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HIV-related stigma, depression, and social support are associated with health-related quality of life among patients newly entering HIV care

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Abstract

Entering HIV care is a vulnerable time for newly diagnosed individuals that necessitates frequent medical visits and initiation of life-long antiretroviral therapy (ART). At this time, there is potential to exacerbate psychosocial difficulties, such as depression and stigma. These psychosocial difficulties contribute to poor health-related quality of life (HRQOL) that in turn, may influence health behaviors including ART adherence, the driver of viral suppression. Understanding HRQOL in people newly entering HIV care is critical and has the potential to guide practice and research. This exploratory cross-sectional study examined demographic, clinical, and psychosocial factors associated with limitations in four specific domains of HRQOL (mobility, usual activities, pain, and depression/anxiety or mood) among persons initially entering outpatient HIV care at four sites in the United States (n = 335). In the unadjusted analysis, female gender was significantly associated with sub-optimal HRQOL with women having increased odds of reporting HRQOL challenges with pain, mood, mobility, and usual activity when compared to

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men. The adjusted models demonstrated attenuation of parameter estimates and loss of statistical significance for the associations with impaired HRQOL observed among women in unadjusted analyses, suggesting psychosocial factors related to HRQOL are complex and interrelated. Findings are consistent with a robust literature documenting gender-related health disparities. Programs aimed at improving HRQOL for persons initially entering HIV care are warranted generally, and specifically for women, and must address modifiable psychosocial factors such as stigma, via mechanisms including coping and social support.

Keywords

HIV/AIDS; Quality of life; EuroQOL; Engagement; stigma

Engagement in care is critical for persons living with HIV (PLWH) newly entering medical care with evidence supporting sustained retention and high-level adherence to antiretroviral therapy (ART) as strategies for decreasing morbidity and mortality rates (1–3). PLWH newly entering HIV care often have new or exacerbated psychological distress (e.g., depression and anxiety) and other psychosocial sequelae such as stigma and sub-optimal social support, which influence health-related quality of life (HRQOL) (4). HRQOL is defined as an individual’s perception of their overall physical and mental health (5). Inadequate social support, high levels of pain, high levels of perceived stigma, increased psychological distress, more recent HIV diagnosis, and poor physical functioning have been associated with worse HRQOL among individuals previously established in care (9–12). Additional factors associated with worse HRQOL include low CD4 T-lymphocyte count and high HIV viral load (VL), as well as increased age and female gender (8; 13; 14).

In the era of contemporary HIV management, assessment of HRQOL continues to be critical, particularly early in the trajectory of HIV medical treatment, a vulnerable time that portends long-term outcomes (6). Recent research examining the relationship between HIV and HRQOL has focused on individuals previous established in HIV care (9–12; 14–16), but little is known about newly diagnosed PLWH initiating HIV care. Understanding factors associated with HRQOL in PLWH initiating HIV care can assist providers in predicting care engagement and adherence, and aid researchers with developing targeted interventions. The primary goal of this study was to assess clinical and psychosocial factors associated with HRQOL among PLWH initiating outpatient HIV medical care.

Methods

Sample and setting

This analysis utilized baseline data from the integrating ENGagement and Adherence Goals upon Entry (iENGAGE) study (NCT1900236, 1R01AI103661) (17). iENGAGE was a randomized behavioral trial aimed to enhance timely and sustained VL suppression among PLWH initiating HIV care at four Center for AIDS Research (CFAR) Network of Integrated Clinical Systems (CNICS) clinical sites in the US (Alabama, Maryland, North Carolina, and Washington) (18; 19). For the purpose of this sub-study, we used baseline clinical and survey data from 335 of 372 study participants who met the following criteria: 1) identified as male or female; 2) identified as Black or White race. These criteria allowed for race and gender comparisons. These analyses did not include patients who self-identified as transgender due to small numbers (n=6).

Measures

Health-related Quality of life.

