

**EXECUTIVE SUMMARY**

# **A NEEDS ASSESSMENT OF OLDER GMHC CLIENTS LIVING WITH HIV**

**An ACRIA Research Study of Older Adults with HIV who are Clients of  
Gay Men's Health Crisis (GMHC), New York, NY**

**by**

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# ACRIA CENTER ON HIV AND AGING

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### Methodology Notes

Recruitment of this convenience sample took place at the offices of GMHC in Manhattan. In order to qualify for participation, an individual had to be HIV-positive, 50 years of age or older, fluent in English, and had accessed services at GMHC in the past six months. Extensive recruitment efforts resulted in a final diverse sample of 205 men and women, resulting in 180 usable surveys. The survey instrument was self-administered by hand using a printed copy (n = 175) or via computer using Survey Monkey (n = 30). On average, participants took 45 to 60 minutes to complete the survey. Prior to data collection, participants provided informed consent. After completing the survey they were debriefed and thanked for their participation. Participants received a movie pass worth \$10 as an incentive for participating in this research project. Research methods and materials were evaluated and approved by the Copernicus Group Independent Review Board (IRB).

The survey instrument obtained information in the following areas: (1) demographic characteristics; (2) HIV/AIDS status; (3) comorbid physical and mental health conditions; (4) informal social supports; (5) caregiving (both receiving and providing care); (6) formal service utilization; (7) mental health; and (8) religion/spirituality. Whenever possible, standardized quantitative measures with known psychometric properties were used to insure validity and for comparison with other published data. Questions were developed based on items in the *Research on Older Adults with HIV* (ROAH) study<sup>1</sup> and the *Caregiving among Older Lesbian, Gay, Bisexual and Transgender New Yorkers* study<sup>2</sup>. When noted in the text, 'significant' refers to statistically significant differences at the  $p < .05$  level.

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<sup>1</sup> Brennan, M., Karpiak, S. E., Shippy, R. A., & Cantor, M. H. (Eds.). (2009). *Research on Older Adults with HIV: An in-depth examination of an emerging population*. New York: Nova Science Publishers.

<sup>2</sup> Cantor, M. H., Brennan, M., & Shippy, R. A. (2004). *Caregiving among Older Lesbian, Gay, Bisexual and Transgender New Yorkers*. New York: The National Gay and Lesbian Task Force Policy Institute.

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## Introduction

In 2010 in New York City, one of the primary HIV/AIDS epicenters in the United States, two-fifths of the over 100,000 or more people living with the disease are over 50 years old, and three-quarters are over the age of 40.<sup>3</sup> The success of anti-retroviral therapies that fight HIV makes it probable that persons aged 50 or older will account for the majority of people living with HIV in the U.S. by 2015.<sup>4</sup> ACRIA's seminal research on this emerging group (ROAH: Research on Older Adults with HIV)<sup>5</sup> found healthcare systems, social support networks, and communities ill-prepared to meet the needs of the aging HIV-infected population.

Social support becomes an increasingly critical resource for people as they age. ROAH found that aging adults were isolated from informal networks due to the stigmas associated with HIV/AIDS, which are further exacerbated by ageism.<sup>6</sup> The fragile networks of many of these older adults, as evidenced by limited availability of others in the network to provide support along with low levels of perceived support sufficiency, will be challenged by the potentially complex care needs of people simultaneously aging with HIV and age-related comorbidities. Without the availability of traditional spouse and child family caregivers, these aging adults with HIV/AIDS will likely turn more and more to formal community supports, including government agencies, community-based organizations (CBOs) and faith-based social services. This may have a substantial impact on already

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<sup>3</sup> New York City Department of Health & Mental Hygiene. (2009). HIV Epidemiology and Field Services Program Semiannual Report. Retrieved from the world wide web May 19, 2010: <http://www.nyc.gov/html/doh/downloads/pdf/dires/dires-2009-report-semi2.pdf> .

<sup>4</sup> United States Senate Special Committee on Aging. HIV over Fifty: Exploring the New Threat. [Web cast]. May 12, 2005. Available at [http://aging.senate.gov/hearing\\_detail.cfm?id=270655&](http://aging.senate.gov/hearing_detail.cfm?id=270655&).

<sup>5</sup> Brennan, M., Karpik, S. E., Shippy, R. A., & Cantor, M. H. (2009). *Older adults with HIV: An in-depth examination of an emerging population*. New York: Nova Science Publishers.

<sup>6</sup> Emler, C.A. (2006). "You're awfully old to have this disease": Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *Gerontologist*, 46(6), 781-790.

challenged healthcare delivery and community-based service programs, whose funding has been scaled back in many instances in recent years.

Given these challenges in meeting the needs of this burgeoning population, the purpose of this study is to better understand and document the dynamics of the informal and formal social support systems of older adults with HIV in New York City. This includes formal and informal caregiving resources, which have not been well studied in previous research on HIV-positive older adults. Prior research which examined the integration of formal and informal care among people with HIV in San Francisco and Los Angeles was conducted during an earlier period in the epidemic among those with an existing HIV/AIDS caregiver, and did not focus exclusively on older adults.<sup>7</sup>

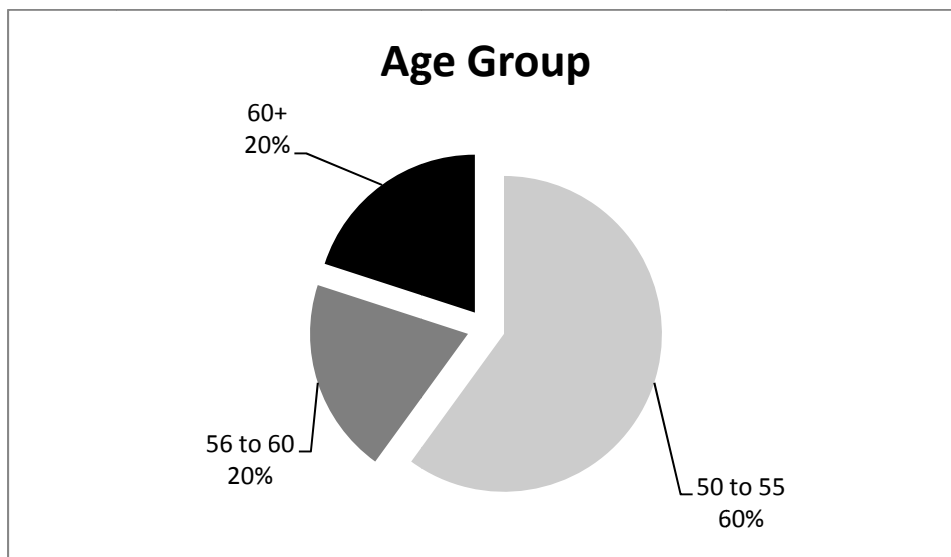
We sought to gain a better understanding of whether and how systems of formal and informal social and supportive care are integrated, and what barriers exist that prevent access to care that is available. This study provides a basis for assessing the needs of older adults with HIV who have an existing connection to an AIDS service organization (ASO) and the HIV service network. An additional goal of this cross-sectional study is to provide data for policy makers and program planners to better meet the emerging needs of this vulnerable population.

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<sup>7</sup> London, A. S., LeBlanc, A. J., & Aneshensel, C. S. (1999). The integration of informal care, case management, and community-based services for persons with HIV/AIDS. *AIDS Care: Psychological and Socio-Medical Aspects of HIV/AIDS*, 10(4), 481-503.

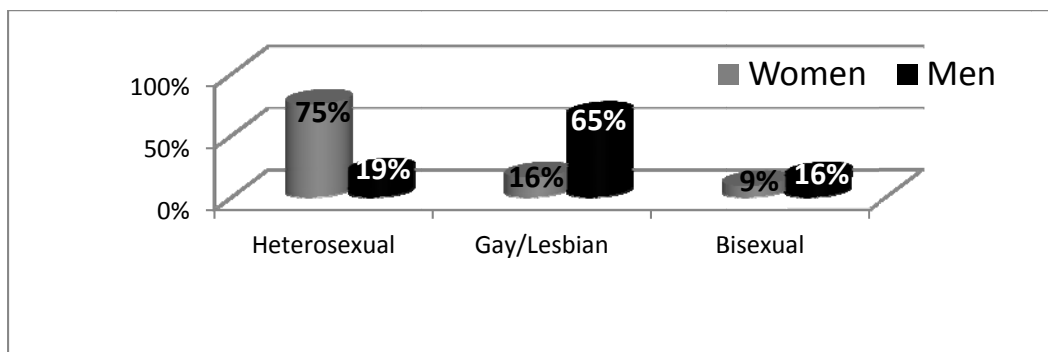
## Demographics

Among the 180 participants in the current study, over three-quarters of the sample were men (78%; n=139) and 22% (n=40) were women.<sup>8</sup> None of the participants identified as transgender. The average age was 55.5 years, with women being significantly younger than males (53.6 vs. 56.1 years, respectively). Figure 1 shows the sample by age group.



*Figure 1. Age Distribution of Sample.*

Over half of participants identified themselves as gay or lesbian (55%), 15% as bisexual and 30% as heterosexual. Sexual identity of participants differed significantly between men and women (see Figure 2).



*Figure 2. Sexual Identity by Gender.*

<sup>8</sup> One person did not answer the question on gender.

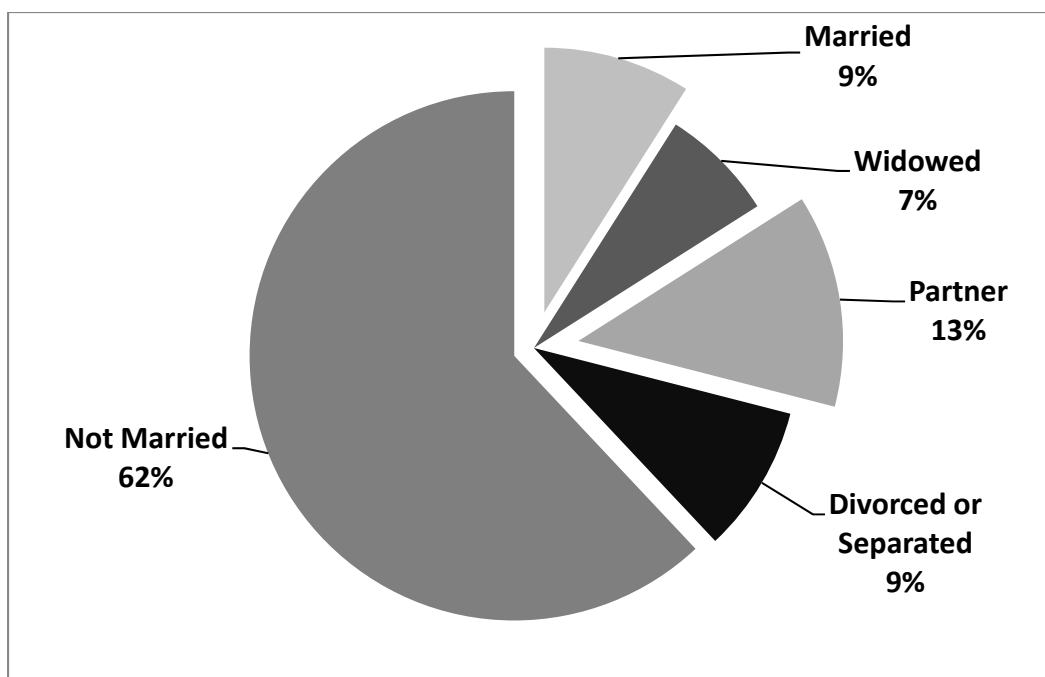


Participants were diverse in terms of race/ethnicity; over one-third of participants were non-Hispanic Black (36%), 32% were non-Hispanic White and 29% were Hispanic. Three percent reported being Asian and 1% reported being Native Americans. No one identified as a Pacific Islander.

Almost one third (28%) of participants reported a history of incarceration. Nearly one-fifth had served in the armed forces (19%).

### Partnership and Relationship Status

The partnership and marital status of the sample is shown in Figure 3. Twenty-two percent of women were either married (14%) or reported a partner (8%) as compared with 20% of older men with HIV who were married (9%) or partnered (14%). This is much lower compared to the general population where 48% of women and 52% of men report being currently married.<sup>9</sup>



**Figure 3.** Partnership/Marital Status of Older GMHC Clients.

<sup>9</sup> Pew Research Center. (2010). The states of marriage and divorce. Retrieved May 19, 2010 from the world wide web:

<http://pewsocialtrends.org/assets/flash/marriage/>.

When asked about current relationship status, close to two-thirds of participants (64%) were not currently in a relationship, a fifth reported being in a same-sex relationship and 16% were in an opposite-sex relationship. Older women with HIV were more likely to report being in a relationship compared with men (49% and 33%, respectively). Two-thirds reported a history of partnership, with 38% reporting they have been partnered once, 24% twice, 20% three times, and 19% four or more times. Men were significantly more likely to report being in a same-sex relationship as compared with women (22% and 14%, respectively).

