


Self-Management Strategies for Coping with Adverse Symptoms in Persons Living with HIV with HIV Associated Non-AIDS Conditions

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Abstract People living with HIV (PLWH) are living longer, but many are now affected by HIV-associated non-AIDS (HANA) conditions and their associated adverse symptoms. An online survey was conducted with 769 PLWH with HANA conditions in the US. Information was elicited on symptoms experienced, self-management strategies employed, and the helpfulness of these strategies. Open ended responses were collected for self-management strategies. A qualitative data analytic approach was used to organize the 4036 self-management strategies into thematic categories, with eight main categories emerging, including: taking medication, modifying activity, altering diet, seeking help, waiting, substance use, managing thoughts and attitudes, and altering the physical environment. Of the self-management strategy subcategories, social support was the most helpful self-management strategy with waiting/doing nothing being the least helpful approach. Findings can be used to inform the development of self-management interventions and to support health care professionals in recommending symptom self-management strategies to their patients.

Resumen Personas viviendo con el VIH (PLWH) están viviendo más tiempo, pero muchas de ellas están siendo afectadas por condiciones relacionadas con el VIH no relacionadas con el SIDA (HANA), y por los síntomas adversos de estas condiciones. Una encuesta en línea fue realizada con 769 PLWH con condiciones HANA en los EE.UU. Se obtuvo información sobre los síntomas presente, las estrategias de automanejo empleadas y la utilidad de estas estrategias. Respuestas con un final abierto fueron obtenidas para las estrategias de automanejo. Un enfoque analítico de datos cualitativos fue utilizado para organizar las 4036 estrategias de automanejo en categorías temáticas, y ocho categorías principales surgieron, incluyendo: tomar medicamentos, modificar actividad, alterar la dieta, buscar ayuda, esperar, usar sustancias, controlar los pensamientos y las actitudes, y alterar el entorno físico. De las subcategorías de estrategias de automanejo, el apoyo social fue la estrategia de automanejo más útil y esperar/no tomar acción fue la estrategia menos útil. Los hallazgos de este estudio pueden ser utilizados para contribuir al desarrollo de intervenciones de automanejo, y para apoyar a profesionales de salud en recomendar estrategias de automanejo de síntomas a sus pacientes.

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Introduction

HIV continues to impose a significant burden on the health and quality of life of 1.2 million Americans [1]. Treatment advances with combined antiretroviral therapy (cART)

have resulted in lower rates of mortality for those infected with HIV and transformed HIV into a chronic illness [2–4]. As persons living with HIV (PLWH) live longer, they are more likely to have similar chronic diseases as their HIV-negative counterparts [5]. At the same time, HIV appears to increase the risk of many non-HIV conditions otherwise known as HIV-associated non-AIDS (HANA) conditions, even after adjustment for age and other known risk factors [6]. These are illnesses associated with or exacerbated by HIV infection, but not AIDS-defining conditions (e.g., opportunistic infections and AIDS malignancies) [7, 8]. HANA conditions can include: coronary artery disease, thrombosis, stroke, liver disease, anal and cervical cancer, osteoporosis, avascular necrosis, anemia, thrombocytopenia, asthma, diabetes, end stage renal disease [9], peripheral neuropathy, and dementia [10–13]. Today, these conditions are responsible for as many as 60% of deaths in developed-world HIV-positive cohorts [5].

The care of PLWH affected by HANA conditions is a stated priority in the recommendations from the Office of AIDS Research HIV and Aging Working Groups [14]. One important area in need of further study is the symptom experience of PLWH with HANA conditions [15]. Since PLWH are living longer and therefore more frequently being affected by HANA conditions, they are also experiencing more symptoms that are important to manage. Reducing symptom burden has been shown to improve functional capacity [16], clinical outcomes [17–20], and quality of life [21, 22]. One approach to coping with symptoms is through self-management, a process whereby an individual undertakes efforts to care for their physical and emotional health by determining actions needed [23], in order to promote his/her own health, prevent his/her own disease, limit illness and restore health [24]. Self-management is considered essential in the management of chronic illness [25].

