



A descriptive, cross-sectional study examining treatment burden in people living with HIV



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ABSTRACT

Aim: (1) describe the percentage of people living with HIV (PLWH) experiencing high levels of treatment burden who are at risk for self-management non-adherence, and (2) examine the relationship between known antecedent correlates (the number of chronic conditions, social capital, and age) of self-management and treatment burden while controlling for sample socio-demographics.

Background: Chronic condition self-management is key to maintaining optimal health in the aging population of PLWH. Despite the efforts of providers, patients, and caregivers, self-management non-adherence is still a factor contributing to poor chronic condition self-management and subsequent poor health outcomes. Recent research has identified treatment burden as a risk factor of poor chronic disease self-management adherence.

Method: Cross-sectional, secondary analysis of a sub-sample of 103 community dwelling, men and women diagnosed with HIV/AIDS derived from a larger parent study examining physical activity patterns in PLWH.

Results: Participants reported an overall low level of treatment burden ($M = 22.84$; $SD = 24.57$), although 16% ($n = 16$) of the sample indicated experiencing high treatment burden. The number of chronic conditions ($r = 0.25$; $p \leq .01$) and social capital ($r = -0.19$; $p = .03$) were significantly correlated with treatment burden. Multivariate analysis testing known antecedent correlates of treatment burden was statistically significant ($p < .05$), but only explained 8% of treatment burden's variance.

Conclusion: Findings have implications for nursing care of PLWH demonstrating a subset of PLWH experience high treatment burden related to chronic condition self-management. Findings also identify characteristics of PLWH who may be at high risk for treatment burden and subsequent self-management non-adherence.

1. Introduction

Successful HIV treatment associated with advances in antiretroviral therapy has resulted in HIV classified as a chronic condition (US Department of Health and Human Services, 2018). Today, adherence to a self-management regimen underpins achieving optimal health for the 1.1 million people living with HIV (PLWH) in the US (Linley et al., 2018). As this population ages, they must manage their HIV as well as other chronic conditions associated with HIV as well as aging (Swendeman et al., 2009). The diagnosis of HIV predisposes PLWH to a higher risk of chronic conditions (Deeks & Phillips, 2009; Greene, Justice, Lampiris, & Valcour, 2013) such as cardiovascular disease (Prevedel, Morocho, Bennett, & Eugenin, 2017), liver failure (Kaspar & Sterling, 2017), and cancer (Klein, Quesenberry, William, & Silverberg, 2018). In addition to a higher risk of chronic conditions associated with

HIV, older PLWH are at risk for chronic conditions related to the aging process due to the risk of developing multiple chronic conditions increasing with age (Ward, Schiller, & Goodman, 2014). Thus, aging PLWH must self-manage HIV, HIV-associated chronic conditions, and aging related chronic conditions.

Self-management of multi-morbidity for PLWH consists of many complex tasks and logistical management of those tasks (Lorig & Holman, 2003; Udhis, 2011). Adherence to these tasks are essential to the effective self-management of chronic conditions, with less than effective adherence leading to poor clinical and health outcomes (Bauer, Briss, Goodman, & Bowman, 2014; Howren & Gonzalez, 2016). Medication adherence (Günthard et al., 2016; Viswanathan, Golin, Jones, et al., 2012), self-monitoring of disease related symptoms (Hood et al., 2016; McBain, Shipley, & Newman, 2015), regular exercise (Bauer et al., 2014; Hoffmann et al., 2016; McCarthy, Whittemore, Gholson, &

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Grey, 2017), and lifestyle changes (Bauer et al., 2014), such as a healthy diet and smoking cessation, are critical elements in effective chronic condition self-management.

In addition to adhering to a self-management regimen, current literature suggests there are many determinants of self-management adherence. Evidence suggests that social resources, such as support from family, friends, and formal/informal support groups, can improve self-management adherence across chronic conditions (Dwarswaard, Bakker, van Staa, & Boeije, 2016; McDonald, Slavin, Pitts, & Elliott, 2015; Taylor et al., 2014). Higher levels of social resources, specifically social capital, has shown to improve medication adherence and quality of life in PLWH (Webel, Sattar, Schreiner, & Phillips, 2016). Social capital was defined as: “the sum of the actual and potential resources embedded within, available through, and derived from the network of relationships possessed by an individual or social unit.” (Nahapiet & Ghoshal, 1998). Sociodemographic characteristics such as income, access to insurance, and education have also been indicated as factors affecting self-management of chronic conditions (Koch, Wakefield, & Wakefield, 2015).

