



# HIV & Aging in Upstate Rural New York State

Findings from

**R**esearch on

**O**lder

**A**dults with

**H**IV

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## **Acknowledgements**

This research effort would not have been possible without the efforts and support of many.

First, we thank the nearly 200 older adults with HIV who took the time to complete the ROAH 2.0 Survey or participated as respondents for the qualitative part of ROAH 2.0. The information that is derived from the ROAH 2.0 effort reflects their too often unheard voices.

Our thanks to Liz Seidel who managed the recruitment challenge in non-urban and rural areas of upper New York State and led the focus group effort.

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## The ACRIA Center on Aging & HIV at GMHC

The ACRIA Center on HIV and Aging seeks to address the unique needs and challenges that older adults living with HIV face as they age. ACRIA's seminal 2006 Research on Older Adults with HIV (ROAH) Study established ACRIA as a leader in research on HIV and aging. The 2016 study ROAH 2.0 was guided by Co-Principal Investigators Stephen Karpiak PhD and Mark Brennan-Ing PhD.

The Center conducts qualitative and quantitative research to create an evidence base to advance the formulation of policy, advocacy, and program development. Through research, education, and advocacy, the Center fosters the open exchange and dissemination of information from scientific communities to AIDS service providers and older adults living with HIV. In 2017 ACRIA entered into a strategic partnership with GMHC, the world's first HIV/AIDS service organization, to create a new and innovative kind of service, research and policy organization.

Summary Reports, and slide sets based on ROAH data will be available at the **National Resource Center on HIV and Aging** ([www.AgingHIV.org](http://www.AgingHIV.org)). Launched in September of 2019 at GMHC, The National Resource Center on HIV and Aging targets the growing populations of older adults living with HIV including Long Term Survivors. The Center's goal is to inform the health choices of these older adults, together with those who provide them with needed supportive services as they age. The vetted information offered by the Center reflects the cumulative expertise of community advisors and staff from across the country. The site is dynamic, providing texts, short videos, sponsored webinars, conference summaries, slide decks, infographics, and the most current research data available. The Center, a program of GMHC, also provides an interactive National Community Map on which users can find supportive programs and conferences happening locally. This effort supports the Resource Center's mission by enhancing interactions that result in programs that meet the needs of older persons living with HIV.

[www.AgingHIV.org](http://www.AgingHIV.org)

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## HIV and Aging: How We Got Here

In the beginning of the AIDS epidemic in the United States, HIV infection was primarily a disease of young adults. By 1993, AIDS was among the top ten causes of death in the United States. In the first year of this decade (2020), HIV remains a serious disease. However, unlike the first decade of the epidemic, today a HIV diagnosis is no longer the inevitable, often rapid, death sentence it once was. This reversal is a result of the extraordinary advances in HIV treatment. Today there are over 2 dozen Anti-Retroviral Therapy (ART) drugs available, many of which offer once a day dosing with few if any side effects. When ART is taken daily the medication effectively blocks the HIV virus from causing the collapse of the immune system (AIDS). While HIV continues to affect people of all ages, the US HIV epidemic is dominated by older adults living with HIV. Estimates based on Center for Disease Control (CDC) Surveillance Reports show that in 2018 over half of the estimated 1.2-1.3 million people infected with HIV in the US were age 50 and older [1].

In every community across the US the number of older adults living with HIV is increasing annually. In some communities that percent is now approaching 65-70%. Those increases are in part due to new cases of HIV in older adults but most of today's older adults were diagnosed with HIV 10-30 years ago. Among the older adult population are those termed Long-Term Survivors. Many Long-Term Survivors were diagnosed with HIV before 1996 when ART became near universally available in the US. These Long-Term Survivors lived through the first decade of the AIDS epidemic and may bear the marks of enduring that harsh era. Regardless of when they were infected, all people aging with HIV are coping with dual challenges: the stresses of growing older along with the challenges of living with HIV. There are likely interactions between the bio-molecular changes that occur due to HIV infection and its treatment, with the biological processes that underlie aging processes. These interactions are complex with no significant interaction identified to date. Aging remains a heterogeneous process that varies often significantly from one individual to another individual. We know that those illnesses associated with aging are associated with certain risk factors. These risk factors exist independent of HIV

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infection. They include substance use, especially smoking and intravenous drug use, poor diet, lack of physical exercise, sedentary life style, stressors associated with mental health disorders as well as the stress of racism, sexual minority status, sexism, ageism and lack of access to health care as well as social supports. These risk factors often characterize older adults living with HIV. Consequently, HIV infection is not the sole determinant of the aging arc of those living with the virus. Data in New York State shows that over 95% of older adults with HIV achieve viral suppression. That is, they are receiving the optimal treatment available for HIV. Therefore, the data provided in this report mainly reflects individuals with viral suppression [2].

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## The Genesis of the ROAH Project

The genesis of this project can be traced to 2005 when ACRIA (AIDS Community Research Initiative of America), recognizing the surging numbers of older adults living with HIV and the distinctive nature of their situation, created the original Research on Older Adults with HIV (ROAH) study. The initial study, a groundbreaking look at nearly 1,000 older adults with HIV in New York City, provided a broad overview of the participants' social, psychological, and health status. A data-based book was published [3], as well as almost 30 peer-reviewed publications, multiple book chapters, and a myriad of abstracts and presentations. ROAH offered insights on the social connectedness, poverty, sexual behavior, substance use, HIV stigma and disclosure, spirituality, service utilization, and unmet needs of HIV-positive older adults. The study documented troublingly high rates of isolation and depression, and it showed that the older adults with HIV are experiencing a heavy burden of comorbid health conditions alongside HIV. The ROAH research findings received prominent international news coverage, became the impetus for the development of the largest sustained training and prevention programs on older adults with HIV in the United States (*Age Is Not A Condom*), caused the formation of an NIH Study Group on HIV and Aging, the White House Conference on HIV and Aging, spurred the development of a web site offering guidance on the clinical management of older adults with HIV ([www.HIV-AGE.org](http://www.HIV-AGE.org)), caused special sessions before the US Senate and House, caused the formation of an NIH Work Group, and inspired similar research projects nationally and internationally. More recently in 2019, there was a launch of a National Resource Center on Aging and HIV targeting the older adult with HIV ([www.AgingHIV.org](http://www.AgingHIV.org)).

In 2015, a decade after the first ROAH effort, ACRIA researchers realized that an updated look at older adults with HIV was needed, as the growth in that population of older adults continues. In 2015 they inaugurated a successor study, the Research on Older Adults with HIV 2.0 Study

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(or ROAH 2.0). That effort was a multiple site research study across the United States (San Francisco, Oakland/Alameda County, Chicago, New York City and Upstate New York).

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## Upstate New York

### *The HIV Epidemic in Upstate New York: Rural Areas*

The last complete year (2018) of HIV surveillance data (NYS, 2019) shows that there were 106,683 people living with HIV in New York. In 2007, 27.3% lived outside of New York City, and in 2018, that percent was 22.1 %. In 2007, 29.5% were women and in 2018, that percent was 28.4 % [2] .

To assess the needs of those older adults living with HIV in New York State’s rural and small urban communities, the ROAH 2.0 team recruited study participants from that region described as Upstate New York. That area is the portion of New York State north of the NYC Metro Area. Upstate NY excludes New York City and Long Island (Nassau and Suffolk counties, and all of Westchester County). Consequently, Upper New York State includes the most rural areas of the state and smaller urban cities (Albany, Schenectady, Utica, Binghamton, Syracuse, Rochester, and Buffalo).

In 2018 in Upper New York State there were almost 14,700 people living with HIV. Of these just over 8,000 were age 50 and older. This was the “pool” from which the study recruited participants [2].

There are no systematic studies of the needs of the at-risk older adult populations and those older adults living with HIV in Upstate New York. Gaps in care have been described in one study of Upstate New York that occurred in 2013 [4]. Participants identified barriers to care including travel distances and the lack of adequate transportation services, hours of operation, and service site locations. These are perceived as barriers. Other people living with HIV/AIDS (PLWHA) who reside in the New York State Finger Lakes Region reported a lack of service providers who accept The AIDS Drug Assistance Program (ADAP) or Medicaid, especially for mental health, dental services, and substance use treatment. Participants from the Western New York State region described the impact of illegal drug dealing. This was especially true in

the Buffalo area. These PLWHA participants also described service shortfalls that result in extensive waiting periods for critical services[4]. There were reports of lack of physician knowledge regarding hepatitis C treatment and care. This may reflect inadequate

	<b>Number living with HIV in NYS excluding NYC and those incarcerated and Westchester/Nassau/Suffolk counties [2]</b>
<i>All ages</i>	14,676
<i>50 and older</i>	8,072
<i>50-59</i>	4,696
<i>60 and older</i>	3,375

reimbursement rates which contribute to the barriers to hepatitis C services. That study also reported a shortage of addiction specialists, psychiatrists, and their associated support services.

The Focus Group data from ROAH 2.0 provides a very powerful insight

into the status of those living in rural New York State (See Appendix A).

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## Executive Summary

The data collected in this research project examined an array of health-related challenges faced on a daily basis by the older adults living with HIV in Upstate New York. The sample of 186 participants can be characterized as older adults living with HIV from rural and small urban areas of the state. Findings of this report are based on the ROAH 2.0 survey (supra). This study cohort reflects the socio-demographic characteristics of the New York State population of people living with HIV. Most participants were cisgender (i.e., not transgender) African American Black or non-Hispanic White males. A majority of the sample had higher than a high-school education.

Excellent or good health was self-reported by the majority of the sample. At the same time, only a quarter of participants confronts less than three coexisting medical conditions in the past year. More than half of participants experienced depression and anxiety. Those individuals primarily received help for depression from outpatient care or private practice, including psychiatrists or counselors. Nonetheless, the outcomes of the measure of depression symptoms in the last two weeks (i.e., the PHQ-9) indicate that over 44% of the sample should be currently receiving help for depressive symptoms. Other common medical conditions were chronic pain, arthritis, fatigue, asthma, diabetes, cognitive problems such as with thinking or remembering, and PTSD symptoms. Participants also face chronic bodily pain which impacts daily functioning.

Sexual health is an important part of life for most participants. Over half of the respondents report being sexually active in the past year. Condom use depends on the type of intercourse and is mostly reported for vaginal sex. STDs were found in 18% of participants, and included mainly Herpes and HPV.

Almost all participants are taking HIV medications. An average of 10 pills per day typically include 3 or more HIV medications, 6 other prescribed pills and 1 over-the-counter not prescribed pill. Majority of participants visit doctors for HIV-related issues three or more times a year and another two or more times per year for non HIV-related issues.

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Physical and mental health-related issues interfere with a wide spectrum of functions, from daily tasks and social activities to work life. Over half of the participants report at least one daily activity to be challenging, for example completing housework or getting to places outside walking distance. When seeking help, they typically look for, among others, personal or family counseling, someone to socialize with, someone to help them get what they are entitled to or aid with home repairs. Participants mostly reached out to Social Security Services, AIDS Service Organizations, and Community Based Organization (CBO) Services for transportation, meal or nutrition aid, self-help group meetings, legal services and peer counseling. Medicaid or Medicare benefits covered a majority of the participants.

However, receiving service poses a challenge in itself. It seems that barriers primarily include lack of knowledge as to where to get the service or transportation to receive it, service cost, application process, and wait times.

