

A photograph of the Golden Gate Bridge in San Francisco, showing the iconic orange-red suspension tower and cables against a clear blue sky. The bridge spans across the water, with the city skyline visible in the distance.

HIV & Aging in San Francisco

Findings from the

Research on **O**lder **A**dults with **H**IV **2.0**

San Francisco Study

Autumn 2018

acria

The ACRIA Center on
HIV and Aging at GMHC

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Let's Kick ASS – AIDS Survivor Syndrome	San Francisco AIDS Foundation (Elizabeth Taylor
The Long-Term Survivors' Facebook Group	50+, Latino, Case Management, and TransLife
Lutheran Social Services of Northern California	Programs)
Lyon-Martin Health Services	San Francisco Community Health Center
Maitri	The Shanti Project
Mission Neighborhood Health Center	Southeast Health Center
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The ACRIA Center on HIV and Aging 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 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.

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Executive Summary

The multi-site Research on Older Adults with HIV (ROAH) 2.0 Study is designed to assess the status of older adults living with HIV in order to inform the development of programs and policies that best address their needs. In total, 197 people with HIV age 50 or over living or receiving services in San Francisco are included in the ROAH 2.0 SF survey research. Additionally, 44 HIV-positive San Franciscans age 50 or older participated in five focus groups. This report focuses on the survey participants, who are primarily cisgender (i.e., not transgender) male, racially diverse, similar in age distribution to older adults with HIV in the city as a whole, and largely made up of long-term survivors.

While the survey focuses on psychological and social factors in the lives of older adults with HIV, it also looked at clinical factors. Almost 60% of survey participants describe their physical health as excellent or good, nearly all participants are receiving antiretroviral therapy, and over 90% report having an undetectable viral load. On the other hand, 41% report their health as fair, poor, or very poor, and many participants said their work or social lives are hampered by their health. Participants reported that they have been coping with a wide variety of health conditions and symptoms in the past year, consistent with prior HIV and aging research. Among the most common were fatigue (reported by 56% of participants), neuropathy (46%), arthritis (43%), and chronic pain (42%). Past year hypertension, cancer, and hepatitis C were also common, reported by 18%, 11%, and 11% respectively. Participants report taking over 10 pills a day on average, including their HIV medications, other prescriptions, and over-the-counter medications.

Many survey participants appear to be confronting serious mental health issues, which is congruent with previous research on the mental health and psychological wellbeing of older adults with HIV. On the PHQ9 measure of depression, 38% scored as having moderate to very severe depression. According to the PTSD Check List, 35% exhibit symptoms of post-traumatic stress disorder by the most conservative criteria. Just over a third of those scored with PTSD and 41% of those with moderate to very severe depression reported receiving no mental health care in the last year. Most participants reported a history of trauma. About half of participants (51%) reported being sexually assaulted before the age of 16. Fifty-two percent have been victims of domestic violence by a partner. On a measure of loneliness, 21% scored as “lonely” and 22% as “very lonely.” Three-quarters of participants said their needs for emotional support are not fully met, and just over a fifth said they need “a lot more social support.” Twenty percent of participants report use of methamphetamine, crack/cocaine, or heroin in the past 3 months.

Other challenges facing the participants include low income, costly housing, and food insecurity/hunger. Over 25% report food insecurity and hunger and a similar percent report not having enough income to cover expenses. Many lack resources to help with tasks of daily living or to get needed care should they

fall sick or be injured. Reported barriers to getting services include eligibility concerns, long wait times, lack of knowledge of what is available, confusing procedures for accessing services, and cost.

Future directions:

- This study suggests access to mental health treatment is a significant problem for some older adults with HIV living with serious mental health issues. Given high rates of PTSD and history of trauma, mental health providers should adopt a trauma-informed approach.
- Because participants exhibit high rates of loneliness and desire more social opportunities, offering more occasions for older adults with HIV to come together, whether building on existing programs or creating new ones, may be a worthy aim.
- As many older adults with HIV in this study struggle with high housing cost burden and hunger, solutions for easing the financial strain of living on a fixed income in a city like San Francisco with rising housing costs should be considered.
- Given the high levels of co-morbidity and polypharmacy in the study population, many would likely benefit from care guided by geriatric medicine's precepts and a coordinated care approach. Expanding combined HIV/geriatric care programs and training HIV care providers in geriatric care principles may be worthy avenues for increasing access to this treatment approach.

Introduction

HIV and Aging: How We Got Here

In the beginning, AIDS in the United States was primarily a disease of the young. In 1983, 69% of AIDS cases were among people not yet 40 years old.¹ By 1993, it was among the top ten causes of death in the United States.² Today, HIV remains a grave disease, but an HIV diagnosis is no longer the brutal death sentence it once was, thanks to dramatic advancements in HIV care. While HIV continues to affect people of all ages, the U.S. HIV epidemic primarily affects older adults: over half of people living with HIV are over the age of 50,³ the definition of “older adult with HIV” we will be using throughout this report. There continue to be new cases of HIV, of course, and some of the older adults living with HIV today were diagnosed in maturity. Other older adults with HIV are long-term survivors, who lived through the harshest years of the AIDS epidemic and may bear the marks of enduring that 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.

The Genesis of this Project

In 2005, ACRIA, 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. In 20 peer-reviewed publications based on the study, researchers 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 co-morbid health conditions alongside HIV.⁴ The ROAH research findings received prominent international news coverage, became the impetus for the development of the largest sustained

¹ Centers for Disease Control and Prevention. (1983). Acquired Immunodeficiency Syndrome (AIDS) Weekly Surveillance Report. December 23, 1983. Retrieved from: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-1983.pdf>.

² Centers for Disease Control and Prevention. (1993). Mortality Patterns -- United States, 1993. Retrieved from: <https://www.cdc.gov/mmwr/preview/mmwrhtml/00040512.htm>.

³ Effros, R., Fletcher, C., Gebo, K., et al. (2008). Aging and infectious diseases: workshop on HIV infection and aging: What is known and future research directions. *Clinical Infectious Diseases*, 47(4), 542–553.

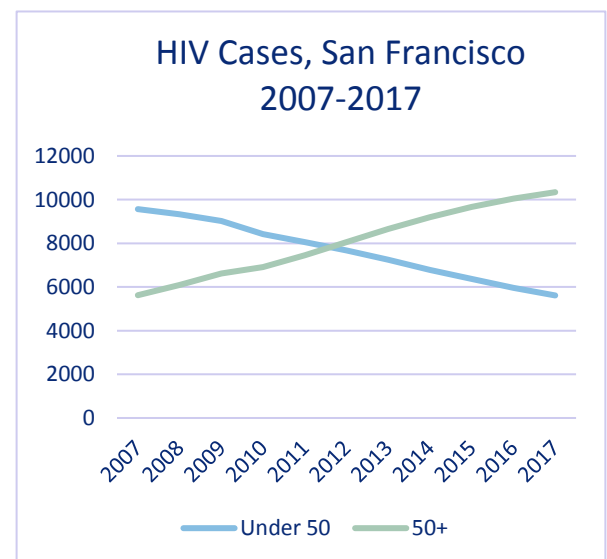
⁴ Brennan, M., Karpiak, S. E., Shippy, R. A., & Cantor, M. H. (Eds.). (2009). *Older adults with HIV: An in-depth examination of an emerging population*. New York, NY: Nova Science Publishers.

training program on older adults with HIV in the United States, spurred the development of a web site offering guidance on the clinical management of older adults with HIV, and inspired similar research projects internationally.

A decade later, ACRIA researchers realized that an updated look at older adults with HIV was needed, as the growth in the population of older adults with HIV continued. In 2015 they inaugurated a successor study, the Research on Older Adults with HIV 2.0 Study (or ROAH 2.0), this time in multiple sites across the United States.

HIV Among Older Adults in San Francisco

San Francisco was a logical site for this new study, given its importance in the history of the epidemic and the prominence of its population of older adults living with HIV. There are over 10,000 people age 50 or over with HIV in the city of San Francisco, representing 65% of all people living with HIV.⁵ Currently, more than 1 in 30 adults over the age of 50 are HIV positive in San Francisco.⁶ As shown in the graph to the right, the number of San Franciscans with HIV who were age 50 or older surpassed the number under the age of 50 in 2012. In the next decade, over 3,000 additional San Franciscans with HIV aged 40-49 will age into the “older adult” category.



The ROAH 2.0 San Francisco Project

The research project in San Francisco had two phases: Initially, five focus groups were held with various sub-populations of older adults with HIV: gay male long-term survivors, African Americans, Asian and Pacific Islanders, Spanish speakers, and transgender people. (A summary of the focus group findings can be found in Appendix A.) In addition to providing a more nuanced, in-depth look at the status of older adults with HIV than survey data can provide, these focus groups informed refinements and additions to the set of survey questions developed for use in multiple cities. Next, older adults with HIV were recruited

⁵ San Francisco Department of Public Health, Population Health Division, HIV Epidemiology Section (2018). *HIV Epidemiology Report 2017*. Retrieved from: <https://www.sfdph.org/dph/files/reports/RptsHIVAIDS/AnnualReport2017-Green-20180904-Web.pdf>

⁶ US Census Bureau. American Community Survey 2016: Age and Sex. American FactFinder Web site. <https://factfinder.census.gov>. Accessed September 2018.

to take a 70-page written survey through agencies, clinics, and other venues known to serve people living with HIV. (For more about the study's methods, see Appendix B.)

This report presents an overview of the characteristics and challenges of older adults with HIV in San Francisco. We begin with a look at the survey participants: Who sat down to take our survey? We look at their identities (gender identity, sexual orientation, and race) and life experiences with HIV/AIDS, immigration, education, and incarceration. Next, we ask what services these older adults are making use of, what needs are beginning to manifest, and what service gaps there are. In the following section, we cover the physical health of the survey participants, including measures of HIV-related health and other conditions that may be affecting their wellbeing. Finally, we examine the psychological, behavioral, and social situation of the survey participants, including their mental health and psychological wellbeing, feelings of loneliness, substance use, and sexual activities.

We intend for this document to not only cast light on the situation of older adults with HIV in San Francisco but also serve as a guide. We hope it will provoke thoughtful conversations on the welfare of older adults with HIV, and that these conversations will in turn foster the development of programs and policy that can enhance the future health and wellbeing of older adults living with HIV in this City by the Bay.

A Portrait of the Participants

Age, Length of Survivorship and AIDS Diagnosis

By design, all participants in ROAH 2.0 were at least 50 years old. In the ROAH 2.0 San Francisco sub-study (referred to here as ROAH 2.0 SF), about half were age 60 or over. In this respect, the study participants reflect the population of older adults with HIV in San Francisco; 45% of the ROAH 2.0 SF sample was age 60 or older, while epidemiological data from the San Francisco Department of Public Health indicates that in the city 43% of all older adults with HIV were 60 or over as of December 2016.

ROAH 2.0 Participants		HIV+ Older Adults in SF	
Age		Age	
	Percent		Percent
50-59	54%	50-59	56%
60-69	36%	60-69	34%
70+	8%	70+	9%
Not reported	2%		

Very few ROAH 2.0 SF participants have been recently diagnosed: just 3.6% had been diagnosed with HIV for five years or less. Half received an HIV diagnosis at ages 30 to 40. A small but significant portion of the participants (8%) were diagnosed with HIV at the age of 50 or older.

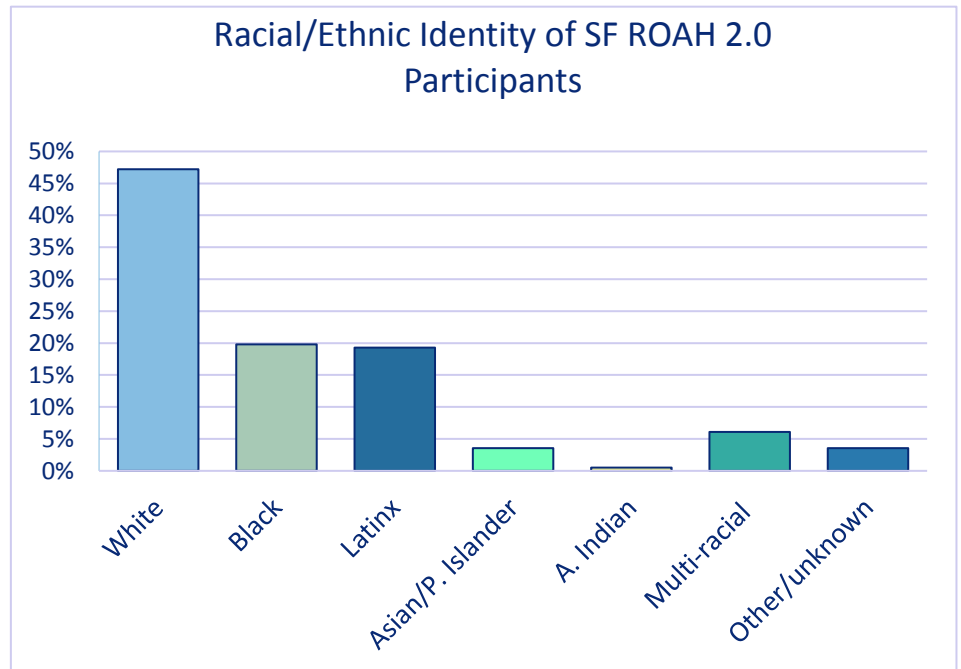
When a person should be considered a “long-term survivor of HIV” is arguable, but many participants would likely fall into this category. One common definition of long-term survivor is having been diagnosed with HIV for 10 years or longer. By this standard, over 92% of ROAH 2.0 SF participants are long-term survivors. Alternately, some consider a person with HIV to be a long-term survivor if they were diagnosed with HIV before 1996, when the introduction of highly-active antiretroviral therapy revolutionized HIV treatment. About 67% of participants met that benchmark. Among all survey participants, 116 (59%) reported having received an AIDS diagnosis at some point.

Race/Ethnicity

Just under half of survey participants identified as white/Caucasian and non-Hispanic. The table shows the racial/ethnic breakdown of participants, with the corresponding values for all older adults with HIV in San Francisco.

Among the survey participants, a lower percentage of participants identified as white, compared to the population of older adults with HIV in

San Francisco. This reflects efforts to oversample Spanish-speaking Latinos, cisgender women and transgender people (who were more likely to be non-white than cisgender men).



The survey was available in English as well as Spanish; 11% were completed in Spanish, all by

Survey Participants		HIV+ Older Adults in SF	
	%		%
White	47%	White	66%
Black	20%	Black	12%
Hispanic/Latino	19%	Hispanic/Latino	15%
Asian/Pacific Islander	4%	Asian/Pacific Islander	4%
American Indian	<1%	Native American	<1%
Other/unknown	4%	Other/unknown	3%
Multi-racial	6%		

individuals who accessed services through the San Francisco AIDS Foundation's Latino Programs. Though all of these individuals were Spanish speakers and more comfortable in Spanish than English, most were not completely monolingual.

