Coefficients from logistic regression model, odds ratios reported (Medicare beneficiaries aged 65 and above in 2016) ^a
	(1)	(2)	(3)	(4)
	HIV	No HIV	Percent difference	HIV
Depression	24.3%	6.2%	291.9%***	2.29*** [2.22, 2.35]
Chronic kidney disease	46.2%	18.9%	144.4%***	1.92*** [1.88, 1.97]
COPD	28.3%	4.1%	590.2%***	1.52*** [1.47, 1.57]
Osteoporosis	14.6%	3.4%	329.4%***	2.17*** [2.06, 2.29]
Colorectal cancer	3.8%	1.3%	192.3%***	1.85*** [1.70, 2.03]
Lung cancer	26.8%	7.7%	248.1%***	1.38*** [1.25, 1.53]
Hypertension	1.4%	0.3%	366.7%***	1.31*** [1.28, 1.33]
Ischemic heart disease	1.3%	0.3%	333.3%***	1.31*** [1.28, 1.34]
Diabetes	29.8%	10.4%	186.5%***	1.06*** [1.04, 1.09]
Chronic hepatitis	13.1%	0.2%	6450.0%***	12.70*** [11.86, 13.59]
End-stage liver disease	2.7%	0.1%	2600.0%***	4.51*** [4.08, 4.98]
N	8,277	330,955		1,024,823

Each individual appears in this table once; in columns one through three it is at age 65, in column 4 it is in 2016 (in which upper age is trimmed at 98 years to avoid the impact of outliers who predominantly do not have HIV). Significance of the differences between (1) and (2) were calculated for each row using a chi-squared test. Not shown are controls for age, race/ethnicity, sex, state, rural/urban residence, and dual enrollment in Medicaid. The omitted group is White, urban, non-Medicaid enrolled males between the age of 65 and 74. Individuals are weighted using probability weights to reflect differential selection probabilities based on HIV diagnosis. 95% confidence intervals are reported in parentheses. Significance levels are shown with *** p-value < 0.001, ** p-value < 0.01, and * p-value < 0.05.

^a Each cell in (4) is a coefficient from a different model. Significance levels have been adjusted using the Bonferroni correction for multiple hypothesis testing to reflect 11 tests.

<https://doi.org/10.1371/journal.pone.0241833.t003>

subpopulations of interest including rural residents, those dually enrolled in Medicaid, minorities, and by sex can be found in [S3 Table](#). People with HIV were, for example, almost 600% more likely to have COPD and over 300% more likely to have osteoporosis, hypertension, and heart disease compared to older people without diagnosed HIV. The difference is particularly striking for chronic hepatitis and end-stage liver disease, diseases which were more than 1,000% more common among older people with HIV compared to older people without diagnosed HIV.

These patterns remained even after adjusting for individual characteristics in the logit models, although there is quite a range in magnitude of these relationships (Column 4 in [Table 3](#) shows the coefficients on the HIV indicator variable for each of 11 separate regressions). The effect sizes are particularly striking for chronic hepatitis (the odds of having hepatitis were over 12 times as likely for older people with HIV, although baseline odds of hepatitis for people without diagnosed HIV were very low), and end-stage liver disease (the odds were over 4 times as likely for people with HIV). Looking at the other rows, compared to older people without HIV, older people with HIV had 2.3 times the odds of depression, 1.9 times the odds of chronic kidney disease, 1.5 times the odds of COPD, 2.2 times the odds of osteoporosis, 1.9 times the odds of colorectal cancer, 1.4 times the odds of lung cancer, 1.3 times the odds of hypertension, 1.3 times the odds of ischemic heart disease, and 1.1 times the odds of diabetes. As a robustness check, we ran these same models on other years to see whether the patterns changed over time, but the results were very consistent across the years ([S2 Table](#)).

The relationships between HIV infection and the odds of each health outcome for beneficiaries in rural areas was often smaller than that seen in urban areas, in particular for the odds of depression, chronic kidney disease, COPD, ischemic heart disease, and diabetes ([Table 4](#)). On the other hand, the increase in odds of having hepatitis was larger for people with HIV in rural areas than in urban areas. Medicaid dual enrollees, even without an HIV diagnosis, had higher odds of many conditions than non-dual enrollees without HIV, hence the additional increase in the OR for every condition (except for lung cancers) associated with having HIV was smaller for people who are dually enrolled in Medicaid than it was for those who were not dually enrolled. The story was more complex for minority beneficiaries compared to non-Hispanic White beneficiaries. The association between HIV infection and odds of COPD, lung cancer, hypertension, and ischemic heart disease was larger for minorities, but the association between HIV infection and odds of osteoporosis, colorectal cancer, end-stage liver disease, and hepatitis was smaller (although underlying hepatitis odds for minorities were quite high). Finally, in the sex comparison, the associations between HIV and the odds of having depression, chronic kidney disease, osteoporosis, hypertension, and diabetes were greater for men than for women (although women had higher rates of osteoporosis and depression overall), while the association was smaller for COPD, ischemic heart disease, and end-stage liver disease.

Incidence

Having an HIV diagnosis was associated with an increased subhazard of every condition in our analysis ([Table 5](#)). Subhazards are not straightforward to interpret on their own, so for this type of analysis, it is more useful to look graphically at cumulative incidence functions ([Fig 2](#)), which plot the probability of observing a particular event (e.g., a diagnosis of depression) by a given time, and is a function of the competing risk of mortality. These graphs show both how the difference in cumulative incidence between people with and without HIV changes as they age, but also gives a sense of the level of each condition in the population overall. We can see, for instance, that the cumulative incidence for diagnosis of depression was nearly 50% by age

Table 4. Logit models of prevalence of health outcomes in 2016 for sub-groups of interest, odds ratios reported (Medicare beneficiaries aged 65 and older in 2016).

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
	Depression	Chronic kidney disease	COPD	Osteoporosis	Colorectal cancer	Lung cancer	Hypertension	Ischemic heart disease	Diabetes	Hepatitis	End-stage liver disease
Urban/Rural residence											
HIV	2.30***	1.94***	1.56***	2.17***	1.86***	1.44***	1.32***	1.32***	1.07***	12.31***	4.45***
	[2.24, 2.38]	[1.89, 1.99]	[1.51, 1.62]	[2.06, 2.30]	[1.69, 2.04]	[1.29, 1.61]	[1.29, 1.34]	[1.28, 1.35]	[1.04, 1.10]	[11.48, 13.20]	[4.01, 4.93]
Rural resident	2.95	6.93**	0.41	1.82	1.48	1.33	0.03**	0.12*	0.17*	1.18	0.98
	[0.67, 12.95]	[2.09, 22.96]	[0.06, 2.97]	[0.23, 14.38]	[0.84, 2.62]	[0.70, 2.53]	[0.00, 0.22]	[0.02, 0.87]	[0.04, 0.69]	[0.28, 4.95]	[0.51, 1.92]
Interaction of HIV status and rural residence	0.89*	0.89*	0.85**	0.92	1.04	0.76	0.90**	0.91*	0.87**	1.56**	1.06
	[0.80, 0.99]	[0.81, 0.97]	[0.76, 0.95]	[0.75, 1.13]	[0.77, 1.41]	[0.52, 1.10]	[0.83, 0.97]	[0.83, 0.99]	[0.79, 0.95]	[1.20, 2.03]	[0.74, 1.51]
Dual enrollment in Medicaid											
HIV	2.55***	2.16***	1.54***	2.45***	1.90***	1.38***	1.32***	1.39***	1.22***	16.90***	6.03***
	[2.45, 2.65]	[2.10, 2.23]	[1.47, 1.61]	[2.27, 2.63]	[1.70, 2.13]	[1.20, 1.58]	[1.29, 1.36]	[1.34, 1.43]	[1.18, 1.26]	[15.59, 18.33]	[5.35, 6.79]
Medicaid enrollee	2.93***	1.51	5.09***	0.76	1.20	4.62*	1.23	1.75*	1.75***	8.22*	4.34
	[1.85, 4.64]	[0.93, 2.47]	[3.25, 7.97]	[0.31, 1.89]	[0.17, 8.62]	[1.42, 15.08]	[0.84, 1.82]	[1.13, 2.71]	[1.13, 2.70]	[1.08, 62.31]	[0.59, 31.77]
Interaction of HIV status and Medicaid	0.76***	0.77***	0.87***	0.72***	0.81*	0.85	0.95*	0.88***	0.82***	0.58***	0.55***
	[0.71, 0.80]	[0.74, 0.81]	[0.81, 0.93]	[0.64, 0.80]	[0.70, 0.97]	[0.69, 1.05]	[0.91, 0.99]	[0.83, 0.92]	[0.78, 0.86]	[0.51, 0.65]	[0.46, 0.67]
Racial and ethnic minorities/non-Hispanic White											
HIV	2.37***	1.99***	1.34***	2.31***	2.12***	1.26**	1.18***	1.30***	1.10***	15.48***	5.11***
	[2.28, 2.46]	[1.93, 2.06]	[1.28, 1.40]	[2.15, 2.48]	[1.90, 2.37]	[1.10, 1.44]	[1.15, 1.21]	[1.26, 1.34]	[1.06, 1.14]	[14.07, 17.03]	[4.52, 5.77]
Racial and ethnic minority	1.94*	1.08	0.75	0.33***	2.57	1.24	0.05**	1.31	0.42	3.99***	3.68
	[1.14, 3.31]	[0.60, 1.92]	[0.35, 1.58]	[0.22, 0.49]	[0.62, 10.72]	[0.17, 8.85]	[0.01, 0.40]	[0.81, 2.13]	[0.10, 1.77]	[2.01, 7.93]	[0.51, 26.47]
Interaction of HIV status and minority	0.98	1.05	1.45***	0.64***	0.77**	1.30*	1.26***	1.07**	1.02	0.78***	0.82*
	[0.92, 1.04]	[1.00, 1.10]	[1.35, 1.55]	[0.57, 0.71]	[0.64, 0.92]	[1.05, 1.61]	[1.21, 1.31]	[1.02, 1.13]	[0.98, 1.07]	[0.69, 0.88]	[0.68, 0.99]
Sex											
HIV	1.86***	1.84***	1.73***	1.73***	1.59***	1.51***	1.24***	1.42***	1.05*	12.06***	5.47***
	[1.78, 1.95]	[1.76, 1.92]	[1.63, 1.83]	[1.62, 1.85]	[1.33, 1.90]	[1.25, 1.82]	[1.20, 1.29]	[1.35, 1.48]	[1.00, 1.09]	[10.78, 13.48]	[4.59, 6.51]
Male sex	0.53***	0.94	1.07	0.08***	1.94*	0.65	0.04**	1.57***	0.15	0.74	1.04
	[0.40, 0.70]	[0.77, 1.16]	[0.83, 1.37]	[0.04, 0.16]	[1.07, 3.51]	[0.23, 1.80]	[0.01, 0.31]	[1.32, 1.86]	[0.02, 1.08]	[0.10, 5.51]	[0.24, 4.41]
Interaction of HIV status and male sex	1.29***	1.07**	0.81***	1.72***	1.19	0.86	1.05*	0.94*	1.07*	0.99	0.73**
	[1.22, 1.37]	[1.02, 1.13]	[0.75, 0.87]	[1.53, 1.92]	[0.97, 1.47]	[0.69, 1.08]	[1.01, 1.10]	[0.89, 0.99]	[1.01, 1.12]	[0.87, 1.14]	[0.59, 0.90]

Each cell is a coefficient from a different model. Not shown are controls for age, race/ethnicity, sex, state, rural/urban residence, and dual enrollment in Medicaid. The omitted group is White, urban, non-Medicaid enrolled males between the age of 65 and 74. Individuals are weighted using probability weights to reflect differential selection probabilities based on HIV diagnosis. 95% confidence intervals are reported in parentheses. Significance levels are shown with *** p-value < 0.001, ** p-value < 0.01, and * p-value < 0.05.

