Psychosocial and Service Use Correlates of Health-Related Quality of Life among a vulnerable population living with HIV/AIDS

Mary M. Mitchell[1], **Trang Nguyen**[2], **Sarina Isenberg**[1], **Allysha C. Maragh-Bass**[3], **Jeanne Keruly**[4], and **Amy R. Knowlton**[1]

[1]Johns Hopkins Bloomberg School of Public Health, Department of Health, Behavior and Society, Baltimore, MD

[2]Johns Hopkins Bloomberg School of Public Health, Department of Mental Health, Baltimore, MD

[3]Harvard School of Medicine, Harvard School of Public Health, Center for Surgery and Public Health, Department of Surgery, Brigham and Women's Hospital, Boston, MA

[4]School of Medicine, Division of Infectious Diseases, Baltimore, MD

Abstract

Among people living with HIV/AIDS (PLHIV), health-related quality of life (HRQOL) is an important clinical metric of perceived well-being. Baseline data from the BEACON study (N=383) were used to examine relationships between HRQOL and negative social support, HIV-related stigma, viral suppression, and physical and mental health service use among a vulnerable population of low-income, urban PLHIV who currently or formerly used substances, and were primarily African American. Factor analyses and structural equation modeling indicated that increases in negative social support, stigma, mental health care visits and HIV physician visits were associated with lower HRQOL, while viral suppression was associated with greater HRQOL. The association between negative social support and HRQOL suggests the importance of intervening at the dyad or network levels to shape the type of social support being provided to PLHIV. HIV-related stigma is another negative social factor that is prevalent in this sample and could be addressed by intervention. Results indicate that greater mental and physical health service use can be used to identify individuals with lower HRQOL. Therefore, findings increase an understanding of HRQOL in this understudied population and have implications for designing interventions to improve HRQOL among PLHIV.

Correspondence concerning this article should be addressed to: Dr. Mary M. Mitchell, Johns Hopkins Bloomberg School of Public Health, The Lighthouse, 2213 McElderry Street, 2nd Floor, Baltimore, MD 21205; Phone (410) 502-9552; Fax (410) 502-5385; mmitch32@jhu.edu.

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All of the authors declare that they have no conflicts of interest.

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Keywords

health-related quality of life; HIV/AIDS; African American or Black; drug use disorder; HIV-related stigma; negative social support

INTRODUCTION

Among people living with HIV/AIDS (PLHIV), health-related quality of life (HRQOL) is an important metric of perceived well-being and merits research attention to its correlates among vulnerable populations. HRQOL has been conceptualized as a global assessment of the effects of health conditions on the whole person, and is especially important for understanding well-being among persons with multiple chronic conditions, such as older populations and PLHIV. HRQOL is the most widely used construct employed to assess subjective health among patients with chronic illness. [1,2] For patients with HIV, biological markers of immune status, namely serum viral load, are often the metrics of major focus in clinical care.

Most measures of HRQOL include mental and physical dimensions of an individual's response to illness signs and symptoms and other aspects of the lived experience of the health condition, rather than focusing exclusively on the physical process of disease. [3] The most widely used HRQOL scales tend to include items regarding general health perceptions, physical functioning, bodily pain, mental health, and social role functioning. [4–6] HIV can have detrimental effects on psychological and physical domains of HRQOL due to direct illness signs and symptoms and potential toxicities of treatments, [7] and due to how people respond to someone living with the virus. Understanding HRQOL is particularly important among PLHIV who are often coping with co-morbid conditions that are highly stigmatized.

Correlates of health-related quality of life

While it is well established that HRQOL is associated with positive social support, [8] less is known about the relationship between negative social support and HRQOL among PLHIV. However, negative support has a greater impact than positive support on psychological and physical health in the general population and likely among PLHIV. [9–11] Negative support has been conceptualized as negatively interpreted or unsupportive behaviors (such as criticism, anger) from supportive others. [11,12] A study by Oetzel and colleagues [13] revealed significant positive associations between HRQOL and positive social support, and, importantly, significant negative associations between HRQOL and a measure of negative support, defined as social undermining, which is expressing disapproval or not valuing the person.