To meet this need, a number of chronic disease self-management programs have been developed which target outcomes related to decision-making, pain management, effective communication, and problem solving skills for those living with chronic illnesses [26, 27]. For example, the Chronic Disease Self-Management Program (CDSMP) is a widely used and well-evaluated program shown to improve a variety of health outcomes including a reduction in visits to the emergency department [26, 28]. Adaptations of the CDSMP have proven efficacious in improving outcomes in persons living with a number of chronic diseases including: dementia [29], sick cell disease [30], arthritis [31], and mental illness [32]. Other self-management programs have successfully improved health status in persons living with chronic obstructive pulmonary disease (COPD) [33], type II diabetes [34], and asthma [35].

While there are a number of extant chronic disease self-management programs available, generic chronic disease

self-management programs may not adequately address the needs of PLWH. PLWH face unique challenges related to disease transmission, stigma, disclosure and medication adherence [27]. A systematic review of HIV self-management programs focused on programs that increase HIV-related knowledge and found that from the six studies, there was insufficient evidence to provide conclusions regarding long-term outcomes [36]. Given the dearth of current programs targeted for PLWH and especially those PLWH with HANA conditions, there is a need to develop self-management programs which have the potential to ameliorate symptom burden and improve quality of life [27, 37].

Despite the importance of self-management strategies for PLWH with HANA conditions, prior research into symptoms and corresponding self-management strategies have typically focused on a single symptom (e.g., depression) [25, 38–41], or were conducted prior to the cART era with reduced pill burden and medication side effects potentially changing the symptom experiences [25]. In addition, two of these studies had small sample sizes—11 and 34 cases—[39, 42], and none drew from a sample of PLWH with a HANA condition. As a result, there is a need to better understand how to self-manage the symptoms of PLWH with HANA conditions in order to optimize their quality of life and outcomes [5]. The goal of our work was to identify the most frequently reported symptoms and the most helpful self-management strategies used by PLWH with HANA conditions to manage their symptoms.

Methods

Design and Survey

We conducted an anonymous online survey from March to August 2016 with PLWH who reported at least one of the following HANA conditions: asthma, bronchitis, cardiovascular disease, COPD, diabetes, liver disease, osteoporosis, renal failure, or arthritis. We selected these conditions after reviewing the literature and consulting with experts in the field; [43–50] these conditions are the most frequent causes of morbidity and mortality in PLWH. To be eligible to participate in the study, individuals had to: be at least 18 years of age, provide informed consent, report having at least 1 HANA condition, and read/write in English.

Study participants were recruited from POZ.com, BGCLive.com, CraigsList and Facebook.com by placing recruitment ads directing interested participants to a survey link. Several study banner ads were used for online recruitment. One such banner ad is illustrated in Fig. 1. Participants did not receive compensation for participating in the survey. All study procedures and materials were approved by the Columbia University Institutional Review

For those living with HIV

Please take our survey about health symptoms and aging.

COLUMBIA UNIVERSITY
IN THE CITY OF NEW YORK

Fig. 1 Study Banner Ad

Board. The survey, built using Qualtrics, collected demographic data (e.g., age, race/ethnicity, gender), information on HANA conditions, and symptom frequency, severity and self-management strategies. Specifically, the survey elicited data about participants' experience over the past 30 days with 28 common symptoms. Following their report of each symptom, participants were asked: "In the past 30 days, what did you do to relieve your symptom [e.g., fatigue]?" A free text box was included for participants to enter a self-management strategy used for each symptom reported. Following their open-ended response to the self-care strategy question, participants were asked to rate how much each self-management strategy helped to relieve the symptom on a scale of 1–5 (1 = not at all and 5 = very much).

