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The Impact of Mental Wellness on HIV Self-Management

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Abstract

As people living with HIV age, they face increasing self-management work related to HIV infection plus the prevention and mitigation of multiple chronic health conditions, including daily health practices (i.e., physical activity, nutrition, engaging in a supportive community, accepting the chronicity of HIV). Our purpose was to describe the relationship between HIV self-management practices and mental wellness (depressive symptoms, perceived stress). 93 adult PLWH on antiretroviral therapy were enrolled and completed a survey. We used descriptive statistics to summarize variables, and Spearman rank correlation and quantile regression to study associations between variables. Participants' average age was 48.6 years, 56% were male, and 87% were African American. Daily self-management practices were associated with depressive symptoms ($r = -0.19$; $p = 0.01$) and perceived stress ($r = -0.14$; $p = 0.06$); engaging with a supportive community and accepting the chronicity of HIV were not associated with mental wellness (all $ps > 0.05$).

Keywords

aging; HIV; mental wellness; self-management

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More than 1.2 million Americans were living with HIV in 2012 (Centers for Disease Control and Prevention 2015a) and, despite advances in HIV treatment, people living with HIV (PLWH) have remained at high risk for other health problems, especially cardiovascular disease, cancers, and kidney disease. Accordingly, substantial self-management work is necessary for this growing population, in order to help them live and age well (Martin et al., 2014). However, PLWH experience unique psychosocial and behavioral challenges related to HIV (e.g., comorbidities, high symptom burden, and HIV-related stigma; So-Armah & Freiberg, 2014) that can limit their abilities to initiate and maintain behaviors that improve health. A self-management approach can address these challenges and is important for PLWH in the chronic phases of the illness (Swendeman, Ingram, & Rotheram-Borus, 2009; Webel et al., 2012; Webel et al., 2013). Self-management is a “dynamic, interactive, daily process in which individuals engage to manage a chronic illness” (Schulman-Green et al., 2012, p.136).

Historically, HIV self-management has focused on HIV-specific tasks including antiretroviral therapy (ART) adherence, symptom management, and working in partnership with the health care team (Millard et al., 2014; Swendeman et al., 2009). However, the aging of PLWH has necessitated additional self-management skills including health promotion activities such as physical activity, eating a healthy diet, stress reduction, and healthy sleep habits. This more global self-management work also has included additional co-morbid disease management tasks such as taking medications for other conditions (leading to polypharmacy) and coordinating health care visits and recommendations from non-HIV providers (Swendeman et al., 2009). Today, HIV self-management can be thought of as having three related components: (a) daily self-management tasks (e.g., physical activity, diet, symptom management), (b) social support, and (c) addressing the chronic nature of HIV (e.g., understanding chronicity, taking steps to control HIV; Webel et al., 2012). When fully practiced, self-management improves health and quality of life, decreases morbidity and mortality, and decreases health care costs (Grey, Schulman-Green, Knafl, & Reynolds, 2015). Additionally, recent evidence has revealed that two specific HIV self-management tasks, engaging in regular comprehensive health care and adhering to ART medications, also decreases transmission of HIV, which is a global public health goal (White House Office of National AIDS Policy, 2015).

Despite the significant benefits of self-management, strategies to sustainably improve and maintain self-management remain elusive. Several barriers to active self-management have been described. Jerant, von Friederichs-Fitzwater, and Moore (2005) qualitatively investigated the perceived barriers to self-management among adults living with multiple chronic conditions. They found that poor communication with health care providers, lack of social support, health information complexity/education, financial/transportation issues, and symptoms of depression and fatigue led to decreased self-management. These findings have been shown to be consistent across populations including seniors with multiple chronic illnesses (Bayliss, Ellis, & Steiner, 2007) and those living with diabetes (Ahola & Groop, 2013). These barriers, in particular the lack of social support and symptoms (i.e., depression and stress), have been associated with reduced HIV self-management behaviors, including adhering to medical treatment and appointments, monitoring symptoms, and engaging with

health care providers (Bottonari, Safren, McQuaid, Hsiao, & Roberts, 2010; Pence et al., 2015; Rabkin, 2008). Depressive symptoms and stress are aspects of mental wellness and, when elevated, may serve as barriers to HIV self-management behaviors. Yet, despite the known relationship between mental wellness and specific self-management behaviors, the association between mental wellness and a comprehensive measure of HIV self-management has not yet been explored.

