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Falling Through the Cracks: Unmet Health Service Needs among People Living with HIV in Atlanta, Georgia

Seth C. Kalichman, Ph.D.[Professor],
University of Connecticut, Storrs CT

Charsey Cherry, M.P.H[Project Manager],
University of Connecticut, Storrs CT

Denise White, M.A.[Researcher Associate],
University of Connecticut, Storrs CT

Mich'I Jones, M.A.[Researcher Associate],
University of Connecticut, Storrs CT

Moirra O. Kalichman, M.S.W.[Project Manager],
University of Connecticut, Storrs CT

Christina Amaral, B.A.[Researcher Associate], and
University of Connecticut, Storrs CT

Connie Swetzes, L.P.N.[Researcher Associate]
University of Connecticut, Storrs CT

Abstract

Despite growing numbers of people living with HIV (PLWH), the landscape of related services is shrinking. This study investigated health and social service needs of men ($N = 489$) and women ($N = 165$) living with HIV in Atlanta, GA. Participants completed confidential measures asking about the health and social services they needed and accessed. Results showed an array of health and social service needs among PLWH; failure to access services was prevalent. Hunger was among the most common basic needs, reported by greater than 60% of men and women. For men, unmet service needs were associated with fewer years since testing positive for HIV, higher CD4+ T cell values, experiencing more stressors and depression, and greater quantity of alcohol use. For women, failure to access services was associated with experiencing depression and not receiving HIV medications. Providing basic services to PLWH remains a public health priority and moral imperative.

Keywords

access to services; HIV services; service needs

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More than 1.1 million people in the United States have been diagnosed with AIDS and there are more than 56,000 new HIV infections diagnosed in the United States each year (Centers for Disease Control and Prevention [CDC], 2007; Hall et al., 2008). HIV epidemics appear to have stabilized in some U.S. cities, while new infections are steadily increasing in others. Annual trends show that the southeastern United States, for example, experienced dramatic increases in new HIV infections over the past decade (El-Sadr, Mayer, & Hodder, 2010). More than half of new HIV infections in the United States occur in the south, and six of the 10 states with the highest number of AIDS cases are in this region (Kaiser Family Foundation, 2008). The rising trend in number of HIV infections detected will likely continue as HIV testing campaigns are expanded. Recent years have seen significant increases in programs to promote HIV testing, with two out of three U.S. health districts receiving increased CDC funding for HIV testing in fiscal year 2006–2007 and even greater investments in HIV testing in 2010 (National Alliance of State and Territorial AIDS Directors, 2010).

In addition to increased detection of new HIV infections, the growing number of people living with HIV (PLWH) is a product of improved HIV treatments. The trajectory of HIV disease has changed from a life threatening illness to a chronic condition (El-Sadr et al., 2010; Kumarasamy et al., 2010). Combination antiretroviral therapies (ART) for HIV infection have added years of longevity and improved the health of those infected with HIV. Deaths from AIDS have declined annually since 1996 when effective treatments first became available (HIV-CAUSAL Collaboration, 2010; Mugavero et al., 2007). Improvements in the prophylaxis and treatment of opportunistic illnesses are also responsible for more PLWH leading productive lives. The growing population of PLWH is, however, placing pressure on HIV-related health and social services.

Juxtaposed to the growing population of PLWH are shrinking HIV-related services. One study of service utilization by more than 2,100 consumers of HIV prevention and care programs in California showed a wide-range of services accessed, with some individuals receiving multiple services and others receiving none. Similar to previous research (Lo, MacGovern, & Bradford, 2002), Fisher and colleagues (2010) found that accessing and utilizing HIV-related services was related to receiving ART.

Although U.S. federal funding for HIV services, provided primarily through Medicare and Medicaid, increased from \$3 billion in 1990 to \$27 billion in 2010 (Kaiser Family Foundation, 2010), medical care for PLWH accounts for most of the increases. However, a third source of federal funding for HIV care comes through the Ryan White CARE Act, enacted in 1990 to expand HIV social and supportive services. Ryan White funding has not seen the same level of investment as Medicaid and Medicare. For example, funding for Medicaid increased 41% from \$3.6 billion in 2002 to \$5.1 billion in 2010, whereas Ryan White funding in 2002 was \$1.9 billion and rose 21% to \$2.3 billion in 2010 (Kaiser Family Foundation, 2009, 2010). In fiscal year 2009, 45% of HIV programs experienced decreased funding and 64% of states expected the decline to continue. Receding resources are placing increased pressure on services that are needed for a growing population of PLWH. Identifying individuals who lack access to HIV services will help project actual service needs and prioritize use of limited resources.