Sample

A total of 769 PLWH from the US completed all survey questions and are the focus of this report. Of these, 537 reported their current sex at birth as male and 215 as female, with the remaining participants failing to reply to this question. All those reporting a sex at birth of female identified as female at the time of the survey, while of those reporting a sex at birth of male, current gender identity was reported as male ($n = 525$), transgender female ($n = 6$), female ($n = 3$), genderqueer ($n = 3$). Participants' ages ranged from 22 to 81 (Mean = 51, S.D. = 11). The majority of participants reported being White ($n = 487$), followed by Black ($n = 204$), and Hispanic ($n = 82$). Further study sample details, including geographic location, are included in Table 1.

Data Analysis

Category Development and Validity

Survey data was imported into NVivo and MS Word for analysis and for category/code development. We developed a coding scheme of self-management strategies using inductive category analysis of the open-ended narrative responses [51, 52]. A priori, we agreed that we would create a separate category of *Not Recommended Self-management Strategies*, which included strategies that are potentially dangerous, illegal or clinically ill-advised by our study team. The purpose of this work was to identify helpful self-management strategies for future use by

Table 1 Study Sample

	n	Frequency (%)
Sex at birth		
Male	537	71
Female	215	29
Gender		
Male	525	70
Female	218	29
Genderqueer	3	0
Trans woman	6	1
Rural/urban		
Big city	300	41
Suburb of a big city	134	19
Smaller urban area	82	11
Suburb of a smaller urban area	47	6
Small town	105	15
Rural area	56	8
Age		
<50 years	200	36
≥50 years	354	64
Sexual orientation		
Bisexual	74	10
Heterosexual	227	30
Homosexual	451	60

PLWH with HANA conditions and therefore we did not include strategies which were not helpful, not clinically advised (e.g., changing/stopping medications), or dangerous (e.g., gambling).

Open coding was used to categorize self-management strategies for each symptom. We then reviewed all of the individual symptom categories and grouped codes into main categories and subcategories on the basis of similarities. For example, the main code *Taking medication or treatment* included subcategories of: take medication or dose (e.g., "Meds," "took meds"); use prescription drugs (described as prescribed but not specified, e.g., "Take antibiotics as prescribed by PCP," "Four different prescription meds prescribed for pain/inflammation"); drug specified (e.g., "Ativan"); took over-the-counter (OTC) medication or remedy (e.g., "I take Tylenol"); had specific medical procedure (e.g., "dialysis").

Reliability

For coding scheme development, responses were coded independently by two coders (SI, HC), both nurses with advanced training in qualitative research methods. Regular meetings were held to discuss the coding process. A third author (RS) assessed findings and resolved coding scheme discrepancies, agreement was reached by consensus. For further verification, additional HIV experts were consulted to review the coding scheme and provide feedback. Using the final coding scheme, we recoded all responses independently and reviewed the codes as a team, symptom by symptom [52].

Data Analysis

MS Excel was used for coding and analysis. The subcategories of *specific activity*, *over the counter remedy*, *specific medication* were later reanalyzed to tailor strategies by symptom. For example, the code *specific activity* was used to categorize “hot bath” for muscle ache symptom and “reading” for difficulty staying asleep. The text was coded at the subcategory level and then combined to explore differences between main codes and subcategories.

Descriptive statistics were used to summarize the coded data. The 5 point scale of helpfulness was dichotomized into not helpful (not at all helpful and very little) and helpful (somewhat helpful, helpful, and very much helpful) to compare usefulness of reported strategies. We also analyzed the frequency of each symptom reported by age group (<50 years as compared to ≥50 years).

Results

The 769 respondents reported a total of 6111 occurrences of the 28 common symptoms during the past 30 days, with an average of 8 symptoms per survey respondent. Symptoms in order of their frequency are listed in Table 2, with percent being the % of all symptoms reported. We identified eight main categories and 20 subcategories (that fell within the 8 main categories) of symptom self-management.