Stigma has also been associated with HRQOL and its dimensions of physical and mental health in PLHIV. Stigma often causes distress because others blame the PLHIV for becoming infected and disapprove of the behaviors that led to HIV infection. [14,15] Stigma among PLHIV has been associated with depressive symptoms [15] and overall quality of life. [16,17]

While depression and HIV/AIDS-related physical signs and symptoms are associated with HRQOL, it is not clear from the prior research the degree to which mental health care or HIV primary care clinic attendance are related to HRQOL. [18,19] Health services use may be proxy measures for mental and physical health status, which are among the primary dimensions in HRQOL.

Few studies have investigated HRQOL among disadvantaged, primarily African American PLHIV with current or former substance use. Furthermore, few studies have examined psychosocial factors as correlates of HRQOL, including HIV-related stigma, negative support provided by social network members, and mental and physical health service use.

The objective of the present study was to examine relationships between HRQOL and psychosocial variables, including social support and stigma; service use; and viral load among a highly vulnerable population of low-income urban PLHIV who currently or formerly use substances, and are primarily African American. Specifically, we hypothesized that having more negative social support, HIV-related stigma, and greater mental and physical health service use would have negative associations with HRQOL, while viral suppression would have a positive association. While previous studies have investigated relationships between social support and stigma with HRQOL[13,16,17], there is no research, to our knowledge, that examines relationships between physical and mental health care service use with HRQOL. Therefore, the analyses of relationships between service use and HRQOL were more exploratory in nature, rather than confirmatory, and likely were proxies for level of physical and mental wellness. It is important to not only increase our understanding of the correlates of HRQOL in this population, but also to understand the significance of both individual-level and network-level factors associated with HRQOL. Therefore, investigating HRQOL among PLHIV may increase the ability to design better interventions to increase HRQOL, regardless of HIV disease status.

METHOD

Procedure

Data were from the baseline survey of the BEACON (Being Active and Connected) study, which examined social environmental factors associated with health outcomes and well-being among disadvantaged PLHIVs and their informal caregivers. PLHIV were recruited from an academic hospital and community venues. Selection criteria included: HIV seropositive adult on antiretroviral treatment (ART); Baltimore City resident; having a history of injection drug use; and willingness to invite a main supportive person or caregiver to participate in the study. All PLHIV completed informed consent and were given $35 for survey participation. Survey items were administered both by Computer-Assisted Personal Interview (CAPI) and Audio Computer-Assisted Self-Interview (ACASI). The study on which this manuscript is based is fully approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Measures

Outcome—The BEACON study assessed HRQOL by gathering data on general health perceptions, physical functioning limitations, social functioning, emotional health, and pain, which were 5 of the 8 domains that were measured by Hays and colleagues in the HIV Costs and Utilization Survey.[20] These domains included general health, physical functioning, social functioning, pain, emotional well-being, energy, and disability. The BEACON study contained three items that measured general health and social functioning; four items measuring physical functioning; an item measuring pain; and 20 items measuring emotional well-being. The general health and social functioning items in the BEACON study were taken from the SF-36, SF-12 and SF-8,[4,5,21] namely general health rating (from 1 = poor to 5 = excellent) and two items assessing the degree to which physical and mental health problems interfered with social functioning (0 = a lot to 2 = not at all). Physical functioning was included in the HRQOL latent factor and measured by four items such as, "How much does your health affect your ability to…bend, lift, or squat," with response options from 0 = a lot to 2 = not at all. Chronic pain was measured based on a single item from the Memorial Symptom Assessment Scale- Short Form, "In the past 6 months, how often have you been bothered by pain" (0 = often/always versus 1 = sometimes/never). [22–24] Mental health status was assessed by the Center for Epidemiologic Studies - Depression (CES-D-20) scale. [25]

Although we did not use a standard quality of life measure, we have construct validity because the measures that we used were the same as measures used in previous HRQOL scales. For example, we used measures from the Medical Outcomes Study Short Form HRQOL survey, which is a widely used scale (SF-36) that has shown validity in the shorter versions (e.g., SF-12, SF-8). Our items also matched those used in the HIV Costs and Utilization survey. From the theoretical and conceptual literature on HRQOL, our items assess the primary domains of HRQOL, including general health and well-being; physical and mental health; pain; and social functioning.