Despite increasing evidence and effort from both health care providers, patients, family, and social support groups, less than full adherence to self-management regimens is common. Treatment burden is “work” associated with self-management and it has been associated with non-adherence to self-management (Sav et al., 2013; Tran et al., 2012; Wallace et al., 2015). The more burdensome some or all parts of the prescribed treatment plan are to an individual, the more difficult it can be for the individual to comply with the task, thus the higher the risk of non-adherence. For instance, if an individual finds the task of taking his/her prescribed medication difficult and/or burdensome, he/she is at higher risk for non-adherence to the prescribed medication regimen (i.e. missing doses, taking medication at incorrect times). Additionally, treatment burden increases with the number of diagnosed chronic conditions (Sav et al., 2016; Schreiner & Daly, 2018). A greater number of diagnosed chronic conditions require more self-management tasks, including (but not limited to) prescription of multiple medications (contributing to polypharmacy), more appointments with specialists, or restrictions on diet. Individuals with such requirements are at greater risk for higher levels of treatment burden.

Treatment burden has been measured in various populations diagnosed with chronic conditions, including hospitalized adults (Tran et al., 2012), adults in a primary care setting (Sav et al., 2016; Tran et al., 2014), and older adults transitioning from a skilled nursing facility (Schreiner & Daly, 2018), but has not been explored in PLWH diagnosed with multiple chronic conditions. Antecedent factors such as age, the number of multiple chronic conditions (MCC), the presence of a caregiver, the diagnosis of diabetes, and the severity of MCC predict treatment burden in people diagnosed with other chronic conditions (Sav et al., 2016; Schreiner & Daly, 2018). Schreiner and Daly (2018) demonstrated the benefit of screening for aggregate and individual areas of high treatment burden. By identifying areas of high treatment burden, interventions, such as diet and exercise training, education (e.g. medication administration, diet education), or an allocation of resources (e.g. home care, social worker, case manager, support groups) can be introduced to reduce burden and increase the likelihood of adherence to a self-management regimen. However, little is known about treatment burden in PLWH despite their elevated risk for multiple chronic conditions. Since treatment adherence is integral to successful chronic condition self-management, it is imperative to understand how many PLWH are affected by high levels of treatment burden and what the antecedent correlates driving high levels of treatment burden. This study aims to describe treatment burden and examine correlates of treatment burden in an ambulatory PLWH population who are diagnosed with MCC.

1.1. Purpose

The purpose of this study was to: (1) describe the number of PLWH experiencing high levels of treatment burden who are at high risk for self-management non-adherence, (2) test the relationship between known antecedent correlates (the number of chronic conditions, social capital, and age) of self-management and treatment burden in community dwelling sample of people living with HIV (PLWH) while controlling for socio-demographics. As an indicator of social support, we tested the relationship between social capital and treatment burden. We hypothesized that social capital would be inversely correlated with treatment burden in PLWH. We justified this hypothesis based on literature demonstrating higher levels of social capital, such as having a robust social network or strong connectedness to one's community, have been shown to improve chronic conditions self-management (Vassilev et al., 2011; Vassilev et al., 2013), which in turn may reduce treatment burden.

2. Methods

2.1. Design and sample

Our study was a descriptive, correlational, cross-sectional secondary analysis of a larger, multi-site study that examined physical activity patterns of PLWH. Treatment burden was a measure embedded in the study for analysis, but was not a primary outcome of the parent study. Participants in the parent study included men and women who: (1) were aged ≥ 18 years, (2) had confirmed HIV (HIV + ELISA with confirmatory PCR or Western blot). Exclusion criteria were: (1) a medical contraindication for exercise determined by the AHA criteria or inability to be physically active without an assistive device (i.e. wheelchair, walker, or cane) (2) cannot understand English or Spanish; (3) expects to move out of the area or plans to become pregnant within 12 months. An additional inclusion criterion for this secondary analysis was diagnosis of two or more Center for Medicare and Medicaid Services (CMS) defined chronic conditions as identified in the patient's medical record.

2.2. Setting and ethical approval

The parent study was conducted at multiple sites. Our secondary analysis was only conducted on a sample from a single site collected in Northeast Ohio. The Northeast Ohio site was a research intensive university affiliated with a tertiary medical center located in an urban, metropolitan area. IRB approval for the primary study was obtained from the study site's IRB.

