Original Article

Symptoms Experience among People Living with Human Immunodeficiency Virus in a Clinic

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ABSTRACT

Introduction: Symptoms assessment is the foremost and first step of health care management. People living with Human Immunodeficiency Virus (HIV) experience various physical and psychological symptoms throughout the disease. Adherence to antiretroviral therapy (ART) and an individual's quality of life is adversely affected by poorly managed severe symptoms. This study aimed to assess the prevalence of symptoms among people living with HIV who attended an Antiretroviral Therapy (ART) clinic.

Methods: A descriptive cross-sectional study was carried out among consecutively selected 208 people with HIV who attended an ART clinic. Memorial Symptoms Assessment Scale (MSAS) was used to assess the symptoms. Data were collected through the interview method. Descriptive (Mean, SD), independent t-test, and one-way ANOVA were used for data analysis.

Results: Among 208 respondents, the most prevalent symptoms in people with HIV receiving ART were numbness and tingling sensation in hands and feet (37.5%), followed by lack of energy (33.7%), pain (29.8%) and weight loss (25.5%). Likewise, the most distressing symptoms were: numbness and tingling sensation in hands and feet (20.2%), lack of energy (19.8%), pain (18.3%), and feeling sad (4.3%). Total symptoms score and physical symptoms occurrence were significantly different according to age, CD4 count, duration of taking ART, and presence of comorbidities.

Conclusions: People living with HIV are experiencing various physical and psychological symptoms despite receiving antiretroviral therapy. These distressing symptoms need to be acknowledged and managed holistically.

Keywords: ART center, Distressing symptoms, Experience, People living with HIV

INTRODUCTION

Globally, 36.2 million people were living with HIV at the end of 2018. An estimated 0.8% [0.6-0.9%] of adults aged 15–49 years worldwide are living with HIV, and 23.3 million are receiving Antiretroviral Therapy (ART).[1] In Nepal, about 30,000 adult people living with HIV. Among them, 56% are on antiretroviral therapy.[2]

Symptoms are defined as perceived health-related experiences described by their intensity, frequency, and duration, interference with daily activities, which vary with time.[3-4] People with HIV receiving ART still experiencing various distressing symptoms because of side effects, progression of opportunistic infections and comorbidities.[5-6]These distressing symptoms are higher in patients with comorbidities and multi-morbidities such as liver disease, viral hepatitis, and metabolic and cardiovascular diseases. [7] The most prevalent symptoms were pain, feeling sad, feeling drowsy, worrying, lack of energy, difficulty sleeping, numbness, weight loss, and fatigue.[8-10] and more than 30% of people with HIV in the USA had an average of 7 or more symptoms at the same time. Better physical function was associated with fewer symptoms ($p = 0.047$).[11] The World Health Organization (WHO) stressed that effective symptom management is critical to HIV clinical care.[1] However, the study evidenced the inadequate

consideration for symptom assessment and management, as healthcare providers identify three times fewer HIV-related symptoms than reported by patients.[6] Symptoms management is an essential component and focuses have been alleviating the burden of distressing symptoms, thereby increasing treatment adherence, decreasing risk behavior and improving patients' quality of life[13]. Therefore, this study aimed to assess the prevalence of distressing symptoms in the previous seven- days period among people living with HIV attending ART clinic.

METHODS

The study was conducted among people living with HIV who were coming for a monthly follow-up visit at the ART center of Narayani Hospital, Birgunj, Parsa. A consecutive sampling method was used to recruit 208 respondents. People living with HIV receiving ART, aged above 18 years, and willing to participate were included in the study, except for pregnant and postnatal mothers. The enumerator collected data for four weeks (Jan 9 to Feb 5, 2017). Bachelor nurses were involved in data collection after orientation about the study and data collection process. Data were collected by in-person interviews using a structured schedule of two parts. The first part consisted of sociodemographic information and clinical variables, including stages of the disease, comorbidities, current CD4 count, viral load, and duration of receiving ART. In contrast, the second part consisted of the standardized instrument. Memorial Symptoms Assessment Scale (MSAS) validated multidimensional instruments to assess the symptom burden of people living with HIV, cancer patients, and patients with advanced illnesses were used.[14-15]

The original version of MSAS evaluates multiple dimensions for 32 symptoms (intensity, frequency, and distress), and a short form (MSAS-SF) evaluates the frequency and distress of symptoms in the past seven days.[14] MSAS-SF has three subscale indices of physical symptom distress (MSAS-PHY) that includes 12 prevalent physical symptoms (lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness), psychological symptom distress (MSAS-PSY) includes six prevalent psychologic symptoms (worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating) and global distress index (MSAS-GDI) includes four psychologic symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and six physical symptoms(lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth), Distress for physical symptoms were rated as "not at all to very much." Psychological symptoms were rated as "rarely to almost constantly" andscore range of 0-4. Based on the prior studies, symptoms rated as "quite a bit" and "very much" was considered as high distressing physical symptoms, and " frequently" and "almost constantly" was considered as high distressing psychological symptoms.[16,4]The 32 individual symptom scores were averaged to produce a total MSAS score.