### **Current Sexual Activity**

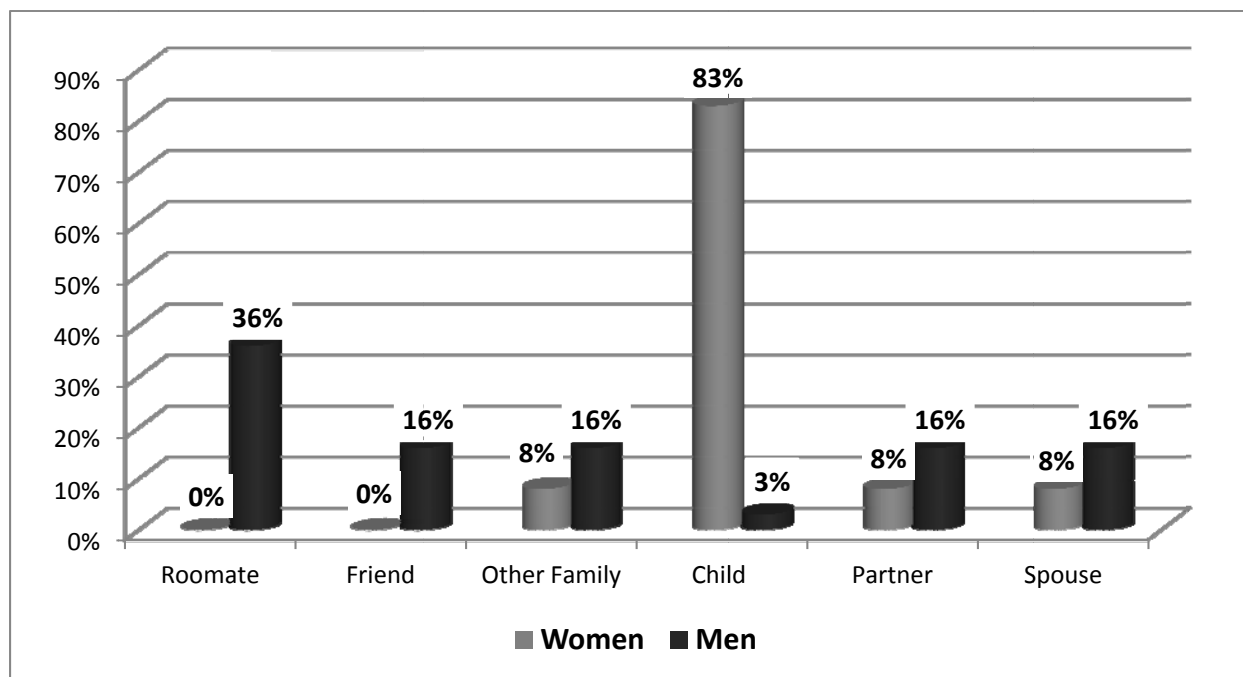
From the options provided to them on the survey, participants described their current sexual activity as follows:

- 36% described themselves as ‘not sexually active’
- 28% chose ‘I have one sexual partner’
- 15% chose ‘I have more than one sexual partner’
- 21% responded ‘I have sex with myself’

### **Living and Housing Arrangements**

Similar to the findings in ROAH, three-quarters of participants lived alone (76%). Among those who resided with others there were significant differences between men and women in the relationships of other household members (see Figure 4); 83% of women lived with a child, while only 3% of men reported living with a child. Men that lived with others were significantly more likely to report a roommate (36%) than were women (0%). Notably, men were twice as likely as women to report living with a spouse or partner (32% versus 16%).

Nearly half of respondents (44%) reported living in rent-controlled or rent-stabilized apartments, for which the annual rent increase is regulated. Fourteen percent lived in market-rate rentals (i.e., rent is not regulated). For those living in a rented apartment, 81% had their name on the lease. Twelve-percent lived in scatter-site apartments (i.e., individual units not concentrated in one building), 10% in congregate (i.e., group) housing, 6% in a rented room, and 8% in single-room occupancy housing (SRO). Only 5% of respondents lived in a condominium, co-op or private home, while 3% did not have a permanent residence.



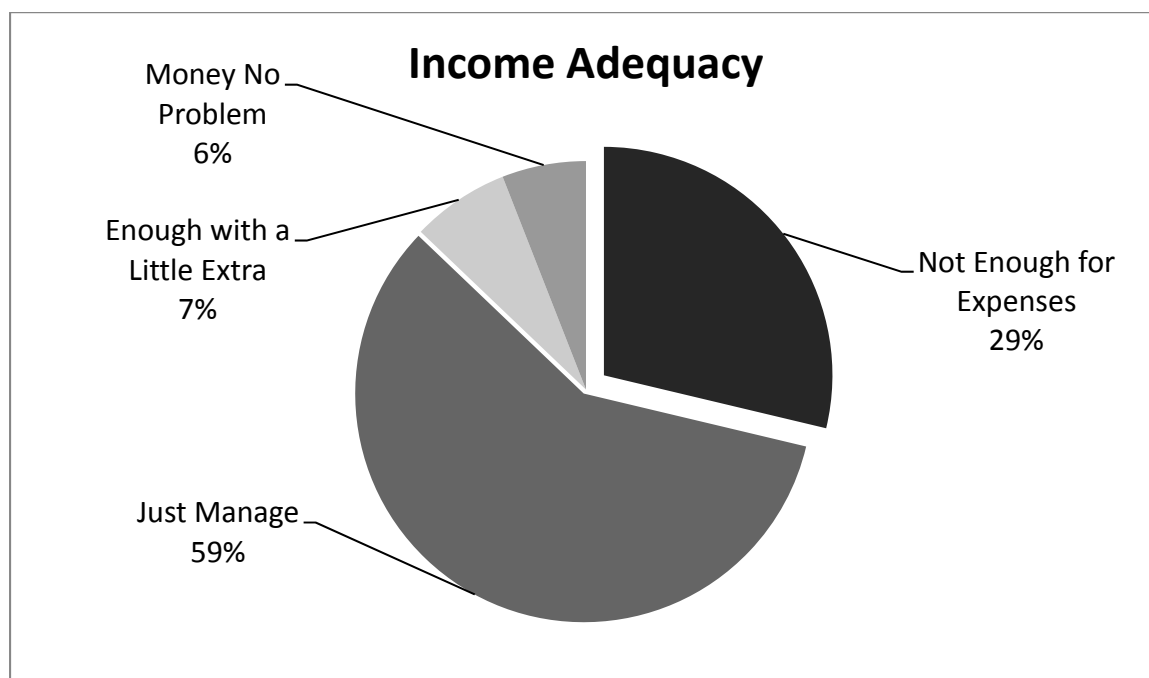
*Figure 4. Other Persons Living in the Household by Gender.*

## Education, Work Status and Income

The majority of participants (90%) have graduated from high school or obtained a GED and over a third (35%) have a college degree or higher educational attainment. Education varied significantly by gender. Among older women with HIV, 24%

reported having less than high-school educations, and 13% had completed college. Levels of education among men were significantly higher, with only 7% having less than a high school education and 41% with college degrees.

Most of the participants were not working; 25% were unemployed, 54% were on disability and 9% were retired. Men were significantly more likely than women to be working (12% and 5%, respectively), while women were more likely than men to report being unemployed (38% and 22%, respectively).



**Figure 5.** *Income Adequacy among Older GMHC Clients with HIV.*

Given the circumstances of participants (i.e., they are often unmarried/unpartnered, live alone, unemployed, and rely on disability payments for income) it was not surprising that nearly one-third of these older GMHC clients reported inadequate incomes for making ends meet (see Figure 5); 29% indicated that they do 'not have enough to cover expenses.' An additional 59% reported they 'just manage to get by' while only 13% reported adequate incomes.

## **Nativity and Spoken Language**

Three-quarters (74%) of the participants were born in the United States. Most participants speak primarily English with family and friends (83%). One-tenth speak both English and Spanish equally with friends and family, 7% communicate mostly in Spanish and only 1% primarily speak a language other than English or Spanish.

## **Religious Affiliation, Participation and Support**

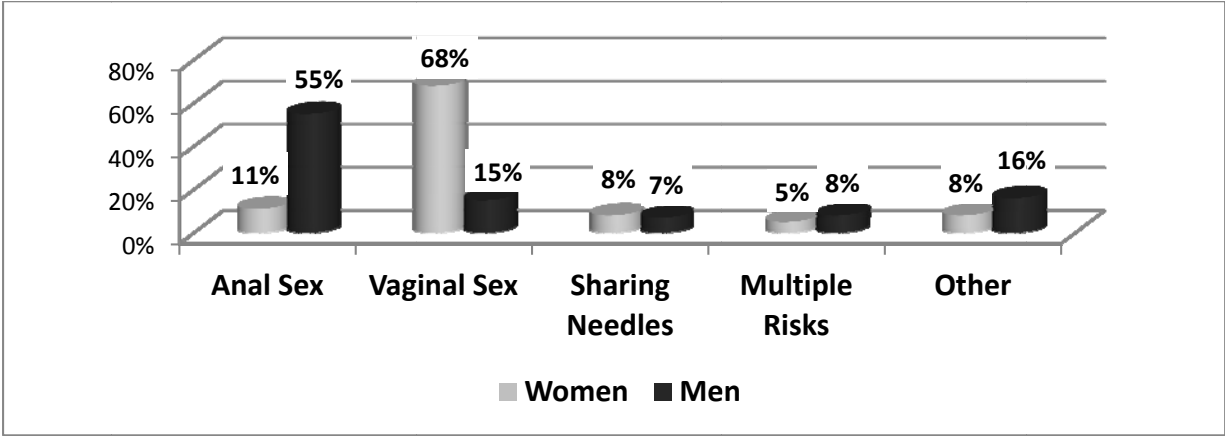
The majority of participants identified their religious affiliation as being either Catholic (38%) or Protestant (27%). However, some identified as Jewish (7%) and Muslim (4%), while 12% reported no religious affiliation.

For 71% of these older GMHC clients, living with HIV had not affected their participation in religious services or involvement with their congregation. Sixteen-percent participated less often than before their HIV diagnosis, while 12% participated more often, similar to the findings of the ROAH study. More than one-third (38%) of participants reported turning to their religious organization for support. In addition, 29% of these older adults with HIV indicated they had turned to a minister, priest, rabbi, imam or other spiritual leader for help over the past year.

## **HIV/AIDS Status and Source of Infection**

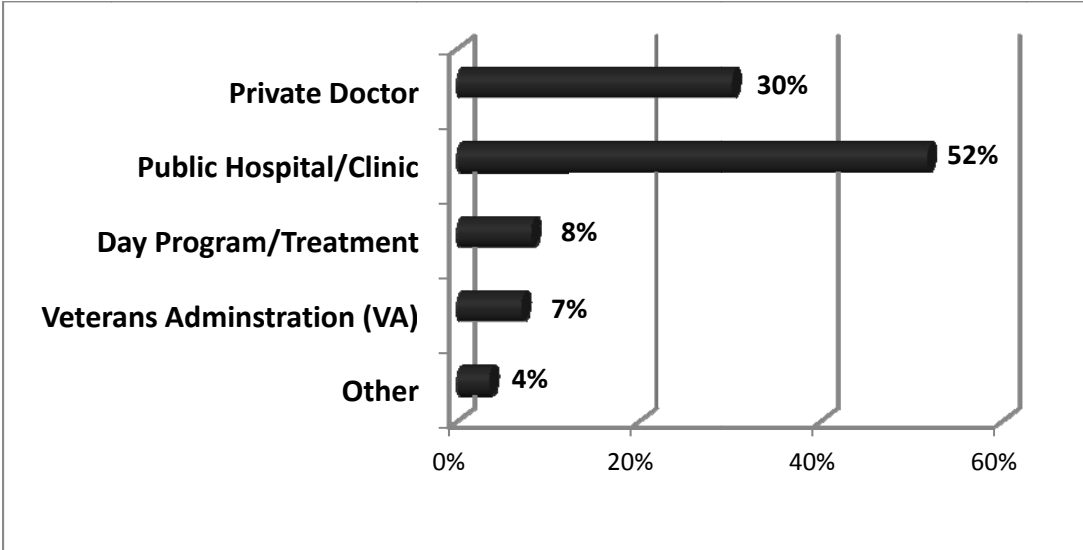
Forty-two percent of participants had been tested for HIV prior to receiving their HIV-positive diagnosis. The average time since diagnosis was 190 months (i.e., 15.8 years). Only 5% had been infected within the past 5 years (approximately from 2004 to 2009), 16% between 5 and 10 years ago (approximately from 1999 to 2003), and 79% had been infected longer than 10 years (prior to 1999). These data indicate that this group of older adults with HIV was primarily composed of long-term survivors. Fifty-five percent had received a diagnosis of AIDS. Most participants (38%) reported a CD4 count range above 500. Thirty-one percent had CD4 counts in the range of 350-500, 17% reported a CD4 count of 201-350, and 14% had counts of 200 or less.

There were significant gender differences in the most common modes of HIV transmission. Women were most likely to report vaginal intercourse as the source of their infection, and men most likely to report anal intercourse (see Figure 6). The other reported modes of transmission were nearly identical for women and men.



**Figure 6.** Mode of HIV Transmission among Older GMHC Clients by gender.

More older GMHC clients reported going to public hospitals/clinics for medical treatment (52%) compared with private physicians (30%). Less than 10% reported attending other programs such as day treatment (see Figure 7).



**Figure 7.** Sources of Medical Treatment among Older GMHC Clients.

## Health & Medications

**Self-rated Health.** When asked to rate their physical health, over two-thirds responded that they are in good or better health; one-fifth reported that their health was 'excellent' and 45% rated their health as 'good.' Another third selected 'fair' (32%) and only 4% rated themselves as being in 'poor' or 'very poor' health.