2.3. Data collection

One hundred sixteen participants took part in the parent study at the Northeast Ohio site. Participants were recruited via flyers describing the study distributed to local HIV clinics and AIDS services organizations, or were told about the study in person while attending visits at the site's HIV research office. Potential participants were given a telephone number to call which connected them with a member of the research team. Screening for inclusion in the study was conducted by a research assistant using an IRB approved script. Study personnel obtained written informed consent prior to collection of any study data. Treatment burden measures were collected using one-on-one participant interviews, and responses were directly entered into Research Electronic Data Capture (REDCap). For the purpose of our secondary analysis, 103 participants with complete data met inclusion criteria.

2.4. Measures

2.4.1. Treatment burden

We used the Treatment Burden Questionnaire-13 (TBQ-13) to measure participant treatment burden (Tran et al., 2012). The TBQ-13 is a psychometrically tested instrument containing 13 items inquiring about burden associated with self-management tasks such as medication administration, self-monitoring of chronic conditions, or changes in diet. The TQB-13 asks the respondent to rank the level of burden for each question with responses ranging from 0- *No Burden*, to 10- *Very High Burden* with summed scores ranging from 0 to 130 (higher scores indicating greater treatment burden). TBQ-13 was our dependent variable measuring the concept of treatment burden and was analyzed as a continuous variable. Construct validity for the TBQ-13 has been tested with the Treatment Satisfaction Questionnaire for Medication demonstrating the expected negative correlation ($r = -0.41$ to -0.53) and with The Complexity of Care Measure demonstrating the expected positive correlation ($r = 0.16$ to 0.40) (Tran et al., 2012). Reliability was calculated with a Cronbach's $\alpha = 0.89$ and test-retest = 0.76 (Tran et al., 2012).

2.4.2. Social resources

The Bullen and Onyx (2007) Social Capital Measurement Tool was used to measure social resources. This psychometrically tested, 36 item instrument measures eight subscales of social capital including: participation in the local community, social agency, feelings of trust and safety, neighborhood connections, friends and family connections, tolerance of diversity, value of life, and workplace connections. The scores of individual items were summed creating a composite score used in analysis. Participants were asked to rate each individual item on a 1–4 Likert-type scale. Higher mean scores indicated greater social capital. Reliability for the measure was calculated via correlation between items resulting in a Cronbach's $\alpha = 0.84$ (Bullen & Onyx, 2007).

2.4.3. Number of MCC

The number of MCC was acquired via electronic medical record chart review as part of the parent study. Nineteen CMS (2017) defined chronic conditions were abstracted from the larger set of diagnosed conditions for use in this study. The total number of CMS defined chronic conditions was summed for analysis in our study.

2.4.4. Demographics

Age was a continuous variable recorded in years. Sex was dichotomized as (0) male, (1) female. Race was dichotomized (0) black, (1) non-black due to the low percentage of non-black participants. Insurance was dichotomized as (0) no insurance, (1) insured. Income was continuous in nature and was represented by 6 categories: (0) No monthly income, (1) Less than \$200, (2) \$200–\$399, (3) \$400–\$599, (4) \$600–\$799, (5) \$800–\$999, (6) \$1000 or more. Education was treated as continuous and was represented by 5 categories: (0) 11th grade or less, (1) High school or GED, (2) Some college or technical school training, (3) Associate Degree, (4) Bachelor Degree, (5) Master's Degree or higher. Employment was dichotomized as (0) unemployed, (1) employed. The length since diagnosis of HIV/AIDS was continuous and measured in years.

2.5. Data analysis

We analyzed study data using SPSS software, version 22 (IBM Corp, 2016). We tested frequency distributions and univariate statistics to ensure our data met statistical assumptions of our planned analyses. Statistical assumptions of linear regression and multi-collinearity between independent variables were tested before conducting multivariate statistical analysis. The variable of insurance lacked variance (97% of the sample was insured) and was excluded from multivariate analysis. We set a priori statistical significance at 0.05.

Table 1

Univariate statistics of study sample examining treatment burden in people living with HIV.