Gender and Sexual Orientation

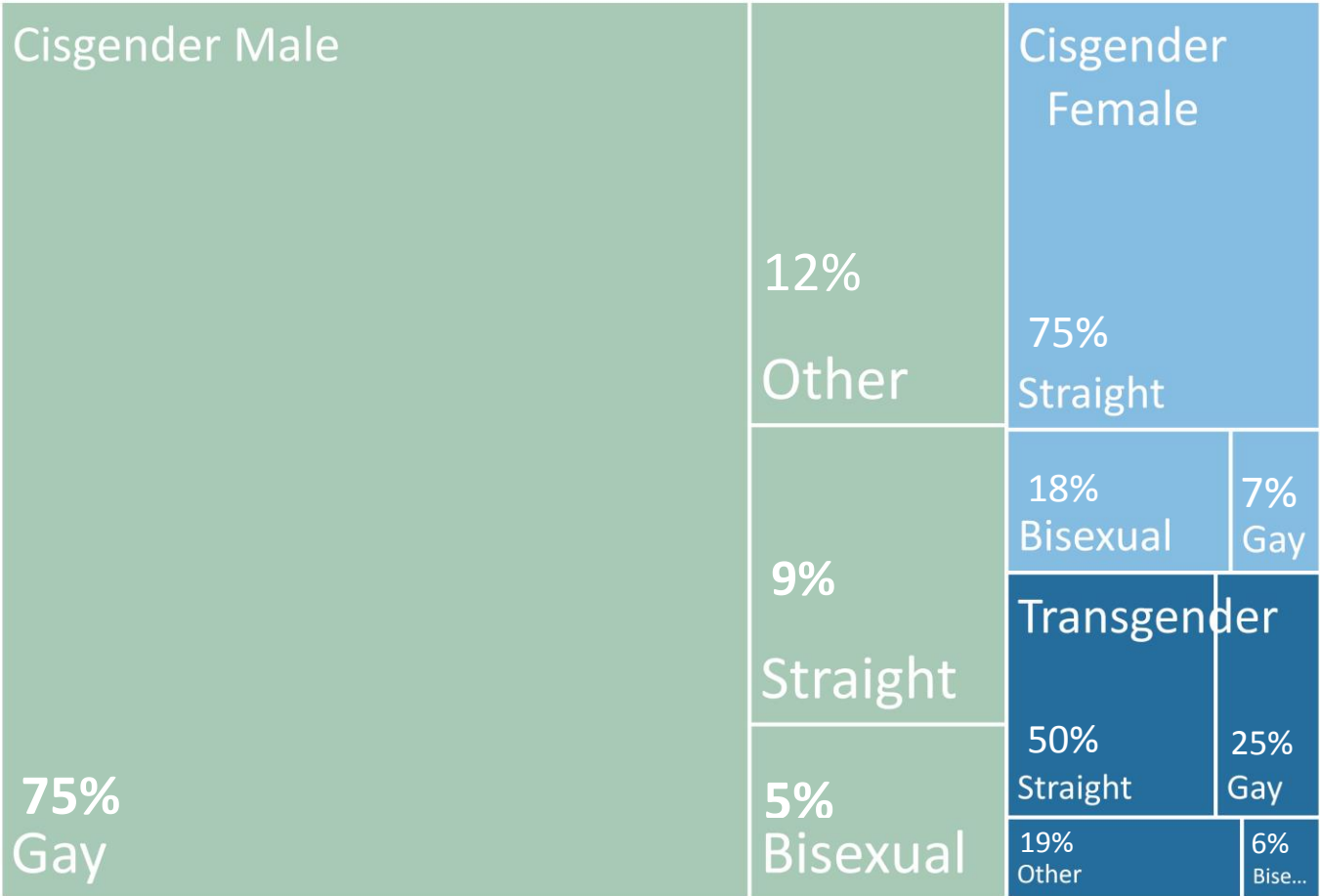
Just as the overall population of older adults with HIV is largely male, the vast majority of the survey participants (73%) identified as cisgender (meaning not transgender) men.

ROAH 2.0 Survey Participants		HIV+ Older Adults in SF	
	Percent		Percent
Cisgender male	73%	Male	93%
Cisgender female	15%	Female	5%
Transgender	8%	Trans women	2%
Multiple/other*	3%		
Missing	2%		

The graphic below shows participants’ gender identity by sexual orientation. Three quarters of cisgender men taking the survey identified as gay, while the same percentage of cisgender women identified as straight.

* Includes 3 individuals who indicated multiple genders and one each who described themselves as intersex, gender queer, or nonbinary.

Gender Identity and Sexual Orientation Among ROAH 2.0 SF Participants

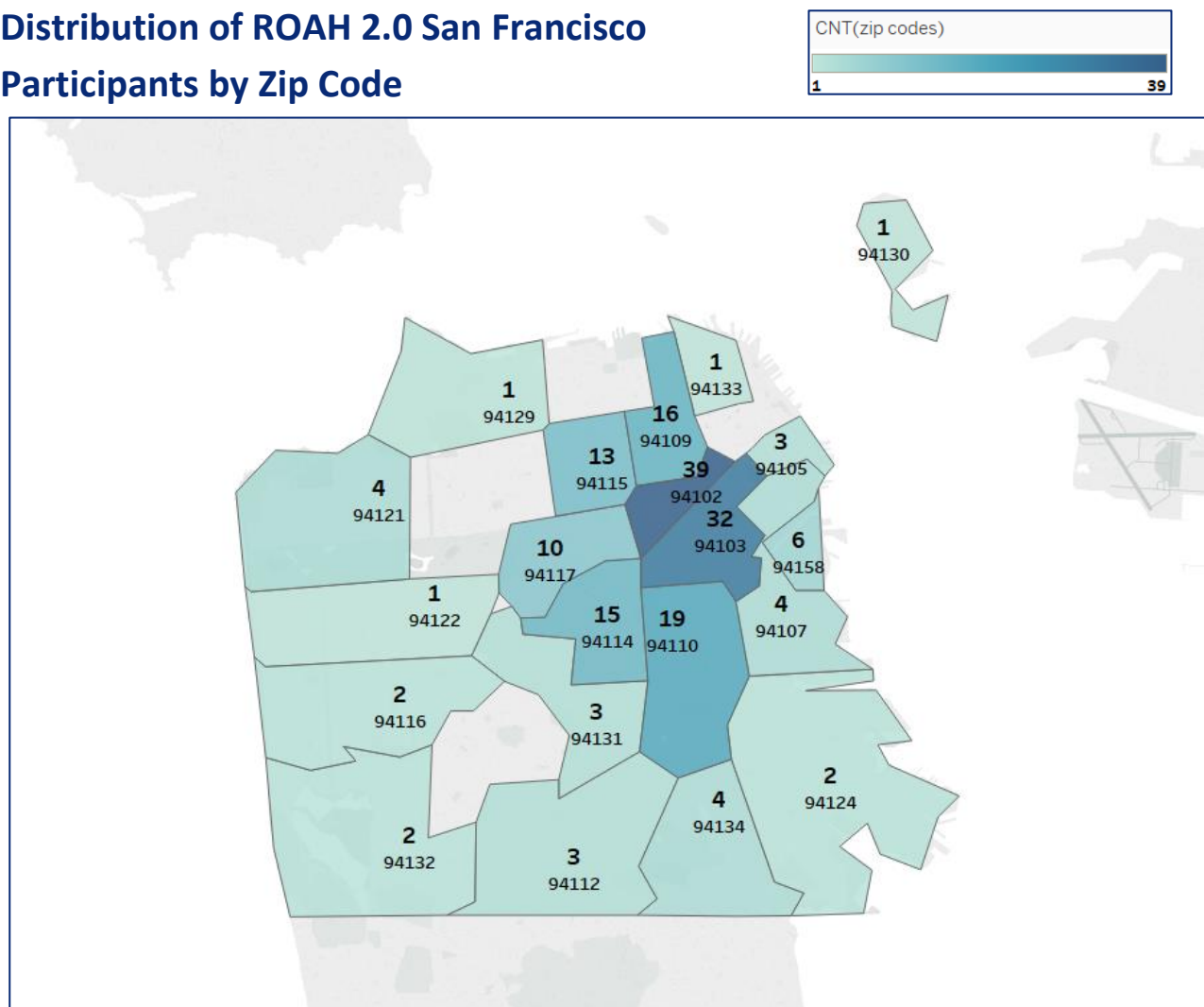


* Note that this image excludes all participants who didn’t report their gender or sexual orientation or whose identity didn’t fall into the categories above (12 individuals). “Other” sexual orientation includes queer, questioning, and same-gender loving along with written-in responses. Percentages represent the share amongst all of that gender identity.

Geography

The ROAH 2.0 SF participants live throughout San Francisco but are particularly concentrated in the Tenderloin, SOMA, Mission, and Castro neighborhoods, which is fairly consistent with an examination of the distribution of older adults with HIV in San Francisco conducted in 2010.⁷ Participants were eligible to participate in the survey if they lived within San Francisco or received HIV services there. Thirteen participants lived outside San Francisco; four in Alameda County, five in San Mateo County, and four beyond the Bay Area. All non-San Francisco residents confirmed receipt of HIV services within San Francisco.

Distribution of ROAH 2.0 San Francisco Participants by Zip Code



⁷ City and County of San Francisco Department of Public Health AIDS Office, HIV Epidemiology Section (2010). *Atlas of HIV/AIDS in San Francisco 2010*. Second Edition. Retrieved from: <https://www.sfdph.org/dph/files/reports/RptsHIVAIDS/HIVAIDSAAtlas2010.pdf>

Disability, Employment & Education

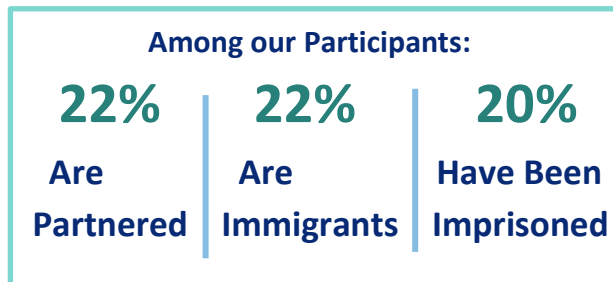
Just 6% of ROAH 2.0 SF participants were employed full-time and 12% were employed part-time. Amongst all participants, 58% were on disability, 13% were retired, 10% were unemployed, and 2% were volunteers.



Participants represented a wide range of educational backgrounds: 11% had not finished high school, while 18% had completed a graduate degree. However, having a high school diploma/GED, some college, or a college diploma were more common: 16%, 28%, and 20% had attained these levels of education, respectively. Additionally, 6% of participants had attended vocational school.

Partnership, Immigration & Incarceration

Just over a fifth of participants (22%) were partnered. Among the partnered participants, 49% were life partners (with no legally recognized partnership), 24% were married, 17% had a registered domestic partnership, 7% had a common law spouse, and 2% were in a civil union. Overall, 67% of participants live alone. The vast majority of those not partnered (81%) live alone.

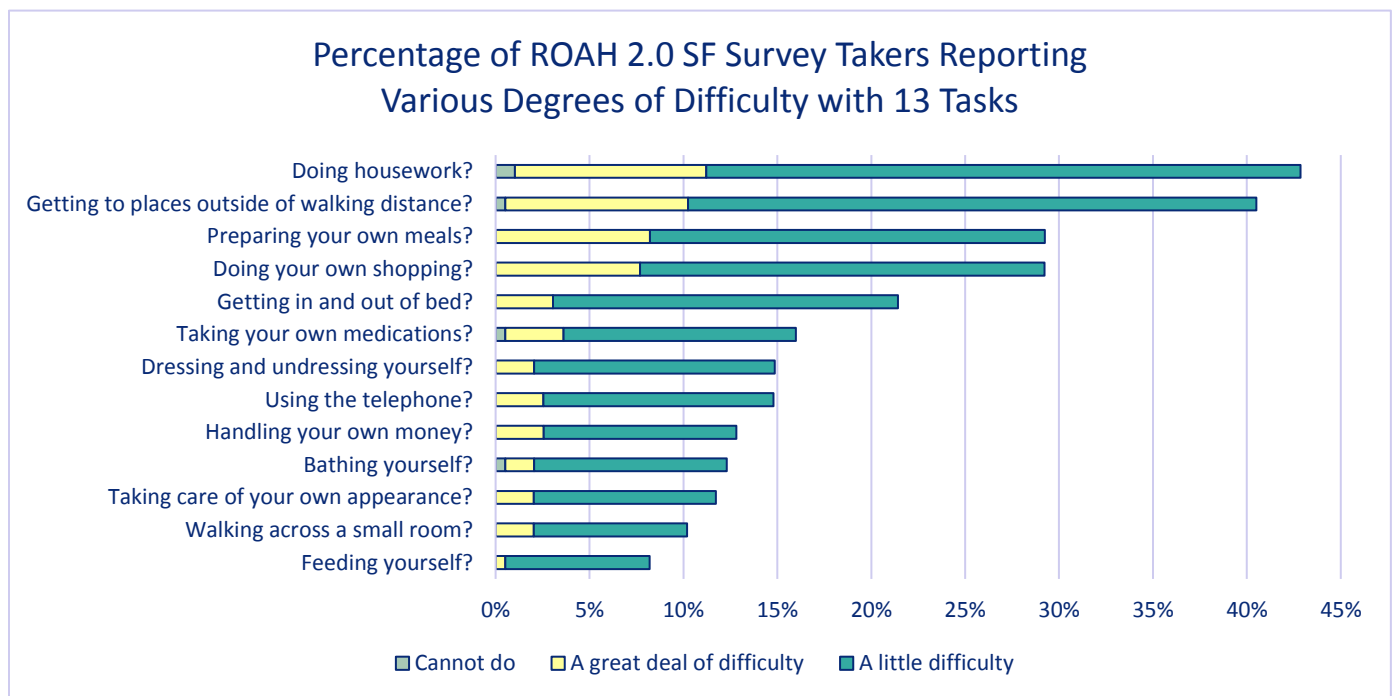


Immigrants comprised 22% of the participants. Two-thirds of immigrants (n=28) came from Latin America; 8 were from Canada, Europe, Asia, or the Pacific. Eighteen of the Latin American immigrants were former Mexican nationals. The remainder came from Argentina, Chile, Cuba, and El Salvador. Among participants, 20% had ever been incarcerated: total prison time ranged from less than a year to 22 years.

Service Use, Needs, and Challenges

Function and Support Availability

To understand the needs of older adults with HIV it is helpful to begin with an understanding of their functional status – their capacity to engage in what’s often called “activities of daily living,” like handling chores, self-care, and errands. Participants were asked to report if they had any difficulty and, if so, to what degree, regarding 13 tasks. Few (just 3 individuals) reported being completely unable to do any of the activities. Many, 59% of participants, had trouble with at least one activity. The average number of activities a participant had trouble with was 2.6.

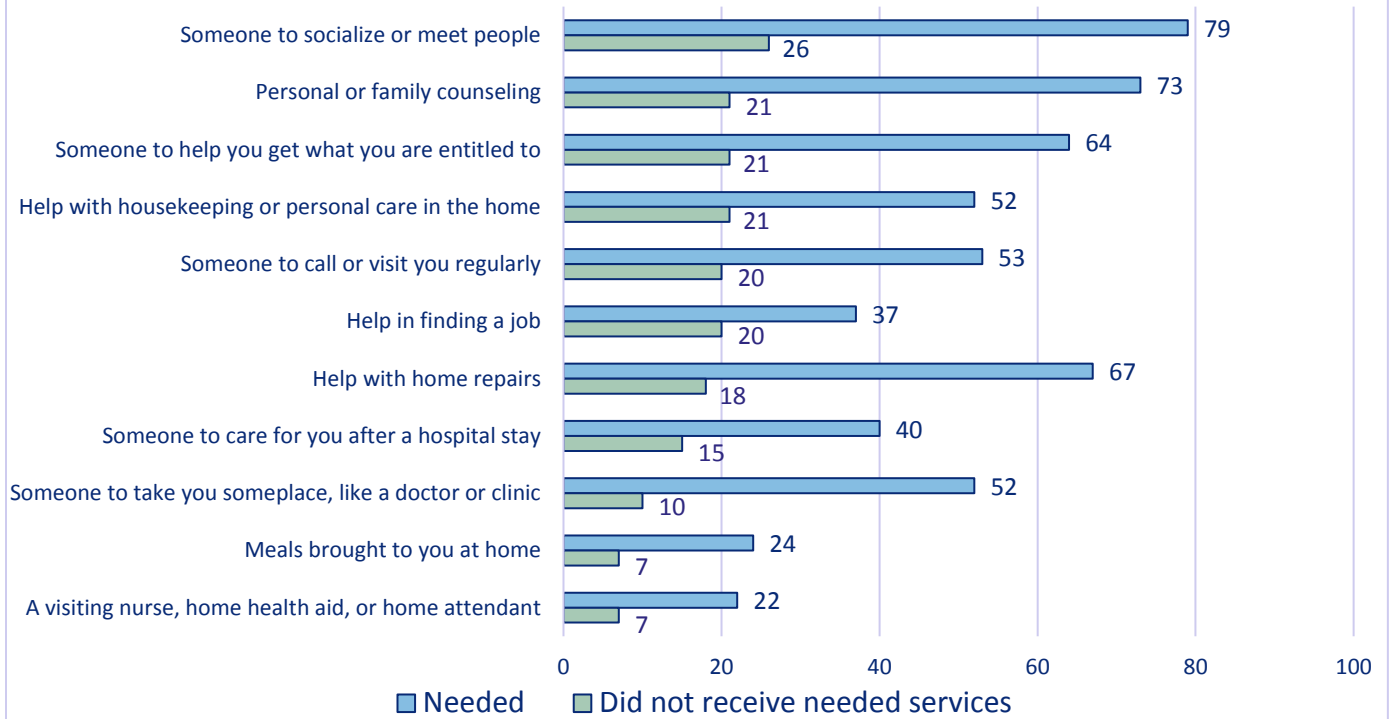


Having a sense of what participants are and are not capable of, we can turn our attention to the extent that the participants’ needs are being addressed. Participants were asked whether they had someone they could count on for help with tasks of daily living and for help with emotional needs. The data illustrates that participants were less likely to have someone they could count on for help with activities of daily living than to have someone they could count on for emotional support. The survey also asked about how much more support the participants need in the same two areas, tasks of daily living and emotional support. Participants were almost twice as likely to report needing “a lot more” emotional help than “a lot more” help with activities of daily living.