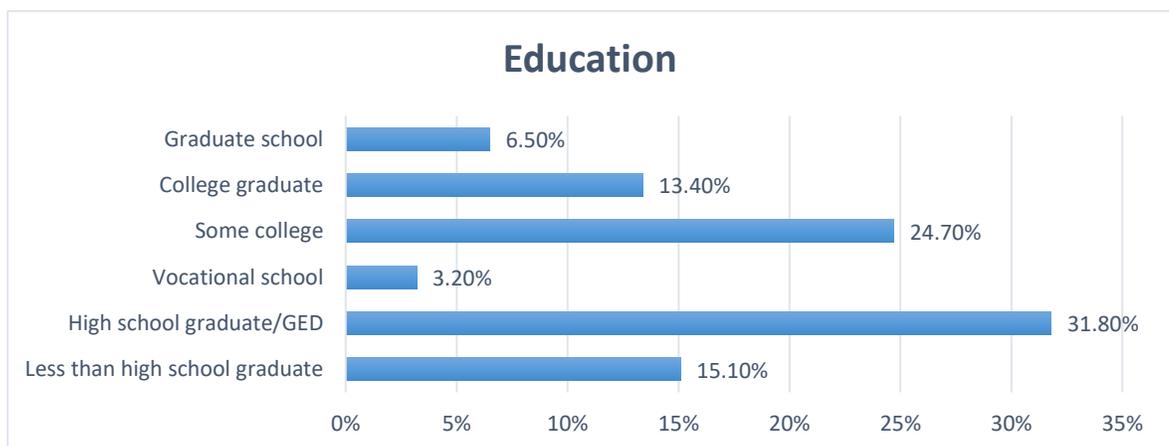
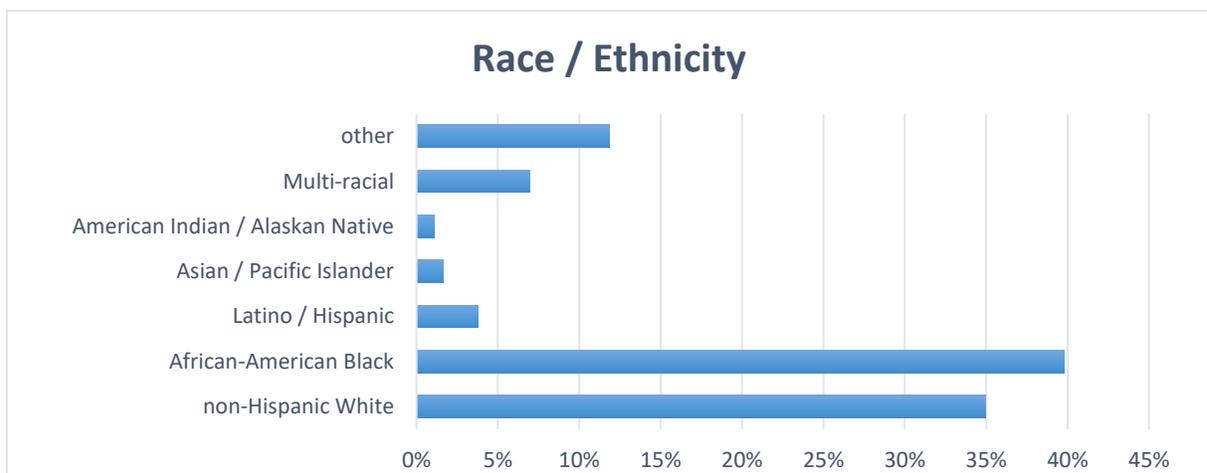
Appendix A summarizes the focus group part of this research effort. It is a very insightful qualitative data that reflects the quantitative ROAH data. But it also illustrates the challenges of transportation, limited choice regards clinical providers as well as supportive services. Living in smaller communities places an increase in the burden of keeping one's serostatus private. The participants repeatedly alluded to their concerns about confidentiality and fear of community reaction.

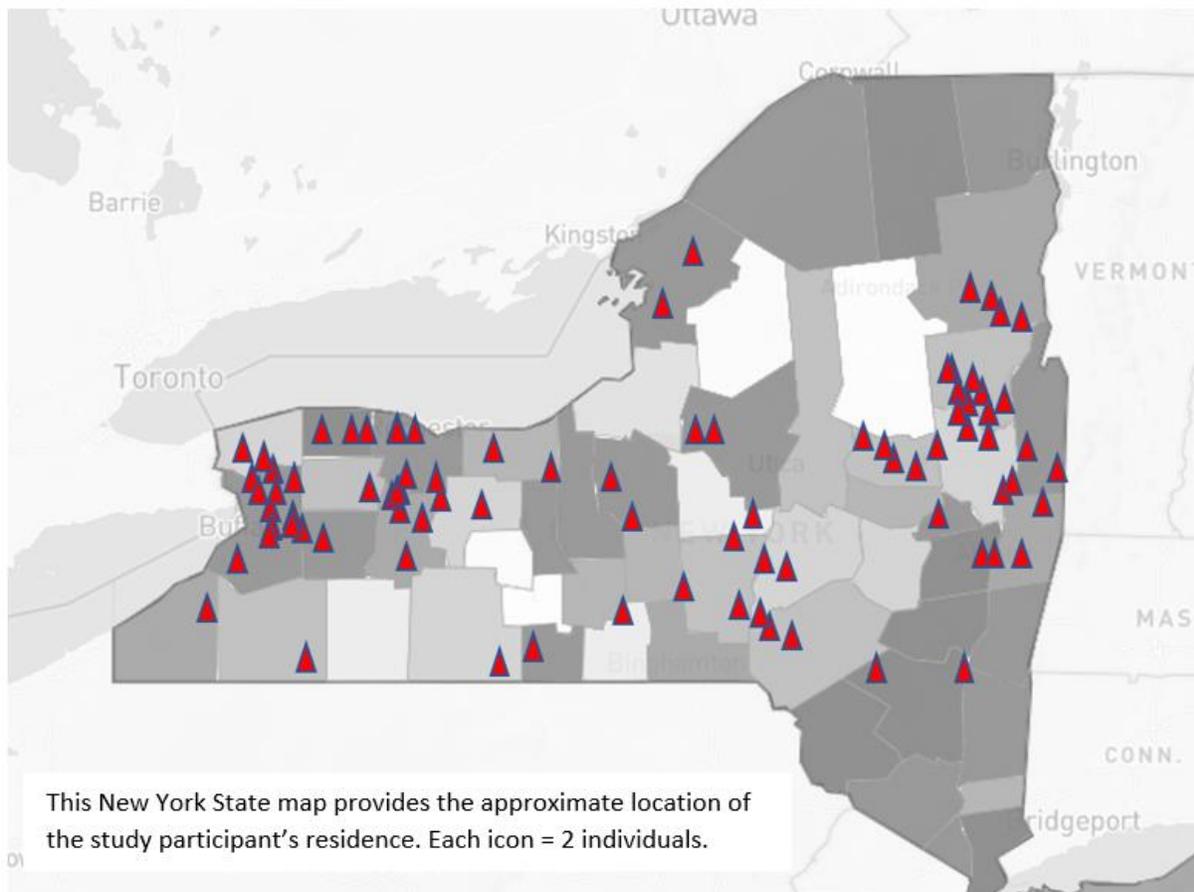
# A Portrait of the Participants

This report is based on survey data collected from 181 older adults living with HIV in Upstate

	Sex at Birth	Transgender	Total
Male	117	2	117
Female	64	0	64

New York. Only individuals ages 50 and older were included according to the ROAH





2.0 research project design. One third of Upstate New York respondents were between 60 and 82 years old.

The gender ratio of participants was about 1:2 (women to men) reflecting New York State trends where 28% of the total population of people living with HIV in 2018 were women [2]. Almost 53% were diagnosed with HIV/AIDS before 1996 [2].

Over 90% of study participants were born in the US. The majority identified as either African American Black (40% of respondents) or non-Hispanic White (35%).

Hispanic individuals made up only 4% of participants. Thus, this group is under-represented in the current study. New York State data shows that 25% of people living with HIV in NYS in 2018 were Hispanic, 28% were African American Black, and almost 32% were Caucasian White non-Hispanic [2].

Years since diagnosis	
5 or less	3.80%
6-10	5.40%
11-15	10.80%
16+	75.30%

Educational attainment was similar to that of the general US population ages 45 or older. Only 15% of participants reported that they did not graduate from high school. Most participants held high school diplomas (32%), some college (25%) or higher degree (20%).

The majority (77%) of participants were not partnered - single, not married, divorced, separated, or widowed. Living alone was reported by 61% of individuals. Living alone and not being partnered places this population at an elevated risk for less than optimal health outcomes as the age [5, 6]. This reinforces research which shows that this older adult population have poor social networks [6-8].



Consequently, many have high rates of emotional loneliness which is related to increased risk for all-cause mortality [9-12].

In total, 68% of participants rented an apartment or house and did not own their property. Approximately 5% reported that they did not have permanent housing. About 40% of the participants received no form of housing assistance while 28% received help from Section 8 (HUD), 12% from HOPWA, and 8% from other sources.

Many individuals were on disability but 10% had full-time work and 11% had part-time work. Of those who were not working, 61% indicated that they would like to be employed and 35% of them were looking for help to find a job. However, only 22% received help finding a job in the past year. Many obtained help from community-based services that assist people with HIV/AIDS with employment and training. The top four reasons for not working were: 1) health limitations, 2) concerned about losing benefits, 3)