Variable	Number of participants (n)	Percentage of participants (%)	
Birth sex:	Male	67	65
	Female	36	35
Race:	Black	92	89.3
	Non-Black	11	10.7
Insurance:	Not insured	3	2.9
	Insured	100	97.1
Income:	No monthly income	6	5.8
	Less than \$200	6	5.8
	\$200–\$399	5	4.9
	\$400–\$599	1	1
	\$600–\$799	41	39.8
	\$800–\$999	12	11.7
Education:	\$1000 or more	32	31.1
	11th grade or less	23	22.3
	High school or GED	32	31.1
	Some college or technical school training	25	24.3
	Associate degree	8	7.8
	Bachelor degree	12	11.7
Employment:	Master's degree or higher	3	2.9
	Unemployed	87	84.5
	Employed	16	15.5

Variable	Range	Mean	Standard deviation
Age	32–71	53.16	7.167
Years since diagnosis of HIV/AIDS	3–33	17.01	7.624
Number of chronic conditions	2–10	3.64	1.754
Social capital	47–139	96.68	18.171
Treatment burden	0–119	22.99	24.492

Descriptive, univariate statistics were analyzed and reported using mean, standard deviation, and range for continuous variables or the number of participants in each group/percentage for dichotomous and categorical variables. Correlations between study variables were calculated using the Pearson R statistical test. Multivariate analysis was performed using linear regression, reporting the overall model (F statistic, degrees of freedom, and p -value), the variance explained by the overall model (adjusted r^2), and any significant independent variables in the model (standardized beta coefficient, p -value). Post-hoc analysis was conducted on dichotomous socio-demographic variables (sex, race, employment status, and insurance status) examining mean differences in treatment burden between groups using Independent Sample t -test analysis (T-score, p -value).

3. Results

Descriptive statistics are in found in Table 1. Our sample mean was approximately fifty years of age, majority African American, male, Medicaid insured, and acquired a high school diploma. The sample had a mean of 3.63 (SD = 1.76) chronic conditions using CMS (2017) definitions. The six most prevalent chronic conditions, other than HIV, in our sample were: hypertension (55.5%), asthma (28.2%), arthritis (26.2%), diabetes (18.4%), and Hepatitis B/C (14.6%)/Hyperlipidemia (14.6%). Our sample's mean treatment burden score was 22.84 (SD = 24.57). Based on Tran's cut-off points (2010) for low, medium, and high treatment burden, our sample experienced low levels of treatment burden, though the sample had a wide variation treatment burden scores. Applying these cut-points, 60 PLWH (58%) reported low treatment burden, 27 (26%) moderate treatment burden, and 16 (16%) high treatment burden.

Table 2
Pearson's correlation between age, the number of chronic conditions, social capital, and treatment burden.

Variable	1	2	3	4
1. Age	–			
2. Social capital	0.17	–		
3. Number of chronic conditions	0.212*	–0.200*	–	
4. Treatment burden	–0.06	–0.194*	0.254**	–

* $p \leq .05$.

** $p \leq .01$.

Examination of descriptive statistics for individual TBQ-13 items showed administrative burden associated with interfacing with the healthcare system ($M = 2.93$; $SD = 3.56$), global impact of burden on their health and wellbeing ($M = 2.03$; $SD = 3.06$), burden associated with lifestyle changes including diet ($M = 1.99$; $SD = 2.42$), and following a prescribed exercise regimen ($M = 1.97$; $SD = 2.85$) were items causing the highest burden related to chronic condition self-management.

When examining the descriptive statistics for the TBQ-13 of those who experienced high levels of treatment burden, paperwork ($M = 7.06$; $SD = 3.42$), remembering to take medications at various times during the day ($M = 5.94$; $SD = 3.77$), the limitations associated with taking medication ($M = 5.69$; $SD = 3.22$) and maintaining the prescribed exercise regimen ($M = 5.5$; $SD = 3.87$) were items causing highest treatment burden.

Correlational analysis (Table 2) examining the association between known antecedent factors (number of MCC, social capital, and age) and treatment burden demonstrated the number of MCC ($r = 0.25$; $p \leq .01$) and social capital ($r = -0.19$; $p = .03$) were significantly correlated with treatment burden.

Multivariate analysis (Table 3) (adjusted $r^2 = 0.83$, $F(9, 93) = 2.03$; $p = .05$) testing the number of MCC and social capital predicting treatment burden was significant when controlling for the influence of sample demographics (age, sex, race, income, education, years since diagnosis of HIV/AIDS). Our model explained 8% of treatment burden's variance with the number of MCC (standardized beta coefficient = 0.004; $p \leq .01$) and years since diagnosis of HIV/AIDS (standardized beta coefficients = -0.22 ; $p = .04$) predicting treatment burden.