The purpose of this study was to examine the HIV service needs, access, and utilization of PLWH in Atlanta, Georgia. Atlanta has more than 23,000 reported cases of AIDS and an HIV and AIDS rate of 23 per 100,000 population; exceeding the average 15 per 100,000 population in other major U.S. cities. The poverty rate in Atlanta is 21% compared to the state of Georgia's 13%. Twelve percent of Atlanta's residents have incomes below 50% of the poverty level. Joblessness in the state of Georgia consistently exceeds U.S. national

unemployment rates (Boston, 2008). In this study, service needs and services accessed were reported from a community sample of PLWH. We mapped identified needs onto existing services to examine gaps. We also examined psychosocial characteristics of the sample such as stress, depression, and substance use as correlates of unmet service needs.

Methods

Participants

Four hundred and sixty-nine men, 165 women, and 20 male transgender PLWH were recruited to participate. We used both targeted venue and snowball sampling techniques to identify individuals in and out of care. Recruitment relied on responses to brochures placed in waiting rooms of HIV service providers and infectious disease clinics throughout Atlanta as well as an explicit systematic approach to word-of-mouth chain recruitment. Specifically, participants were given study brochures and encouraged to refer their HIV-infected friends to the study. These procedures were designed to extend recruitment beyond service settings in order to achieve a broad community sample.

Interested persons contacted our research program to schedule an intake appointment. The study entry criteria were age 18 years of age or older and proof of positive HIV status using a photo ID and either a matching ART prescription bottle, HIV clinic card, positive HIV test result, lab report, or any other proof of HIV status. Participants received \$25 for completing the study measures, which required approximately 1 hour. Data were collected during September 2008 to November 2009 and all procedures were approved by the University of Connecticut Institutional Review Board.

Measures

Measures were collected using an instructor-guided self-administration procedure in groups of four to eight persons. Participants were shown, page by page, how to complete the study measures by using a projected facsimile of the instruments, assuring that instructions for all measures were carefully described and that participants were given privacy to minimize demand characteristics and response biases. Participants who requested assistance reading the measures were interviewed (< 10%) and their data were included in the analyses.

Demographic characteristics—Participants were asked their gender, sexual orientation, age, years of education, income, ethnicity, employment status, and other demographics. We also assessed insurance status by asking participants if they (a) paid for their own medical coverage or received insurance through work (private); (b) received medical care paid for by the government or state, such as Medicaid, Medicare, or drug assistance (public); or (c) whether they did not have any means of paying for their medical care (uninsured).

Stress, depression, and alcohol use—Our measure of HIV-related stress was adapted from previous studies of mental health and HIV (Leserman et al., 1999). Fourteen stressors were responded to with respect to the amount of stress each caused the participant in the previous 6 months, using a 3-point scale (0 = *did not occur/caused no stress*, 1 = *a little stress* and 2 = *quite a bit of stress*). Example stressors included going on disability, serious illness, discrimination and stigma experiences, starting a new treatment, and financial problems. An HIV-related stress index was calculated by taking the sum of responses. Scores ranged from 0 to 28, and the stress index was internally consistent ($\alpha = .83$).

Depression symptoms were assessed using 10 items reflecting cognitive and affective symptoms of depression. Items were drawn from the Centers for Epidemiological Studies Depression Scale (CESD; Kalichman, Rompa, & Cage, 2000a; Radloff, 1977). Participants

were asked how often they experienced specific thoughts, feelings, and behaviors in the previous 7 days (responding 0 = *no days*, 1 = *1–2 days*, 2 = *3–4 days*, 3 = *5–7 days*). Scores ranged from 0 to 30 ($\alpha = .85$).

To assess alcohol use participants completed the first two items of the Alcohol Use Disorder Identification Test (AUDIT), a self-report instrument designed to identify individuals for whom the use of alcohol places them at risk for developing alcohol-related problems. The first two items of the AUDIT represent a standard index of frequency and quantity of current alcohol use (Conigrave, Hall, & Saunders, 1995).

