

An Emerging Issue
HIV/AIDS and Aging
In the San Francisco Eligible Metropolitan Area (EMA)
San Francisco, San Mateo and Marin Counties

Addressing the Service Needs of PLWHA 50+
The HIV and Aging Workgroup

A Joint Project of
The San Francisco EMA HIV Health Services Planning Council
The San Francisco Mayor's Long Term Care Coordinating Council



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The Service Needs of an Emerging Population: Older People Living With HIV/AIDS In San Francisco, San Mateo and Marin Counties

Introduction

Only in recent years has attention begun to turn towards the people living with HIV/AIDS 50 years of age and older. In 2003 the AIDS Community Research Initiative of America (ACRIA) initiated studies on the aging population and in 2006 they released the first comprehensive look at this population, the Research on Older Adults with HIV (ROAH) study which was designed as a 1000 person cohort analysis in New York City.

According to the ROAH study, ACRIA's preliminary findings in its early research "indicate that the aging HIV population does not have access to social support networks that provide support upon which the typical aging adult relies. Without these functional informal support networks these older adults find themselves relying on costly formal care services. Enormous resources have contributed to changing the death sentence of an HIV/AIDS diagnosis to the reality of a longer life. It is disconcerting that those who now live with HIV will face a healthcare system and communities ill prepared to care for them as they age with the disease."¹

In San Francisco, the aging nature of the HIV/AIDS epidemic is significant. In 2004, the population 50 years of age and older accounted for approximately 30% of all HIV/AIDS cases. Just four years later, this population accounted for approximately 40% of all HIV/AIDS cases. In 2008, 47% of San Franciscans with an AIDS diagnosis were 50 years of age and older and of these 13% were over 60 years of age.²

Although the population of older people living with HIV/AIDS in San Francisco is approaching a majority, an inventory conducted of publicly funded programs serving this group found no programs and no dollars allocated for targeted programs. Although there are a few support groups through community based organizations that exist for older people living with HIV/AIDS, the number is inadequate and limited in that these groups primarily targeted older gay men. No services from any funding stream targeting other demographics were identified.

In early 2009, members of the HIV Health Services Planning Council (HHSPC) and the Mayor's Long Term Care Coordinating Council (LTCCC) began meeting to discuss ways that the two planning bodies might collaborate to begin to address the issues related to HIV/AIDS and aging in San Francisco. The HIV Health Services Planning Council is responsible for prioritizing and allocating federal Ryan White funds and working with HIV Health Services in the Department of Public Health and the Mayor's Long

¹ Karpiak, S and Shippy, R Andrew; "Research on Older Adults with HIV (ROAH)" 2006

² HIV Epidemiology Section, AIDS Office, Department of Public Health "2008 San Francisco HIV/AIDS Epidemiology Annual Report", 2008

Term Care Coordinating Council makes recommendations to the Department of Aging and Adult Services.

In mid 2009, both councils approved the formation of a workgroup that would fall under the jurisdiction of, and include members of both councils and as well as community members. The Joint Workgroup on HIV and Aging held its first meeting in October 2009 and agreed to approach its work in a multi-phase fashion.

The goals of phase one are:

- 1) To look at the service needs of the older population living with HIV/AIDS.
- 2) Make actionable recommendations to both the Long Term Care Coordinating Council and the HIV Health Services Planning Council that fall within their authorities and purviews.
- 3) Provide recommendations that are more general in scope that may facilitate future research, initiatives and programs in the future on these social service needs.

In January 2010, the San Francisco HIV Health Services Planning Council, the Department of Aging and Adult Services, the Department of Public Health and a number of community based organizations hosted two events –a briefing for policy makers and community leaders at the Haas Fund on HIV and Aging presented by Sean Cahill, PhD, Director of Public Policy at GMHC in New York City and a forum for providers from both the HIV services and Aging and Adult services sector held at the San Francisco LGBT Center. These events were the kick off of efforts from the public, non-profit and foundation sectors to highlight the needs of this “emerging population” that are complex and new in the fields of both HIV care and Elder care.

This paper is meant to begin addressing these issues in a concrete way. We are only scratching the surface of this issue and while we are making initial substantive recommendations on service needs, which not only include social services but medical, treatment and prevention needs— to name but a few, our overarching goal is to shed more light on the issue of HIV/AIDS and aging.

Methodology

It is clear that due to the lack of targeted resources for older people living with HIV/AIDS and the growing percentage that they represent among the overall population of people living with HIV/AIDS in San Francisco it is imperative to understand the needs of this population.

However there have been only a few small scale efforts to research these needs. In 2007 the HIV Health Services Planning Council (HHSPC) held a community forum for PLWHA 50 and over. In the *2008 San Francisco EMA HIV/AIDS Health Services Needs Assessment* commissioned by the HHSPC, one of the areas of focus was the population 50 years of age and older. In 2010, the Council once again identified this population for more analysis and conducted two focus groups for people living with HIV/AIDS 50 years of age and older as part of its targeted needs assessment activities.

In addition to these very small needs assessment activities, the Joint Workgroup on HIV and Aging developed a short on-line self-select, self-report survey attempting to glean additional information

In January 2010, the HIV Epidemiology Section of the San Francisco Department of Public Health provided some specific epidemiological data for this population, which it presented to the workgroup and to the HIV Health Services Planning Council's Consumer and Minority Affairs Committee.

This paper utilizes these data sources and needs assessments in conjunction with national data and studies, that are more comprehensive but not specific to San Francisco, to report on some basic issues that deserve attention and some preliminary recommendations for the Long Term Care Coordinating Council, the HIV Health Services Planning Council and local policy makers on the social service needs of people aging with HIV/AIDS.

Due to the limitations of the data and information used in this document, it is not meant to be a definitive report. Instead, it should be seen as the catalyst for more robust work in the near future on the issues of older people living with HIV/AIDS. The Joint Workgroup on HIV and Aging believes that this issue is too important to wait for more comprehensive research and is confident that the information and recommendations herein are sound and will move the needs of older people living with HIV/AIDS to the level of attention and importance they deserve.

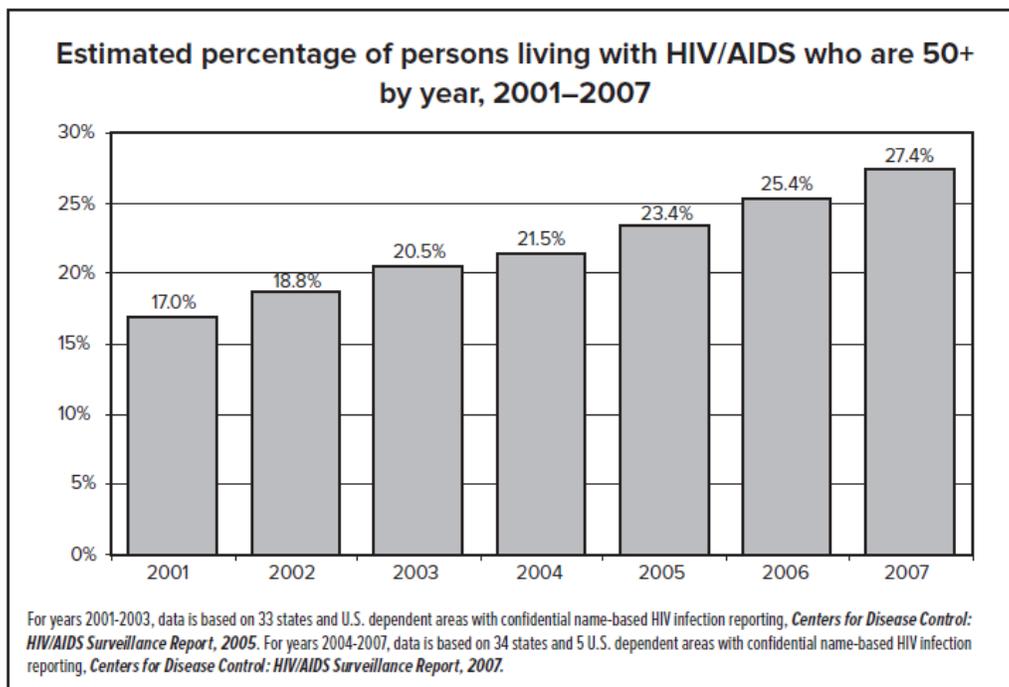
This report and its recommendations focus attention on social services for older people living with HIV/AIDS. It only provides some basic data on new infections among this population to highlight the fact that it deserves attention in the city's prevention efforts. San Francisco's new prevention plan has only recently been released and any recommendations regarding prevention impacting older people need to be thoughtfully and deliberately considered within the context of this plan and the San Francisco Department of Public Health's HIV Prevention section's *New Direction* proposal. This report was prepared before such an analysis was possible and prevention issues will be addressed during Phase II of the Workgroup.

Finally, although this report will touch on some of the health issues associated with HIV/AIDS and aging, medical, clinical or treatment recommendations are not within the purview of the Joint Workgroup on HIV and Aging.

Epidemiology

The overall increase of the Older Population Living with HIV/AIDS

According to the Centers for Disease Control (CDC), the number of persons aged 50 years and older living with HIV/AIDS has been increasing steadily in recent years. This increase is in part due to antiretroviral therapy (ART), which has made it possible for many PLWHA to live longer and partly due to newly diagnosed infections in persons over the age of 50. As the US population at large continues to age, it is important to recognize the specific challenges faced by older Americans and to ensure that they get information and services to help protect them from infection.³ One estimate is that more than half of all people living with HIV in the United States will be over 50 years of age in 2015.⁴ The CDC reports that from 2001 to 2007, this segment of the population increased by over 61%, going from 17% of the HIV-positive population to about 27%.⁵



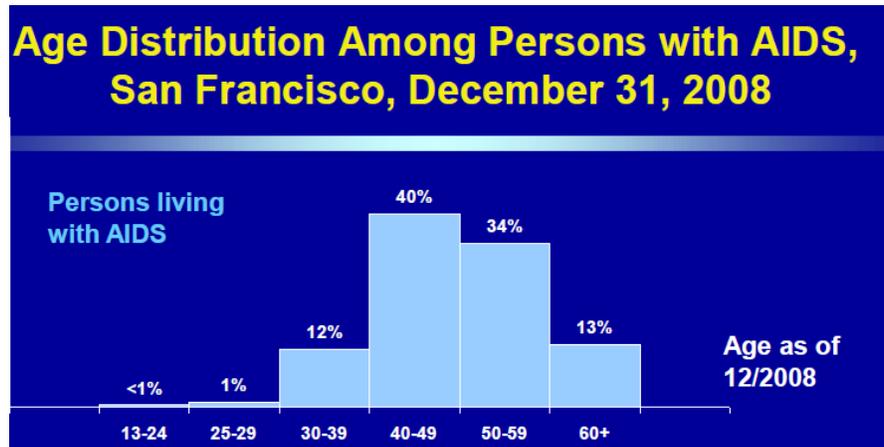
Cahill, S, et. Al "Growing Older with the Epidemic" GMHC April 2010

³ CDC "Topics- Persons over 50 years old"

⁴ Rita B. Effros et al., "Workshop on HIV Infection and Aging: What is Known and Future Directions" *Aging and Infectious Diseases* 47 (2008)

⁵ CDC "Cases of HIV Infection and AIDS in the United States and Dependent Areas" 2007

According to the San Francisco Department of Public Health, 40% of people living with HIV/AIDS are over 50 years of age. For those with an AIDS diagnosis, 47% are over 50.⁶



HIV Epidemiology Section, AIDS Office, Department of Public Health “Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging”, 2010

In San Francisco, 13% of people living with AIDS are over 60 and 40% are between 40 and 49 and will likely be aging into their 50’s in the coming decade.⁷ It is clear that the needs of older people living with AIDS in San Francisco will grow exponentially over the next 10 years. People living with an AIDS diagnosis tend to be less healthy and require more medical and social services than people living with HIV.

Analyzing the data for people living with HIV/AIDS in San Francisco, the number of people 50 and older has increased by more than 43% in the four year period between 2004 and 2008 and this group accounted for 40% of all people living with HIV/AIDS in San Francisco.