Post-hoc analysis examining mean differences between dichotomous socio-demographic variables (sex, race, employment status, and insurance) were not statistically significant ($p > .05$) though African-American participants ($n = 92$) experienced higher treatment burden ($M = 24.26$; $SD = 24.46$) than Non-African American participants ($n = 11$; $M = 12.36$; $SD = 23.10$).

Table 3
Multivariate analysis of independent variables (sample demographics, number of chronic conditions, and social capital) and the dependent variable treatment burden.

Variable	Unstandardized beta coefficient	Standardized beta coefficient	T-Score	p-Value
Constant	39.82		1.94	0.06
Age	–0.12	–0.04	–0.35	0.73
Sex	–3.37	–0.07	–0.66	0.51
Race	–12.61	–0.16	–1.64	0.11
Education	1.49	0.08	0.77	0.45
Monthly income	–0.55	–0.04	–0.37	0.71
Employment	8.72	0.13	1.28	0.21
Years since diagnosis HIV/AIDS	–0.72	–0.22	–2.14	0.04
Number of chronic conditions	3.97	0.31	2.95	0.00
Social capital	–0.12	–0.09	–0.91	0.37

Note: Dependent variable- treatment burden.

4. Discussion

In our community dwelling sample of PLWH, we found that they experienced low levels of burden associated with the self-management of diagnosed chronic conditions. The number of MCC was positively associated with treatment burden, which supports previous literature (Sav et al., 2016; Schreiner & Daly, 2018) and that social resources were negatively correlated with treatment burden, supporting our hypothesis. Our proposed model of the number of MCC, social resources, and sample demographics was significant in predicting treatment burden, with the number of MCC and years since diagnosis of HIV/AIDS being significant independent variables, though only 8% of variance was explained. These findings support previous studies of treatment burden and help identify PLWH who may at risk for higher levels of treatment burden. The identification of PLWH experiencing high treatment burden may help providers develop targeted interventions, education, and/or resources aimed at reducing treatment burden in specific areas of self-management.

Our community-dwelling sample experienced a low level of treatment burden as a whole. Comparison between our study's treatment burden levels and Tran et al.'s (2012) initial findings were generally similar. Tran et al.'s sample of French speaking participants ($n = 502$), of which over 50% were surveyed as hospital inpatients, exhibited a low level of treatment burden ($M = 30.1$; $SD = 25.3$). Specific items causing high treatment burden in the Tran study were somewhat similar to our findings. Descriptive statistics were not available for comparison in Tran et al.'s initial 2012 study, but were described in Tran's 2014 study, which adapted the Treatment Burden Questionnaire for use in English speaking populations. According to Tran et al. (2014), self-management tasks causing highest burden were: ($M = 6.1$; $SD = 3.6$), financial burden related to their care ($M = 5.6$; $SD = 3.6$), how their need for healthcare is burdensome on relationships with others ($M = 4.9$; $SD = 3.7$), burden associated with doctor appointments ($M = 3.9$; $SD = 3.3$), burden associated with arranging medical appointments and/or transportation ($M = 3.8$; $SD = 3.4$), and administrative burden interfacing with the healthcare system ($M = 3.8$; $SD = 3.4$).

Though similarities between these studies exist, there also are notable differences. Tran's sample was larger ($n = 502$), slightly older ($M = 59.3$; $SD = 17.0$), included more females (53% compared to our 35%), and were more highly educated (35% compared to our 22%). Tran's treatment burden levels were more evenly distributed among classifications. In Tran's study, approximately 47% ($n = 240$) experienced low burden, 28% ($n = 140$) moderate, and 24% ($n = 122$) high burden as compared to our study which had approximately 58% ($n = 60$) participants experiencing low, 26% ($n = 27$) moderate, and 16% ($n = 16$) high burden. Additionally, Tran et al.'s mean level of treatment burden was approximately 8 points or 6% greater than the

mean of our sample. These differences can be attributed to Tran's hospitalized sample likely being more acutely ill than our ambulatory sample.