Our purpose was to describe the relationship between HIV self-management and mental wellness (depressive symptoms and perceived stress). Additionally, as women often report lower levels of mental wellness and as there are potential differences in mental wellness between those with high and low ART adherence, we examined the relationship between HIV self-management and mental wellness separately in men and women and then in those who reported optimal medication adherence ($\geq 90\%$) and suboptimal medication adherence ($< 90\%$; Pence et al., 2015). We hypothesized that: (a) higher levels of HIV self-management were related to lower levels of depressive symptoms and perceived stress, and (b) the relationship would be stronger in women and those who had achieved optimal HIV medication adherence.

Methods

We conducted a prospective cohort study to examine the relationships between HIV self-management, age, gender, and mental wellness (Webel et al., 2014). In this cohort study, ($n = 102$), participants completed two data collection visits, 1 year apart. Subjects were purposively enrolled into four strata: men younger than 50 years, men 50 years of age and older, women younger than 50 years, and women 50 years of age and older. As part of the cohort study, participants completed a battery of measures including a self-report survey, 7-day actigraph, and physical activity measures, heart rate variability testing, anthropomorphic measures (height, weight, waist-to-hip-ratio), vital signs, and serum measures (Webel et al., 2014; Webel et al., 2015). The data presented in this analysis come from the second data collection time point of that study. All procedures were approved by the University Hospitals, Case Medical Center Institutional Review Board.

Sampling and Recruitment

Subjects were recruited from an HIV Research Registry, at HIV clinics and service organizations using letters and flyers. To be eligible for the study, interested parties needed to be adult (≥ 18 years of age), have a confirmed HIV diagnosis, currently prescribed ART, and English speaking. Due to study procedure restrictions, subjects were excluded if they had a diagnosis of insulin dependent diabetes or if they had a cardiac pacemaker. These exclusion criteria were applied because, in the parent cohort study, subjects wore a cardiac Holter monitor for which insulin dependent diabetes and cardiac pacemakers have been contraindicated (Webel et al., 2014).

Procedures

Potential participants were screened via telephone to determine initial eligibility and consented to medical chart abstraction to confirm study eligibility. All eligible subjects were

scheduled for an enrollment appointment at the research offices at Case Western Reserve University. At this appointment, study staff: (a) verified informed consent for study participation, (b) had subjects complete a release of medical information from their HIV clinics, and (c) helped subjects complete several self-reported measures assessing demographics, HIV self-management, and mental wellness (depressive symptoms and perceived stress) on the Web-based data management tool REDCap (Harris et al., 2009). Data were collected between December 2012 and April 2013. Participants were compensated with a \$50 cash card for their time.

Measures

Demographic and medical characteristics—Demographic characteristics (gender, age, education level, employment, and housing status) were obtained by self-report. Medical data (current medications, self-reported HIV medication adherence [3-day visual analog scale anchored with 0 and 100%], co-morbid health conditions [current health care diagnoses recorded in the medical record], plasma HIV RNA levels, year of HIV diagnosis) were abstracted directly from the participant's medical chart by the study team.

HIV self-management—HIV self-management was assessed using the HIV Self-Management Scale (Webel et al., 2012). This 20-item scale measures three specific domains of HIV self-management: (a) Daily Self-Management Health Practices (e.g., physical activity, diet); (b) Social Support and HIV Self-Management; and (c) Chronic Nature of HIV Self-Management. Items are scored 0-3: *all of the time*, *some of the time*, *none of the time*, as well as *not applicable*. Each of the three domains were scored and reported separately. Examples of the items include: *Staying physically active is an important part of my HIV management strategy*; *When I feel overwhelmed, I find that talk to my counselor or attending support groups is helpful*; and *I have accepted that HIV is a chronic condition that can be managed*. Webel et al. (2012) demonstrated that the scale was a reliable ($\alpha = 0.72-0.86$), stable ($\alpha = 0.61-0.85$), and valid measure of HIV self-management. In our study, the Cronbach's alphas were 0.74 for the Daily Self-Management Health Practices Sub-Scale, 0.90 for the Social Support and HIV Self-Management Sub-Scale, and 0.75 for the Chronic Nature of HIV Self-Management Sub-Scale. Higher scores indicate increased self-management.