Trends in persons living with HIV/AIDS by demographic and risk characteristics, 2004- 2008, San Francisco

AGE	2004 Number (%)	2005 Number (%)	2006 Number (%)	2007 Number (%)	2008 Number (%)
0 - 19	42 (<1)	38 (<1)	35 (<1)	34 (<1)	31 (<1)
20 – 29	648 (4)	656 (4)	635 (4)	642 (4)	622 (4)
30 - 39	3,552 (24)	3,245 (22)	2,993 (20)	2,804 (18)	2,624 (17)
40 49	6,127 (42)	6,293 (42)	6, 296 (41)	6 290 (41)	6 234 (40)
50+	4,349 (30)	4,791 (32)	5,273 (35)	5,736 (37)	6,246 (40)

2008 San Francisco HIV/AIDS Epidemiology Annual Report

⁶ HIV Epidemiology Section, AIDS Office, Department of Public Health 2008 San Francisco HIV/AIDS Epidemiology Annual Report

⁷ HIV Epidemiology Section, AIDS Office, Department of Public Health “Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging”, 2010

Compared with the national data, San Francisco has a significantly higher number of PLWHA over 50 years of age than the national average. In 2007, the last year in which a comparison can be made, 37% of the city’s residents living with HIV/AIDS were over 50 which is 9.6% higher than the national percentage of 27.4%.

By assuming a 3% increase per year, based on averaging the annual increase from 2004-2008, it is likely that by 2012 more than 50% of San Franciscans living with HIV/AIDS will be 50 or older.

New Infections among older people living with HIV/AIDS

According to the CDC, persons living with over 50 years of age accounted for 15% of new HIV/AIDS diagnoses.⁸ An October 2009 AIDS Action briefing to Congress puts the percentage higher, reporting that 16.8% of new HIV/AIDS diagnoses are 50 years of age and older.⁹

In 2006, persons 50 years of age and older accounted for 10.3% of estimated new HIV infections (n=54,230). Among males, 10% were men aged 50 years and older (n=39,820). Among females, 11.4% were females aged 50 years and older (n=14,410).¹⁰

In 2005, the rates of HIV/AIDS among persons 50 and older were 12 times as high among African Americans (51.7/100,000) and 5 times as high among Hispanics (21.4/100,000) compared with white people (4.2/100,000).¹¹

In San Francisco the average rate of new HIV diagnoses for people 50 years of age and older averaged 11.6% per year between 2004 and 2008.

Year of HIV Initial Diagnosis

Age at HIV Diagnosis (years)	2004	2005	2006	2007	2008
0 – 12	<1%	<1%	0%	0%	0%
13 – 24	9%	9%	10%	11%	10%
25 – 49	80%	80%	75%	78%	80%
50+	12%	11%	15%	11%	9%

2008 San Francisco HIV/AIDS Epidemiology Annual Report

Late Testers among older people living with HIV/AIDS

According to a CDC Report, among persons newly diagnosed with HIV, the probability of being diagnosed with AIDS within 12 months increases with age.¹²

While there are a variety of possibilities for people being “late testers” (people who have an AIDS diagnosis within 1 year of testing for HIV), many articles found in a literature review of the subject, including “Delayed Presentation and Late Testing for HIV” (Giardo Enrico MD, et al., *Journal of*

⁸HIV/AIDS among Persons Aged 50 and Older” CDC Fact Sheet, February 2008

⁹ Johnson, R., “HIV and Aging: Growing Older with the Epidemic, AIDS Action Congressional Briefing”, October 2009

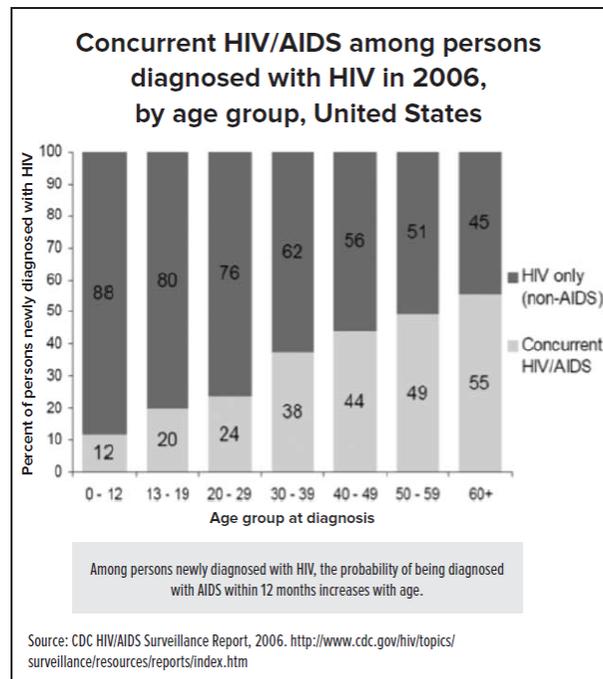
¹⁰ *Ibid.*

¹¹ *Ibid.*

¹²CDC HIV/AIDS Surveillance Report, 2006. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm>

Acquired Immune Deficiency Syndromes, August 2004) and “Sexual Risk Behaviors in Late Middle Age and Older HIV Seropositive Adults” (Lourdes Illa, Brickman, et al., *AIDS and Behavior*, April 2008), point to assumptions on the part of the medical provider and the patient about risk factors.

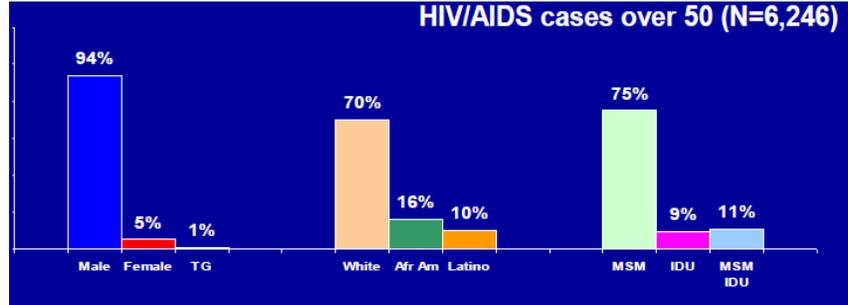
While these data have a direct impact on developing appropriate prevention interventions for older people, they also indicate that medical providers and social service providers should reevaluate their assumptions of sexual and substance use risk with older people.



Older patients are twice as likely as younger patients to be diagnosed with AIDS and to be diagnosed during hospitalization. Older patients, as well as their providers, may perceive that they are at low risk of HIV infection, perhaps making them less likely to be tested. Also, the availability of HAART may reduce the sense of urgency with which people seek HIV testing today.¹³

¹³ “Late diagnosis of HIV is a problem for older patients, many of whom aren't diagnosed until they've already developed AIDS”, Agency for Healthcare Research and Quality, US Department of Health and Human Services <http://www.ahrq.gov/research/nov07/1107RA21.htm>

Demographics of the Older Population Living with HIV/AIDS in San Francisco



HIV Epidemiology Section, AIDS Office, Department of Public Health "Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging", 2010

In San Francisco, the population of people living with HIV/AIDS 50 years of age and older is diverse. While the percentage is higher among Whites and African Americans for this age group compared to the overall population of PLWHA, the race/ethnicity breakdown of the population shows comparable diversity between older PLWHA and the total population of PLWHA.¹⁴

Race /Ethnicity of PLWHA in San Francisco			
	PLWHA (N=15,757)		PLWHA (50 plus) (N=6,767)
Race/Ethnicity			
White	64%		70%
African American	14%		16%
Latino	15%		10%
Other	7%		4%

HIV Epidemiology Section, AIDS Office, Department of Public Health "Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging", 2010

In terms of gender the demographic breakdown, the population of PLWHA over 50 is nearly identical to the gender make up of the overall population of PLWHA in San Francisco.

Gender Identity of PLWHA in San Francisco		
	(N=15,757)	(50 plus) (N=6,767)
Gender		
Male	92%	93%
Female	6%	5%
Transgender	2%	2%

HIV Epidemiology Section, AIDS Office, Department of Public Health "Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging", 2010

¹⁴ HIV Epidemiology Section, AIDS Office, Department of Public Health "Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging", 2010

According to the HIV Epidemiology Section, AIDS Office, Department of Public Health, approximately 7% of the 50 plus population is homeless at the time of HIV/AIDS diagnosis.¹⁵

In San Francisco, among the 50 plus population approximately 75% have had AIDS for 10 years.

Additionally by looking at the age at time of HIV diagnosis and the median CD4 count, the population of people living with HIV/AIDS over 50 tends to have lower CD4 counts than their younger counterparts.¹⁶

Age at HIV dx	Number	% received CD4	Median CD4 ct
13-29	424	82%	456
30-39	687	85%	432
40-49	546	84%	401
50 plus	227	86%	363

HIV Epidemiology Section, AIDS Office, Department of Public Health “Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging”, 2010

Epidemiology Conclusions

The HIV/AIDS epidemic is graying and in San Francisco the number of older people living with HIV/AIDS is higher than the national average and we believe could account for more than 50% of all HIV/AIDS cases in 2012.

The number of new infections and “late testers” among people over 50 years of age pose some significant challenges.

Many older persons are sexually active but may not be practicing safer sex to reduce their risk for HIV infection.¹⁷ Some older persons inject drugs or smoke crack cocaine, which can put them at risk for HIV infection. HIV transmission through injection drug use accounts for more than 16% of AIDS cases among persons aged 50 and older.¹⁸

Some older persons, compared with those who are younger, may be less knowledgeable about HIV/AIDS and therefore are less likely to protect themselves. Many do not perceive themselves as at risk for HIV, do not use condoms and ultimately do not get tested for HIV.¹⁹

The CDC reports that older persons of color may face additional barriers in the form of discrimination and stigma that can lead to later testing, diagnosis and an increased reluctance to seek services.²⁰

¹⁵ HIV Epidemiology Section, AIDS Office, Department of Public Health “Status of the HIV/AIDS Epidemic- San Francisco Presented to the Joint Workgroup on HIV and Aging”, 2010

¹⁶ *Ibid.*

¹⁷ Lindau ST et al. “A study of sexuality and health among older adults in the United States”. *New England Journal of Medicine*; 2007; 357:762–74.

¹⁸ Linsk NL. “HIV among older adults” *AIDS Reader* 2000; 10(7):430-40.

¹⁹ “HIV/AIDS among Persons Aged 50 and Older” CDC Fact Sheet, February 2008

²⁰ *Ibid.*

According to the CDC, “Health care professionals may underestimate their older patients’ risk for HIV/AIDS and thus may miss opportunities to deliver prevention messages, offer HIV testing, or make an early diagnosis that could help their patients get early care.

Physicians may miss a diagnosis of AIDS because some symptoms can mimic those of normal aging, for example, fatigue, weight loss, and mental confusion. Early diagnosis, which typically leads to the prescription of Antiretroviral Therapy (ART) and to other medical and social services, can improve a person’s chances of living a longer and healthier life.

The stigma of HIV/AIDS may be more severe among older persons, leading them to hide their diagnosis from family and friends. Failure to disclose HIV infection may limit or preclude potential emotional and practical support.”²¹

Many of the trends and concerns coming from an analysis of data on late testers and new infections must be addressed through adequate prevention efforts and healthcare provider education.

This population is diverse and will need to have social services delivered in ways that reflect not only their age and their HIV status but their gender identity, their ethnicity and their sexual orientation.

Since this population has a higher percentage of late testers with an average lower median CD4 count, it is likely that older people entering the system of care will have greater medical and social service needs. The next section of this paper will provide an overview of some of the complexities of the medical issues faced by older people and how they will exacerbate the strains on the system of care for older people living with HIV/AIDS.