Basic survival needs—Participants reported their personal needs for housing, food, and transportation. Housing concerns were assessed by asking participants if they had current concerns about having a place to sleep at night. To measure food insufficiency and hunger we used five indicators derived from the U.S. Food Security Scale (Cook & Frank, 2008), a measure validated in past research in U.S. urban settings. Items focused on food anxiety, meal quality, and food sufficiency in the previous 6 months. For transportation needs, participants reported if they were able to get where they needed to go and whether they were able to get to a clinic or doctor. Housing, food, and transportation items were scored dichotomously for each experience in the previous 6 months. (Items shown in Results section.)

Service needs and service utilization—Participants were asked whether they required assistance and received services for 12 needs. Access and utilization of services were assessed within three major domains: basic survival needs (i.e., housing, food, transportation services), mental health services (i.e., counseling, treatment for depression, substance abuse treatment), and supportive services (i.e., adherence counseling, social support, spiritual guidance). We included basic survival needs in this assessment, but in this case participants indicated whether they required and received services for those needs. Unmet service needs were defined by participants indicating that they were unable to access services that they said were needed in each domain. An index was created by summing the number of unmet service needs.

Participants also indicated whether they received services for housing, food, transportation, support groups, case management, and other needs from 45 HIV service providers in Atlanta. Specifically, we located providers using a comprehensive directory of HIV services in Atlanta and asked participants if they had received services from each agency in the previous 6 months. We also contacted each provider to determine whether they were still operating at the time of the study.

Participants were also asked to rate their overall access to services using two items. First, participants indicated whether they were able to get the services they needed by marking one of three options: *I am able to get the services I need*, *I am able to get some but not all of the services I need*, and *I am not able to get the services I need*. The second item concerned perceptions of HIV services in Atlanta using three response options: *There are fewer services available to me than in the past*, *There are just as many services for me to access now as ever*, and *There are more services available to me now than ever before*.

Health characteristics—We assessed a broad range of health parameters. HIV-related symptoms were measured with a previously developed instrument concerning experience of 14 common symptoms of HIV disease (Kalichman, Rompa, & Cage, 2000b). Participants also indicated whether they had ever been diagnosed with an AIDS-defining condition and their most recent CD4+ T cell count and viral load. Participants reported whether they had been hospitalized for HIV-related health problems and if they ever or currently were taking

ART. Participants receiving ART were asked to complete a self-report adherence visual analogue rating scale to assess ART adherence in the previous month. The adherence visual analogue scale has demonstrated excellent concurrent validity with objective measures of adherence (Bangsberg, Hecht, Charlebois, Chesney, & Moss, 2001; Giordano, Guzman, Clark, Charlebois, & Bangsberg, 2004; Kalichman et al., 2009).

Data Analyses

Because transgender persons represented fewer than 3% of the sample and were biologically male we included them with men for all subsequent analyses. Descriptive analyses comparing men and women were performed on demographic, health, needs, and service utilization characteristics. Gender comparisons on continuous measures used independent t-tests and categorical variables were analyzed with contingency table chi-square tests. To examine independent predictors of unmet service needs, we conducted multiple regression analyses, entering key demographic and health characteristics, stressors, depression, and alcohol use as predictors of unmet service needs separately for men and women and for the entire sample.

Results

The characteristics of persons in the study are shown in Table 1. The majority of participants were African American men with between 11 and 12 years of education. Most participants were unemployed and receiving disability benefits. While a majority of participants reported receiving public or private health benefits, one in five women and two in five men stated they had no medical insurance. Men and women differed in their health status, which can affect access to services reserved for PLWH. On average women had higher CD4+ T cell counts, although they also experienced more HIV-related symptoms and were more likely to have been diagnosed with an AIDS-defining condition. Nearly three of four participants were taking ART, with an average of 80% adherence. Drinking alcohol was common in the sample, with men reporting greater current frequency and quantity of alcohol use than women. However, men and women did not differ on measures of stress and depression.

Basic Survival Needs

Table 2 shows men and women's basic survival needs in the previous 6 months. Men were significantly more likely to indicate housing concerns than women, with more than half of men worrying about having a place to stay compared to 41% of women. Food insufficiency and hunger were frequently reported by both men and women, with greater than 60% of men and women stating that they had run out of food and one in four reporting that they had to choose between buying food and paying for medicine in the previous 6 months. Transportation needs were also common, with more than half of participants unable to get where they needed to go, and one in three unable to get to a clinic.

