

**HIV and Aging – A Survey in Three San
Francisco Area Counties – San Francisco City and
County, San Mateo County, Marin County**

Loren Meissner, M.A.

Brian de Vries, Ph.D.

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**in association with the San Francisco Eligible
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Executive Summary

Over fifty percent of those diagnosed with HIV (Human Immunodeficiency Virus) in San Francisco (City and County) are aged fifty or older (SFDPH, 2012). Beginning in December 2012 and ending in February 2013, a survey was conducted in San Francisco, San Mateo and Marin Counties in California about service utilization among those aged 50 and over diagnosed with HIV. This survey was adapted from a survey used in the 2009 GMHC Study report by Brennan and colleagues (2010) in New York City.

Participants were recruited through e-mails, fliers, and newspaper notices, primarily through the agencies at which the surveys were conducted. Venues were six social service agencies in the San Francisco, San Mateo and Marin Counties serving people living with HIV and/or elders. Participants attended one of the 12 survey events, completed a 45 page written survey and received a stipend (\$20 Safeway grocery store gift card); the available sample size was 160 participants. Thus, the participant sample was skewed toward those who use social service agencies and those of low to moderate SES (socio-economic status).

Results revealed that most participants had access to HIV medications and had their HIV well managed. The majority of participants (91%) reported currently taking HIV medications. The most frequent viral load reported was “undetectable.” Only 16% of those who reported a viral load reported it as detectable. Also, 80% identified themselves as male, 11% female and 8% MTF transgender. Most in the group are long term HIV survivors (93% have had HIV 10 years or longer).

A significant number are not emotionally close to and about half did not have their physical and emotional needs supported by their families - more true for younger participants (age 50 - 55). Most participants were relying on informal friend networks and agencies. Almost 10% of those who said they required regular assistance because of HIV or other illness, disability or frailty now or in the past, reported that they had no one to provide such care. State, local and federal programs are generally used for financial help. Other results support previous research in both San Francisco (Allgaier, 2010) and New York (Brennan et. al, 2010) such as demographic variables and biopsychosocial markers. The high cost of living in the San Francisco area, social isolation, housing, economic security, and transportation are key social considerations among this population. A significant minority, almost 15% (14.6%) of participants, reported living in SRO's (single room occupancy housing), or being homeless.

Most participants were generally pleased with most of the services they received most of the time. However, the top 10 concerns about barriers to service with percentage of participants who indicated them:

- Service not free (39%), Don't know where to get services (37%),
- Cost of service (34%), Don't know that the service exists (33%),
- Red tape (31%), Service wait times (31%),
- Staff not helpful (23%), Providers don't like participant (23%),
- Communication problems (16%), Fear that they won't be treated (16%).

As the Allgaier/SF EMA Planning Council 2010 report mentioned, there is confusion in the perception of service consumers between services related to HIV, services related to aging and in most cases, services related to LGBT (Lesbian, Gay, Bisexual, and Transgender) issues as well.

Definitive conclusions from these data are confounded by the issues that (1) some medical issues could be related to HIV or they could be related to general aging; (2) most (79%) in the survey were LGB (Lesbian Gay Bi) and some of their problems could be related to HIV or related to LGBT aging; (3) most in the group are long term survivors who have been scarred by the HIV pandemic which killed nearly two thirds of those diagnosed with AIDS in San Francisco since 1981, including friends and partners; and (4) general experiences of stigma as an elders in the predominant LGBT youth culture, increasing isolation. It is anticipated that future research papers will use these data to compare with the original New York 2009 GMHC survey.

Introduction

In the Fall of 2012, an inauspicious milestone in the chronology of HIV was attained: over 50% of those living with HIV in the City and County of San Francisco were aged 50 or over (SFDPH, 2012). Nationally in the U.S., it is projected that over half of those living with HIV will be age 50+ by 2015 (Effros et al, 2008). Allgaier (2010) released a report about the condition of those living with HIV in the San Francisco area (San Francisco, San Mateo and Marin Counties) largely based on inferences about San Francisco conditions being similar to those in New York, drawing upon an earlier New York based ACRIA (Community Research Initiative of America) ROAH (Research on Older Adults with HIV) study (Brennan, Karpiak, Shippy & Cantor, 2009). In the San Francisco area-based Allgaier report, additional input was received from an online survey of 117 participants as well as focus groups held in 2010 of 14 people commissioned by the San Francisco Eligible Metropolitan Area (San Francisco, San Mateo and Marin Counties) HIV Health Services Planning Council (Planning Council).

In the Spring of 2012, the author of the present report received prior permission from the authors of the 2009 GMHC New York Survey and then approached the San Francisco EMA HIV Planning Council via the Planning Council's Consumer and Minority Affairs Committee with a request for support to replicate the New York GMHC survey adapted for the San Francisco Eligible Metropolitan Area. The Planning Council committee agreed to do this, and Council staff pledged logistical support in terms of \$20 Safeway cards for participants and printing and staff time to coordinate survey events and help with clerical overhead. The Planning Council administers the Ryan White (U. S. Federal HIV funding) for the three counties (San Francisco, San Mateo, Marin) and wanted to know about service utilization in order to assess needs and prioritize funds for services and agencies.

Method

An IRB (Institutional Review Board) protocol in support of this study was filed with the Committee for the Protection of Human Subjects at San Francisco State University (SFSU) in May 2012; final approval was obtained in September, 2012. A pilot of the survey was conducted at a survey event in early December 2012 for quality control of the survey document and to have a run-through of the survey event logistics. Based on feedback from the pilot, a revised protocol was submitted to the SFSU IRB and approved in mid-December 2012. The final protocol ID number at San Francisco State University is H12-20ab.

One hundred and sixty one participants were given a written survey on paper, 45 pages in length written in English. There were no online or computer options offered. Criteria for participation in the survey were that the participant must declare (self-identify or self-certify - no medical records or official documents were checked):

- That they were HIV positive (had a diagnosis of being infected with the Human Immunodeficiency Virus)
- That at the time of the survey they were age 50 or older
- That they resided in one of the following counties in the State of California USA:

San Francisco City and County

San Mateo County (the county immediately to the south of San Francisco, which includes SFO San Francisco International Airport)

Marin County (the county immediately to the north of San Francisco and to the north of the Golden Gate Bridge).

Homeless people who primarily frequented San Francisco, San Mateo County or Marin County were also allowed to participate in this study. The demographic area did not cover the two major Bay Area cities other than San Francisco and their suburbs; i.e., it did not include Oakland (Alameda County) and San Jose (Santa Clara County). This geographic area was chosen because the three counties covered (San Francisco, San Mateo County, Marin County) are the counties within the San Francisco EMA (Eligible Metropolitan Area) of the HIV Health Services Planning Council.

The survey was an adaptation of the New York GMHC 2009 study (GMHC is a HIV/AIDS service agency serving those affected by HIV) (Brennan, Karpiak, London, and Seidel, 2010). An example of an adaptation was that the San Francisco area survey replaced questions about what borough of New York the participant or their family or friends resided in with questions about whether they lived in or near the San Francisco Bay area. Local San Francisco area service agencies and providers replaced their New York counterparts.

Additionally, the San Francisco area survey asked more questions about transportation. For example, it mentioned BART (Bay Area Rapid Transit), Caltrain (San Francisco to San Jose commuter rail) and local Bay Area public bus and transit systems, instead of New York transportation agencies. It also asked more detailed information about Viral loads (a key marker for the HIV condition), and how the participant believed he or she contract HIV. The list of HIV medications was updated to include new medications FDA approved or in FDA trials since 2009.

Consistent with the GMHC survey, this survey also asked participants for various demographic information.

The survey listed a range of services and/or needs (along the lines of those in the GMHC study), such as

- Food Pantries (food banks) or delivered meals
- Financial counseling
- Legal services
- Housing assistance
- Substance use counseling
- Psychological counseling

The survey also asked if the participant used or needed the service, whether they got help, and if so if the service was helpful to them. The survey also used some standard mental health and ADL (Activities of Daily Living) scales. The survey also had sections

for brief optional open-ended responses about (if applicable) why participants were not getting the help they needed and services they would like to see provided. The average time most participants took to complete the survey was approximately one hour.

Surveying was done at six community service agency venues in San Francisco, San Mateo and Martin Counties during the period of December 2012 through February 2013. There were twelve total survey events at these six venues. Recruitment was done primarily through fliers in agencies. Also e-mails on e-mail lists related to either HIV and/or aging were used to recruit. The local San Francisco LGBT newspaper (Bay Area Reporter) mentioned and promoted the survey and various survey venues on three different occasions during this period.

In order to have sufficient seating space, survey forms and incentive \$20 Safeway cards available, and so as to provide accommodation for the disabled, RSVP's (reservations) were requested in advance. There was an approximately 20% "no-show" rate at any given survey event, a lower rate when the weather was warm and sunny, a higher rate when was cold and/or rainy. However, given that some of the "no-shows" eventually rescheduled, there was an over-all 15% no-show rate (i.e., high participation among those recruited who signed up). The 161 figure includes completed surveys.

Two people withdrew from the survey. One was encouraged to withdraw by the researcher from taking the survey because that person had already taken the survey before (there were also other surveys about LGBT aging taking place around the same time as this survey was going on creating possible confusion). Another person self-withdrew without any prompting from the researcher, during the intake, because that person was below the age of 50.

One completed survey was not used by the researchers: notwithstanding that person signing a form that they were age 50 or over, the person reported an age of 48 in the survey instrument question about their age. An age of less than 50 does not meet the criteria for the research participation. Accordingly, the final data set included 160 completed valid surveys.