²¹ *Ibid.*

Physiological and Mental Health Issues

Physiological Issues

In September 2008 “Newsweek” published an article that was one of the first instances of high profile reporting by a national news magazine on HIV and Aging. The article was titled “A Lot of Unknowns: *Medical advances are helping many HIV Patients live into old age. But that blessing presents its own unique set of tribulations.*” This reflects the sentiments expressed at an HIV and Aging Forum that the San Francisco HIV Health Services Planning Council held in 2007 when one participant stated: “*I’ve been living with this disease since the early 1980’s and I am tired of always being on the cutting edge of the epidemic.*”

Long term effect of Antiretroviral Medications (ARVs)

According to GMHC’s policy paper, “Growing Older With The Epidemic”, life expectancies for people on therapy (and who adhere to their medication regimens) are still only two-thirds that of the general population. For intravenous drug users with HIV, the figure is even lower. These statistics point to important areas of concern because we are only beginning to see the effects of therapy on longevity.²²

Researchers know that HIV and age make for a complicated balancing act – a convoluted interplay of the disease itself, natural aging symptoms and the side effects of antiretroviral medication that may enhance those symptoms. Part of the aging process is already about a loss of immunity. So the fact that HIV is an immune disease may be one reason why PLWHA tend to age faster, in everything from body changes to cardiovascular disease. But PLWHA can also be plagued by ongoing side effects of antiretroviral therapy (ART), which range from high blood pressure to neurocognitive disorders.

Drug Toxicity

According to the GMHC paper “Growing Older with the Epidemic”, antiretrovirals are less toxic than they used to be, but they are not entirely benign: side effects include liver toxicity, osteoporosis, pancreatitis, lipodystrophy (fat loss and redistribution), peripheral neuropathy (numbness in extremities), and buildup of lactic acid, to name a few.²³ The paper goes on to report that research suggests that older adults may be less able to metabolize antiretrovirals, which can lead to increased toxicity.²⁴

Aging and T-Cell Production

HIV and aging both diminish the production and health of T-cells, a key component of the body’s defense against infection. As people get older, the organ where T-cells mature (the thymus) shrinks, and as a result older adults produce fewer T-cells than younger people.²⁵ HIV infection also depletes T-cells, and HIV-positive individuals typically have a “naïve” T-cell population similar to someone 20 to 30

²² Cahill Sean., et al. “Growing Older With the Epidemic”; GMHC, April 2010

²³ *Ibid.*

²⁴ Bhavan et al., “The Aging of the HIV Epidemic.”, Current HIV /AIDS Reports; October 2008

²⁵ Douek, Daniel et al, “Changes in Thymic Function with Age and During the Treatment of HIV infection”, Nature 396 (671`2), 1998; 690-695

years older.²⁶ Older age has also been linked to decreased production of cytokines that regulate T-cell production and maintenance, which may also influence immune recovery in older PLWHA.²⁷

Inflammation

According to an article by Tim Horn reporting on an Immune-Based Therapies Strategy Workshop held in February 2010 in San Francisco, hosted by Project Inform and Treatment Action Group and published on POZ AIDSmeds.com, “‘Aging’ and ‘inflammation’ have become familiar words in the HIV lexicon, up there with terms like ‘CD4 cells’, ‘viral load’ and ‘antiretrovirals’. There’s a good reason for this: People living with HIV appear to age faster—as seen in the premature onset of age-associated diseases and immune system deficits—than those not infected with the virus. This is likely because of chronic inflammation, a lingering effect of HIV’s perseverance, even when antiretroviral (ARV) therapy is working to the best of its ability.

The connection between inflammation and aging isn’t simply a quirky phenomenon. It is now a major variable in HIV research, notably in studies exploring the ‘natural history’ of untreated HIV infection and treatment clinical trials. In fact, researchers are taking note of the anti-inflammatory properties of various compounds—agents that can work alone or in tandem with viral load–reducing ARVs to calm the body’s overzealous inflammatory response to HIV and potentially slow the aging process in people living with HIV.”²⁸

In the same article Horn quotes Steven Deeks, MD, a professor of medicine at the University of California San Francisco, who has been studying the issues of HIV, inflammation and aging.

Treatment adherence struggles and side effect problems aside, prolonged survival with HIV isn’t without its risks. “HIV infection and its treatment may affect the presentation and management of common age-associated complications,” Deeks said. “There are also poly-pharmacy issues, in which there is a greater risk of drug interactions when drugs used to manage HIV are combined with medications used to treat diseases typically associated with aging.”

Using cardiovascular disease as an example, Deeks explained that a very small population of so-called elite controllers—people living with HIV able to keep their viral loads undetectable and their CD4 counts well within the normal range without the use of ARV treatment—have a higher risk of heart disease compared with HIV-negative individuals. “This finding,” he said, “points to an effect of HIV-associated inflammation rather than to effects of the virus or its treatment.”

Cognitive decline was another aspect Deeks explored. There are a number of possible reasons why neurologic deficits can be documented in some people otherwise responding well to ARV therapy, including low-level replication of HIV in the central nervous system, active substance abuse and the presence of other infections such as hepatitis C. “Persistent inflammation is another possibility to consider, especially in patients starting antiretroviral therapy with low CD4 cell counts.”

²⁶Robert C. Kalayjian and Lena Al-Harhi, “The Effects of Aging on HIV Disease”, in R.H. et al (eds.), *HIV and the Brain*, Current Clinical Neurology (New York Humana Press, 2009)

²⁷ Kavita P. Bhavan et al., “The Aging of the HIV Epidemic”.

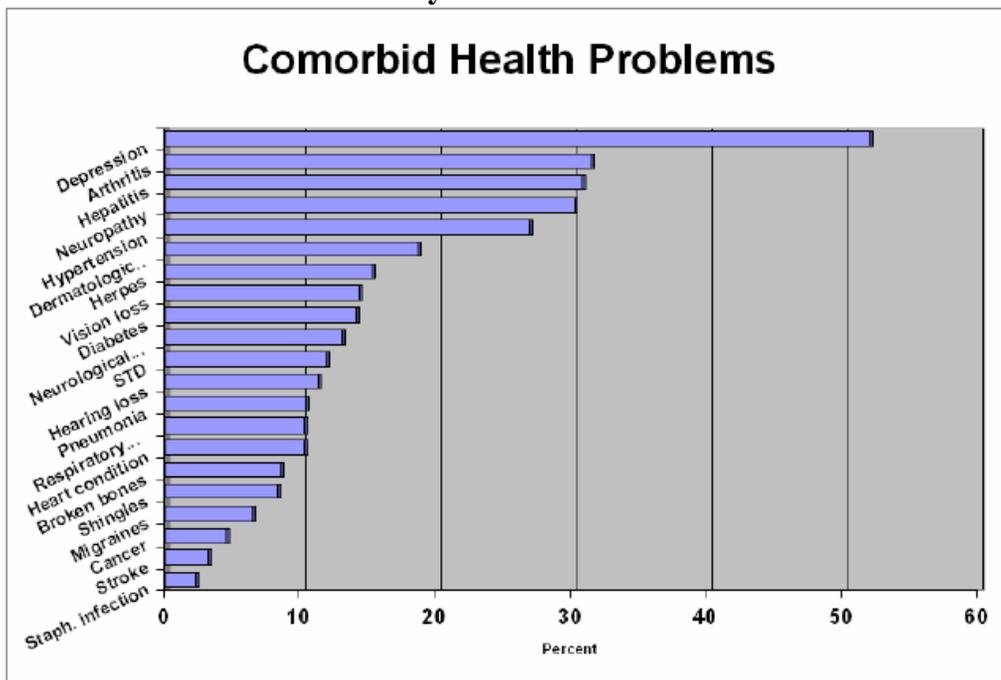
²⁸ Horn, Tim; “HIV and Aging The Potential Role of Inflammation”; POZAIDSmeds.com, April 2010

Osteopenia and osteoporosis—moderate and severe bone mineral loss, respectively—may also be caused by ongoing inflammation in people on HIV treatment. “Alcohol use and the direct effects of certain drugs on bone metabolism may play a role.”

Co-Morbidities

According to the GMHC paper, non-AIDS co-morbidities are becoming increasingly important. In recent years, less than a third of all deaths in HIV-positive individuals were associated with diseases traditionally linked to HIV infection. In many cases, however, it is not clear whether these co-morbidities are caused by the virus, aging, antiretroviral therapy, or some other risk factor found among some HIV positive older adults. What is clear is that HIV-positive individuals are likely to have more diseases than HIV negative individuals, regardless of age, many of which are not specifically AIDS-related.²⁹ In the ROAH study, 91% of the sample of 914 older adults living with HIV in New York City had at least one comorbidity; 77% had two or more. These conditions include hypertension, neuropathy, hepatitis, arthritis, and depression.³⁰

ROAH Study Comorbidities Chart³¹



In another study “Co-Morbidities in older patients with HIV: A Retrospective Study” a study of 162 patients 50 years or older who sought treatment at the Oral Medicine Clinic of the New Jersey Dental School University of Medicine and Dentistry of New Jersey in Newark NJ, a total of 144 of the 162 study subjects (88.8 %) reported having at least one comorbidity. Among those who reported having a comorbidity, 26 (18.0 %) reported having one, 40 (27.8 %) reported having two, and 78 (54.2 %) reported having three or more.

²⁹ Cahill Sean., et al. “Growing Older With the Epidemic”; GMHC, April 2010

³⁰ Karpiak, S and Shippy, R Andrew; “Research on Older Adults with HIV (ROAH)” 2006

³¹ *Ibid.*

reported having three or more. Among all study subjects, 72 (44.4 %) reported having hepatitis C (HCV), 67 (41.4 %) reported having hypertension, 27 (16.7 %) reported having psychiatric disorders, 26 (16.1 %) reported having COPD, 25 (15.4 %) reported having anemia, and 24 (14.8 percent) reported having heart disease.³²

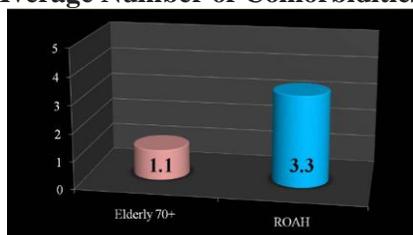
“Co-Morbidities in order patients with HIV: A Retrospective Study Chart”³³

Self-reported comorbidity prevalence for total study population			
COMORBIDITY	TOTAL (n = 162) (N [%])	MEN (n = 119) (N [%])	WOMEN (n = 43) (N [%])
Hepatitis C Virus	72 (44.4)	59 (49.6)	13 (30.2)
Hypertension	67 (41.4)	43 (36.1)	24 (55.8)
Psychiatric Disorders	27 (16.7)	17 (14.3)	10 (23.3)
Chronic Obstructive Pulmonary Disease	26 (16.1)	17 (14.3)	9 (20.9)
Anemia	25 (15.4)	15 (12.6)	10 (23.3)
Heart Disease	24 (14.8)	14 (11.8)	10 (23.3)
Stroke	18 (11.1)	12 (10.1)	6 (14.0)
Diabetes Mellitus	20 (12.4)	17 (14.3)	3 (7.0)
Kidney Disease	16 (9.9)	13 (10.9)	3 (7.0)
Neurological Disorders	13 (8.0)	10 (8.4)	3 (7.0)
Orthopedic Disease	13 (8.0)	10 (8.4)	3 (7.0)
Bleeding Disorders	11 (6.8)	6 (5.0)	5 (11.7)
Cancer	6 (3.7)	4 (3.4)	2 (4.7)
Tuberculosis	2 (1.2)	2 (1.7)	0 (0.0)
Other*	81 (50.0)	62 (52.1)	19 (44.2)

According to a citation in the GMHC report “Growing Older with the Epidemic: *HIV and Aging*”, liver disease is the most common non-AIDS related complication as a cause of death for HIV-positive individuals, and older patients experience a four-fold increase in liver-related mortality compared with younger adults with causes including hepatitis infection, alcohol use and diabetes. The report goes on to state that “people with liver disease are at greater risk of diabetes in general, and one study found that the risk of diabetes in older HIV-positive veterans is higher in the HAART era than it was during the pre-HAART era.”³⁴

The ROAH study showed three times the numbers of co-morbidities for their study population of people living with HIV than all elderly 70 and older.³⁵

Average Number of Comorbidities³⁵



³² Heidi Hansen and Michael Glick, Marina Gallottini Magalhães, Barbara Greenberg, “ Comorbidities in older patients with HIV: A Retrospective study” *Journal of American Dental Association* 2007; 138; 1468-1475