Independent Measures—Negative support, which was defined as either too little support or conflictive support, was measured with ten items from the Social Exchange Scale [11] (e.g., "In the past 30 days, how often did someone you know let you down when you needed help?" with response options from 0 = most or all of the time to 2 = rarely or none of the time). HIV stigma was measured by six items (e.g., "Thinking about having HIV, how much do you fear you will lose your friends?"), with response options 0 = very much to 3 = not at all, which were measures developed for the SAIL study.[26] Recent mental health care or treatment was measured with the item, "In the past year, have you received any counseling, therapy, or medication for your nerves or any emotional problems, not including drug treatment?" Number of HIV medical visits was measured by, "In the past 6 months, how many primary healthcare visits for HIV or AIDS have you had?" HIV primary care was defined as "a visit to a doctor or nurse to have a checkup during which you may have discussed HIV medications, had your blood drawn, or talked about your blood test results." [27] Viral load was measured by the Roche Cobas Amplicor and values were dichotomized with undetectable (<50 copies per mL) = 1 versus detectable (50 copies per mL) = 0. [28]

Data Analysis—Frequencies of demographic and independent variables were run in SPSS 22.0. [29] For constructs measured with multiple items, exploratory factor analysis with oblique rotation was conducted in Mplus[30] to determine the optimal number of factors for each construct. For the HRQOL factor, second-order confirmatory factor analyses were conducted, due to the second-order factor structure of the physical functioning factor being loaded on the overall HRQOL factor. A correlation matrix was constructed to present the bivariate associations among all of the manifest variables and latent factors. A structural model was fit in Mplus[30] and, in the case of lack of fit, modification indices were used to explore whether theoretically sound modifications would improve the fit of the model.

RESULTS

The majority of the PLHIV sample was male (61.4%), had a high school education or less (83.8%), and earned less than $1,000 per month (79.9%)(Table 1). Approximately two-thirds had used substances in the past 6 months (63.3%) and were virally suppressed (70.7%). Nearly all of the respondents (95.6%) reported at least some stigma on one or more of the HIV stigma items (Table 2).

Exploratory factor analyses, used to fit the negative support, stigma, and physical functioning latent factors, achieved adequate factor loadings of the measured variables on each of their respective factors (Table 2). Loadings ranged from .50 to .79 for negative support, .56 to .87 for stigma, and .83 to .94 for physical functioning. Reliability for the factors is reflected in the factor loadings for the indicator variables. Each of the factors including negative social support (Confirmatory Fit Index [CFI] = .97, Tucker Lewis Index [TLI] = .96, Root Mean Square Error of Approximation [RMSEA] = .07 [.05, .09]), stigma (CFI = 1.00, TLI = 1.00, RMSEA = .09 [.06, .12], and physical functioning (CFI = 1.00, TLI = 1.00, RMSEA = .06 [.00, .13] achieved good model fit.[31] Bivariate correlations between latent factors and measured variables indicated significant correlations were between HRQOL and each of the predictors (all p's < .001)(Table 3). In addition, a sizable correlation (r = .46, p < .001) existed between negative support and stigma.

Due to the second-order factor structure of the HRQOL factor, a confirmatory, rather than exploratory, factor analysis was run with five measured indicator variables and one latent factor for physical functioning limitations. Loadings ranged from .48 to .88 and the HRQOL factor achieved good fit (CFI = .98, TLI = .98, RMSEA = .07 [.06, .09]).[31] The loadings provide statistical support for the reliability of the HRQOL factor.

After fitting the measurement model, we ran a structural equation model regressing the HRQOL factor on factors for negative social support and stigma, and on measured variables for number of mental health visits, number of HIV visits, and viral suppression. Examination of modification indices led to adding residual correlations between four variable pairs (ie., reduced social functioning due to physical limitations with bending down, depressive symptoms, and reduced social functioning due to mental health; and between pain and moderate exercise) in order to improve the fit of the measurement model. The resulting model achieved good fit (CFI = .95, TLI = .94, RMSEA = .04 [.04, .05].[31] HRQOL was negatively associated with negative social support, stigma, mental health care

usage, and HIV primary care visits. HRQOL was positively associated with viral suppression (Figure 1). The predictors explained 50% of the variance in the HRQOL factor.

DISCUSSION

Our findings revealed interpersonal- and network level factors that were associated with HRQOL among vulnerable PLHIV, above and beyond viral load, an individual factor emphasized in the literature. We identified two latent factors, namely, HIV-related stigma and negative social support, which were associated with reduced HRQOL. Our study results suggest the importance of intervention at the dyad and network levels that use psychosocial approaches to enhance mental and physical health outcomes among this vulnerable population.