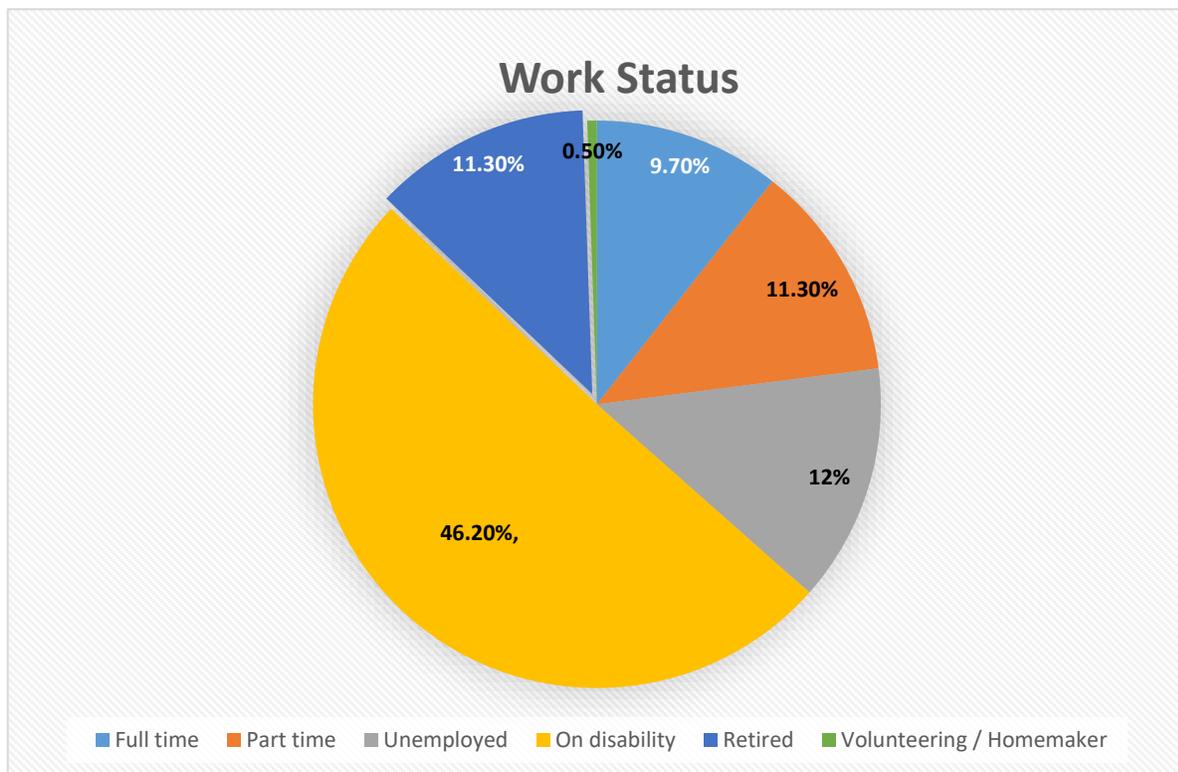
**Food Security**

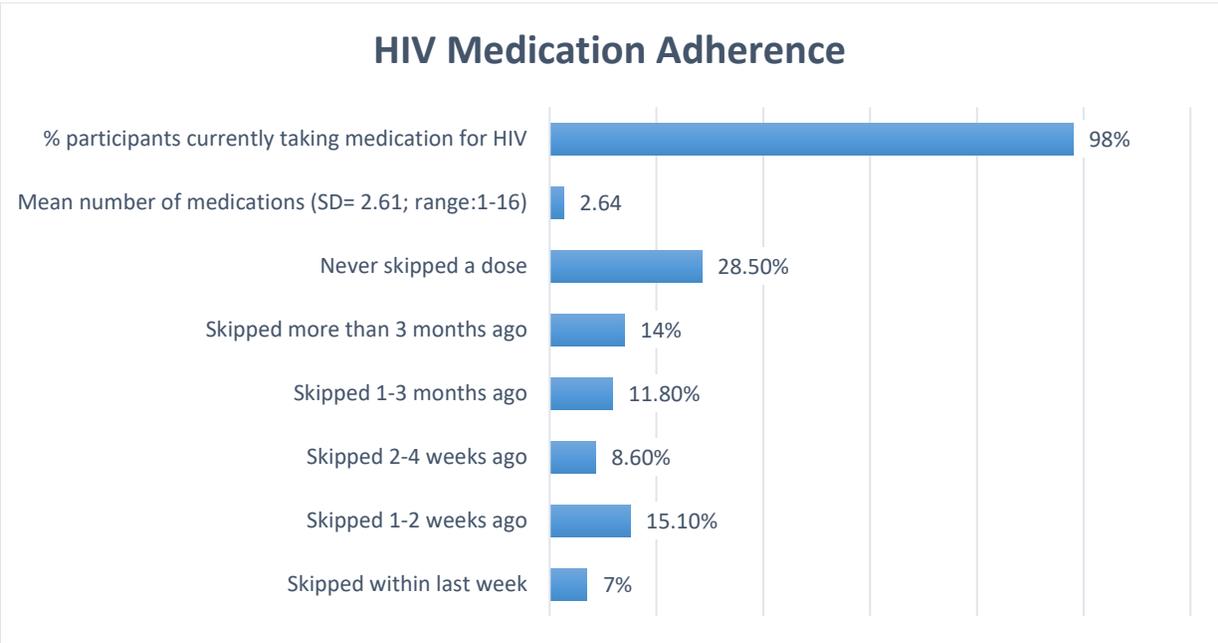
- 60% were Food Secure
- 12.4% were Food Insecure without hunger
- 23.10% were Food Insecure with hunger

unable to find work, and 4) employers refuse to hire older age workers.

Their income insufficiency is further apparent as 23% of participants stated that they did not have enough money for food. Taken together, older adults living with HIV experience an inordinate level of stress and burden related to insufficient funds for basic needs such as housing or food.

Participants reported an average of 23 years living with HIV. Of note, 88% reported 10 years or longer since diagnosis. At the same time, over half (53%) of participants were diagnosed before the introduction of anti-retroviral therapy (ART) in 1996. Half of the participants believe they were infected through anal sex, another 34.4% through vaginal sex, followed by 17.2% by sharing needles. Almost 42% of the individuals indicated that they had been diagnosed with AIDS at some point in their lives. Currently, 88% of participants reported undetectable viral loads and 65% had CD4 counts checked within the past 3 months.



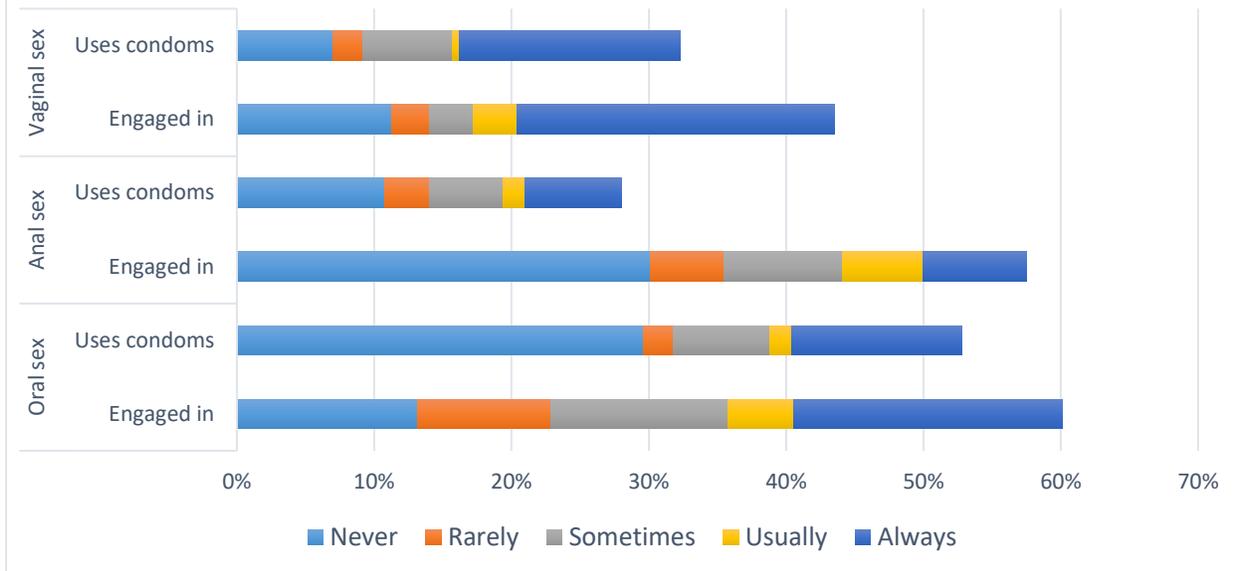


Almost all (98%) participants are taking HIV medications. The persons in this study on average take 10 pills daily. Those include 3 pills for HIV, another 6 prescribed pills for other medical conditions, and 1 over the counter not prescribed pill. In total, the number of pills taken each day varies between 1 and 26 for each study participant.

*Sexual Health*

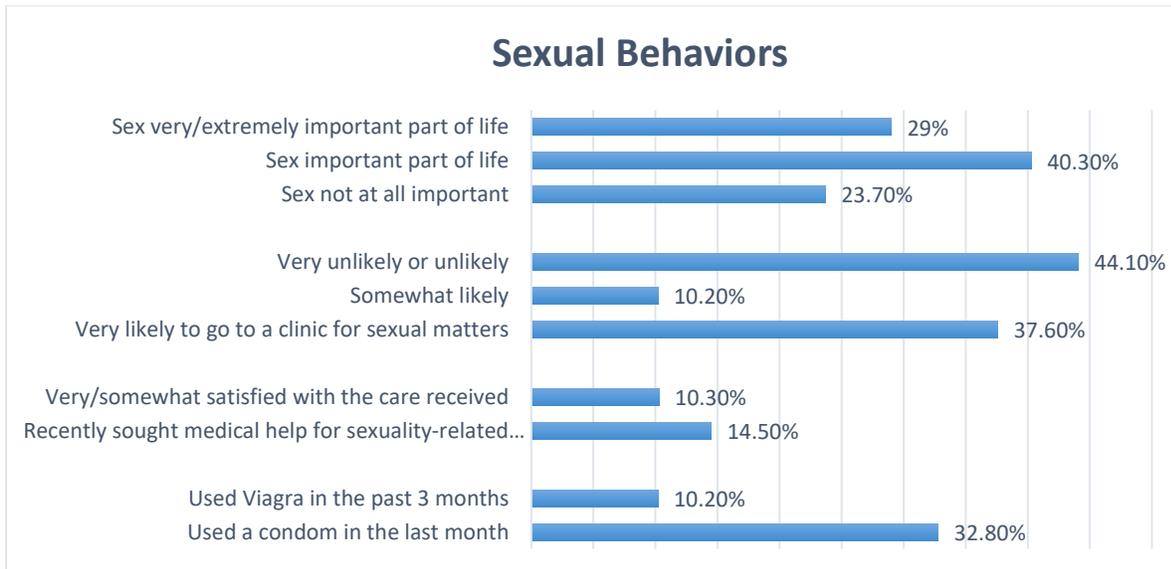
The myth that older adults refrain from engaging in sexual activity is not supported by this study. Most of the participants (58%) reported being sexually active in the past year. Thirty-seven percent of all participants had sex in the past month. Among those who had sex in the past year, 33% said they had sex once a month or less often. Participants most often engage in oral sex, followed by vaginal and anal sex. Condoms are more likely used for vaginal sex, with (16% reporting always using a condom) than oral sex (12%) or anal sex (7%).

## Sex and Condom Use in the Past-Year Sex

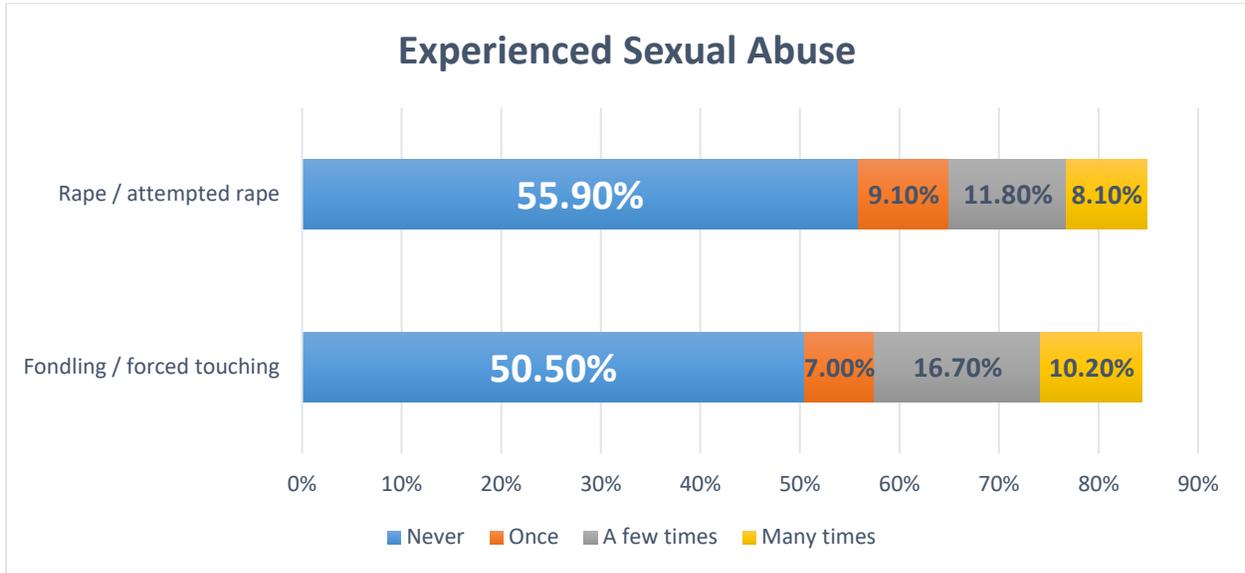


Sexual behavior data shows that sex is viewed as not an important part of life by near 24%. Over 44% said they would not seek help from a clinic for sexual health matters. Just over 14% recently sought help from a clinic, but only 10% were very or somewhat satisfied with the care they received.