As stated earlier, the venues were various social service agencies and primarily recruiting and attendance was among clients of these agencies. This resulted in the survey results having an "agency bias;" that is to say, the survey results are more likely to reflect the situation of those in the service areas covered who use agencies and social services and are clients of such agencies than the entire population of HIV-positive age 50 and older in the geographic areas covered. Also, despite some attempts to do so, the survey was not held in any medical clinics due to local and federal (HIPAA - Health Insurance Portability and Accountability Act) privacy laws. Similarly, the researcher allowed participants to self-certify their HIV status to avoid major obstacles and timeline delays which would have been caused if access to medical records or providers had been used to verify HIV status.

The study also had an SES (Socio-Economic Status) bias; venues were agencies, attracting those with low to moderate SES and often on public assistance. However, the population surveyed may fit well with the needs of the Planning Council, which administers Ryan White funding, as this population—those who need services—is the primary target for Ryan White funding.

Responses were manually coded in Excel spreadsheet (510 columns times 160 participants = 81,600 data elements) then analyzed in SPSS (IBM SPSS Statistics). The coding did, under some circumstances, involve some editing on the part of the

researcher. For example, some of the participants used the survey form as an attempt to write more about themselves than was asked via extra written comments on the survey form. These comments, while valuable in other ways than in terms of database recording, were re-directed to the narrative comment sheet and not included in the database. Some participants appeared to be confused by some of the survey questions and the instructions. A typical example of this was where a participant indicated that they lived alone and in the survey this response was coupled with instructions to skip to the next section. However, this person answered the next question within the section, “who do you live with?” and indicated “other” and manually wrote in “myself”. This was coded more accurately as living alone and not coded as living with “other”. While it might be interesting to know how many participants live with animals and how living with animals contributes to or detracts from their ability to manage their lives in a future study, that question was not asked in either the GMHC or present study. Therefore the response from a participant that they lived with their dog to the question about living with others was also excluded from analyses. Since there may have been others who also had pets and did not report this, there was no way to accurately tabulate the “living with pet” factor in the survey.

Others stated that they were not born in the USA but were born in the self-identified foreign countries of “Texas”, “California” and “San Francisco.” Again the researcher recorded these responses on the comments sheet but did not record these as “foreign born” in the database. One person reported that they were diagnosed with HIV in 1957. Since the first cases of what would eventually be called HIV disease occurred in 1981 in the San Francisco Department of Public Health statistics and since the person was age 57, the researcher presumed the participant had entered their birth year in place of the diagnosis year and disregarded that diagnosis year in the database.

Further challenges to data entry included the failure to follow instructions by participants. On some occasions, the instructions asked participants to check only one box in a series but several participants checked multiple boxes in the series. In these cases, the researcher did not enter any response because the researcher did not feel it appropriate to choose for the participant among the multiple responses. On other occasions, participants gave a range of numbers when a finite specific number was called for. In this instance, the researcher averaged the number and rounded down to the nearest whole number. In one case, a participant wrote they had 5-10 friends in a question asking for the number of friends. The researcher entered the number 7. In one case the participant indicated they knew 10-20 people with HIV. The researcher entered the number 15.

There are other significant factors in relation to the results reporting: In general, the report presents all three counties as an aggregate, only reporting statistically significant ($p < .05$) differences by county. This was to keep statistics, charts and graphs simple and readable as opposed to complex and difficult to decipher. Another major issue was some residents took the survey in counties other than that in which they resided. Therefore the following decision rules were used for county assignment:

1. If the person reported a zip code (postal code), their survey was assigned to the county of their zip code.
2. If the person was homeless or declined to provide a zip code, the survey was assigned to the county in which the survey venue was located.

Results

Analysis Strategy

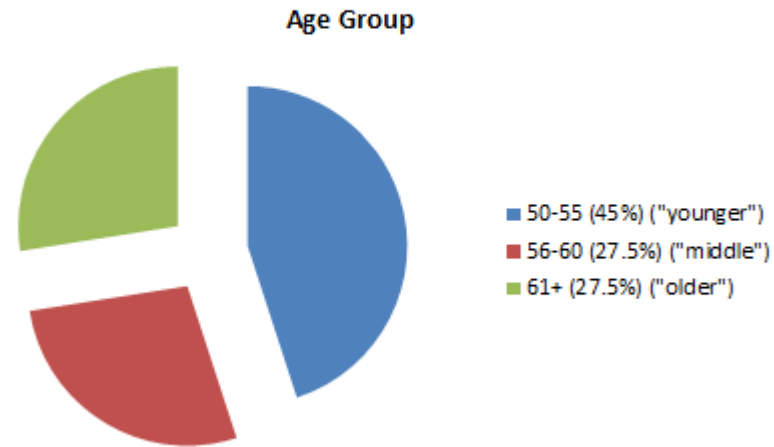
The results reported below are grouped by topical areas as presented in the survey; these include a demographic description of the sample. Although the topic results may vary by any number of demographic variables, we chose four central demographic variables for comparison purposes: age (grouped as those 50-55 [“younger”], 56-60 [“middle”], and over 60 years of age [“older”]) (Figure 1); race/ethnicity (including the three most frequently cited racial and a “multi-racial/other” racial group) (Figure 2); county (given the origins of this report and location of participants, including San Francisco, San Mateo, and Marin) (Figure 3); and gender (including those identifying as male, female, and MTF transgender) (Figure 4).

Demographics

A total of 160 surveys were tallied across the three counties surveyed, San Francisco, San Mateo, Marin: 117 (73%) were from San Francisco, 31 were from San Mateo (19%), and 12 were from Marin (8%). Overall, there were 129 participants who identified as male (80%), 17 who identified as female (11%), 13 who identified as transgender (12 male to female; 1 female to male), and 2 who identified as “other” (intersex). The percentages of males were comparable across the counties; there were a greater proportion of females in the San Mateo sample, and a greater number of transgender persons from San Francisco; 11 of the 13 transgender participants came from San Francisco. African-Americans in the sample were both more likely to identify as transgender (9 of the 13 transgender persons in the sample) and more likely to identify as bisexual than were participants from other racial groups. To preserve confidentiality, those who identified as “other” gender categories are excluded from the following analyses; additionally and based on the same rationale, the single participant who identified as female-to-male transgender was not included in the category “transgender” for analyses below.

Participants ranged in ages from 50 to 76 years. For analytical purposes, three age groups were created, as represented in Figure 1 below. This age group distribution was also comparable across counties, although San Mateo County had a somewhat greater proportion of participants in the age range of 56 to 60 years.

Figure 2: Overall Age Groups



Racial/ethnic identification was comparable across counties. Overall, just more than half of participants reported that they were “White/Caucasian” (50% of those in Marin, 51.6% of those in San Mateo, and 55.6% of those in San Francisco). A somewhat higher percentage of African-Americans were in the San Mateo sample; Asian-Americans were only in the San Francisco sample, and Native Americans, as well as those who identify as multi-racial, were only in the San Mateo and San Francisco samples.