Data were collected after obtaining ethical approval from the Institute of Medicine's Institutional Review Committee (IRC) [Reference no.160 (6-11-E)2/073/074] and hospital authorities. All the respondents explained the study's objective; written consent was taken for voluntary participation in the study. Information about the stage of disease, CD4 count, duration of taking ART, and duration of illness were collected from the treatment record file. Data were analyzed using IBM Statistical Package for the Social Sciences (SPSS) version 20. Descriptive and inferential statistics (one-way ANOVA, independent t-test) were used for data analysis with an acceptable significance level of <0.05.

RESULTS

Half of the respondents (51%) were between the age of 30 and 39, with a mean age of 35.89±8.62. More than half of the respondents (62.5%) were male, 77.9% were married, 86.5% were Hindu, and almost all (96.2%) were employed. Regarding stages of illness, 51.9% were in the second stage, and only 7.7%were in the fourth stage. Furthermore, the majority (69.2%) have taken ART for less than five years. Regarding the current CD4 count, the mean CD4 count was 422.4, and 39% had a CD4 count of less than 350, which was the cut-off value at the time of starting ART. Only 14.4% had associated comorbidities; among them, 43.4% had pulmonary tuberculosis, followed by hypertension and diabetes mellitus (Table 1).

Among 32 symptoms, the most commonly occurring symptom was numbness and tingling sensation in hands and feet (37.5%), followed by lack of energy (33.7%) and pain (Table 2).Numbness and tingling sensation in hands and feet (20.2%), lack of energy (19.8%), and pain (18.3%) were the common distressing physical symptoms experienced by respondents. Similarly, feeling nervous (11.0%), feeling sad (4.3%), and having difficulty sleeping (2.4%) were the distressing psychological symptoms for them (Table 3).

While calculating the difference between demographic characteristics, clinical variables with distress sub-scale (PHYS, PSY, and GDI), and total symptom score, the study showed a significant difference between the age of respondents (p=0.042), current CD4 count (p=0.046) and presence of comorbidities (p=0.000) with total symptoms score. Respondents who had comorbidities experienced more symptoms rather than those who had no comorbidities (Table 4)

Similarly, there was a significant difference between physical symptoms with the duration of taking ART (p=0.02), current CD4 count (p=0.006), and presence of comorbidities (p=0.001) (Table 5)

Table 1: Sociodemographic and Clinical Variables of the Respondents (n=208)

Variables	Number	Percentage
Age (in Years)		
20-29	40	19.2
30-39	106	51.0
40-49	47	22.6
50-59	11	5.3
>60	4	1.9
Mean age and SD 35.89 ±8.6		
Sex		
Male	130	62.5
Female	76	36.5
Transgender	2	1.0
Marital Status		
Married	162	77.9
Unmarried and widow	46	22.1
Religion		
Hindu	180	86.5
Islam	14	6.7
Buddhism	11	5.3
Others	3	1.4
EthnicGroup		
Madhesi	102	49.3
Brahmin/ Chhetri	50	24.0
Dalit	19	9.1
Janajati	12	5.7
Muslim	14	6.7
Others	11	5.2
Clinical variables		
Stage of Illness		
1	25	12.0
2	108	51.9
3	59	28.4
4	16	7.7

Recent CD4 Count		
< 350	81	39.0
>350	127	61.0
Presence of Comorbidities		
No	178	85.6
Yes	30	14.4
Duration of ART		
<1 year	24	11.5
1-5 years	120	57.7
>5 years	64	30.8

Table. 2 Symptoms Experienced by Respondents (n=208)

Symptoms	Number	Percentage
Numbness and Tingling Sensation in Hands/feet	78	37.5
Lack of Energy	70	33.7
Pain	62	29.8
Dry mouth	58	27.9
Weight loss	53	25.5
Cough	51	24.5
Lack of Appetite	51	24.5
Diarrhea	44	21.2
Worrying	43	20.7
Feeling sad	43	20.7
Sweating	42	20.2
Nausea	35	16.9
Don't look like Myself	34	16.3
Change in food taste	34	16.3
Feeling nervous	34	16.3
Feeling irritable	34	16.3
Difficulty in sleeping	30	14.4
Difficulty Concentrating	27	13.7
Feeling blotted	26	12.5
Shortness breath	21	10.1
Mouth Sore	20	9.6
Constipation	20	9.6
Vomiting	19	9.1
Dizziness	18	8.7
Hair loss	18	8.7
Itching	15	7.2
Change in skin	13	6.3
Problem with sexual interest or Activity	6	2.9
Swelling of arms or legs	5	2.4
Problems with urination	5	2.4