## Sexual Behaviors



One in every three participants experienced sexual abuse in a form of rape or attempted rape, or, fondling and forced touching. These latter two were more common. This data supports the high rates of PTSD found in the study [12] (See Mental Health Section).



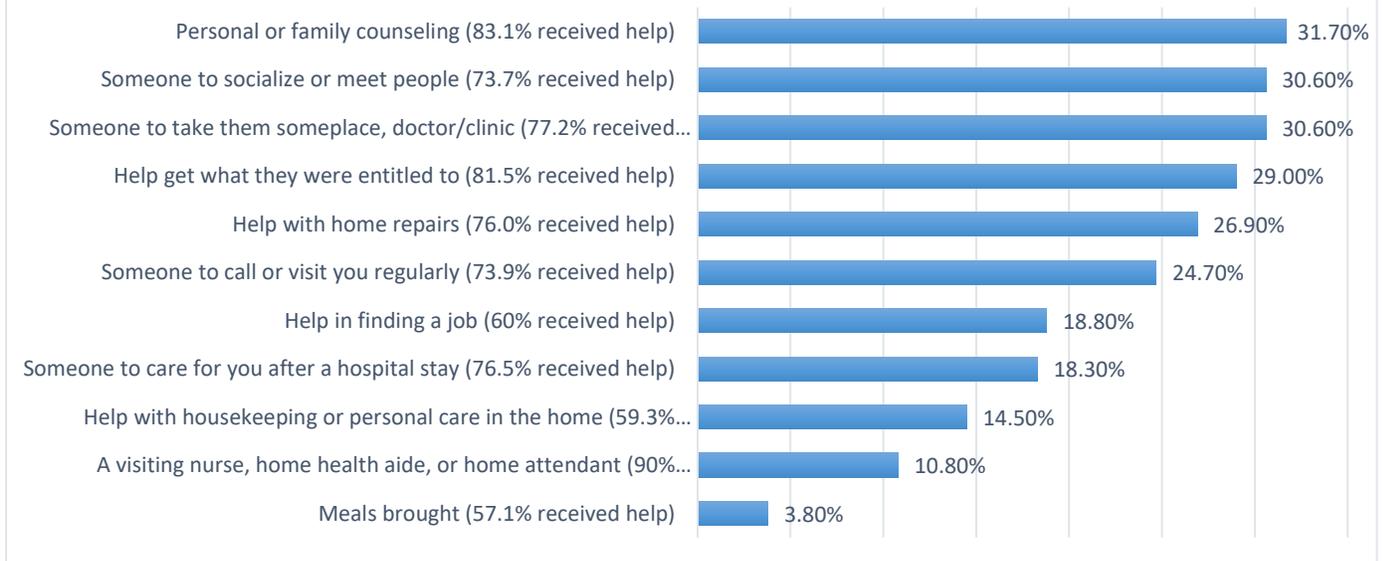
## Service Use, Needs, and Challenges

ROAH 2.0 focused on the use of those non-clinical services which are shown to be critical to achieve optimal health as one ages. These services are often referred to as “wrap around services”. These community-based services are also the first to be reduced during financial short-falls. They are often based in community organizations including ASOs as well as government entities. The literature and surveys data show that for many these services may exist but the patient is not aware of them. This is even true of the Case Managers for people with HIV[13]. This lack of awareness can be traced to the fact that all involved are not familiar with the large panoply of services that are associated with and target older adults [14].

Challenges to daily living are pronounced in the majority (52%) of our sample of older adults living with HIV in Upstate NY. On average, participants reported facing difficulties in 2 out of 13 Activities of Daily Living (ADL). Trouble completing housework is the most common ADL reported by 33% of participants. Also, 30% reported having trouble getting to places outside of walking distance. Furthermore, doing one’s own shopping (22%) and preparing their own meals (17%) were significant challenges in everyday life.

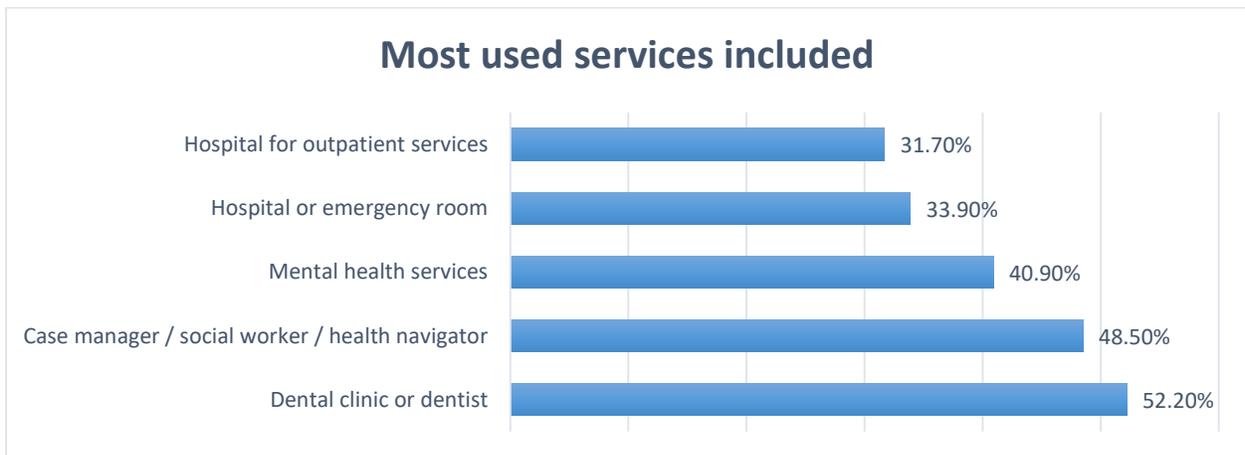
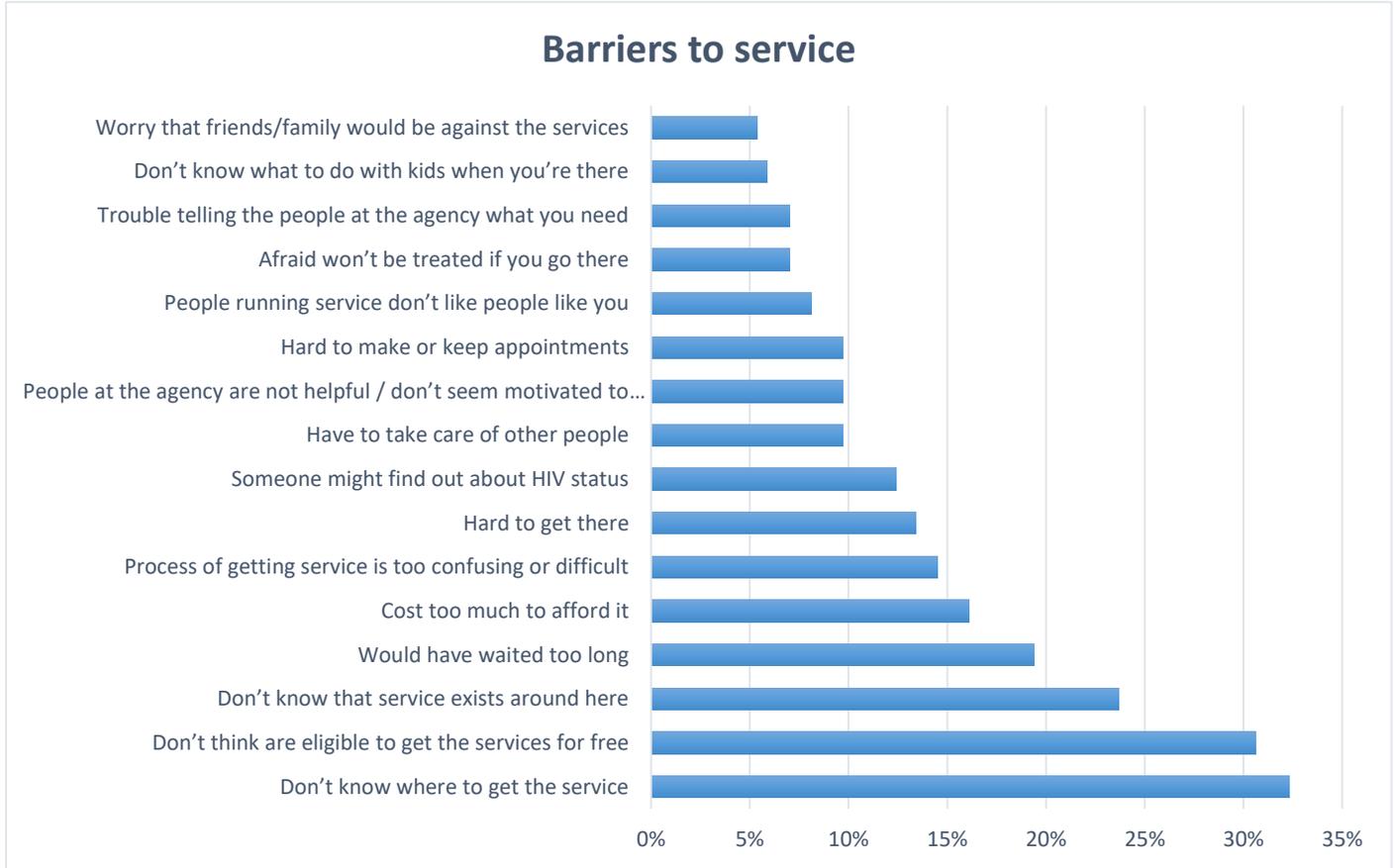


## In the past year participants reported that they mostly needed ...

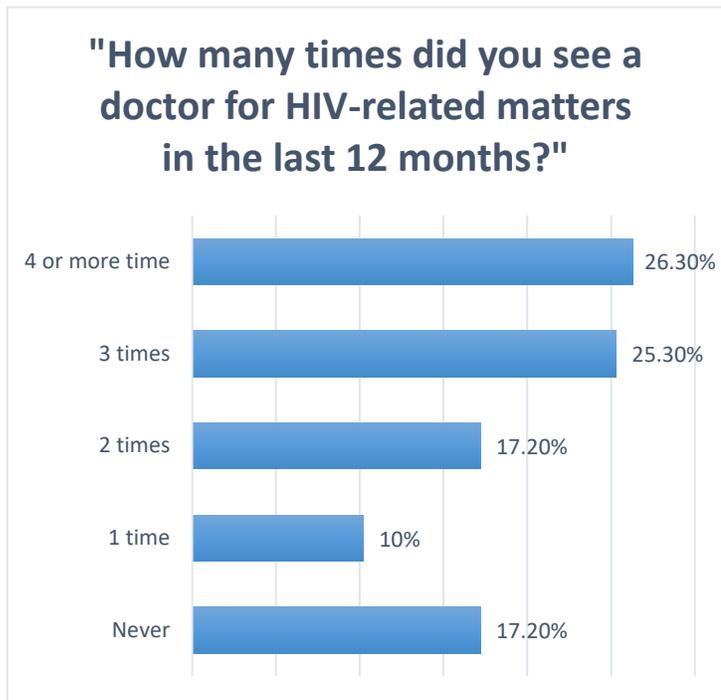


Participants reported that in the past year they needed personal or family counseling (32%), someone to socialize with or to meet people (31%), someone to take them someplace (doctor or clinic) (31%), help getting benefits to which they are entitled (29%), or help with home repairs (27%). Importantly, those who expressed a need, also said that in the majority of cases, the need was addressed. None-the-less, about 25% report that their need was not addressed. Addressing this gap in unmet need may in part require raising awareness about the range of government and community services that are available. In fact, this conclusion is supported by study evidence of barriers to services. One third of participants noted that they do not know where to get the services that they need. Another 31% of the participants do not think they are

eligible to get services without incurring costs. While 24% of participants do not know that the service exists in their immediate community.