Figure 3: Overall Racial/Ethnic Identity

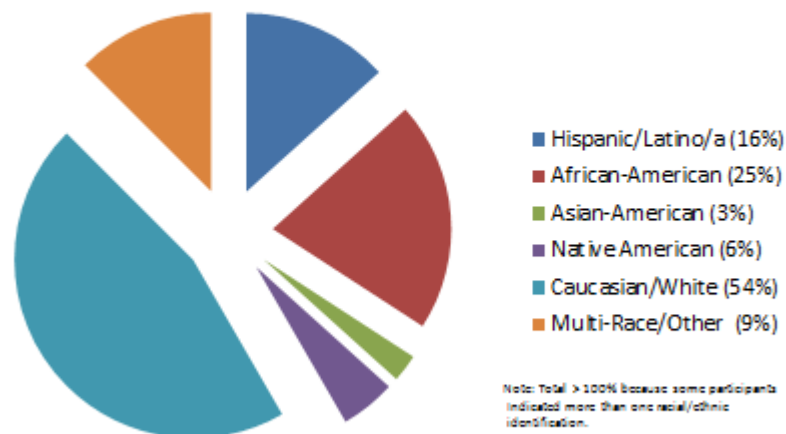


Figure 3: County

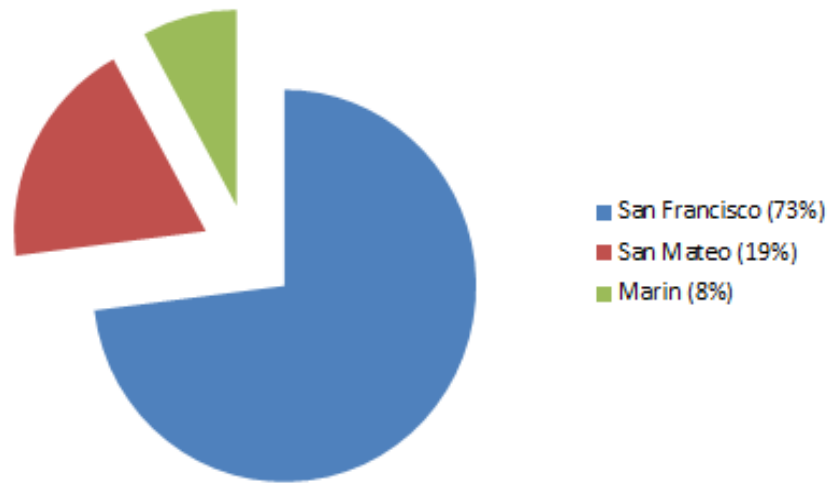
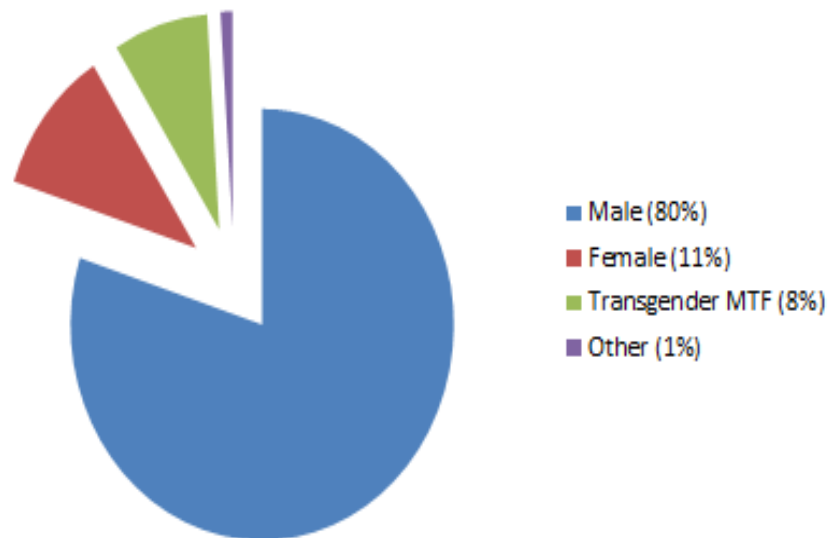
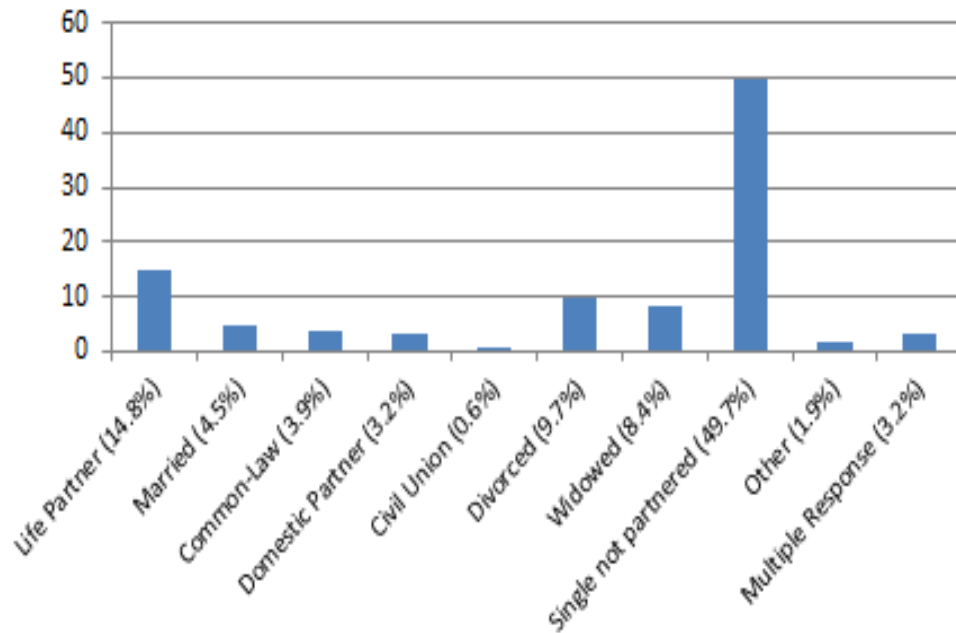


Figure 4: Gender



Relationship statuses varied dramatically, as is more generally the case during this period of relationship recognition complexity (see Figure 5 below). Still, the majority of the participants identified as single, not partnered or married.

Figure 5: Relationship Status



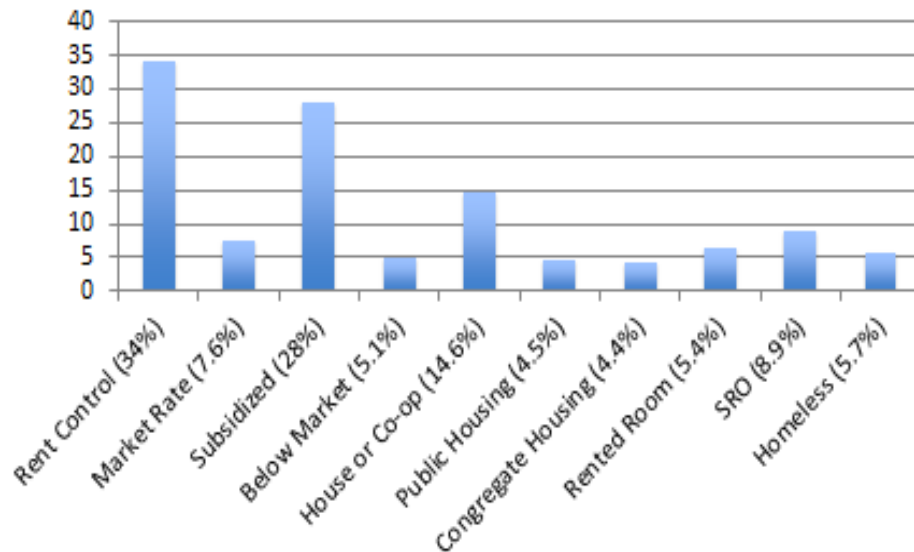
Considered more simply, just over 42% (42.5%) of participants reported that they were currently in a relationship of some form; this includes 2 participants, 1.3%, who reported their current relationship status as poly-amorous (multiple relationships at the same time). The remainder and the majority of participants reported that they were not currently in a relationship. Males and those identifying as transgender (recall that all of whom were male to female for these analyses) were more likely to be single than were those identifying as female. Older participants (i.e., those ages 60 and older) were more likely to be single; in fact, more than three-quarters (76.2%) of those in the “older” age group (age 60+) reported their relationship status as single. These relationship statuses were comparable across counties and racial groups. (In another survey question, 71% reported that they had been in a relationship of some form sometime in their life for six months or more.)

In response to a question about living arrangements, the majority of participants reported that they live alone (61% compared with 39% who report living with another person or persons). These percentages did not differ by racial group or county, although they did differ by gender: Males and those identifying as transgender were more likely to live alone (67% and 54%, respectively) than were females (31%).

In terms of physical living arrangements, as may be seen below (Figure 6), a variety of options were provided and endorsed by participants. Overall, participants primarily lived in rent-controlled buildings, subsidized housing, and cooperative

buildings. It is important to point out, however, the unstable or marginal housing of a significant minority of participants; that is, aggregating across SROs (single room occupancy), and those who were homeless comprise nearly 15% (14.6%) of the sample!

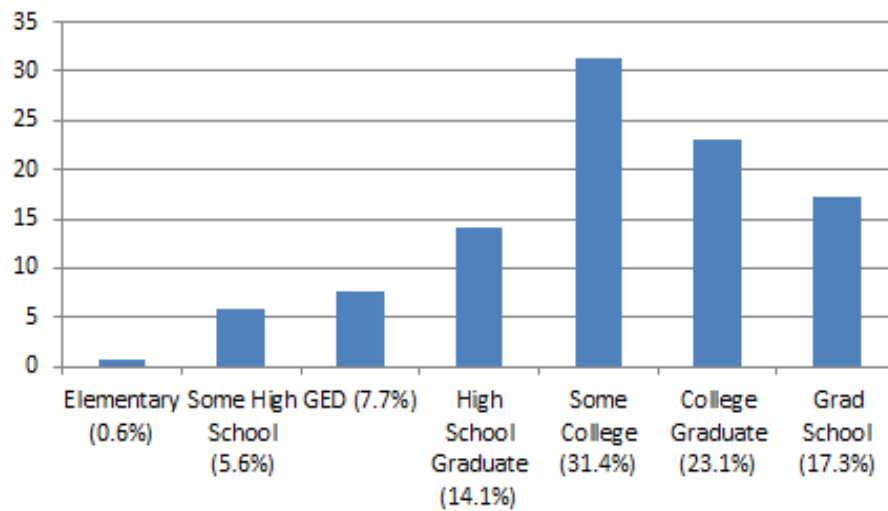
Figure 6: Housing



These physical living arrangements rarely differed by the demographics of the study. The only differences noted were the following: those who identified as white/Caucasian were more likely to live in cooperative housing or their own home, as were older participants, relative to younger participants; transgender and younger persons were more likely, than were those who identified as cisgender (i.e., not transgender) and those who were older, to report living in public housing (although the sample size is sufficiently small so as to put into question the validity of these statistics); African-American participants were more likely than participants of other racial identities to live in SRO's, as were those who lived in San Francisco City/County (relative to the other counties).

The modal (most frequent response) level of education of the sample overall was the completion of some college: i.e., just under one-third of the sample (31.4%) had some college as presented in Figure 7 below. Few demographic differences were noted: those identifying as male reported higher levels of education than did those identifying as either female or transgender; African-American participants reported lower levels of education than did participants from other racial groups; older participants reported higher levels of education than did younger participants.

Figure 7: Overall Highest Education Level



Several other questions were included to understand the basic demographic context of this sample. For example, a question was included addressing income sufficiency: 49% of participants reported they had just enough income to “get by,” 19% not enough, 16% enough and a little extra, and 10% reported that money was not a problem for them. Appraisals of income sufficiency did not differ by any of the other demographic variables examined (i.e., age, race, sexual orientation/gender identity, and county). The vast majority (87%) spoke English (perhaps not surprising because the survey was in English), 5% spoke Spanish and 6% reported that they were multi-lingual, usually English-Spanish. The only demographic difference revealed by subsequent analyses was that those who identified as Latino/a and those who identified as multi-racial were more likely to speak Spanish than were participants from other racial groups.

About one-third of participants (32%) reported some form of incarceration (having ever been in jail or prison). This percentage differed by both gender and race. Men were significantly more likely to have been incarcerated than were with women or those who identified as transgender; Both Caucasian and African-American participants similarly reported higher percentages of incarceration than did those who identified Latino/a and/or multi-racial.

In response to survey questions on religion, 27% reported no religion, 16% Catholic, 9% Protestant, 3% Jewish, 4% Muslim, 3% Buddhist, 5% Atheist, 21% Other, with 2% reporting more than one religion. Only 32% reported getting support from their place of worship.