Service Utilization and Perceived Service Needs

Services accessed by PLWH in the previous 6 months are shown in Table 3. Nearly half of participants reported accessing services for basic survival needs of housing, food, and transportation. Men and women had similar experiences accessing services to meet basic survival needs. Ten percent of participants indicated that they were unable to obtain housing and food services that they needed.

A similar pattern of access was observed for mental health services. The majority of participants received mental health counseling, but 10% were unable to do so. A greater proportion of participants received substance abuse treatment than mental health care, with fewer participants unable to access substance use services. Other services varied in their

accessibility, with social support services, assistance with discrimination, and legal aid being among the more difficult services to access. Overall, 43% of men and 37% of women indicated that they had received at least one non-medical health and social service in the previous 6 months. The only significant difference between men and women on service access was for social support services, where men were less likely to access social support services than women.

More than 80% of men and women received services from HIV service providers (see Table 4). Two thirds of participants indicated that they were able to get all of their service needs met while only a small number, less than 7%, could not access any services they needed. One third of participants believed that there were fewer services available now than in the past, with about as many participants indicating that more services have become available. Our attempt to verify whether agencies were still in business at the end of the study found that 5 of the 45 agencies had closed since the start of data collection.

Correlates of Unmet Service Needs

Analyses examined key demographic, health, emotional, and alcohol use characteristics in relation to the number of services participants needed but were unable to access. Results of the multiple regression analyses predicting number of unmet service needs, separate for men and women and for the total sample, are shown in Table 5. For men, a greater number of unmet service needs was associated with fewer years since receiving a positive HIV test, higher CD4+ T cell values, greater stressors and depression and greater quantity of alcohol use ($F[12, 475] = 15.76, p < .001, R^2 = .26$). For women, a greater number of unmet service needs was associated with not receiving HIV medications and greater depression ($F[12, 152] = 4.08, p < .001, R^2 = .18$). For the total sample, results showed that fewer years since testing HIV positive, greater stressors, and depression significantly predicted a greater number of unmet service needs ($F[12, 641] = 18.53, p < .001, R^2 = .24$).

Discussion

The current study identified a substantial need for support services among PLWH. Most significant were needs for basic day-to-day survival. More than half of participants had concerns about having a place to stay and were unable to access food. We also found that one in four had to choose between paying for food or medicine in the previous 6 months. Transportation needs were also great, with one in three persons reporting that they were unable to get to a clinic. Previous research has shown that beyond the obvious health threats brought by homelessness and hunger, unstable housing and food insufficiency are directly related to HIV-related health outcomes (Leaver, Bargh, Dunn, & Hwang, 2007; Weiser et al., 2003; Weiser et al., 2009). The most basic survival needs are often not those covered by HIV service organizations, pointing to a larger problem of unmet needs beyond PLWH. It should also be noted that our findings are likely underestimates of basic survival needs because we recruited participants through snowball sampling procedures, assuring that participants were connected to at least one other PLWH. Individuals living with HIV who are more isolated may be even less engaged in health and social services.

Participants who were receiving services reported a high degree of utilization, including programs provided by HIV organizations. The most frequently accessed services provided housing, food, and transportation. However, a concerning number of participants indicated needing basic survival services that they were unable to access. Overall, more than 40% of participants reported being unable to access services for basic needs, with many participants having multiple unmet service needs. In addition, 30% of participants believed that there were fewer services available now than in the past, a perception that is consistent with funding trends. We observed that 10% of service providers closed during the course of this

study. With current guidelines moving toward initiating HIV treatment immediately upon receiving a positive test for HIV, the demand for HIV-related social services should be expected to grow. It is reasonable to expect that unmet services will only worsen as resources shrink and the population of PLWH increases.

Among men, the number of unmet service needs was associated with fewer years since HIV diagnosis, higher CD4+ T cell counts, higher stress, depression, and consuming greater quantities of alcohol. For women, the number of unmet service needs was associated with not receiving HIV treatment and greater depression symptoms. These findings suggest that a lack of services occurs earlier in the course of HIV disease, perhaps prior to illness onset and treatment initiation. It is, therefore, crucial that social services identify potential points of engagement outside of medical care through outreach efforts. Recently diagnosed and untreated persons pose considerable challenges for service engagement because they are least likely to be connected to routine care. Stronger linkages are needed between HIV testing centers, HIV case management, and non-HIV-specific social services. Resources should be invested in onsite referrals, follow-up, and creating a social service safety net for individuals not yet receiving HIV treatment.

