ORIGINAL RESEARCH

HIV-related symptoms reported by older people living with HIV

Alejandra-Ximena Araya, PhD; Evelyn Scarlett Iriarte, MsN; Kareen Berger, PhD

Abstract

Introduction: Older people living with HIV experience symptoms that may influence their psychosocial well-being, quality of life and adherence to treatment. **Objective:** To analyze the symptoms in relation to their frequency and intensity that PMVVIH report with sociodemographic and clinical variables. **Material and Methods:** A cross-sectional study in 46 elderly people in an ambulatory clinic in Santiago, Chile. Socio-demographic, clinical variables and variables related to HIV were measured. For the analysis of data, descriptive statistics, chi-square and contingency tables were used. **Results:** The most frequent symptoms were: Fears and/or worries, depression, loss of memory and muscular pain. The symptoms with greater severity were: Fears and worries, prominent veins in lower extremities and gas and / or swelling. Years living with HIV and university education were correlated with a high number of symptoms. **Discussion:** The largest number of years living with HIV and having a complete university education correlates positively with the frequency of symptoms associated with HIV. It is important to evaluate the amount and intensity of the symptoms of PMVVIH. A better self-management of symptoms associated with HIV can have an impact on the perception of the quality of life of this group of people. **Key words:** HIV Infections, aged, signs and symptoms

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Introduction

It is estimated that 3.6 million people over the age of 50 are living with the Human Immunodeficiency Virus (HIV) worldwide. 1,2 In Chile, when analyzing by age groups, it is observed that the highest rates are between 29 and 49 years old. However, in Chile the rates of new HIV cases in groups over 50 years have increased by 30% between 2014 and 2018.3 This situation confirms the fact that older people living with HIV (PMVVIH) are being a group with behaviors risk 2 for the transmission of the virus and, in turn, a group that will demand more health care in the coming years.

HIV is considered a chronic disease in countries where antiretroviral therapy (ART)

is available .4 As with other chronic diseases, HIV-related symptoms are a major concern for those with the disease. HIV-positive people experience a constellation of concurrent symptoms across different levels of HIV markers and regardless of their ART status.5 The etiology of an HIV-related symptom is difficult to determine because symptoms can arise from the disease itself, from the secondary effects of ART, opportunistic infections and / or the product of other comorbidities, which are more common in this age group as a result of aging.

Symptoms can influence the psychosocial well-being and health outcomes of those who suffer from them. For example, having a high number of HIV-related symptoms has been associated with poor quality of life 6,7, lower adherence to medication 8, depression8, diagnosis of more advanced stages of the disease 6, sexual risk behaviors 9 and instability in viral load.10 In Chile there is little scientific evidence on the symptoms associated with HIV; The results of one study reveal that many people living with HIV with high CD4 counts and low or undetectable viral loads are not free of symptoms 11. Likewise, there are no published studies that focus on describing the symptoms associated with the disease. in older people. The objective of this study is to analyze the symptoms reported by PMVHIV, with respect to their frequency and intensity, with sociodemographic and clinical variables.

Material and method

Study design and sampling. Cross-sectional study with a sample of 46 PMVIH from an outpatient clinical center in Santiago de Chile. Eligible participants were people over 50 years of age living with HIV, without hospitalizations in the last 30 days, without a diagnosis of dementia or other mental disorders, if they were ART users they must have taken it for at least three months before enrollment to avoid reports symptoms related to treatment side effects.

All study procedures were approved by the Ethics Committee of the corresponding health service. PMVIH were informed about the study by their healthcare provider during their routine medical appointments. People who were interested in participating were referred to the principal investigator to verify the eligibility criteria and obtain informed consent. Afterwards, they were applied in a questionnaire to measure the variables under study and their medical records were reviewed to obtain information on clinical conditions.

Measurement of variables.

(i) Socio-demographic: The data collected were: age, sex (woman / man), sexual orientation (men who have sex with men / bisexuals and heterosexuals), marital status (single, cohabiting, married, separated, widowed), have children (yes / no), number of children, level of education (basic, secondary, technical and university education), employment status (full-time, part-time, unemployed, retired), health system (private / public).

(ii) Clinical conditions: Clinical data included number of HIV-related symptoms, intensity of HIV-related symptoms (mild, moderate, severe), years living with HIV, age at HIV diagnosis, being in treatment with ART (yes / no), time of HIV infection (years), last CD4 count, undetectable viral load (<80 copies / ml), have comorbidities (yes / no), number of comorbidities.