Just fewer than 16% (15.9%) reported having served in the U.S. Armed Forces. This percentage did not differ by any of the demographic variables examined.

HIV Specific Issues

HIV History

The range of dates of participant first diagnosis of HIV positive ranges from 1981, the first year that the San Francisco Department of Public Health began recording HIV statistics, to 2012. The mean year in the responses was 1992 (representing living with the disease for over 20 years). The mode (most frequent) year was 1993 (20 years ago). Forty-two percent have been HIV positive over 20 years. Most in the group are long term survivors (93% have had HIV 10 years or longer)

Participants reported a wide range of sources of infection. Almost half (46%) reported infection via anal sex only; 9% reported infection through vaginal sex; 1% reported infection through needle use only; and 0.5% reported infection through some “other” means. Seven percent of participants reported infection through both anal sex and needles. Of those who reported being infected via a sex act, the majority (72%) reported unprotected sex as the cause they believe infected them. Interestingly, a significant minority either did not know or declined to respond to questions on source of infection.

The average (mean) CD4 of those who remember their CD4 count was 549; the mode (most frequent) CD4 was 800. The mode (most frequent) viral load was zero (undetectable). Only 16% of those who reported a viral load reported it as detectible.

HIV medications

The majority of participants (91%) reported currently taking HIV medications. A full listing of the diverse medications taken for HIV, and their frequency of use, may be found in Appendix 2 (below). The three most frequent medications taken by the participants for HIV by over 20% of participants (i.e. more than n = 32 participants) were Norvir (Ritonavir), Truvada (Viread +Emtriva) and Reyataz (Atazanavir).

Health

Physical Health

Participants were asked a series of questions about health, including an overall self (subjective) appraisal as well as the presence of a variety of conditions. In response to the former, participants rated their overall health on a 5-point scale, with lower values representing poor and very poor health, mid-range values representing fair health and higher values representing good and excellent health. The overall rating for this sample was 3.6 representing fair to good health. African-Americans rated their health more favorably than did participants from other racial groups; transgender participants similarly rated their health more favorably than did those identifying as cisgender (i.e. non-transgender).

Participants were asked to identify the illnesses or chronic conditions with which they were living from a list of 27 diseases or chronic illnesses. The number of conditions endorsed by the participants of this sample ranged from 0 to 12. The modal (most frequent) number of conditions was 2; the mean (average) number of reported conditions was 3.6. This mean did not differ by gender or county; somewhat surprisingly, this mean also did not differ by age group. Those who identified as Hispanic/Latino/a as well as those who identified as white reported a greater number of conditions (4.1 conditions in

both instances) than did those who identified as African-American (2.6) and/or another (other) racial group (2.2).

A listing of the conditions queried, along with percentages of those afflicted, appear in the tables below.

Table 1: Illness and Chronic Conditions: Most Frequently Indicated Average Number of Conditions = 3.6

- Anxiety (48%)
- Depression (43%)
- Arthritis (36%)
- Dermatological (29%)
- Neuropathy (28%)
- Hepatitis C (19%)
- Impotence (18%)
- Hypertension (15%)
- Hearing Difficulties (15%)
- Diabetes (12%)
- Herpes (11%)
- Vision Difficulties (11%)
- Heart Problem (10%)
- STDs (10%)
- Broken Bones (10%)

Table 2: Illness and Chronic Conditions: Less Frequently Indicated

- Migraine (9%)
- Shingles (8%)
- Nervous Disorder (8%)
- Cancer (8%)
- Pneumonia (7%)
- Hepatitis B (5%)
- Respiratory (4%)
- Staph Infection (4%)
- Syphilis (4%)
- Hepatitis A (3%)
- Stroke (2%)
- Menstrual Problems (1%)

Analyses by race, age group, gender and county revealed surprisingly few differences. (Analyses were only conducted when sample sizes permitted; specifically, analyses were performed for those conditions identified by 20% or more of the sample, meeting the minimal criteria for statistical reliability.) Interestingly, it was only for the

conditions of neuropathy, anxiety, and dermatological issues that significant differences were revealed and in all cases, African-American participants were the least likely to identify these conditions.

Questions addressing basic and instrumental Activities of Daily Living (ADLs) were posed of the sample. These questions were framed in terms of difficulties experienced in the conduct of communication; managing money, medications, and home maintenance; locomotion (i.e., getting places, walking, getting in and out of bed); nutrition (i.e., shopping, preparing meals); and personal upkeep (i.e., bathing, maintaining one's appearance, dressing). Using 4-point scales ranging from 1 "no trouble" to 4 "can not do without help," mean (average) responses ranged from 1.1 (dealing with feeding oneself and representing no difficulties in doing so) to 1.6 (dealing with difficulties completing housework and representing "little trouble"). Given this modest range and in an effort to represent difficulties in ADLs in general, a composite scale was created. The mean of this scale was 1.2, again reflecting little difficulty; there were no differences by any of the four demographic measures considered (and described above).

Mental Health

A standard measure of depression (Center for Epidemiological Studies—Depression: CESD, Anderson and colleagues, 1994) was included on the survey. This measure queried participants about the extent (on a 4-point scale ranging from 0 "none of the time" to 1 "a little of the time" to 2 "some of the time" to 3 "most of the time") to which they were bothered, troubled, depressed and, in contrast, happy and hopeful, for example, during the previous week. The mean (average) value on this scale for the participants of this sample of 2.1 (scores could range from 0 to 3), representing feeling depressed "some of the time" (also offered as about 3 or 4 of the past 7 days). This represents an elevated (high) depression level, possibly reflecting the troubling circumstances of life. As above, no significant differences were found when analyzed with the demographic measures considered.

The Patient Health Questionnaire 9 (PHQ-9: Kroenke Spitzer & Williams, 2001) was included on the survey. This scale provides 9 statements to which participants are to indicate how often, during the previous two weeks, they have been bothered by a series of problems. The scale provides responses from 1 "not at all" to 2 "several days" to 3 "more than half the days" to 4 "nearly everyday" to statements such as "feeling tired or having little energy" or "feeling bad about yourself" or "thoughts that you would better off dead or hurting yourself in some way." The mean (average) value on this scale for the participants of this sample of 2.4 (scores could range from 1 to 4), representing feelings of low self-esteem, depressions, inability to get going (for example) "several days" during the previous two weeks (also described in the question as about 3 or 4 of the past 7 days). This represents moderate levels of discomfort/distress. As above, no significant statistical differences were found when analyzed with our demographic measures described above.

Finally, a series of positive emotions was provided to participants to which they were asked to indicate the extent to which they "felt" this emotion over the previous few days. Participants rated each of the following five emotions on a 5-point scale ranging from 1 "not at all" to 5 "extremely:" excited, enthusiastic, alert, determined, or inspired. The mean (average) value on this scale (across all emotional expressions) for participants was 3.1, representing moderate experience of these feelings over the past several days.

Examining across the various physical (i.e., number of conditions, ADL difficulties) and mental health (i.e., CESD, PHQ-9, emotional expression) conditions,

revealed several significant associations (statistical correlations). In particular and as expected, the number of conditions had a statistically positive relation to ADL difficulties: greater difficulty with activities of daily living was associated with a greater number of conditions with which a participant was living. Additionally, CESD was (statistically) positively related to both the number of conditions reported by participants as well as difficulties with ADLs (e.g., higher scores of depression accompanied higher scores on these measures of physical health limitations) and (statistically) negatively related to emotional expressivity (e.g., higher depression was related to lesser emotional expression).

Social Networks and Social Support

The role of a supportive network of others has been addressed in a wide variety of empirical studies, finding strong and positive associations between support availability and engagement and well-being. Several questions were included in the survey examining the presence of (potentially) supportive others (biological and legal family members as well as friends) and appraisals of relationship closeness and the exchange of support. These are analyzed and reported in the text below.

Social networks are populated by individuals and organizations, the former receiving the greatest proportion of attention and research. Participants were asked a series of questions about the presence of various family members as well as friends and neighbors. These are described in Table 3 below.

Table 3: Potential Social Network Members

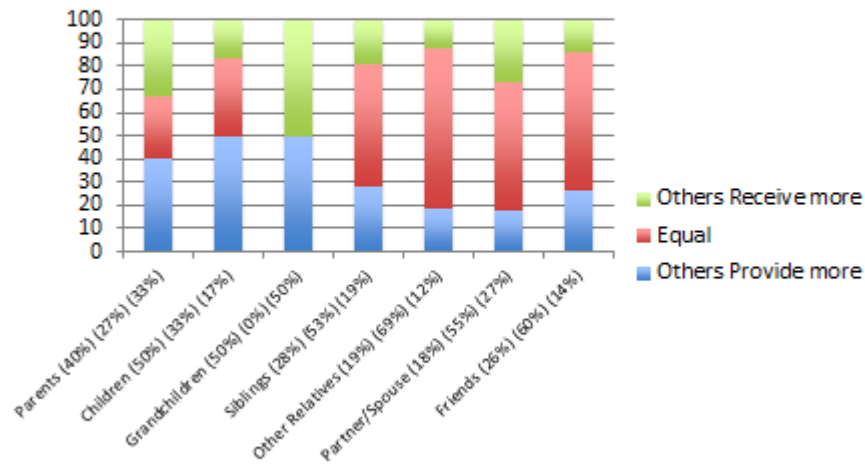
Relationship	Number (n) who have such a relationship (%)	Mean (n)	Range (n) (percentage within range)
Parents	54 (34%)	.8	0 (41%) – 2 (19%)
Children	34 (21%)	2.4	0 (2%) – 14 (1%)
Grandchildren	17 (11%)	4.7	1 (4%) – 17 (1%)
Siblings	122 (76%)	3.2	0 (1%) – 12 (2%)
Other Relatives	124 (78%)	1.8	0 (70%) – 30 (1%)
Friends	118 (74%)	4.8	0 (8%) – 30 (1%)

Approximately three-quarters of the sample had at least one sibling, another relative and/or a friend. About one third still had a surviving parent, less than one-quarter had children and just over 10 percent had grandchildren. As might be expected, older participants were least likely to have living parents (only 17% of those age 60 and older had living parents compared with 59% of those ages 50 to 55). Participants from San

Mateo County were much more likely to have children (80%) compared to residents from other counties (which averaged just over 40%). Females were also much more likely to have children than were either males or those identifying as transgender (with respective percentages of 88%, 48%, and 29%). African American participants were more likely to have children than those participants who identify as another race (although the sample sizes for these analyses become sufficiently small to render the results statistically unreliable). There were no gender, age, county, or racial differences on the presence of siblings, other relatives, and friends.