The outcome of interest was HRQOL measured by the EuroQOL, a validated instrument for measuring health status (20; 21). The EuroQOL instrument consists of 5-domains (EQ-5D), Mobility, Self-Care, Usual Activity, Pain/Discomfort, Depression/Anxiety, each assessed by a single question and analyzed separately (22; 23). For this study, we will refer to Depression/ Anxiety as Mood and Pain/Discomfort as Pain. Response options (none, moderate, and severe) were collapsed into a binary variable with categories of “none” and “moderate to severe”, a common way to analyze EuroQOL (9).

Depression.

Measured using the 8-item Patient Health Questionnaire (PHQ-8), characterizes depressive symptoms experienced by participants over the past 2 weeks on a 4-point Likert-like scale (“not at all” = 0 to “nearly every day” = 3) (24–26). Scores were summed with a range of 0-24. A score of 10 or greater is consistent with major depression, a commonly used cutoff point (24). In our sample, the PHQ-8 had a Cronbach’s alpha of .86.

Social Support.

Measured using the 4-item abbreviated Medical Outcomes Study Social Support Survey (MOS-4) (27; 28). Four types of social support are measured, each by a single item: informational support, tangible support, positive social interaction, and affectionate support. Items were rated on a 5-point scale ranging from “none of the time” (1) to “all of the time” (5). A composite score was obtained by summing responses to all items, with higher scores reflecting greater availability of support. Cronbach’s alpha in this study sample was 0.92.

HIV-related Stigma.

We assessed multiple dimensions of HIV-related stigma using two scales: anticipated stigma and the revised HIV Stigma Scale. The Anticipated Stigma scale consisted of 27-items assessing participants’ perceived likelihood of being treated differently because of their HIV status by family, friends, or healthcare workers (29). Each subscale consisted of 9-items with responses ranging from 1 (very unlikely) to 5 (very likely). The Cronbach’s alpha in this study sample was 0.91. The revised HIV Stigma Scale consisted of four subscales: enacted stigma, disclosure concerns, negative self-image, and concern with public attitudes about PLWH (30). Items for each subscale were rated using a 4-point Likert-like scale ranging from “strongly agree” (1) to “strongly disagree” (4). Composite scores for each scale were generated by summing responses to all items associated with the subscale, with higher scores reflecting higher stigma. The Cronbach’s alpha in this study sample was 0.94.

Demographic.

Demographic data included site, and self-reported gender, race, health insurance status, and HIV transmission risk factors.

Clinical data.

The most recent CD4 T-lymphocyte (cell/cubic ml) and HIV VL (copies/ml) values were extracted from electronic medical records.

Data Analysis

All data were analyzed using SAS version 9.4. Statistical significance was set at a 2-sided 95% confidence level ($\alpha = 0.05$). Participants were clustered within 4-sites; therefore, we controlled for site in all models. Unadjusted univariate logistic regression analyses were used to assess the association between each demographic, clinical, and psychosocial variable and poor HRQOL for each specific EQ-5D domain. Variables found to be significantly associated with each HRQOL domain were entered into the multiple logistic regression analyses to examine which variables were independent predictors of each HRQOL domain. Sequential multivariable models were used to assess the relationship between non-modifiable and modifiable variables and HRQOL. In model 1, race, gender, age, and type of insurance were included as non-modifiable socio-demographic factors. In model 2, we added the 4 social support variables, each stigma variable, and depression (PHQ8), which are considered modifiable psychosocial factors and potential intervention targets.

Results

Sample Characteristics

Participant demographic and clinical characteristics are presented in Table 1. Descriptive statistics on the five HRQOL domains and the modifiable psychosocial predictor variables (i.e., social support, depression, disclosure, and stigma) are presented in Table 2.

Bivariate and Multivariate Analyses

Detailed results of bivariate analyses for each EuroQOL domain are presented in Table 3, with sequential multivariate analyses presented in Tables 4 and 5.