<https://doi.org/10.1371/journal.pone.0241833.t004>

Table 5. Competing risk models of the hazard of developing conditions over time, subhazard ratios reported (Medicare beneficiaries who are observed at age 65 between 2011 and 2016).

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
	Depression	Chronic kidney disease	COPD	Osteoporosis	Colorectal cancer	Lung cancer	Hypertension	Ischemic heart disease	Diabetes	Hepatitis	End-stage liver disease
Basic model											
HIV	2.73***	2.31***	1.67***	2.61***	2.59***	1.97***	1.41***	1.60***	1.25***	11.50***	4.41***
	[2.56, 2.89]	[2.17, 2.44]	[1.55, 1.80]	[2.26, 2.95]	[2.04, 3.14]	[1.52, 2.43]	[1.35, 1.48]	[1.51, 1.70]	[1.18, 1.32]	[10.15, 12.86]	[5.59, 5.24]
Extended model—Urban/rural residence											
HIV	2.98***	2.58***	1.80***	2.71***	2.66***	2.08***	1.51***	1.69***	1.34***	12.62***	4.86***
	[2.85, 3.13]	[1.47, 2.70]	[1.70, 1.91]	[2.44, 3.01]	[2.24, 3.15]	[1.73, 2.50]	[1.45, 1.57]	[1.62, 1.78]	[1.28, 1.41]	[11.54, 13.81]	[4.21, 5.62]
Interaction of HIV status and rural residence	0.80**	0.91	0.81*	1.05	1.24	0.93	0.95	0.91	0.86	1.11	0.64
	[0.69, 0.94]	[0.78, 1.06]	[0.68, 0.98]	[0.75, 1.46]	[0.80, 1.94]	[0.53, 1.62]	[0.84, 1.07]	[0.77, 1.06]	[0.74, 1.01]	[0.83, 1.48]	[0.38, 1.09]
Extended model—Dual enrollment in Medicaid											
HIV	4.46***	3.87***	2.75***	4.36***	3.51***	2.23***	1.90***	2.27***	1.97***	25.18***	9.73***
	[4.16, 4.79]	[3.62, 4.13]	[2.50, 3.03]	[3.72, 5.11]	[2.75, 4.47]	[1.65, 3.02]	[1.80, 1.32]	[2.12, 2.44]	[1.84, 2.11]	[22.37, 28.34]	[7.96, 11.90]
Interaction of HIV status and Medicaid enrollment	0.56***	0.56***	0.56***	0.52***	0.68*	0.90	0.70***	0.65***	0.58***	0.42***	0.38***
	[0.51, 0.61]	[0.51, 0.61]	[0.50, 0.63]	[0.43, 0.64]	[0.50, 0.94]	[0.63, 1.30]	[0.66, 0.76]	[0.59, 0.70]	[0.53, 0.63]	[0.38, 0.49]	[0.30, 0.49]
Extended model—Racial and ethnic minority/non-Hispanic White											
HIV	3.05***	2.85***	1.67***	3.22***	3.88***	2.00***	1.40***	1.67***	1.42***	16.06***	5.56***
	[2.86, 3.25]	[2.67, 3.05]	[1.54, 1.81]	[2.80, 3.72]	[3.17, 4.75]	[1.56, 2.56]	[1.32, 1.47]	[1.57, 1.79]	[1.33, 1.53]	[14.14, 18.24]	[4.59, 6.73]
Interaction of HIV status and Black race	0.87**	0.84***	1.04	0.62***	0.48***	1.03	1.09*	1.00	0.86**	0.71***	0.73*
	[0.79, 0.95]	[0.77, 0.99]	[0.93, 1.17]	[0.50, 0.78]	[0.34, 0.67]	[0.73, 1.46]	[1.01, 1.18]	[0.91, 1.10]	[0.79, 0.95]	[0.61, 0.83]	[0.55, 0.97]
Interaction of HIV status and Asian race	1.60	1.06	1.35	1.06	0.00	3.99***	1.24	1.43	1.31	0.21***	2.18
	[0.99, 2.63]	[0.70, 1.60]	[0.66, 2.76]	[0.48, 2.35]	[0.00, 0.00]	[1.21, 13.17]	[0.86, 1.80]	[0.97, 2.12]	[0.89, 1.93]	[0.11, 0.42]	[0.84, 4.69]
Interaction of HIV status and Hispanic ethnicity	1.11	0.85***	2.75***	1.00	0.65	1.08	1.29***	1.00	1.01	0.95	0.80
	[0.97, 1.27]	[0.74, 0.97]	[1.23, 1.76]	[0.77, 1.30]	[0.39, 1.09]	[0.50, 2.31]	[1.16, 1.44]	[0.87, 1.16]	[0.88, 1.15]	[0.75, 1.20]	[0.57, 1.14]
Extended model—Sex											
HIV	2.24***	2.54***	2.00***	1.78***	1.70**	2.40***	1.54***	2.18***	1.48***	10.97***	4.72***
	[2.07, 2.42]	[2.34, 2.76]	[1.77, 2.16]	[1.55, 2.04]	[1.18, 2.45]	[1.77, 3.25]	[1.44, 1.65]	[2.00, 2.67]	[1.37, 1.60]	[9.55, 12.60]	[3.66, 6.08]
Interaction of HIV status and male sex	1.50***	1.01	0.87**	2.94***	1.82**	0.81	0.98	0.72***	0.86**	1.21*	1.00
	[1.37, 1.65]	[0.92, 1.11]	[0.77, 0.98]	[2.43, 3.55]	[1.23, 2.69]	[0.57, 1.16]	[0.90, 1.05]	[0.65, 0.79]	[0.79, 0.94]	[1.04, 1.41]	[0.76, 1.33]

Each column is from a different model. Not shown are controls for race/ethnicity, sex, rural/urban residence, and dual enrollment in Medicaid. The omitted category is non-Hispanic White, female, non-dually enrolled, urban beneficiaries without diagnosed HIV. Individuals are weighted using probability weights to reflect differential selection probabilities based on HIV diagnosis. Robust standard errors are clustered by beneficiary. 95% confidence intervals are reported in parentheses. Significance levels are shown with *** p-value < 0.001, ** p-value < 0.01, and * p-value < 0.05. Confidence intervals and p-values for the basic model have been adjusted using the Bonferroni correction for multiple hypothesis testing.

<https://doi.org/10.1371/journal.pone.0241833.t005>

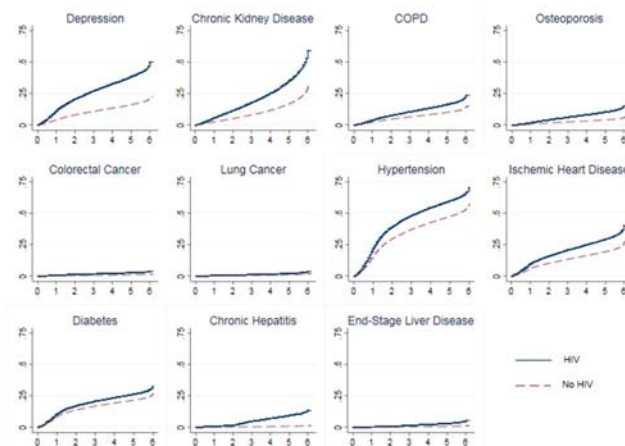


Fig 2. Cumulative incidence functions by HIV status. The y-axis is probability of diagnosis of each comorbidity and the x-axis is years since age 65.

<https://doi.org/10.1371/journal.pone.0241833.g002>

72 for people with HIV, whereas it was closer to 20% for people without a diagnosis of HIV. There's a similarly large gap for chronic kidney disease, where people with HIV have a cumulative incidence by age 72 of nearly 60%, while people without HIV have a cumulative incidence of approximately 30%. The gaps for the other conditions analyzed are smaller but still significant. For instance, the probability of a diagnosis of COPD for people with HIV by age 72 was nearly 25%, compared to approximately 15% for people without diagnosed HIV. We can also observe that although the differences in cumulative incidence were different for people with and without HIV for colorectal cancer, lung cancer, and end-stage liver disease, these were much less common conditions compared to some of the others analyzed such as hypertension or chronic kidney disease. The overall pattern of results of the subgroup analyses are similar to those observed in the prevalence models. However, results were often more strongly significant in these incidence models.

Discussion

This paper analyzed a large, nationally representative sample of Medicare beneficiaries aged 65 and older from 2011 to 2016 to compare the health and survival status of older people with HIV to an older US population not living with HIV. Prior research has found that older people with HIV have high adherence to treatment which results in high levels of viral suppression [25, 26]. Adherence to treatment and viral suppression are both associated with better health outcomes [51]. Nonetheless, we found that older people with HIV have a higher overall hazard of mortality as well as a higher odds of having depression, chronic kidney disease, COPD, osteoporosis, colorectal cancer, lung cancer, hypertension, ischemic heart disease, diabetes, chronic hepatitis, and end-stage liver disease compared to those without HIV, even after adjusting for demographic characteristics. Some of these differences were quite large in magnitude, particularly for hepatitis and end-stage liver disease. Finally, we found that the incidence of diagnosis over time of every condition analyzed is higher for people with HIV, after accounting for the competing and differential risk of mortality.

Our results differed significantly by population subgroup. We found that older people with HIV are more likely to be from potentially underserved populations, including minorities (49% of older people with HIV) and dual Medicaid enrollees (43% of older people with HIV). We also found that minorities and dual Medicaid enrollees overall had higher hazards of

mortality as well as higher odds and incidence of many conditions (even without an HIV diagnosis), and that an HIV diagnosis is associated with even larger disparities.