Our findings contribute to the conceptual and methodological understandings of contextually specific aspects of the social environment that represent social risks to a vulnerable, chronically ill population's HRQOL. Indeed, it goes beyond previous social support literature that tends to conceptualize social support as invariably positive and operationalizes it simplistically; most often as perceived availability of emotional support. [32,33]

Interestingly, we found that negative aspects of the social environment, namely negative social support and stigma, had some of the strongest associations with HRQOL, as did recent mental health care. These findings are consistent with prior literature indicating that negative as compared to positive experiences or events have greater associations with mental health, which is the negativity effect. [34] Indeed, stronger associations have been found between negative constructs and low HRQOL than between positive constructs and high HRQOL. [13]

Social support is an important factor in preventing morbidity and mortality and an be strengthened in this population of PLHIV, most of whom have informal caregivers. However, some of the relationships between PLHIV and their caregivers can be strained due to drug use and other stressors common in this marginalized population, such as stigma and low socioeconomic status. Therefore, it is important to examine the effects of negative social support as a focus of intervention to potentially improve HRQOL.

Considerable research attention has established adverse effects of perceived (internalized) HIV-related stigma on HIV health outcomes. Our results suggest that stigma was highly associated with but distinct from negative interactions with caregivers and ostensibly supportive others as well as mental illness, indicated by mental health service use. This is consistent with the literature on social pain, defined as the emotional response to the perception that one is being excluded, rejected or devalued by a significant individual or group.[35] For the study population, multiple stigmas from drug use, poverty, and disability, in addition to HIV, may covary with negative social interactions and perceptions of the social environment. Indeed, HIV-stigma is common in this population with nearly all of the respondents (95.6%) reporting at least some stigma on one or more of the stigma items in our study, which makes this construct particularly salient to our sample of PLHIV. Previous research has found that stigma is associated with poorer mental health[36], and depression in

particular, which is one of the measures in our HRQOL factor. Therefore, it is reasonable that the stigma and HRQOL constructs would be associated in our study. However, further research is merited on support networks and caregiving relationship dynamics on HIV health outcomes in vulnerable populations and ways to promote effective caregiving and network functioning as a way to improve PLHIVs' HRQOL.

Our study indicated that negative support was associated with lower HRQOL. For example, PLHIV reporting that supportive others' "meddled" in their affairs, offered unwanted advice, or were critical or irritating, have been found to be associated with negative psychological outcomes. [37,38] Our study suggests that dyadic- or network-focused interventions to promote support exchange and the social skills required may help ensure network members' provision of support matched to the type of support needed.

Results indicated that primary care visits were important to include in the model, as this variable was expected to covary with the HRQOL construct, which was comprised of both mental and physical health indicators. Primary care visits were relatively high in this sample, given that it is recommended that PLHIV have at least one HIV visit in the previous 6 months, while sample members had 3.7 visits on average in the past 6 months. This could be an indicator of good access to care, but it could also be an indicator of having more physical health problems, which would likely be associated with HRQOL.

Findings also indicated that mental health problems were prevalent in this disadvantaged population of PLHIV with a sizable proportion of the sample (49.3%) having sought mental health care services in the past year. Due to the number of sample members coping with mental health issues, this was a salient variable to include in the model that further describes the important correlates of HRQOL. Our substantial R-square value (.50) suggests that we were able to include important correlates of HRQOL that explained a great deal of variance in the outcome.

Limitations

We chose to use a universal measure of HRQOL rather than an HIV-specific measure that includes illness symptomology. While the Medical Outcomes Study measures are widely used, [39] they may not adequately assess the level of burden and hardship that impact physical and mental health as a result of HIV/AIDS. Our outcome variable did not include items on vitality or pain interference with regular or occupational activities as included in standard measures of HRQOL; [4,5,21,40] rather, our measure emphasized physical and emotional health interference with social activities (i.e., social functioning), and multiple components of psychological symptoms (CES-D), including social and somatic symptoms. However, the model fit and congruence of our findings with previous literature on HRQOL in PLHIV support the validity of our HRQOL measure for the study population and the factor loadings support the reliability of the indicator variables that loaded on the latent factors. In addition, the second order HRQOL factor has better psychometric properties than summed measured variables, which have measurement error that can attenuate associations with correlated variables. Another limitation is that our data are cross-sectional, which precludes conclusions regarding the causal direction of associations. Prospective studies are needed to identify additional antecedents and mediators of HRQOL. Furthermore,

generalizability of the findings to other former or current drug using PLHIV may be limited as most of the sample was recruited from an academic clinic and the entire sample reported engagement in HIV care and treatment.