Categories of Self-Management Strategies

Participants listed a total of 4034 self-management strategies with an average of 14 strategies (± 3.8 , range 5–22) per symptom. Of these strategies, 2167 (53.6%) were rated as being somewhat, quite a bit or very helpful, while 1869 (46.3%) strategies were rated as a little or not at all helpful. In our final analysis, we excluded responses of multiple strategies for a single symptom, that is, responses including

a list of strategies, since we were unable to determine the level of helpfulness of each of the discrete strategies.

The eight main categories of self-management in order of frequency were: (1) Take medications or treatment; (2) Modify activity; (3) Alter food in diet; (4) Seek help; (5) Wait; (6) Substance use; (7) Manage thoughts or attitudes; and (8) Alter physical environment (Table 3). Of the participants who used “waiting” as a self-care strategy, only 9% found this to be at least somewhat or more helpful. A much higher number of respondents found the following strategies to be helpful: taking medication (76%); substance use (76%), seeking help (76%); manage thoughts or attitudes (62%); alter food in diet (61%); modifying activity (54%); and alter physical environment (42%).

There were 530 (12%) of the responses reporting multiple (2 or more) distinct strategies, 120 (2.41%) that were not-applicable responses or unsure (e.g., had no idea how to self-manage symptom), and 95 (1.91%) reporting nothing helped. These were not included in the self-management strategies total. Table 3 presents self-management strategy categories, subcategories, frequency, and percent of persons who found the strategy to be more than a little helpful. Seeking help through social supports subcategory was rated as the most helpful self-care approach across all symptoms with 94% of participants who used this strategy reporting it to be at least somewhat helpful.

Self-Management Strategies by Symptom

Table 4 provides a summary and examples of the top three self-management strategies reported for the ten most frequently endorsed symptoms. *Taking medication*, whether reported in general (e.g., “take medication”), listing an over the counter medication, or a specific prescription drug, was the most common self-management strategy. Specified drug classes or specified drugs by symptom included taking Selective Serotonin Reuptake Inhibitors (SSRIs) (e.g., Zoloft, Celexa) for depression; benzodiazepines (e.g., Ativan, Xanax) for anxiety; Gabapentin for neuropathy; and Ambien for difficulty falling asleep.

Waiting to see if the symptom would resolve or lessen despite doing nothing was also a very common strategy. Participants reported both passive and active forms, such as waiting for the symptom to pass or pushing one’s self to keep going despite the bothersome symptom. Participants also frequently reported doing specific activities to alleviate symptoms, which were unique for each symptom. For example, for low energy or fatigue, specific activities included getting more rest and sleeping more.

The subcategories of *consume specific foods/drinks* and *avoid/cut back specific foods* were categorized differently by each symptom, and were not top self-management strategies. For low energy and fatigue, examples of specific