This project benefited from using a large, population-representative, longitudinal sample, which allowed us to observe individuals over multiple years and to demonstrate the need to consider selective mortality in future research looking at the aging population of people with HIV. There were, however, some limitations due to data constraints that future work should try to address. The first and foremost is that we cannot observe what occurred among individuals in our sample when they were younger, which is when most were infected or diagnosed, and we do not know their initial date of diagnosis. We also do not have certain types of clinical information such as their use of ARTs or CD4 count or viral load. This means we cannot disentangle whether these observed differences in mortality and health are due to the impact of HIV itself, the effect of prolonged use of ARTs, or other individual characteristics that may be associated with HIV that we do not observe. For instance, people with HIV have higher rates of tobacco use, and tobacco use is associated with a higher risk of having a number of the health outcomes studied in this paper as well as higher mortality [52]. It is also possible that people with HIV have higher diagnosis rates for conditions because of more frequent contact with the medical system, particularly for conditions that are known to commonly co-occur with HIV. Hence, our findings in this paper should not be considered direct estimates of the effect of the HIV virus on health status, rather we are estimating the health status of individuals with HIV whose health status and mortality hazard may vary from those without HIV for multiple reasons.

Concerning the analyses about chronic hepatitis, due to limitations in what is reported in claims data, our analyses focused on chronic hepatitis generally, although people with HIV are known to be at higher risk for hepatitis C in particular [53]. The Centers for Disease Control (CDC) guidelines also specify that everyone born between 1945 and 1965 (a range capturing most of our sample) be tested for hepatitis C at least once, as they are at higher risk for this disease [54]. Therefore, while our results for hepatitis are not unexpected, the extremely high rates of co-occurrence of HIV and hepatitis in older people with HIV reaffirm the need for screening, particularly for hepatitis C. Hepatitis C infection can result in significant health complications, but is now curable.

While our data do not allow us to analyze the underlying factors contributing to these outcomes, our results nonetheless raise important questions regarding the role of social determinants of health for people with HIV. People with HIV are disproportionately more likely to be from underserved and vulnerable groups, including men who have sex with men, transgender people, people of color, and those with lower socioeconomic status [55], and these disparities may affect HIV prevention; testing; and access to care, treatment, and support services, leading to potentially worse health outcomes and poorer survival. Stigma and social isolation are widely documented challenges for many people with HIV, particularly for men who have sex with men and transgender individuals, and older people with HIV tend to be particularly isolated with limited social networks [18, 56–58]. As these individuals age and develop more chronic conditions and increasingly complex care needs, they often have fewer resources and family members to rely on [59]. Thus, older people with HIV may be more dependent on formal care but may also face significant barriers to access, including having fewer personal resources relative to their healthcare needs and stigma. Compounding these challenges, older people with HIV also have higher rates of mental health conditions, including depression, as well as higher rates of substance use and homelessness, all of which can contribute to challenges in accessing and adhering to care [18].

In addition to the personal health and social implications for older people with HIV, these results have important implications for community partners and programs as they plan for an

aging population, including Medicare, Medicaid, and the Health Resources and Services Administration's Ryan White HIV/AIDS Program, which provides a comprehensive system of care to low-income people with HIV in the United States, including over 230,000 people with HIV aged 50 and older (approximately half of all people with HIV aged 50 years and older in the United States) [1, 60].

These results are also important for clinicians caring for people with HIV, who are most likely to be treated by primary care physicians or infectious disease specialists [61] and therefore may not have the same level of experience with caring for older adults as specialists in gerontology or geriatrics. This suggests a need for training of medical professionals on the intersecting issues of aging and HIV, particularly in how to deal with multi-morbidity, polypharmacy, and the need for personalized care and maximizing functional capacity. It also points to the need for increased coordination and integration of services, including HIV services and geriatric services, as well as an increased focus by providers on prevention, screening, and treatment for other conditions for which older people with HIV are at higher risk. The Ryan White HIV/AIDS Program's AIDS Education and Training Centers are one important mechanism by which medical professionals can share information with each other on lessons learned in treatment and coordinating care for older people with HIV.

Understanding the degree to which individuals living with HIV may have different health-care needs, regardless of the underlying causes of differences in health status for these individuals, is of policy interest. Future research should study the underlying reasons for differences in health status, as well as at what age these differences begin to appear, to better understand particular clinical interventions that may be applicable to treating comorbidities in this population.

While much attention is currently being devoted to ending the HIV epidemic, which is an important initiative, a cure does not yet exist for those currently living with HIV, and so it is also important that efforts continue to be made to improve health outcomes and quality of life for this population. Our findings of markedly higher odds of comorbid conditions, in combination with previous work linking comorbidities with decreased quality of life among older people with HIV [62, 63], highlights the need for further efforts to improve care for these individuals.

Supporting information

S1 Table. Alternate specifications of the Cox proportional model, hazard ratios reported (Medicare beneficiaries).

(DOCX)

S2 Table. Logit models of health outcomes, additional years, odds ratios reported (Medicare beneficiaries aged 65 and above in 2011, 2013, or 2016, depending on row).

(DOCX)

S3 Table. Health outcomes by population subgroup (Medicare beneficiaries aged 65 and over between 2011–2016).

(DOCX)

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HIV POLICY
— IN THE —
UNITED STATES

**MEETING THE NEEDS OF
PEOPLE AGING WITH HIV**
ON THE PATH TO ENDING
THE HIV EPIDEMIC



MAY 2021

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This brief is a product of the HIV Policy Project of the **O’Neill Institute for National and Global Health Law** and was supported by **Gilead Sciences, Inc.** It was developed with input from community stakeholders and in partnership with Gilead Sciences. The views expressed are solely those of the authors.

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With high-quality care and ongoing treatment, people living with HIV can live long and healthy lives. Someone who is newly diagnosed with HIV and soon receives antiretroviral therapy (ART) can live a typical lifespan. This is incredible news that few could have imagined 30 years before effective HIV treatment, or “highly active antiretroviral therapy” (HAART), became available. Nonetheless, too many people who are aging with HIV feel invisible within the broader HIV community and are deeply hurt that their issues and needs appear to be low on the advocacy agenda and ignored by policymakers. Today, more than half of people living with HIV in the United States are aged 50 or older, and a growing number of people are living and aging with HIV into their 70s and beyond.¹ As the new Administration re-establishes the White House Office of National AIDS Policy (ONAP) and assesses the state of HIV in the United States, this provides a fresh opportunity to spotlight the needs of people who are aging with HIV and deliver necessary corrective policy actions.

POLICY ACTION IS NEEDED TO IMPROVE THE HEALTH OF OLDER PEOPLE LIVING WITH HIV

A greater focus on HIV and aging is needed. To meet the needs of older people living with HIV, policy action must address the following:

1

DEVELOP models of care and prevention for people aging with HIV and train and equip the clinical and non-clinical workforce.

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2

EXPAND opportunities for older people living with HIV to make social connections through community-based programs that address isolation, stigma, and trauma.

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3

MAINTAIN Medicare Part D drug access protections (e.g., Six Protected Classes) and expand focus on high-quality care and quality of life.

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4

ALLOCATE more funding to programs that support financial security and access to employment, housing, food, and public benefits for the aging HIV population.

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5

PROMOTE the meaningful participation of older people living with HIV in the Ending the HIV Epidemic (EHE) Initiative and in broader advocacy efforts.

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ENDING THE HIV EPIDEMIC IN THE UNITED STATES INVOLVES MORE THAN REDUCING NEW HIV TRANSMISSIONS AND SUPPORTING PEOPLE WITH HIV TO ACHIEVE VIRAL SUPPRESSION.

The burdens of HIV, aging, and related health comorbidities, combined with the social and structural challenges that people aging with HIV face, necessitate not only a focus on HIV-related outcomes, but also a comprehensive response aimed at treating comorbidities and improving long-term health and quality of life. Concerted action is needed to meet the needs of older people living with HIV. This must include programs across the federal government and a commitment to health equity and intersectional policy approaches that take into account the overlapping systems of discrimination or disadvantage (e.g., race, class, sex, gender identity, sexual orientation, immigration status) impacting the lives of older people living with HIV.

Older people living with HIV include many long-term survivors who have lived with HIV for more than ten years, as well as older people who have been diagnosed with HIV more recently. Some long-term survivors were diagnosed with HIV before HAART became available, and others were diagnosed after 1996, when HAART became more widely available.² It is possible to be a long-term survivor and be under the age of

50. This issue brief focuses on people aged 50 and older regardless of whether they are long-term survivors, but it is acknowledged that the aging process among long-term survivors and others under the age of 50, including people living with HIV through perinatal transmission, warrants attention. Long-term survivors from the pre-HAART era often have distinctive experiences compared to those who came later. These survivors received their diagnosis when HIV regularly resulted in death, and many spent the early years after their diagnosis believing they would die young and watching partners and friends die from AIDS. As such, they often experienced considerable trauma that is difficult to resolve. Some struggle with mental health problems as a result of this trauma, and those who did not plan for a future may now struggle with financial instability.

There are a number of common challenges that older people living with HIV face as the result of HIV, aging, and the complex interplay of HIV and aging-associated factors. Yet these challenges are sometimes obscured when the focus is on HIV viral suppression as the primary health outcome. Compared to all people with HIV, people with HIV aged 55 and older have higher rates of viral suppression and retention in care.³ In 2018, 64 percent of people with HIV aged 55 and older

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OLDER PEOPLE WITH RECENTLY DIAGNOSED HIV ARE PEOPLE WHO ARE AGED 50 OR OLDER AND HAVE BEEN LIVING WITH HIV FOR LESS THAN TEN YEARS.

LEVERAGING RESOURCES ACROSS THE FEDERAL GOVERNMENT

Many programs in the federal government exist to support older people. It is important to take advantage of all resources, not just federal HIV programs, to meet the needs of people aging with HIV. Educating HIV stakeholders about resources that already exist for aging populations can help more people living with HIV access critical services without having to create new services specifically for this population. The following are just a handful of examples of federal resources that focus on older people:

Program of All-Inclusive Care for the Elderly (PACE): The Program of All-Inclusive Care for the Elderly provides comprehensive medical and social services for certain frail, older people living in the community, most of whom are dually eligible for both Medicare and Medicaid. An interdisciplinary team (including not only doctors, nurses, dietitians, physical therapists, and social workers, but also activity coordinators, home care liaisons, occupational therapists, personal care attendants, and drivers) provides older individuals enrolled in PACE with coordinated care. PACE provides services primarily in adult day health centers, and those services are supplemented by in-home and referral services in accordance with the enrollee's needs. Most financing for PACE services comes from fixed monthly Medicare and Medicaid payments for each enrollee, which allows providers to cover needed services, including social determinants of health, rather than only those services reimbursable under Medicare and Medicaid fee-for-service plans.

Older Americans Act (OAA): The Older Americans Act funds a range of critical services to help older people live independently in their homes and communities. These services include home-delivered and congregate meals, job training, senior centers, health promotion, benefits enrollment, caregiver support, transportation, and more.