Mental wellness—Two constructs were used to assess mental wellness: depressive symptoms and perceived stress. Depressive symptoms were assessed using the Center for Epidemiologic Studies Depression Scale (CESD). The CESD is a psychometrically sound ($\alpha = 0.84-0.90$), self-report measure that has 20 items scored 0-3, which are summed to create a total score (range = 0-60; Radloff, 1977). Respondents considered the previous week and scored each item according to that timeframe. Examples of items from the CESD include, *I felt hopeful about the future* and *I enjoyed life*. In our study, Cronbach's alpha for the CESD was 0.91. Higher scores indicate greater levels of depressive symptoms.

Perceived stress was measured with Cohen's 10-item Perceived Stress Scale. This widely used and psychometrically validated ($\alpha = 0.74-0.91$) scale has 10 Likert-style items and is scored on a range of 0-40, with higher scores indicating greater perceived stress (Cohen,

1988; Lee, 2012). Respondents considered their feelings and thoughts in the previous month and rated items such as, *In the last month how often have you felt nervous and stressed?* In our study, Cronbach's alpha for the Perceived Stress Scale was 0.84.

Analyses

All data were directly imported from the Web-based data collection system, REDCap, into a data management program (Harris et al., 2009). Distributions of all demographic variables, HIV self-management, and mental wellness variables were checked using frequency analyses and graphs. Summary statistics (means and standard deviations for continuous variables and frequencies and percentages for categorical variables) were computed for presentation. Correlations between continuous variables were estimated and its significance was tested at a 5% level. We studied associations between HIV self-management and mental wellness (stress and depressive symptoms) using quantile regressions. All the analyses were performed using statistical software Stata 13.0 (StataCorp, 2013).

Results

Ninety-three participants completed all procedures, of which 52 (56%) were male and 81 (85%) were African American; the average age was $48.6 (\pm 9.4)$ years. On average, participants had been living with HIV for $14.1 (\pm 7.3)$ years, had a current CD4+ T cell count of $589 \text{ cells/mm}^3 (\pm 344 \text{ cells/mm}^3)$, and had been on HIV ART for $9.5 (\pm 5.6)$ years. Additional sample characteristics can be found in Table 1.

Overall, participants reported that the chronic nature of HIV was the strongest practiced aspect of HIV self-management (mean 2.77 ± 0.37), followed by daily health practices (mean 2.22 ± 0.42), and then social support (mean 1.98 ± 0.96). Women reported modestly higher HIV self-management scale scores than men, as did those who were adherent to their HIV medications (Figure 1). Women reported significantly higher scores on the Chronic Nature of HIV Self-Management Scale ($z = -2.1, p = 0.03$) and those who were adherent to their medications reported significantly higher scores on the Daily Self-Management Health Practices Scale ($z = -2.3, p = 0.02$). No other differences were observed.

The Daily Self-Management Health Practices Scale was the only HIV self-management domain associated with mental wellness. Daily health tasks were negatively associated with depressive symptoms ($r = -0.19, p < 0.05$). Depressive symptoms were strongly and positively correlated with perceived stress ($r = 0.54, p < 0.05$). No other correlations were observed (see Table 2).

In examining the effect of mental wellness on HIV self-management, the strongest effects were observed with the Daily Self-Management Health Practices Scale. Within the entire sample, controlling for gender and decade of age, perceived stress negatively impacted daily health practices ($\beta = -0.27, p = 0.03$), as did depressive symptoms ($\beta = -0.17, p < 0.01$). In examining this relationship by gender, we found the same pattern in women. In women, controlling for decade of age, perceived stress negatively impacted daily health practices ($\beta = -0.04, p = 0.10$), as did depressive symptoms ($\beta = -0.02, p < 0.01$). These relationships were not significant for male participants. Of those who did not adhere to their HIV

medications, depressive symptoms negatively impacted daily health practices ($\beta = -0.03$, $p < 0.01$). No other relationships were observed and additional detail on these analyses can be found in Table 3.