Use of dental services/clinics were indicated by 52% of participants. Almost half (49%) of participants said they used services provided by a case manager/social worker/health navigator. Another 41% of individuals indicated that they had reached out for mental health services. Hospital emergency room visits and hospital outpatient services were used by 34% and 32% participants, respectively. A quarter of participants also used community/neighborhood clinics. More than a quarter of participants reported seeing a doctor four or more times a year for HIV-related issues, and another four or more times for non-HIV-related matters.

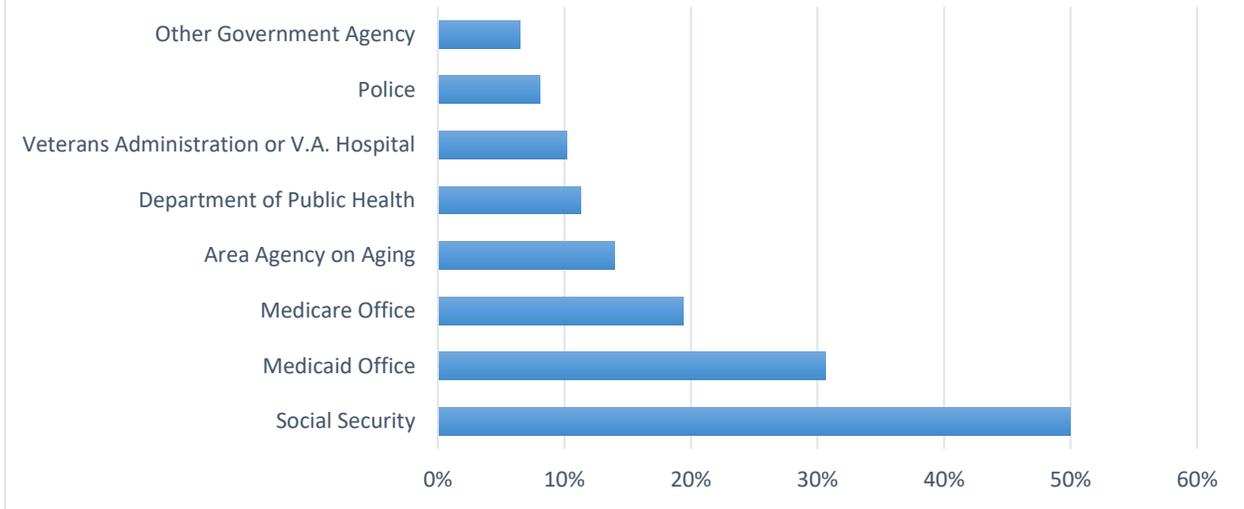


The wide range of services used by these older adults can be further divided into US Government-based services, Community services, and services provided by Community-based organizations. Among government-based services, Social Security services was most prominently accessed (50%). Another

31% of individual received services provided by the Medicaid Office, 19% by Medicare Office and less than 15% by other Government services.

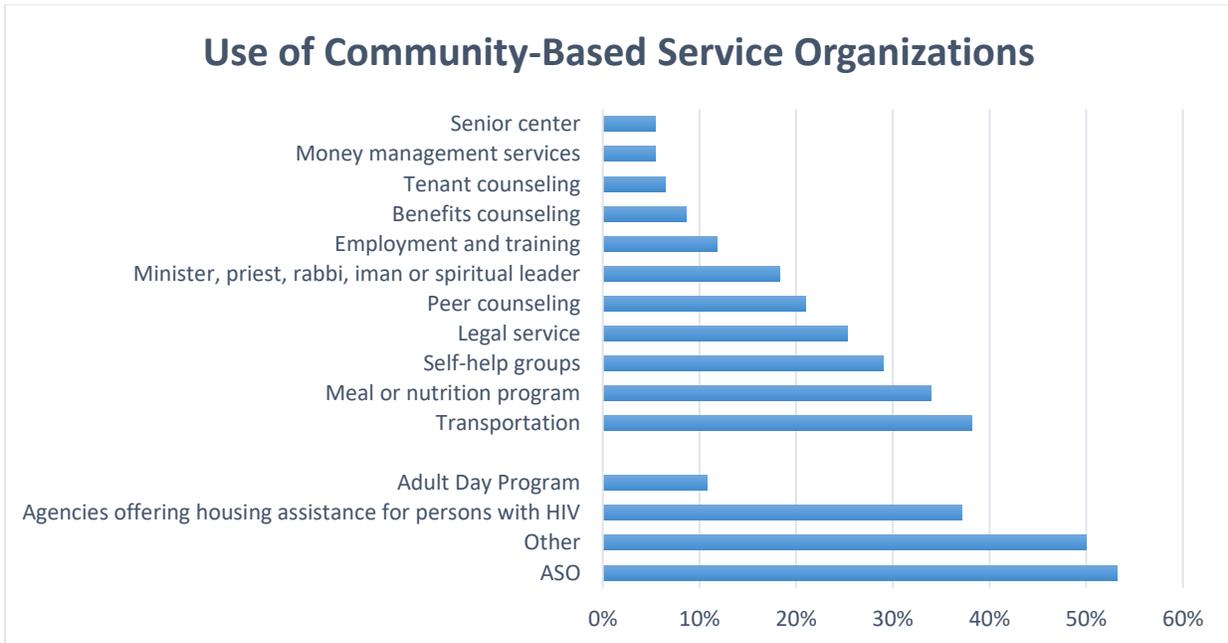
Benefits received were primarily from Medicaid (65% of participants) and Medicare (45%). Almost 40% of individuals received SSDI benefits and another 33% received SSI. This was closely followed by receipt of LINK/SNAP benefits to address previously mentioned food insecurity (29% of the sample).

## Use of Government Services



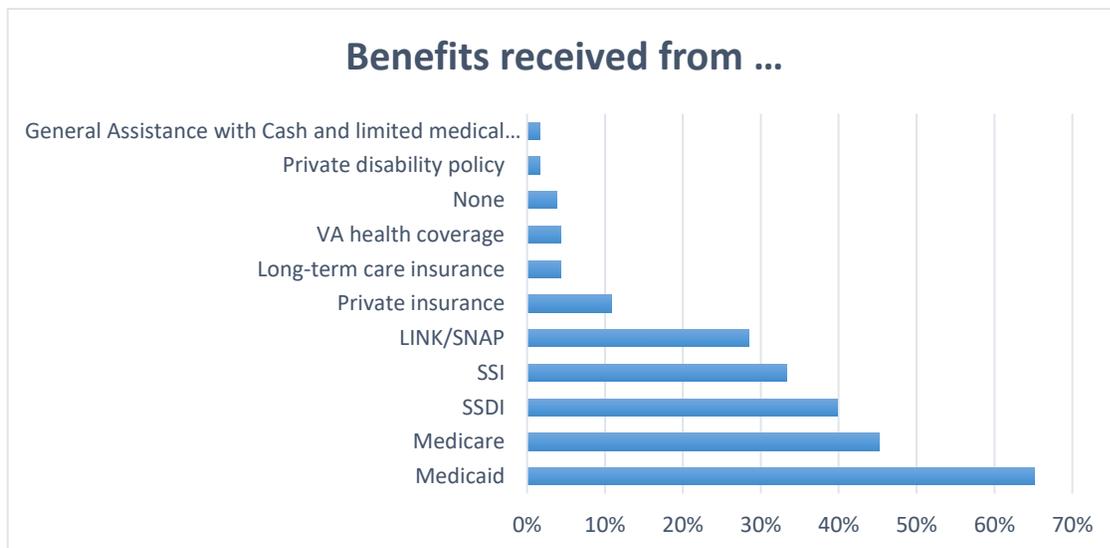
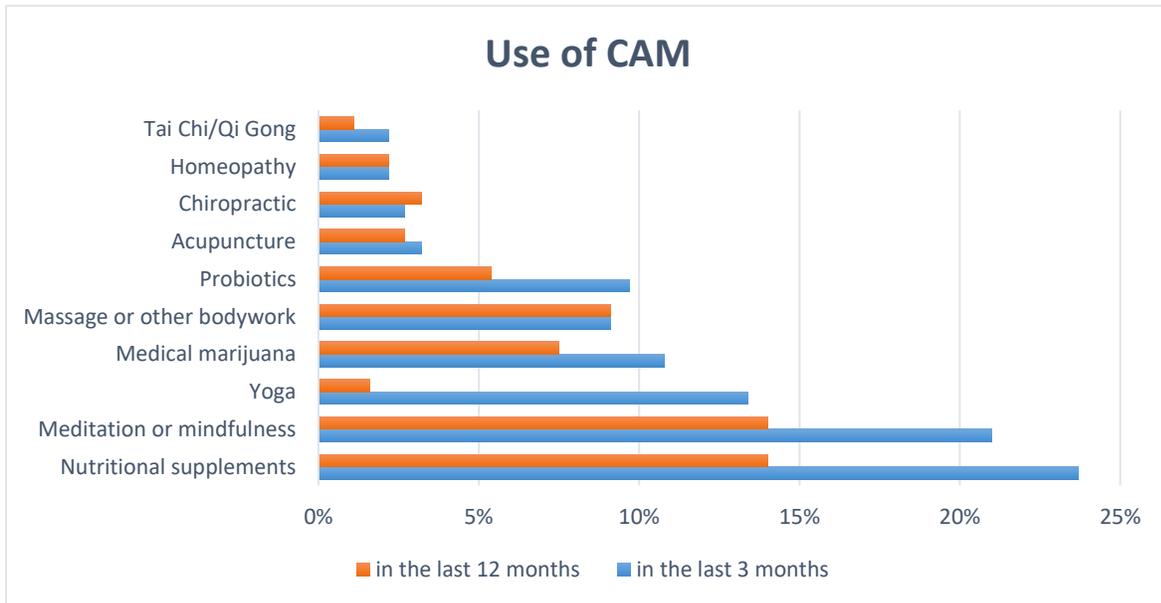
Community services were also accessed by about a half of participants. Those included ASOs (AIDS Service Organizations) (53% participants), other Community Based Organization Services (CBOs) (50%), agencies offering housing assistance for persons with HIV (37%) and Adult Day Programs (11%).

## Use of Community-Based Service Organizations



Participants also utilized transportation (38%) and meal or nutrition programs (34%), attended self-help group meetings (29%), or received help from legal service (25%) and peer counseling (21%).

Less than a quarter of participants reported using complimentary, alternative medicine or holistic therapies (CAM). Of those, the most commonly used were nutritional supplements, and meditation/mindfulness practices.



# Medical Conditions

Self-reported health status is a subjective indicator of health - “Excellent” or “Good” health was reported by 65% of participants. The remainder (35%) reported Fair, Poor, or Very Poor health. Almost 75% of participants had more than three medical conditions. Having two or more chronic conditions is a definition of multimorbidity. Only 25% of participants experienced three or fewer coexisting medical conditions. Almost the entire sample was experiencing multimorbidity (having 2 or more chronic incurable conditions). Multimorbidity rates are the rule and not the exception for this population. Over 2 % in the study sample reported more than 16 comorbid conditions.