Support with Tasks of Daily Living	Emotional Support
Do you have someone you can count on to help?	Do you have someone you can count on to help?
27% Most/all of the time	39% Most/all of the time
21% Some of the time	25% Some of the time
26% Only occasionally	21% Only occasionally
26% Not at all	15% Not at all
How much more support did you need?	How much more support did you need?
41% I got all the help I needed	28% I got all the help I needed
28% A little more	26% A little more
19% Some more	25% Some more
11% A lot more	21% A lot more

The survey looked at the need for 11 specific services. On average, participants felt they needed about three of the eleven services. Their needs in these areas were mostly met; 67% of needs were satisfied. However, 34% of respondents had an unmet need in at least one category, and 12% had 3 or more unmet needs. “Someone to socialize or meet people,” “personal or family counseling,” and “help with home repairs” were the three most common needs. Along with help getting “what you are entitled to” and “housekeeping or personal care,” they were also the most frequently unmet needs.

Number of SF ROAH 2.0 Participants in Need of Various Services and the Those Who Did Not Receive These Services



Participants were asked who they would turn to if they needed help with activities like bathing and taking medication due to an accident or illness. Family was often a preferred avenue: 21% of participants said they would turn to a partner or spouse, 3% to a child or parent, and 3% to another relative. After family, turning to a friend or neighbor (26%) was the next most common choice. Two in ten participants (20%) would rely on no one but themselves should they be injured or fall ill. Just over one in ten (11%) were uncertain who they might rely upon. The remainder specified that they would first seek help from an AIDS service organization (9%) or other community-based organization (6%).

Typical older adults most often depend on family for care when ill or injured. In the general population only 13% of older adults receive informal care from a friend or neighbor, rather than a relative.⁸ In contrast, 26% of the ROAH participants say they would rely on a friend or neighbor. Just

⁸ AARP Public Policy Institute (2015). *Caregiving in the U.S. 2015*. Retrieved from: <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>

27% predicted they would rely on a family member. Many ROAH participants may not have the option of relying upon a family member for care. The high share of participants without a clear idea of who else they might turn to or who felt they would need the help of community organizations – 46% – suggests that many do not have social networks ready to help with maintaining health and the challenges of day-to-day living

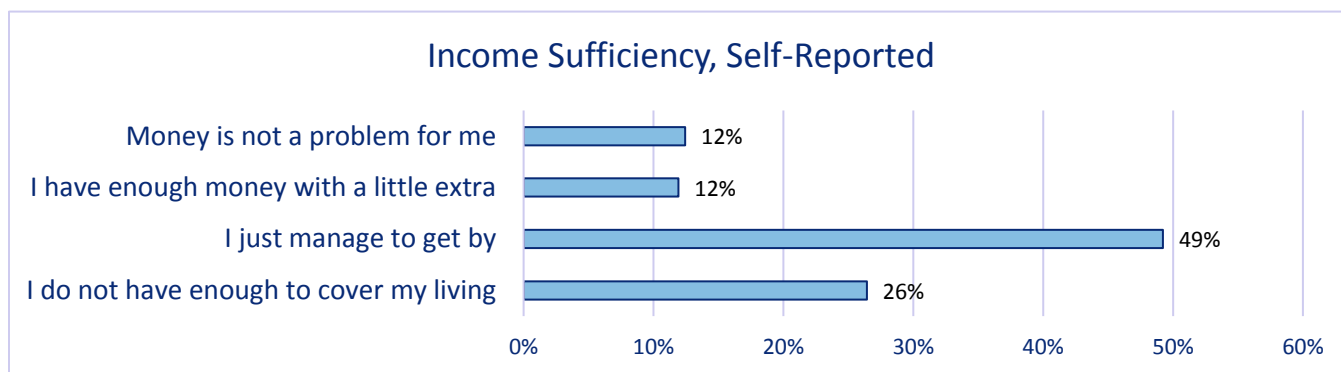
Barriers to Services

An array of services that older adults with HIV may be eligible for already exist in San Francisco. What is stopping the participants from finding services that meet their needs? The perception that services are not available, difficult to find or hard to access, or are not free/too costly, were leading problems. Other barriers to services were the perception that service providers are unhelpful, transportation difficulties, trouble making or keeping appointments, and the sense service providers might be biased against the participant.

Problem rank	Problem description	Percentage with this problem
1	You don't think you are eligible to get the services for free	41%
2	You would have to wait too long to get the services	39%
3	You don't know where to get the services	36%
4	The process of getting services is too confusing or difficult	33%
5	The services cost too much for you to afford	29%
6	You don't think the services exist around here	22%
7	The people at the agency are not helpful or don't seem motivated to help	19%
8	It's hard for you to get there (transportation)	17%
9	It's hard for you to make or keep appointments	15%
10	The people who run the services don't like people like you	13%
10	You are afraid that you won't be treated if you go there	13%
11	You have trouble telling the people at the agency what you need	12%
12	You have to take care of other people	11%
13	The people at the agency don't speak the same language as you	10%
14	Somebody might find out about your HIV status if you go there	9%
15	You worry that your family/friends would be against the services	6%
16	You don't know what to do with your kids when you're there	3%

Income Sufficiency, Housing, and Food Security

Given San Francisco's high cost of living and that few survey participants were employed, it's unsurprising that many face economic challenges. Asked about their financial situation, 49% of participants said they "just manage to get by." The second largest share of participants (26%) said their income was not sufficient to cover their expenses. About a quarter (24%) said they were more financially stable.



Housing is a key factor for health and wellbeing. Housing status reflects your financial situation and shapes your capacity to protect your health. Over half of ROAH 2.0 SF participants live in a rented apartment or house (56%) or rented room (11%). Eight percent of participants live in a non-rented co-op, condo, or home. Over a tenth of participants (11%) stay at a single room occupancy hotel, and 7% said they do not have a permanent residence.

Housing Status	%
Do not have a permanent residence (n=14)	7%
<i>Staying at a shelter (n=7)</i>	
<i>Staying with friends temporarily (n= 2)</i>	
<i>Living outside/in a car (n=1)</i>	
<i>Did not specify (n=4)</i>	
Rented apartment or house	56%
Rented room	11%
Single Room Occupancy (SRO)	11%
Co-op, condo, or homeowner	8%
Public Housing	4%
Not-for-Profit Housing	2%

Housing expenses can drastically affect one’s capacity to pay for necessities. Participants were asked to approximate the portion of their income they spend on housing; 42% spent about half or more than half of their budget on housing costs, which means they would be considered “severely cost-burdened” by the U.S. Department of Housing and Urban Development.

A sizeable share of respondents receive some form of housing assistance, including HOPWA (Housing Opportunities for Persons with HIV/AIDS) certificate, section 8 voucher, and other types of housing subsidy or aide.

Housing Benefits	Percent
HOPWA	17%
Section 8	21%
Other housing assistance	23%
Don’t know	4%
Receive no housing benefits	36%

Participants took a 4-question hunger and food security assessment, which asked about their access to filling, balanced meals and how often they have eaten less than they felt they needed to or skipped meals entirely. The table below shows that a large portion of respondents are living with food insecurity, meaning uncertain or insufficient access to food, a condition that can lead to hunger. A substantial share (25%) report food insecurity with hunger.⁹

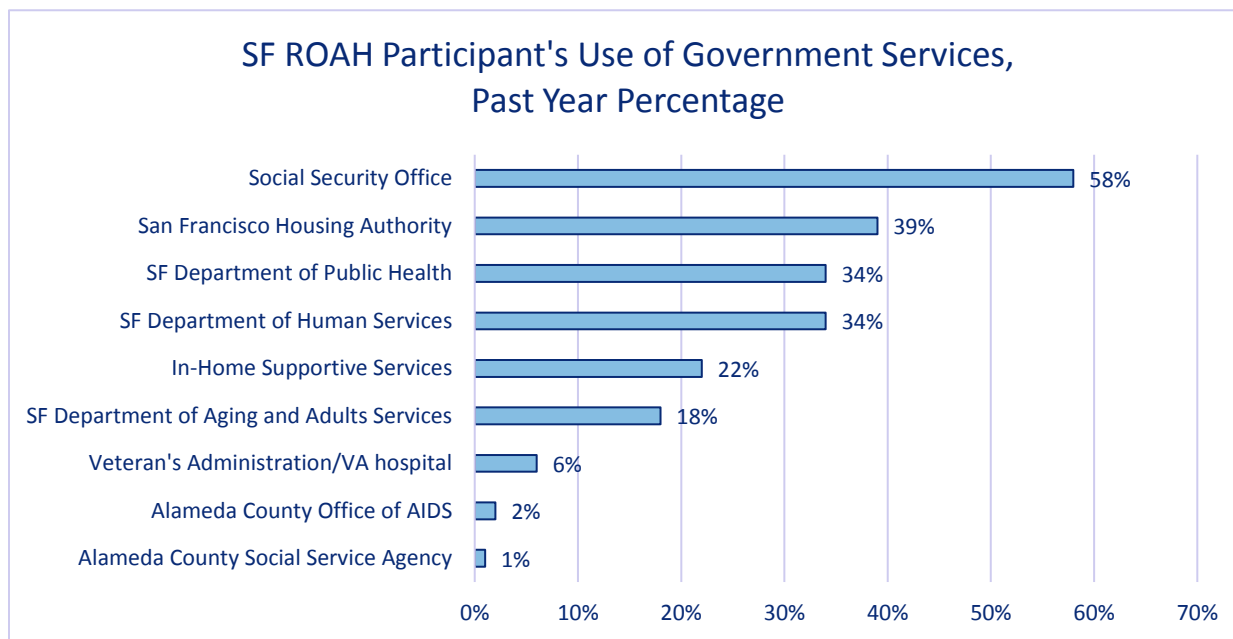
Food Security/Hunger, Past Year	Percent
Food secure	56%
Food insecure without hunger	19%
Food insecure with hunger	25%

⁹ Adams E.J., Grummer-Strawn L., Chavez G. (2003) Food insecurity is associated with increased risk of obesity in California women, *The Journal of Nutrition*, 133(4), 1070-1074.

Government and Community Assistance

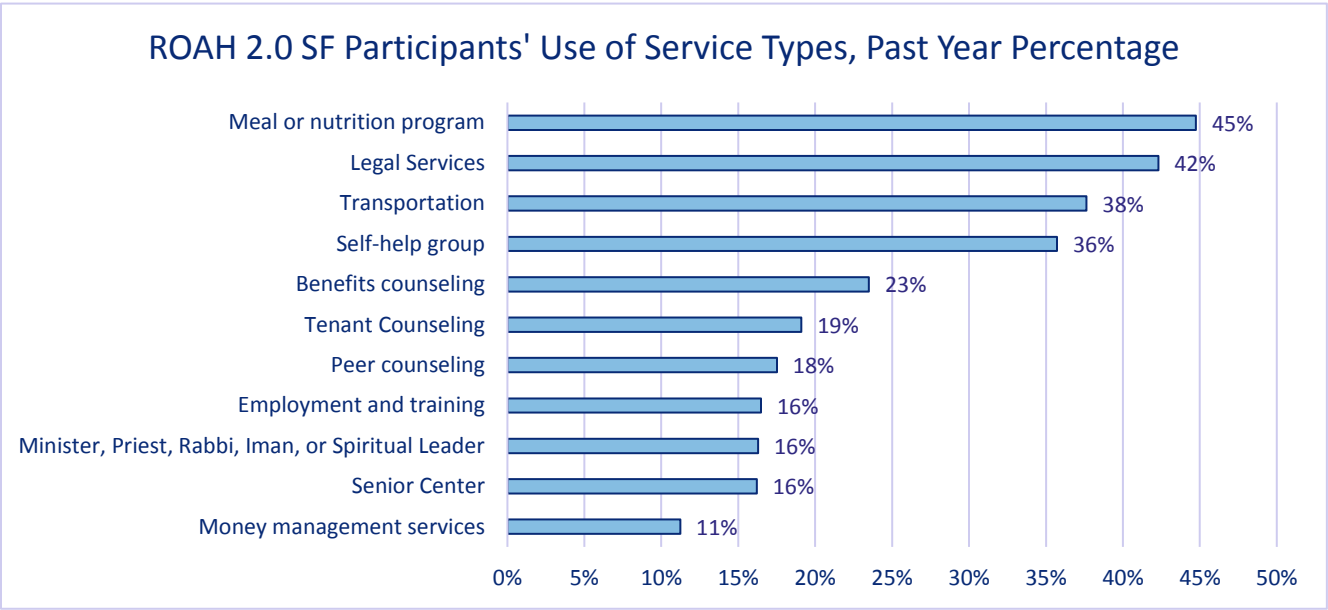
Participants were asked to indicate whether they had accessed services from AIDS service organizations, community agencies that provide services to individuals living with HIV, and/or other-community based organizations in the previous year. Participants most commonly reported accessing services at community-based organizations (CBOs), with 119 reporting use, followed by 116 participants receiving services at AIDS service organizations (ASOs). The high rates of persons obtaining services from CBOs and ASOs may reflect our recruitment strategy, which was largely centered at agencies serving persons living with HIV.

People also reported turning to government agencies. In the past year, 16% of ROAH 2.0 SF participants had not used any government services, but in total the sample turned to an average of 3 government agencies.



Participants also reported on their use of 11 types of services. Given the high rates of food insecurity in this population, it is not surprising that the most commonly accessed service was meal and nutrition programs, with 45% reporting use. Participants also turned to community-based organizations for legal services (42%) and benefits counseling (23%). Thirty-eight percent turned to CBOs for transportation related needs, including programs that alleviated costs and provided rides to services. Nearly a fifth (19%) of participants received tenant counseling, reflective of high cost of housing and concerns about housing costs voiced during the ROAH 2.0 SF focus groups. Respondents sought guidance and support through participation in self-help groups (36%), counseling from peers (18%), and spiritual leaders (16%). Only 16% reported using an employment/training program or attending a senior center, which is expected given the

low rates of employment and the relatively young age of the group. Assistance with money management was the least accessed service, with only 11% reporting use.