Discussion

Among 335 participants newly entering HIV medical care enrolled in the iENGAGE behavioral clinical trial, we observed important sub-group differences in HRQOL. Women had increased odds of reporting worse HRQOL than their male counterparts across most quality of life domains. Sequential multivariable models demonstrated attenuation of parameter estimates and loss of statistical significance for many of the associations with impaired HRQOL observed in unadjusted analyses, particularly those seen among women. We postulate that complex relationships exist between the independent variables we measured and HRQOL that explain the observed findings in sequential multivariable modeling. For example, the attenuation of the relationship with poor HRQOL among women when sequentially adding other socio-demographic and psychosocial factors to models suggests that these additional, staged variables contribute to lower HRQOL reported by women across multiple domains. These results suggested a potential role for insurance type, perhaps as a proxy for socio-economic status, and the psychosocial domains of social support, stigma, and depression, as contributors to the poor HRQOL reported by women, and potentially modifiable intervention targets.

Study data indicate that gender-specific strategies to address HRQOL are needed among women initiating HIV care. This is vital as depression and suboptimal ART adherence have been associated with poor HRQOL (12; 31). Women living with HIV have lower rates of ART adherence, higher rates of depressive symptoms, and worse HRQOL when compared to their male counterparts (8; 32–34). The intersection of depression, worse HRQOL, and suboptimal adherence appear to be more challenging for women highlighting the need for interventions addressing these domains to enhance wellbeing and HIV outcomes, including HRQOL.

Social support is a modifiable factor associated with HRQOL. In this study, persons who reported higher perceived social support were less likely to have impaired pain and mood-related HRQOL (see Table 3). The importance of this relationship has been documented previously (11; 14). Access to social support has the potential to improve outcomes such as HRQOL (11). Therefore, future research should consider social support interventions and programming as a potential method of enhancing HRQOL among persons new to HIV care.

Consistent with previous studies, higher perceived HIV-related stigma was associated with poor HRQOL (8; 10; 35). Fear of perceived HIV-related stigma or discrimination often leads PLWH to isolate themselves from others (36). In addition, fear of stigma could result in disengagement from HIV care (i.e., missed medical visits, poor medication adherence, and medication discontinuation) and subsequent poor health outcomes (37). Therefore, stigma-reduction interventions are critical at care entry as they have potential to improve engagement in care and medication adherence, but also to enhance HRQOL in PLWH.

This study is not without limitations. First, we reported on cross-sectional data, which limits our ability to infer causality. At the conclusion of the iENGAGE study, we will assess changes in HRQOL at 48-weeks follow-up relative to the baseline assessment in both the intervention and control groups. Second, the enrolled sample is not representative of all PLWH in the US, but results may be generalized to PLWH in similar clinical settings. In addition, this study was not powered to detect difference in HRQOL between White women and other race-by-gender variables; therefore, stratified results should be interpreted with caution. Last, the measures were largely self-reported increasing the potential of information bias and social desirability bias. Yet, self-administered electronic questionnaires, as were used in this study, have been shown to reduce such bias (38).

Conclusion

Our findings suggest that social support, depression, and HIV-related stigma were significantly related to HRQOL across multiple domains, with women experiencing more problems than men. Researchers should use qualitative and mixed methods approaches to gain a better understand of the complex relationships between non-modifiable and modifiable factors and HRQOL, in order to inform targeted interventions aimed at improving HRQOL among PLWH initiating medical care. Our findings of group differences in HRQOL among women who are new to HIV care can be used to inform multifaceted, gender-specific interventions aimed at optimizing HRQOL and reducing health disparities, centering on social support, and addressing stigma and depression.

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Table 1.

Demographic and Clinical Characteristics of the Participants.

Variable	**Categories**	***N or Mean (SD)***	**%**
Age (years)		37.6 (12.3)	
Race	Black	227	67.8
	White	108	32.2
Gender	Male	267	79.7
	Female	68	20.3
Race x Gender	Black Male	174	51.9
	White Male	93	27.8
	Black Female	53	15.8
	White Female	15	4.5
HIV Risk Factor	Heterosexual	114	35.1
	IVDU	19	5.9
	MSM	192	59
Insurance Type	Private	142	42.9
	Public	113	34.2
	Uninsured	76	22.9
Baseline CD4 T-Lymphocyte count (cells/ml)	Overall	380.6 (267.2)	
	<200	88	27.3
	200-350	79	24.5
	>350	155	48.1
	Missing	13	
Baseline Viral Load (copies/mL)	<10,000	85	28.3
	>10,000	215	71.7
	Missing	35	

Table 2.