Discussion

Self-management is a central health goal for everyone living with a chronic disease, including those living with HIV (Martin et al., 2014). However, what influences a global construct of HIV self-management, beyond HIV-specific behaviors, is unknown. We evaluated the impact of mental wellness on HIV self-management and found evidence that depressive symptoms were associated with successful HIV self-management. As we transition into an era focused on living well with HIV, our evidence reveals that one specific domain, Daily Self-Management Health Practices Scale was particularly impacted by one aspect mental wellness— depressive symptoms. As PLWH age they develop chronic co-morbidities that could be prevented or mitigated by being physically active; eating a healthy diet; managing stress and symptoms; and balancing work, family, and health responsibilities (Justice, 2010). Effective, tailored interventions to improve these self-management behaviors are needed, (Webel et al., 2012; Webel et al., 2015), yet this is some of the first evidence describing the impact of mental wellness on the totality of self-management practices in PLWH. Clinically, this implies the need to assess and address any deficits in the patient's mental wellness before and concurrently while trying to treat and prevent conditions such as cardiovascular disease, cancer, and neurocognitive decline through self-management.

As hypothesized, women and participants who were non-adherent to ART reported a stronger, negative relationship between self-management and mental wellness (i.e., less mental wellness was associated with less self-management). Women and those who are non-adherent to ART are at high risk for developing additional chronic illnesses, but daily health practices could improve their health. Yet, although women report higher levels of HIV self-management, diminished mental wellness (depressive symptoms) was shown to strongly and negatively impact that self-management. Women living with HIV have reported more distressing symptoms (Do et al., 2014) than men, potentially compounding the severity of this relationship. Our findings add to the growing body of literature suggesting that mental wellness is a key component of a comprehensive HIV wellness plan in women living with HIV (Warren-Jeanpiere, Dillaway, Hamilton, Young, & Goparaju, 2014).

We were surprised that there was no relationship between the social support aspects of HIV self-management and mental wellness. Our sample had been living with HIV for an average of 14 years, and as such, may have already developed a stable social support system resistant to fluctuations in mental wellness. Specifically, the items assessed by this scale, including the need to attend support groups, the need to talk to a counselor, and the motivation derived from listening to others' stories (Webel et al., 2012), may not be as applicable as people live longer with and adjust to a chronic HIV diagnosis. Future work should examine the role of social support on the global construct of HIV self-management through the lifespan in order to better understand this relationship.

Limitations of our study include drawing our sample from one geographic location. Although our population was demographically representative of the growing HIV epidemic in the United States (Centers for Disease Control and Prevention, 2015b), there may be unique aspects of HIV care in this location that limit generalizability of our findings. We used a cross-sectional, descriptive research design, making it impossible to characterize the directionality of HIV self-management and mental wellness. Additional, longitudinal research designed to investigate this directionality, as well as stability over time and other multi-level constructs impacting HIV self-management, is necessary to design and test interventions to improve HIV self-management. Additionally, the association between stress and self-management did not reach statistical significance at the pre-determined level ($p = 0.05$), but did indicate a trend toward statistical significance. Future work should examine this relationship in a larger sample to better understand this relationship.

Conclusion

HIV self-management underpins the health of PLWH. Our evidence reveals that the depressive symptom component of mental wellness has a significant impact on HIV self-management and, in order to improve HIV self-management, we also need to address mental wellness in this growing population.

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Key Considerations

- Mental wellness was consistently associated with successful daily HIV self-management practices.
- This relationship between mental wellness and self-management was negative, with women and those who were non-adherent to HIV medications demonstrating more diminished mental wellness.
- It may be helpful to assess and address mental wellness before and intermittently when trying to treat and prevent conditions in people living with HIV infection such as cardiovascular disease, cancer, and neurocognitive decline through self-management.