³³ *Ibid*

³⁴ Cahill Sean., et al. “Growing Older With the Epidemic”; GMHC, April 2010

³⁵ Karpiak S, “ An In-depth Examination of an Emerging Population Who Are These Older Adults Living with HIV”, NYS AIDS Conference 2008

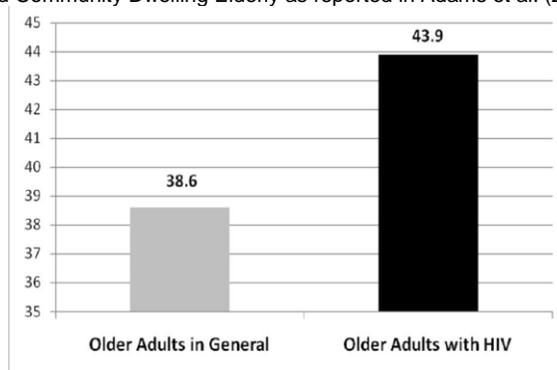
Mental Health

Depression

While there are a variety of mental health issues that can be present for people living with HIV/AIDS, the most common issue is depression. The ROAH study shows that depression is the most common comorbidity for older people living with HIV/AIDS and that 2/3 were moderately depressed.³⁶

In an April 2010 article in “AIDS Care”, data from ROAH were further analyzed and showed that 39.1% of participants exhibited symptoms of major depression and much of this was significantly related to increased HIV-associated stigma, increased loneliness, decreased cognitive functioning and reduced levels of energy.³⁷

Comparison of UCLA Loneliness Scale Scores between Older Adults with HIV and Community Dwelling Elderly as reported in Adams et al. (2004)



According to the researchers there is no single evident reason that these numbers are so high. The ROAH cohort was already in care and arguably had access to a wide array of supportive services for the management of depression. The researchers hypothesized that it is possible that symptoms of depression are confused with physical ailments and that many treating physicians are focused on HIV and see depressive symptoms as an expected reaction to living with HIV. The ROAH study concludes that the co-occurrence of HIV and depression may add to continued distress on the immune system and that healthcare providers should be prepared to assess and treat the comorbid physical and mental health conditions that aging adults will present.³⁸

Substance Use

The ROAH study found that a majority of the study’s cohort used cigarettes (84%), alcohol (81%) or illicit drugs in their lifetime (84%). Current drug use was reported as follows: crack (16%), cocaine (15%), heroin (7%) and crystal meth (5%).³⁹

³⁶ Karpiak, S and Shippy, R Andrew; “Research on Older Adults with HIV (ROAH)” 2006

³⁷ Grov C, Golub SA, Parsons JT, Brennan M, Karpiak SE.,” Loneliness and HIV-related stigma explain depression among older HIV-positive adults”.

³⁸ Karpiak, S and Shippy, R Andrew; “Research on Older Adults with HIV (ROAH)” 2006

³⁹ *Ibid.*

According to the CDC, some older persons inject drugs or smoke crack cocaine, which can put them at risk for HIV infection. HIV transmission through injection drug use accounts for more than 16% of AIDS cases among persons aged 50 and older.⁴⁰ In one study, although drug users 50 years and older were less likely than a younger cohort to share needles, they were just as likely as younger drug users to engage in risky sexual behavior. The researchers also found that older users who smoked crack engaged in behaviors that were deemed extremely risky (for example, injecting drugs, having multiple sex partners, and exchanging sex for drugs or money). Older injection drug users living with HIV tend to be poorer and to have less social support than their younger counterparts.⁴¹

Aging and substance abuse are also known to increase the risk of cognitive declines, although to what degree these factors act synergistically in this population remains unclear. That said, studies indicate that older adults with HIV or AIDS may be at greater risk for cognitive declines than their age-matched, HIV-negative peers.⁴²

Physiological and Mental Health Issues Conclusions

Clearly the physiological and mental health issues that older people living with HIV face are remarkably complex. Combining issues of drug toxicity, long term use of ARVs, effects of drug combinations used to treat HIV, other health issues related to aging and “usual” comorbidities in general, effects of inflammation, mental health and substance use history creates a daunting challenge for healthcare providers but also for older people living with HIV/AIDS themselves. Navigating the many unknowns and the complexity of the landscape successfully is essential for older people living with HIV/AIDS to enjoy better health and a decent quality of life. Simply put, support services must be equal partners with medical care in order to ensure that life is not just extended for older people but that one’s quality of life is improved and meaningful.

⁴⁰ Centers for Disease Control and Prevention Website- HIV/AIDS Persons Aged 50 and Older
<http://www.cdc.gov/hiv/topics/over50/challenges.htm>

⁴¹ Kwiatkowski CF, Booth RE. HIV risk behaviors among older American drug users. *Journal of Acquired Immune Deficiency Syndromes* 2003; 33(suppl 2): S131–S137.

⁴² Hardy DJ, Vance DE. The neuropsychology of HIV/AIDS in older adults. *Neuropsychol Rev* 2009; 19(2): 263–72.

Data and Needs Assessment Information of Older People Living With HIV/AIDS in the San Francisco EMA

The San Francisco HIV Health Services Planning Council (HHSPC) began to direct some focus on the aging population and HIV in 2007 and held a small community meeting to discuss the subject. Everyone at the meeting was a long term survivor of HIV/AIDS and there is one comment that came from that meeting which summed up the sentiments of the meeting participants: *“I am tired of always being on the cutting edge of the epidemic.”*

Since 2007 the HHSPC has directed more resources to listening to the needs of older people living with HIV/AIDS. In 2008, the council directed that a focus group for adults over 50 living with HIV/AIDS be part of the large scale needs assessment of the severe need population that was done that year. In late 2009 the council joined forces with the Long Term Care Coordinating Council to form the Joint Workgroup on HIV and Aging which includes community members in addition to members of both councils. In 2010 as part of the HHSPC’s targeted needs assessment work, two focus groups for people over 50 were conducted and an on-line survey was conducted.

2008 Comprehensive Needs Assessment (1 Focus Group targeting PLWHA 50+)⁴³

The 2008 focus group primarily examined the unmet HIV service needs and barriers to care. Notably, participants did not report any barriers or challenges to receiving medical care. But the key challenges that they mentioned were:

- 1) Awareness of available services and benefits and having difficulty navigating a complex system of services.
- 2) Eligibility for services and benefits. Focus group participants explained that due to income requirements for many services some middle income individuals often face challenges accessing needed services such as dental care.

The unmet needs articulated by the participants in this focus group were:

- 1) Complementary Alternative therapies
- 2) Housing
- 3) Activities and Social Support
- 4) Mental Health

Focus group participants spoke about the challenges they currently face as well as those they anticipate as they continue to age. Many of them were concerned about developing resistance to medications and spoke of the importance of alternative complementary therapies for people who may have medication side effects and other issues associated with long term use of medications. Additionally focus group participants discussed the importance of having providers who are culturally competent when it comes to older people with HIV/ AIDS. They added that many seniors are not comfortable in “mainstream facilities.”

⁴³ Harder + Company, SFHPC 2008 Comprehensive Needs Assessment, September 2008

2010 Focus Groups (2 Focus Groups – 1 for PLWHA 50-59 years old and 1 for PLWHA 60+)⁴⁴

In 2010, Harder + Company convened several focus groups and presented their findings to the Joint Workgroup on HIV and Aging in May. Many of the same themes from the 2008 focus group were repeated and expanded upon. The topics covered in these focus groups included health services, social support, older adult services, other general services, challenges in accessing care and unmet needs.

The demographics for the focus groups were:

- 12 males, 1 female, 1 transfemale
- 7 African American, 6 White
- Average age: 56 years old (50 – 67 years)
 - Focus Group 1 - Age 50-60 (n=10)
 - Focus Group 2 - Over 60 (n=4)
- 71% (n=10) identified as gay or homosexual
- More than half had some college education
- Average time living with HIV was 17 years; shortest time living with HIV was 4 years; and one participant has been living with HIV for 29 years

Barriers to healthcare included transportation, long wait lists for specialist care (e.g., urologist), and not being able to see a doctor as needed. As in the 2008 focus group, some participants expressed frustration with finding information and navigating the system.

Participants emphasized the need for other services such as stable housing, transportation and food. In order to stay healthy, participants also mentioned the need for exercise, adequate sleep, proper medications, and as in the 2008 focus group, many participants spoke of the need for complementary care such as herbal medicines and the importance of support groups in their lives and the need for more opportunities for social interaction and daytime activities.

Participants spoke about the need to prepare providers for geriatric HIV care. Participants shared how their medical needs are changing as they age and providers are not prepared or educated to understand their emerging needs. One participant stated: *“I think it gets into a very confusing area for the doctors. They don’t know because there are so many side effects to HIV meds and they aren’t quite sure if you are dealing with an HIV problem or an aging problem.”* Some participants noticed doctors having difficulty differentiating which symptoms are tied to aging or HIV.

Several participants expressed worries about the long term effects of HIV medications on their physical health. One individual said: *“We don’t know the [effects] of long-term use of taking HIV drugs for people over 50.”*

Mobility issues came up as a concern for a few participants as well as how to keep an active and healthy lifestyle as they age. Other concerns include depression, hearing loss, and general health problems associated with aging.

⁴⁴ Harder + Co, “Follow-up Needs Assessment: Over 50 and Living with HIV” May 2010

One participant stated, *“I worry about being African American with high blood pressure and diabetes. Mostly just keeping blood pressure at a normal level and not stressing out so much...”* Another individual said, *“With aging in particular, if you are a gay man and HIV positive, it’s a very ageist society – the gay community. Getting old in itself can become depressing.”*

Many participants expressed anxiety about the future and not knowing what to expect in regards to their health and well being. One individual stated: *“I’m 67 and I’ve had issues both age and HIV related...now the only thing I’m not sure of is what will happen as I turn 70, 75...What is it I can expect health wise? Where do you get that information?”*

Focus group participants were asked for their recommendations on how best to meet the needs of older people living with HIV/AIDS and they made the following five recommendations:

- 1) Increase opportunities for social interaction and connection with each other such as support groups and social activities.
- 2) Provide a centralized information source & service coordination for seniors, specifically.
- 3) Train and prepare providers for a growing elderly population living with HIV.
- 4) Provide and expand resources related to housing and finances for aging PLWH.
- 5) Expand research on geriatric HIV including long term effects of HIV medication.

Joint Workgroup on HIV and Aging On-Line Survey⁴⁵

The HIV and Aging Workgroup wanted to obtain information on issues that are not apparent in the Epidemiological data. The on-line survey would be one more tool to use for making decisions along with Harder + Co 2010 focus groups and previous needs assessments findings.

The survey went live on April 13, 2010 in English and Spanish and closed on May 7, 2010. 117 individuals participated in the survey which, according to the data reported in the Epidemiology section of this paper is a sampling of > 1.5% of the population of people living with HIV/AIDS in the EMA. While the survey is self report and self select thus making its results less scientific, due to the sample size, there is a sense that the results of this survey, while not scientific, are significant.