Physical Health and Medical Care

HIV-Related Health, Antiretroviral Therapy and Adherence

Most participants' HIV was apparently well managed. All but 7 participants (96%) reported that they were currently taking antiretroviral medication. (Four said they were not taking HIV medication, while three did not reply to this question.) Among those taking HIV medications, 92% reported having an undetectable viral load, a key indicator of HIV treatment success. This is a high percentage relative to the share of all people with HIV in San Francisco who are virally suppressed, just 73%. Ninety-four percent those who reported their current CD4 said it is now above 200 and 62% reported a CD4 count above 500, a level considered normal in a person with a healthy immune system.¹⁰

These strong parameters of HIV control and immune health reflect the power of newer generation antiretroviral medications, as well as participants' adherence to their regimens. Self-reported medication adherence varied: 16% of participants said they had missed a dose of their HIV medications in the last week, while 31% said they had not skipped a dose in the last 3 months or have never missed a dose at all. In the United States, about 55% of people living with HIV have sub-optimal rates of adherence.¹¹

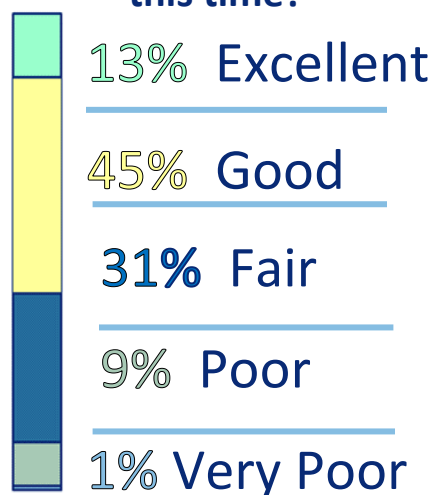
¹⁰ NAM aidsmap. (2017). CD4 Cell Counts [Fact Sheet]. Retrieved from: <http://www.aidsmap.com/CD4-cell-counts/page/1044596/>

¹¹ Mills E.J., Nachega J.B., Buchan I., et al.(2006) Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a metaanalysis. JAMA, 296(6), 679-690.

General Health and Co-morbidities

HIV-related health is only part of the story, of course. People with HIV are vulnerable to all the potential health problems that anyone is susceptible to, and older adults with HIV are particularly susceptible to age-related diseases.¹²

How would you rate your physical health at this time?

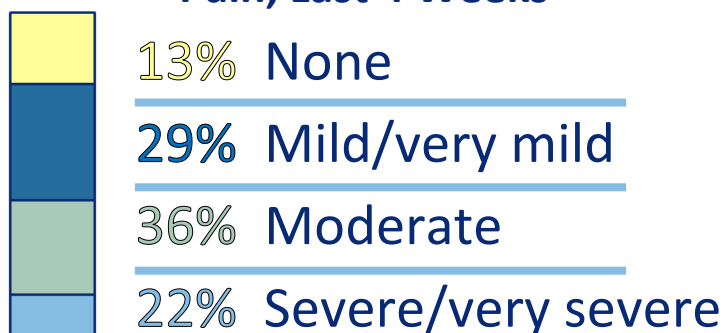


On the whole, most participants felt they were in fine health, with just under half saying their physical health is “good” or “excellent.” Only 10% of the participants felt their health is “poor” or “very poor.”

Participants also reported on how much pain they experience and how it affects their daily lives. Over half of participants said that in the last 4 weeks their pain had been very severe, severe, or moderate. Over a quarter (28%) of participants reported they had pain that had interfered with accomplishing tasks (including house work) in the past 4 weeks “quite a bit” or “extremely.” The same

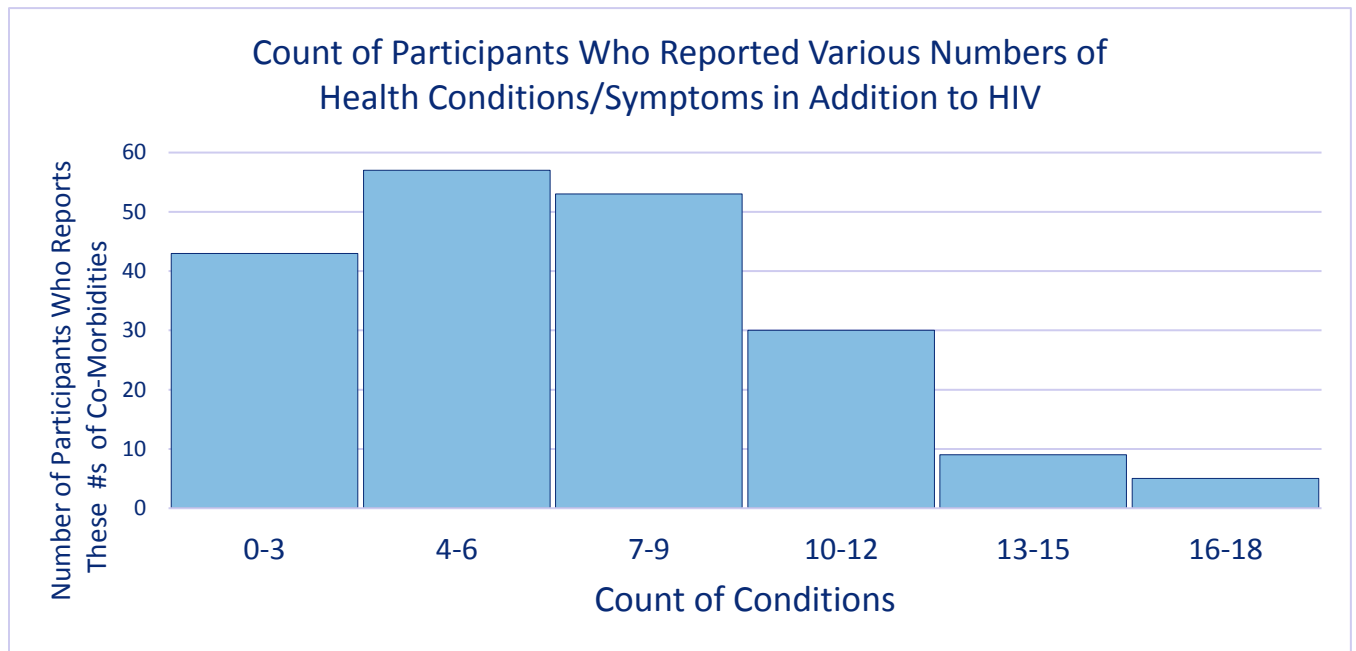
share of participants reported that their health had limited their ability to engage in social activities like visiting with friends or relatives “all of the time” (6%), “most of the time” (8%), or “a good bit of time” (14%). Most of the remaining participants (two-thirds) said that their health impedes their social life to some degree. Just 41 participants (24%) said their health never got in the way of socializing.

Pain, Last 4 Weeks



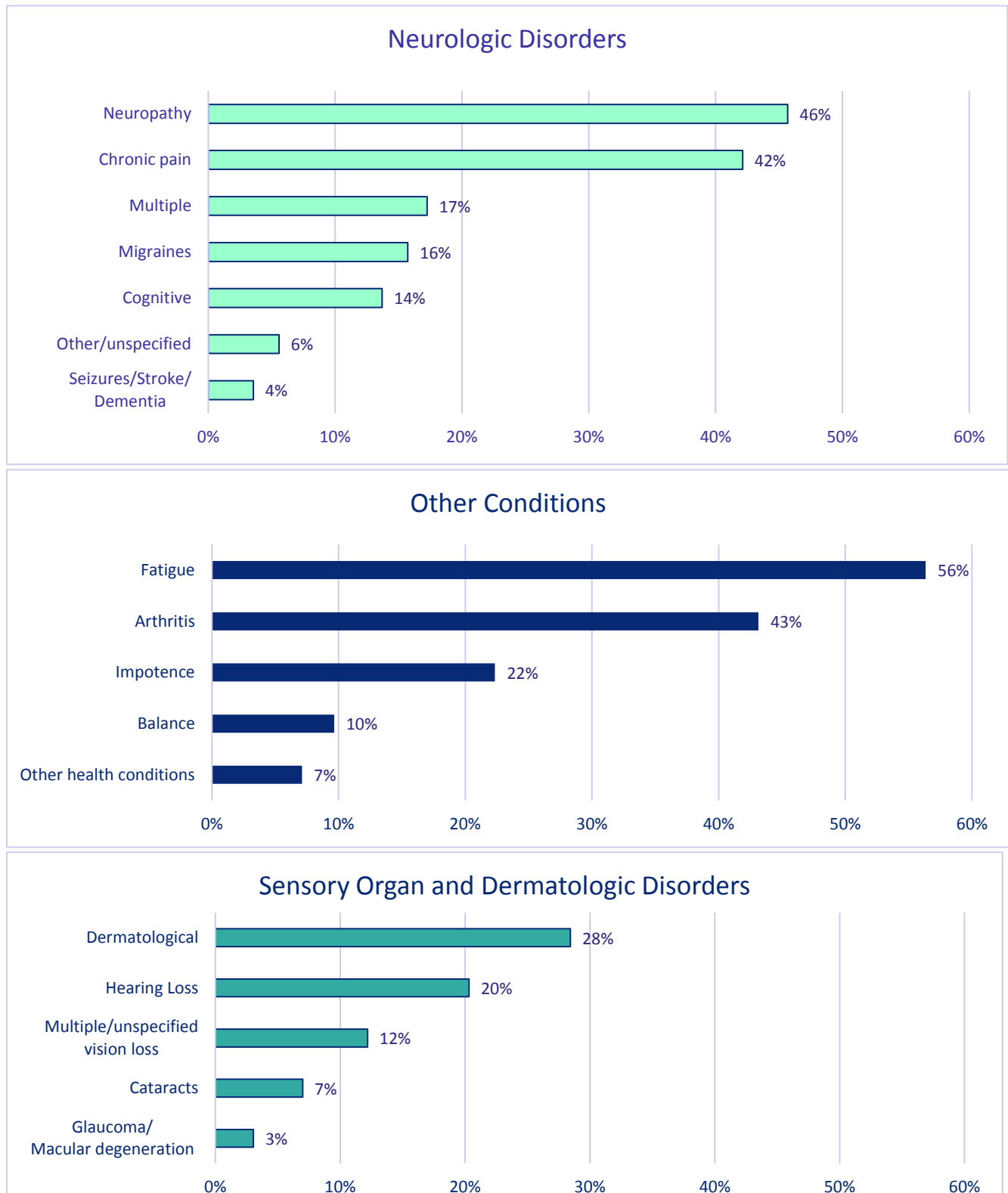
¹² Önen NF, Overton ET, Seyfried W, et al. (2010) Aging and HIV infection: a comparison between older HIV-infected persons and the general population. *HIV Clinical Trials*, 11(2),100–9.

Participants were asked about co-morbidities, the health conditions and symptoms they have experienced in addition to HIV. The participants indicated having an average of 6.7 physical and mental conditions/symptoms each in addition to HIV (out of a total possible count of 59). The bar charts on the following page show how many participants reported experiencing each of the physical health problems. (Three mental health disorders are reported on later in the report, in the section on mental health.) All but two of the 56 physical conditions and 3 mental health conditions were reported by at least one participant. The count of conditions/symptoms reported by participants ranged from 0 to 18.



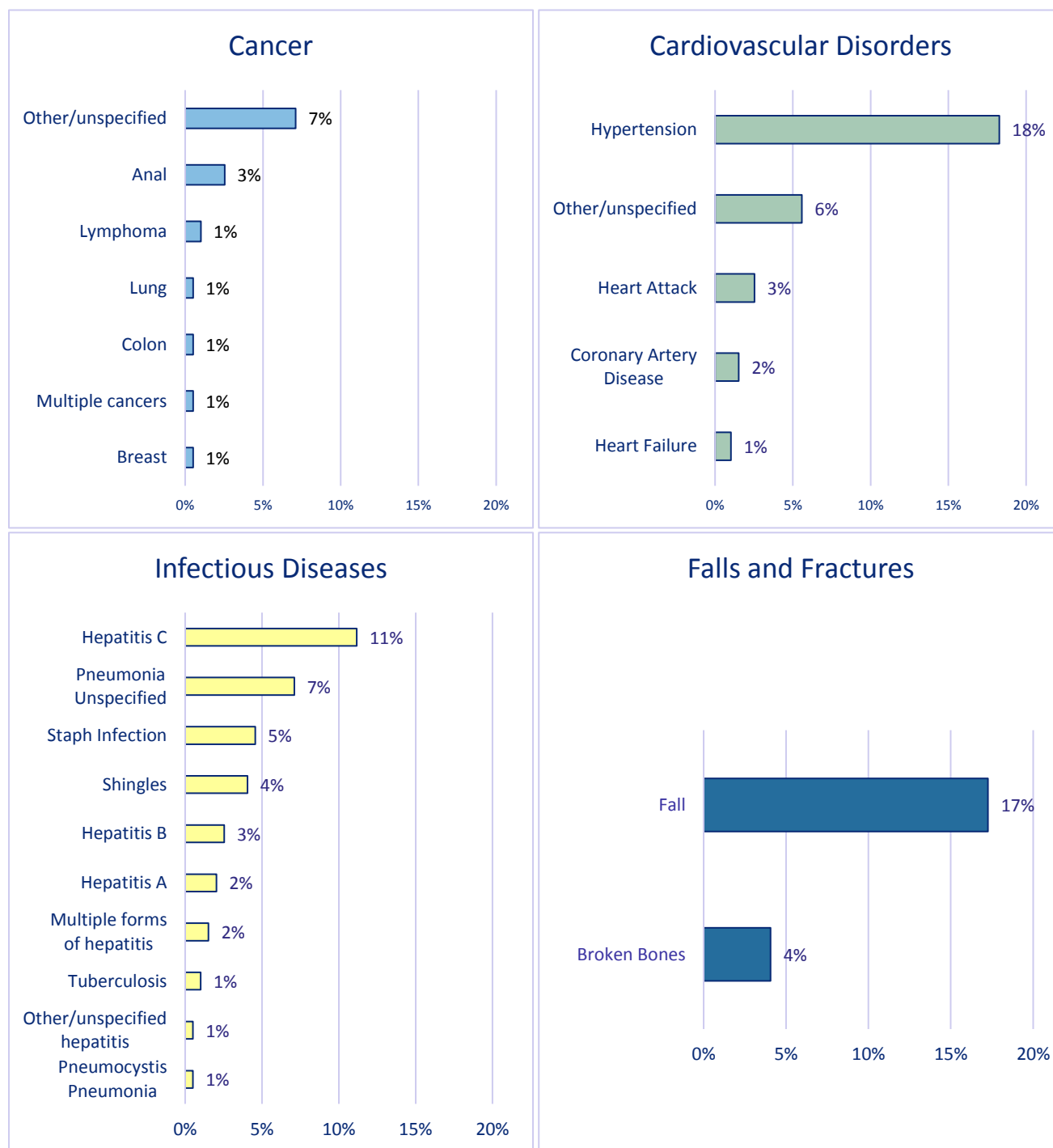
Percentage of ROAH 2.0 SF Participants Reporting Various Health Problems, Past Year