Administration for Community Living (ACL): The Administration for Community Living was created in 2012 as a new agency under the United States Department of Health and Human Services (HHS) to coordinate operations of federal agencies that promote community-based living (e.g., the Administration on Aging, the Administration on Disabilities, and the Center for Integrated Programs). ACL funds services and supports provided primarily by states and networks of community-based organizations, and it works to ensure that the preferences and the needs of older adults and people with disabilities are at the center of the system of services and supports. ACL's health and wellness programs address behavioral health, prevention of injuries and illness, chronic disease self-management, and other issues. Its 'employment first' initiatives help to eliminate barriers to employment and help people with disabilities access meaningful and integrated employment. ACL's programs also address abuse and rights violations of older people and people with disabilities, empower individuals to advocate for their own needs, provide grants and technical assistance to improve business practices of community-based organizations, and fund research and development of evidence-based approaches.

Housing Programs: Low-income housing programs are available for older people through the United States Department of Housing and Urban Development (HUD). There are many HUD programs with varying age and income eligibility requirements. HUD's Section 202 Supportive Housing for the Elderly program addresses both affordability and the connection between housing and supportive services. Under the program, HUD provides interest-free capital advances to nonprofits to develop housing that offers project-based rental assistance and supportive services for very low-income elderly residents.

were virally suppressed, whereas only 56 percent of all people with HIV were virally suppressed.⁴ Metrics of viral suppression and retention in care, however, do not provide a complete picture of the health and well-being of older people living with HIV. Older people living with HIV are more likely to have multiple comorbidities that impact their health and quality of life. People aging with HIV also face social and structural challenges that are too frequently overlooked and ignored. More focused efforts are needed to understand and address the issues facing the aging population of people living with HIV and to support effective advocacy and programs for and by older people living with HIV.

AGING-RELATED CHALLENGES AMONG PEOPLE LIVING WITH HIV

While rates of sustained viral suppression must still be improved for older people living with HIV, it is important to embrace a holistic approach to the health of this population. Older people living with HIV face physical

health challenges. These include both HIV-related and other comorbidities. Compared to their age peers who do not have HIV, older people living with HIV have higher rates of comorbidities associated with aging, such as cardiovascular disease, liver disease, diabetes, cancer, and neurocognitive impairment,^{5,6} as well as higher rates of geriatric syndromes, such as falls and frailty.⁷ Multiple comorbidities can place older people living with HIV at an increased risk of functional decline and disability.⁸ Because of multiple comorbidities, concurrent use of multiple medications (also known as polypharmacy) is common among older people living with HIV, which increases the risk of drug–drug interactions.⁹ Older people living with HIV also deal with various oral health problems, including tooth loss, receding gums, and deterioration of the jawbone, which can cause pain and challenges with eating and maintaining healthy nutrition. As a result, many have dental bridges, partial dentures, or full dentures. Furthermore, many older people with HIV face mental health issues, such as depression and substance use disorders.^{10,11} For example, rates of depression among

CRITICAL NEEDS FOR RESEARCH ON HIV AND AGING

The aging of people living with HIV presents new challenges in how to address HIV and aging-related conditions, such as health comorbidities, concurrent use of multiple medications, and psychosocial factors, and how to develop models for clinical care and community support. More research is needed to better understand the interaction of HIV and aging and identify strategies for prevention and treatment of aging-related conditions.

ACCELERATED VERSUS ACCENTUATED AGING

Current research evidence is insufficient to determine if HIV leads to accelerated aging or accentuated aging. Accelerated aging can be defined as an age-related decline that arises earlier than expected and increases progressively. In contrast, accentuated aging is an increased burden of disease multimorbidity.

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Scientists acknowledge that more research is needed to answer questions about accelerated aging. It is difficult to attribute accelerated aging to HIV because people living with HIV also experience higher rates of other conditions, such as poverty, diabetes, depression, hepatitis co-infection, and substance use disorders, which impact aging-related health outcomes and call for syndemic approaches to understanding these interrelated and overlapping factors. Additionally, the risk for poorer aging-related outcomes may be greater among older people living with HIV because of less than optimal antiretroviral medications in the early years of the HIV epidemic, long-term toxicity of some antiretroviral medications, lack of consistent viral suppression over time, and the compounding effects of HIV and aging on chronic inflammation. For example, inflammation results from the immune system of people living with HIV being constantly activated as the body works to fight HIV. A chronically inflamed immune system, in turn, has been associated with cardiovascular disease, cancer, and other comorbidities that appear in higher rates among people living with HIV.

Further studies surrounding the aging process should assess how novel, integrative biomarkers can be used to meaningfully predict an individual's biological age and to understand the effects that HIV and subsequent treatment have on the natural aging process. There is also a need for longitudinal cohort studies of people living with HIV with sociodemographically-matched control groups.

FUTURE RESEARCH DIRECTIONS

Other priority areas for clinical research include (1) understanding biological and neurological mechanisms behind aging with HIV to better inform targeted and efficacious treatments and regimens for HIV, (2) investigating feasible and sustainable interventions to promote better daily function and health outcomes for people living with HIV, and (3) increasing implementation science to enhance clinical experience and treatment for older people living with HIV. Significant gaps exist in research on HIV and aging among women and transgender people, and more research is needed on HIV and aging among gay and bisexual men and among heterosexual men. Aging as a woman comes with challenges that men do not experience, such as experiencing menopause and other sexual and reproductive health changes and having a disproportionate burden of certain chronic comorbidities. While some studies have reported that, compared to women who do not have HIV, women living with HIV experience menopause at an earlier age and experience heightened menopausal symptoms, there is a need for more studies on older women living with HIV and dealing with menopause. Studies should assess the safety and efficacy of hormone therapy on symptoms of menopause, cardiovascular risk, and bone disease among this population. There is also a need for studies on hormone therapy among transgender people aging with HIV, aging women who are maintaining their HIV and have caretaking responsibilities, and women and transgender people diagnosed with HIV in old age. Additional research should be conducted to study the experiences of older people living with HIV in congregate living facilities, with a focus on the experiences of women, transgender people, gay and bisexual men, and people of color. Moreover, research is needed on the long-term effects of COVID-19 on older people living with HIV and on social determinants of health among this population.

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older people living with HIV are five times greater than among peers who do not have HIV.¹² At the same time, older people living with HIV are less likely to receive mental health care than their younger counterparts.¹³ In fact, older people living with HIV may confront additional challenges getting into care due to stigma, trauma, isolation, and lack of support from their family, friends, and community.^{14,15}

POLICY ACTIONS THAT SUPPORT OLDER PEOPLE LIVING WITH HIV

Big and complex issues can immobilize policymakers and lead to inaction. There are so many actions and initiatives that could be implemented to better support people who are aging with HIV that it is hard to move forward. The following priorities offer the HIV community, policymakers, and program administrators a place to start:

1

Develop models of care and prevention for people aging with HIV and train and equip the clinical and non-clinical workforce.

While federal policy cannot overcome every challenge, federal leadership is essential. The federal government must invest resources and implement approaches through HIV and health programs to better support older people living with HIV and their health care providers. Priority programs include programs within the Health Resources and Services Administration (HRSA), HIV prevention programs at the Centers for Disease Control and Prevention (CDC), HIV research programs at the National Institutes of Health (NIH), and health programs at the Department of Veteran Affairs (VA).

HRSA's Ryan White HIV/AIDS Program is a federal program that provides a

comprehensive system of care for people living with HIV and is uniquely positioned to lead the way in better meeting the needs of people living with HIV as they age. Ryan White HIV/AIDS Program services that are critical to helping older people living with HIV overcome challenges include (1) physical health, oral health, mental health, and substance use disorder services, (2) case management, care coordination, and insurance navigation, (3) medical transportation, emergency housing, and food services, and (4) cost-sharing assistance. Additionally, the Ryan White HIV/AIDS Program works to build capacity within the health system for supporting the aging HIV population, and the program can lead the way on addressing psychosocial issues among older people living with HIV and promoting the adoption of trauma-informed care approaches for this population.

Ryan White HIV/AIDS Program-funded clinics and providers are experienced in providing complex care provision for people living with HIV. The HIV/AIDS Bureau (HAB) of HRSA, which administers the Ryan White HIV/AIDS Program, works with these clinics and providers to identify and share effective strategies to meet the unique needs of older people living with HIV. Over the past year, HRSA HAB has supported clinics and providers by holding an Aging Institute at the 2020 National Ryan White Conference on HIV Care and Treatment and by developing two reference guides to build and expand the knowledge and practice of health care teams in serving people aging with HIV. The first reference guide, *Optimizing HIV Care for People Aging with HIV: Incorporating New Elements of Care*, identifies commonly occurring health care and social needs of people aging with HIV and highlights the screenings and assessments for these needs.¹⁶ The second reference guide, *Optimizing HIV Care for People Aging with HIV: Putting Together the Best Health Care Team*, discusses how all members of the health care team can contribute to the care of people aging with HIV.¹⁷

Older people living with HIV have physical and mental health needs that are not fully addressed in the current health system. The complexity of these needs necessitates a more individualized, multidimensional approach to providing care. A number of approaches have been proposed, including educating HIV and primary care providers about aging and aging-related conditions, incorporating geriatric consultation and assessment into HIV care, and providing older people living with HIV with enhanced care coordination and linkage to community organizations that serve older individuals. Meeting the needs of older people living with HIV often requires a multidisciplinary care team, including primary care providers, HIV specialists, and geriatricians, as well as therapists and social workers, depending on the circumstances.