Some sort of a relationship does not necessarily mean relational closeness, however. Questions examining frequency of contact and perceived closeness were asked of participants; the latter of these is presented below. As can be seen in the Figure 8 below, over half of participants reported feeling at least somewhat close with their family members and friends. The mean rating of closeness did not differ by any of the four demographic variables assessed: gender identity, age, racial identity, or county of residence.

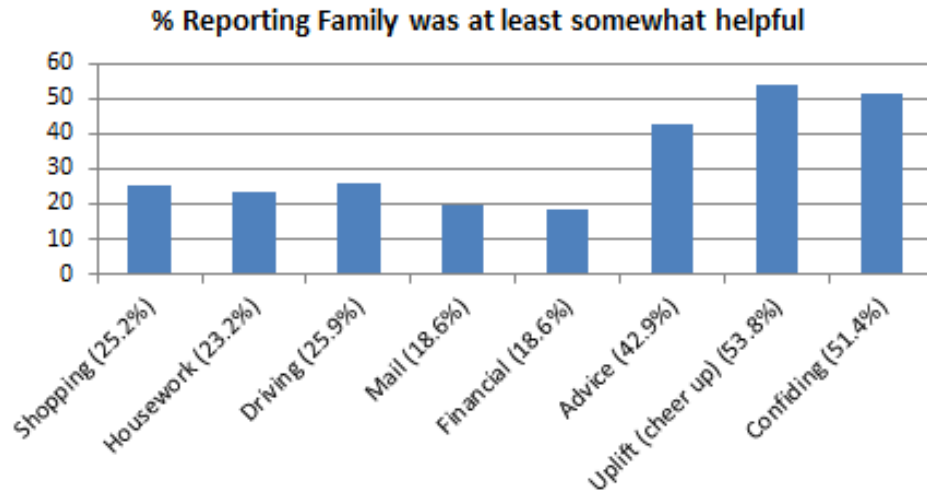
**Figure 13: Helping One Another:
Others Providing More, Receiving More, or
Equal help to Participant**



Just as presence and closeness are not necessarily related, neither are closeness and helpfulness. That is, close relationships need not imply helpful relationships, although these two elements are commonly linked. When asked about the helpfulness of family on a variety of dimensions, the overall pattern of responses was one of moderate helpfulness—at best. In Figure 9 below, families were reported to be “at least somewhat helpful” (encompassing “somewhat helpful,” “moderately helpful,” and “extremely helpful”) for less than 30% of participants on issues shopping, household upkeep (and meal preparation), driving participant to places, mail and other correspondence, and managing money and paying bills. Just over 40% report that families were at least somewhat helpful in offering advice; about half of participants noted that their families were helpful when they needed to be “cheered up” and when talking about personal or private matters. Very few differences were noted when these assessments of helpfulness

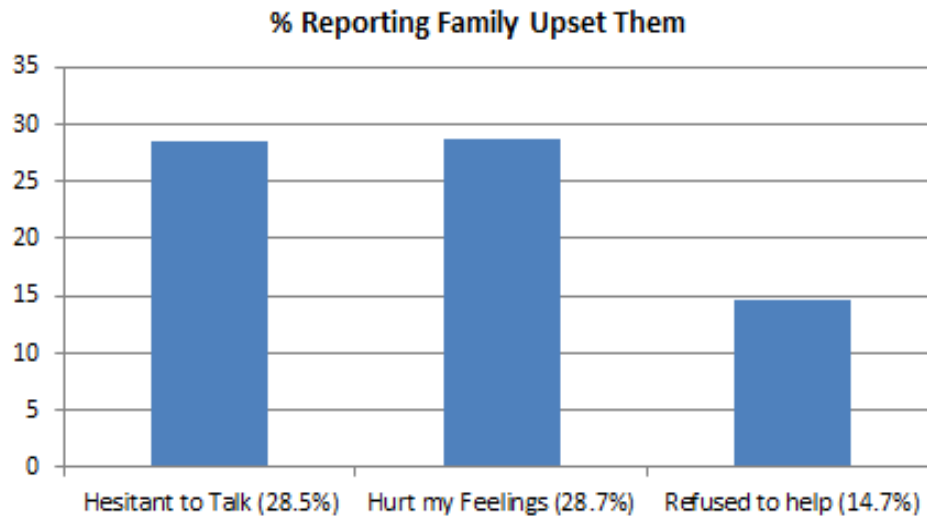
were compared with the key demographics. In appraisals of helpfulness with mailing and other correspondence, younger persons (ages 50 to 55) found families less helpful than did older participants. Hispanic/Latino/a participants reported that families were less helpful, than did participants from other racial backgrounds, with financial matters.

Figure 9: Family Helpfulness



In addition to offering support, in varying degrees, families (and others) have also been noted to upset individuals. Three questions were posed along these lines in the survey inquiring about family reluctance to speak, hurting feelings and/or refusing to help when asked, as noted in Figure 10 below. There were no differences by any of the key demographic measures.

Figure 10: Family Upset participant



Comparable questions were asked with respect to friendship. That is, how helpful are friends with varying tasks and to what extent do friends create the same types of upset? Analyses of these measures appear in Figures 11 and 12 below.

Figure 11: Friend Helpfulness

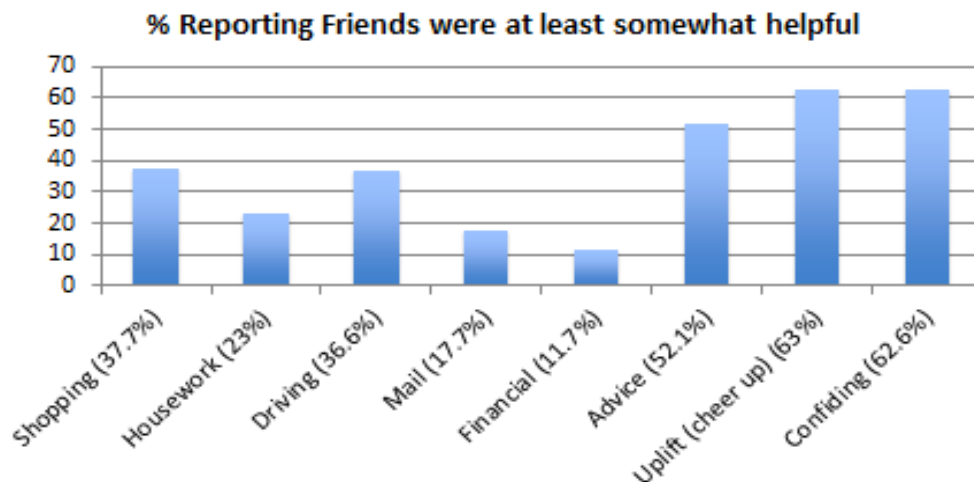
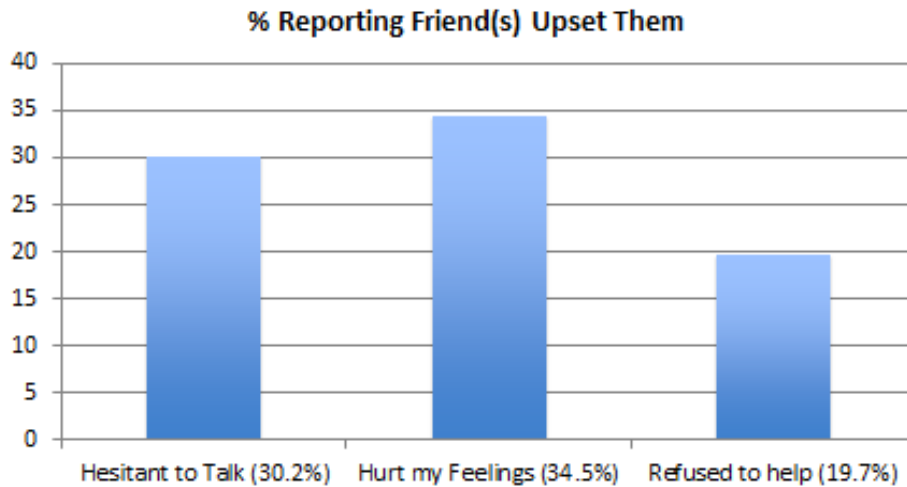