Based on Memorial Symptoms Assessment Scale (MSAS)

Table 3. Most Frequently Distressing Physical Symptoms During Past Seven days (n=208)

Physical Symptoms	Distress Level					
	Not at all/ a little bit		Somewhat		Quite a bit/ Very much	
	N	%	N	%	N	%
Numbness and tingling sensation in hands/feet	3	1.4	33	15.9	42	20.2
Lack of energy	7	3.2	22	10.7	41	19.8
Pain	3	2.4	19	9.1	36	18.3
Lack of Appetite	3	1.4	27	13.0	21	10.1
Cough	8	3.8	25	12.0	18	8.7
Dry Mouth	7	5.3	35	6.7	16	7.7
Weight loss	14	6.7	28	13.5	15	7.2
Diarrhoea	12	5.8	21	10.1	12	5.8
Change in the way food taste	2	1.0	22	10.6	11	5.3
Nausea	11	5.3	14	6.7	10	4.8

Table 4. Most Distressing Psychological Symptoms During Past Seven days (n=208)

Psychological Symptoms	Rarely		Occasionally		Frequently/Almost constantly	
	Number	Percentage	Number	Percentage	Number	Percentage
Feeling Nervous	1	0.5	8	3.8	23	11.1
Feeling sad	12	5.8	22	10.6	9	4.3
Worrying	11	5.3	23	11.1	9	4.3
Feeling irritable	6	2.9	22	10.6	7	3.4
Difficulty sleeping	13	6.3	12	5.8	5	2.4
Difficulty in concentrating	3	1.4	21	10.2	3	1.4

Table 5. Difference Between Demographic Characteristics, Clinical Variables, and Total Symptoms Score (n=208)

Variables	No	Total Symptoms Score Mean(SD)	p-value
Age (In years)			0.042*,**
<35 years	125	10.0(6.5)	
>35 years	83	12.1(7.8)	
Gender			
Male	130	10.7(7.0)	0.536*
Female	76	11.3(7.4)	
Transgender	2	6.0(2.8)	
Treatment Duration			
<5 year	144	11.4(8.0)	0.085*
>5 year	64	9.6(4.1)	
Present CD4 count			
< 350	81	12.1(8.6)	0.046**
> 350	127	10.1(5.8)	
Stage of Disease			
1	25	10.7(6.3)	0.103
2	108	9.8(6.2)	
3	59	12.3(8.6)	
4	16	12.9(6.9)	
CComorbidities			
Yes	30	15.2(9.2)	<0.001**
No	178	10.1(6.4)	

** Independent t-test, **p-value significant at <0.05*

Table 6. Difference Between Demographic Characteristics, Clinical Variables and Distress Subscales (n=208)

Variables	No	Distress Subscales		
		MSAS-PHY	MSAS-PSY	GDI
		Mean (SD)	Mean (SD)	Mean (SD)
Age(In years)				
<35 years	125	12.5(9.9)	9.8(5.6)	8.8(7.2)
>35 years	83	14.1(11.4)	12.0(6.6)	11.1(8.8)
		0.111	0.010*	0.0423*
Gender				
Male	130	12.4(10.0)	10.9(6.1)	9.4(7.9)
Female	76	15.3(11.3)	10.4(6.3)	10.4(8.0)
Transgender	2	7.0(1.4)	9.0(4.2)	6.50(3.5)
p*- value*		0.114	0.819	0.566
Treatment Duration				
<5 year	144	14.5(11.6)	11.2(6.4)	10.4(8.7)
>5 year	64	10.9(7.2)	9.62(5.3)	8.1(5.6)
***p*-value**		0.023*	0.080	0.050
Present CD4 count				
< 350	81	15.9(12.4)	11.2(6.2)	10.9(8.4)
> 350	127	11.8(8.9)	10.4(6.0)	8.9(7.5)
p*-value*		0.006	0.361	0.076
Stage of Disease				
1	25	15.1(11.7)	8.9(4.9)	9.2(8.4)
2	108	12.24(9.0)	10.8(6.1)	8.8(7.6)
3	59	1.6(12.52)	11.4(6.9)	10.8(8.3)
4	16	18.3(10.0)	10.0(4.7)	12.2(7.5)
***p*-value**		0.136	0.364	0.259
Presence of Comorbidities				
Yes	30	19.2(12.8)	10.3(6.3)	13.4(9.6)
No	178	12.5(9.8)	10.8(6.1)	9.1(7.4)
***p*-value**		0.001*	0.693	0.006*