Demographics of Respondents

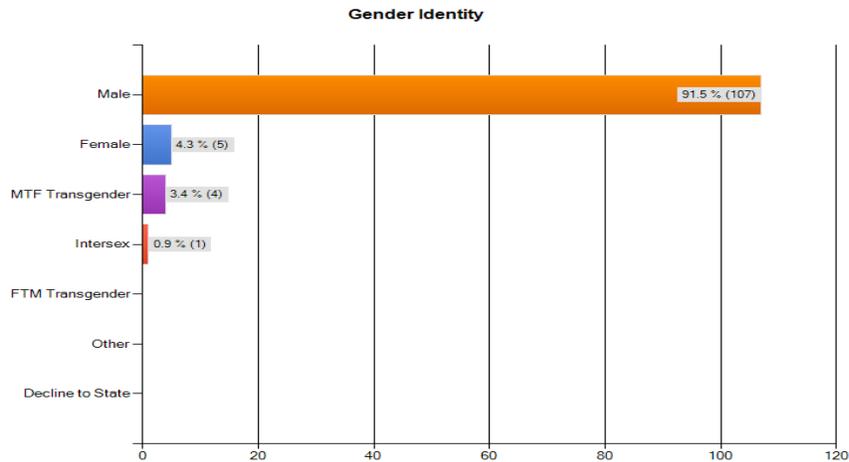
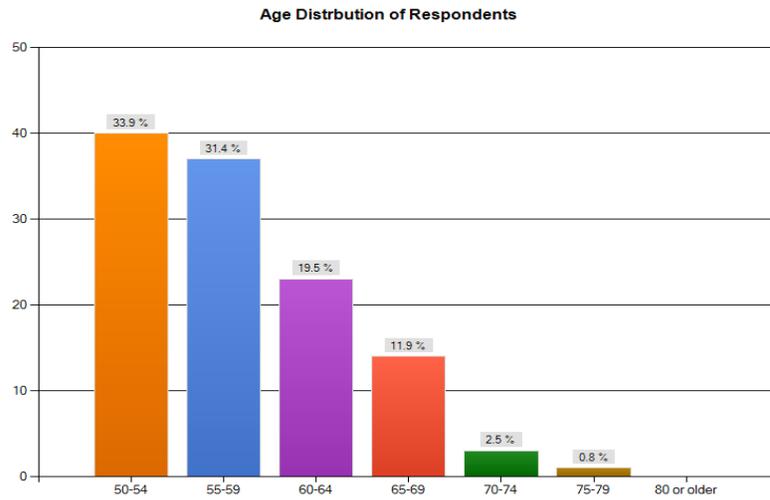
The county distribution of the respondents was reflective of the epidemic within the three counties of the San Francisco EMA:

<u>County</u>	<u>#</u>	<u>%</u>
San Francisco	104	88.8%
San Mateo	9	7.7%
Marin	4	3.4%

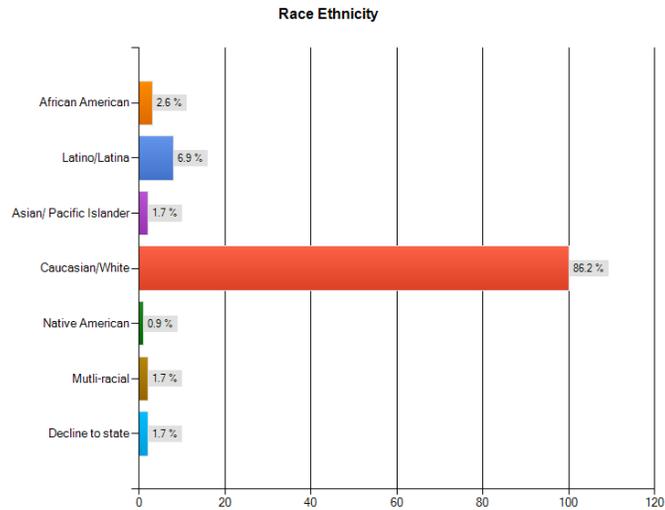
The age range of the respondents was broad with 1/3 aged 50-54, 1/3 aged 55-59 and 1/3 aged over 60. 4 respondents were 70 and older. The gender identity was reflective of the demographics reported in the

⁴⁵ Randy Allgaier, Director of the SF HHSPC provided the analysis for all data from the on-line survey

epidemiological data: 91% were male, 4.3% were female, 3.4% were MTF transgender and .9% identified as intersex.

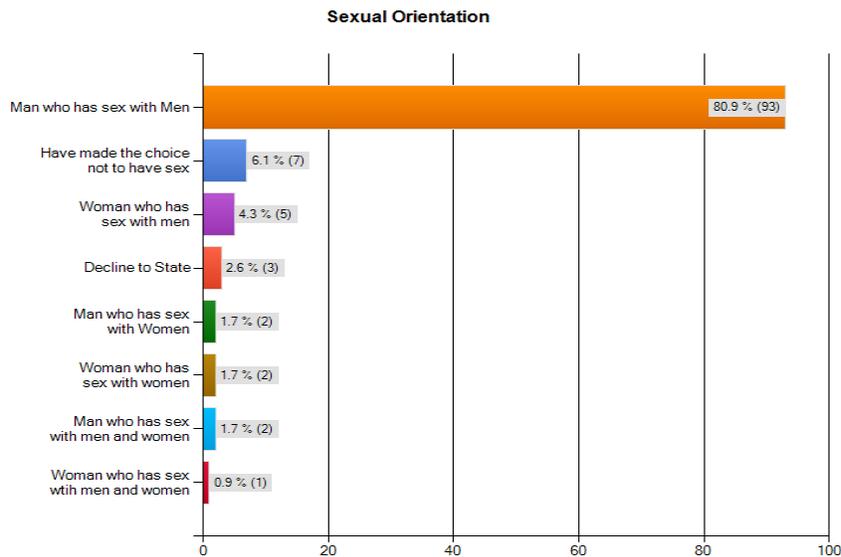


The race/ethnicity of respondents was oversampled among White/ Caucasian, undersampled among African Americans and slightly undersampled among Latino/Latina. The survey drilled down among API, Native American and Multi-racial which were bundled together in the epidemiological data on the 50 and older population as “other.” Respondents were also given the option of “decline to state.”



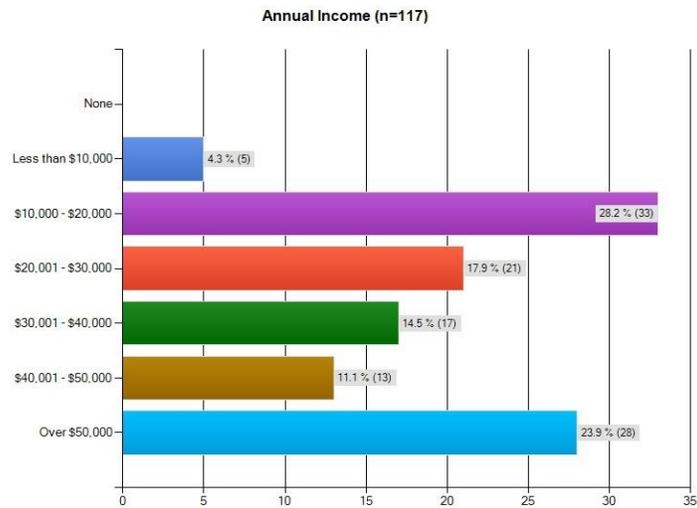
The epidemiological data does not provide information on sexual orientation. Instead it provides data on behavioral risk categories. According to the San Francisco Department of Public Health, for the population that is over 50 years of age, 75% report MSM and 11% report MSM IDU. Other risk categories do not report sexual behavior.⁴⁶

The sexual orientation of respondents reported out as 81% MSM with a variety of other sexualities being reported. When the survey was developed, it was decided that an option of “have made the choice not to have sex” would be added. This choice was the second most common “sexual orientation” among the survey’s respondents (6.1%).

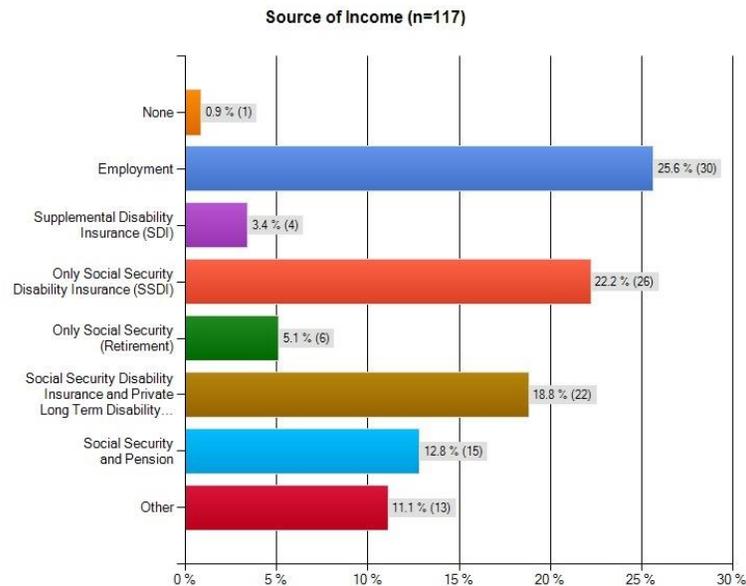


⁴⁶ HIV Epidemiology Section, AIDS Office, Department of Public Health “2008 San Francisco HIV/AIDS Epidemiology Annual Report”, 2008

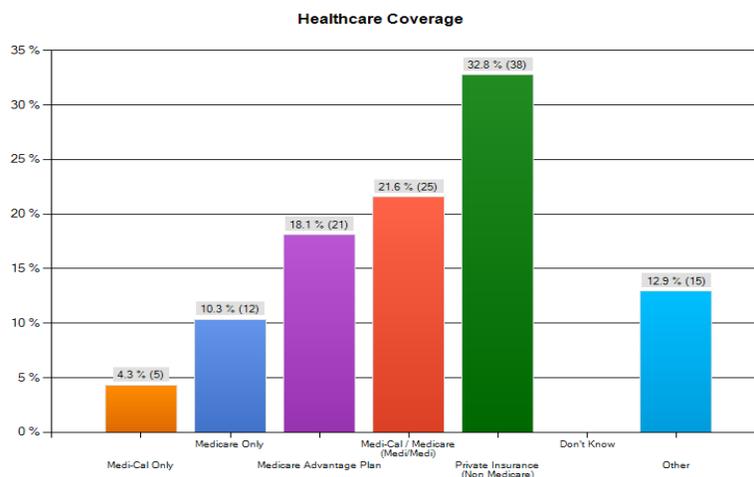
The income level of respondents was also diverse. Nearly 1/3 of respondents reported incomes at below 200% of poverty, 43% reported annual incomes between \$20,000 and \$50,000 and 24% reported incomes above \$50,000.



Nearly two-thirds of respondents reported that their income was derived from retirement and/or disability benefits (public and private) and about 25% were currently employed.



One third of respondents cited their source of healthcare coverage as private and the vast majority, more than half of the respondents, cited Medicare or Medicare Advantage as one source of their coverage.



More than 75% of respondents have been HIV + for more than 20 years, 93% of respondents have been HIV-positive for more than 10 years, 96.6% were on HIV medications, of those on HIV medications, 86.5% have been on HIV medications for more than 10 years.

Survey Findings

1. Economic Concerns

Although the survey respondents had diverse incomes, concerns about economic hardship and decreased financial stability crossed all income levels and was identified as a significant issue for the majority of respondents.

Previous to this survey, there has been anecdotal evidence that there is a group of aging adults living with HIV/AIDS that will age out of their current economic security. This security stems from being the beneficiaries of private long-term disability (LTD) policies that they either bought individually or were provided by employers before these individuals became disabled. For most of these individuals the LTD policy wraps around the Social Security Disability Insurance Income (SSDI) and can make the difference between poverty and self-sufficiency. Nearly all LTD policies stop paying benefits when the beneficiary reaches retirement age (usually 65). The rationale is that these individuals are no longer “disabled from employment” since they have reached retirement age.

The survey drilled down into this issue. 18.9% of the survey respondents were currently receiving a private LTD benefit. All of those receiving this benefit were aware that most of these private LTD policies will no longer pay benefits upon reaching retirement age. Approximately half of these individuals (52%) have planned for this eventuality and a little less than half (48%) had not. Even though a little over half of these LTD beneficiaries have planned for it, nearly 86% think that their quality of life will be compromised when they no longer receive LTD benefits and 4.8% do not know.