(iii) HIV-related symptoms: The Revised Signs and Symptoms Checklist for People with HIV Disease (SSC-HIVrev) was used to assess HIV-related symptoms.12 The

SSC-HIVrev was originally created in English. Therefore, a Spanish version of this scale was developed for the study following the translation / back translation method. 13 First, three Chilean HIV care providers evaluated the content validity of the Spanish version of SSC-HIVrev for the clarity and coherence of the articles and then it was tested with 10 Chileans with unknown HIV status. The SSC-HIVrev has three parts. Only parts 1 and 2 were included in the analysis; given that the majority of people with HIV in Chile were male and the gynecological data in part 3 would have limited applicability. Part 1 consists of 45 items regarding HIV-related symptoms that are grouped into 11 factors. Part 2 consists of 19 HIV-related symptoms that are not grouped into a single factor. Participants assessed 64 items on HIV-related symptoms to assess symptom intensity, and were asked to report intensity using a scale from 0 (not present) to 3 (severe). Possible ranges are 0-64 for the number of symptoms and 0-192 for the intensity of the symptom. The internal consistency SSC-HIVrev for this study was 0.92.

Statistic analysis. Descriptive statistics were used to assess HIV symptom status, sociodemographic status, and clinical condition. Means and standard deviations were calculated for continuous variables and percentages for categorical variables. The correlation between the sociodemographic and clinical variables of the participants with respect to the frequency of symptoms was made with chi-square and contingency tables. A p value <0.05 was considered significant. IBMSPSS for Windows Version 25.0 were used for data analysis.

Results

Sociodemographic characteristics: Table 1 shows the sociodemographic and clinical characteristics of the participants. The average age of the sample was 60 + 6.4 years with a range of 50 and 76. Of the total sample, 82.6% were male and the rest female; of these, the majority identified themselves as men who have sex with men or bisexuals (43.5%). Of the total sample, 65.2% reported having children with an average of 3 + 1.2 children. The educational level was predominantly university (43.5%), with a mostly full-time job (58.7%). Regarding the health system, the majority belonged to the public care system (63%). PMVIH reported having support networks that they could count on in case of emergency (95.7%).

Clinical characteristics of the sample: The mean time they lived with HIV since diagnosis was 5 years, the age of diagnosis being 53 + 8.4 years. Most of the participants received ART (87%), had CD4 counts above 350 cells / mm3 (63%), and undetectable viral loads (84.4%). Lamivudine / Zidovudine and Efavirenz were the most frequently used types of ART. 41.3% of the sample had comorbidities, being type 2 diabetes mellitus (10.9%) and arterial hypertension (10.9%) the most frequently reported diseases.

Characteristics of the frequency of HIV-related symptoms: Table 2 shows the 15 most frequent symptoms with their respective intensities. PMVIH reported an average frequency of 12.4 + 8.3 different HIV-related symptoms. The most commonly reported symptoms were: Fears and worries (56.5%), depression (56.5%), memory loss (50%) and muscle pain (50%). On the other hand, those symptoms that were not reported by any PMVIH were: nipple discharge, breast pain, and pain or nodules in the genitals (0%).

Table 1. Sociodemographic and clinical characteristics of the participants. (n=46)

	M (SD)	% (n)
Características sociodemográficas		
Age	57,8 (6,4)	
Male		82,6 (38)
Sexual orientation		47,6 (20)
Marital status		
- Single		39,1 (18)
- Married		43,4 (20)
- Separate		13,0 (6)
- Widow/Widower		4,3 (2)
Having children		65,2 (30)
Mean number of children	2,7 (1,2)	
Highest level of education completed		
- Elementary school		6,5 (3)
- High school		32,6 (15)
- Technical school		15,2 (7)
- College		43,5 (20)
Employment status		
- Full-time		58,7 (27)
- Part-time		10,9 (5)
- Unemployed		19,6 (9)
Health insurance		
- Public		63,0 (29)
- Private		37,0 (17)
Clinical characteristics of participants		
Number of HIV-related symptoms	12,4 (8,3)	
Intensity of HIV-related symptoms		
- Mild	30,4 (14)	
- Moderate	32,6 (15)	
- Severe	37,0 (17)	
Years living with HIV	5,0 (5,1)	
Age at the time of diagnosis	53,0 (8,4)	
HIV CDC classification at the time of diagnosis		37,8 (17)
Taking ART		87,0 (40)
Years living with ART	4,8 (4,8)	
CD 4 count: > 350 cell/mm^3		64,4 (29)
Undetectable viral load level (< 80 copies/mL)		84,4 (38)
Having comorbidities		41,3 (19)
Mean of comorbidities	1,6 (0,7)	

Tabla 2. Frecuency and intensity of HIV-related symptoms among elderly population (N=46)

Síntomas relacionados con el VIH	Frecuencia del síntoma (%)	Intensidad del síntoma (%)		
		Leve	Moderado	Severo
Fear and/or worries	56,5	23,9	21,7	10,9
Depression	56,5	26,1	28,3	2,2
Difficulty concentrating	50,0	32,6	15,2	2,2
Muscle aches	50,0	30,4	19,6	0,0
Gas and/or bloating	47,8	26,1	13,0	8,7
Skinny arms and legs	47,8	23,9	19,6	4,3
Prominent leg veins	45,7	17,4	17,4	10,9
Anxiety	45,7	21,7	19,6	4,3
Fat deposit in the abdomen	43,5	26,1	10,9	6,5
Joint pain	43,5	28,3	15,2	0,0
Shortness of breath with activity	43,5	26,1	0,0	0,0
Weakness	41,3	19,6	15,2	6,5
Dry mouth	41,3	19,6	15,2	6,5
Thirst	41,3	19,6	15,2	6,5
Insomnia	41,3	19,6	17,4	4,3