*p-value significant at <0.05

DISCUSSION

Symptoms assessment is the major component and first step of health care management. Severe and troublesome symptoms affect adherence to ART and the quality of life of people living with HIV/AIDs.[10] The present study shows that 51.9% were in the second stage, only 7.7% were in the fourth stage, and two third of the respondents had been taking ART for less than five years. This finding correlates with the study done in Namibia[13] which showed that the average time duration on ART was 3-4 years.

People living with HIV may experience a variety of multiple symptoms simultaneously.[17] In the present study, the most prevalent symptoms reported by respondents were numbness and tingling sensation in hands and feet (37.5%), lack of energy(33.7%), pain (29.8%), dry mouth (27.9%), weight loss (25.5%), diarrhea (21.2%), worrying (20.7%), feeling sad (20.7%), sweating (20.2%) and nausea (16.9%) which is consistent with a study conducted by Merlin et al.,[8] reported that the most common symptoms were pain (61.9%) lack of energy (57.1), numbness and tingling sensation in hands and feet (46.2%), sweating (43.0%) and dry mouth (32.7%) diarrhea (31.4%). Similarly, a study by Brand [14] and Harding et al.[4] identified similar symptoms to the present study. In various studies [9,11, 14], psychological symptoms were reported as the most prevalent, whereas in the present study, physical symptoms were more

prevalent. The possible reason for underreporting of psychological symptoms might be the social and religious beliefs around the consequences of psychological and mental disorders in Nepal .[18]

The symptoms responsible for distress were highly variable. Among the reported symptom, the percentage describing it as highly distressing was most significant for numbness. Tingling sensation in hands/feet (20.2%), lack of energy (19.8%), pain (18.3%), and lack of appetite (10.1%) were the most distressing physical symptoms, whereas feeling nervous (11.0%), feeling sad (4.3%), worrying (4.3%) and feeling irritable (3.4%) were related to the psychological symptoms. A study conducted by Brand [14] in Namibia also found that pain (47.7%), worrying (41.2%), feeling sad (33.3%), feeling irritable (20.9%), and difficulty sleeping (29.6%) were the most distressing symptoms. Likewise, a study conducted by Dhingra et al. [19] found the percentage for highly distressing was greatest for worrying (54.8%), weight loss (52.1%), feeling sad (51.5%), pain (44.0%), lack of appetite (41.9%), dry mouth (37.8%) and feeling nervous (35.6%) which was alike with our study findings. However, the study done by Lee et al.,[20] in HIV clinics and community sites in the San Francisco Bay area found that the most distressing symptoms were hair loss (52%) followed by "I don't look like myself" (48%), the problem with sexual interest (47%), feeling sad (43%) and sweating (41%). This variation might be due to the study setting.

The total symptom score was significantly different according to the age and CD4 count of the respondents; these findings parallel with other studies' findings as the prevalence and distress of symptoms were not associated with CD4 count and stage of the disease.[10,15] Moreover, the present study showed that respondents having comorbidities experienced more symptoms (p=0.000). Females experienced high physical symptoms and global distress, likewise in a study conducted by Koole et al.[15] also concluded that females experience higher symptoms burden, however in a study conducted by Nami Sango et al.[21] documented that being male was associated with psychological symptoms of distress, which corresponded with our study findings as male experience higher psychological symptoms distress. This study has significant limitations as being a single-center study that may need more generalization in other settings and populations. The cross-sectional design did not permit an evaluation of changes in symptoms over time, so further study is recommended for a longitudinal study.

CONCLUSION

The study concludes that people living with HIV experience distressing symptoms despite taking regular ART. The most typical physical and psychological symptoms are numbness and tingling in hands and feet, followed by lack of energy, pain, nervousness, sadness, and difficulty sleeping. Likewise, the most distressing symptoms are numbness and tingling in hands and feet, lack of energy, pain, nervousness, sadness, and difficulty sleeping. The total symptoms score and physical symptoms differ according to age, CD4 count, and the presence of comorbidity in people living with HIV. Therefore, healthcare providers and institutional policy should regularly practice comprehensive assessment and management of symptoms during follow-ups at ART centers considering the age, CD4 count, and presence of comorbidities of the people living with HIV.

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