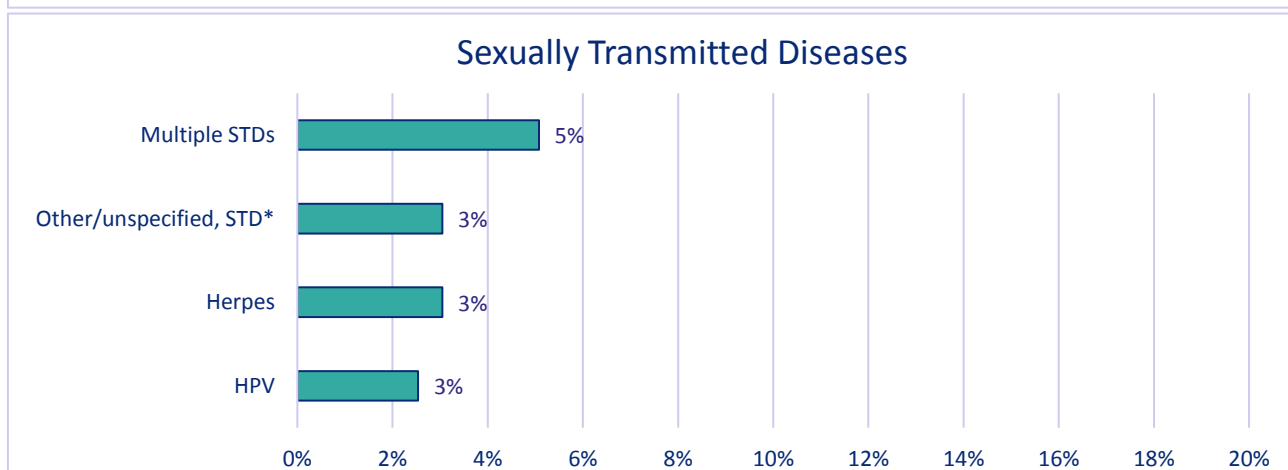
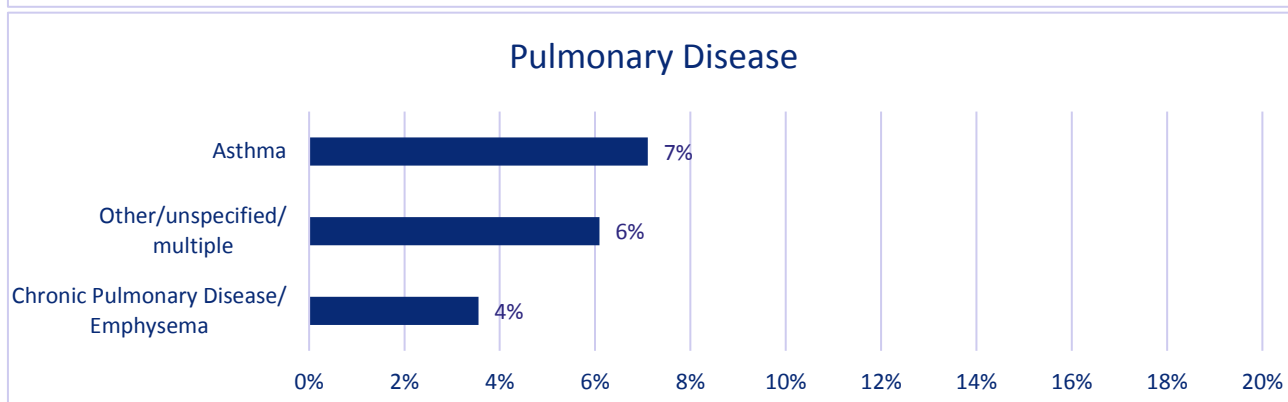
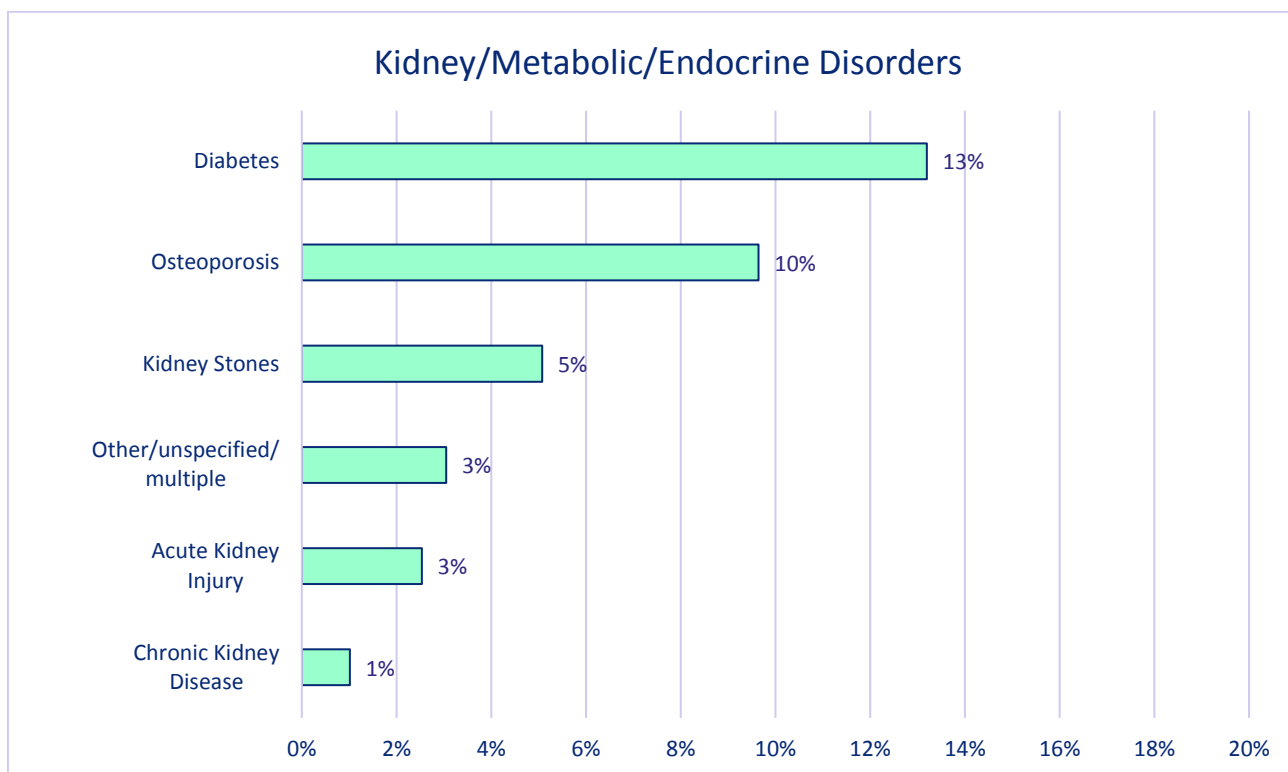
I . Most Common Classes of Disorders



Percentage of ROAH 2.0 SF Participants Reporting Various Health Problems, Past Year

II. Less Common Classes of Disorders

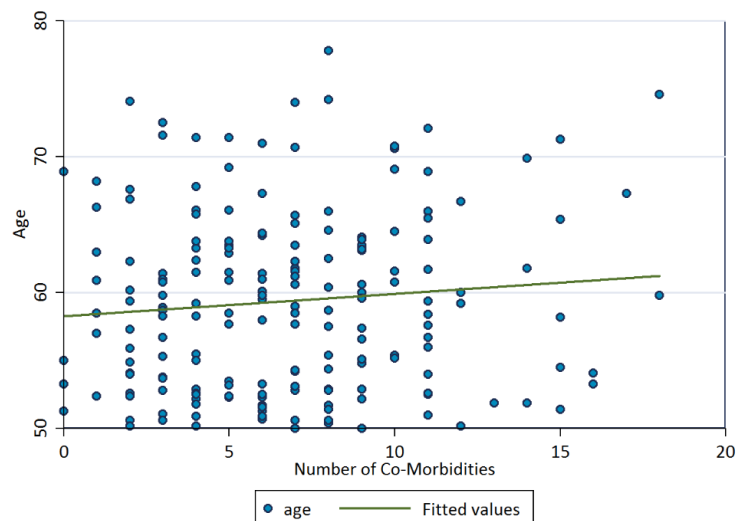




* Other/unspecified STDs includes chlamydia (n=2), gonorrhea (n=1), syphilis (n=1), and unspecified (n=2).

Though we would expect older people to have more health problems, there appears to be little association between age and number of co-morbidities among ROAH 2.0 SF participants. (See below.)

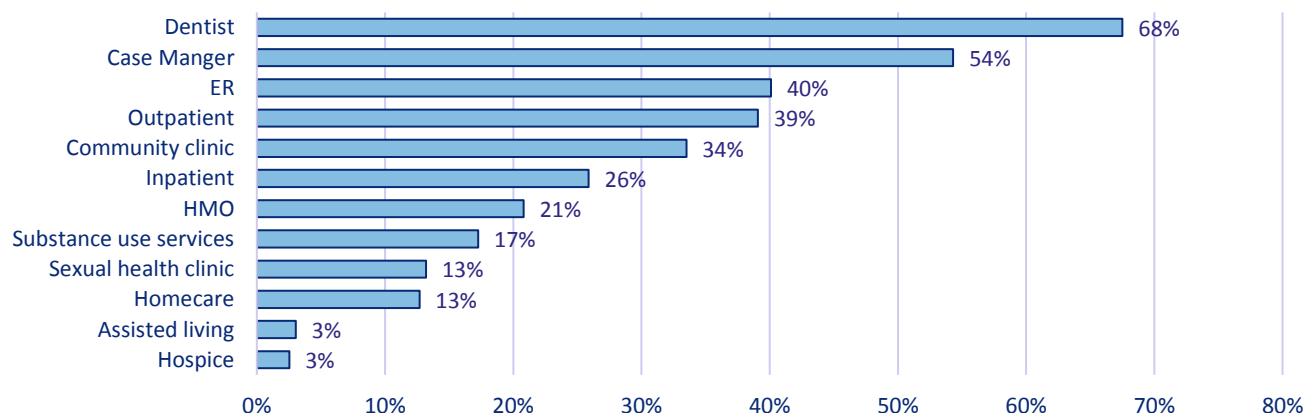
Relationship Between Age and Number of Co-Morbidities
Among ROAH 2.0 SF Participants



Health Service Usage

Participants reported on their use of health services in the past 12 months. Seventy percent of participants reported seeing a physician for HIV care three or more times in the past year, and 58% reported seeing a doctor for non-HIV matters three or more times in the past year. Aside from doctor's offices, the dentist or a dental clinic was the most frequently reported point of access to the health care system for participants, with 68% reporting use of dental services in the last year. Case management was also common, reportedly used by 54% of participants. Hospitals were another frequent point of access: 40% had gone to an emergency department, 39% received outpatient services, and 26% were treated as an inpatient.

ROAH SF Participants Reporting Use of Health Services, Past Year



Mental Health and Wellbeing

Psychological Wellbeing

Psychological wellbeing reflects whether a person is flourishing – feeling good and functioning well.¹³ In the ROAH 2.0 SF survey, three key elements of psychological wellbeing of Ryff’s six-factor model – environmental mastery, purpose in life, and self-acceptance – are assessed with questions from the Psychological Well-Being Scale. Scores on each of the 3 scales range from 9-54 with higher scores indicating higher levels of wellbeing.

Environmental mastery	
Definition	An individual’s ability to adapt and manage the environment around them to meet personal needs and values
Higher scores indicate	Feeling in command of the situation; able to cope, adjust, and adapt to problems

The average environmental mastery score of the ROAH 2.0 SF participants was 36, 4.5 points above the scale mid-point of 31.5. Environmental Mastery scores were significantly higher among black participants (40.2) when compared to both white (35.0) and Latino respondents (34.3). No significant gender or age differences were found. These findings suggest that ROAH 2.0 participants on the whole felt somewhat confident in their ability to manage themselves in the environment around them despite the challenges of living with HIV.

Purpose in life	
Definition	A sense of meaning in one’s past and present life
Higher scores indicate	Having goals and a sense of direction; seeing meaning in life both past and present

Of the 3 psychological well-being scales, ROAH 2.0 SF participants scored lowest on this domain, scoring just above the scale’s midpoint (31.6). When analyzing these findings by race, white and Latino participants scored below the scale point averaging 29 and 30, respectively. The average score among black respondents was 34.9. No differences emerged by gender or age category.

¹³ Ryff, C.D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069-1081

Self-Acceptance

Definition	The ability to accept both positive and negative aspects of oneself
Higher scores indicate	Feeling positively about one's current self and past behaviors and choices

On average, ROAH 2.0 participants scored 4.5 points above the scale midpoint of 31.5 for self-acceptance suggesting that participants largely maintain a positive outlook on life despite facing the stigma of living with HIV. Black respondents scored an average of 38.4, significantly higher than Latinos (31.9). When analyzed by gender, transgender respondents scored highest at 40.4, followed by cisgender women (35.2) and cisgender men (33.2). There were no differences by age group.

Comparison with the General Population: The ROAH 2.0 SF participants' scores on each of the three domains of psychological wellbeing (environmental mastery, purpose in life and self-acceptance) were compared with the scores of participants in a nationwide, representative study of adults.¹⁴ Scores on these measures were significantly lower among ROAH 2.0 SF participants than in the national sample. This is consistent with previous research, which has found lower levels of psychological well-being among older adults living with HIV.¹⁵ The lower scores among this study's older adults with HIV sample suggest that the challenges of living with HIV, combined with other stressors commonly faced by this population (including low economic status and the presence of depressive symptoms) negatively impact psychological well-being.

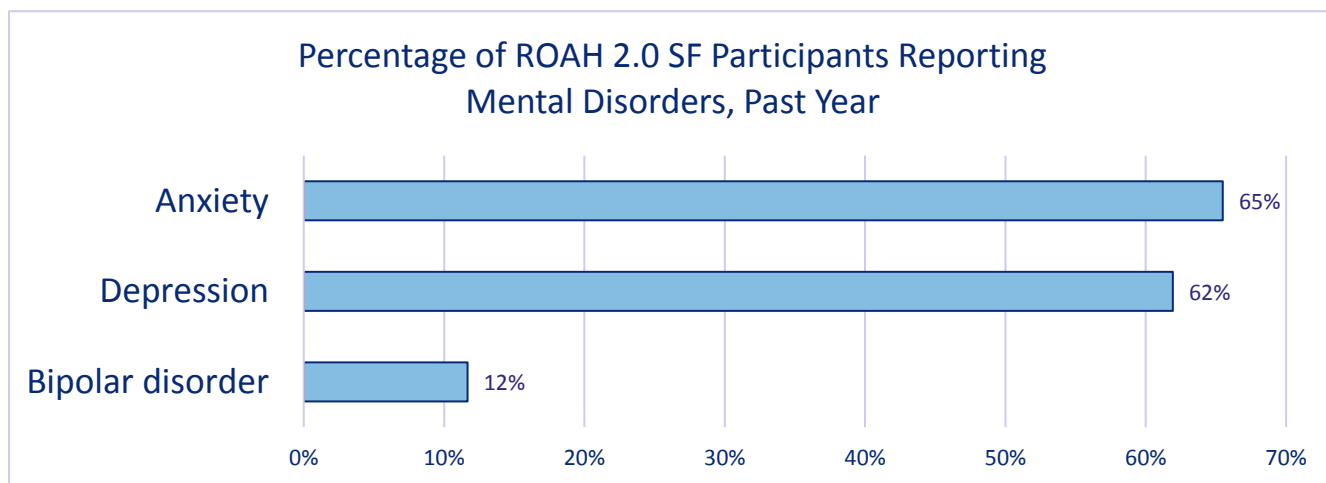
Mental Health

Participants were specifically asked if they had been diagnosed with anxiety, bipolar disorder, and depression, and a high share reported having each condition in the past year. Past-year depression and anxiety were reported by well over half of participants. Prevalence of bipolar disorder was lower (reported by 12%) but still high if you take into consideration bipolar disorder's severity and lower prevalence (present in 2.8% of the population in the United States¹⁶).

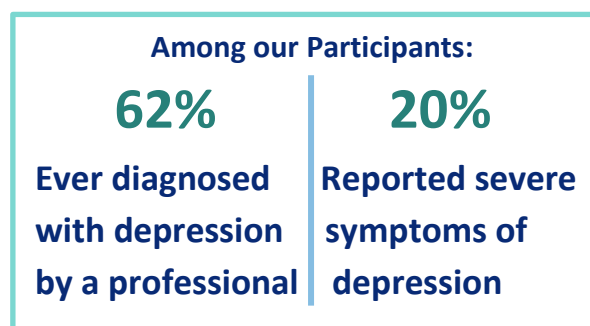
¹⁴ Ryff, C. D., & Keyes, C. L. M. (1995). The structure of psychological well-being revisited. *Journal of Personality & Social Psychology*, 69(4), 719-727.