The Ryan White HIV/AIDS Program needs continued investment and improvement. In addition, the Ryan White HIV/AIDS Program must build upon its AIDS Education and Training Center (AETC) program, the Special Projects of National Significance (SPNS) program, and other efforts to develop innovative models of care for older people living with HIV and to ensure that the clinical and non-clinical workforce is trained and equipped to serve these people as they age. Programs at CDC, NIH, and the Department of Veterans Affairs also have roles in supporting effective approaches for older people living with HIV. Policy action is needed to:

- **Increase funding for the Ryan White HIV/AIDS Program and make changes within and to the program that support older people living with HIV.** Congress must continue its commitment to the Ending the HIV Epidemic (EHE) Initiative and increase funding for the Ryan White HIV/AIDS Program. The Ryan White HIV/AIDS Program is essential to meeting the physical, mental, and oral health care needs of older people living with HIV. Going forward, it is important to ensure that resources are being optimally used

for the services that people aging with HIV increasingly find that they need. Some services for which there is particular unmet need are mental health services, oral health services, and non-medical supportive services, including housing and employment services. While the 75/25 rule requires that at least 75% of funds under Parts A and B of the Ryan White HIV/AIDS Program and funds for early intervention services under Part C be applied to core medical services and no more than 25% of those funds be applied to supportive services, a waiver for this rule is available that, if granted, allows for more than 25% of funds to be used for supportive services. Ryan White HIV/AIDS Program recipients do receive waivers, and more recipients should use the waiver process to facilitate the expansion of supportive services within the program, which are necessary for improving access to and retention in care. In addition to the waiver process being a way to accomplish structural change, structural changes can be made through administrative action or through legislative action, such as reauthorization of the Ryan White HIV/AIDS Program. A needed structural change that can be made administratively or legislatively is the inclusion of employment services as an allowable non-medical supportive service. Although many changes can be made through administrative action, reauthorization would provide an important opportunity to improve the Ryan White HIV/AIDS Program so that it better meets the needs of people aging with HIV. For example, the Ryan White HIV/AIDS Program is prohibited by law from paying for inpatient care. Given that people living with HIV continue to be hospitalized at high rates and their hospitalization rates increase with older age, inpatient care may be a particular need for some older people with HIV who are uninsured. Changing the law to permit the Ryan White HIV/AIDS Program to pay for inpatient care would require reauthorization or other legislative action.¹⁸

- **Expand the geriatrics and HIV workforces and create opportunities for improving their knowledge, skills, and collaboration in the care of older people living with HIV.** The United States faces a critical shortage of doctors who specialize in geriatrics, even as nurse practitioners fill some of this gap by specializing in gerontology and delivering critical outpatient care to older people.¹⁹ Likewise, fewer doctors are pursuing careers in HIV, as evidenced by the fact that more than one-third of Infectious Diseases fellowship programs did not fill their available training slots in 2019.²⁰ Many HIV providers also have aged and retired. The transition to new providers can sometimes be unsettling for older people living with HIV. The shift to deliver more HIV care through primary care providers, despite its many advantages, has raised yet another challenge for some older people used to meeting regularly with their infectious disease specialists. In addition to providing more resources, such as educational loan repayment programs, to incentivize health care professionals to work in the geriatrics and HIV fields, there is a need for creating more educational opportunities for HIV providers to learn about aging and to acquire the skills needed to treat aging-related syndromes. Also, there is a further need for adapting care models by embedding geriatricians within HIV clinics and primary care practices. Some opportunities and resources already exist. For example, HRSA, through its Bureau of Health Workforce, funds the Geriatrics Workforce Enhancement Program and the Geriatrics Academic Career Award Program. As part of the Ryan White HIV/AIDS Program, the Northeast/Caribbean AETC has developed a Care of People Aging with HIV Toolkit, which provides links to screening and assessment instruments and to programs and papers that offer clinically useful materials. The National HIV Curriculum, funded by the AETC Program, provides ongoing, up-to-date information, including a

special topic on “HIV in Older Adults,” needed to meet the core competency knowledge for HIV care. More funding for the AETC program could be used to train both clinical and non-clinical providers to provide appropriate services and supports for older people living with HIV. The SPNS Program also can play a role in developing and evaluating new approaches to both clinical and supportive care delivery for older people living with HIV.

- **Provide more resources for prevention and treatment messaging, healthy aging campaigns, and research focused on older people living with HIV.** People aged 50 and older accounted for one in six new HIV diagnoses in the United States in 2018.²¹ HIV testing and prevention services may not adequately reach older people because health care providers may mistakenly assume that older people are not sexually active or because some older people may not perceive themselves as at risk for HIV. People aged 50 and older also may not always see themselves as old, which raises challenges for engaging older people living with HIV in geriatric HIV programs and other aging programs. It is important that CDC supports the development and delivery of culturally and linguistically appropriate prevention and treatment messaging for older people, especially older people of color and lesbian, gay, bisexual, or transgender (LGBT) older people. More funding should be directed toward launching social marketing campaigns that address HIV, aging, and related stigma. These campaigns should target the general public and priority populations. Efforts also should focus on encouraging health care providers to talk with older people about drug use and sexual behaviors and to offer appropriate HIV testing and status-neutral prevention and care services. NIH should be appropriately funded to engage in coordinated cross-division research focused on older people living with HIV, including research on

GOLDEN COMPASS PROGRAM PROVIDES A SUCCESSFUL MODEL OF CLINICAL SERVICES FOR PEOPLE AGING WITH HIV

A number of clinical programs have implemented care models to better meet the needs of people aging with HIV. Programs like the Golden Compass Program in San Francisco have implemented a consultative model, where HIV clinical providers refer people living with HIV to geriatricians and other aging specialists. While geriatric consultative services may be embedded in or external to these programs and often include supportive services and linkage to community-based organizations, the foundation of a consultative model is the comprehensive geriatric assessment (CGA), which is a multidimensional, multidisciplinary diagnostic process focused on assessing an older person's medical, psychological, and functional capability in order to develop a coordinated and integrated plan for treatment and long-term follow-up focused on the individual's needs.

THE 6Ms: AN APPROACH TO COMPREHENSIVE CARE FOR OLDER PEOPLE LIVING WITH HIV

Optimal care for addressing aging and HIV should embrace what geriatric HIV specialists call the 6Ms: matters most, mind, mobility, medications, multicomplexity, and modifiable factors.

- (1) Matters most** means that clinicians should have an understanding of the personal health goals and care preferences of the people to whom they provide care. Clinicians should align care with those goals and preferences.
- (2) Mind** refers to cognitive function and goes beyond depression and anxiety to thinking about and managing neurocognitive health and dementia. To promote cognitive function, clinicians must inquire about safety, including safe driving and considerations for safety and social support at home. It is also important to diagnose and treat mood disorders, explore how comorbidities and polypharmacy impact cognition, and encourage older people living with HIV to maintain physical, mental, and social activity to maintain cognitive function.
- (3) Mobility** refers to ensuring that older people living with HIV maintain their physical functioning, such as through regular exercise. A key component of mobility is fall prevention, including home safety assessments to ensure the home is safe from tripping and slipping.
- (4) Medications** are a reality for older people living with HIV, which can mean polypharmacy and drug-drug interactions. Clinicians should only prescribe necessary medications. Also, clinicians should consider opportunities to reduce the medications that a person aging with HIV must take and to discontinue prescriptions that could increase risk of falls or other adverse effects.
- (5) Multicomplexity** acknowledges the difficulty in managing comorbidities within complex social and living conditions. Clinicians should assess these conditions and help older people living with HIV manage comorbidities.

Continued on next page

(6) Modifiable means prioritizing interventions that target the most modifiable factors that can impact multiple systems. This includes encouraging regular physical activity, healthy diet, discontinuation or reduction of substance use, meaningful social connections, and the development of positive coping skills for stress management.

COMPONENTS OF THE GOLDEN COMPASS PROGRAM

Drawing on the 6Ms, the Golden Compass Program at the Ward 86 outpatient HIV clinic at San Francisco General Hospital was launched in January 2017 as a geriatric HIV program designed to help older people living with HIV navigate their golden years. The program involves a team of medical doctors, including a medical director, cardiologist, and geriatrician, as well as a registered nurse, a pharmacist, a program coordinator, and a medical assistant. People who participate in the program maintain their primary care provider, and they have consultations with an HIV-focused geriatrician and cardiologist in the same familiar clinic environment. The Golden Compass Program is framed around the idea of a compass and focuses services around four points:

- (1) Heart and Mind (Northern Point)** focuses on comorbidities and includes on-site cardiology, cognitive evaluations, and brain health classes;
- (2) Bones and Strength (Eastern Point)** focuses on bone health, fitness, and physical function, through exercise classes and on-site geriatric consultation;
- (3) Dental, Hearing, and Vision (Western Point)** ensures appropriate screenings for dental concerns and sensory impairment and provides linkage to and navigation assistance for dental, audiology, and optometric/ophthalmology services; and
- (4) Networking and Navigation (Southern Point)** focuses on social and community-building activities.

OUTCOMES OF THE GOLDEN COMPASS PROGRAM

In the first year and a half of the Golden Compass Program, 198 people living with HIV aged 50 years or older participated in the program. Over 90% of participating providers and people living with HIV were satisfied with the program. Provider adoption was high, with 85% of providers referring at least one patient to the geriatrics clinic and 59% of providers referring to the cardiology clinic. Co-location of services, pharmacy and geriatric assessments, and social support from classes were valued.

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psychosocial issues and implementation science to facilitate uptake and sustainability of geriatric HIV programs or other aging programs among people living with HIV and among health care providers. The Department of Veterans Affairs is leading the way in HIV testing, prevention, treatment, and research for veterans. The VA should continue to investigate best practices for connecting veterans to HIV and aging services and serve as a model for implementing these services in other settings.

2

Expand opportunities for older people living with HIV to make social connections through community-based programs that address isolation, stigma, and trauma.

Social isolation refers to living without companionship, social support, or social connectedness and has been associated with decreased quality of life, poor health, increased health care utilization, functional decline, and premature death among older people.²² People living with HIV are at increased risk of social isolation due to stigma and social rejection. Older people living with HIV are particularly vulnerable because they experience the dual threat of HIV stigma and ageism. Many of these people also have additional stigmatized identities related to their race, sexual orientation, gender identity, and other characteristics. Older people living with HIV, especially older people of color, experience higher rates of social isolation than their younger counterparts, with one study finding that more than 38 percent of older people and 54 percent of older people of color were at risk of social isolation compared with 25 percent of those aged 20 to 39.²³ Older people living with HIV, especially those who are women, people of color, or LGBT individuals,

experience various forms of trauma. Acknowledging and responding to trauma experiences of people aging with HIV is also essential for meeting their needs.

Social networks have been shown to be an important element in the lives of people living with HIV. People living with HIV who report adequate social and emotional support from these networks are more likely to be in care, adhere to treatment, and have better physical and mental health outcomes.^{24,25,26} Family, friends, and, to a lesser degree, neighbors play a significant role in the composition of social networks for people living with HIV. Since these traditional social networks are often inadequate, networks of people living with HIV (PLHIV networks) and community-based organizations, such as AIDS service organizations (ASOs), Area Agencies on Aging (AAAs), and faith-based organizations, are critical alternative sources of support. However, many older people remain disconnected from both traditional and alternative support networks. To address social isolation, stigma, and trauma among older people living with HIV, policy action is needed to:

- **Strengthen and expand PLHIV networks and increase funding for community-based organizations that provide social support services for older people living with HIV.** PLHIV networks are a key mechanism for enhancing support to older people living with HIV and can help to ameliorate negative experiences around aging with HIV. These networks must be bolstered now and into the future. More funding is needed for community-based organizations that serve the aging HIV population. Access to social support services is critical for older people living with HIV, so that they can build and maintain personal connections, stay active, and participate in their local communities. This may be particularly true for racial, sexual, and gender minorities who are more likely to be socially and financially isolated

POSITIVE LIVING CONFERENCE ADDRESSES HIV, AGING, AND SOCIAL ISOLATION

Okaloosa AIDS Support and Informational Services, Inc. (OASIS Florida), now in its 30th year of operation in northwest Florida, is dedicated to preventing HIV transmission and supporting all people who are affected by HIV. OASIS Florida has organized the Positive Living Conference since 1997. This annual conference is the nation's oldest and largest gathering of people living with HIV and brings together approximately 450 attendees each year from all over the country. Over 95 percent of attendees are people living with HIV, and the vast majority of them are over the age of 50. The conference includes interactive workshops on different topics, such as "HIV and Aging" and "Healthy Relationships," and ends with an open mic session where all attendees are encouraged to share and be heard.