Table 2 Symptom Frequency

	Overall Frequency (%)	Frequency by age group* - n (frequency %)		
		<50 years (n = 200)	≥50 years (n = 354)	p ⁺
Overall low energy or fatigue	523 (8.6)	147 (73.5)	239 (67.5)	0.17
Muscle aches/pain	438 (7.2)	112 (56.0)	200 (56.5)	0.98
Depression (e.g., feeling worthless, hopeless)	391 (6.4)	111 (55.5)	174 (49.2)	0.18
Anxiety or fear (e.g., feeling nervous)	335 (5.5)	91 (45.5)	152 (42.9)	0.62
Difficulty staying asleep	335 (5.5)	91 (45.5)	157 (44.4)	0.86
Difficulty falling asleep	323 (5.3)	102 (51.0)	122 (34.5)	0.0002 ⁺
Neuropathy (numbness or tingling in hands/feet)	296 (4.8)	60 (30.0)	159 (44.9)	0.00078 ⁺
Decreased sex drive	276 (4.5)	59 (29.5)	148 (41.8)	0.0054
Difficulty remembering things	270 (4.4)	65 (32.5)	129 (36.4)	0.40
Difficulty concentrating/easily distracted	237 (3.9)	69 (34.5)	113 (31.9)	0.60
Problems achieving or maintaining an erection (male only)	237 (3.9)	38 (19.0)	134 (37.9)	6.459e-06 ⁺
Shortness of breath with activity	229 (3.8)	61 (30.5)	104 (29.4)	0.86
Diarrhea	229 (3.8)	71 (35.5)	91 (25.7)	0.019
Thirst/dry mouth	200 (3.3)	58 (29.0)	91 (25.7)	0.46
Constipation/gas/bloating	189 (3.1)	52 (26.0)	85 (24.0)	0.68
Lightheadedness/dizziness	175 (2.9)	51 (25.5)	74 (20.9)	0.26
Clumsy walking/balance difficulty/dropping things frequently	167 (2.7)	36 (18.0)	88 (24.9)	0.079
Dry eyes	158 (2.6)	41 (20.5)	81 (22.9)	0.59
Unplanned weight loss/gain	157 (2.6)	54 (27.0)	59 (16.7)	0.0053
Heartburn/reflux	154 (2.5)	42 (21.0)	72 (20.3)	0.94
Ringing in ears/noise intolerance	150 (2.5)	34 (17.0)	80 (22.6)	0.15
Cough	129 (2.1)	33 (16.5)	45 (12.7)	0.27
Changes in appetite	118 (1.9)	35 (17.5)	51 (14.4)	0.40
Nausea/vomiting	111 (1.8)	44 (22.0)	38 (10.7)	0.00054 ⁺
Difficulty with urination	105 (1.7)	16 (8.0)	63 (17.8)	0.0024
Fevers/night sweats/chills	94 (1.5)	32 (16.0)	36 (10.2)	0.061
Speech difficulties (e.g., slowed speech, reversing numbers, words, letters)	62 (1.0)	15 (7.5)	32 (5.9)	0.64
Pain or discomfort during sex	23 (0.4)	9 (4.5)	8 (2.3)	0.23
Total	6111			

* Not all participants reported their age and so total frequency by age group does not equal the overall frequency

+ After correcting for multiple comparisons a significant p value at 95% confidence is 0.00089

foods or drinks mentioned included drinking coffee and energy drinks and eating fruit and vegetables. Examples of drinks for relieving sleeping difficulties included drinking tea and avoiding coffee.

Not Recommended Self-Management Strategies

There were 35 reported self-management strategies coded as outlier responses that were considered not recommended, not clinically advised, or dangerous. Changing or stopping medications, including HIV medications, was reported by some respondents as a self-management strategy but was deemed by our study team as not

recommended without first consulting with a healthcare provider. Twenty-one respondents reported changing their medication without clarifying that it was under the consultation of a healthcare provider. Examples of free text responses are: “cut dosage of one Rx,” “changed medication,” and “increased dosage of Sertraline.” Five respondents reported stopping medication as a response to having symptoms of lightheadedness/dizziness (n = 3), diarrhea (n = 1), and muscle aches/pain (n = 1). Having shortness of breath with activity led one respondent to restart adhering to her HIV regimen. Strategies reported for managing depression, which are not recommended, included: “planning suicide” (n = 1), “gambling” (n = 1), and

Table 3 Self-management strategy categories, subcategories, frequency, and percent of persons who found the strategy to be more than a little helpful