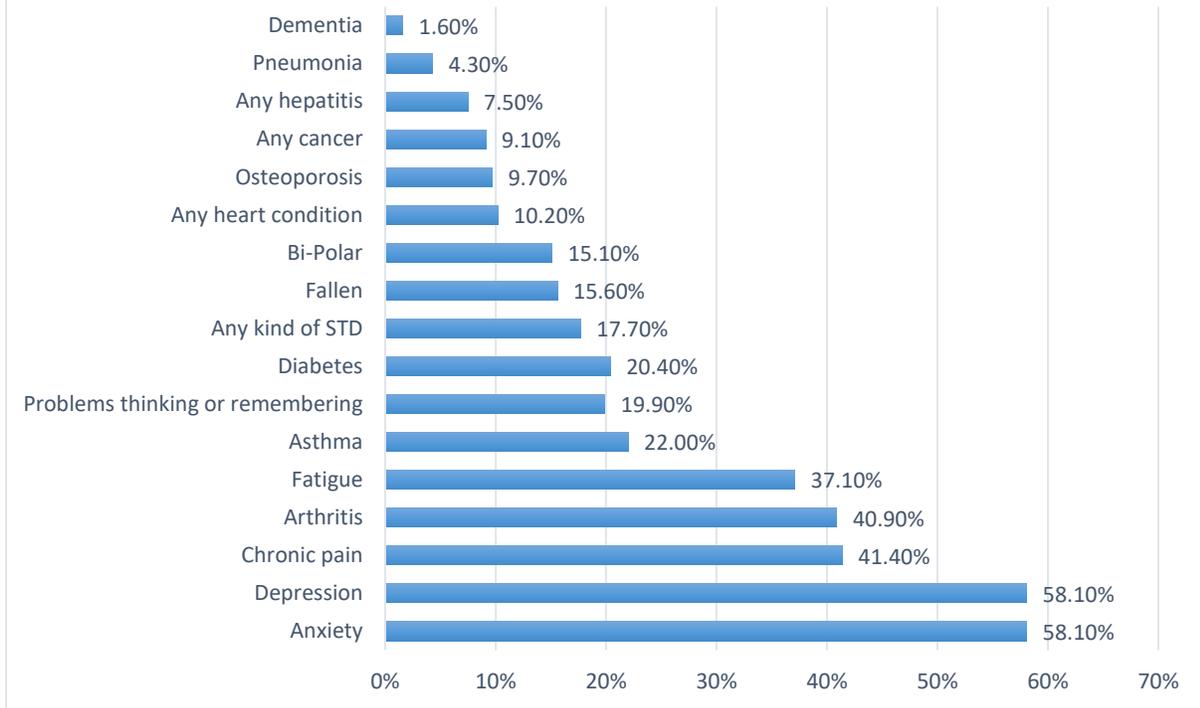
**Percent of participants reported experiencing**

- **anxiety (58%)**
- **depression (58%)**
- **chronic pain (41%)**
- **arthritis (41%)**
- **fatigue (37%)**
- **asthma (22%)**
- **diabetes (20%)**
- **cognitive problems (20%)**

The list of comorbid conditions reported by participants showed that more than half of participants experienced anxiety (58%) or depression (58%). Other common medical conditions were chronic pain (41%), arthritis (41%), fatigue (37%), asthma (22%), diabetes (20%), and “cognitive” problems with thinking or remembering (20%).

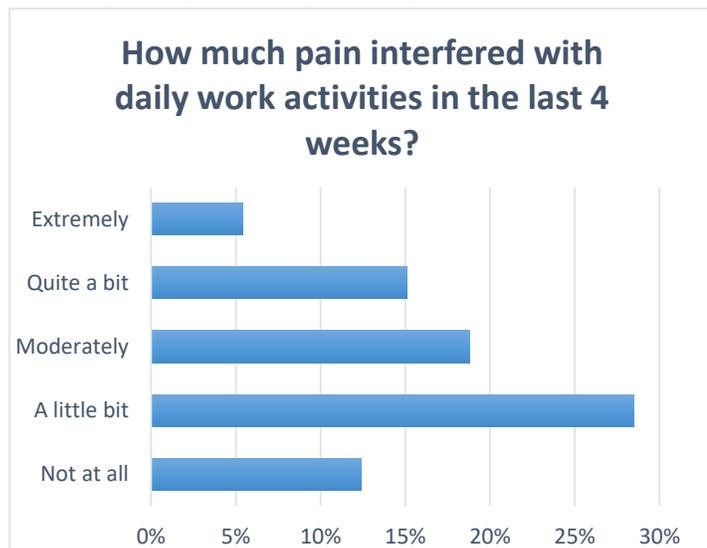
<b>Number of Medical Conditions</b>	<b>Percent of the Sample</b>
<b>0-3</b>	<b>25.3</b>
<b>4-6</b>	<b>30.6</b>
<b>7-9</b>	<b>24.4</b>
<b>10-12</b>	<b>12.4</b>
<b>13-15</b>	<b>5.4</b>
<b>16-25</b>	<b>2.2</b>

### In the last year experienced...



Sexually transmitted diseases (STDs) were reported in 18% of participants. Herpes and HPV were the most common, affecting 8% and 5% of participants respectively.

The intensity of bodily pain in the past four weeks ranged between “mild” and “moderate” in majority of participants. Chronic pain interferes with work life in 68% of the sample and negatively impacts social activities in 56% of participants.



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## Mental Health

Primary depression is estimated to be higher in people living with HIV than among non-infected individuals[15-17]. Unmanaged depression can impact health. For the older adult with HIV this is important since chronic depression has been shown to inhibit immune responsiveness[18-21]. Depression is also associated with increases in inflammation as evidence by elevations in inflammatory markers, such as interleukin 6 and tumor necrosis factor, thereby further increasing risk for disease [22]. Inflammation may be a contributing factor for the onset of depression; chronic inflammation may be an underlying mechanism for the interactions among age, HIV, depression and other comorbid conditions. Often the impact of depression is indirect. For example, depression can adversely affect adherence to ART and other treatments [23, 24].

In older adults living with HIV, there is some plateauing of depressive symptoms with increasing

**Of those participants who owned a pet, 99% indicated that the pet had a positive influence over their mental health, with 94% also pointing to positive effects on their physical health**

age, but they do not achieve the lower levels seen in HIV-negative older adults in the general population. Suicide rates remain. Depression is also related to physical comorbidities, and often depression is correlated positively with the number of medical diseases/conditions [25].

Depressive symptoms are risks for vision and hearing loss, dermatological problems, heart and respiratory conditions, diabetes, impotence and broken bones [26-30].

Medications for anxiety were taken by 48% of the individuals (who reported anxiety in the past year). Of those participants who were diagnosed with depression, 34% indicated taking prescription medications. The majority (82%) of individuals with possible depression as determined by the PHQ-9, receive help from either outpatient care, clinic or private practice. Also, 60% sought help from psychiatrists. Anxiety and depression were reported by 58% of participants, making these the most common health conditions in the study sample. These rates are commensurate with most studies of mental health in all adults living with HIV and specifically in older adults with HIV[21, 31]. The PHQ-9 scale scores which range from 0-27

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Among Participants	
<p><b>59%</b></p> <p>Ever diagnosed with depression by a professional</p>	<p><b>48%</b></p> <p>Report feeling down, depressed or hopeless during the last two weeks</p>

provide a snapshot of the enormity of this problem when screening for depression. Scores of 4 or lower on this scale suggest that professional help may

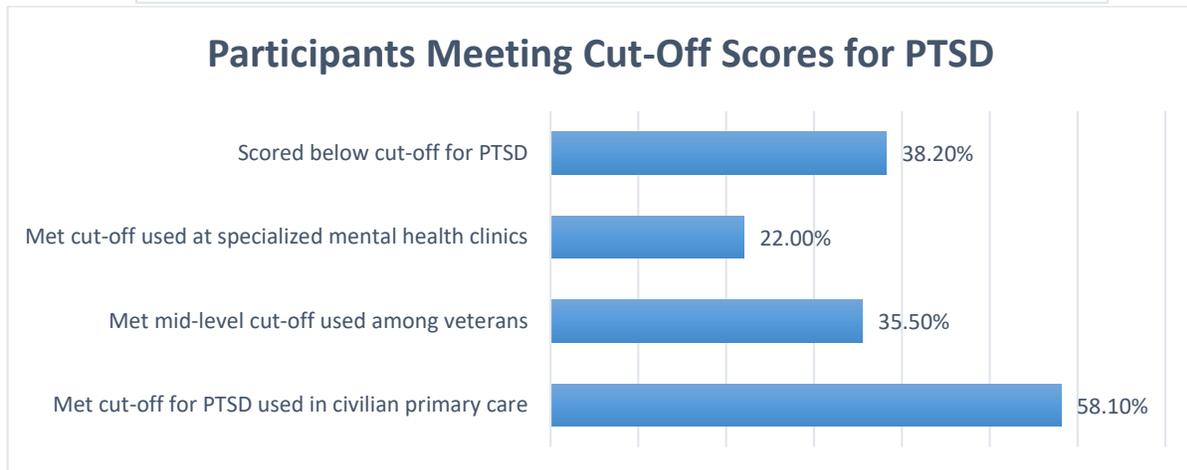
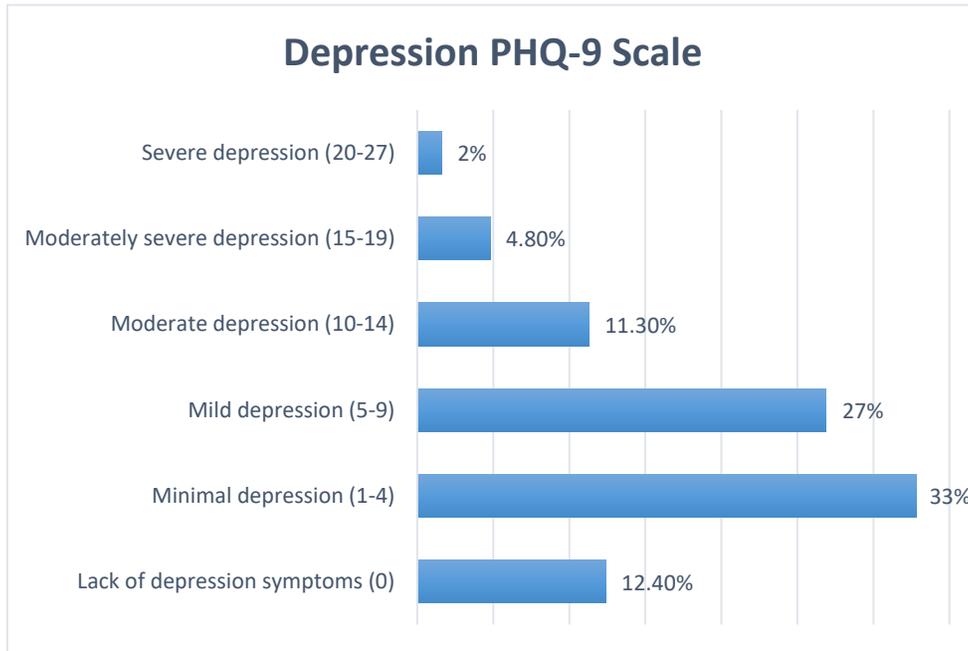
not be currently needed. Scores between 5 and 14 signify the need to monitor the person and repeat the PHQ-9 at next follow-up. Scores greater than 14 imply the immediate need for professional help and treatment [32-34]. Most of these participants should receive a more comprehensive clinical consultation and possibly treatment for their depression. Reports show that with appropriate care these conditions can be managed and/or resolved in people with HIV including older adults with HIV [35].

Study participants did receive care from counselors, 35% psychologists, and 23% social workers. Almost 14% were hospitalized for depression. Less than 1% did not receive any type of help.

Understanding depression involves looking at individual symptoms [36-39]. Participants primarily reported feeling tired or having little energy. This was accompanied by trouble falling or staying asleep or sleeping too much. They further indicated feeling down, depressed or hopeless. More than half of the participants experience those symptoms between several days and almost every day in the past two weeks. The study found that a quarter of the participants had the following symptoms at least several days in the last two weeks: poor appetite or ate too much; trouble concentrating on things; feeling bad about themselves; or little interest or pleasure in doing things.