Descriptive Statistics on HRQOL, Depression, Social Support, and Stigma.

Variable	Categories	N or Mean (SD)	% or range
EuroQOL			
Depression/anxiety	Moderate/extreme	182	54.7
Pain	Moderate/extreme	147	44.4
Mobility	Some problems/unable	47	14.1
Self-care	Some problems/unable	10	3
Usual Activities	Some problems/unable	63	18.9
Social Support	Information Support	3.22 (1.38)	1.00 – 5.00
	Tangible Support	2.90 (4.52)	1.00 – 5.00
	Affectionate Support	3.61 (1.44)	1.00 – 5.00
	Positive Social Interaction	3.43 (1.32)	1.00 – 5.00
Depression	None	214	68.1
	Moderate/Severe	100	31.9
Disclosure of HIV Status	Yes	256	76.6
	No	78	23.4
Anticipated Stigma	Family	2.67 (1.37)	1.00 – 5.00
	Friends	2.75 (1.28)	1.00 – 5.00
	Healthcare provider	1.80 (0.94)	1.00 – 5.00
Earnshaw HIV Stigma	Enacted	2.17 (0.71)	1.00 – 4.00
	Disclosure	3.05 (0.60)	1.00 – 4.00
	Negative Self Image	2.28 (0.74)	1.00 – 4.00
	Public	2.70 (0.68)	1.00 – 4.00

Table 3.

Unadjusted Models for Pain, Depression, Mobility & Usual Activity

Variable	Pain OR (95% CI)	Depression OR (95% CI)	Mobility OR (95% CI)	Usual Activity OR (95% CI)
Female	**2.28 (1.30 – 4.01)**	**2.44 (1.35 – 4.40)**	**2.98 (1.52 – 5.84)**	**2.36 (1.26 – 4.41)**
Male	1.0	1.0	1.0	1.0
Black	1.17 (0.71 – 1.93)	0.61 (0.37 – 1.00)	1.55 (0.71 – 3.40)	1.03 (0.54 – 1.95)
White	1.0	1.0	1.0	1.0
Black Female	**2.41 (1.15 – 5.04)**	1.44 (0.68 – 3.06)	**5.05 (1.62 – 15.76)**	2.29 (0.94 – 5.55)
Black Male	1.22 (0.69 – 2.14)	**0.56 (0.33 – 0.98)**	2.27 (0.79 – 6.50)	1.16 (0.54 – 2.47)
White Female	**3.39 (1.05 – 10.88)**	2.72 (0.71 – 10.43)	**7.67 (1.86 – 31.55)**	**3.94 (1.18 – 13.16)**
White Male	1.0	1.0	1.0	1.0
Age (per 10 years)	**1.22 (1.01 – 1.46)**	**0.79 (0.66 – 0.95)**	**1.68 (1.32 – 2.15)**	**1.35 (1.09 – 1.67)**
HIV risk factor				
Heterosexual	**2.22 (1.36 – 3.62)**	1.38 (0.85 – 2.23)	**3.60 (1.81 – 7.15)**	**2.38 (1.31 – 4.32)**
IVDU	1.24 (0.48 – 3.25)	**3.39 (1.08 – 10.62)**	1.36 (0.29 – 6.46)	1.51 (0.46 – 4.90)
MSM	1.0	1.0	1.0	1.0
Insurance Type				
Public	**3.08 (1.67 – 5.66)**	1.05 (0.58 – 1.88)	**4.33 (1.82 – 10.30)**	**3.43 (1.63 – 7.20)**
Uninsured	**1.86 (1.03 – 3.36)**	1.55 (0.86 – 2.78)	**3.00 (1.23 – 7.32)**	1.56 (0.70 – 3.52)
Private	1.0	1.0	1.0	1.0
CD4+ T cell count				
<200	1.57 (0.91 – 2.71)	**0.52 (0.30 – 0.91)**	1.07 (0.51 – 2.22)	1.78 (0.91 – 3.46)
200- 350	0.67 (0.37 – 1.19)	0.57 (0.32 – 1.00)	0.59 (0.24 – 1.41)	1.05 (0.50 – 2.17)
>350	1.0	1.0	1.0	1.0
Social support				
Emotional	**0.79 (0.67 – 0.93)**	**0.81 (0.69 – 0.95)**	0.83 (0.67 – 1.04)	0.88 (0.72 – 1.07)
Tangible	0.95 (0.82 – 1.10)	**0.84 (0.72 – 0.97)**	0.95 (0.77 – 1.17)	1.04 (0.87 – 1.25)
Affectionate	**0.82 (0.70 – 0.96)**	**0.68 (0.57 – 0.80)**	0.90 (0.72 – 1.12)	0.84 (0.69 – 1.01)
Positive social interaction	**0.72 (0.60 – 0.85)**	**0.65 (0.54 – 0.78)**	**0.71 (0.55 – 0.90)**	**0.76 (0.62 – 0.94)**
Total (per 10 units)	**0.90 (0.83 – 0.97)**	**0.85 (0.78 – 0.92)**	0.92 (0.82– 1.03)	0.92 (0.84 – 1.02)
Anticipated Stigma				
Family	**1.22 (1.03 – 1.45)**	**1.42 (1.20 – 1.69)**	**1.41 (1.09 – 1.81)**	1.23 (0.99 – 1.51)
Friend	**1.23 (1.03 – 1.47)**	**1.53 (1.27 – 1.84)**	**1.60 (1.21 – 2.11)**	**1.33 (1.06 – 1.67)**
Healthcare provider	1.14 (0.90 – 1.44)	1.09 (0.86 – 1.38)	**1.59 (1.17 – 2.17)**	1.07 (8.80 – 1.44)
HIV Stigma				
Enacted stigma	1.27 (0.92 – 1.76)	**1.90 (1.35 – 2.67)**	**1.86 (1.14 – 3.03)**	1.39 (0.92 – 2.11)