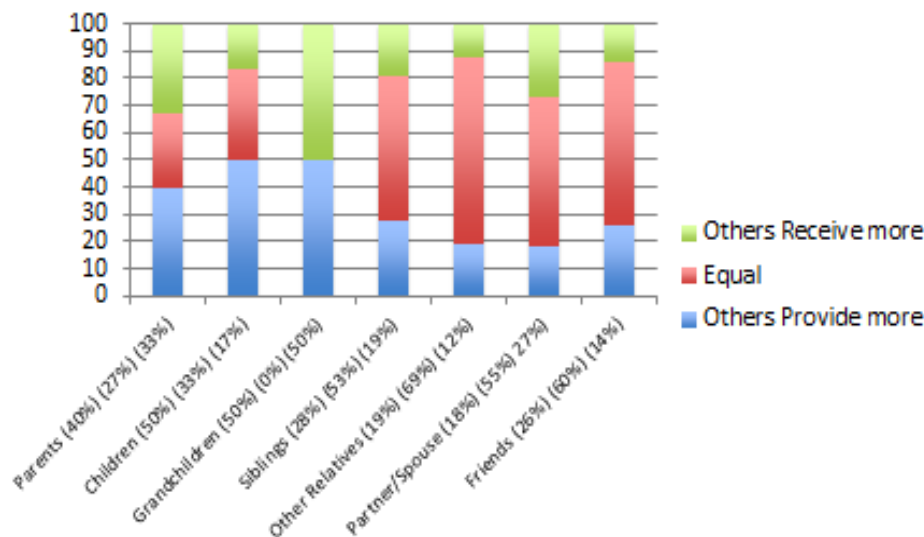
Figure 12: Friend(s) Upset



Several significant differences were noted by gender identity, county, and race. Those identifying as female were somewhat more likely to report that friends were at least somewhat helpful with correspondence; it is worth noting, although the differences are not significant, that females rated friends more helpful on all dimensions of support than did either males or those who identify as transgender. Examining by county, those participants who live in Marin rated their friends as more helpful in offering advice and on personal matters than did participants living in San Mateo County; those living in San Francisco did not differ significantly on “advice” from either of these two groups. (Remember, Marin had a small sample size, making results from Marin not statistically reliable). Examining by racial groups, those who identified as a race other than White, African American or Hispanic/Latino/a rated their friends are more helpful with issues of correspondence and money management; these group sizes are sufficiently small, however, so as to render these latter results statistically unreliable. Moreover, these few differences may emerge from the number of statistical comparisons conducted (i.e., by chance alone) and additional research is needed to confirm these differences.

It is worth noting from a review of the two related Figures 11 and 12 above, however, the differences between these reports of the helpful connections with friends with those of family. Overall, friends were rated as more helpful than was family; an exception to this pattern, however, concerned ratings of housework and financial assistance. Along such lines, questions were asked of participants if they felt that others in their social networks provided more help, received more help, or if there was a balance in this exchange. The results of these analyses, with no differences attributable to the demographic measures, are reported below in Figure 13 below.

Figure 13: Helping One Another:
Others Providing More, Receiving More, or
Equal help to Participant



As may be seen in Figure 13 above, reciprocity was highest among siblings, other relatives, partners and especially friends. Inequalities were more common in the other relationships and particularly noteworthy with younger participants who were more likely to be care-providers, in a variety of ways.

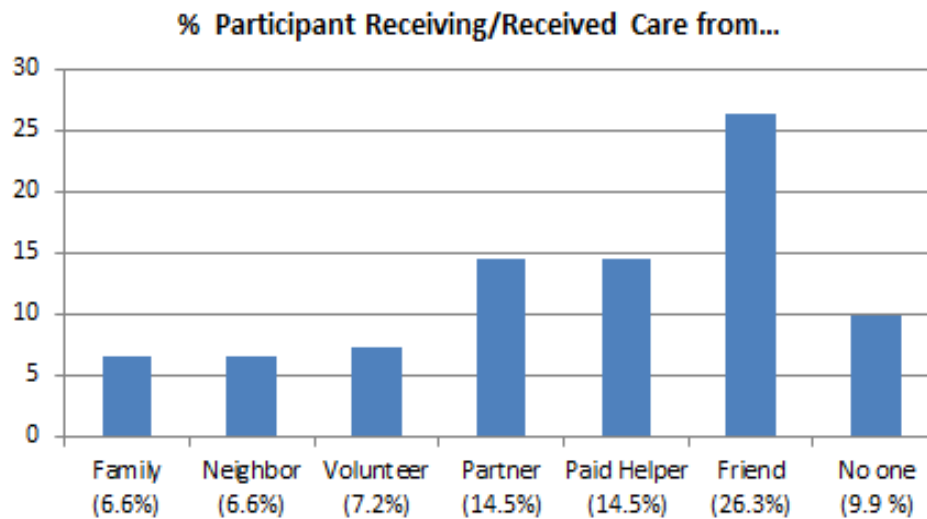
Caregiving

Contained in the discussions above are significant references to both caregiving and care-receiving—important and familiar elements in the lives of those aging with HIV. A series of questions asked participants about the current and past experiences with caregiving.

For example, almost one-half of the sample currently (18%) or previously (31%) required assistance due to their HIV and/or other illnesses, disabilities or frailties. No significant demographic differences were revealed in this analysis.

When asked about the provider of this care, participants identified network members as well as representatives from agencies and organizations, as seen below (Figure 14).

Figure 14: Provision of Care: past and present



Importantly, almost 10% (9.9%) of those participants who indicated that they required regular assistance because of HIV or other illness, disability or frailty either now or in the past, reported that there was no one to provide such care. These ranges did not differ by demographic measures with the following interesting exceptions: those identifying as female were more likely to receive care from their families; those who identified as African American or “other” were significantly less likely to report that a friend would assist them; and those identifying as transgender did not report any family members are caregivers.

Participants were asked about the HIV-status of the identified caregiver. In San Francisco, 38.9% of the caregivers described above were also reported as being HIV positive. The percentage was dramatically less in San Mateo County (10%); the numbers were too small for statistically reliable reporting on the Marin County sample.

As several recent publications have identified, the association between caregiving and care-receiving is complex and certainly not one-way. That is, the receipt of care is not independent from the provision of care. A series of questions were included in this survey addressing this issue.

Almost one-quarter of the sample (23.4% overall) reported that they are, or have been (within the past five years), a caregiver. Percentages were comparable across county and, somewhat surprisingly, gender identity. This caregiving was slightly more likely to have previously taken place (3-5 years ago—38%) although fairly evenly divided across those recently having been caregivers (1-2 years previously—29%) and currently caregiving (32%). Care-recipients included partners (somewhat more frequently for men than for women), other family members (more frequently for women than for men) and friends (comparable for men and women). Of those for whom care was provided, almost half were HIV-positive (46.2%). Almost the same percentage (44%), and sizable given the context, reported that their caregiving responsibilities interfered with their ability to take care of themselves.

Service Use

The survey included several series of questions addressing service use. These questions were grouped primarily according to the agency delivering the services.

Social Security, Medical, Medicare, Pubic Housing and the County Health Department were the agencies most frequently mentioned. Few differences were noted by select demographic measures. However, persons ages 50 to 55 were more likely to go to the Social Security office than were those over the age of 56; Females were more likey to use the services of the Public Health Department than were males or those who identified as transgender. Participants from San Mateo were most likely to use the County Aging Services and Health Department as well as the Veteran’s Affairs services.

Questions more particular to county and non-profit service organizations were also posed. The results of these analyses are reported below (Table 4).

Table 4: Community Agcy Service Use

Agency	Overall % Usage	Gender	Age	County
AIDS Service Org.	49%		Y > O	
HIV Housing Assist.	31%		Y > O	SF, M > SMC
U of P Dental Clinic(SF)	25%			SF > SMC, M
Openhouse (SF)	20%		O > Y	SF > SMC, M
SF Gen. Ward 86	19%	T > M, F		
Edison Clinic (SMC)	12%			SMC > SF, M
St. Mary Med. Ctr (SF)	10%			
Mental Health Assn (SMC)	10%			SMC > SF, M
Willow Clinic (SMC)	9%			SMC > SF, M
Healthy SF	8%		Y > O	
Marin Health	5%			M > SF, SMC

Legend: Y = younger; O = Older; SMC = San Mateo Co; M = Marin; SF = San Francisco; F = Female; M = Male; T = Transgender.

A special note is need here in regard to interpreting the service use tables (Tables 4 and 5) The “greater than (>)” symbol in these tables is proportional (higher likelihood) , i.e., not an absolute number or an absolute percentage. For example in Table 4 for Openhouse: a higher proportion of older (age 61+) were more likely to use the service than do younger (age 50-55). Another example in Table 4, S F General Ward 86: Transgender persons were more likely to use the service than cisgender (non-transgender) Males or Females.

As expected, services in the county in which participants resided were used more frequently by these participants. Of perhaps greater interest, younger participants (i.e., those ages 50 to 55) were more likely to use AIDS Service Organizations, AIDS Housing agencies and Healthy SF services, compared to older participants; the inverse was true for

the services offered by Openhouse (i.e. participants aged 56+ were more likely to use Openhouse). The services offered by the San Francisco General Hospital Ward 86 were more likely used by those identifying as transgender relative to those identifying as either male or female.

As an overall identification and appraisal, participants were asked to identify and rate the services used, from a list of service types provided. The list of service types, percent usage, and any differences by the key demographic measures are provided in Table 5 below.

Table 5: Overall Support Service Use

Agency	Overall Percent Usage	Gender	Age	Race	County
Meal/Food/Nutrition	63%	F, T > M			
Mental Health	54%				SMC, M > SF
Case Management	53%	F, T > M	Y > O		SMC, M > SF
Transportation	50%	F, T > M	Y > O		
Legal	47%				
HIV Prevention	35%	F, T > M		Afr > others	
Group Svcs Program	30%			Afr > others	
Substance Use Counseling	25%			Afr > others	

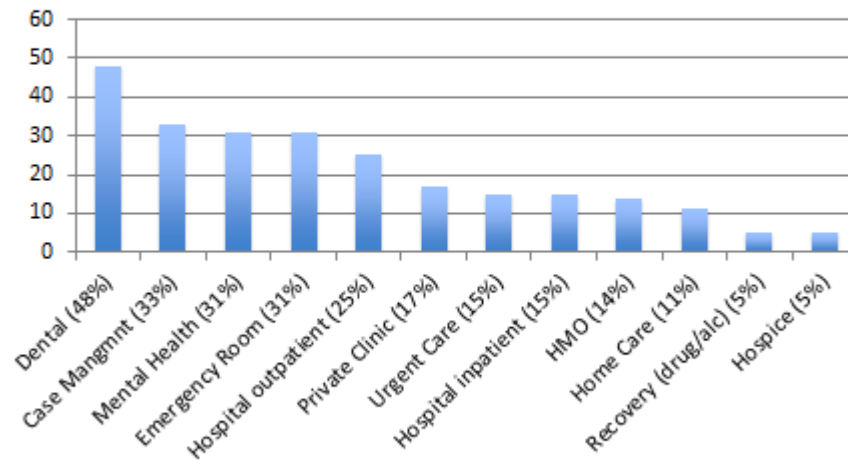
Legend: F = Female, M = Male, T = Transgender; Y = younger, O = Older; Afr = African American; SMC = San Mateo Co., M = Marin, SF = San Francisco.