**Comorbid Health Conditions.** We asked participants about other health conditions they had experienced over the past year in addition to HIV. Some of these conditions are HIV-related, some are age-related, some are chronic conditions prevalent among older persons, and some are other conditions that are not easily grouped in the aforementioned categories. The most common comorbidity reported was depression (53%), followed by arthritis/joint problems (38%), neuropathy (29%), hepatitis C (25%), herpes (22%), and hypertension (19%). As see in Table 1, older GMHC clients reported experiencing a wide range of HIV- and age-related health conditions, along with a broad range of other chronic conditions. With the exception of strokes and migraines, which were both more prevalent among women, the prevalence of the most comorbidities are similar between women and men.

The number of comorbid conditions reported ranged from 0 to 15, and older adults with HIV reported 3.4 comorbid conditions on average. Only 10% of the sample did not report any comorbid health problems.

<b>Table 1</b>			
<b>Prevalence of Comorbid Health Conditions among Older GMHC Clients</b>			
	<b>Total %</b>	<b>Men %</b>	<b>Women %</b>
<b>HIV-Related:</b>			
<i>Hepatitis C</i>	24.6	24.5	25.0
<i>Dermatological/Skin</i>	19.6	20.1	17.5
<i>Herpes</i>	22.3	24.5	15.0
<i>Neuropathy</i>	29.1	28.1	32.5
<i>Pneumonia</i>	7.8	7.9	7.5
<i>Respiratory (PCP, Tuberculosis)</i>	6.1	5.0	10.0
<i>STD</i>	14.0	15.1	10.0
<i>Shingles</i>	7.8	7.3	2.5
<i>Staph Infection</i>	5.0	6.5	0.0
<i>Syphilis</i>	8.9	10.1	5.0
<b>Age-Related:</b>			
<i>Hearing Loss</i>	14.5	14.4	15.0
<i>Impotence (Men)</i>	17.9	21.6	0.0
<i>Menstrual Difficulties (Women)</i>	1.1	0.0	5.0
<i>Vision Loss</i>	16.8	15.8	20.0
<b>Chronic Illness:</b>			
<i>Arthritis/Joint Problems</i>	38.0	38.1	37.5
<i>Broken Bones</i>	7.3	7.9	5.0
<i>Cancer</i>	5.0	6.5	0.0
<i>Diabetes</i>	11.2	10.1	15.0
<i>Heart Condition</i>	11.7	12.9	7.5
<i>Hepatitis A</i>	2.2	2.2	2.5
<i>Hepatitis B</i>	4.5	5.0	2.5
<i>Hypertension</i>	19.0	17.3	25.0
<i>*Stroke</i>	2.8	1.4	7.5



	<b>Total %</b>	<b>Men %</b>	<b>Women %</b>
<b>Other:</b>			
<i>Depression</i>	52.5	55.4	42.5
<i>*Migraines</i>	7.3	5.0	15.0
<i>Nervous System Disorder</i>	6.1	7.2	2.5
<i>Other Health Issue</i>	2.8	2.2	5.0
* $p < .05$ , ** $p < .01$ Chi-square tests of significance			

## Vision and Hearing

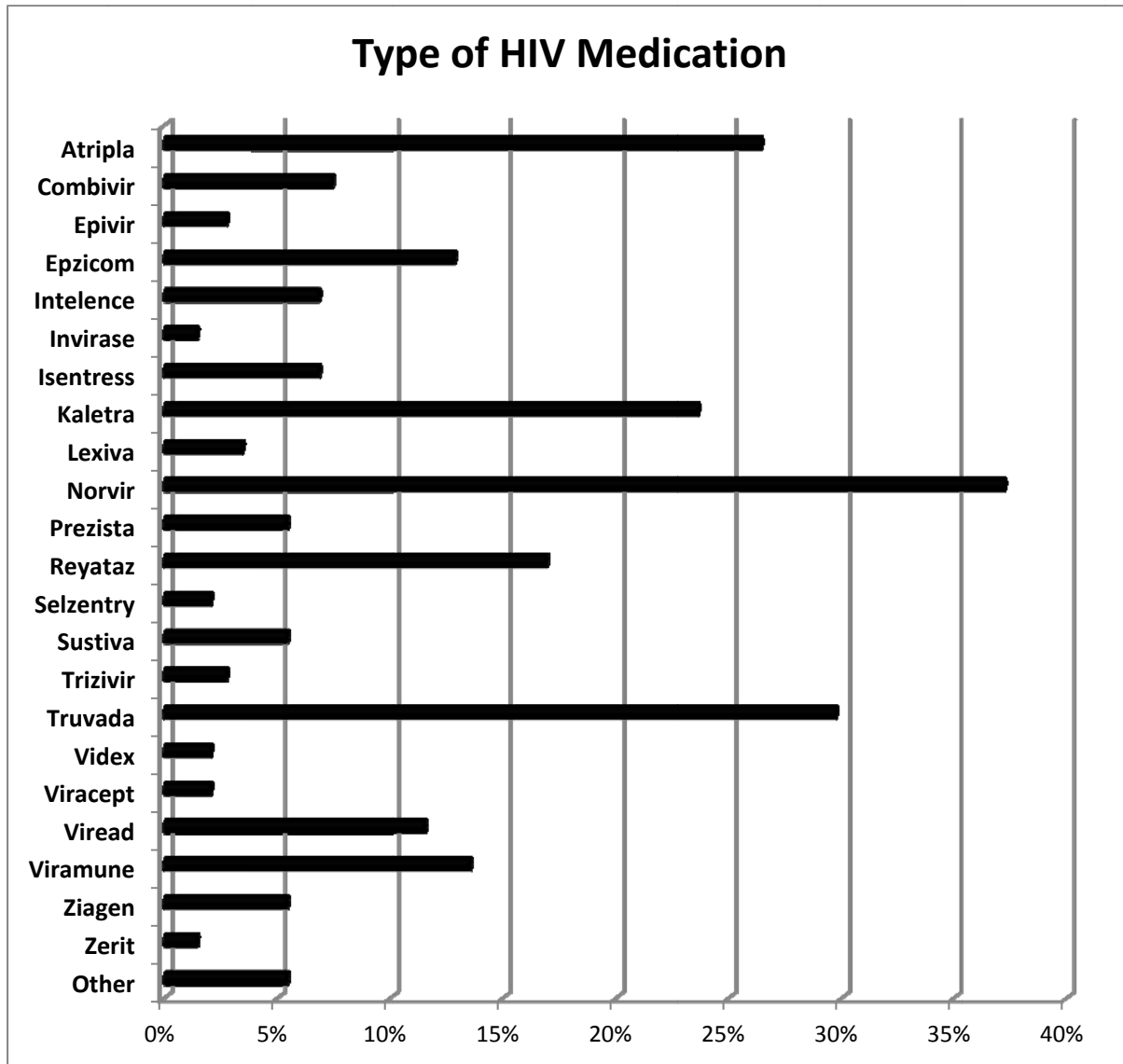
Self-reported problems with vision and hearing function were prevalent in this sample of older adults with HIV. Fifty-one percent reported 'a little' trouble with vision and 11% reported 'a lot' of trouble, even when wearing glasses or contact lenses. With regard to hearing, 27% reported 'a little' trouble and 6% reported 'a lot' of trouble with hearing, even when using a hearing aid. Identical items used in the nationally representative Health and Retirement Study (HRS) of adults 50 to 61 years of age indicated that 13% reported any trouble with vision (versus 62% of the current study sample) and 11% reported any trouble with hearing (versus 33% of older adults with HIV in this study)<sup>10</sup>.

## HIV Medications/HAART

Eighty-five percent of the respondents reported taking medication for HIV (see Figure 8). Though all the medications were reported to be in use, two were used by a third of the respondents: Norvir (37%) and Truvada (30%). One-quarter of the respondents used Atripla (26%) and Kaletra (24%). In addition, the following medications were used by more than ten percent of the respondents: Reyataz (17%), Epzicom (13%), Viramune (14%),

<sup>10</sup> Su, Y., & Brennan, M. (November, 2002). Behavioral risk factors for dual sensory loss in older adults. Poster session presented at the Annual Scientific Meeting of the Gerontological Society of America, Boston, MA.

and Viread (12%). There were no significant differences between men and women in HIV medication use with the exception of Viread, which was reported by 15% of men and 0% of women.



*Figure 8. Types of HIV Anti-retroviral Medications Used by Older Adults with HIV.*

### Use of CAM

Almost half of respondents (44%) reported using complimentary or alternative medicine (CAM). Of 80 older GMHC clients using CAM, the majority used vitamins (80%), followed by

acupuncture (51%), meditation (51%), nutritional supplements (49%), massage (44%), tea (44%), yoga (31%), herbs (31%), chiropractic (21%), and Reiki (15%). Among CAM users, men were significantly more likely to report the use of massage as compared to women (48% versus 31%), while women were significantly more likely to report using herbs for treatment than men (50% versus 26%).

## Mental Health

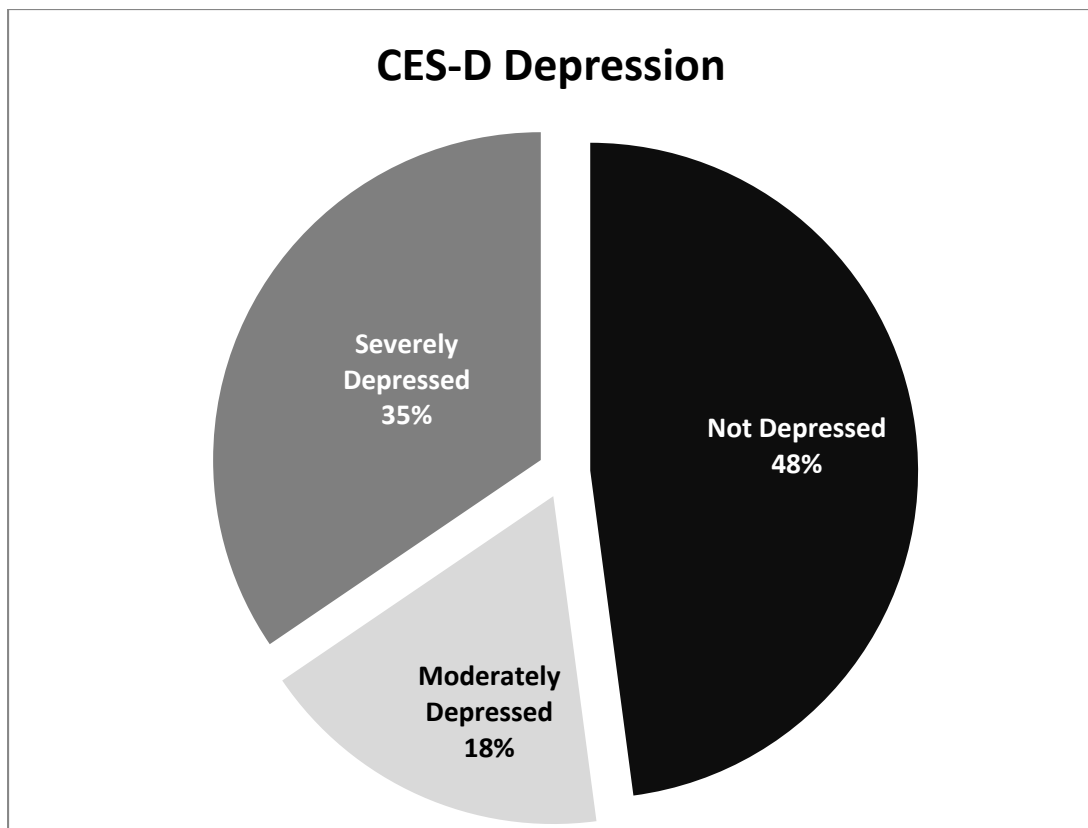
In this study, depressive symptomatology was measured with the ten-item Center for Epidemiologic Studies Depression Scale (CES-D).<sup>11 12</sup> Scores range from 0 to 30 with higher scores indicating more depressive symptoms. Scores of 10 or higher are considered clinically significant. In this sample, the average CES-D score was 11, and 52% of participants had a score of 10 or higher. Many researchers have defined CES-D scores of 14 or higher as indicative of severe depression.<sup>13</sup> Thirty-five percent of respondents had scores at or above 14 and are classified as severely depressed, while another 18% are moderately depressed. The average number of depressive symptoms was not significantly different between men and women.

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<sup>11</sup> Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.

<sup>12</sup> Andersen, E. M., Malmgren, J. A., Carter, W. B., & Patrick, D. L. (1994). Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *American Journal of Preventive Medicine, 10*, 77-84.

<sup>13</sup> Swenson, S. L., Rose, M., Vittinghoff, E., Stewart, A., & Schillinger, D. (2008). The influence of depressive symptoms on clinician-patient communication among patients with type 2 diabetes. *Medical Care, 46*(3), 257-65.