Despite an apparent floor effect of treatment burden in our sample, descriptive examination of individual question scores provided insight into areas of high burden that can contribute to ineffective chronic self-management, including prescribed changes to diet and exercise, especially in those PLWH who experience high levels of treatment burden. It is also noteworthy that some participants experienced low overall treatment burden, but also scored 6 or greater in one or more treatment burden items, indicating high treatment burden in a specific aspect of their self-management regimens. A better understanding of these at-risk areas of self-management adherence can help us achieve the goals identified in a personalized health plan. This initial work allows us to better understand what populations and sub-populations are at risk for self-management non-adherence due to high levels of treatment burden and helps us identify specific areas (e.g. medication management, diet, exercise) of self-management that are most affected. We can then begin to develop and test interventions, education, and/resources tailored to the needs of the individual (Collins & Varmus, 2015).

The finding that more MCCs increases the level of treatment burden is expected and consistent with the existing treatment burden literature (Sav et al., 2016; Schreiner & Daly, 2018; Tran et al., 2012). The finding that lower social capital is associated with higher treatment burden supports our hypothesis that social resources can reduce treatment burden in this population. These data are novel in the treatment burden literature and will need to be further examined in future studies. This finding may suggest the need for provider assessment of social resources in the context of treatment burden and exploration of increasing social capital as a way to decrease self-management related treatment burden.

Correlational analysis between age and treatment burden were non-significant. This findings support Schreiner and Daly (2018), though Sav et al. (2016) found age was negatively correlated with levels of treatment burden. A possible explanation for this non-significant finding between age and treatment burden is that our sample lacked variance in age ($M = 53.16$; $SD = 7.17$) limiting detection of statistical significance. Also, our finding that years since diagnosis of HIV is a predictor of treatment burden may signify that the early phases of one's chronic illness trajectory is more explanatory of treatment burden than age in PLWH. Thus, individuals who are newly diagnosed with a chronic condition may experience higher treatment burden due to the need for integration of new self-management tasks and requirements, such as medication administration, regardless of the individual's age. Therefore, as clinicians, it may be particularly important to take into account the potential of high treatment burden in individuals early in their chronic illness trajectory.

We also noted difference between treatment burden in African Americans ($M = 24.26$; $SD = 24.46$) and White ($M = 12.36$; $SD = 23.10$) participants. African-American participants ($n = 92$) experienced higher treatment burden than White participants ($n = 11$), though we lacked heterogeneity of the sample to detect statistical significance. Chronic disease self-management literature (Berkman, 2009; Gwynn et al., 2016; Horrell et al., 2017) demonstrates that African Americans often experience worse health related outcomes as compared to White counterparts. Further examination is needed to explore treatment burden in a PLWH population with an adequately powered, racially stratified sample.

4.1. Limitations

Though treatment burden was measured in this population, it was not the main focus of the parent study, thus limiting our ability to collect data on known antecedent variables of interest, such as the presence of caregiver assisting with chronic condition self-management. Our sampling techniques introduced potential sampling biased

effecting the generalizability of our results as our sample was majority African-American, Medicaid-insured, and receiving established HIV/AIDS treatment at a medical center/HIV clinic. As identified by Koch et al. (2015) access to insurance and medical providers are essential in effective self-management of chronic conditions. Those PLWH who are uninsured and lack the means to receive regular medical care were not represented in this study, though it is logical to believe they are at high risk for treatment burden due to their barriers to effective self-management. Other races diagnosed with HIV/AIDS were also under-represented in this study, thus further research is needed to understand the sociodemographic impact on treatment burden in PLWH.

The floor effect related to treatment burden scoring found constrained sample variance in measuring and analyzing treatment burden as our dependent variable. Correlational/multivariate analysis of adequately powered samples of PLWH experiencing moderate and/or high treatment burden may yield more significant results. Comparisons of treatment burden questionnaire descriptive statistics between our study and Tran et al. (2014) were not fully equivalent due to our use of the Treatment Burden Questionnaire 13 as compared to the use of the Treatment Burden Questionnaire 15 used in the other studies. The Treatment Burden Questionnaire 15 consisted of two additional items: treatment burden related to financial aspects of care and treatment burden related to difficulties with healthcare providers.

5. Conclusion

This study identified a small percentage of PLWH who are suffering from high treatment burden and specific types of burden that were high in our sample. In addition, potential risk factors associated with treatment burden in PLWH were confirmed and findings suggest that increasing social capital could reduce treatment burden. Results point to the potential benefit of treatment burden screening in order to improve self-management adherence. These results can help inform nurses how to improve the self-management adherence in PLWH who are affected by treatment burden in the clinical setting.

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