¹⁵ Brennan, M., Karpiak, S. E., Shippy, R. A., & Cantor, M. H. (Eds.). (2009). Older adults with HIV: An in-depth examination of an emerging population. New York, NY: Nova Science Publishers.

¹⁶ Merikangas, K.R., Akiskal, H. S., Angst, J., Greenberg, P. E., Hirschfeld, R. M. A., Petukhova, M., & Kessler, R. C. (2007). Lifetime and 12-Month Prevalence of Bipolar Spectrum Disorder in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 64(5), 543–552.



Depression: Previous research told us to expect very high levels of depression amongst the ROAH 2.0 SF participants,¹⁷ and, indeed, this is what was found. Depression was measured in three ways. As shown above, 62% of ROAH 2.0 SF participants checked-off depression amongst a long list of other conditions, indicating having been depressed in the past year. Participants were later asked to say if they had ever been diagnosed with depression, and how recently. Being ever diagnosed with depression was also reported by 62% of participants; slightly more than half (51%) were first diagnosed over 15 years ago. Finally, depressive symptoms were measured with validated scales, including the PHQ-9, a widely used assessment of characteristic symptoms of depression.¹⁸



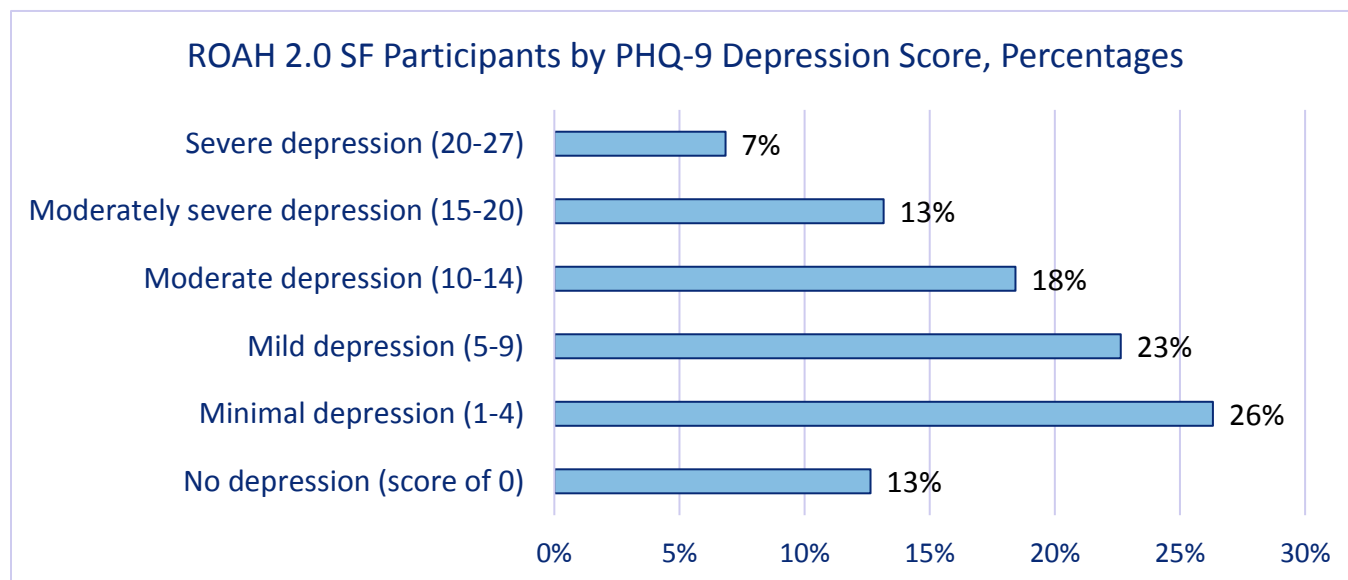
Scores on the PHQ-9 by the participants ranged from 0, the minimum score, to 27, the maximum possible score. Scoring above 10 is a strong indicator that a person has some form of depression.¹⁹ About two in five (38%) of those who completed the PHQ-9 scored over this threshold, meaning they likely have at least moderate depression. One in five (20%) had a score above 15, suggestive of severe or very severe depression.

¹⁷ Grov, C., Golub, S. A., Parsons, J. T., Brennan, M., & Karpiak, S. E. (2010). Loneliness and HIV-related stigma explain depression among older HIV-positive adults. *AIDS Care*, 22(5), 630–639.

¹⁸ Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine*, 16(9), 606–613.

¹⁹ Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), 606–613.

Scores on the PHQ-9 can also be broken down by how well the participants meet the standard diagnostic definition of depression; 22% had a score that suggests a clinician should consider the diagnosis of major depression and 8% had a score suggestive of a diagnosis of another depressive disorder.



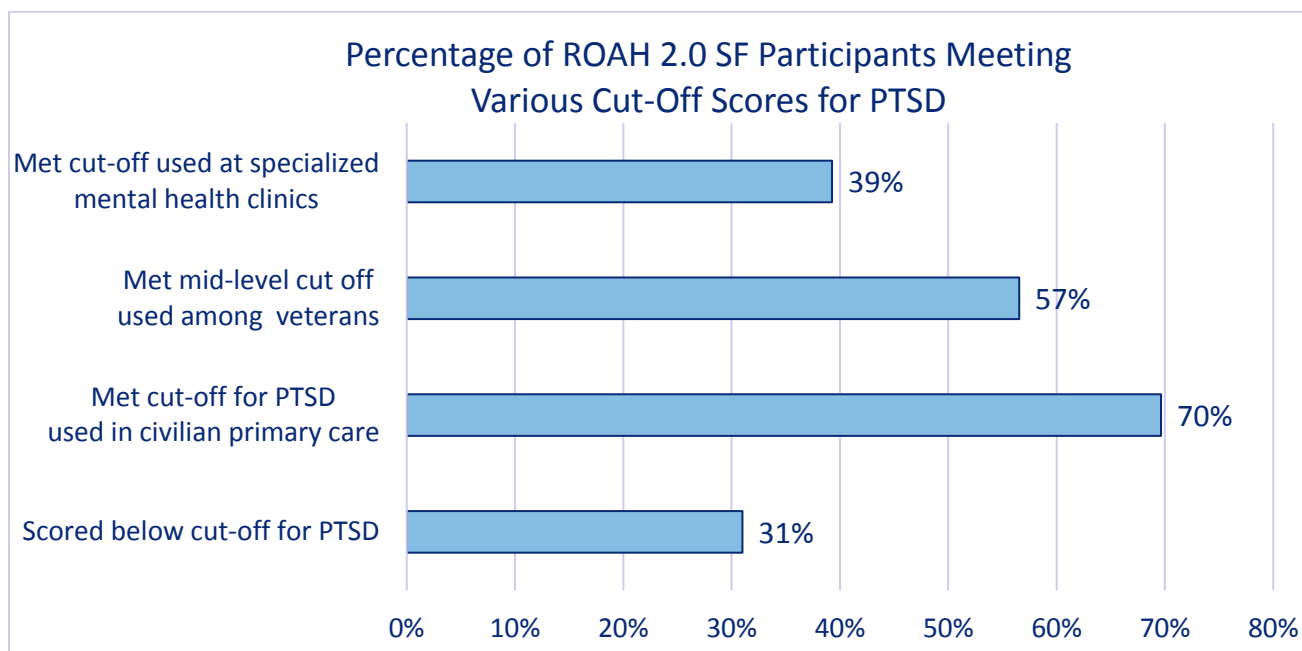
Trauma: A history of trauma is common amongst people living with HIV, and the struggle of living with HIV (possibly enduring stigma, discrimination, fear of death and illness, and loss of peers who are also HIV positive) can itself be traumatic.²⁰ Post-traumatic stress disorder (PTSD) is a prolonged harmful reaction to a shocking, scary, or dangerous event that can cause disordered thoughts, behaviors, and feelings.

Self-reported symptoms of PTSD were common. There are several ways to assess responses to the PTSD Checklist, the 17-item validated scale used in ROAH 2.0 SF.²¹ The median score on the checklist was 39 out of a maximum score of 85. Depending on what criteria you apply, the rate of PTSD among the participants may range from 35% (the percentage who show the standard symptom pattern and the highest level of symptom severity) to 70% (based on a lower cut-off point for symptom severity appropriate for civilian primary care). This is at the high end of previously reported rates of PTSD among people living with HIV, which have ranged from 10% to 74% (versus 8% in the general population).²²

²⁰ Greene, M., Hessel, N.A., Zepf, R., et al. (2016) Geriatric Assessments and Association with VACS index among HIV-Infected Older Adults in San Francisco. *Journal of Acquired Immune Deficiency Syndromes*, 72(5), 534–541.

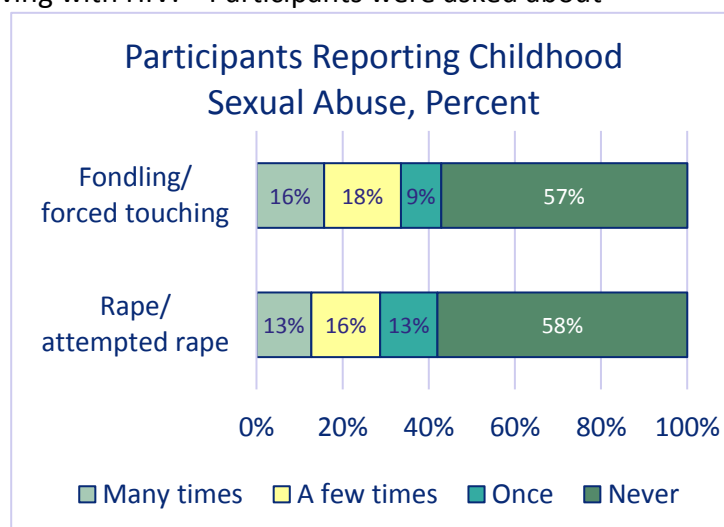
²¹ National Center for Posttraumatic Stress Disorder. (2012). Using the PTSD Checklist (PCL) Retrieved from: <https://sph.umd.edu/sites/default/files/files/PTSDChecklistScoring.pdf>.

²² Applebaum, A. J., Bedoya, C. A., Hendriksen, E. S., Wilkinson, J. L., Safren, S. A., & O’Cleirigh, C. (2015). Future directions for interventions targeting PTSD in HIV-infected adults. *The Journal of the Association of Nurses in AIDS Care : JANAC*, 26(2), 127–138.



While living with HIV can be traumatic, people may also be more likely to have experienced traumas independent from their experiences as people living with HIV.²³ Participants were asked about experiences of sexual abuse before the age of 16, including unwanted touching, rape, and attempted rape. About half (51%) had had at least one of those experiences. Additionally, 52% of those who answered the set of questions on interpersonal violence reported being a victim of domestic violence by a partner at some point in their lives.

Those reporting either type of sexual abuse had significantly higher scores on the PTSD Checklist than those who reported neither, with an average score of 44 vs. 37($p < .01$).



Mental health care: In the past year, 44% of participants reportedly had received mental health services of some kind. Even more, 47%, said they take medications to treat anxiety or depression. Among those who had ever been diagnosed with depression, 91% had received community-based care and 16%

²³ LeGrand, S., Reif, S., Sullivan, K., Murray, K., Barlow, M. L., & Whetten, K. (2015). A review of recent literature on trauma among individuals living with HIV. *Current HIV/AIDS Reports*, 12(4), 397–405.

had been hospitalized for treatment of depression. Among those with moderate to very severe depression, 41% reported receiving no mental health care in the past year. Among those with post-traumatic stress disorder assessed by the most conservative criteria, 35% reported receiving no mental health care in the past year.

Social Connection and Loneliness

Loneliness is the subjective experience of feeling socially isolated.²⁴ Prior research has found that loneliness is more common in older adults. The negative effects of loneliness are well documented with research findings that loneliness is related to depression and poor health outcomes in persons living with chronic illnesses.

Loneliness was measured with 10 questions. Higher scores indicate higher levels of loneliness. The ROAH 2.0 SF participants exhibited high levels of loneliness with 21% scoring in the “lonely” range and 22% scoring in the range considered “very lonely.” This echoes the findings of a study of 356 older adults with HIV at the UCSF Silver Project, which found 58% of participants reported some degree of loneliness.²⁵

Stigma

HIV-related stigma – fears, prejudices, or negative attitudes about HIV – remains a pressing challenge for people with HIV.²⁶ A 13-question, validated measure of HIV stigma asked ROAH 2.0 SF participants how often they had certain experiences, such as feeling ashamed of their illness or fearing their family would be harmed because of their HIV status. The participants’ scores ranged from 13 to 50 (versus a possible range of 13 to 52, higher scores meaning worse stigma), with an average score of 21 ± 8 . In comparison, the ROAH 2.0 SF scores are slightly lower than the scores found among older (age ≥ 50) adults in a recent study in the Pacific Northwest, who had an average score of 23.²⁷

²⁴ Hawkey, L. C., & Cacioppo, J. T. (2010). Loneliness Matters: A Theoretical and Empirical Review of Consequences and Mechanisms. *Annals of Behavioral Medicine : A Publication of the Society of Behavioral Medicine*, 40(2)

²⁵ Greene, M., Hessel, N. A., Perissinotto, C., Zepf, R., Parrott, A. H., Foreman, C., ... & John, M. (2018). Loneliness in older adults living with HIV. *AIDS and Behavior*, 22(5), 1475-1484.

²⁶ Florom-Smith, A. L., & De Santis, J. P. (2012). Exploring the Concept of HIV-Related Stigma. *Nursing Forum*, 47(3), 153–165.

²⁷ Emlet, C. A. (2005). Measuring Stigma in Older and Younger Adults with HIV/AIDS: An Analysis of an HIV Stigma Scale and Initial Exploration of Subscales. *Research on Social Work Practice*, 15(4), 291-300.

Sexual Health

Despite the stereotype that older adults do not have sex,²⁸ many of the participants (65%) reported being sexually active in the past year. However, a large portion of those who are sexually active share report having sex less frequently than older adults at large in the United States.²⁹ Thirty-two percent of all participants had sex in the past month. Among those who had sex in the past year, 40% said they had sex once a month or less often.