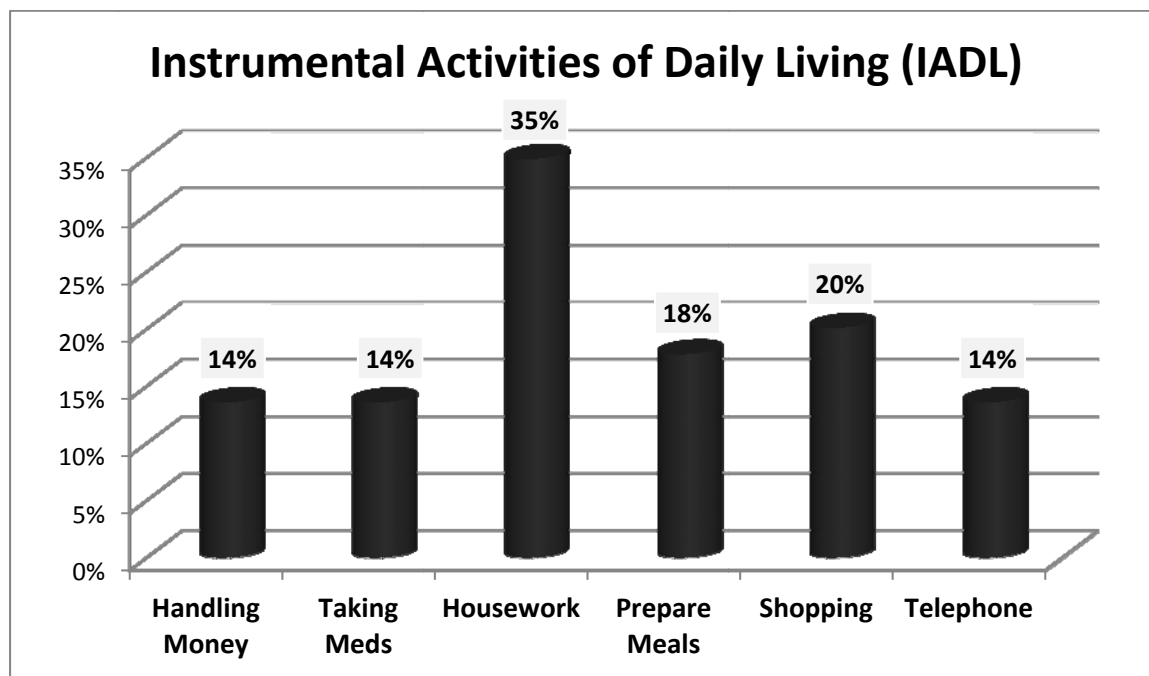
*Figure 9. Classification of CES-D Symptomatology Scores.*

## Activities of Daily Living (ADLs)

Multiple research efforts support the observation of an early onset of age-related illnesses in the population aging with HIV. Data from the present sample (Table 1) are congruent with these findings which would suggest concomitant challenges to functional ability. As a result we asked respondents about any difficulty they encountered with 7 instrumental and 6 personal care activities of daily living (i.e., IADL and PADL, respectively).<sup>14</sup> The proportion reporting any difficulty with these tasks is presented in Figures 10 and 11. In the current sample, the task with the greatest reported level of difficulty was in the IADL domain, namely, 'doing housework, such as sweeping or dusting,

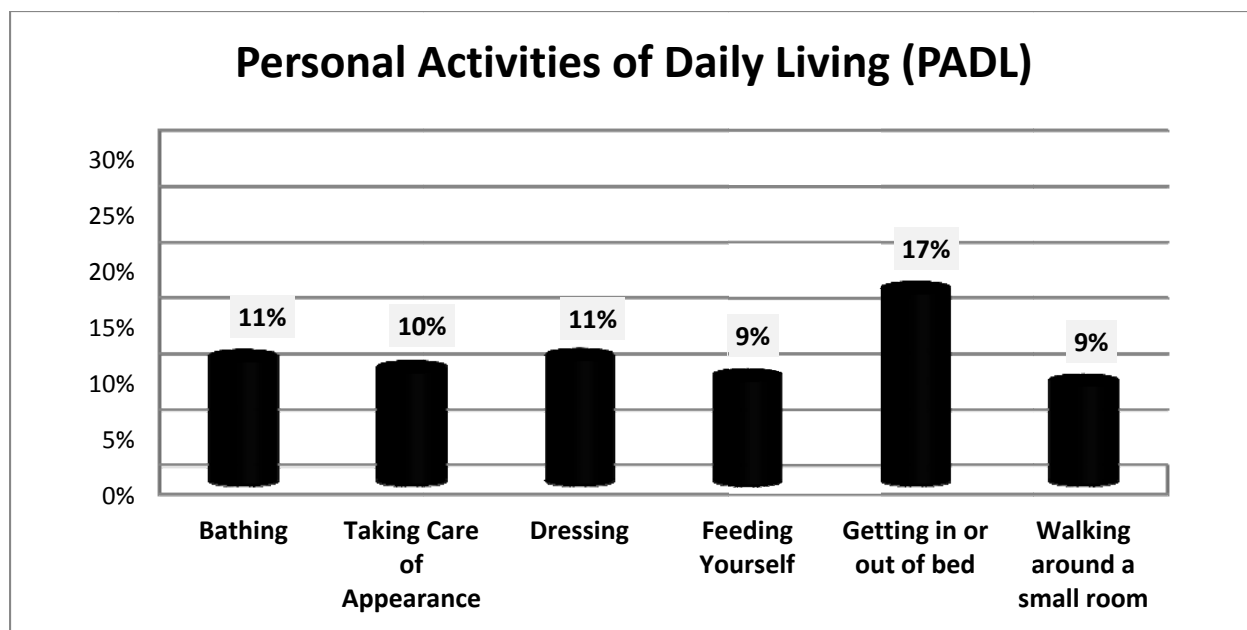
<sup>14</sup> Fillenbaum, G. G. (1988). *Multidimensional functional assessment of older adults: The Duke Older Americans Resources and Procedures*. Hillsdale, NJ: Lawrence Erlbaum Assoc.

washing dishes or laundry' (35%). For the remaining IADL tasks, the proportion reporting difficulty ranged from 10% and 20%. The only significant gender differences in IADL difficulty was for shopping and taking medication. Women were significantly more likely than men to report difficulty with shopping (32% versus 17%) as well as with taking medication (24% versus 13%).



**Figure 10.** *Difficulty with IADL Tasks.*

Overall approximately 10% of older GMHC clients reported difficulties with each of the specific PADL tasks, with the greatest proportion reporting problems getting in or out of bed (17%).



**Figure 11.** *Difficulty with PADL Tasks.*

On average, respondents reported difficulty with 1.3 IADL tasks and 0.6 PADL tasks. In the current sample of older adults with HIV with a mean age of 56 years, 46% reported difficulty with one or more IADL tasks and 22% reported difficulty with at least one PADL task. These data indicate a significantly higher level of ADL task difficulty among older adults with HIV compared to the general population. For example, 2004 data on adults 75 and older from the U.S. Health and Retirement Study (HRS) which used items largely similar to the current study<sup>15</sup> found that only 10% reported difficulty with IADL tasks, and 26% reported difficulty with PADL tasks.<sup>16</sup>

<sup>15</sup> The HRS survey differed somewhat from the current study in measurement of PADL and IADL tasks. In the current study, we asked about PADL difficulty with taking care of appearances, but did not ask about difficulty using the toilet. With regard to IADL tasks, we included 2 that were not asked in the HRS; taking public transportation and housework. Thus in total the HRS asked about 6 PADL and 5 IADL tasks versus 6 PADL and 7 IADL tasks assessed in the current study.

<sup>16</sup> Freedman, V. A., Martin, L. G., Schoeni, R. F., & Cornman, J. C. (2010). Declines in late-life disability: The role of early- and mid-life factors. *Social Science Medicine*, 66(7), 1588-1602.

## Social Networks and Informal Supports

With aging people rely increasingly upon their social networks for informal support and caregiving. But as people age, their social networks often decrease in size due to events such as relocation, illness and death. For older adults with HIV, research suggests this trend of decreasing network size is exacerbated. Consequently, the social networks of many of these individuals are inadequate to provide needed levels of support. In addition, many people living with HIV rely on friends for informal support. But many of these friends are also HIV-positive. While these friends serve as a critical source of support they may be less likely to provide supportive care as they too will likely face the challenge of managing multiple comorbid illnesses, and may at times need support themselves.<sup>17 18</sup>

The current study assessed the presence of potentially supportive people in these networks of older GMHC clients, and also determined if those network members were “functional.” A functional member of the social network is defined as having monthly face-to-face contact and/or talking on the phone at least weekly, and has been used in other large-scale studies of older adults.<sup>19 20</sup> Functional social network members are considered to be relatively available to provide assistance in times of need, and it is their presence in a social network that provides a good indicator of social support sufficiency (see Figure 12).

### ***Presence of Social Network Members and Functionality.***

Overall, the average size of the participants’ total social network was 8.9 people, although this varied significantly by gender. Older

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<sup>17</sup> Cantor, M. H., Brennan, M., & Karpiak, S. E. (2009). The social support networks of older adults with HIV. In M. Brennan, S. E. Karpiak, R. A. Shippy, and M. H. Cantor (Eds.), *Older adults with HIV: An in-depth examination of an emerging population*, pp. 61-74. New York: Nova Science Publishers.

<sup>18</sup> Shippy, R. A., & Karpiak, S. E. (2009). The aging HIV/AIDS population: Fragile social networks. *Aging & Mental Health*, 9(3), 246-54.

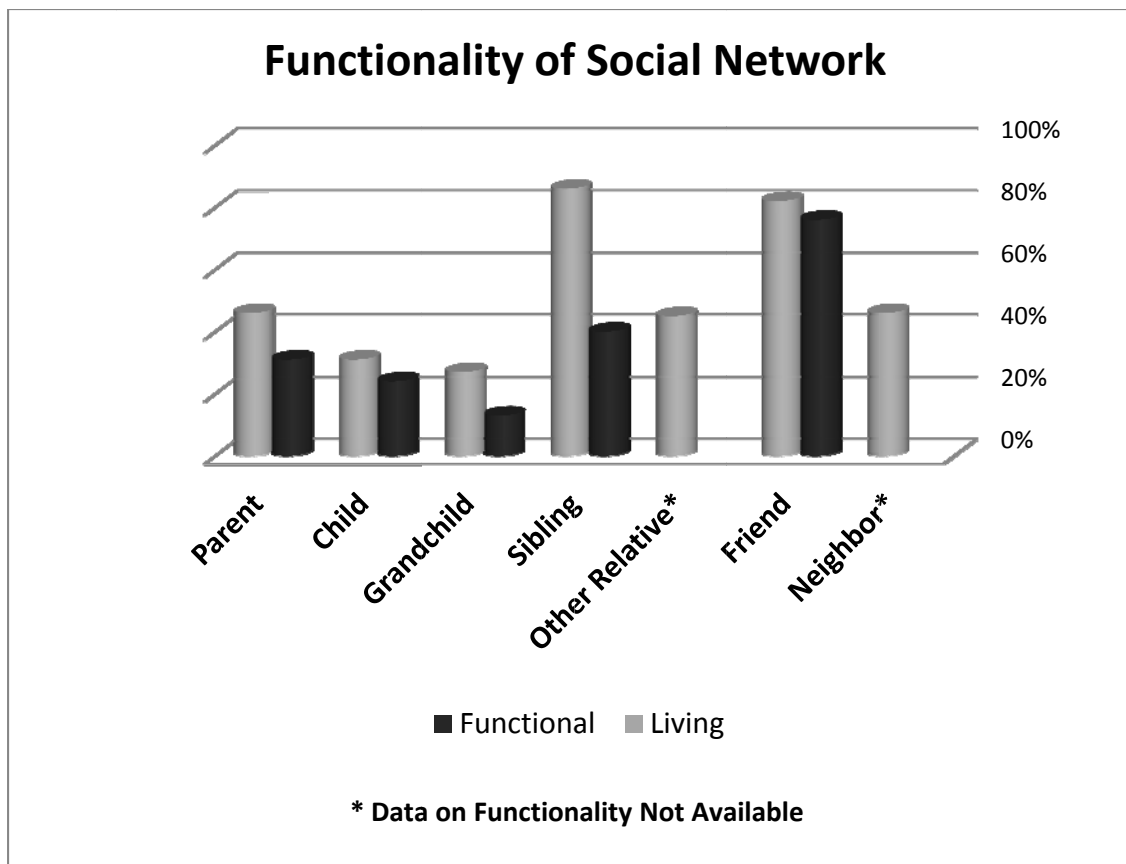
<sup>19</sup> Cantor, M. H., & Brennan, M. (2000). *Social care of the elderly: The effects of ethnicity, class and culture*. New York: Springer.

<sup>20</sup> Cantor, M. H., Brennan, M., & Shippy, R. A. (2004). *Caregiving among Older Lesbian, Gay, Bisexual and Transgender New Yorkers*. New York: The National Gay and Lesbian Task Force Policy Institute.

women who were GMHC clients reported having 10.9 people in their network on average, greater than the 8.2 people in the networks of the men. While the size of the social network in this sample was comparable to that observed in the ROAH study (i.e., 9.6 people).

As illustrated by Figure 12, the limited social networks of older adults with HIV that have been documented in previous research were also evident in this sample. Notably, the proportion reporting a child was only 31%, and even fewer had a functional child (24%). As noted earlier, only 16% reported the presence of a spouse or partner. Because spouses/partners and children form the core of social supports for most adults, these findings reinforce the concern that many adults with HIV will be without adequate social support resources as they grow older. Compared to men, women were significantly more likely to report the presence of children and grandchildren in their networks. Seventy-seven percent of women had children as compared with 19% of men, while 65% of women reported a functional child as compared with 12% of men. With regard to grandchildren, women were significantly more likely than men to report either a grandchild (61% and 17%, respectively), as well as a functional grandchild (40% and 6%, respectively).