Figure 1. Self-Management Scale Scores by Group¹

¹Data are presented as mean self-management scale score with error bars indicating standard deviations. ²Indicates people who reported taking at least 90% of their HIV medication in the last 7 days

Table 1
Sample Characteristics (*n* = 93)

Demographic Characteristics	Mean (SD) ^a
Age, years (Range = 20 - 66)	48.6 (9.4)
Gender (%)	
Male	52 (56)
Female	39 (42)
Transgender	2 (2)
Race (%)	
African American	81 (85)
Caucasian/White	11 (12)
Education Level (%)	
11 th grade or lower	20 (21)
High school or GED	24 (26)
2 years of college or technical training	23 (25)
College degree (e.g., BA, BS) or higher	13 (11)
Currently Employed (%)	13 (14)
Permanent Housing (%)	82 (88)
HIV Characteristics	
Number of years since HIV diagnosis (Range 1-32)	14.1 (7.3)
CD4+ T cell count (Range = 59 – 1,904 cells/mm ³)	589 (344)
Number of years on antiretroviral therapy (Range = 0 - 22)	9.5 (5.6)
CD4+ T cell count nadir (Range = 0 - 741 cells/mm ³)	172 (155)
Number of subjects with viral suppression (< 75 copies/mL; %)	63 (67)
Number of subjects with additional chronic illnesses (%)	85 (91)
Overall Level of Self-Management (Range 0-3)	
Self-Management: Daily Health Tasks Scale	2.22 (0.42)
Self-Management: Social Support Scale	1.98 (0.96)
Self-Management: Chronic Nature of HIV Scale	2.77 (0.37)
Mental Wellness	
Depressive Symptoms (Range = 0 - 60)	16.4 (11.6)
Perceived Stress Scale (Range = 0 - 40)	16.6 (4.9)

Note. GED = graduate equivalency degree; BA = Bachelor of Arts; BS = Bachelor of Science;

^a all statistics presented as means (standard deviations), unless otherwise noted.

Table 2
Associations Between HIV Self-Management and Mental Wellness^a

Variable	Self-Management 1: Daily Health Tasks (SM1)	Self-Management 2: Social Support (SM2)	Self-Management 3: Chronic Nature of HIV (SM3)	Depressive Symptoms
SM1				
SM2	0.27 ^b			
SM3	0.29 ^b	.018 ^c		
Depressive Symptoms	-0.19 ^c	.004	-0.05	
Perceived Stress	-0.14 ^d	0.07	-0.04	0.54 ^b

Note.

^aCorrelations were assessed using Kendall's Tau b Correlational Analyses, due to small sample size;

^bindicates a *p*-value < 0.01;

^cindicates a *p*-value < 0.05,

^dindicates a *p*-value = 0.1;

SM = self-management.

Table 3
Median Regression of HIV Self-Management Daily Tasks by Mental Wellness

Variable	B Coefficient	T	p-value	95% Confidence Interval
Entire Sample (n = 91)				
Stress	-0.27	-2.28	0.03	-0.05 -0.00
Decade of Age	-0.04	-0.65	0.52	-0.16 0.08
Gender	0.03	0.23	0.82	-0.20 0.26
Constant	2.83	7.16	0.00	2.04 3.62
Depressive Symptoms	-0.17	-3.50	< 0.01	-0.27 -0.01
Decade of Age	-0.12	-1.89	0.06	-0.24 0.01
Gender	-0.81	-0.72	0.48	-0.31 0.14
Constant	3.12	9.34	0.001	2.45 3.79
Women (n = 39)				
Stress	-0.04	-1.67	0.10	-0.08 0.1
Decade of Age	0.98	1.00	0.32	-0.10 0.30
Constant	2.38	3.89	0.00	1.13 3.63
Depressive Symptoms	-0.02	-2.71	0.01	-0.33 -0.01
Decade of Age	0.04	0.49	0.63	-1.34 0.22
Constant	2.31	4.99	0.001	1.38 3.26
Subjects Reporting < 90% Medication Adherence (n = 45)				
Stress	-0.02	-0.94	0.35	-0.06 0.02
Decade of Age	-0.05	-0.47	0.64	-0.25 0.16
Constant	2.62	3.91	0.00	1.27 3.97
Depressive Symptoms	-0.03	-4.88	< 0.001	-0.34 -0.16
Decade of Age	-0.19	-2.55	0.02	-0.33 -0.04
Constant	3.56	8.94	0.00	2.76 4.367