Our findings should be interpreted in light of their methodological limitations. Our measures, for example, relied entirely on self-report and may be biased toward socially desirable responses. The direction of self-report bias in this study is somewhat unknown as some participants may have under-reported needs and service access whereas others may have over-reported needs and access. In any case, caution should be taken when interpreting the relative prevalence of service utilization and unmet service needs. We did not assess barriers and facilitators to accessing services. How participants become aware of and obtain services was also not covered in our assessment. In addition, our study was conducted in one city in the southeastern United States and may therefore not generalize to other cities and regions. Finally, the landscape of HIV services is rapidly changing, suggesting that the current findings will require replication over time as well as different locations. With these limitations in mind, we believe that the current findings have implications for planning services for PLWH.

Clinical Considerations

As programs commence to test entire populations of people at risk for HIV, policy makers must address the crisis of shrinking social and basic human services. Unstable housing and insufficient food interfere with service engagement, HIV treatment adherence, and health outcomes. Therefore, it remains a public health priority, as well as a moral imperative, to provide an array of basic services that meet the survival needs of people who test HIV positive. Transportation, mental health services, and substance abuse treatment are needs that cannot be neglected. The shrinking horizon of HIV services will place greater demands on an already overtaxed social service system. Cities most burdened by HIV will likely face the greatest crises in care. There remain significant perceived and actual barriers to engaging people in HIV care including stigma, discrimination, and marginalization (Mallinson, Rajabiun, & Coleman, 2007). Better approaches to integrating services and reducing costs for comprehensive care are needed if the growing population of PLWH is to receive even the most basic of services.

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Table 1

Demographic and health characteristics of men and women living with HIV

	Men (N = 489)		Women (N = 165)		<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Age	44.6	7.8	46.3	7.8	2.3*
Years Education	12.6	2.0	11.6	1.8	5.8**
Years since positive HIV test	12.7	6.9	11.8	5.8	1.5
CD4+ T cell count	404.6	261.9	543.7	395.7	4.4**
HIV symptoms	4.2	3.7	5.1	3.7	2.6**
Percent medication adherence	78.5	33.5	83.2	29.3	1.3
Stress index score	6.0	5.1	6.0	5.3	0.1
Depression score	8.5	6.2	8.7	6.2	0.3
<hr/>					
	<i>N</i>	%	<i>N</i>	%	χ^2
<hr/>					
Ethnicity:					
African American	442	90	154	93	
White	27	6	9	6	
Latino	20	4	2	1	3.3
Income					
< \$10,000	335	69	130	78	
\$11–20,000	111	23	23	14	
> \$21,000	39	8	12	8	6.9+
Sexual orientation:					
Gay	254	52	3	2	
Bisexual	76	16	9	6	
Heterosexual	157	32	151	93	181.7**
Employment:					
Unemployed	136	28	35	21	
Employed	50	10	10	6	
Disabled	270	56	111	68	

	Men (N = 489)		Women (N = 165)		t
	M	SD	M	SD	
Other	25	6	7	5	8.0
Insurance:					
Private	23	5	6	4	
Public	261	55	126	77	
Uninsured	192	40	32	20	25.2**
AIDS diagnosis	231	47	98	60	7.1**
Hospitalized for HIV	250	52	57	54	2.4
Currently taking ART	348	72	125	76	1.6
Viral load undetectable	249	69	92	74	0.8
Frequency of current alcohol use					
Never	201	41	105	64	
Monthly	81	16	21	13	
2-4 times/month	129	26	31	18	
2-3 times/week	52	10	6	4	
4+ times/week	26	5	2	1	29.1**
Quantity of current alcohol use (among drinkers)					
1-2 drinks	180	36	43	26	
3-4 drinks	72	15	8	5	
5-6 drinks	25	5	5	3	
7-9 drinks	3	1	0		
10+ drinks	10	2	2	1	32.3**

Note. ART = antiretroviral therapy;

+ $p < .10$,

* $p < .05$,

** $p < .01$

Basic survival needs identified for previous 6 months among men and women living with HIV

Table 2

Survival Need	Men (N = 489)		Women (N = 165)		χ ²
	N	%	N	%	
Housing					
Worried about having a place to stay	261	53	66	41	8.1**
Food insufficiency/hunger					
Ran out of food and could not get more	313	64	102	62	0.3
Had to choose between food and medicine	132	27	41	25	0.3
Worried whether food would run out before having money for more	334	69	109	66	0.4
Food bought did not last before having more money	318	65	101	61	0.8
Could not afford to eat balanced meals	300	61	98	59	0.2
Transportation					
Unable to get where I needed to go	283	58	85	52	2.0
Unable to get to a clinic when needed to	179	36	64	39	0.3

Note.