**Figure 12.** *Social Network Elements and Functionality.*

Looking beyond spouse/partners, children and grandchildren, the vast majority of older GMHC clients reported siblings in their networks (86%); however, less than half (40%) reported a functional sibling. In addition, 45% reported having at least one or more distant relatives with whom they were in frequent contact (e.g., cousin, nieces and nephews). The social networks of the older adults with HIV in the current study are dominated by friends. Fully 82% of respondents reported friends in their social networks, and most of these friends are functional (i.e., 76% reported a functional friend). Neighbors may serve as additional supports in times of need, and 46% of the current sample reported knowing one or more neighbors well.

The ability of these social network members to provide support may be limited by their own HIV diagnosis. Twelve-percent of respondents reported having a relative with HIV, while three-quarters reported that they have at least one friend living

with HIV. These ties with others who are living with HIV may both generate demands for care as well as provide sources of assistance to these older GMHC clients living with HIV.

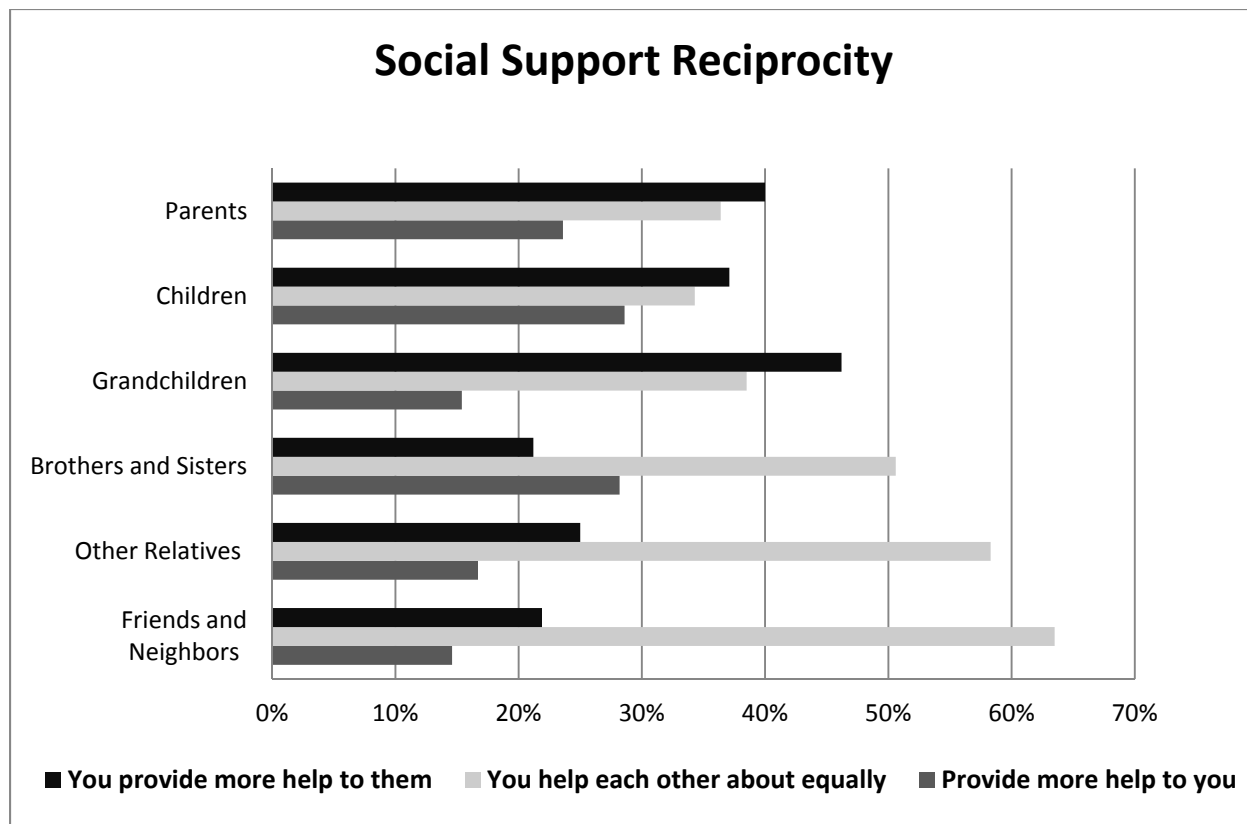
***Closeness to Members of the Social Network.*** Although the social networks of older adults with HIV were limited, most respondents reported feeling close to social network members when they were present. Just under half of participants report feeling ‘very close’ to their parents, and another quarter were ‘somewhat close’ while the remaining quarter of respondents reported feeling ‘not too close’ or ‘not close at all’. Almost three-quarters of participants with children (72%) report feeling very close to their children. Of individuals with grandchildren, 86% reported feeling either ‘very close’ or ‘somewhat close’ to them. A sibling was the most frequently reported living family member, but a smaller percentage of participants reported feeling ‘very close’ (40%) to them than felt ‘very close’ to parents, children or grandchildren (49%, 72%, and 60%, respectively). However, this varied significantly by gender, with 57% of women reporting feeling ‘very close’ to their sibling, compared to 36% of men. Not surprisingly, since friends are the people who one chooses in life, the vast majority of participants (96%) reported feeling ‘very close’ or ‘somewhat close’ to their friends, and there were no significant gender differences in this regard.

***Receipt of Assistance from Family, Friends & Neighbors.*** Older GMHC clients were asked whether or not they received assistance with instrumental tasks (i.e., shop/run errands, keep house/prepare meals, drive/escort to places, help with mail/correspondence, help manage money) and emotional support (i.e., advice on big decision, need cheering up, talk about personal matters) from both family and friends. With regard to family, more received support is emotional rather than instrumental, with 38% to 43% of respondents endorsing emotional support items, as compared with 12% to 18% of respondents indicating help with instrumental tasks. A similar picture emerged with regard to friends; 45% to 52% received various types of emotional support but the proportion reporting instrumental help from friends ranged from 9% to 23%. However,

in line with the composition of the social networks of older adults with HIV, respondents reported higher levels of both instrumental and emotional support from friends than family members.

Notably, even though many participants said they knew their neighbors well, the level of assistance received from neighbors was minimal, with over three-quarters of participants indicating that they and their neighbors help each other ‘not at all’ or ‘only in emergencies’.

***Social Support Reciprocity.*** Many older adults with HIV *receive* assistance from family and friends. However, it is important to recognize that many of these individuals also *provide* support for these social network members (see Figure 13). We assessed the degree of reciprocity in their support exchanges for each element in the social network by asking respondents to indicate whether they received more support than they provided, provided equal levels of support, or provided more support than they received. As can be seen in Figure 13, regardless of the type of relationship in the social network, respondents were more likely to provide more help or equivalent amounts of help as compared to receiving more help than they provided. This finding illustrates that while many older adults with HIV have extensive needs for assistance from their informal networks, many also serve as important sources of social support to their families, friends and communities. Thus, it is more accurate to characterize older adults with HIV as having inter-dependent helping relationships with their social networks rather than characterizing these individuals as dependent on their networks for assistance.



*Figure 13. Reciprocity in Social Network Support Exchanges.*

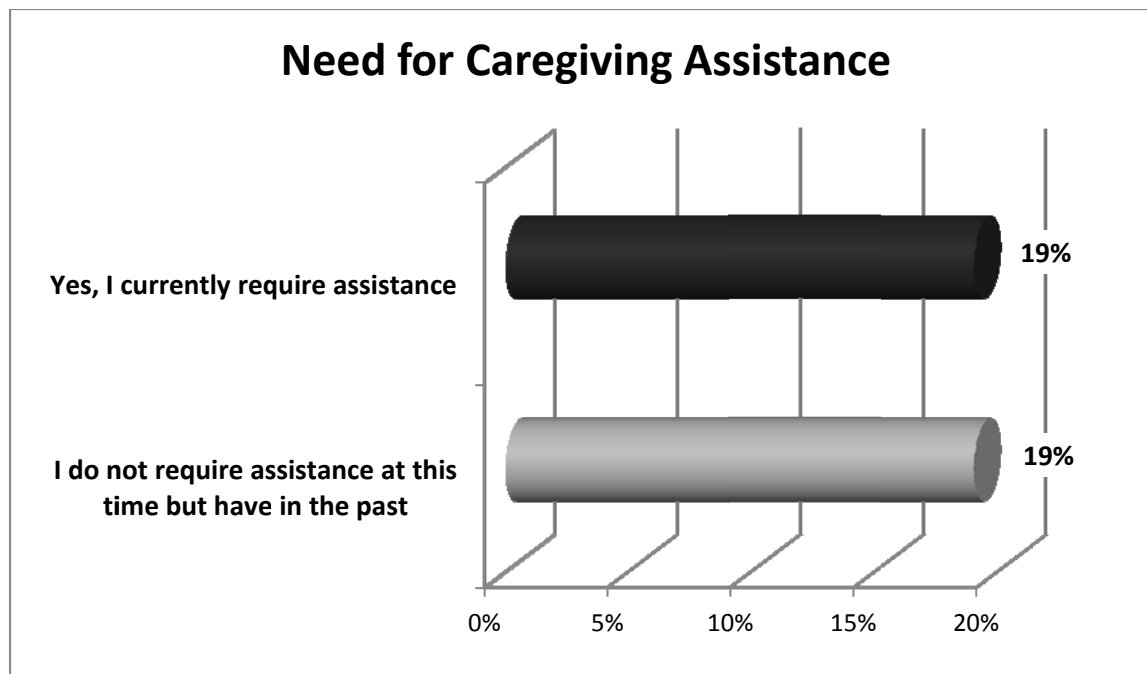
**Perceptions of Support Availability and Adequacy.** Older GMHC clients were asked about the availability of social support in the areas of instrumental help with daily tasks (e.g., cooking, cleaning, getting a ride) and emotional support (e.g., advice, someone to talk to) was available either, ‘all/most of the time,’ ‘some of the time,’ ‘only occasionally,’ or ‘not at all.’ Only 15% of respondents reported that instrumental help was available all/most of the time, while an additional 25% indicated it was available some of the time. Twenty-three percent indicated instrumental support was available occasionally, but nearly two-fifths (38%) indicated that instrumental support was not available to them at all. We also asked about the adequacy of instrumental support in the past year (i.e., ‘received all the help needed,’ or ‘needed a little more,’ ‘needed some more,’ or ‘needed a lot more help’). Only 40% indicated they had received all of the instrumental support they needed in the past year, while 60% indicated needing more help (i.e., 26% a little more, 23%, some more, and 11% a lot more help).

The picture was somewhat better with regards to emotional support with 31% indicating that emotional support was available all/most of the time and 31% reporting such support was available some of the time. An additional 21% indicated that emotional support was available only occasionally, while 17% -- nearly one-in-five-- reported no available emotional support. Despite the greater availability of emotional support, unmet need in this area was even higher than in the instrumental domain, with only 33% indicating they received all the emotional support they needed. Of the remainder, 21% needed a little more, 24% said some more, and 23% indicated they needed a lot more emotional support.

## Caregiving

***Receipt of Caregiving Assistance.*** With the high rates of health comorbidities and functional disability in the current sample, it was not surprising that a sizeable proportion of older GMHC clients with HIV indicated that they either currently require caregiving support because of HIV or other illness, disability or frailty (19%), or had needed such support in the past (19%; see Figure 14).

Those who reported current or past receipt of caregiving were asked who had provided the assistance. These older adults with HIV were most likely to report receiving caregiving from a paid helper (38%), followed by a friend (34%). Partners/spouses/significant others and other family members were the next most frequently reported source of caregiving support (16% and 26%, respectively), followed by neighbors (12%) and volunteers (12%). Women were significantly more likely than men to name a family member as a caregiver (47% and 20%, respectively). Of these, a quarter of those currently or previously providing care were HIV-positive. However, over one-fifth of those who had current or past caregiving needs reported that they had relied on themselves alone and lacked caregiving resources (21%).