Variable	Pain OR (95% CI)	Depression OR (95% CI)	Mobility OR (95% CI)	Usual Activity OR (95% CI)
Disclosure concern	0.94 (0.64 – 1.39)	**1.98 (1.33 – 2.96)**	1.05 (0.60 – 1.84)	1.21 (0.73 – 1.99)
Negative self image	1.34 (0.98 – 1.84)	**2.67 (1.86 – 3.75)**	**1.74 (1.12 – 2.72)**	**1.52 (1.02 – 2.26)**
Public Stigma	1.25 (0.89 – 1.76)	**1.45 (1.03 – 2.05)**	1.66 (0.98 – 2.79)	1.49 (0.94 – 2.37)
Depression				
Moderate- severe	**2.89 (1.73 – 4.81)**	---	**2.68 (1.36 – 5.27)**	**4.84 (2.62 – 8.95)**
None	1.0	---	1.0	1.0
Disclosure				
Yes	0.92 (0.55 – 1.55)	0.89 (0.53 – 1.50)	0.74 (0.36 – 1.50)	0.88 (0.46 – 1.67)
No	1.0		1.0	

Table 4.

Adjusted Models for Pain and Depression

Variable	**Pain (*n* = 327)**		**Depression (*n* = 329)**	
	Model 1	**Model 2**	**Model 1**	**Model 2**
Black	0.97 (0.57 – 1.65)	0.90 (0.46 – 1.81)	**0.50 (0.29 – 0.86)**	0.75 (0.35 – 1.61)
White	1.0	1.0	1.0	1.0
Female	1.78 (0.98 – 3.26)	1.24 (0.53 – 2.90)	**3.77 (1.93 – 7.37)**	**4.02 (1.42 – 11.42)**
Male	1.0	1.0	1.0	1.0
Age (per 10 years)	1.13 (0.93 – 1.37)	1.17 (0.90 – 1.52)	**0.69 (0.56 – 0.84)**	**0.65 (0.46 – 0.91)**
Insurance Type				
Public	**2.62 (1.39 – 4.93)**	**2.45 (1.06 – 5.65)**	1.02 (0.54 – 1.94)	0.97 (0.39 – 2.43)
Uninsured	**1.90 (1.04 – 3.47)**	1.31 (0.61 – 2.85)	1.57 (0.85 – 2.90)	1.75 (0.75 – 4.12)
Private	1.0	1.0	1.0	1.0
Social support				
Emotional	--	0.91 (0.66 – 1.26)	--	1.09 (0.74 – 1.59)
Tangible	--	1.31 (0.99 – 1.73)	--	1.23 (0.91 – 1.66)
Affectionate	--	0.95 (0.70 – 1.28)	--	**0.63 (0.44 – 0.93)**
Positive social interaction	--	0.76 (0.52 – 1.11)	--	1.11 (0.72 – 1.70)
Anticipated Stigma				
Family	--	1.20 (0.88 – 1.64)	--	1.03 (0.73 – 1.45)
Friend	--	1.15 (0.76 – 1.74)	--	1.42 (0.89 – 2.27)
Health care provider	--	1.07 (0.74 – 1.56)	--	0.91 (0.57 –1.46)
HIV Stigma				