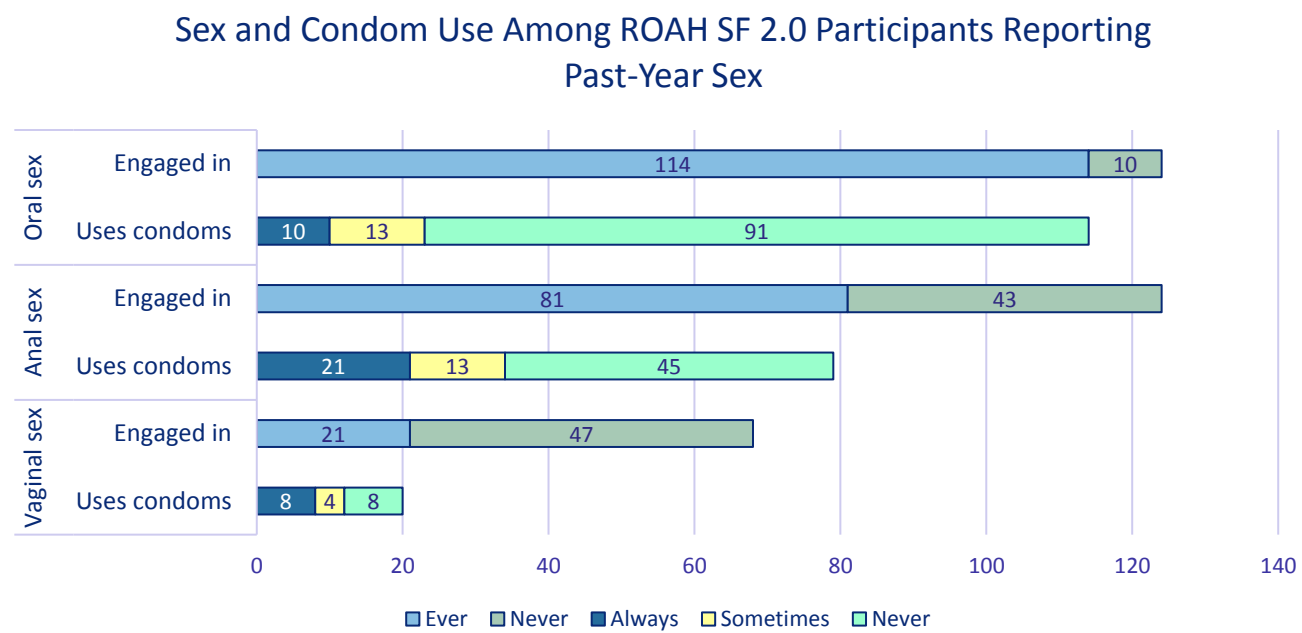
Among our Participants:

65%

Had Sex in
the Past Year

32%

Had Sex in
the Past Month



Participants who reported past-year sex were asked about what kinds of sex they have and how often they use condoms when doing these sex acts. Among these participants, 92%, 63%, and 17% reported having oral, anal and vaginal sex. Most did not consistently use condoms when performing these three types of sex. This finding needs to be seen in the context of the participants’ health and their use of other risk reduction strategies. Nearly all participants reported an undetectable viral load, and for those

²⁸ Gewirtz-Meydan A, Hafford-Letchfield, T, Benyamini, Y, Phelan, A, Jackson, J, & Ayalon, L. (2018). Ageism and sexuality. In L. Ayalon & C. Tesch-Römer (Eds.), Contemporary perspectives on ageism: Vol. 19. International perspectives on aging (pp. 149–162). Berlin: Springer.

²⁹ Karraker, A., DeLamater, J., & Schwartz, C. R. (2011). Sexual frequency decline from midlife to later life. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 66B(4), 502–512.

participants who have sustained viral suppression there is negligible risk of sexual HIV transmission.^{30,31} Further, sexual partner choice and use of pre-exposure prophylaxis for HIV (PrEP) can further mitigate risk. Among sexually active participants, 44% reported that their most recent sexual partner was HIV positive, and among the remainder with an HIV negative partner, 18% said they believed that partner uses PrEP.

Substance Use

Substance use poses dangers to people living with HIV. It can interfere with access to health care and HIV treatment, cause disease and injury, and lead to addiction and increased risk for other mental health disorders.³² Substance use, including use of illicit drugs and misuse of prescription drugs, is common among the participants. Three quarters report ever using at least one drug illegal in the state of California – methamphetamine, cocaine/crack, or heroin – and 20% report such use in the past 3 months. Of these, lifetime cocaine use was most common, but recent use of methamphetamine was most common, with past 3-month use reported by 17% (n=34) participants. Marijuana, however, was the most often reported type of federally controlled substance used by participants, either ever (n=152) or in the past 3 months (n=92).

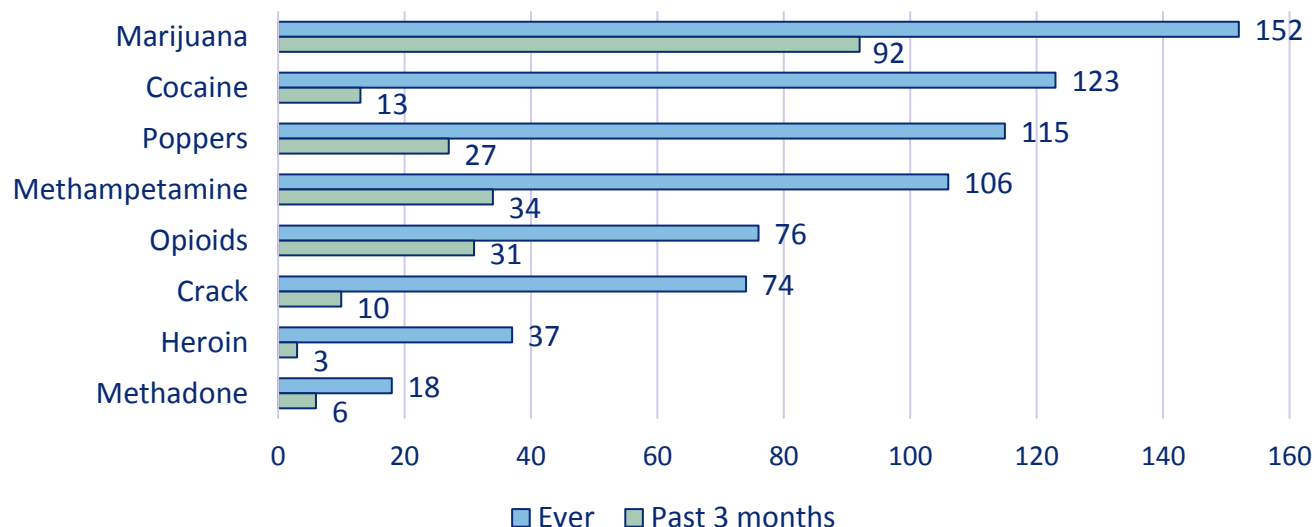
Nearly 90% of the participants who reported opioid use said they were taking medication that had been prescribed to them. On the other hand, 20% of participants who have been prescribed opioids reported having used prescription drugs for reasons other than prescribed or more frequently than prescribed. In total, 14% of participants reported prescription drug misuse.

³⁰ Rodger A, Cambiano V, Bruun T, et al. (2016). Sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy. *JAMA*, 316(2), 171-181

³¹ Rodger A et al.(2018). Risk of HIV transmission through condomless sex in gay couples with suppressive ART: the PARTNER2 study expanded results in gay men. 22nd International AIDS Conference, Amsterdam, abstract WEAX0104LB.

³² Altice, F. L., Kamarulzaman, A., Soriano, V. V., Schechter, M., & Friedland, G. H. (2010). Treatment of medical, psychiatric, and substance-use comorbidities in people infected with HIV who use drugs. *Lancet* (London, England), 376(9738), 367–387.

Counts of ROAH 2.0 SF Participants Reporting Substance Use, Lifetime and Past 3 months



Alcohol and tobacco use are common among people with HIV.³³ Tobacco use among people with HIV substantially increases the risk of death from both HIV-related causes and all causes.³⁴ Alcohol use is associated with high risk sex and drug injection, lowered odds of antiretroviral adherence and viral suppression, and physical and mental disorders.³⁵ A large share of participants drank alcohol at some point in their lives (88%), and 69%

Among Participants:

69% Currently drink alcohol

22% Currently use tobacco

³³ Pacek, L. R., & Cioe, P. A. (2015). Tobacco use, use disorders, and smoking cessation interventions in persons living with HIV. *Current HIV/AIDS Reports*, 12(4), 413–420.

Mdodo R., Frazier E.L., Dube S.R., et al. (2015). Cigarette smoking prevalence among adults with HIV compared with the general adult population in the United States: cross-sectional surveys. *Ann Intern Med*, 162(5), 335–344.

Chander, G., Josephs, J., Fleishman, J., Korthuis, P., Gaist, P., Hellinger, J., ... for the HIV Research Network. (2008). Alcohol use among HIV-infected persons in care: results of a multi-site survey. *HIV Medicine*, 9(4), 196–202.

³⁴ Helleberg, M., Afzal, S., Kronborg, G., Larsen, C.S., Pedersen, G.F., Pedersen, C., Gerstoft, J., Nordestgaard, B.G., & Obel, N. (2013). Mortality attributable to smoking among HIV-1-infected individuals: a nationwide, population-based cohort study. *Clinical infectious diseases: an official publication of the Infectious Diseases Society of America*, 56(5), 727–34.

³⁵ Chander, G., Lau, B., & Moore, R. D. (2006). Hazardous alcohol use: a risk factor for non-adherence and lack of suppression in HIV infection. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 43(4), 411–417.

Scott-Sheldon, L. A. J., Walstrom, P., Carey, K. B., Johnson, B. T., Carey, M. P., & the MASH Research Team. (2013). Alcohol use and sexual risk behaviors among Individuals Infected with HIV: A systematic review and meta-analysis 2012 to early 2013. *Current HIV/AIDS Reports*, 10(4), 314–323.

Baum, M. K., Rafie, C., Lai, S., Sales, S., Page, J. B., & Campa, A. (2010). Alcohol use accelerates HIV disease progression. *AIDS Research and Human Retroviruses*, 26(5), 511–518.

Sullivan, L. E., Goulet, J. L., Justice, A. C., & Fiellin, D. A. (2011). Alcohol Consumption and Depressive Symptoms Over Time: A Longitudinal Study of Patients With and Without HIV Infection. *Drug and Alcohol Dependence*, 117(2-3), 158–163.

currently drink. Binge drinking (6 or more units of alcohol on a single occasion if female or 8 or more if male) was reported by 26% of participants who consume alcohol; 9% said they binged weekly or daily/near daily. Current tobacco use was reported by 22% of participants, while 35% had used tobacco in the past but no longer use it, and 43% never used tobacco. The rates of current and former smoking found among the ROAH 2.0 SF participants are low relative to the findings of studies of people with HIV at large.

Forty-three (26%) of participants said they consider themselves “currently in recovery.” Alcohol and methamphetamine were the most common forms of addiction participants had recovered from, each reported by 21 individuals. Few (5) were in recovery from heroin. Being in recovery from addiction to other unspecified substances besides alcohol, methamphetamine, or heroin was reported by 13 individuals. Sixteen individuals said their recovery was longstanding (with at least 10 years of sobriety), and 12 were newly recovered, with less than 3 months of “sober time.”

Implications

This section draws lessons from findings of the ROAH 2.0 San Francisco Study, including the ROAH 2.0 survey research detailed in the pages before this one and the focus groups, which are reported on in Appendix A. Below is a discussion of four areas where services for older adults with HIV might be improved: mental health treatment; social support; financial, housing, and nutritional assistance; and care for co-morbidities.

Mental health treatment

Improving Access: Lack of access to mental health treatment is a significant problem for some older adults with HIV, ROAH 2.0 SF survey data indicates. This is consistent with findings from the ROAH 2.0 SF focus groups: better access to mental health care was ranked as an urgent need by the focus group participants. Many of the survey participants report receiving mental health care and nearly half report taking medication for anxiety/depression, but it seems mental health care needs to be better targeted and more effectively delivered. Many of those who appear to be most in need of mental treatment aren't receiving it. Among those who had symptoms of moderate or severe depression, 41% had not received mental health services in the past year. Similarly, 38% of those who would be considered likely to have PTSD by the most stringent standards had received no mental health care in the past year.

Tailoring Treatment to Older Adults with HIV: It's worth considering how we can maximize the effectiveness of mental health treatment for older adults with HIV. There are indications that the roots of the anxiety, depression, and PTSD we are seeing in this population are longstanding. Over 83% of participants were first diagnosed with depression over 5 years ago (and over half more than 15 years ago). Duration of trauma symptoms wasn't asked by the survey, but we do know that many of the survey participants have a history of trauma stretching back to childhood, as 51% reported sexual abuse before the age of 16. Additionally, among those who answered the set of questions on interpersonal violence, 52% reported being a victim of domestic violence by a partner at some point in their lives. Therapies that address traumatic histories may be effective avenues for addressing the high rates of mental illness in this population. Those offering mental health treatment should take into account both the trauma intrinsic to living with HIV (especially the trauma of living with HIV prior to the introduction of highly active antiretroviral therapy in 1996) and the other traumas common amongst people living with HIV.³⁶ (Providers of medical care should also be delivering trauma-informed care to this population.)

³⁶ LeGrand, S., Reif, S., Sullivan, K., Murray, K., Barlow, M. L., & Whetten, K. (2015). A review of recent literature on trauma among individuals living with HIV. *Current HIV/AIDS Reports*, 12(4), 397–405.

More generally, we should ensure that mental health care providers who serve older adults with HIV are aware of and sensitive to the unique constellation of factors that are associated with poor mental health. In the ROAH 2.0 SF focus groups, a number of participants expressed the desire for their experiences to be better acknowledged and understood. They doubted that people who didn't understand this could effectively help them. Sensitivity to the situation of older adults with HIV means not only understanding the challenges of this population, but also appreciating and tapping into their resilience.³⁷ (See the ROAH 2.0 SF Focus Group report in Appendix A for more on mental health needs and a discussion of factors facilitating positive aging among older adults with HIV.)

Enhancing Social Support

The ROAH 2.0 SF survey participants report feeling loneliness (43% scoring “lonely” or “very lonely”). This is consistent with past studies,³⁸ and ROAH 2.0 SF focus groups participants reported the same longing for personal connection. Loneliness and isolation were chief complaints among focus group participants, sometimes traced to lack of family support. Strikingly, one focus group participant stated, “There are things that are worse than AIDS, like loneliness.”

Offering more opportunities for older adults with HIV to socialize, whether building on existing programs or creating new ones, must be made a primary goal. Survey participants reported desiring more opportunities to socialize and many focus group participants were similarly eager for more opportunities to spend time with others. When providing social opportunities to older adults, it will be important to listen carefully to older adults with HIV in determining what types of social opportunities they would favor.

Financial, Housing and Nutritional Assistance

It is evident that the ROAH 2.0 SF participants are enduring serious financial strain. About half characterize their income as “just enough to get by” and a quarter say, “I do not have enough to cover my living expenses.” Seven percent of all participants reported having no permanent residence and 11% reported living in an SRO. Housing is a significant strain on the budget of most participants, costing so much that it absorbs about half or more than half of their total income. SF ROAH 2.0 focus group

³⁷ Emlet, C.A., Tozay, S., & Raveis, V.H. (2011). “I’m Not Going to Die from the AIDS”: Resilience in aging with HIV disease. *Gerontologist*, 51(1), 101–111.

³⁸ Emlet C.A. (2006). An examination of the social networks and social isolation in older and younger adults living with HIV/AIDS. *Health and Social Work*, 31:299–308.

Shippy R.A., Karpiak S.E. (2005). Perceptions of support among older adults with HIV. *Research on Aging*, 27:290–306. doi: 10.1177/0164027504273780.

participants also stressed their high concern about being able to maintain their housing in San Francisco. It is likely that older adults with HIV in San Francisco, so often reliant on fixed incomes, are becoming increasingly vulnerable to displacement or homelessness as the city's market rate housing prices surge. (A small but significant share of survey participants, 7, had been evicted in just the last six months.) Inadequate income, high housing costs, and homelessness are complex problems with few inexpensive solutions, but they cannot be ignored.

Making certain everyone has enough to eat may seem to be a less intractable problem. However, despite 45% of the survey participants having accessed nutritional services in the past year, many of them are experiencing hunger or food insecurity (19% food insecure without hunger and 25% food insecure with hunger). Curiously, those accessing nutrition support services were not significantly less likely to report hunger or food insecurity. Forty-three percent of those with hunger in addition to food insecurity were already getting nutrition services. Additional inquiry into why there is so much hunger and food insecurity among the ROAH 2.0 SF survey participants and what barriers are impeding their access to adequate nutrition is warranted.