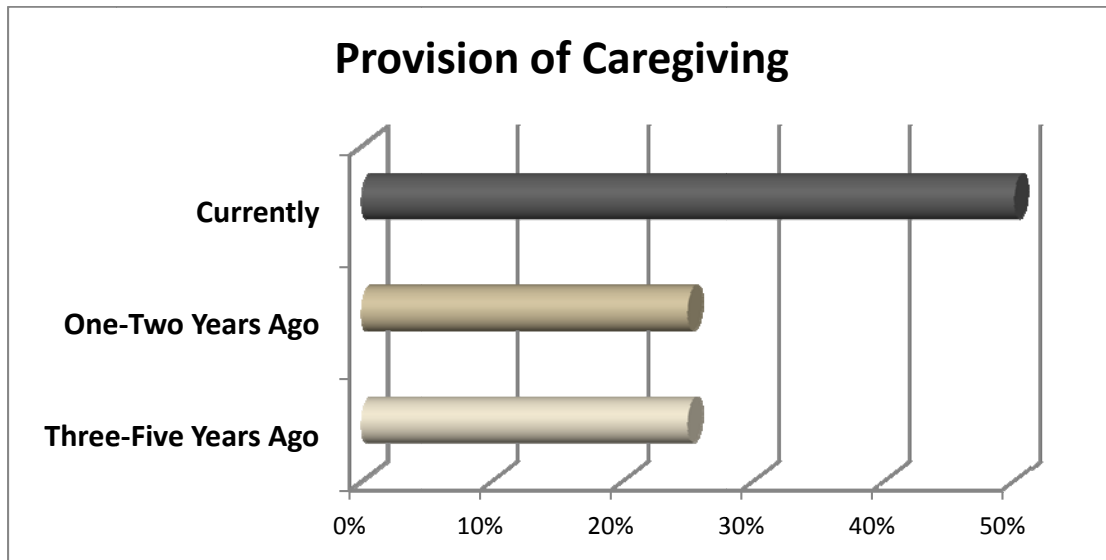


**Figure 14.** Current and Past Needs for Caregiving Assistance.

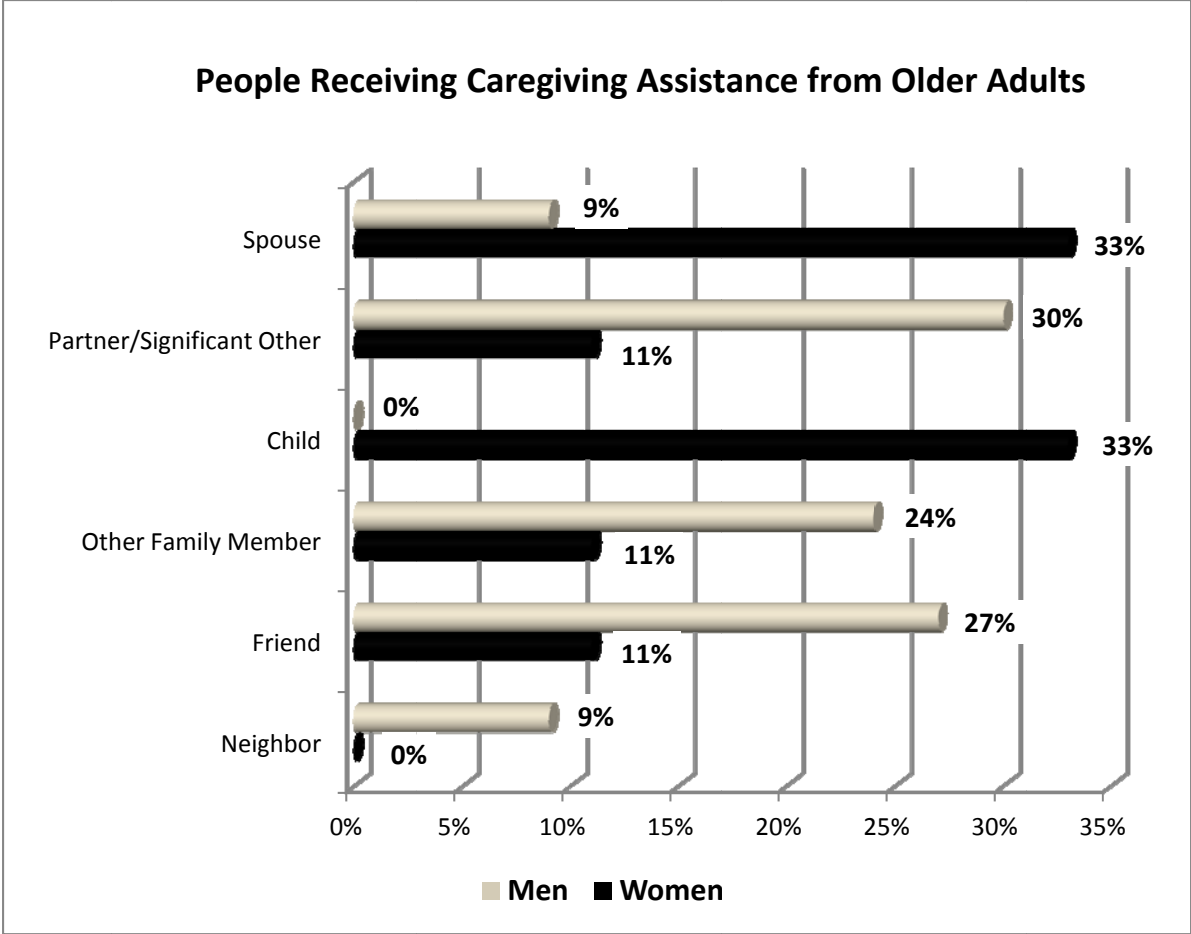
**Older Adults with HIV as Caregivers.** While older adults with HIV may require caregiving assistance, many provide such help to members of their social networks. Nearly one-third of participants reported being a primary caregiver within the last five years (29%). Of those who reported being caregivers, 50% are currently providing care, with the remainder having provided care 1 to 3 years ago (25%) or 3 to 5 years ago (25%).

Most often, the older adult with HIV was providing care to a partner/spouse/significant other (42%). The next most likely to receive care were friends (23%) or other family members (21%), followed by children (7%) and neighbors (11%). There were significant gender differences in the relationship of the person receiving care to the older adult with HIV (see Figure 16). Women were significantly more likely than men to care for a spouse or child, while men were more likely than women to care for a partner/significant other, other family member, friend, or neighbor. Thirty-nine percent of those receiving care from the older adults with HIV were also HIV-positive. Further, over one-third of the older adults with HIV who were primary caregivers

indicated that their caregiving responsibilities interfered with their ability to take care of themselves.



**Figure 15.** *History of Caregiving Assistance among Older Adults with HIV.*



**Figure 16.** Relationship of Care Recipient to Older Adults with HIV Caregivers.

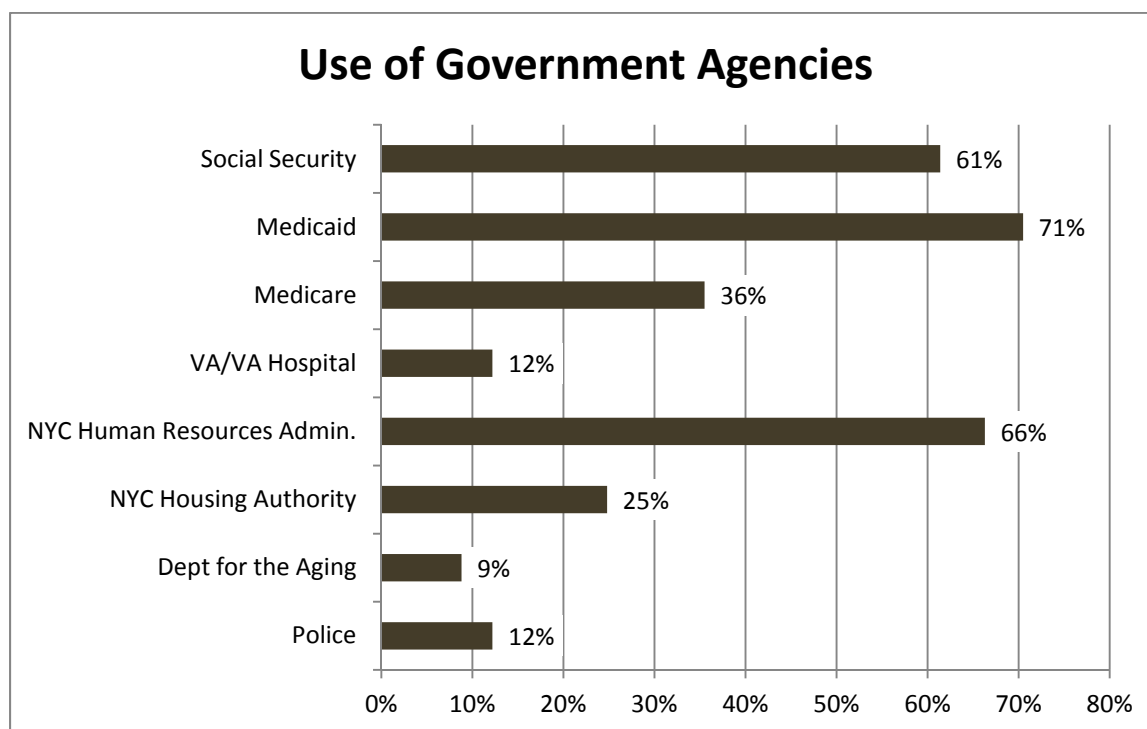
### Use of Formal Services

Participants were asked about their use of services from government, AIDS service organizations (ASOs), health-related providers, community-based organizations (CBOs), and other agencies during the past year. Specific questions were also asked about use of and satisfaction with GMHC services. Here we describe the use of various non-GMHC services; in the next section we focus on GMHC services.

**Government Offices and Agencies.** The use of government agencies (see Figure 17) reflects the high proportion of the current sample that is disabled (54%) or retired (9%). The Social Security and Medicaid offices were among the most frequently utilized (61% and 71%, respectively), followed by the New York



City Human Resources Administration (HRA). Over one-third had accessed the Medicare office and one-quarter had utilized the New York City Housing Administration (NYCHA) for assistance with public housing. The use of the Veteran’s Administration (VA) or VA Hospital (12%) was in line with the proportion of respondents who had served in the military (19%). Twelve percent reported calling on the police during the previous year, and men were significantly more likely than women to report turning to the police (14% versus 4%). Given the relatively young average age of this GMHC older client sample (i.e., 56 years), it is not surprising that few had sought services from the Department for the Aging (DFTA) for which eligibility is generally age 60 or older.

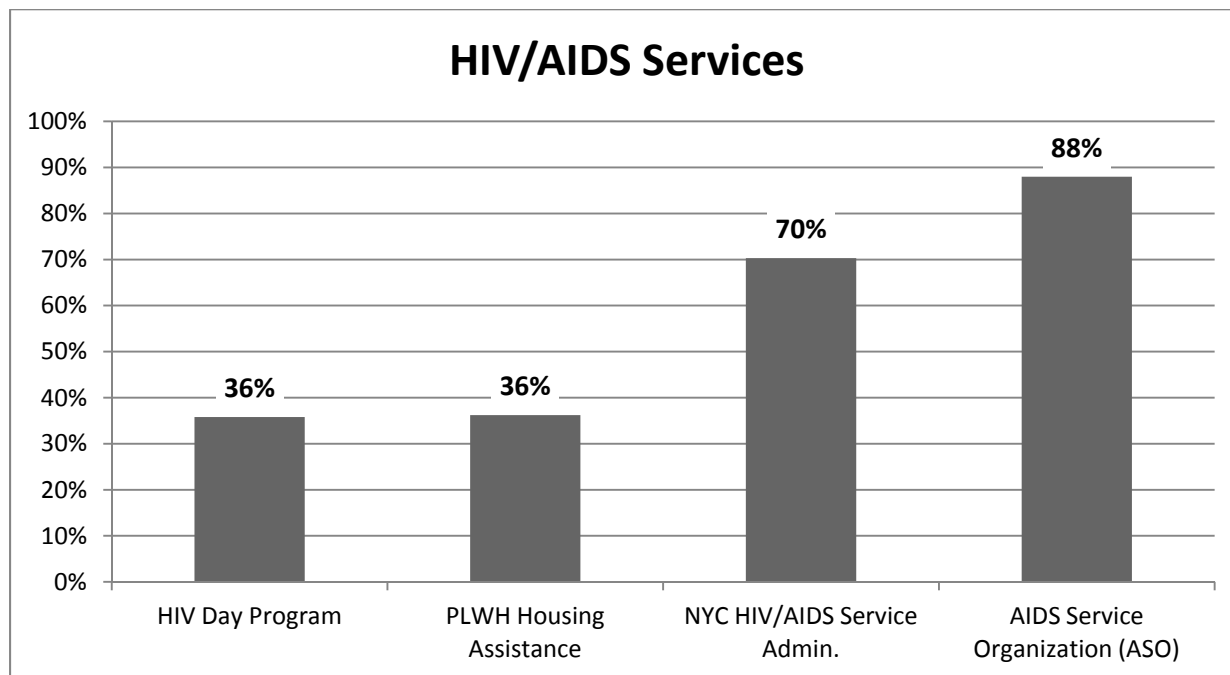


*Figure 17. Use of Government Agencies and Services.*

**HIV/AIDS-related Services.** Nearly all respondents reported receiving assistance from an ASO in the previous year (88%; see Figure 18)<sup>21</sup>. Men were significantly more likely than women to have accessed these services (92% and 74%,