Trauma poses an additional burden on the mental health and affects everyday living [40-43]. In this study, trauma was assessed with the Post-traumatic stress disorder (PTSD) Checklist (PCL). Scores on PCL range from 17 to 85, with higher scores signifying experiencing more severe levels of trauma. There are several criteria for PCL outcomes. Due to the most conservative

criteria used by specialized mental health clinics, 22% of participants showed significant PTSD symptoms. At the same time, according to more “liberal” criteria, 58% showed PTSD symptoms.



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## Appendix A: Focus Group/Interviews

Understanding the unique needs of older adults with HIV in Upstate New York is essential as over half of people living with HIV in Upstate New York are now age 50 or older. Additionally, most research on this population is focused in large urban centers, which may not reflect challenges unique to populations living in small cities or rural areas. Findings from these interviews were used to tailor the Research on Older Adults with HIV (ROAH) 2.0 survey for Upstate New York. In total, 14 individuals with HIV age 50 or over receiving services in Upstate New York shared their perspectives on HIV and aging.

### **Key findings:**

Participants draw on their personal strengths to cope, including maintaining a positive attitude, and advocating for themselves.

Challenges facing participants included stigma and lack of privacy. Participants related these experiences to living in a small town or rural area.

More than half of participants described transportation barriers that made it difficult to get to services.

While most participants praised their health care providers, a few reported difficulties finding quality providers in their area that take Medicaid or Medicare. Participants encountered difficulties accessing dental and mental health care.

Participants desired more opportunities to socialize, and more programs specific to older adults with HIV.

Participants living in rural areas had privacy concerns and felt it impacted their ability to form relationships.

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## Summary of Identified Themes

The primary themes identified in the fourteen interviews by the research team were:

- 1) Factors facilitating positive aging
- 2) Challenges and unmet needs
- 3) Desired services/changes
- 4) Caregiving

### Factors Facilitating Positive Aging

**Personal strengths:** Nearly all participants said they draw on personal resources as they grow older with HIV. They mentioned optimism, gratitude, resilience, self-advocacy, and a sense of humor as factors that enhance their lives. Several participants talked about adopting a “positive” attitude. One woman attested that her personal strength, modelled after her mother (a “strong lady”), helps her weather personal tribulations. Another woman discussed maintaining her imperturbable spirit despite grieving the recent loss of her husband:

*I have some things I’m dealing with, but instead of sitting around drowning in it, I’m getting on top of it.*

*Self-advocacy was a factor mentioned by three of the participants. For example, one respondent said, “[I] like to have control over my life, no matter what I’ve encountered.” The ability to advocate for one’s self helped participant secure better medical care and social services.*

Others talked about taking things one day at a time and accepting their present situation as it is, “accepting the fact that I have it, there’s nothing I can do about it.” Humor was mentioned by several participants. Another older adult underlined his gratitude about his/her situation, saying, “I’m one of the one lucky ones.”

**Self-care:** When asked what they required to age well with HIV, nearly all participants mentioned positive health behaviors including exercising, eating well, taking prescribed medications consistently, and avoiding excessive drug and alcohol use, as bedrock requirements. Five participants mentioned good nutrition as a prerequisite for positive aging, and several said that a nutritional program offering instructions on diet and how to pay for groceries had been useful to them. Medication adherence was mentioned by three participants. Two said exercise was critical, one commenting that “the more regularly I exercise, the better I feel.” One participant attributed his long survival with HIV, in part, to living a “clean life” since “drugs and alcohol wear your body down a lot faster.”

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**Access to good medical care:** Most participants offered high praise of their health care providers and many noted that rapport with and trust of their health care providers is critical. Once you have a good health care provider, along with effective medications and advanced medical care, “it all falls in place,” one participant said. *Treatment gives a person with HIV back a sense of normalcy,* another participants commented:

*I have no problem aging with HIV. Back then, it was a death sentence. Now it’s just a chronic disease. And it’s treatable. You can keep it under control, you’re just normal like anyone else.*

Several participants said that being active in managing their health conditions (not just complying with doctor’s instructions, taking their pills, and showing up to appointments), was important to their health. Participants described monitoring their own lab reports and seeking doctors who provide quality care and extended appointments. Two long-term survivors of HIV remembered how fortunate they were to see doctors in the mid-1990s who had the confidence to prescribe them with early antiretroviral treatments. One had chosen to switch doctors, from a specialist who couldn’t or wouldn’t prescribe Efavirenz (lamivudine) to a local family doctor who would in order to get access to the medication. Being a “take charge person” has been critical to getting good medical care, he concluded.

**Social support:** Just under half of participants mentioned social support, whether formal or informal, as something that helps them age well with HIV. All but one of the participants who mentioned social support as an element supporting positive aging with HIV were members of a support group for people living with HIV. Some of those who had been helped by support groups regretted that support groups aren’t more pervasive in the region:

*Support groups, which you don’t find a lot of anymore, ... as well as having a partner, has been helpful in keeping me healthy, I believe. Someone else to rely on, helps a lot.*

Partners, family, friends, and fellow hobbyists were also cited as sources of informal support by participants. Several described a robust support system consisting of a variety of different kinds of relationships. For some, the support of family was particularly important:

*My family was willing to accept, didn’t make me feel there was something wrong with me. That they still loved me anyway, that’s what made me able to cope with [having HIV].*

A female participant said that although her social circle doesn’t always respond to her the way she prefers, “*My kids keep me going. My people that I love keep me going.*”

**Meaningful service:** Almost a third of the participants mentioned service to others as a coping method. One participant who works as a peer advocate and mentor to others with HIV described how this work was a healing experience:

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*I cope fairly well. The first ten years, I was definitely in denial, but I started working in the field and got a better perspective on it... Changing just one person's life, which I've done already, if I don't do anything else, that's a great thing for me.*

A woman whose husband recently died reported that her outreach work with people with HIV and at risk of HIV, along with studying the bible and attending church services, has been useful to her as she grieves.

For one older adult the information he's learned in the course of working with people with HIV, hepatitis C, and addiction has helped him personally and as well as enabling him to be a better resource to others:

*The more knowledge you have, the better off you are, and the more you can share with your community. ... And volunteering is very useful, giving back to somebody else.*

## Challenges and Unmet Needs

**Stigma, discrimination and lack of privacy:** Stigma was mentioned as a challenge by the majority of participants. One man described barriers to receiving services which were largely fueled by inherent HIV/AIDS stigma:

*I don't tell everybody. I'm still holding that secret all the time. ... Sometimes people notice me, that I have it. They notice I'm HIV. .... It kind of hinders me, in a sense, from just being myself. Because not everyone is accepting. They say they're accepting, but that's just saying.*

Many related their experiences of stigma, discrimination, and disrespect for privacy to living in a rural or small-town setting. One person recalled that he had already faced ostracism in his small town as a boy and young man because he was effeminate and known to be gay. He chose to keep his HIV status a secret to avoid being further isolated, but a close friend who was also HIV positive revealed that the participant was positive to a few family members:

*I knew it would change my life. I was really angry. ... I live in a town of 3,000 with a very small school system and a small community. I'm sure it was known in a matter of days or weeks. Things aren't the same for me now.*

Now, this man says, he doesn't interact "with only but a few people." Another said he felt concern that people his age might be biased against or hold ignorant beliefs about people with HIV. He recounted how worried he felt about the potential judgment of older church members:

*If someone found out, some of the old folks, you know – I was out there helping prepare food – what would they say? That's the only scary part about having HIV, other people not understanding the disease. ... Growing older, you wonder if your peers of the same age understand. You don't know who understands and who doesn't.*

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In addition to compromising their capacity to relate to others socially, thereby contributing to the community, several said that concerns about stigma, discrimination and lack of privacy have interfered with their ability to trust and access services and health care. One older adult explained that her status hinders access to social services:

*I don't feel comfortable with county social services. ... We live in a county where everyone knows everyone. And even though it's supposed to be confidential and everyone's trained for it, that's just not the reality.*

Internalized stigma by health care providers together with failures of confidentiality, was cited as why some participants were unable to access health care. A husband/wife pair reported that an orthopedist refused them treatment out of fear that caring for a person with HIV could be risky to the health of the provider.

**Transportation difficulties and distance:** Over half of the participants said their distance from local services and care or difficulty with transportation causes difficulties, and several described transportation as their foremost struggle. Travel time to HIV care and service providers they said, is often lengthy – often over an hour's drive one way. One participant explained that a local AIDS service organization's faraway flagship location offered more services to clients than a local branch. *"It would be more beneficial if they had these services here,"* she commented. In some cases, the distances to the nearest AIDS service organization from the most rural areas are so lengthy that the services are effectively unavailable. *"Out here in the middle of nowhere, there's no services,"* one person commented. *"The only services out here are Medicaid. And that's it. They don't have no HIV or AIDS organizations or nothing out here."*

Some participants reported receiving transportation assistance, mostly assistance getting to medical appointments. One person said the medical transportation service she receives "work wonderful." Several car owners said they receive gas cards from a local AIDS service organization. However, an Albany area resident was highly dissatisfied with the local medical transportation and the bus service he uses. He reported that the medical vans in his area are often used by more riders than they are designed to accommodate and frequently run late. Five times he's missed medical appointments due to the van's tardiness, he reported. Furthermore, he reported struggling to use and pay for the Albany area bus system, saying that carting his groceries on the bus at his age is too hard.

Difficulties with transportation are heightened when an individual is ill and socially isolated. A woman who had been receiving treatment for cancer for a year and a half, described the challenges of getting to her frequent medical appointments. Friends were often unable or unwilling to bring her to these appointments and arranging for medical transportation was logistically challenging.

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*I'm not a needy person. I don't like depending on people. But this year-a-half, that was a big traumatic experience. I needed help. People said, 'Oh, I'm going to drive you.' Or 'I'll take you to appointments.' It wasn't like that. That was more stress on me.*

**Difficulty accessing quality medical, dental, and mental health care:** Several of the older adults with HIV in upstate New York interviewed for this project reported difficulties accessing quality care, complicated by reliance on public health coverage and concerns about the quality and confidentiality of medical care in more remote areas.

Some explained that though health care providers willing to serve people with HIV may be closer at hand, they travelled vast distances to reach an HIV care provider who they perceive as experienced, highly skilled, and respectful of their privacy. One woman described seeking “quality” care at a location four to five hours away round-trip, though she must rely on a friend to drive her there. Another commented:

*I have some excellent doctors, even though I have to travel a distance. Unfortunately, in the county, doctors aren't so savvy with HIV or even any chronic disease; they do the basic stuff.*

Participants also reported that concerns about confidentiality drove them to seek care at more distant venues. The pervasive concerns among the participants about their HIV status being revealed affected their access to medical care. One person, discussing the problem of needing to travel far for medical care, said that though there is a local hospital, “*We'd rather not go to it.*” Because the local hospital interviews patients behind a thin panel “*their privacy is not that private*” and he prefers to go elsewhere.

For those reliant on Medicaid or Medicare, the difficulty of identifying competent HIV providers who accept these government insurance programs is an additional barrier. At times, participants said long trips to the doctor became necessary because no local provider offering needed specialist care would accept publicly funded health coverage. For example, one participant described struggling to find a doctor who could treat her injured shoulder and accept her Medicaid or Medicare coverage. She ultimately had to drive 50 miles from her home to receive that care.

Worse, some participants said they had been completely unable to find certain kinds of care. Getting dental and mental health treatment pose special problems. Some described struggling to treat dental complications of antiretroviral therapy. After being rejected by four different oral surgeons and taking a six hour bus trip to a surgeon who ultimately rejected him due to his inadequate insurance, one participant reported being told, “there is no dental for you” and being forced to receive care from a doctor who didn't feel well equipped to handle his problems.