The differences within demographic categories are consistent and interesting. Female and those identifying as transgender were more likely to use meal/food/nutrition, case management, transportation, and HIV prevention services; younger persons (ages 50 to 55) were more likely than those older to also use case management and transportation services; African Americans were more likely than those of other racial identities to use HIV prevention, group, and substance abuse counseling services; finally, residents of San Mateo and Marin counties were more likely than those who live in San Francisco to use mental health and case management services, not surprising in San Mateo County, since the Mental Health Association in San Mateo County fills a gap created by the closing of a HIV service organization there. (Again, the Marin result is not statistically reliable due to small sample size in Marin.)

Those who used such services were also asked to rate the services on 4-point scales from 1 “not helpful at all” to 2 “not too helpful” to 3 “somewhat helpful” to 4 “helpful.” The ratings were consistent across all service types and ranged from 3.41 (for Legal and Mental Health services) to 3.6 (for case management and meal services). Similarly consistent were the ratings by gender, racial groups, race, and age; the only marginal ($p = .06$) differences appeared in the evaluations of case management wherein residents from Marin county rated these services somewhat lower than did residents from either San Mateo or San Francisco counties (again, Marin had a small sample size which impacts statistical reliability).

A comparable series of questions was posed inquiring about use of general medical service use. The results of these analyses appear in Figure 15 below, presented in a different format than the above given the few differences that were found on the demographic variables.

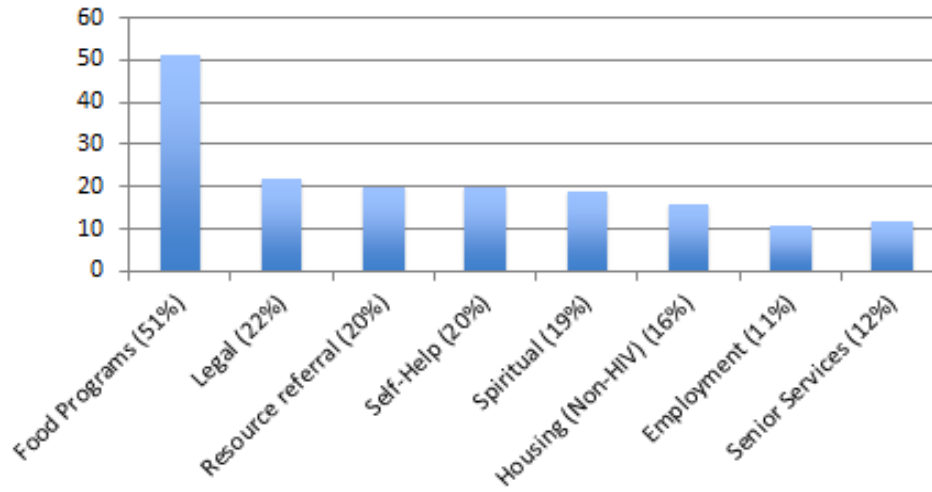
Figure 15: Health-Related, Medical Service % Use



Only four significant differences were noted on the above variables: females reportedly used dental services more frequently than did either males or those identifying as transgender; African-American participants also reported the use of dental services more frequently than those of other racial identities. Older participants (i.e., those over the age of 60) were more likely to report using hospital outpatient services than were younger participants; in contrast, younger participants (i.e., those ages 50 to 55) were more likely to use home care services than were older participants.

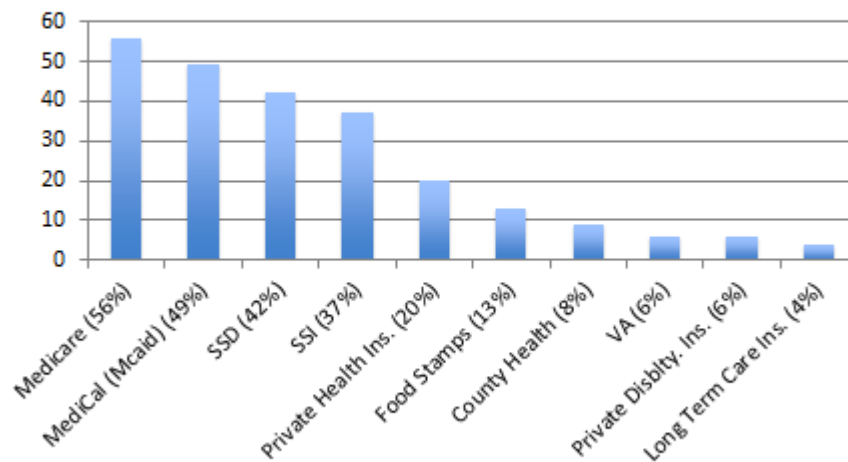
Finally, a series of questions about community-based service organization use was included. The results of these analyses are reported in Figure 16 below. Few differences were found by the demographic measures used. In this case, the only differences noted were among the non-HIV housing services offered within communities (wherein females and those identifying as transgender were more likely to report using such services) and among senior center use (predictably used more frequently by older, rather than younger, participants).

Figure 16: Community-Based Service Organization % Use



The benefits to which participants had access in support of these services were also queried. The results of these analyses are reported in Figure 17 below.

Figure 17: Benefits %



Significant differences were only noted primarily with the measures of gender identity and age. With reference to the former, those participants who identified as transgender were more likely to both access county health services (than were those identifying either as female or male) and have long-term care insurance, although this latter finding is statistically unreliable given the small population sample size. Both

females and those identifying as transgender were more likely than males to access Social Security Supplemental Income assistance. With reference to the latter, older participants, relative to younger participants, were more likely to have both Medicare and Private Health Insurance. (The only racial difference was also found on the measure of Private Health Insurance, which was more likely among those identifying as White than other races.) Younger persons, relative to older persons, were more likely to have Social Security Supplemental Income assistance.

Reasons for Unmet Needs

Seventeen potential barriers to service access were provided in a table in the survey questionnaire. Participants were asked to indicate if any of these posed problems for their service access and usage. The results of these analyses are presented in Figures 18 and 19.

Figure 18 highlights the ten most frequent service barriers as perceived by the participants. These include costs (the first and third most frequently identified barriers), knowledge of service location and existence of service (the second and fourth most frequently identified barriers), red tape, wait times, and staffing issues (such as, staff not being perceived as helpful, the sense that the providers of services do not like the participant using the service and fear of not being treated, as well as communication problems). All of the above barriers were perceived by more than 15% of the participants in the sample. Among these top ten perceived barriers, few differences were noted in the demographic comparisons made. The following are the four exceptions: residents of San Francisco County were more likely than were residents of the other counties to report that they did not know if such services existed; both African-Americans and Caucasians, relative to either Latino/a participants and those who identified as “other” race were more likely to identify communication problems and a fear that they would not be treated if they attempted to access the service; younger participants, relative those age 56+, were also more likely to identify this latter fear (not being treated).

**Figure 18: Barriers to Service Use %
(Perceived By Participant) Top 10**

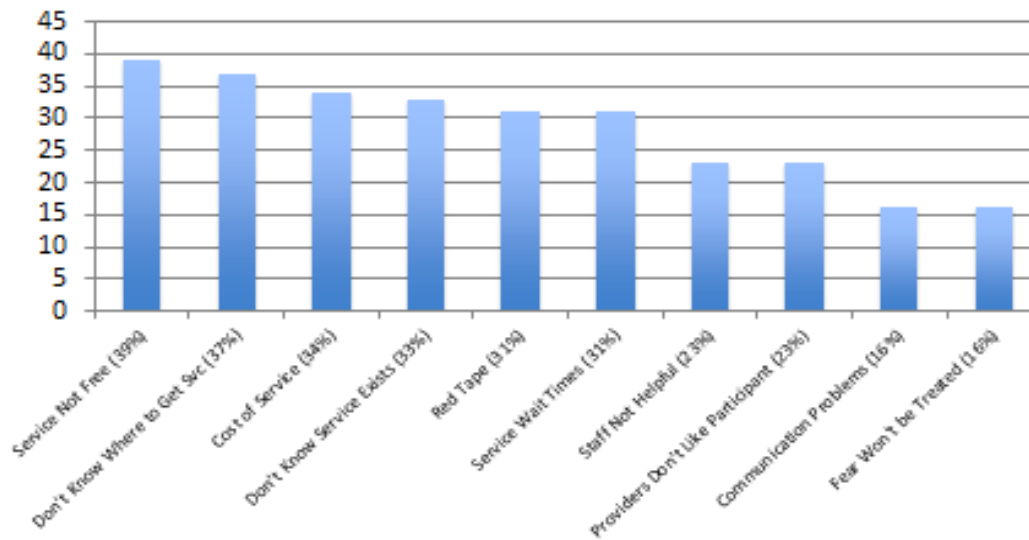
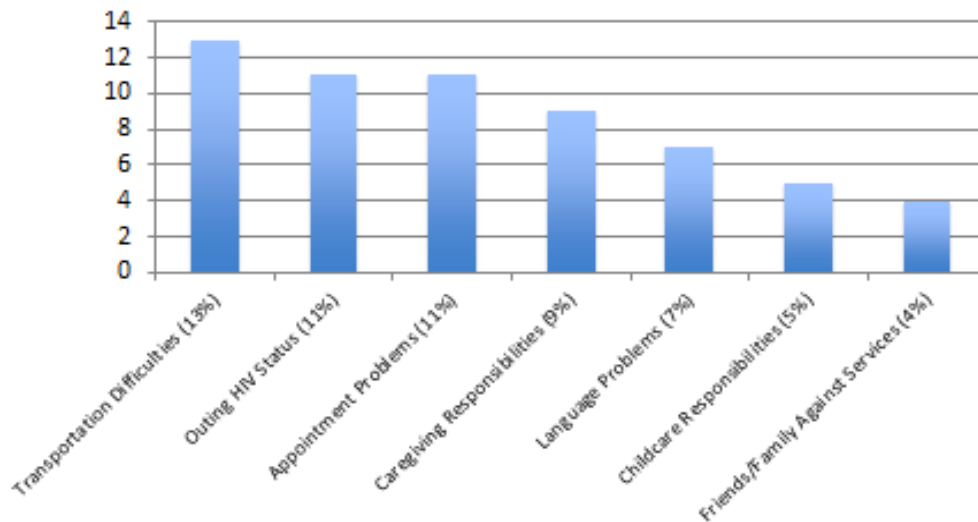