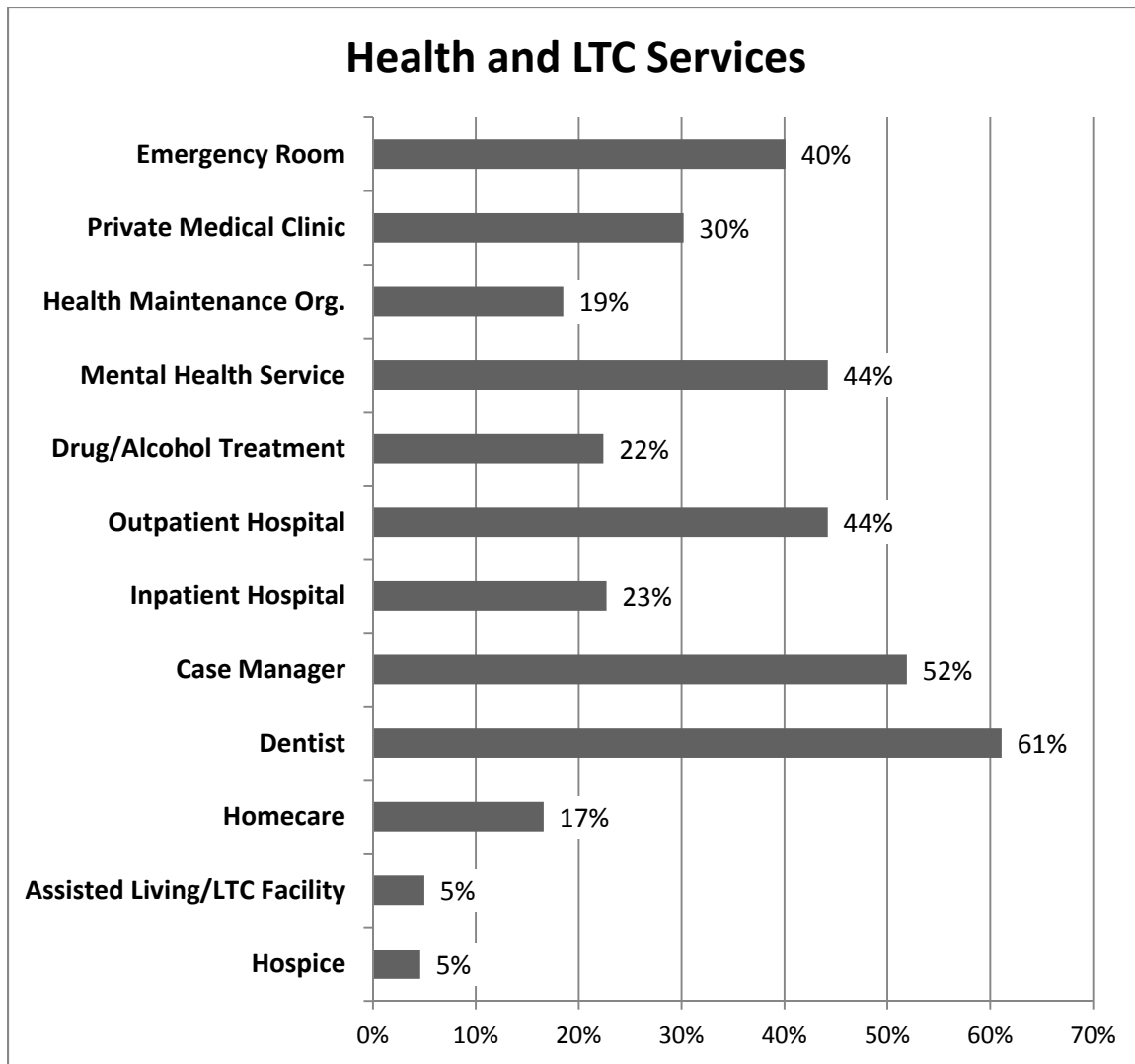
<sup>21</sup> Because all participants were GMHC clients in the past 6 months, the fact that less than 100% endorsed this item suggests that it was interpreted as ASOs other than GMHC.

respectively). However, there were no significant gender differences in the use of other HIV/AIDS services. Seventy-percent had utilized the New York City HIV/AIDS Services Administration (HASA), and approximately one-third had used housing programs for people with HIV or HIV Day programs.



**Figure 18.** Use of HIV/AIDS Services.

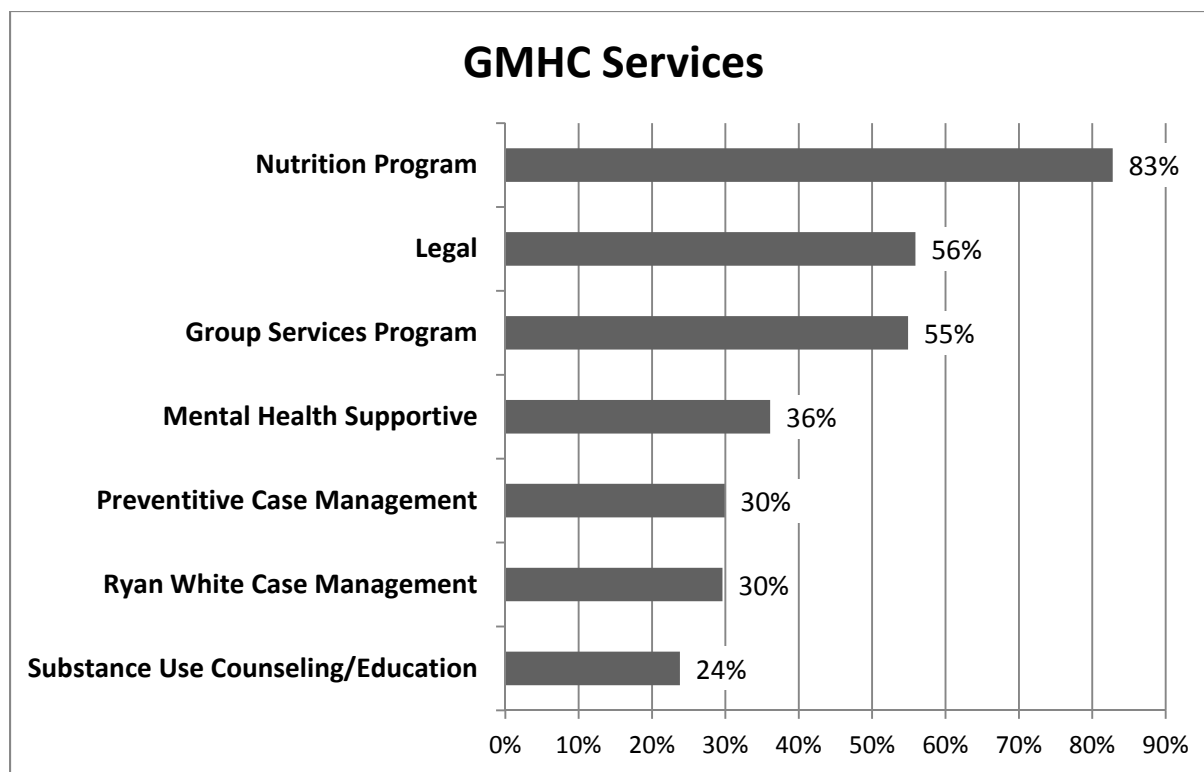
**Health and Long-term Care Services.** Higher proportions of older GMHC clients reported accessing hospital emergency room services in the previous year (40%), compared with either private clinics (30%) or health maintenance organizations (HMOS; 19%). Nearly half had used mental health services, and 22% reported using drug or alcohol treatment services (see Figure 19). Forty-four percent had utilized outpatient hospital services and 23% have had an inpatient hospital stay. Over half had used case management, and nearly two-thirds had seen a dentist in the previous year. Almost one-in-five (17%) reported the use of homecare services, and small percentages had used a long-term care (LTC) facility (5%) or hospice (5%).



*Figure 19. Use of Health Care and Long-term Care (LTC) Services.*

## Use of Services at GMHC

As noted, older GMHC clients were asked which specific services they had used at GMHC and how helpful they found these services (see Figure 20).



**Figure 20.** Use of Services at Gay Men’s Health Crisis (GMHC) by Older Adult Clients.

The most frequently accessed services at GMHC were the Meal/Nutrition Program<sup>22</sup> (83%), followed by Legal Services<sup>23</sup>

<sup>22</sup> Nearly 100,000 meals are served annually by GMHC. In addition, GMHC offers individual nutritional counseling sessions which are tailored to fit the client’s needs. Also provided by the organization are six group nutritional classes that cover HIV related topics.

<sup>23</sup> Legal services involve a staff of experienced attorneys, accredited immigration advocates, and volunteers, who provide free legal services to people living with HIV/AIDS. Clients are assisted in a variety of areas including immigration matters, eviction prevention, and family law issues. Direct legal

(56%), and Group Services Program<sup>24</sup> (55%). Although less frequently utilized, there were significant differences by gender in use in some of the other GMHC programs. Women were more likely than men to report the use of both Preventative Case Management (44% and 26%, respectively) and Ryan White Case Management (44% and 26%, respectively). Women were also more likely than men to report use of the substance use counseling and education services (40% versus 19%).

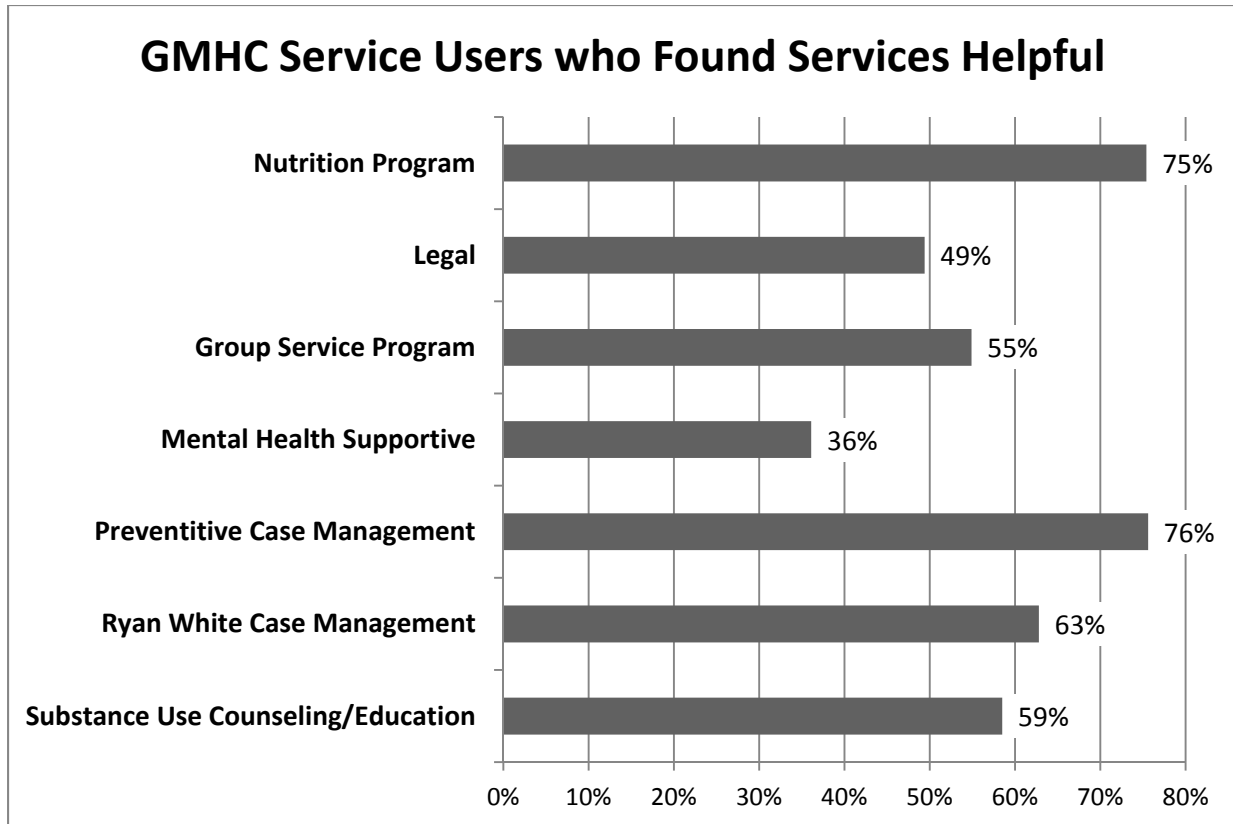
Respondents were also asked how helpful they had found these GMHC services to be (i.e., 'helpful,' 'somewhat helpful,' 'not too helpful,' 'not helpful at all'). The proportion of respondents who reported the services to be 'helpful' is shown in Figure 21 below. Overall, the majority of GMHC clients who received services found them to be helpful without qualification.

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advocacy, representation, pro se advice, and appropriate referrals are also provided. Legal services are not offered for criminal cases.

<sup>24</sup> Group Services offers affirming spaces to help HIV+ people reduce isolation and stigma, learn healthy relationship skills, get support coping with a variety of challenges, explore their sexual orientation and gender identity, and connect with others in a safe environment.

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*Figure 21. Rating of Services at Gay Men's Health Crisis (GMHC) by Older Adult Clients.*

## Additional Service Needs and Unmet Need

Older women and men with HIV were asked about their needs for services commonly received by older adults in the past year, whether or not such needs were met, and who provided the help when available.

**Meals.** Twenty-two percent of older GMHC clients needed meals brought to them at home. Of those needing meals at home, over three quarters (79%) 'got the help that they needed'. Meals-at-home were accessed most frequently through GMHC (43%) or other AIDS services or community-based organizations (ASOs or CBOs; 54%), followed by family members (31%) and friends/neighbors (29%). Women were significantly more likely

than men to report need in this area (39% and 17%, respectively), but there were no significant gender differences in receipt of help or source of support.

**Housekeeping.** Nearly one quarter of participants (23%) said they needed help with housekeeping, with a significantly higher proportion of women reporting they needed help with housekeeping than men (35% and 20%, respectively). Of those that needed help two-thirds said they received the help that they needed. The most common source of support were other ASOs/CBOs (52%), followed by friends and neighbors (37%), family (26%), and GMHC (22%).

**Home Repairs.** Twenty-nine percent reported needing help with home repairs, and nearly two-thirds (64%) received the help they needed. Of those that needed help with home repairs, other ASOs/CBOs were the most frequently named source of help (61%), followed by friends and neighbors (39%), family members (21%), and GMHC (18%).

**Finding a Job.** Twenty-nine percent of respondents reported needing help finding a job, and 60% said they received all the help they needed. Again, other ASOs/CBOs were most likely to provide this type of help (52%), followed by GMHC (39%). Friends/neighbors provided help with finding a job to about one-third of those needing this help (32%), while family was a source of support in this domain for relatively few respondents (13%).

**Personal or Family Counseling.** Forty-one percent reported that they needed assistance in the past year in the form of personal or family counseling and over three-quarters said they received the help that they needed (78%). Formal service providers were most often turned to for this type of help; 44% received help from GMHC in this area and 72% got help from other ASOs/CBOs. Friends/neighbors and family were relatively infrequent sources of this type of support (18% and 14%, respectively).