The Positive Living Conference and other conferences and networks for and by people living with HIV are critically important for combating social isolation among people aging with HIV and for addressing broader issues that they face. Many older people with HIV deal with stigma, loneliness, and depression in addition to physical health comorbidities. These issues are particularly challenging for those living in rural areas. Conferences and networks allow older people living with HIV to connect with and support each other, discuss relevant and interesting topics, and define their own agendas.

Source: Positive Living Conference. <https://aumag.org/2018/09/08/positive-living-conference-september-14-16/>.

from resources available to other groups. Faith-based organizations are made up of a large population of older people, and those providing HIV services are a critical lifeline for older people living with HIV, especially in communities of color.

- **Identify ways to leverage technology for social support and connection and to overcome barriers that older people living with HIV face in using technology.**

The COVID-19 pandemic has led to a significant expansion in the use of telehealth services. Technology also can play an important role in providing social support services and addressing the isolation, stigma, and trauma that older people living with HIV experience. Services providers at community-based organizations should pursue opportunities to communicate with people using cell phones or social media and hold support groups and social activities online in a manner that

is consistent with federal and state laws and privacy protections. At the same time, many older people living with HIV lack access to technology or may be reluctant or unaccustomed to using it. Funding may be needed to provide necessary technology, education, and assistance to these individuals. More research on how older people living with HIV use or prefer to use technology also may be necessary.

3

Maintain Medicare Part D drug access protections (e.g., Six Protected Classes) and expand focus on high-quality care and quality of life.

Medicare, the federal health insurance program for people aged 65 and older,

as well as working age people with disabilities, is an important source of health coverage for people aging with HIV, both those who qualify because of age and those who qualify because of a disability. Medicare consists of several parts. Part A covers hospital care, while Part B covers physician services, outpatient care, and some home health and preventive services. Part C, called Medicare Advantage, is a voluntary managed care alternative to traditional Medicare coverage, and Part D is the voluntary outpatient prescription drug benefit. The majority of Medicare beneficiaries with HIV have low incomes that make them dually eligible for Medicare and Medicaid. Medicaid provides additional cost-sharing assistance and covers long-term services and supports (LTSS) that are not covered by Medicare. Medicare is now the largest source of federal financing for HIV care and treatment.²⁷ More than half of Medicare spending for beneficiaries living with HIV is Part D drug spending.²⁸

Medicare Part D prescription drug plans currently are required to include at least two drugs per class on their formularies and to cover substantially all drugs in six protected classes, including antiretrovirals. The other protected classes are immunosuppressants, anticonvulsants, antidepressants, antineoplastics, and antipsychotics. There is an additional protection for HIV antiretroviral drugs: plans are not permitted to require prior authorization or step therapy for these medications. On the last day of the Trump Administration (January 19, 2021), the Centers for Medicare and Medicaid Services (CMS) announced changes to the Part D program that would allow participating Part D plans to disregard the protected classes policy and only cover one drug per class, with no exemptions for people currently taking a specific protected class status medication.²⁹ The proposed changes would have allowed Part D plans to begin limiting access to prescription drugs for five protected classes in 2022 and for antiretroviral drugs in 2023. In March 2021,

the Biden Administration rescinded these changes,³⁰ but since the protected class policy has been threatened with change or elimination since the establishment of the Part D program, it is necessary to guard against problematic new restrictions on drug coverage. Maintaining the protected class policy is particularly important for older people living with HIV because the policy ensures access to a broad range of drugs for the treatment of HIV and comorbidities. Older people living with HIV also have co-occurring mental health disorders, substance use disorders, and other health conditions that require various drug treatments. In addition to preserving Medicare drug access protections, CMS should consider opportunities to:

- **Refine quality measures, monitor social determinants of health, and support complex care management within Medicare.** CMS can take more proactive steps in promoting optimal care for older people, including those living with HIV. It is important to examine whether current reimbursement mechanisms adequately serve older people who have complex needs and may require more time with a health care provider. There are also opportunities for CMS to address the quality of health care services provided to Medicare beneficiaries and to refine the Star Rating System, which sets quality measures for Medicare Advantage and Part D plans and helps beneficiaries pick a plan based on quality performance. In addition to improving quality measures in the Star Rating System to better measure outcomes and incentivize value-based care, CMS should help Medicare Advantage and Part D plans focus on people with multiple chronic conditions and work with providers on integrating social determinants of health into electronic health records. Taking these steps is important for a wide range of Medicare beneficiaries, not just people living with HIV.

- **Support access to long-acting HIV products that could benefit older people living with HIV.** CMS, along with other payers and federal agencies, including HRSA, should ensure appropriate access to long-acting HIV treatment and prevention options, which do not require daily dosing. The Food and Drug Administration approved a long-acting injectable product for HIV treatment in January 2021, and more long-acting products for HIV treatment and prevention are under development as injections, implants, or oral medications. These products have the potential to facilitate greater adherence in ways that improve health and quality of life. For older people living with HIV to benefit from long-acting products, federal agencies should provide guidance to purchasers, prescribers, and the public on how the products will be evaluated and integrated into drug formularies.

4

Allocate more funding to programs that support financial security and access to employment, housing, food, and public benefits for the aging HIV population.

Structural factors, such as poverty, unemployment, and lack of housing, contribute to new HIV transmissions and poor health outcomes. While people living with HIV who are employed have better adherence to medication and better physical and mental health outcomes,^{31,32} people living with HIV often face significant barriers to entering or re-entering the workforce. These barriers include workplace discrimination and risking the loss of benefits or services from programs with income eligibility limits, such as Medicaid, the Ryan White HIV/AIDS Program, or the Supplemental Security Income (SSI) Program, if individuals earn too much income. Older people living with

HIV face additional employment challenges. Research from one study demonstrates that older age and HIV disease have independent and additive adverse effects on employment status, even though they are not an indication of low work functioning.³³ In a research study out of the United Kingdom, higher quality of life among people living with HIV was strongly associated with having paid employment, having a higher level of income, and not being on public benefits.³⁴

Other major areas of concern for many older people living with HIV include food and housing insecurity and the management of finances and health care benefits. People living with HIV who are food insecure often forego critical medical care and are less likely to be virally suppressed.³⁵ Research has demonstrated relatively high levels of food insecurity among older people living with HIV, underscoring a need to implement targeted food assistance strategies for this group.³⁶ For many older people living with HIV, affordable and safe housing is difficult to obtain. Whereas those who are homeless or unstably housed have worse overall health outcomes, those moving into assisted living facilities or nursing homes face stigma surrounding HIV and, if they are LGBT individuals, homophobia or transphobia. Still another concern for people aging with HIV is navigating issues with public benefits like Social Security and Medicare benefits. To address these various structural challenges, policy action is needed to:

- **Create employment opportunities for people aging with HIV, including within the HIV workforce.** Federal agencies, including the Department of Health and Human Services, the Department of Housing and Urban Development, the Department of Labor, and the Department of Education, should coordinate to develop and fund a plan focused on promoting vocational training and employment opportunities for people aging with HIV, including within

THE REUNION PROJECT AND TPAN COLLABORATE ON “POSITIVELY AGING”

Created in 2015, The Reunion Project (TRP) is a national alliance of long-term survivors of HIV working in collaboration with local and national HIV advocates, providers, and researchers. Between 2015 and 2018, TRP tasked local leaders in six major urban cities with organizing local town halls and other events in an effort to reunite and mobilize survivors. In March 2018, TRP also organized a national roundtable forum consisting of survivor experts, long-term survivors, caregivers, and others. The main objective of the forum was to create a powerful and sustainable Coalition of Survivorship. Following the forum, four stand-out issues to be addressed going forward were identified:

- (1) Research regarding actual lived experiences**, the impact of technology, aging, and comorbidities, and differing effects across different geographical regions;
- (2) Systems-based and individual/community-based programs** concentrated on awareness, skills, and support for mental health, well-being, and economic justice;
- (3) Creating safe spaces, networks, and wider-reaching partnerships** to increase access to information, representation, and justice; and
- (4) Advocacy to achieve the above-stated goals and other goals.**

In May 2019, TRP joined with the Test Positive Awareness Network (TPAN) to create *Positively Aging*, a collaboration designed to address the needs of older people living with HIV. *Positively Aging* seeks to innovate the delivery of TPAN’s direct services (medical care, mental health services, case management, and social activities) in Chicago to older persons living with HIV, engage older persons living with HIV through an expansion of TRP’s national peer-driven support network, and disseminate educational resources about HIV and aging to a national audience through TPAN’s magazine, *Positively Aware*.

Sources: (1) Fawcett D. The Reunion Project seeks to build an HIV research agenda for long-term survivors. *TheBodyPro*. October 1, 2018. <https://www.thebodypro.com/article/the-reunion-project-seeks-to-build-an-hiv-research>. (2) Positively Aging. <https://www.tpan.com/positively-aging>.

the HIV workforce. These agencies must work with state and local government partners, community-based organizations, and people living with HIV to create and implement interventions that provide job-related information, skills, and resources to people aging with HIV, support these individuals to obtain and maintain employment, and focus on ensuring that policies do not deter them from engaging in the workforce. It is also important to address stigma and discrimination that older and other people living with HIV face due to their

HIV status or LGBT identity when seeking services from workforce development or vocational rehabilitation programs. Additionally, addressing the employment needs of young and middle-aged people living with HIV can serve as prevention of unemployment, underemployment, and economic insecurity as these people age into their older years. The COVID-19 pandemic has increased economic insecurity and also increased the need for employment-related services and resources.

- **Increase funding for food assistance for people aging with HIV.** Increased funding for food and nutrition services is critical to meeting the needs of low-income people living with HIV as they age. The need for these services is only heightened by the public health and economic crises brought on by the COVID-19 pandemic. Due to these crises, food and nutrition programs across the country have experienced an unprecedented surge in requests for home-delivered meals and other services from older adults, including older people living with HIV, who are homebound and/or economically vulnerable. Investment in research is also needed to identify the scope of food insecurity among older people living with HIV and to understand the impact of different food interventions for this population. HRSA's HIV/AIDS

Bureau should continue to monitor the provision of food and nutrition services for all people in the Ryan White HIV/AIDS Program and track related health outcomes and cost savings. Given that funding decisions for Ryan White HIV/AIDS Program services are made at the local or state level, it is important to incorporate information on the provision of food and nutrition services for different age groups into the needs assessment process that Ryan White Planning Councils conduct each year.