Figure 19 highlights the remaining seven service barriers; the frequency of perception of these becomes sufficiently small that statistical analyses are less reliable. These percentages range from about 4% of participants who reported that their friends and family would be against their usage of this service to just over 13% who reported transportation difficulties in accessing the service. The only demographic differences noted in follow-up statistical comparisons on these barriers related to race: African-Americans were more likely, than were those of other racial identifications, to report that they feared that others would discover their HIV status if they used this service, and that language, childcare, and fear their friends and family would weigh against service use. Both African-American and Caucasian participants, relative to Latino/a and those who identified their race as “other,” were more likely to cite both transportation and appointment problems as barriers to service access and usage.

**Figure 19: Barriers to Service Use %
(Perceived By Participant) (Other)**



A selection of comments from participants in regard to services desired and/or their perception as to why they did not get the services they needed is included in Appendix 3.

Discussion

Most participants were moderately well connected in terms of medical care, had their HIV relatively well managed, but were often struggling with other co-morbidities. Most were long-term HIV survivors coping with isolation and loneliness. Family support was mixed, and family support was not always related to closeness. Many had networks of friends to support them.

Some participants had difficulties with understanding the survey questions as illustrated in the examples above of erroneous entries by participants. These difficulties may have been caused by any number of factors related to the setting (background noise and physical context), the survey itself (type and/or format of questions and survey), and/or individual issues (including cognitive deficiencies, language barriers, literacy or education barriers, or life stresses of living with HIV). Attempts were made to catch all errors and inconsistencies. These factors might also have influenced the accuracy of the responses.

San Francisco and the counties in which the survey was conducted, are high cost of living areas compared to most of the United States. However, the majority of those surveyed rely on public assistance or public disability such as Social Security SSI (Supplemental Security Income) or SSD (Social Security Disability). These income sources do not have an allowance which adequately matches the costs associated with living in expensive cost of living cities and nearby suburbs. Thus, in order to compensate for this high cost and low income, some live in sub-standard housing such as SRO's

(Single Room Occupancy housing) and in areas that have above average crime rates. Nevertheless, and in the presence of some service deficiencies, most participants are generally happy about the majority of the services they receive and, in many cases, are happy with their service providers.

Making definitive conclusions about the cause of this population's problems is also confounded by the issues such as

- Some medical issues could be related to HIV or they could be related to general aging
- Most in the survey (79%) identify as LGB (Lesbian, Gay, or Bisexual) and some issues could be related to HIV or related to LGBT aging
- Most in the group are long term survivors (93% have had HIV 10 years or longer)
- The emotional context within which many HIV-positive persons of living with a disease that has killed nearly two thirds of those diagnosed with AIDS in San Francisco since 1981, including friends and partners
- General stigmatization of elders in the predominant LGBT youth culture, increasing isolation.

In the Allgaier (2010) San Francisco area policy paper a key concern noted by those participants was that they did not know where to go for services between organizations serving the aging, and organizations serving people with HIV. While efforts have been made to address this, not knowing where to get services (37%), not knowing that services exist (33%) and red tape (31%) remain as concerns (Figure 18).

The future use of this study results and dataset

In addition to this report, it is also anticipated that future academic papers will be prepared. There is a wealth of information to be gleaned from this dataset, and these data can be used as the basis for several papers about the experience of aging with HIV in the San Francisco area and perhaps multiple papers comparing San Francisco with the original 2009 GMHC survey and potential future parallel surveys in other geographic areas.

It is hoped that these data and analyses will assist the San Francisco area Planning Council to help better understand and address the needs of their clients. Their service is clearly critical.

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Appendix 1

Survey website and contact information for the authors

For more information on the study, a copy of the full report, and future developments, please join/follow the Study website (Yahoo group):

<http://health.groups.yahoo.com/group/hivaging>

Contact information for the authors:

Loren Meissner Jr., M.A. Gerontology

P O Box 1301

San Bruno CA 94066-7301

LMeissne@yahoo.com

Professor Brian de Vries, Ph.D.

San Francisco State University

HSS Building, Room 227

1600 Holloway Avenue, San Francisco, CA 94132

bdevries@sfsu.edu

Appendix 2

Medications taken – raw numbers, not percentages

The following is a list of medications and the number of people taking them (number [n=], not percentage). Since many participants take more than one medication, the total will not add up to 160:

Norvir (Ritonavir)	57
Truvada ((Viread +Emtriva)	49
Reyataz (Atazanavir)	40
Isentress/Raltegravir)	28
Prezista/Darunavir	23
Atripla (Sustiva + Viread + Emtriva)	22
Epzicom (Ziagen + Epivir)	21
Viread (Tenofavir DF)	17
Viramune XR (Nevirapine)	16
Epivir ((Lamivudine , 3TC)	14
Intelence (Etravirine)	11
Ziagen (Abacavir)	9
Kaletra (Lopinavir + Ritonavir)	8
Complera (Edurant + Viread + Emtriva)	6
Combivir (Retrovir + Epivir)	5
Trizivir (Retrovir + Epivir + Ziagen)	5
Sustiva (Efavirenz)	5
Retrovir (Zidovudine; AZT)	4
Invirase (Saquinavir)	3
Emtriva (Emtricitabine)	3
Selzentry (Maraviroc)	3
Aptivus (Tipranavir)	2
Lexiva (Fosamprenavir)	2

Videx EC (Didanosine; ddI)	2
Zerit (Stavudine; D4T)	2
Fuzeon (T-20)	2
Stribild (Cobicistat + Elvitegravir + Emtricitabine + Tenofovir)	2
Crixivan (Indinavir)	1
Viracept (Nelfinavir)	1
Rescriptor (Delavirdine)	1
Edurant (Ralpivirine)	0

Appendix 3

A selection of comments from participants as to services desired and/or why they did not get the services they needed

San Francisco:

“I did not get the help I needed it for socialization because I choose to isolate myself due to depression. When I choose to get assistance in socialization, I have resources”

“I did not always know what resources were available to me for a particular problem/need/. There is no ONE person I can go to with the questions. I would like a case manager!”

[Services needed]: “More of:

- Resource identification/linkages (case management?)
- Benefits counseling
- Tax preparation/assistance
- Financial Planning
- Legal assistance”

“I can’t get in contact with my doctor.”

[Services needed]:

“

- “End of life planning and disposition
- Better help from AIDS Legal Referral Panel
- Better grocery access
- More food stamps
- More discounts for cable/internet/cell phone
- Group therapy
- Physical therapy/guidance”

.” I need assistance with housekeeping (chronic fatigue, inability to bend).”

[Why I did not get the help I needed]: “I was too embarrassed to ask.”

[Services needed:] “Cooperation between HIV Employment and Companies/stores-services to the public, not just HIV non-profits who distribute monies to support other [doctors?]Let us be employed and working.”

“I am complex = HIV+. I get all my needs met from that (HIV+). I am mired in the workers comp system. I have been denied SSDI. I have only limited \$ >500 month. Can’t work. Mobility impaired. Homeless. [These factors] exacerbate my HIV conditions.”

[Services needed:] “[1] Possibly a clearing house for all services, help with SSI, SSD. [2] Dental service extremely long wait if even able to use [get in???”

[Are there any other programs or services that could be helpful to you?] “Well a program like 311 run by United Way plus more education to social workers about what is available. I have been referred to West Side Crisis several times and they can never help me since I get services at Ward 86. Same with South of Market Mental Health- no services for me because I go to Ward 86. “

San Mateo County:

[Are there other services you would like to see provided?] “More food availability.”

[Perceived barriers]: “No help [not getting the help I need?]. Still in recovery from [a local disaster]. Not able to properly take care of myself, sometimes can’t drive a car. “

Services needed: “Housing. I was approved and I was away and the time and I lost the benefit. Please help!!!! “

In addition, some mentioned that while they get emotional/spiritual support from church, they are afraid to ask for physical/material help because they do not want to disclose their HIV status.

Some mentioned transportation barriers.

Marin

Due to the small number of participants in Marin, the authors were not comfortable in publishing direct quotations from Marin participants, for privacy reasons. To paraphrase some of the comments, some participants in Marin perceived:

- Not enough mental health services
- Services not at convenient times
- Need for better transportation (several mentioned this). No access to car. Bus routes not convenient
- Need for restoration of service cut-backs