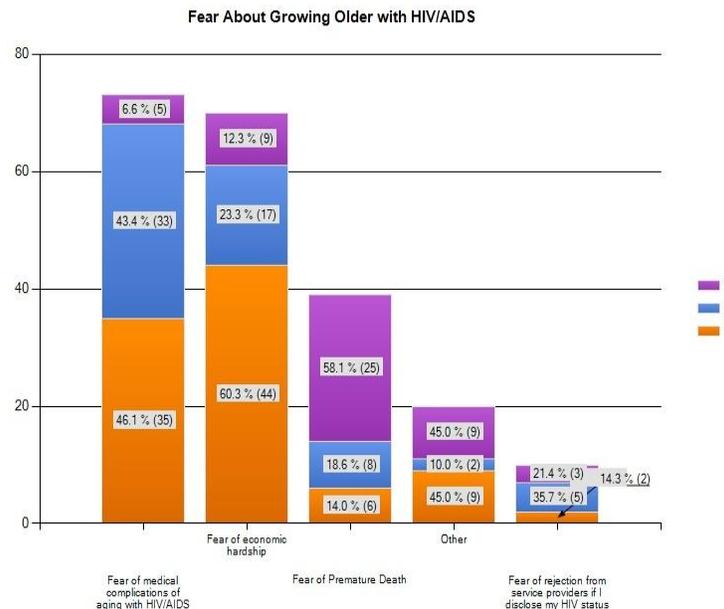
Respondents were asked to comment about how they expect their quality of life to change when their LTD policies cease paying benefits; below is a sampling of these comments:

- *“I didn't expect to live this long (61 now) and haven't saved, have no 401K or other savings/retirement plan. When my income drops to merely Social Security, after LTD runs out at age 65, and when the meager savings I do have run out, I will have to conserve, eat*

and live meagerly in order to remain in my present home, and still live in this expensive city, if I'm able. I fear for my welfare & my ability to obtain survival necessities when I reach age 65 and beyond."

- *"I am not sure I will be able to afford rent and food, and live with a lot of fear about the future."*
- *"I can barely pay all my monthly bills now. With less income, I could not pay my monthly bills."*
- *"I will become impoverished."*
- *"Poverty."*
- *"I don't know if I can afford to live."*

All respondents were asked to identify their three top fears about aging. A significant number (n=44 or 37.6%) of respondents identified "fear of economic hardship" as their number one fear. When tallying the top three fears together, "fear of economic hardship" was nearly the same as "fear of medical complications of aging and HIV."



2. Isolation

Social withdrawal and isolation—whether caused by the physical or cognitive effects of HIV and its treatment, the stigmatization often associated with HIV or a combination thereof—are common in older people living with HIV / AIDS.⁴⁷

According to the authors of the ROAH study, loneliness scores are not related to frequency of contact or the social network size. But they do measure the quality of that support. Levels of loneliness have been shown to be negatively related to self-rated health and life satisfaction and positively correlated with depression in older adults.

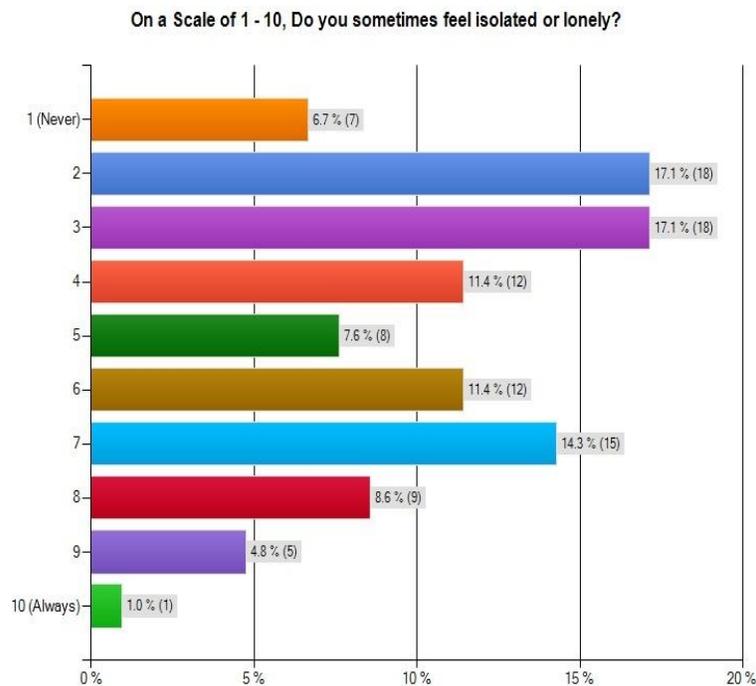
⁴⁷ Vance, David E. PhD, MGS, Aging with HIV: Clinical Considerations for an Emerging Population, AJN, American Journal of Nursing: March 2010 - Volume 110 - Issue 3 - pp 42-47

The UCLA Loneliness scale is designed to assess perceptions of inadequate support from a person’s social network. The scale contains both positive and negative statements about feelings of loneliness. The ROAH cohort did participate in a loneliness assessment and the findings were that loneliness is a significant issue for older adults living with HIV with an average score of 53, as opposed to an average score of 32 for the general population of older adults.⁴⁸

For the purposes of the HIV and Aging Workgroup’s on-line survey, nothing nearly as technical as the UCLA loneliness scale was utilized. Nevertheless, the workgroup did want to get a sense of the isolation experienced by respondents.

Survey participants were asked: “On a Scale of 1 - 10, Do you sometimes feel isolated or lonely? (1= Never and 10= Always). Nearly half of the respondents indicated a level of 5-10 of isolation, 28% indicated a level of 7 or higher.

Although not a rigorous measure of loneliness, it is safe to say that a significant number of the participants identified themselves as somewhat to extremely lonely.



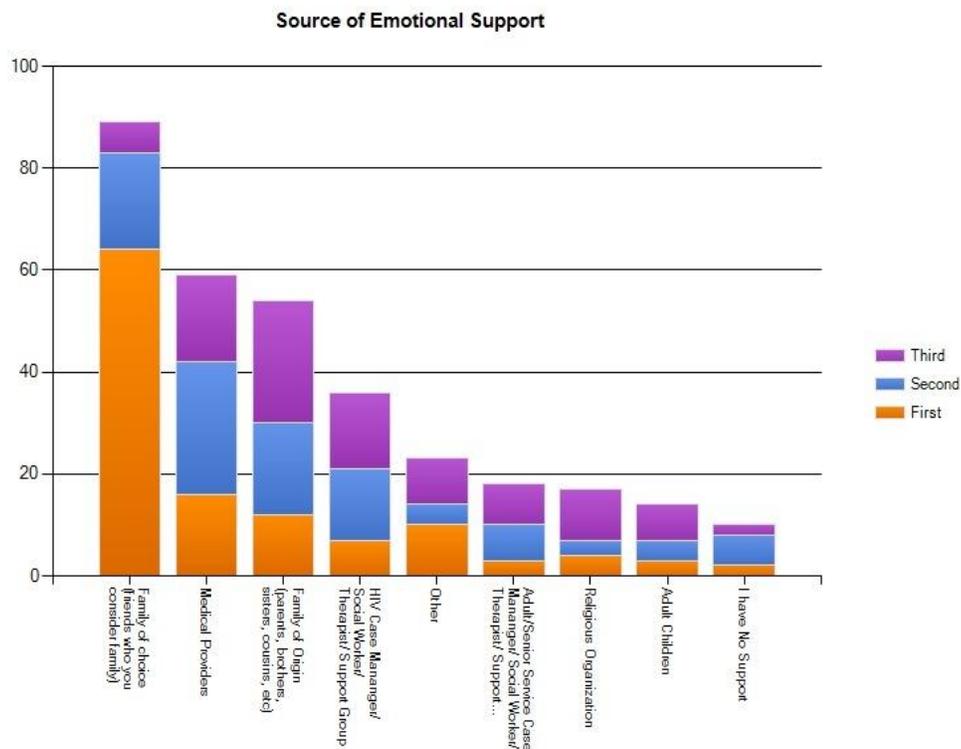
The group that reported the highest level of loneliness were those that had chosen “not to have sex”, with over 70% (n=7) rating their level of loneliness at 6-10. Individuals who were employed showed no statistical variance in this simple measure of loneliness and, as a matter of fact, showed the highest percentage of individual ratings of 9-10. Individuals with incomes of \$50,000 or higher, as a group, assessed themselves as the “least lonely.”

⁴⁸ Karpiak, S and Shippy, R Andrew; “Research on Older Adults with HIV (ROAH)” 2006

Often one’s living situation correlates to loneliness and isolation. The survey did not ask about living situation but in the ROAH cohort, 70% of HIV-positive people over 40 lived alone versus 39% of the general population 50+ in New York City.⁴⁹ According to one study 54% of gay and bisexual men in New York City “not partnered”, as opposed to 36% who are partnered and gay men, are very likely to live alone (66%).⁵⁰

A corollary to loneliness is the support systems one has in place. In order to add context, survey respondents were asked to indicate the three most important sources of emotional support. By a significant number “Family of choice” was cited as the most significant source of support with 83% ranking it among the top 3 sources of support and nearly 60% citing it as the most important source of emotional support.

Medical providers were the second most cited source of emotional support. 55% of respondents cited medical providers as one of the three most important sources of emotional support and nearly 15% identified medical providers as their most important source of emotional support.



3. Non-Medical Service Needs

⁴⁹ *Ibid.*

⁵⁰ Cantor et. al, “Caregiving among older LGBT New Yorkers, 2004

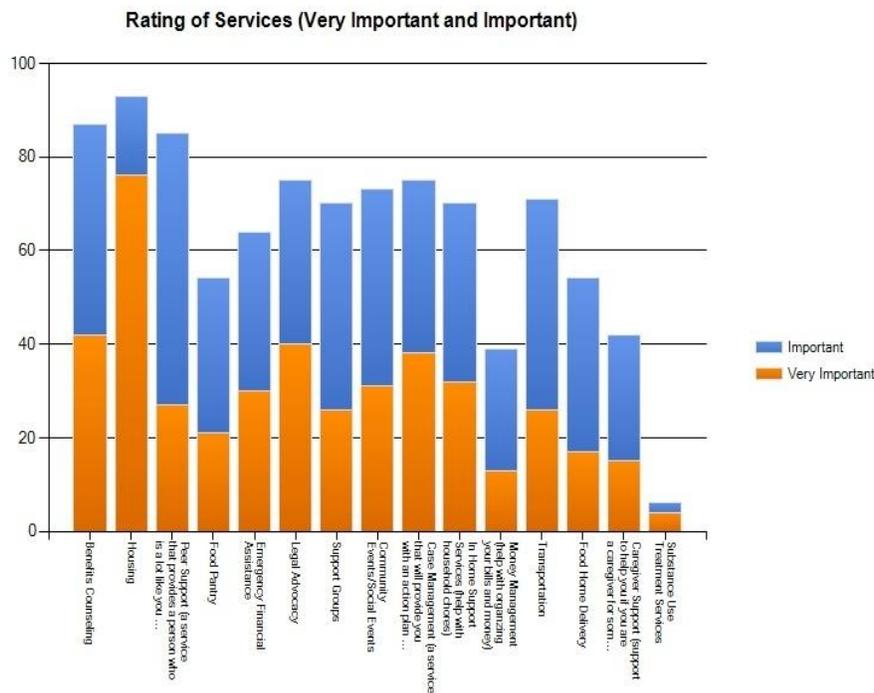
Respondents were asked to rate the importance of non-medical services that are currently funded in San Francisco through HIV Health Services in the Department of Public Health or through the Department of Aging and Adult Services.

Housing was identified as the most important need with 90% responding that it was important or very important (73.8% - “very important” and 16.5% - “important”). Peer Support was identified by 84% of respondents as important or very important. Benefits counseling was identified by 83.7% as important or very important. Legal Advocacy was identified by nearly 75% as important or very important. Social Events and Community Support were identified by 73% as important or very important.

Housing is at a premium in San Francisco and was cited as a critical need in the 2008 comprehensive needs assessment of severe need individuals living with HIV in the San Francisco EMA.⁵¹ Housing was also identified as the most important service in making a difference in one’s ability to access primary medical care in a recent study, *HIV Positive Voices in America*, released in April 2009.⁵²

The needs expressed for legal services and benefits counseling for older people living with HIV/AIDS in San Francisco parallel the complexity in array and eligibility for benefits that intersect those available to people disabled, those available to people living with HIV, those that are means tested and those available to older people.

The chart below shows the importance attributed to various services by respondents



⁵¹ Harder + Company, SFHPC 2008 Comprehensive Needs Assessment, September 2008

⁵² Allgaier, R. et. al, “HIV Positive Voices in America”, CAEAR Coalition and National Association of People with AIDS, 2009

4. *Comfort and Knowledge of the System of Care*

Respondents were asked about their knowledge of the HIV service system and the adult and aging service system in their county of residence and how comfortable they would be in getting services at an HIV /AIDS focused program or at an Aging and Adult Services program.