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Characteristics of the intensity of HIV-related symptoms: For PMVIH with intensity of mild symptoms, the highest prevalence is memory loss (32.6%), arm numbness / tingling (32.6%), numbness / tingling feet or toes (32.6%) and numbness / tingling of fingers (32.6%). Regarding symptoms of moderate intensity, depression (28.3%), fears and worries (28.3%), anxiety (19.6%), muscle pain (19.6%) and thin arms and legs (19, 6%). As for the symptoms with greater severity referred to by PMVIH, there are fears and worries (10.9%), the presence of prominent

veins in the lower extremities (10.9%) and the presence of gas and / or bloating (8 , 7%).

Correlation between frequency and intensity of symptoms with sociodemographic and clinical variables. The greater number of years living with HIV and having a complete university education is positively correlated with the frequency of symptoms associated with HIV, that is, the greater the number of years living with HIV, the greater the reporting of a high number of symptoms related to HIV. HIV Contrary to what was expected, no correlation was found between reports of a high number of HIV-related symptoms and the following sociodemographic characteristics: age, being a man, being homo or bisexual, having a job, having comorbidities, living with a spouse / partner, having children, or the number of close friends and / or relatives. The following clinical characteristics were not significant either: disease stage at diagnosis, ART intake, CD4 count, and viral load. In the multiple regression analysis, years living with HIV and having completed college remained significantly related to the number of HIV-related symptoms, representing 5.7% of the variance in the number of HIV-related symptoms, $F(2, 203) = 6.1$, $p = 0.003$.

Discussion

The profile of PMVIH corresponds to people of 60 years of age, male, homosexual and / or bisexual, with a university educational level and full-time employees. In addition, PMVIH state that they have support networks. Regarding the clinical profile, the majority of older people receive ART, have comorbidities and were diagnosed at an early age.

Frequency and intensity are key components in HIV-related symptoms. Having a high number of HIV-related symptoms has been associated with a poor quality of life 6,7, lower adherence to medication 8,14, diagnosis of AIDS6, sexual risk behaviors 9 and instability in viral load.10 Without However, other researchers have found no association between the number of HIV-related symptoms and CD4 5 counts or viral load.15 Therefore, there are mixed findings related to HIV biomarkers and the frequency and intensity of symptoms. . On the other hand, a higher prevalence of frailty has been associated with PMVIH and a greater deficit in areas of executive functioning and memory 16-18, thus affecting the level of functionality of the person, mainly in the instrumental activities of daily life. 19

With regard to the number of symptoms related to HIV, these can vary according to race / ethnicity 20-22. It has been reported that a low number of these symptoms can cause important problems in patients on ART.23 Fears, worries and depression were the most frequent symptoms in this sample. It is striking that both symptoms are from the psychological area and are not directly related to HIV status or as a side effect of ART. Fatigue in PMVIH can result from the stressful events associated with the disease and is linked to the anxiety and depression that accompany these events. 20 This is consistent with previous findings, which indicate that the experience of symptoms is in accordance with the person's way of life and their experience prior to diagnosis.24

This study showed how the greater number of years living with HIV and having a complete university education is positively correlated with the frequency of symptoms associated with HIV. This coincides with what was reported by a study carried out in Brazil where those who only had secondary school studies could not make clear reference to the

signs of living with this disease. 25 However, other studies have shown a positive relationship between the intensity of fatigue and a greater deterioration in functionality with fewer years of schooling. twenty

Living with HIV in advanced ages implies the acceleration and accentuation of the negative effects of aging, which is generally accompanied by a series of comorbidities.24,26 Physiological changes associated with aging and the alteration of metabolism in older people, in addition of polypharmacy, exposes them to drug toxicity and drug interactions. 27,28 This limits the identification of symptoms experienced by PMVIH, which affects the difficulty of differentiating their etiology. For example, specific comorbidities, such as depression, significantly increase the severity of fatigue, impacting the socialization and functioning of the people who experience it. twenty-one

Among the limitations of this study are that the participants constitute a select group compared to other PMVIH who may receive less medical attention and control. Likewise, unlike other countries, this group, apart from receiving high-quality care, receives free ART treatment. Future studies should focus on identifying HIV-related symptoms that often do not occur in isolation, but rather in a group or pattern 25 and longitudinal studies aimed at characterizing populations of older women in order to establish differentiating elements according to sex. In addition to the above, it is suggested to consider a comprehensive assessment as part of routine controls regarding symptoms associated with HIV in older people. The use of symptom self-report instruments can help health personnel to guide their care directed at these people. Better symptom management can impact the perception of the quality of life of people living with HIV infection.

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