Main category/subcategory of self-care strategies	Frequency (overall %)	% who found this strategy to be more than a little helpful
Take medications or treatment	1437 (36)	76%
Take medication	1403 (35)	76%
Specific medical treatment/procedure (physical therapy, dialysis)	34 (1)	74%
Modify activity	798 (20)	54%
Specific activity*	491 (12)	46%
Increase physical activity (be active, exercise, go for a walk)	108 (3)	56%
Activity reduction (rest, relaxation, take it easy)	72 (2)	68%
Complementary or alternative health activities (yoga, meditation, breathing techniques)	79 (2)	75%
Modify daily routine	33 (1)	61%
Repositioning (sit up or elevate head while sleeping)	15 (0)	73%
Wait (I didn't do anything, wait patiently until problem goes away, just live with it)	940 (23)	9%
Alter food or diet	433 (11)	61%
Hydrate (drink more water)	127 (3)	68%
Consume specific foods/drinks* (yogurt, eat fruit)	119 (3)	66%
Alter food or diet in general (change diet, eat less/more)	100 (2)	45%
Take supplements (probiotics, vitamins/minerals)	66 (2)	64%
Avoid/cut back specific foods (cut out caffeine, sugar, dairy)	21 (1)	57%
Seek Help	260 (6)	76%
Health care professionals (doctor, nurse, physical therapist)	113 (3)	52%
Social support (family, talk with friends, church, be social)	147 (4)	94%
Substance use	80 (2)	76%
Use substance (alcohol, drugs, marijuana/medical marijuana)	62 (2)	87%
Reduce substance use (includes smoking)	18 (0)	39%
Manage thoughts or attitudes (Try to be happy, distraction, praying, motivation, cry)	50 (1)	62%
Alter physical environment (Use air conditioning/fan, open windows, less covers)	38 (1)	42%
Total	4036 (100)	54%

* Specific activity varied by symptom

“self-medicating” (n = 1). Lastly, one respondent wrote, “I pushed through my work day even though I feared losing consciousness at any moment,” as a self-management strategy for lightheadedness/dizziness.

Discussion

We report findings from a sample of 769 PLWH living with HANA conditions who described the self-management strategies they used to alleviate their everyday symptoms. Findings from this study contribute to the current literature, which has a dearth of information on the symptom burden as well as self-management strategies used to deal with these symptoms in the cART era. In our work, the most frequently reported symptoms were low energy or fatigue, muscle aches and pains, depression,

anxiety/fear, and sleeping difficulty. There are notable differences from similar work which was conducted in 2004 in which the most frequently reported symptoms were: fatigue, anxiety/fear, diarrhea, neuropathy, nausea/vomiting and depression [25]. Given the advancements in the HIV drug regimens and the improvements in the side effect profiles, it is not surprising that today PLWH are not experiencing diarrhea and nausea/vomiting as frequently as in the past. Fatigue, muscle aches and pains and sleeping difficulty are the most frequently reported symptoms in our study suggesting the need to understand if this change in symptom frequency is related to the HANA conditions, the aging process, mental health, stigma or living with the disease for a longer amount of time than was likely the case in 2004.

Although not the most frequently used strategy, the subcategory of *seeking help through social support* had the