93% of respondents “would be comfortable” receiving services from an HIV organization. 72.6% said they knew about HIV services in their county well enough, quite well or very well. Of the 7% that would not be comfortable receiving services from an HIV organization the two most frequent reasons were 1) income is too high and 2) bad experiences with certain providers.

24% of San Francisco respondents knew HIV services “a little but not enough” or “not at all.” 44% of San Mateo respondents knew HIV services “a little but not enough” or “not at all.” 50% of Marin respondents knew HIV services “a little but not enough” or “not at all.” Those that knew “a little but not enough” or “not at all” tended to be higher income. 43% had incomes at >\$40,000/year- about 10% higher than all respondents in this income level.

From some of the comments made by those that did not know the HIV service system very well, it was clear that they were currently at an income that they perceived made them currently ineligible for services, although some of these individuals were also clear that as they age, their current income will likely decrease, and in some cases, decrease substantially.

A sampling of some of these comments:

“I'm in the middle, not poor enough for any kind of assistance, and not rich enough to not worry about it.”

“Did not plan to be alive and so made no plans for retirement. (I) will never be able to afford to retire. (I) am dealing with age discrimination on the job market now.”

“I was diagnosed in 1985, spent what little money I had because I thought I was going to die like all my friends. Now in 2010 I'm so very worried what I will do when I reach retirement age. I'm 61 now.”

“While I'm managing today, the future remains unclear.”

The comfort level with aging and adult services was substantially less for respondents than their comfort level within the HIV/AIDS service system: 72.5% would be comfortable receiving services from aging and adult services organizations as opposed to the 93% comfortable with an HIV/AIDS organization. Of the 27.5% that would not be comfortable receiving services from an adult/aging services organization, the two most frequent reasons were: 1) fear of HIV-phobia and homophobia and 2) did not consider themselves eligible.

While the comfort level with receiving services through an “adult and aging” identified organization was much lower than the comfort level in receiving services through an HIV/AIDS identified organization, nearly three in four respondents would be comfortable receiving services from an adult and aging services organization. However, when asked how well they knew adult and aging services, less than

13% said that they knew about aging and adult services well enough, quite well or very well. Thus nearly 9 out of 10 did not know the aging and adult service system of care well enough. It seems that there is a substantial number of individuals who are comfortable with the concept of receiving services at an adult and aging service organization, but have no real knowledge about these organizations, their culture or their services. This is reflected in some of the comments from respondents. Below is a sampling of some of the comments received when asked why they would be comfortable in accessing these services.

“Probably depending upon the services offered.”

“Not really sure. I don't know how homophobic they might be.”

“I can use all the help I can get...”

“I'm open about it all, and open for all services.”

There was no variance in age between the age of “all respondents” and those respondents who knew “little but not enough” or “nothing at all” – so age is not a factor among our survey respondents. Income was also not a factor.

While insufficient knowledge of aging and adult services was very high in all counties, it was noticeably higher in San Mateo and Marin

<u>County</u>	<u>% that did not know AAS System</u>
San Francisco	80%
San Mateo	89%
Marin	100% *

*Marin total n=4

Data and Needs Assessment Information Conclusions

Some of the issues that were raised by focus group participants and survey respondents were similar to the overall population of people living with HIV/AIDS in the EMA. Housing, transportation and food are identified as top priorities for all people living with HIV/AIDS and housing was identified as the number one need for the older population as well. Transportation and food were identified as top tier needs among the focus groups and were identified as a need among survey respondents. Food and Food Pantry combined were identified as a very high priority among survey respondents as was transportation.

Of particular note is the value that peer support services, support groups and social and community events had for participants in the focus groups and the survey. When this information is contextualized within the rubric of the notable social isolation reported, it brings to light the invaluable and critical nature of these types of services.

Both benefits counseling and legal advocacy were identified as significant service needs for older people living with HIV/AIDS. With the complexity of benefits that are associated with HIV/AIDS, disability, senior status, and retirement, older people living with HIV/AIDS are navigating a labyrinth of programs that may or may not wrap around one another, conflict with one another, and have differing eligibility criteria.

It is also clear that there are definitely two systems of care – HIV/AIDS and Adult and Aging services. Not surprisingly, people with HIV/AIDS are very comfortable and fairly knowledgeable about the HIV/AIDS service system but lack the knowledge of adult and aging services. While a significant number of people said they would be comfortable with the concept of getting services from an aging and adult service agency, the number of individuals who do not know anything about these services is profound and among those who are trepidatious about these services, concerns about homophobia and HIV-stigma (or discrimination) are significant.

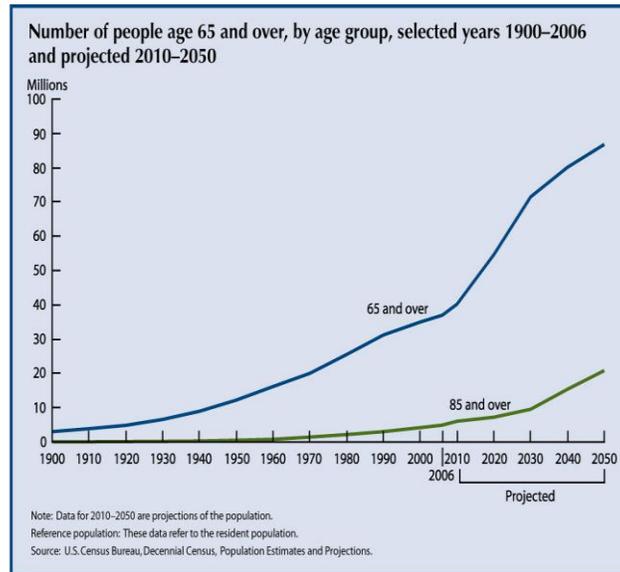
Aging with HIV/AIDS within the context of an Aging Society

Population Growth of Older People

It is important to look at HIV and aging within the context of a society that is aging. While the needs of people living with HIV/AIDS are unique and complex, the United States population is growing older and this will have an enormous impact on all sectors of society, government and healthcare.

According to the US Census the 65+ population numbered 35 million in 2000. In 2006, an estimated 37 million people in the United States—12 percent of the population—were 65 and older. Projections forecast that by 2030, approximately 71.5 million people will be 65 and older, representing nearly 20 percent of the total U.S. population.⁵³

The chart below shows the large growth of the population 65 and older from 1900 to 2006 and the even greater projected growth from 2006 to 2050. It also shows the growing numbers of persons 85 and older and their large projected growth to 2050.⁵⁴



San Francisco is an “older city” than the state of California or the nation. According to data compiled by the San Francisco Human Services Agency, in 2007 19.4% of San Franciscans are 60+ compared to 15.2% statewide and 17.4% nationally.⁵⁵

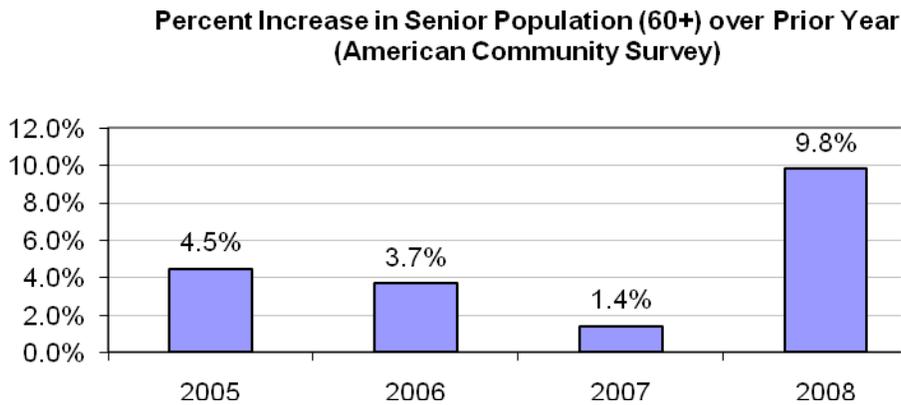
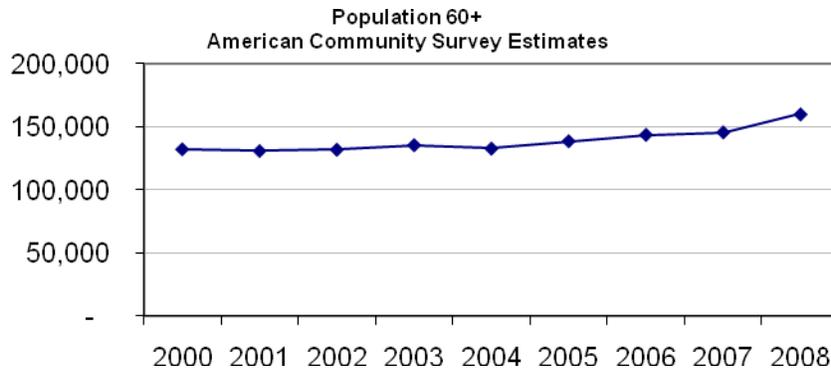
Locally there has been an annual rise in the number of people in San Francisco 60 and older. Most notably the 60+ population had a nearly 10 percent increase from 2007 to 2008.

⁵³ Federal Interagency Forum on Aging-Related Statistics, AgingsStats.gov, “Older Americans 2008: Key Indicators of Well Being.”

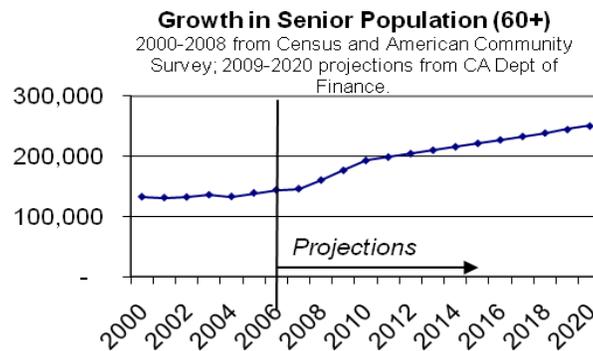
⁵⁴ *Ibid.*

⁵⁵ Data provided by Diana Jensen, Senior Planning Analyst, San Francisco Human Services Agency, based on 2008 American Community Survey Data

The following charts provided by the San Francisco Human Services Agency show the growing numbers of older San Franciscans in recent years and the trends for the future.⁵⁶



Consistent with the national trend, it is projected that San Francisco will see a significant increase in the number of people 60+ for the coming decade.



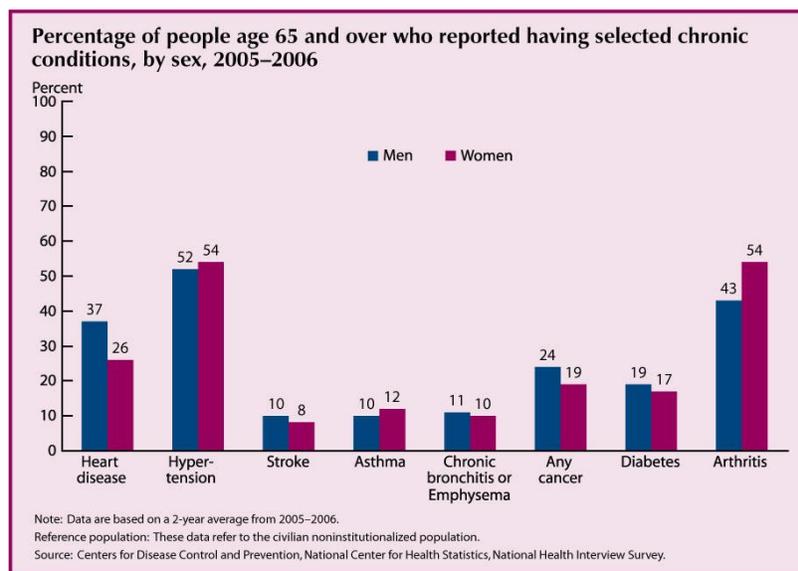
⁵⁶ Data provided by Diana Jensen, Senior Planning Analyst, San Francisco Human Services Agency, based on 2008 American Community Survey Data and projections from the CA Department of Finance

Health Issues

This growing number of older people in the nation will also impact healthcare needs, since according to the Federal Interagency Forum on Aging-Related Statistics there are a significant number of people aged 65 and over that have chronic health conditions.