**
p < .01

Table 3
Basic service utilization in previous 6 months among men and women living with HIV

Need	Men (N = 489)		Women (N = 165)		X ²
	N	%	N	%	
Survival need services					
Housing					
Received any housing assistance	218	45	80	49	
Did not need housing assistance	204	42	73	44	
Unable to get housing assistance	66	14	12	7	4.6 ⁺
Food security					
Received any food assistance	235	48	70	42	
Did not need food assistance	201	41	81	49	
Unable to get food assistance	52	11	14	9	3.2
Transportation					
Received any transportation assistance	229	47	89	54	
Did not need transportation assistance	181	37	56	34	
Unable to get transportation assistance	79	16	20	12	2.9
Mental health needs					
Received mental health counseling	261	54	95	58	
Did not need mental health counseling	174	36	56	34	
Unable to get mental health counseling	53	11	14	9	1.6
Substance use treatment					
Received treatment	144	30	57	35	
Did not need treatment	331	68	103	62	
Unable to get treatment	13	3	5	3	1.6
Additional services unable to access					
Adherence counseling	21	4	7	4	0.1
Telephone access	53	11	14	2	0.7
Social support	70	14	16	10	2.3*
Spiritual support	21	4	6	3	0.1
Medical and insurance navigation	33	7	12	7	0.1

Need	Men (N = 489)		Women (N = 165)		X ²
	N	%	N	%	
Help with discrimination	44	9	17	11	0.3
Legal aid	63	13	15	9	1.6
Total number of services unable to access					
0	279	57	104	63	
1	71	15	18	11	
2	41	8	15	9	
3	33	7	14	9	
4+	65	14	14	9	4.8

Note.
+ $p < .10$,
* $p < .05$

Table 4
AIDS Service Utilization and Perceived Access Among Men and Women Living with HIV

Need	Men (N = 489)		Women (N = 165)	
	N	%	N	X ²
Supportive services received from HIV service providers				
In Previous 6 months				
Food	179	37	62	38 0.1
Housing assistance	198	41	60	36 0.9
Transportation services	116	23	42	26 0.7
Support groups	167	34	68	41 2.6 ⁺
Case management	230	47	88	53 1.9
Other services	279	57	98	59 0.2
Any Services	400	82	133	81 0.1
Availability of services				
Fewer services are available	158	32	48	29
The same services are available	197	40	55	34
More services are available	133	27	60	36 5.4 ⁺
Perceived access to services				
Able to get services needed	310	64	110	68
Able to get some but not all services	148	30	44	27
Not able to get any services	30	6	11	7 0.8

Note.

⁺ p < .1

Table 5
Multivariate Regression Analyses Predicting Number of Basic Services Unable to Access in Previous 6 Months

Predictor	Men			Women			Total		
	β	t		β	t		β	t	
Age	0.01	0.07		-0.07	1.06		-0.02	0.75	
Education	0.03	0.90		0.09	1.29		0.05	1.6	
Years since testing positive for HIV	-0.13	3.05**		-0.07	1.02		-0.10	2.89**	
T-cell count	0.09	2.14*		-0.09	1.23		0.02	0.71	
Viral load	0.01	0.35		-0.01	0.02		0.01	0.33	
HIV symptoms	0.06	1.34		0.08	0.87		1.15	0.24	
AIDS diagnoses	-0.01	0.34		-0.04	0.57		-0.01	0.37	
Receiving HIV treatments	-0.03	0.72		-0.17	2.26*		-0.06	1.70	
Stressors	0.18	3.74**		0.90	0.91		0.17	3.89**	
Depression	0.34	7.36**		0.26	2.94**		0.33	8.05**	
Frequency of alcohol use	-0.08	1.54		0.05	0.47		-0.06	1.34	
Quantity of alcohol use	0.11	2.00*		0.09	0.89		0.08	1.68	

Note.

* $p < .05$,

** $p < .01$