Table 4 Top 3 self-management strategies for the top 10 Symptoms

Symptoms	Top 3 strategies	<i>n</i>	Examples
Overall low energy or fatigue	Specific activities	76	Stay inside and rest, took smaller chunks of activity, sleep hygiene
	Take medication	23	Take sleeping aid, take medication for energy
	Increase physical activity	19	Forced myself to exercise more, walk
Muscle aches/pain	Take medications	101	Aleve, Ibuprofen
	Specific activities	15	Jacuzzi, hot baths, massage, ice, stretching
	Activity reduction	10	Rest
Depression	Take medication	83	Zoloft, Wellbutrin, took my meds
	Specific activities	14	Go to store, got a dog
	Seek help from healthcare professionals	12	Made an appointment for therapy, I see psychologist for grief therapy
Anxiety or fear	Take medication	85	Took prescribed anxiety meds
	Specific activities	24	Relax, go for walks around the block
	Complementary or alternative health activities	11	Meditation, diaphragmatic breathing, exercise
Difficulty staying asleep	Take medication	64	Remeron, Zolpidem, Nyquil
	Specific activities	18	Heat or cold compression, I read
	Substance use	7	Switch to wine instead of vodka martini, smoke weed
Difficulty falling asleep	Take medication	91	Sleeping pill, took medicine, pain meds, take pill
	Specific activities	11	Avoid taking naps during the day, took warm showers
	Substance use	11	Drink, cannabis
Neuropathy	Take medication	57	Gabapentin, Lyrica, opioid pain meds, Tramadol, methadone, benzodiazepine
	Specific activities	11	Stopped walking, shaking it out, baths with Epsom salt
	Wait	6	Wait till it's over, nothing, I sucked it up and took it
Decreased sex drive	Take medication	21	Took male enhancement pills
	Specific activities	19	Masturbate, stopped having sex, don't get in relationships or dating, watch more porn
	Wait	3	I have not done anything, just live with it, just waited until I felt in the mood again
Difficulty remembering things	Specific activities	43	Write myself notes, use datebook for reminders of appointments and tasks, tried to put things in a consistent location, verbalizing
	Take medication	8	Medication, antidepressants
	Wait	7	Wait patiently until problem goes away, nothing but lay down and try to recall what I did
Difficulty concentrating/easily distracted	Specific activities	27	Try to limit distractions, used post-it notes, frequent breaks from reading, quit my job, exercise my memory
	Take medication	16	Medications
	Manage thoughts/attitudes	3	Redirected myself on new task

highest percentage of respondents rating it as at least somewhat helpful or higher (94%) across all symptoms. This is an important strategy to consider since past research has shown that social support is significantly correlated with quality of life [53], further supporting the need for social support as a self-management approach for PLWH. There is also considerable evidence to suggest that social support is a means for ameliorating negative health outcomes [54]. Therefore future interventions for palliating symptoms and improving quality of life should consider social support as an intervention component.

The category of *Take medication/treatment*, which was comprised of over-the-counter medications, prescription drugs, including HIV medications, or other specified medications accounted for 36% of the total reported strategies. In particular, prescription drug use was listed as a common self-management strategy for HANA symptoms. This category is consistent with other evaluations of self-management strategies for HIV symptomatology [25].

In the US, prescription drug use is a common first line strategy [55]. This is especially true for depression and other mental health conditions, which is a common

symptom experienced by PLWH [56]. In the case of depression, researchers report a notable increase in the number of anti-depressant prescriptions and decrease in rates of psychotherapy over the past ten years [57]. At the same time, however, there is growing evidence that antidepressants are not as effective as initially believed and are associated with various uncomfortable side effects, and that relapse is more common when the medication is discontinued compared to when psychotherapy methods are used as treatment [57]. This suggests that despite our participants' preference for use of medications for relieving depressive symptoms, other self-management strategies may be more effective, especially over the long-term. In addition to the mental health medications not working very well, many people do not want to take them and depressive symptoms can be fleeting, further supporting the use of cognitive behavioral therapy [58], as well as suggesting the need for more focus on addressing mental health symptoms in chronic disease management.

Similarly, participants who experience neuropathy reported taking specific medications (e.g., Gabapentin and Lyrica) and specific activities (e.g., “took my shoes off,” “rest”) as the most frequently used self-management strategy. Yet prior research has suggested that taking a hot bath, staying off the feet, and walking are effective strategies for relieving neuropathy in PLWH and impose no financial burden on patients [40]. Overreliance on prescription medications for treatment of depression and other symptoms could be due to medications being the only option offered to patients by their care providers [57] or preference for a “quick fix” by the patient or provider. However, it is also possible that, as in the case of pain management, care providers feel restricted to prescribing medications, because many insurance companies will not pay for non-pharmaceutical interventions such as acupuncture or massage therapy [59]. Further, study of the use of non-pharmaceutical treatments for the relief of symptoms in PLWH with HANA conditions is warranted.