The co-morbidities in the ROAH study reflect that people living with HIV/AIDS are experiencing these same chronic health conditions with heart disease, arthritis and hypertension being among the five most co-morbid conditions for the ROAH cohort.

The following chart shows the percent of men and women reporting selected chronic conditions. Over half of men and women reported hypertension with arthritis and heart disease as the next most common conditions.⁵⁷



Depression is the most common comorbidity for older people living with HIV/AIDS in the ROAH cohort and among them, 2/3 were moderately to severely depressed. Among the overall population of older Americans, from 1998 to 2004, 11 to 12 percent of men over 65 had clinically relevant depressive symptoms, as did 17 to 19 percent of women.⁵⁸ Clearly depression is an issue for older Americans, most especially women, but depression is reported significantly higher among people living with HIV/AIDS.

Ageing with HIV/AIDS within the context of an Ageing Society Conclusions

The overall population of the United States is older with an increasing percentage of the population at age 60 and over. San Francisco already has an older population as a percentage of the total population of the city than that of the state of California and of the nation.

⁵⁷Federal Interagency Forum on Aging-Related Statistics, AgingsStats.gov, "Older Americans 2008: Key Indicators of Well Being."

⁵⁸*Ibid.*

The aging American society will have profound effects on every aspect of life and its impact will be felt in social services, healthcare, societal norms, medical research and government at the local, state and federal levels.

People living with HIV/AIDS who are growing older are doing so in a society that is dramatically aging. The strain that the increasing number of older people will have on entitlement programs such as Medicare (even with healthcare reform in place) and Social Security is an issue that is currently a policy and political debate in Washington DC and the future viability and structure of these programs remains precarious. Since a significant number of people living with HIV/AIDS (younger and disabled as well as older) rely on these programs, their ongoing stability is important.

There will likely be an increased demand for services targeting the aging community. People with HIV/AIDS who are older are just one segment of that growing community. While the future economic health of the nation, the state and the city are unknown, currently the economic environment is not one that allows for planning resource rich new initiatives and programs and any plans for this growing population of older adults must be done at a time of diminishing resources.

Overall Conclusions and Recommendations

Responding to HIV and Aging in San Francisco: 10 Conclusions

1. The population of people over 50 living with HIV/AIDS is already substantial and above the national average. It is likely that this population will be 50% of all people living with HIV/AIDS in San Francisco by the end of 2012. In order to adequately respond to the HIV/AIDS epidemic in the San Francisco EMA, addressing the needs of older people living with HIV/AIDS is essential.
 - **Conclusion: Due to the large numbers of older people living with HIV/AIDS in San Francisco, it is critical that San Francisco shift a substantial amount of its focus to address the needs of this population.**

2. While there are unique issues faced by older people living with HIV/AIDS, the demographic breakdown around gender, race, ethnicity and sexual orientation are diverse and closely mirror the demographics of the overall epidemic in the EMA. It is essential to recognize that as people age, they do not lose the need for services to be delivered in ways that are sensitive to an individual's gender, race, ethnicity and/or sexual orientation. There is another layer of awareness that services need to have- age related sensitivity. For example, rather than seeking services based solely on her age, an African American woman with HIV/AIDS who is 60, may wish to access services at an agency that focuses on African American women, but that agency may need to learn how better to serve her needs as an older woman.
 - **Conclusion: This population of older people living with HIV/AIDS is diverse and will need to have social services delivered in ways that reflect not only their age and their HIV status but their gender identity, their ethnicity and their sexual orientation.**

3. According to a CDC report, among persons newly diagnosed with HIV, the probability of being diagnosed with AIDS within 12 months, increases with age. According to the CDC, "Health care professionals may underestimate their older patients' risk for HIV/AIDS and thus may miss opportunities to deliver prevention messages, offer HIV testing, or make an early diagnosis that could help their patients get early care."
 - **Conclusion: Many of the trends and concerns coming from an analysis of data on late testers and new infections must be addressed through adequate prevention efforts and healthcare provider education.**

4. The healthcare needs of people living with HIV/AIDS who are older are complex. HIV and aging make for a complicated balancing act – a convoluted interplay of the disease itself, natural aging symptoms and the side effects of antiretroviral medication that may enhance those

symptoms. Combining issues of drug toxicity, long term use of ARVs, effects of drug combinations used to treat HIV, other health issues related to aging and “usual” comorbidities in general, effects of inflammation, mental health and substance use history, creates a daunting challenge for healthcare providers but also for older people living with HIV/AIDS themselves. Navigating the many unknowns and the complexity of the landscape successfully is essential for older people living with HIV/AIDS to enjoy better health and a decent quality of life.

- **Conclusion: Support services providers must be equal partners with medical providers in order to ensure that life is not just extended for older people but that it is one with as much meaning and quality as possible.**
5. Concern regarding economic hardship and decreased financial stability crossed all income levels and was identified as a significant issue for the majority of respondents. Economic hardship is as critical an issue as medical complications for older people living with HIV/AIDS. For some individuals who are currently financially stable and self reliant, that stability may be severely compromised as one ages and there may be an increased demand for services by people who currently do not need them.
 - **Conclusion The system of care for people living with HIV/AIDS must plan for an increase in the numbers of people needing services due to loss of economic stability associated with circumstances related to aging.**
 6. Social withdrawal and isolation—whether caused by the physical or cognitive effects of HIV and its treatment, the stigmatization often associated with HIV, or a combination thereof—are common in older people living with HIV or AIDS. While isolation is an issue for older people in general, loneliness is a significant issue for older people living with HIV/AIDS and research has shown a substantially higher level of loneliness for older people living with HIV/AIDS than the general population of older people. Older people in the San Francisco EMA living with HIV/AIDS reported a high level of loneliness. This affects a number of issues, from medical care, because medical providers are identified as an important source of emotional support for people living with HIV/AIDS, to the need for psychosocial support, because older people living with HIV/AIDS identify peer support, support groups and social and community events as critical to their wellbeing.
 - **Conclusion: Reducing social isolation for older people with HIV/AIDS is a critical component of successfully meeting the needs of this population.**
 7. The system of income and healthcare benefits is extremely complex for older people living with HIV/AIDS and includes an array of programs and eligibility criteria that intersect those available to people disabled, those available to people living with HIV, those that are means tested and those available to older people.
 - **Conclusion: To ensure that older people living with HIV/AIDS have the income and healthcare benefits and legal advocacy that can help their quality of life it is critical that expertise about these various benefits be available.**

8. There are definitely two systems of care - HIV/AIDS and Adult and Aging services. Not surprisingly, people with HIV/AIDS are very comfortable and fairly knowledgeable about the HIV/AIDS service system but lack the knowledge of adult and aging services.
 - **Conclusion: There must be efforts at cross talk between different city agencies and departments and there must be a common information source for the services available to older people living with HIV/AIDS.**

9. People living with HIV/AIDS who are growing older are doing so in a society that is dramatically aging, both nationally and locally. This growing number of older people in the nation will also impact healthcare needs since, according to the Federal Interagency Forum on Aging-Related Statistics, there are a significant number of people aged 65 and over that have chronic health conditions.
 - **Conclusion: The strain that the increasing number of older people will have on entitlement programs is an issue that is currently a policy and political debate in Washington DC and the future viability and structure of these programs remains precarious. Since a significant number of people living with HIV/AIDS (younger and disabled as well as older) rely on these programs, their ongoing stability is important.**

10. There will likely be an increased demand for older adult services in the future due to the aging of our society happening at a time of economic uncertainty and significant cuts in public funding.
 - **Conclusion: Planning for programs for older people living with HIV/AIDS must consider the stark funding environment and look at the development of innovative and collaborative programs that are cost effective and ideally, cost neutral.**

Responding to HIV and Aging in San Francisco: Recommendations to the City and County of San Francisco

1. The Mayor should convene an HIV and Aging summit that would bring leaders from all city departments and agencies, foundations, business leaders, policy makers and community leaders together to identify and craft a unified strategy to address the needs of older people living with HIV/AIDS.
2. San Francisco should take the lead in bringing together leaders from cities throughout the United States who are also addressing HIV and Aging for information sharing and the development of best practices guidelines.
3. San Francisco should explore partnering with research partners such as the University of California San Francisco, Center for AIDS Prevention Studies and/or the AIDS Community Research Initiative of America and/or the San Francisco State University Health Equity Initiative to conduct more robust research and needs assessments of older people living with HIV/AIDS in the county/city.

4. San Francisco should aggressively explore innovative ways to provide accessible and affordable housing for older people in San Francisco- especially those living with disabilities including HIV/AIDS.
5. San Francisco should take the lead in addressing HIV and Aging in the Bay Area, specifically the three counties of the San Francisco EMA- San Francisco, San Mateo and Marin.

Responding to HIV and Aging- Recommendations to San Mateo and Marin Counties

1. The relevant agencies in San Mateo and Marin counties should hear a presentation of this data.

Responding to HIV and Aging in San Francisco: Recommendations to the Long Term Care Coordinating Council

Recommendations to the Long Term Care Coordinating Council recognize the advisory role of the council and strive to be cost neutral.

1. The Council should advise that HIV/AIDS issues should be a regular topic in trainings to the staff of the Department of Aging and Adult Services.
2. The Council should advise that trainings about the needs of people with HIV/AIDS should be made available to case managers in programs funded by the Department of Aging and Adult Services.
3. The Council should consider advising that regular information should be provided to clients of senior centers about HIV/AIDS issues.
4. The Council should advise that staff in Department of Aging and Adult Services funded Senior Centers should be able to demonstrate sensitivity to the needs of people living with HIV/AIDS.
5. The Long Term Care Coordinating Council should have one seat designated for a member of the HIV Health Services Planning Council.

Responding to HIV and Aging in San Francisco: Recommendations to the HIV Health Services Planning Council

Recommendations to the HIV Health Services Planning Council recognize the role of the council in allocating Ryan White resources, prioritizing services and issuing directives to the Department of Public Health, HIV Health Services Section and strive to be cost neutral.

1. The Council should issue a directive to the grantee that states: “The grantee must fund one Case Management program that demonstrates an ability to work with programs in both HIV services and Aging and Adult services and expertise in the needs of older people living with HIV/AIDS.”
2. The Council should issue a directive to the grantee that states: “The grantee must fund one benefits counseling program through the HRSA category “Case Management (Non-Medical)”

that demonstrates expertise in the healthcare and income benefits and eligibility criteria that are needed by people 60 years and older living with HIV/AIDS.”

3. Due to the complexity of care for older people living with HIV/AIDS, the Council should add “People over 60 years of age” to the “Special Populations” definition.
4. The Council should re-consider raising the current priority levels of a) Psychosocial Support, b) Case Management (Non-Medical) which is a HRSA category that allows for funding Benefits Counseling, and c) Legal advocacy.
5. This report should be put on the agenda for the Points of Integration Committee (a joint committee of the HIV Health Services Planning Council and the HIV Prevention Planning Council) with a request that the Prevention Planning Council address the issue of HIV prevention in the older population.
6. The HIV Health Services Planning Council should have one seat designated for a member of the Long Term Care Coordinating Council.

Final Comments

These conclusions and recommendations are only the beginning of addressing the important issue of HIV and Aging in the San Francisco EMA. There is much more research and work to do.

It is particularly challenging to address these issues in a time of economic uncertainty and in a period when our society as a whole is experiencing an “aging bubble.” There are limited and diminishing public resources available to meet the needs for an aging population in general and an aging population with HIV in particular. Meeting these challenges will require creative uses of existing resources, developing partnerships, opening up funding silos and engaging the public and private sectors to seek innovative solutions.

It is wonderful and exciting that we are in a place where we are looking at aging with HIV rather than dying from AIDS. The HIV/AIDS community has spent the last 15 years moving from a model of palliative care for a deadly disease to a model of chronic care for a very serious illness that many people are able to manage. However, aging with HIV presents new challenges for research, medical care and support services. Quality of life is as important as quantity of life. Ensuring this balance will result in successfully meeting the needs of people living with HIV/AIDS now and in the future.

Acknowledgements

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