Managing Co-Morbidities

While it seems that ROAH 2.0 SF participants largely have well managed HIV (judging by the percentage reporting taking HIV medication and having a recent undetectable viral load), their health is in many cases challenged by a high burden of non-HIV disease. Some of these diseases, such as peripheral neuropathy, may be the consequence of HIV or HIV treatment. Others are separate problems that share risk factors with HIV, such as hepatitis C. Still others, like heart disease and stroke, are associated with lifestyle factors that may be more common among people living with HIV. As a consequence of their various health problems, many of the participants report substantial pain levels and disability. They also take many medications, many of them over-the-counter drugs and prescriptions drugs for non-HIV conditions. Polypharmacy can lead to side-effects, drug-drug interactions, falls, and reduced quality of life.³⁹

Care guided by geriatric care principles – which emphasize function and quality of life, the avoidance of polypharmacy and other potentially harmful treatment, special attention to the diseases associated with aging, consideration of the social characteristics of the patient, and a multi-disciplinary approach⁴⁰ – could

³⁹ Holtzman C, Armon C, Tedaldi E, et al. (2013). Polypharmacy and risk of antiretroviral drug interactions among the aging HIV-infected population. *J Gen Intern Med.*, 28(10), 1302–1310.

⁴⁰ Flacker, J., Eskildsen M., Price T., et al. (2012). Computer based learning workbook, 3rd edition. POGOe-Portal of Geriatrics Online Education. Retrieved from: <http://www.pogoe.org/productid/21036>.

be helpful to older adults with HIV coping with many disorders and a high pill burden.⁴¹ Efforts like the Golden Compass clinic at Zuckerberg General Hospital are making geriatric care integrated with HIV care accessible to some older adults with HIV.⁴² To the extent possible, more older adults with HIV should see a physician trained in geriatrics. However, given the national shortage of geriatricians,⁴³ it may be impossible for all older adults with HIV in San Francisco to be treated by a specialist in geriatrics. Enhancing HIV care providers' familiarity with the fundamentals of geriatric care, so that more older adults with HIV can benefit from the geriatric care approach, may be a fruitful tactic.⁴⁴

⁴¹ Greene, M., Steinman, M. A., McNicholl, I. R., & Valcour, V. (2014). Polypharmacy, drug–drug interactions, and potentially inappropriate medications in older adults with human immunodeficiency virus infection. *Journal of the American Geriatrics Society*, 62(3), 447-453.

⁴² Siegler E.L., & Brennan-Ing, M. (2017). Adapting systems of care for people living with HIV. *JANAC*, 28(5), 698-707.

⁴³ U.S. Department of Health and Human Services Health Resources and Services Administration, Bureau of Health Workforce National Center for Health Workforce Analysis (2017). National and Regional Projections of Supply and Demand for Geriatricians: 2013-2025. Rockville, Maryland.

⁴⁴ Kearney, F., Moore, A. R., Donegan, C. F., & Lambert, J. (2010). The ageing of HIV: implications for geriatric medicine. *Age and ageing*, 39(5), 536-541.

Appendix A: Focus Group Report

In order to investigate the experiences, challenges, strengths, and wants of older adults with HIV, ACRIA convened five focus groups in San Francisco with five sub-populations: 1) male gay and bisexual long-term survivors of HIV 2) African Americans 3) transgender persons 4) Asian/Pacific Islanders, and 5) Spanish-speaking Latinos. Findings from these focus groups informed adaptations to the Research on Older Adults with HIV (ROAH) 2.0 survey for the Bay Area, and serve as an independent source of data about San Francisco's older adults with HIV. Forty-four persons with HIV age 50 or over living in or receiving services in San Francisco shared their perspectives on HIV and aging in November and December 2016.

Key findings:

- Among the approaches that helped participants cope were embracing personal growth and a positive attitude, practicing self-care, viewing their lives through a religious or spiritual framework, taking on work or volunteer responsibilities that feel meaningful, and relying on social support.
- Challenges facing the participants included housing instability and poverty, loneliness and isolation, mental health problems and stress, and a range of physical co-morbidities.
- Participants requested more and different kinds of opportunities to socialize with other older adults with HIV and better access to mental health care.
- While a few participants felt confident that care would be available to them if they became sick or injured, many were uncertain and afraid of what would happen if they were no longer able to care for themselves. Several expressed reluctance or even dread at the prospect of relying on formal long-term care services.

FACTORS FACILITATING POSITIVE AGING

Wisdom and positive attitude: Many participants described gaining judgment or perspective as they aged. Participants reported they had grown with the disease, found themselves, and discovered wisdom as they grew older. They shared that insight attained through hard experience helped them reject unhealthy behaviors (like drug use), embrace their own goals and dreams, discontinue pursuits they now regard as shallow and empty, and confront potentially threatening situations without fear.

For many of the participants, adopting a positive attitude was a key part of their personal development as they age. Maintaining optimism, cultivating self-esteem, and avoiding people with negative outlooks were often mentioned. An Asian/Pacific Islander group participant remarked:

I try not to dwell on something that's a negative thing to, you know, make myself all frustrated or stressed out or things like that. I try to keep myself in a positive mood and I try to like do for other people if I can, you know.

Self-care: Eating well, exercising, avoiding illicit drug use, and taking medications as prescribed were described as important for maintaining health as one ages. One participant argued:

Aging well is a job. It's not something that happens. You have to work out. You have to exercise; you have to eat right, keep at it.

Having regular medical attention for HIV made some participants more aware of other medical conditions that might affect their health:

I feel fortunate in a way to have been diagnosed with HIV because for the last, what, 35 years, some medical facility has been watching my health and I've been watching it also, you know, so I feel like I know a lot about my body.

Religion/spirituality: Religion or spiritual practices were identified as a source of support by participants in three of the five groups (with the two exceptions being the long-term survivors and Asian/Pacific Islander groups). God was frequently described as a leader and a guiding light in participants' lives.

I say to myself, '---, you are going to be alright, you are going to go forward, think positive and you [don't] focus on the negative.' But sometimes you get lost. You lose strength. You lose optimism. You lose faith. And faith is the last thing we have left. And without faith you cannot go on.

Meaningful work or service: Participants described work, hobbies, and volunteerism as giving them a sense of meaning or purpose in life and thus contributing to their wellbeing. The activities participants described as providing them with meaning or motivation ranged from baking pies to running a business to caring for a terminally ill friend. One participant in the Spanish-language group said being a volunteer has been valuable because through that work, he "know[s] that [he] may be needed somehow by someone."

Social support: Social support was more often described as inadequate, but a number of participants listed their social connections as something that facilitates aging in a positive way. Asked what makes aging with HIV easier, one African American group participant answered:

Having strong support networks of people and friends that, that I can talk to about, you know, what I'm going through.

Several members singled out support groups and AIDS service organizations as positive forces.

I have nine brothers, and no support from anyone. I am alone. I take it all myself, everything. [The San Francisco AIDS] Foundation is my family. I live here. I come and greet everyone. Sometimes when I am not due I come and say, 'Hi,' and I go home happy.

A long-term survivor group participant described his attendance at a town hall meeting organized by an advocacy organization for long-term survivors held two years ago as a revelatory experience:

You're gonna laugh, but for me that was the first time I actually realized I'm not alone. There are a whole bunch of us out here and the stuff that we need, the stuff that we need to do for each other is new to us.

CHALLENGES AND UNMET NEEDS

Housing and other financial stressors: Participants in all five groups spoke repeatedly and adamantly about the difficulty of accessing or affording appropriate housing. They pointed out that adequate housing was a prerequisite for leading a healthy lifestyle and identified the tight housing market in San Francisco as a major stressor. Participants spoke about being forced to stay in living situations where they felt unsafe and disrespected and the difficulty of making long-term plans while living in a precarious housing situation. Inadequate income was discussed with regards to being able to afford essentials like food and housing. Participants highlighted the difficulty of living on Social Security payments or General Assistance. On the demographic survey distributed at the outset of the focus groups, 56% of respondents said they just managed to get by and 26% had not enough money. Less than a fifth of participants said money was not a problem or that they had a little extra.

Loneliness/isolation: Loneliness and isolation were mentioned with high frequency in the five focus groups, particularly amongst participants who were without partners or alienated from their families. Isolation was described as a paramount concern. One participant in the gay and bisexual men long-term survivor group remarked,

There are things that are worse than AIDS, like loneliness.

Similarly, a member of the transgender group said:

The most important thing is that it don't matter what lead up to it, it's that we need each other. We feed off each other.

Lack of family support contributed to isolation in several cases. Participants described being rejected by transphobic or homophobic relatives. Some gay and transgender participants also remarked on lacking

children. A member of the long-term survivor's group said he missed having the support structure children can provide for older adults. A participant in the transgender group, observing that many of the group members had pets, argued that that if the group members were cisgender and straight they would have children instead of (or in addition to) animal companions, but being a trans woman in this society made parenthood unattainable.

Mental health and stress: Poor mental health was an often cited challenge. Depression, post-traumatic stress disorder and substance use disorders were often mentioned as significant elements of participants' personal history. The mental health issues described were often severe. ("I guess I go into depression and I just lock myself into the room for months, probably years," one participant said.) A long history of living with HIV was described as a cause of psychological distress. For example, one member of the Asian/Pacific Islander group said:

Mental health is a big issue because, you know, we've been living with this for so long. We've lived decades with this and it has ingrained itself into our system, into our brain. There is this kinda of a PTSD issue that's involved, you know.

Stress was another often-mentioned difficulty. It was described as a factor that accelerates aging and liable to "kill you quicker than HIV."

Comorbidities: Physical illness was also a frequent concern, though less often than mental health. Participants reported a spectrum of disorders, including cancers, neuropathy, edema, kidney stones, infections, and chronic pain. Others declared themselves in good health or that they felt their aging was on par with their HIV-negative friends. In two of the groups, several participants voiced the thought that HIV might make them more vulnerable to age-related disease:

My outside, my lab work, appears to be good, but I'm worried what's really going on in my inside.

In the long-term survivors group, some felt strongly that HIV "accelerates" aging:

I'm going to be 66 in January, early. I'm telling you, this is an 80-some-year-old body I'm walking around in, and all of those opportunistic infections that I've overcome have taken their toll, as does the [medications].

DESIRED SERVICES/CHANGES

Social support: Participants proposed more and different forms of social support for older adults with HIV. In the long-term survivors' group, participants were apparently aware of programs designed to provide social support, but some found them lacking. One participant spoke emphatically about yearning to be part of group involving less casual banter and more deep engagement. Another remarked that the

negativity and constant complaining in existing groups for older adults with HIV was off-putting. A participant in the Asian/Pacific Islander group said he would like to see a group for older adults with HIV. Transgender group members described wanting less structured opportunities to socialize. One suggested a drop-in center for older adults with HIV, emphasizing that she wanted a place that was warm feeling and not rule bound where she could socialize casually with people like herself:

I don't have a problem with authority, but I've earned the right to know what I want and what I don't want, and I don't like for somebody to sit back and tell me, oh, you can't do something when I want to do something because I've earned that right to do what I want to do as long as it's not hurting anybody else. So, that's what I mean about having a place where it's not a counselor there and all that. No, I'm too old for all of that stuff. You know, go sit in a group. I've been there, done that, too old for that shit.

Mental health care: While a number of participants reported receiving satisfactory mental health care, needing and having difficulty accessing quality mental health services was a common complaint. A long-term survivor group participant described mental health services in San Francisco as non-existent. A member of the Asian/Pacific Islander group described difficulty finding a therapist. While desire for mental health services was not universal, a member of the API group argued that members of the group might be unaware of their need for mental health treatment because they had never been screened for mental health issues.

A participant in the Spanish-language group recounted a hurtful encounter with a psychiatrist, who gave a glib, ageist explanation of the man's panicked feelings:

He said, 'Look: You are getting old and manic.'... I tell you that it left me feeling hopeless. Even now that I am telling you about it, I feel I want to cry. Because he left that wound when he told me, 'You're getting old and manic.'

A Spanish-speaking group participant who was generally happy with his mental health care said he wishes that there were mental health providers with specific training in the issues facing people aging with HIV.

Burial: Participants in the transgender and African-American groups both expressed concern about how they would be buried. Lacking savings, life insurance, or family that could provide for a funeral and burial, some participants worried that their death would go un-memorialized.

There should be some kind of way that you don't have to die unknown. You don't have to be found in your apartment. You can be able to be put away properly without the city taking care of you or burning you up.

What really hurts me is that I see a lot of these well to do lesbian and gays have their funerals and all this beauty and everything, and when it comes to us, we're thrown in the cremation bin and thrown at sea.

CAREGIVING

In four of the five focus groups, time was allotted to discuss participants' anticipated needs for caregiving as they age. Many participants had little conception of what they would do should they become unable to care for themselves. A few participants felt they could rely on family or friends to care for them, and one participant was investigating long-term care insurance. Some said they would be very reluctant to accept help. A transgender group participant said:

I have always been a very strong woman and I only... I don't ask for help even if I'm death ridden. I really would have to really, really, really be sick to ask for help because I'm very proud of who I am.

The remaining participants who addressed this question were largely pessimistic about the options available to them. Two participants described being so fearful of old age and dependency that they preferred suicide to the available options. In-home care was considered desirable by some, but several participants felt leery of allowing a non-relative into their homes.

The long-term survivors group discussed the appeal of living with other older people, particularly others who are HIV positive and LGBT, and their fear of being isolated or forced to hide their identity if they have to live in a mainstream long-term care facility that is not sensitive to their needs.

I'm seeing people, you know, older than myself, gay people, who are essentially returning to the closet because they don't want to be differentiated. They don't want to be distinguished as HIV [positive] or gay because they will suffer discrimination at the hands of some of these care providers. I don't want that. I want to be in a gay-friendly environment. I want to be among people of my own kind, my peers, my social comparables [sic], and I don't think I'm gonna find that in a skilled nursing facility or out in the larger community.

Appendix B: Methodology

ROAH 2.0 San Francisco is a mixed-methods research project including 44 focus group participants and 197 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 San Francisco. The study protocol and materials were approved by GMHC's institutional review board.

Five focus groups were conducted initially, in November and December 2016. Each group included members of a particular sub-population of older adults with HIV: 1) male gay and bisexual long-term survivors of HIV, 2) African Americans, 3) transgender persons, 4) Asian/Pacific Islanders, and 5) Spanish-speaking Latinos. The groups discussed participants' self-perception with regards to aging, services participants have or currently receive, factors facilitating and undermining positive aging, barriers to receiving services, additional services desired, and concerns about anticipated caregiving and long-term care needs. Focus groups were professionally recorded and transcribed, analyzed with thematic coding, and summarized in a report released in December 2016. (See Appendix A for a summary of these findings.)

The ROAH 2.0 survey, crafted by the ACRIA research team and the ROAH Research Advisory Committee (see Appendix C), a team of experts on HIV and aging, was tailored to the concerns of San Francisco's population of older adults with HIV based on insights gleaned from the focus groups and consultation with the HIV and Aging Work Group. To make the survey suitable for San Francisco a few adaptations were made, including expanding the section on housing and revising the section on services to reflect the types of organizations and the range of services available in San Francisco.

The next phase of the study was administration of the survey to a planned sample of 200 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 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. The survey was first piloted with 23 individuals in January 2017 to confirm the clarity and appropriateness of the questions. Minor tweaks were made in response to this feedback. Survey data collection continued through August 2018. Two sessions were held for Spanish-speakers. San Francisco AIDS Foundation Latino Programs staff recruited and screened 26 participants for this session and led the data collection sessions with oversight from ACRIA staff. Transgender individuals and women were deliberately oversampled.

In total, 208 participants took the ROAH 2.0 SF survey in San Francisco by mid-August 2018. Five surveys were discarded for being incomplete or appearing to be completed arbitrarily. An additional four surveys by individuals who live outside of San Francisco were moved to the ROAH 2.0 Alameda County sample because, though the participants said that they receive HIV services in San Francisco during the screening process, they indicated only receiving services in Alameda County on the survey itself. This left 197 participants in the ROAH 2.0 SF sample.

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 SF 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 city 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 a number of 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.

Appendix C: Research Advisory Council

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