- **Increase financial support for federal and state initiatives to address homelessness and housing insecurity among people aging with HIV.** The Housing Opportunities for Persons with AIDS (HOPWA) program has never been funded to meet the level of need. There is

OLDER WOMEN EMBRACING LIFE (OWEL) FOCUSES ON THE NEEDS OF OLDER BLACK WOMEN LIVING WITH HIV

Older Women Embracing Life (OWEL) is a network of older women in the Mid-Atlantic region that is leading efforts to meet the comprehensive needs of women, especially Black women, living and aging with HIV. OWEL was formed in 2005 because of the limited awareness of the impact of HIV on older women. Older women often face challenges disclosing their HIV status due to stigma and fear; they also lack opportunities and venues for connecting with each other and receiving emotional support. In many communities, support groups are not readily available for older women living with HIV. Social service and health care providers also may not be aware of the unique needs of this population. This is particularly true for older Black women, who are the group that OWEL primarily serves. In addition to dealing with HIV and aging, these women face challenges related to their race and sex, may have caregiving responsibilities taking care of children, grandchildren, or elderly parents, and often confront other issues.

Despite challenges associated with HIV and aging, the goal of OWEL is to foster a community of women who are living full, productive, and happy lives. To achieve this goal, OWEL develops and implements projects and programs that are aimed at promoting women's physical, emotional, spiritual, and mental health and helping women access services and manage various other aspects of their lives. These projects and programs include:

Continued on next page

SUPPORT GROUPS AND INTERVENTIONS

OWEL provides mentoring and support to women struggling with the realities of an HIV diagnosis. Since its formation, OWEL has offered monthly support groups for women living with HIV. These support groups typically meet at local churches and provide social support and networking for women living with HIV, as well as opportunities to educate and train women about HIV care and treatment, supportive services, civic engagement, and other topics. In addition to support groups, OWEL has delivered evidence-based interventions, including Sister to Sister and the Women Involved in Life Learning from Other Women (WILLOW) intervention. These interventions are aimed at increasing self-efficacy in HIV management and HIV prevention.

PEER NAVIGATION SERVICES

Members of OWEL also provide peer navigation and support services to help women with medical appointments and medication adherence as well as to foster a sense of community and connection. These services may include sending text messages to remind or encourage women to take their medication, making phone calls to let them know that someone is thinking about them, and checking in about experiences with health care providers. OWEL also holds interagency roundtables to bolster individuals' care plan development and compliance.

HEALTH FAIRS, WORKSHOPS, CONFERENCES, AND COMMUNITY EVENTS

The Legends and Young'uns Conference is an annual regional conference organized by OWEL that brings together women living with HIV, including long-term survivors and those who are newly diagnosed with HIV, to address the unique needs these women have. Through presentations and interactive workshops, the conference focuses on a variety of issues, such as the clinical manifestation of HIV, retention and engagement in care, reproductive health, behavioral health, and pre-exposure prophylaxis (PrEP). OWEL also organizes an annual campaign called Teach and Test, in which its members conduct outreach to older people in residential high-rise buildings and senior service facilities about testing for HIV and living with HIV. Similarly, OWEL holds events such as Testing for Turkeys, which offers free HIV and hepatitis C testing and gives away turkeys for Thanksgiving, and a Speakers Bureau, which involves women with HIV going to places of worship and other community settings to share their stories. These events are also a way to disseminate information about local organizations and connect women to resources in the community.

ADVOCACY AND RESEARCH

Working closely with health departments and academic institutions, OWEL advocates for research on older women living with HIV and for the inclusion of these women in public health activities and data reporting. OWEL seeks to make sure that older women are part of HIV research and engages researchers around involving these women from the conception of research questions through evaluation and study completion. Additionally, OWEL educates women on the importance of participation in research studies and helps to recruit women for studies and share the results of studies with women.

Sources: Older Women Embracing Life, Inc. <http://www.owelinc.org>.

also increasing need for housing supports amid the COVID-19 pandemic. More funding should be allocated for HOPWA and for housing programs that support both transitional and subsidized housing for older people living with HIV.

- **Expand navigation services that help older people living with HIV learn about and resolve issues with Social Security and Medicare benefits.** Some older people living with HIV qualify for disability benefits administered by the Social Security Administration, namely Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). SSDI provides cash assistance to people with disabilities, with payment levels based on contributions made during their prior work history. SSI provides cash assistance to people with disabilities and people aged 65 or older to ensure a minimum payment level (\$794 per month for an individual or 74% of the federal poverty level in 2021).³⁷ Whereas SSDI payments can be well above this level, low-wage people receiving SSDI also can receive SSI up to this payment level, which creates a minimum payment level, yet one that ensures that they live in poverty. Navigating these disability benefits is complex, and many people have difficulties with Social Security offices, which sometimes threaten to terminate benefits. Legal services, including those covered by the Ryan White HIV/AIDS Program, are critical for some individuals to maintain and navigate Social Security disability benefits programs. Like Social Security, Medicare is complex and raises its own challenges. People often are not familiar with how Medicare operates. This is the case for many older people who are enrolling or are enrolled in Medicare, despite having benefits counselors who support them. Understanding and navigating Medicare benefits is particularly challenging for people aging with HIV who may have to deal with high costs of HIV medications and other treatments for comorbidities. The

Access, Care, and Engagement Technical Assistance (ACE TA) Center of the Ryan White HIV/AIDS Program already exists to assist people living with HIV in accessing and using Medicare or other health coverage, as well as to provide training for service providers. Additional efforts to expand navigation services for public benefits may be needed.

5

Promote the meaningful participation of older people living with HIV in the Ending the HIV Epidemic (EHE) Initiative and in broader advocacy efforts.

Older people living with HIV must be meaningfully engaged in the Ending the HIV Epidemic (EHE) Initiative and in responding to the issues that are important to them. Their voices matter and need to be bolstered now and in the future. Not only do older people living with HIV bring knowledge of their own needs that is critical to informing and implementing the EHE Initiative, but their experience dealing with stigma and advocacy has shaped the system of HIV services delivery and will help to ensure that the system continues to evolve. It is important to create opportunities for older people living with HIV to define their own policy agenda and inform how services are delivered for them.

People aging with HIV should be involved in all aspects of HIV programs and services, including as senior leadership, clinical staff, community health workers, and peer educators. In particular, more must be done to ensure older people living with HIV who are gay and bisexual men of color, transgender people of color, and women of color are fully involved in the HIV response. Additionally, older people living with HIV should be fully involved in responding to COVID-19—which places older people at higher risk for hospitalization and death

and disproportionately affects many communities that are most heavily impacted by HIV—as well as other health concerns that they have, such as viral hepatitis, sexually transmitted infections, substance use, and mental health. Meaningful engagement with diverse groups of older people living with HIV is also crucial for addressing the social and structural factors that lead to health inequities. To have an impact on HIV and other critical issues, advocacy efforts must aim to:

- **Engage government leaders on HIV and aging issues and strengthen diverse representation in HIV decision-making processes.** Older people living with HIV must be active in national, state, and local advocacy. AIDSWatch, the largest annual constituent-based national HIV advocacy event, and related events at the state and local level are opportunities for older people living with HIV to meet with their legislators and educate them about HIV and aging issues. Two critical areas to focus advocacy are calling for all states to expand Medicaid and pushing for policies to expand access to community-based long-term services and supports. In addition to engaging legislators and other government officials in a variety

of ways, older people living with HIV should consider participating in Ryan White Planning Councils to ensure they have input on setting HIV priorities and allocating funds for services based on their needs.

- **Work with people and organizations outside of the HIV field.** People aging with HIV must broaden the focus of their advocacy. Addressing issues that extend beyond HIV, such as Medicaid expansion efforts, expansion of the geriatrics workforce, financial support for community-based programs, and barriers to employment, may require building partnerships with aging groups, disabilities groups, and other advocates. Another priority issue is life planning for the rest of life, so that older people can have a future with joy, health, safety, purpose, companionship, employment, housing, and financial stability. Aging organizations already engage in a number of HIV-related activities, such as through the Administration for Community Living, which has supported projects and initiatives with HIV partners, including the AIDS Community Research Initiative of America (ACRIA).

CONCLUSION

The health care and social needs of people living with HIV are complex, and those needs change as people with HIV age. To be successful at ending the HIV epidemic in the United States, we must keep the needs of older people living with HIV at the center of our efforts.

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CELEBRATE LGBT PRIDE MONTH - Facts about LGBT Elder People and Eldercare

LGBT OLDER PEOPLE

- 2X as likely to be single and live along than non-LGBT people.
- 4X less likely to have children than non-LGBT people.
- **More likely to face poverty and homelessness and have poor physical and mental health.**

CAREGIVING

- **21% of older LGBT people have provided care to friends, compared to only 6% of non-LGBT older adults.**
- **LGBT people become caregivers at a higher rate than non-LGBT people and make up 9% of the caregivers in the U.S.**
- LGBT caregivers are more likely to be caring in isolation, which can exacerbate stress and lead to caregiver burnout.
- 54% of LGBT eldercare recipients receive care from their partners.
- 24% of LGBT eldercare recipients receive care from a friend.

CULTURAL COMPETENCY

- **Many LGBT people have reported delaying or avoiding necessary medical care because they fear discrimination or mistreatment by health care staff.**
- Nearly 1 in 4 transgender people report having to teach their health care provider about transgender issues in order to receive appropriate care, and 15% report being asked invasive or unnecessary questions unrelated to the health care they are seeking at the time.
- **88% of LGBT older people say they would feel more comfortable with long-term care services if they knew staff had been specifically trained about the needs of LGBT patients. More than two thirds say this would make them feel much more comfortable.**

SOCIAL ISOLATION

- **59% of LGBT older people report feeling a lack of companionship and 53% report feeling isolated from others.**
- Research has shown that loneliness and isolation are associated with poor physical health. Some experts have equated the health risks of prolonged isolation to those of smoking 15 cigarettes a day.
- 25% of SAGE care management clients in New York City report having no one to call in case of an emergency.

WELLNESS

- Nearly one in three LGBT people smoke, a rate that is more than 50% higher than the general population.
- LGB older people are significantly more likely to drink alcohol excessively than heterosexual older adults, and transgender older adults are more likely to drink excessively than their non transgender counterparts.
- **39% of LGBT older adults have had suicidal thoughts, 48 and 2 of every 5 transgender people have attempted suicide in their lifetime.**

DISCRIMINATION

- About two-thirds of LGBT older people have experienced victimization at least three times in their lives.
- More than half of LGBT older people report being discriminated against in employment and/or housing.
- **It's been reported that LGBT older people have received inferior, neglectful health care or have been denied health care altogether.**
- Research has shown that repeated experiences of discrimination can lead to long-term negative health outcomes.