Conclusions

Our research adds to the scientific study of the HRQOL of a vulnerable PLHIV population. Our study advances the investigation of HRQOL by elucidating complexities of social environmental factors involved in HRQOL among vulnerable persons with serious chronic conditions. Our findings indicate that social and structural factors are associated with HRQOL above and beyond the effects of viral load emphasized in the HIV HRQOL literature.

HRQOL was correlated with negative aspects of the social environment. These results suggest the importance of interpersonal and network-oriented intervention approaches to promoting the study population's HRQOL by improving their network support, and reducing HIV-related stigma and negative support perceptions. Such interventions are especially indicated for persons who often use physical and mental health services and those with a detectable viral load.

Acknowledgments

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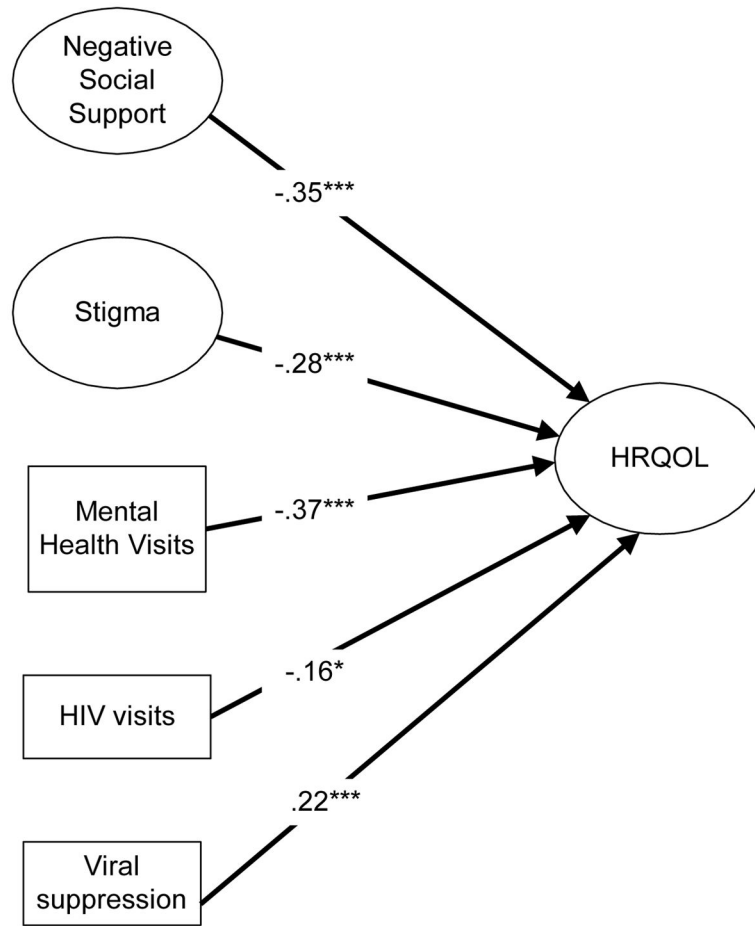
Figure 1.
Negative social support, HIV-related stigma, health service use, and viral suppression associated with health-related quality of life among former or current drug using persons living with HIV/AIDS. (Beacon Study; N = 383).

$R^2 = .50$.

Model fit: CFI = .95, TLI = .94, RMSEA = .04, 90% CI = .04, .05.

$* p < .05, *** p \quad .001$.

Table 1

Sample demographic characteristics for PLHIV (N = 383) in the BEACON study.

Variable	N (%) or Mean (SD[a])	Range
Sex (male)	235 (61.4)	
Education (High School/GED or less)	321 (83.8)	
Income (< 1,000 per month)	306 (79.9)	
Race/ethnicity (African American/Black)	329 (85.9)	
Current substance use	243 (63.3)	
Age	48 (6)	28–63

[a]SD = Standard Deviation

Table 2

Frequencies and means of measured variables and latent factor loadings (BEACON study; N = 383).