Enacted stigma	--	0.61 (0.33 – 1.13)	--	1.19 (0.60 – 2.37)
Disclosure concerns	--	0.98 (0.50 – 1.94)	--	1.31 (0.61 – 2.81)
Negative self-image	--	0.89 (0.53 – 1.49)	--	1.54 (0.85 – 2.81)
Public	--	1.02 (0.56 – 1.88)	--	**0.47 (0.23 – 0.96)**
Depression				
Moderate- severe	--	**2.68 (1.26 – 5.70)**	--	**11.45 (4.04 – 32.50)**
None	--	1.0	--	1.0

Table 5.

Adjusted Models for Mobility and Usual Activities

Variable	Mobility (*n* = 328)		Usual Activities (*n* = 330)	
	Model 1	**Model 2**	**Model 1**	**Model 2**
Black	1.21 (0.53 – 2.79)	01.20 (0.34 – 4.25)	0.85 (0.43 – 3.27)	0.55 (0.22 – 1.40)
White	1.0	1.0	1.0	1.0
Female	1.79 (0.86 – 3.75)	0.76 (0.18 – 3.23)	1.67 (0.85 – 3.27)	1.21 (0.43 – 3.42)
Male	1.0	1.0	1.0	1.0
Age (per 10 years)	**1.62 (1.24 – 2.12)**	**1.68 (1.07 – 2.65)**	1.24 (0.99 – 1.57)	**1.42 (1.01 – 2.00)**
Insurance Type				
Public	**3.23 (1.30 – 8.05)**	**6.24 (1.51 – 25.84)**	**2.95 (1.36 – 6.40)**	**3.61 (1.22 – 10.72)**
Uninsured	**3.55 (1.37 – 9.17)**	2.80 (0.63 – 12.42)	1.66 (0.72 – 3.79)	1.30 (0.40 – 4.23)
Private	1.0	1.0	1.0	1.0
Social support				
Emotional	--	1.18 (0.69 – 2.04)	--	0.95 (0.62 – 1.48)
Tangible	--	1.39 (0.86 – 2.25)	--	1.49 (0.99 – 2.25)
Affectionate	--	1.05 (0.62 – 1.78)	--	0.82 (0.54 – 1.22)
Positive social interaction	--	0.57 (0.29 – 1.10)	--	0.80 (0.49 – 1.30)
Anticipated Stigma				
Family	--	1.20 (0.68 – 2.13)	--	1.12 (0.74 – 1.68)
Friend	--	2.04 (0.88 – 4.76)	--	1.54 (0.89 – 2.68)
Health care provider		**2.40 (1.36 – 4.24)**		0.79 (0.47 – 1.31)
HIV Stigma				
Enacted stigma	--	0.99 (0.33 – 3.03)	--	**0.42 (0.18 – 0.98)**
Disclosure concerns		1.05 (0.27 – 4.13)		1.77 (0.67 – 4.71)
Negative self image	--	1.48 (0.61 −3.60)	--	0.76 (0.38 – 1.52)
Public		0.33 (0.10 – 1.15)		0.95 (0.40 – 2.25)
Depression				
Moderate- severe	--	0.63 (0.18 – 2.18)	--	**4.00 (1.53 – 10.44)**
None	--	1.0	--	1.0