HEALTHCARE

- Research has repeatedly shown that LGBT people have higher rates of poor physical health and mental distress.
- 41% of LGBT older people report having a disability, compared to 35% of heterosexual older adults.
- A national study of transgender people found that in the prior year, 23% of respondents avoided going to a doctor when they needed to because they feared being mistreated, and 33% did not go because they could not afford it.

HIV/AIDS

- **In 2018, 17% of all new HIV diagnoses in the U.S. were in people aged 50 and older.**
- Researchers estimate more than 50% of patients with HIV have an HIV associated neurocognitive disorder, which can impact memory, motor skills, and other aspects of cognitive function, as well as cause depression or psychological distress.
- **50% of all Americans living with HIV are over 50 years old.**

HOUSING

- **34% of LGBT older people worry about having to hide their identity in order to access senior housing**
- In a matched-pair test across 10 ten states, 48% of same-sex couples experienced adverse treatment when seeking senior housing.
- Nearly one-quarter (23%) of transgender individuals report having experienced some form of housing discrimination in the past year.
- **21 states and 5 territories have no explicit laws prohibiting housing discrimination based on sexual orientation and/or gender identity.**

FINANCIAL SECURITY

- **Transgender people in the U.S. are more than twice as likely to be living in poverty as non-transgender people. Transgender people of color are more than three times as likely.**
- **In general, LGBT people are poorer and have fewer financial resources than their non-LGBT counterparts.**
- Research has shown that LGBT people are likelier to be subject to employment discrimination, making their earnings—and their Social Security payments—lower. One-third of LGBT elders live at or below 200% of the federal poverty level.

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Older Adults with HIV/AIDS: A Growing Population

NEWSROOM

September 18, 2021

Brian Altman, Deputy Director, Administration on Aging and Andrea Callow, Program Analyst, Office of Policy Analysis and Development

September 18th marks National HIV/AIDS and Aging Awareness Day—a day we celebrate the growing number of people living long and active lives with HIV. When HIV emerged in the early 1980s, people who contracted the virus could expect to live only a few years with their diagnosis. Thanks to advances in treatment, people who are 50 and older, many of whom have been living with HIV for decades, are a large and growing population. [Research](#) has shown that people with HIV who are successfully treated with antiretroviral therapy can have a lifespan similar to that of their HIV negative peers, living well into their 70s and 80s. Currently, [over half of adults living with HIV are over the age of 50](#), and by 2030 over 70 percent of the HIV positive population in the United States [will be over 50](#); older people of color are [disproportionately affected by HIV](#), as are older men who have sex with men.

September 18th is also a day to raise awareness of the aging-related health and social service needs of older adults living with HIV. They are an [extremely diverse population](#) with distinct needs that will continue to evolve as they age.

With its extensive experience providing services to meet the need of a growing, and increasingly diverse, population, ACL's aging network plays an important role in the lives of older adults across the country. Armed with the [array of programs](#) funded by ACL to help older adults stay healthy, active and living in their communities, the network is helping support the healthy aging of people living with HIV. For example:

OAA Health and Wellness Programs

Most programs and services provided by the aging network can be beneficial for people aging with HIV, but a few, such as the [Positive Self-Management Program \(PSMP\)](#) developed at Stanford University more than 20 years ago, are specifically designed for people living with HIV. With a [grant](#) from ACL under the [OAA Chronic Disease Self-Management Education program](#), the Central Maine AAA recently began working with MaineGeneral Health's Horizon Program to implement PSMP for older Mainers with HIV.

Programs don't need to be specifically focused on HIV – many of ACL's health and wellness programs can be tailored to the needs of older adults living with HIV. [Open Hand Atlanta](#) is offering chronic disease self-management education to people living with HIV in conjunction with their signature [nutrition and education](#) programs and services. The [Council for Jewish Elderly](#) in Illinois, a 2021 recipient of a falls-prevention grant from ACL, is implementing two programs that will reach over 1,300 older people in Illinois and New York living with HIV and/or in low-income, minority, and LGBTQ+ communities.

Insurance Counseling

ACL programs help people living with HIV access critical insurance to pay for medical care and medication. [State Health Insurance Assistance Programs \(SHIPs\)](#) provide counseling and guidance to help people navigate complex enrollment and benefits decisions in Medicare and other health insurance programs.

[SHIPs](#) also are collaborating with other HIV service providers to meet the needs of people aging with HIV. For example, many people living with HIV who become eligible for Medicare due to age or disability are also eligible for the [Ryan White program](#), which provides health care and supportive services to moderate-income individuals living with HIV. Coordination of benefits issues can arise when someone receiving Ryan White services becomes eligible for Medicare or other insurance programs and participates in multiple programs simultaneously.

The staff and volunteers of the Iowa SHIP participated in cross training with the state's Ryan White program grantees to improve their ability to address these complex benefits questions and better meet the needs of people participating in both programs.

New State Plan Guidance

ACL recently updated its [State Plan Guidance](#), which provides instructions for states to follow when developing their multi-year state aging services plans and details target populations that should be a focus of each state. For the first time, this guidance requests that states include a description of strategies to serve older adults living with HIV, as well as the objectives and measures (data elements and sources) the state will use to demonstrate progress.

The State Plan Guidance applies to plans developed and submitted to ACL starting in 2022,

but some states are leading the way. [Illinois](#) and [California](#) included efforts targeting older adults with HIV for aging services in the plans they submitted in 2021.

Support for the Aging Network

To ensure inclusivity and cultural competency, ACL funds a number of [resource centers](#) dedicated to providing support and guidance to grantees on how to best serve the needs of diverse older adults and people with disabilities. One example is the [National Resource Center on LGBTQ+ Aging](#), which includes [resources](#) and [training](#) for ACL network partners serving older adults with HIV.

The reach of the ACL aging network allows it unique access to address the health and social support needs of older adults living with HIV, and ACL's programs provide powerful tools to support them in healthy aging. On this day of observance and celebration, we should also look to the future and develop creative and sustainable ways to best serve the diverse populations of older adults in our communities, which include an increasing number of people aging with HIV.

Last modified on 09/21/2021



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

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ARTICLE INFO

Keywords:

HIV
Rural
Aging
Older adults
Qualitative
Providers

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.

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

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E-mail address: kaquinn@mcw.edu (K.G. Quinn).<https://doi.org/10.1016/j.ssmqr.2022.100113>

Received 15 December 2021; Received in revised form 31 May 2022; Accepted 4 June 2022

Available online 10 June 2022

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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; Nachege 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),

Table 1
Demographics characteristics of key informants and their organizations (n = 27).

Continuous Variables	M	SD
Informant age (n = 20; range: 32–72)	50.0	11.0
Informant years at agency (n = 22; range: 1–31)	11.8	9.9
Percent of clients: 50+ years old (n = 16; range: 10–75)	40.0	16.3
Percent of clients: Rural (n = 18; range: 15–100)	49.7	28.9
Categorical Variables	n	%
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.

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.

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

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% (Frean 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.

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.

Acknowledgements

We are grateful to our study team who made this work possible, especially Kevin Brown and Erika Christenson. We are also grateful to the organizations and individuals who participated in this study and were willing to share their experiences with us. This study was supported by the National Institutes of Health: R56NR019443 (Walsh and Petroll) and K01MH118939 (John).

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Many Seniors Rely on Public Transportation to Drive Healthcare Access

PatientEngagementHIT

October 27, 2022 - More than 3 million seniors in the United States reported recently using public transportation, with over 600,000 turning to these services for healthcare access, [according](#) to a new study led by University of Maryland School of Medicine (UMSOM) researchers.

Attending healthcare appointments and participating in social activities are essential elements of healthy aging, but involvement is often limited by a lack of transportation, researchers stated.

Access to transportation is a [top social determinant of health](#). Past studies have shown that transportation barriers [are one of the leading causes of missed appointments for seniors](#). Public transportation may bridge these gaps and drive health equity for the senior population.

To conduct the study, researchers analyzed data about over 5,600 seniors from the National Aging and Trends Study, a nationally representative survey of Medicare beneficiaries aged 65 and older.

Nearly 1 in 10 seniors who live in cities reported using public transportation, and 20 percent of those respondents said they relied on trains and buses to access their scheduled doctor appointments.

Despite public transportation being a potential health equity driver, these faulty public infrastructures also cause concern as potential access barriers due to their broken-down infrastructure and accessibility issues.

Researchers found that many senior public transit users are left to weather extreme heat, flooding, or cold conditions for over 25 minutes as they wait. When severe weather impacts public transit, it can deepen existing health inequalities. Additionally, such factors could worsen chronic conditions like heart failure, kidney disease, or diabetes.

“While our data was collected before the Covid pandemic, we know the pandemic disrupted public transportation, which is still continuing due to financial strain, staffing shortages, and cutbacks to transit services across the county,” study senior author Jason Falvey, DPT, PhD, Assistant Professor of Physical and Rehabilitation Science at UMSOM, said in a press release. “We worry about the impact that this disruption is having on the nearly 700,000 older Americans who rely on subways and buses to get to their medical appointments.”

Surpassing weather challenges, [accessibility posed the biggest barrier to public transit](#). Seniors who use wheelchairs were 65 percent less likely to use public transit than those who didn't, likely because

public transit does not make accommodations for such medical equipment.

The study findings also showed that older adults who lived in areas with cracked or broken sidewalks were far less likely to use public transit, which may amplify other known barriers to transit use, including malfunctioning elevators at underground or elevated train stations.

“Disruptions to public transportation may widen health care disparities for Black and Hispanic older adults who are more likely to rely on these services,” said Mark T. Gladwin, MD, vice president for Medical Affairs at the University of Maryland, Baltimore. “We have an imperative to invest in transportation infrastructure because it is a vital public health need for our most vulnerable populations in Baltimore and beyond.”

Addressing the infrastructure needs of the United States is a long-term endeavor that will require costly investments.

Currently, ridesharing services have risen in popularity in an effort to remove transportation as a barrier to care, especially for those who cannot access public transit.

Earlier this year, [CVS Health partnered with Uber Health to provide transportation support to patients seeking access](#) to medical care, work, or an educational program.

Additionally, in 2021, [Lyft launched non-emergency medical transport arms](#), Lyft Pass for Healthcare. The program lets patients schedule their own rides, which is helpful when patients have medical needs they didn't expect.

“Transportation, where we focus our day-to-day here at Lyft, is unto itself a social determinant of health, but it's also a conduit to others, it's all interrelated,” Buck Poropatich, the head of Lyft Healthcare, [said during an Xtelligent Healthcare Media's Social Determinants of Health Virtual Event](#), which was separate from the Lyft Pass for Healthcare announcement.

“And a lack of transportation is going to amplify things like food insecurity, social isolation, unemployment, et cetera,” he added. “So, transportation cannot be an afterthought; it has got to be a starting point for these conversations if you're going to think about holistically, solving or addressing some of these gaps and some of these needs.”