Latent Factors Health-Related Quality of Life[a]	Excellent	Very good	Good	Fair	Poor	Factor Loadings
General health	70 (18.3)	66 (17.2)	137 (35.8)	89 (23.2)	21 (5.5)	.48
	Not at all	**A bit**	**A lot**			
Physical health Interference	193 (50.4)	149 (38.9)	41 (10.7)			.88
Mental health interference	213 (55.6)	123 (32.0)	47 (12.3)			.72
Physical Functioning[b]	**Not at all**	**A bit**	**A lot**			.64
Bend, lift, squat	147 (38.3)	152 (39.6)	84 (21.9)			.83
Walk one block	212 (55.2)	126 (32.8)	45 (11.7)			.90
Walk uphill	115 (29.9)	154 (40.1)	114 (29.7)			.94
Moderate activities	135 (35.2)	169 (44.0)	79 (20.6)			.83
	Always/Often	**Some/Never**				
Pain, bothersome[€]	122 (32.4)	255 (67.6)				.62
	Mean (SD)	**Range**				
Depressive symptoms	14.3 (10.09)	0–51				.50
Negative Support[c]	**Rarely/none**	**Some/little**	**Most/all**			
Let you down	182 (47.4)	148 (38.5)	53 (13.8)			.61
Insufficient time	199 (51.8)	138 (35.9)	46 (12.0)			.65
Asked for too much	206 (53.6)	117 (30.5)	60 (15.6)			.50
Meddle in your affairs	191 (49.7)	138 (35.9)	54 (14.1)			.53
Leave you out	243 (63.3)	115 (29.9)	25 (6.5)			.68
Unwanted advice	162 (42.2)	157 (40.9)	64 (16.7)			.56
Forget or ignore you	221 (57.6)	137 (35.7)	25 (6.5)			.79
Thoughtless	205 (53.4)	141 (36.7)	37 (9.6)			.73
Angry, upset	189 (49.2)	162 (42.2)	32 (8.3)			.72
Not enough attention	204 (53.1)	142 (37.0)	37 (9.6)			.74

Latent Factors
Health-Related Quality of Life[a]

	Excellent	Very good	Good	Fair	Poor	Factor Loadings
Stigma, HIV[d]	Not at all	Just a little	Somewhat	Very much		
Need to hide HIV	186 (48.6)	90 (23.5)	69 (18.0)	38 (9.9)		.56
Others blame you	262 (68.4)	55 (14.4)	45 (11.7)	21 (5.5)		.71
HIV is a punishment	236 (61.6)	44 (11.5)	50 (13.1)	53 (13.8)		.56
Others uncomfortable around you	179 (46.9)	91 (23.8)	85 (22.1)	27 (7.0)		.63
Fear will lose friends	224 (58.5)	70 (18.3)	49 (12.8)	40 (10.4)		.87
Fear family rejection	317 (82.8)	23 (6.0)	27 (7.0)	16 (4.2)		.79
Measured Variables	Yes	No				
Mental health care[£]	189 (49.3)	194 (50.7)				
Viral load suppression	251 (70.7)	104 (29.3)				
	Mean (SD)	Range				
HIV clinic visits, no. [€]	3.7 (2.9)	1–23				

[a] Comparative Fit Index (CFI) = .98, Tucker-Lewis Index (TLI) = .98, Root Mean Square Error of Approximation = .07 [.06, .09].

[b] CFI = 1.00, TLI = 1.00, RMSEA = .06 [.00, .13].

[c] CFI = .97, TLI = .96, RMSEA = .07 [.05, .09].

[d] CFI = 1.00, TLI = 1.00, RMSEA = .09 [.06, .12].

[€] Prior 6 months;

[£] Prior year.

Table 3

Correlation matrix for all study latent factors and measured variables reported by persons living with HIV/AIDS who currently or formerly used drugs (BEACON study; N = 383).

		I	II	III	IV	V	VI
I	HRQOL	1.00	−.46***	−.46***	−.39***	−.22***	.05***
II	Negative Support		1.00	.46***	−.06	−.03	−.02
III	Stigma			1.00	.15*	.03	.02
IV	Mental health care				1.00	.14*	.02
V	HIV visits, no.					1.00	−.02
VI	Viral Load						1.00