Several respondents described similar struggles getting mental health treatment and concluded that the treatment they need is out of their reach because few providers accept Medicare or

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Medicaid. Private insurance's premiums are too expensive, and free or low-cost clinics may offer erratic service.

Staff turnover at clinics, poor coordination between HIV care providers and other specialists, and long wait times for appointments were also mentioned as barriers to care. One participant's routine HIV bloodwork was delayed because his primary care provider left the clinic where he receives his HIV care. The health care system didn't recognize the problem until his podiatrist happened to check his records and ordered the lab tests.

**Loneliness/isolation:** A few participants complained about loneliness or social isolation, and more hinted at it in their comments and stories. One commented:

*A lot of us, at our age, we really -- with myself anyways -- it's isolationist. There's no place to go, so you kinda just sit at home.*

One participant, who said he doesn't talk about his HIV status unless asked, said he has found it "very difficult" to make friends. One participant described finding himself in a predicament because he lacks a social circle:

*I do not have any family. They abandoned me, so I'm alone. And, yes, it is very, very difficult. Because even if I go to the hospital, I have to have someone pick me up. Who can I ask to pick me up, when I have no one?*

On one occasion, he was forced to pretend a stranger was his wife picking him up in order to be allowed to leave the hospital.

In some cases, isolation is exacerbated by the fear of one's HIV status being exposed. One participant noted that when he and a friend tried to recruit people with HIV to participate in a support group in his former hometown, the attempt sputtered because, so few were willing to identify themselves as HIV positive.

**Comorbidities:** Consistent with previous research,<sup>4</sup> many of the participants described coping with other diseases in addition to HIV. Reported comorbidities included diabetes, hypertension, plantar fasciitis, orthopedic problems, and depression (both bipolar and otherwise). For several participants, such comorbidities, not HIV, are their primary health concern. Two participants described fatigue severe enough to make daily activities difficult.

## Desired Services/Changes

**None:** Six participants reported that they could think of no services not available to them that they would like to receive, despite reporting problems with HIV stigma, transportation, and isolation. Various participants said they were "fine," "self-sustainable," and "very fortunate,"

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when asked what additional services they need. One participant, said he has no current needs, but suggested, “Maybe [I’ll have more needs] when I get older?” Another said:

*Being honest with you right now I can’t really say [what services I might need], because right now my daughter is here for me for everything. I don’t really need to reach out too much for help because she’s always here for me.*

One older adult said he has no unmet need because he is a strong advocate for himself, able to overcome the barriers that present themselves. As an example, he described convincing a local AIDS service organization to refill his heating oil tank when it fell low over the winter after he used up the initial tankful of oil he had been granted.

**Better opportunities for social support:** About half of the participants, including a few who initially said they had no need for further services, said they would like to have more opportunities for socialization, especially with others with HIV. A few participants complained about lack of opportunities to socialize with others with HIV in support group settings. For example, one said:

*I can see people being unable to socialize or not having any contact, especially with HIV and AIDS groups. There used to be support groups and that’s fizzling out. You don’t see no support groups for HIV and AIDS no more, especially way out here.*

Other participants said they would like to see more help organizing support groups locally and to have family-oriented social opportunities at AIDS service organizations. One participant, who struggled to start a support group in his hometown, said he wishes someone with special expertise in founding and running support groups could come and help locals start their own groups. A participant with children and grandchildren said she was unhappy that her local AIDS service organization now only allows clients, not their families to attend activities. “I want my grandkids to be part of my social life, so [they realize] there’s other people like my mama, my grandma,” she said.

**Programs for older adults with HIV:** When asked whether they would like to have access to services tailored to older adults with HIV, most of the participants expressed interest. Older adults with HIV have distinctive needs and interests that ought to be provided for separately from younger cohorts, they felt. None of those interviewed knew of a program specifically for older adults with HIV in their region, though a few participants noted that by happenstance the support groups they belong to are mainly composed of people over the age of 50. One man said the closest thing he had to an older adult program was an HIV support group originally for people age 30 and over, whose age minimum was later lowered to 25.

Some participants had the sense that older adults with HIV are a forgotten population:

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*I notice this with the HIV – when you’re diagnosed, they’re all there doing everything, but as you get older, they’re focusing more on the new clients, the new diagnoses, the new patients. ... Well, what about the older people? What are we now? It doesn’t matter. That’s how it feels. ... It’s like, “You’re getting old and we all get old and we all die.” Well, ok. But I still matter here. You feel like you’re just a number now. You’re just nothing.*

A handful of the participants liked the idea of an HIV support groups for older adults or long-term survivors. A few others said they’d like to learn more about the way that HIV affects people as they get older and about recent advancements in treatment.

Another suggestion was to air or post public service announcements about older adults with HIV to combat the stigma they face in the region. The participant *suggested the campaign discuss older adults and HIV: it should show “how we survived – we’re survivors, and [and that HIV is] not killing us and it’s not going to kill them or kill people who come into contact with us. We’re not lepers.”*

## Caregiving

Participants responses to questions about their future caregiving needs varied considerably, from complete lack of concern to serious concern, while others said that they haven’t given the topic serious thought yet. About a third of participants expressed strong confidence that their caregiving needs would be met satisfactorily, often by family members. One participant, who said he has discussed his needs with a younger sister, remarked, *“I think we’ve got that covered.”* Another participant said, *“My daughter is going to always be here for me.”*

Other participants, without arrangements in place for younger family or friends to care for them, expressed concerns about the affordability, quality, and kinds of caregiving services that would be available to them. They worried about what services might be available to people reliant on public benefits and whether they might be forced to go to a nursing home.

For some, these concerns about caregiving were tempered by their current good health and a sense that their current health coverage would provide them with suitable care. However, several participants felt their understanding of what options they could expect to be entitled was imperfect. One participant said, *“I think you can access whatever services you might need,”* but also acknowledged his own ignorance about eligibility for services:

*I need to learn more about what I’ll be able to get as I get older as far as medical services, if there would be any restrictions. The more information the better.*

Finally, three older adults said that they had not given serious thought to caregiving. One said she might have help from her children. Another said perhaps his health insurance would provide home health care, but he was uncertain about what would be available long-term: “I

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never really thought about it, actually, because I'm pretty stable." For a third the subject was simply too daunting to consider:

*No, I haven't given [my future caregiving needs] any thought. Again, it gets overwhelming. It's wonderful to sit here and talk like this, but when you start thinking about it, it gets overwhelming because you don't feel like you can do anything different than what you've been doing, you know what I mean?*

## Issues Distinctive to Upstate New York

Some of the facilitators and barriers to positive aging for older adults with HIV face are common across regions. In each of the four sets of qualitative data ACRIA gathered in New York City, San Francisco, and Alameda County, and Upstate New York, some of the same issues were raised. Social support is advantageous when present, but when it is absent, isolation can be crippling. Mental health problems are common, but mental health treatment is often out of reach. Unless family is ready to step in, future caregiving needs are difficult to plan for, however, each region has its own character. Unsurprisingly, in Upstate New York, participants were more likely to report trouble with transportation and needing to travel long distances for services and care. The Upstate participants were especially vocal about the problem of maintaining their privacy as a person living with HIV and had more concerns about disclosure and discrimination.

Several Upstate participants discussed how where they are located affects their situation. They noted that people with HIV are quieter and more discreet in the region, in some cases to the detriment of their ability to connect with others and suggested this may be related to living in sparsely populated places. Three individuals contrasted larger cities of Upstate New York (Buffalo and Albany) with the rest of the region. There is more pressure for people with HIV to "hide" in the more rural parts of Upstate New York, they said. One interview drew a contrast between his peers living with HIV in Albany and those in his hometown:

*I'm not trying to speak prejudiced or anything, but it seems like it's a different class of people in Albany that are HIV positive. I have met some people who are married and things like that. It's just the mental. I don't know, it's hard to explain. I want to be able to get out of the suburbs, where people might be afraid to talk about anything.*

Living in Upstate New York may have advantages, some people said New York state offers relatively generous health benefits to people with HIV. One person regretted that other states are not as generous with services and benefits for people with HIV. *If southern states could match the services in New York, he could move somewhere warm, he said with frustration.* Three people saw certain aspects of country living – living amidst nature and caring for animals – as benefits of living Upstate. They discussed hiking the Adirondacks as a social activity, the peacefulness of spending time in nature, and the sense of purpose that comes from needing to care for pets or farm animals.

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## Appendix B: Methods

ROAH 2.0 Upstate New York is a mixed-methods research project including focus group participants and 186 survey participants. Inclusion criteria included being age 50 or over on the date of participation, having been diagnosed with HIV, and living or receiving services in Upstate New York. The study protocol and materials were approved by GMHC's institutional review board.

Fourteen older adults living with HIV were interviewed in Summer 2017. Participants were required to be age 50 or older, HIV positive and receiving services in Upstate New York. Recruitment was conducted through flyers distributed to AIDS Service Organizations. Interested participants called ACRIA, were screened for eligibility, and scheduled for a phone interview. Participants were consented over the phone and agreed to be audio recorded. Each interview was led by an ACRIA staff member using a question guide with eight prompts covering participants' self-perception with regards to aging, services participants have or currently receive, factors facilitating and undermining positive aging barriers to receiving services, additional service desired, and concerns about anticipated caregiving and long-term care needs. Protocols were approved by GMHC's Institutional Review Board, New York, NY. Interviews lasted between 30 minutes and an hour. Participants were mailed a \$25 gift card and a copy of the informed consent.

Research staff conducted the interviews with older adults with HIV to gather qualitative data on their experiences, challenges, and needs and inform any needed revisions to the ROAH 2.0 survey. Focus groups were not conducted since the research staff found that assembling typical focus groups was not possible due to transportation barriers. Interviews were reviewed by research staff and reviewed for themes. Emergent themes were categorized and summarized accompanied by illustrative quotes to produce the summary report.

The next phase of the study was administration of the survey to older adults with HIV. Participants were recruited through clinics, social service agencies, and AIDS service organizations, who posted fliers at their facilities and in some cases personally reached out to

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eligible individuals. (See the acknowledgements section of this report for a list of recruitment venues.) Prospective participants were invited to call a member of the research staff, who gave them a basic explanation of the study protocol and screened them for eligibility. All participants provided written informed consent and received a \$40 gift card as an incentive. Participant identity, place of residence, and age was verified by checking photo identification. Survey data collection continued through Winter 2019.

Survey data was entered into Qualtrics, a secure online platform for data capture, and each entry was checked for accuracy against the hardcopy survey. Survey responses were analyzed using Stata 13. Mean imputation was used for computation of scores for the Sowell Stigma Scale, PHQ9, PTSD Check List, and Ryff's Scales of Psychological Well-being. ROAH 2.0 participants' scores on the Ryff sub-scale were compared with the scores from a national sample of 1,108 community-based adults with an average age of 46. The national study used scores based on 3-item, rather than 6-item, versions of the Ryff Scales, so data reported from each sample was standardized to the same metric before analysis. Data visualization was rendered in Microsoft Excel and Tableau.

There are several limitations to this research. Convenience sampling methods were used to recruit participants. Recruitment occurred primarily through community-based organizations serving clients living with HIV, limiting generalizability to older adults with HIV in the country not connected to treatment or services: The ROAH 2.0 sample may be better connected to care or in higher need of services. Data was self-reported. Self-reported health conditions were not verified with clinical data. The survey contained several questions on sensitive topics such as substance use and trauma. To limit underreporting the survey was self-administered. Finally, the cross-sectional nature of the study limits analysis as causality cannot be inferred.

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## Appendix C: Research Advisory Council

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	Sex at Birth	Transgender	Total
Male	117	2	117
Female	64	0	64