Unlike a subset of 34 people who experienced depressive symptoms in another study who reported using non-traditional complementary/alternative therapies as the most common strategies for managing symptoms of depression [38], in our study only 3 reported using complementary strategies for relieving depression, such as meditation and oil. In comparison, 18 used complementary/alternative strategies for anxiety.

Waiting for the symptom to run its course or doing “nothing” was one of the top reported strategies for dealing with difficulty concentrating, fatigue, difficulty falling and staying asleep, and decreased sex drive. Each of these symptoms is part of the symptom profile of depression [60]. Since depression is common among PLWH [56], it is possible that if the symptoms are the result of undiagnosed

or inadequately treated depression, patients may not know how to relieve the symptom or may lack motivation to find a solution. Therefore, providers should be sure to adequately assess patients for symptoms and for the effectiveness of depression treatment, as well as be aware of the overlapping presentation of depression and other symptoms experienced by PLWH.

Finally, for the symptom of decreased sex drive, “waiting” was the most frequently reported self-management strategies. Participants may have reported waiting due to the lack of availability of other self-management strategies as well as inadequate communication between providers and patients on this topic [61, 62]. Oftentimes, individuals who are living with sexual dysfunction try to talk with their providers about it [61, 62]. However, providers may feel that it is not their responsibility to address sexual matters, are embarrassed to discuss the topic, or perceive they lack adequate knowledge and experience to address the issue or lack resources to provide the needed support [61]. Healthy sexual functioning is an important aspect of quality of life for many individuals and therefore it is important for healthcare providers to discuss this topic with their patients during their visits. Importantly, clinicians should be sure that when talking about sex with PLWH, the discussion goes beyond prevention of transmission of HIV to also include discussion about sexual functioning.

There are a number of existing chronic disease self-management programs which have been well-evaluated. Yet PLWH, especially those living with HANA conditions, have complex needs that may not be well addressed by generic programs. In addition, because of the heterogeneity of PLHIV, programs may need to be further targeted to specific groups of PLHIV. That is, a program for men and women might look very different and is likely warranted. Given that there is a dearth of self-management programs developed in the cART era [63–65] and of those that exist they have not been rigorously evaluated. There is a particular shortage of programs for those living with HANA conditions, supporting the need for these findings to fill a gap in the current evidence base. Moreover, the findings reported in this paper can be used as the foundational knowledge base for the development of self-management programs for PLWH with HANA conditions. Finally, future work should evaluate the use of these self-management strategies for improving outcomes.

Limitations

We used a convenience sample recruited from various online sources, and thus the generalizability of our findings is limited to individuals who access these types of sites,

and more specifically to those who were exposed to the banner ads. Our sample was comprised of a larger portion of male participants so the information collected may better represent the symptom experience and self-management strategies of males. At the same time, HIV prevalence is higher in males in North America [66]. Those taking time to fill out survey and participate may be more likely to self-manage their own health and therefore may also not be fully representative of all PLWH with HANA conditions. Finally, this paper is limited to reporting self-care strategies that were rated as being at least somewhat helpful by our survey respondents. Our study is limited in that the findings do not provide information on the effect of each self-care strategy on symptom amelioration, quality of life or overall functioning.

Conclusions

This study employed a contemporary research design, recruitment from online social and sexual networking sites, to study symptoms and self-management strategies of PLWH, which are data that are not available from most clinical data sets. Findings from this study increase the knowledge base regarding the symptoms affecting PLWH with HANA conditions and the self-management strategies used to palliate these symptoms. PLWH with HANA conditions use a wide range of self-management strategies to manage symptoms. Overall, taking medication was a predominant self-management strategy, however seeking support from others was reported at a higher rate to be a more helpful strategy than taking medications. Depression and sexual dysfunction continue to be prevalent and bothersome symptoms and may best be ameliorated through self-management strategies. Helpful self-care strategies identified in this study can be used to guide self-management interventions which have the potential to improve quality of life in PLWH with HANA conditions.

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Compliance with Ethical Standards

Conflict of interest The authors declare no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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