**Post-hospital care.** One-quarter (24%) of older adults with HIV reported needing caregiving help after a hospital stay, and women were significantly more likely than men to need such support (36% and 21%, respectively). Eighty-one percent reported that they had received the help that they needed. Informal caregivers were most often utilized for help after a hospital stay, primarily family members (56%) and friends/neighbors (36%). Formal services were used for post-hospital care less often, with 25% using services of another ASO/CBO and a small proportion turning to GMHC (6%).

**Assistance in getting to doctor or clinic.** Nearly one-third (31%) of participants said they needed someone to take them to a doctor or clinic. The vast majority (92%) of participants got the help they needed in this regard. Friends/neighbors were the most likely to provide this help (50%), followed by family (33%). Formal services were used for this type of support less often; other ASOs/CBOs (28%) and GMHC (11%).

**Someone to call or visit regularly.** Almost one-third (31%) of participants reported the need for someone to call or visit regularly and once again the vast majority received this help (87%). Informal social network of family and friends/neighbors most often provided this support (62% and 58%, respectively). GMHC and other ASOs/CBOs were not frequently utilized as sources for calls or visits (11% and 20%, respectively).

**Visiting Nurse or Home Health Aide.** While relatively few older people with HIV reported needing a visiting nurse/home health aide (13%), women were significantly more likely than men to report that they needed this type of help (26% and 10%, respectively). Most (81%) received the help that they needed in this area. Other ASOs/CBOs were the most likely to provide this type of support (68%), followed by friends/neighbors (26%), family (16%) and GMHC (11%).

**Government entitlements.** One of the highest reported areas of unmet need was for assistance with government entitlement programs; 41% of participants needed assistance in this regard, and 71% of those needing this help received



assistance. Other ASOs/CBOs were the most frequently reported source of help (52%), while one-quarter turned to GMHC (25%). Informal members of the social network were rarely the source of help in this area (family --12%, friends/neighbors -- 12%).

**Socialization.** Just over half of participants (53%) indicated that they needed a place to socialize or meet people and most had this need met (83%). GMHC was used as a resource by 71% of the participants that needed a place to socialize or meet people, this was followed by other ASOs/CBOs (48%), friends/neighbors (41%), and lastly family(16%).

## Barriers to Services

We asked older adults with HIV about barriers to receiving services in the community. These barriers can be grouped in terms of access barriers, staff and organizational barriers, and contextual issues. Responses are shown in Table 2 below. Seventy-three percent of older GMHC clients reported at least one barrier to service, and the average number of barriers reported was 4.1.

As a group, access barriers appeared to be most significant with majorities of respondents not knowing where to access services and not knowing if services are available locally. Other access issues included being able to afford services or being eligible for free services, long waiting times to receive services, and problems with the process of applying for needed services. A smaller, but substantial percentage of participants (32%) indicated that transportation to service locations was a problem.

Staff and organizational barriers were less frequently mentioned than access barriers, but still affected between one-quarter and one-half of older adults with HIV. In this group, the most frequently mentioned barriers were feelings that agency staff was not helpful or motivated to help, or that agency staff did not like

“people like me.” Communication problems were also frequently mentioned including language differences between staff and clients, or difficulty on the part of clients articulating their needs to staff.

Contextual barriers were reported at approximately the same level as staff and organizational barriers. Nearly one-third mentioned difficulty in making and keeping appointments, while approximately one-quarter had child care or other caregiving issues. Importantly and speaking to the continuing challenge of stigma for people with HIV, nearly one-third were afraid that their HIV status would be disclosed to others if they accessed needed services.

There were a number of significant gender differences in perceived barriers to service. But regardless of statistical significance, there was a clear pattern of a greater proportion of women with HIV reporting more barriers to services than men on all items and they do so in all three barrier domains (see Table 2). Specifically, a significantly higher percentage of women than men reported that; (1) they don't know where to go for services, (2) it's hard to get there, (3) service providers don't like people like them, (4) staff does not speak the same language that they do, (5) they have trouble expressing what they need to staff, (6) they have child care issues, (7) it is hard to make/keep appointments, and (8) they are concerned that their HIV status might be disclosed. There were no significant gender differences in the percentage reporting at least one barrier or the average number of barriers to service reported.

<b>Service Barrier</b>	<b>Total %</b>	<b>Women %</b>	<b>Men%</b>
<b>Access Barriers</b>			
Don't Think Services are Available Locally	<b>55.2</b>	<b>68.4</b>	<b>52.6</b>
* Don't Know Where to Go for Services	<b>57.3</b>	<b>77.3</b>	<b>52.9</b>
Would have to Wait Too Long for Services	<b>53.6</b>	<b>57.7</b>	<b>52.5</b>
Unable to Afford Services	<b>51.7</b>	<b>60.9</b>	<b>49.5</b>
Unable to Receive Free Services	<b>55.9</b>	<b>70.8</b>	<b>52.4</b>
Process of Getting Services Too Confusing or Difficult	<b>48.0</b>	<b>50.0</b>	<b>47.5</b>
*** Hard to Get There (Transportation)	<b>32.2</b>	<b>59.1</b>	<b>26.0</b>
<b>Staff and Organizational Barriers</b>			
** Service Providers Don't Like People Like Me	<b>39.8</b>	<b>65.0</b>	<b>34.1</b>
Afraid Won't Receive Treatment	<b>27.6</b>	<b>42.1</b>	<b>24.4</b>
*** Staff Doesn't Speak the Same Language as Me	<b>22.5</b>	<b>50.0</b>	<b>16.4</b>
* Trouble Expressing Needs to Staff	<b>30.7</b>	<b>50.0</b>	<b>25.0</b>
Staff are Unhelpful or Unmotivated	<b>44.4</b>	<b>50.0</b>	<b>43.0</b>
<b>Contextual Barriers</b>			
* Don't Know What to Do with Kids When Getting Services	<b>27.1</b>	<b>50.0</b>	<b>21.3</b>
Caregiving Interferes with Getting Services	<b>25.3</b>	<b>26.3</b>	<b>25.0</b>
* Hard to Make/Keep Appointments	<b>30.7</b>	<b>50.0</b>	<b>25.6</b>
Family/Friends Don't Approve of Services	<b>17.8</b>	<b>30.4</b>	<b>14.1</b>
** HIV Status May Be Disclosed	<b>30.1</b>	<b>54.5</b>	<b>23.5</b>
<b>* <math>p &lt; .05</math>; ** <math>p &lt; .01</math>; *** <math>p &lt; .001</math> Chi-square tests of significance.</b>			

## Conclusions and Implications

This study extends the seminal work of ACRIA's ROAH study<sup>25</sup> to provide a more complete picture of the population aging with HIV in New York City with regard to caregiving and service utilization. The study group in this research effort was drawn from the clients of GMHC who were 50 years and older, and who had utilized GMHC services in the previous six months. Given these recruitment criteria, 78% of the samples are male, which is comparable to New York City epidemiology; 73% of older adults with HIV in New York City are men.<sup>26</sup> Participants were racially diverse with over one-third of participants being Non-Hispanic Black, 32% Non-Hispanic White and 29% Latino.

The demographic characteristics of this study group were similar to ROAH. The average age was 55 years. Participants had been living with HIV on average for 16 years. Only 5% had been infected with HIV in the past five years. These are largely long-term survivors. However, there was a much higher proportion of LGBT respondents in the current sample; over half of participants described themselves as gay or lesbian (55%) and 30% as heterosexual, while in ROAH two-thirds identified as heterosexual. At the time of the study over one-third of participants were not sexually active. The majority of participants (90%) graduated high school and over one-third had a college degree or more education. Over 80% of the study sample was not working with over half being on disability. Almost two-thirds of the sample was not involved in a relationship and over 70% reported living alone.

The health status and level of comorbidities in the GMHC sample were similar to other groups of older adults with HIV. Over

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<sup>25</sup> Brennan, M., Karpiak, S. E., Shippy, R. A., & Cantor, M. H. (2009). *Older adults with HIV: An in-depth examination of an emerging population*. New York: Nova Science Publishers.

<sup>26</sup> New York City Department of Health & Mental Hygiene. (2009). HIV Epidemiology and Field Services Program Semiannual Report. Retrieved from the world wide web May 19, 2010: <http://www.nyc.gov/html/doh/downloads/pdf/dires/dires-2009-report-semi2.pdf>.

two-thirds of the sample reported that they are in ‘good’ or ‘excellent’ health, and 85% were on ARV medications. The most common comorbid health condition was depression (53%), followed by arthritis/joint problems (38%), neuropathy (29%), hepatitis C (25%), herpes (22%), and hypertension (19%). In line with reported comorbidities, the level of depressive symptoms in the current sample was high; over half were found to be severely or moderately depressed. Self-reported problems with vision and hearing were more prevalent in this population compared with other adults of the same age, with 51% reporting a “little” trouble with vision and 11% having “a lot of trouble”. With regard to hearing, 27% reported a “little” trouble while 6% reported “a lot” of trouble.

This study is one of the first to assess difficulty with Activities of Daily Living (ADLs) among older adults with HIV. Higher levels of difficulty (35%) were reported for the Instrumental ADL measures (i.e., IADLs) such as apartment cleaning, maintenance etc. Smaller proportions of the sample reported difficulties with personal ADLs (i.e., PADLs) with 10% to 20% reporting difficulties with activities such as dressing, grooming, etc.

This GMHC study cohort manifests the same fragile social networks that were first observed by Shippy and Karpiak<sup>27</sup> and later in ROAH<sup>28</sup> among the New York City older adult HIV population. Namely, older adults with HIV often do not have a spouse/partner or other close kin (i.e., children) present in their networks, and often rely on friends. Concomitantly, perceptions of support availability and adequacy are low. These current data suggest that older adults with HIV may not be able access the kind of support that is typically derived from family of origin and friends. This may cause them to become increasingly reliant upon publicly-funded formal care resources, and ultimately may lead

<sup>27</sup> Shippy, R. A., & Karpiak, S. E. (2009). The aging HIV/AIDS population: Fragile social networks. *Aging & Mental Health*, 9(3), 246-54.

<sup>28</sup> Brennan, M., Karpiak, S. E., Shippy, R. A., & Cantor, M. H. (2009). *Older adults with HIV: An in-depth examination of an emerging population*. New York: Nova Science Publishers.

them to be relegated to costly long term health care facilities early in their life span. The broader implications of these data are the greater need to develop appropriate community-based supports for the long-term care of older adults, including people aging with HIV. However, we did find that these older adults also provide critical support to their social networks, with the majority either giving greater or equivalent levels of assistance compared to what they receive themselves. While two-in-five report current or recent needs for caregiving assistance, nearly two-thirds have provided care to someone else within the last five years, most often to a partner/spouse, friend or other family member.

This study is also one of the first to assess in detail the service utilization patterns and related issues among older adults with HIV. The use of services was high in all domains including government, HIV/AIDS services, and health and long-term care services. At GMHC, the most frequently used services were the nutrition program, followed by legal services and the group services program. For nearly all the programs, the vast majority of GMHC older clients reported that the services were helpful or somewhat helpful. When asked about service needs in a variety of domains (e.g., meals at home, repairs, employment help, post-hospital care), most received the help they needed. However, many participants reported unmet needs for assistance, which indicates that there is a need for additional community-based supports for people aging with HIV.

When asked about barriers to services in the community, most said they did not know where such services existed locally and whether or not they were eligible. Transportation to services, fear of long wait lines, and lack of knowledge about what services are available and where to access such services were some of the major barriers perceived by older GMHC clients. The study found that for many participants HIV/AIDS stigma was still a barrier as they said that agency staff were not helpful and thought that staff did not like “people like me.” Almost one-third had difficulty in making and keeping appointments, and one-quarter had child care or other caregiving issues. Significantly, the power of stigma remained present, as nearly one-third were afraid that their HIV

status would be disclosed to others if they accessed needed services. In many domains, older women with HIV perceived significantly greater barriers to services than their male peers.

There are a number of major implications that arise from these study data. High levels of health comorbidities, as well as vision and hearing problems, and depression are manifested in higher rates of ADL difficulty, especially with instrumental ADLs necessary to live independently in the community. Two-fifths of this group report the need for caregiving supports, either currently or recently. Social networks are fragile and limited, and as the data indicate, many older adults with HIV who needed post-hospital or visiting nurse care relied on community-based organization and ASOs to get the help they need. As this population ages, the need for care and community supports can only be expected to increase. All of this is occurring in an economic environment that has witnessed the pull-back of government and community-based programs to support older people with HIV due to budget cuts and financial concerns. One could speculate that the reliance on community-based programs would be even greater if these older adults with HIV did not perceive such high levels of barriers to service.

These data suggest that we will need to expand support for older adults with HIV going forward. In addition, we need to conduct longitudinal research on older adults with HIV to better understand the contribution of mental and health comorbidities to functional disability over time, as well as the interface between informal and formal systems of social supports to insure a decent quality of life for older adults as they age with HIV. In order to meet these service needs, policy makers and program planners should explore how older adults with HIV can engage the aging-services network so that they can be mainstreamed into existing programs. However, several obstacles to this exist, including raising awareness and increasing knowledge about aging and HIV among service providers, addressing stigma as a barrier to service in mainstream settings, and the concomitant pullback in aging service funding that has paralleled the loss of monies to support HIV/AIDS programs in the community.





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