Symptoms and Quality of Life of People Living with HIV Infection in Puerto Rico

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***Background*: People living with HIV infection are confronted with physical and psychological symptoms that impact their quality of life. This study explored the symptom experience of people living with HIV infection in Puerto Rico and its correlation with quality of life.**

***Methods*: A cross-sectional descriptive design was used to survey 44 men, women, and transgender people living with HIV infection. Measures included a demographic questionnaire, sign and symptom checklist, and a quality of life instrument.**

***Results*: The sample was 50% male with a mean age of 42.1 years; the participants had been living with HIV infection an average for 9.8 years. The top five symptoms reported by the sample included: muscle aches (81.8%), depression (77.2%), weakness (70.5%), fear/worries (70.5), and difficulty concentrating (65.9%). Symptom frequency was significantly related to four dimensions of quality of life: overall function (r=-0.58), life satisfaction (r=-0.59), health worries (r=0.32) and HIV medication worries (r=0.59). The symptom experience was not related to financial worries, disclosure worries, or sexual functioning. Individuals who reported taking HIV medications reported significantly fewer symptoms than those not taking HIV medications (t=3.061, df=42, p<0.01).**

***Conclusions*: These results suggest that people living with HIV infection in Puerto Rico experience a wide array of physical and psychological symptoms and that these symptoms have a correlation with their perceived quality of life. Better management of symptoms may have an impact on perceived quality of life for people living with HIV infection.**

Key words: HIV/AIDS, Symptoms, Quality of life, Puerto Rico

The HIV/AIDS epidemic has spread widely across the globe and, currently, the Caribbean has the second highest prevalence of the epidemic in the world after Sub-Saharan Africa (1). Recent figures show that 1.4 million people are living with HIV in Latin America (1). Puerto Rico has been severely affected by HIV/AIDS since the beginning of the epidemic. Of the more than 31,586 reported cases of AIDS, 68% have died (2). Since 2003, 6,175 new cases of HIV have been identified (2). Therefore, the true impact of the HIV/AIDS epidemic has probably been underestimated. Although the availability of antiretroviral therapy (ART) medications has reduced the death rate from AIDS, the rate of HIV infection has not declined (3).

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A diagnosis of HIV disease places unique burden on every aspect of the daily life of persons afflicted with this disease. People living with HIVinfection are confronted with physical and psychological challenges related to the disease, medication modalities, and other health conditions. The experience of HIV-related symptoms is a significant part of that challenge. Symptom experience is a dynamic process and includes the patient's perception, evaluation, and response to symptoms (4).

Although symptom management is an essential component of HIV care, it is also often a neglected one. Many symptoms experienced by patients are under recognized and under treated. Symptoms related to HIV disease include dyspnea, fever, fatigue, nutrition problems, anxiety, sleep disturbance, depression, and anemia (5). On the other hand, complex treatment also causes symptoms such as nausea, vomiting, pain, diarrhea, headache, neuropathy and numbness (6). Thus, constellations of HIV-related symptoms negatively affect the quality of life of people living with HIV infection. Effective management of symptoms is important for

improving quality of life and for potentially maintaining a complicated daily regimen of ART (7).

The prevalence of symptoms, symptom etiology, symptom distress, and functional status has been documented in a number of studies (8-13). The distress associated with the diagnosis of HIV infection can result in anxiety about a range of issues including treatment, mortality, stigma and change in daily life as well as depression and fear (14-15). Few studies have addressed the HIV symptom experience of Hispanic/Latino people (16); and specifically understanding the symptom experience of people living with HIV infection has been under explored in Puerto Rico.

The purpose of this study was to describe self-reported symptom experience among a sample of men, women, and transgender living with HIV infection in Puerto Rico and to explore potential relationships of HIV symptoms with quality of life.

Methods

Research questions

Two study questions were addressed:

1. What is the frequency of symptoms in a sample of people living with HIV infection in Puerto Rico?
2. Is there a relationship between HIV symptoms and perceived quality of life?

Design

A cross-sectional descriptive design was used to gather self-reported data on the presence of symptoms in a sample of 44 participants (22 men; 21 women; 1 transgender) living in a community housing project in Puerto Rico. The participants in this study were part of a larger international study on self-care symptom management of HIV/AIDS conducted by members of the University of California, San Francisco International HIV/AIDS Nursing Research Network. Eligibility criteria included the following: a) male, female, or transgender 21 years of age or older, b) self-reported HIV positive, c) speak and understand Spanish, and d) able to provide informed consent. The protocol was reviewed and approved by the Institutional Review Boards of the University of Puerto Rico and University of California, San Francisco. To assure confidentiality and privacy, access to the HIV positive residents of the community housing project was provided by the director of the support program. A research assistant and the investigator recruited all participants who potentially met study criteria. The participants were recruited and given a detailed overview of the study, including time required for participation and potential risks and assurances of confidentiality. Informed written consent was obtained from each participant. Participants received a $20 incentive immediately following their participation in the study. Three self-reported instruments were utilized in this study, including a socio-demographic questionnairie, the HIV/AIDS Targeted Quality of Life Instrument HAT-QoL, (24) and the Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev). The instruments were translated into Spanish from the original English. The questionnaires were adjusted to the Spanish dialect spoken in Puerto Rico and then examined for content validity by a panel of experts in the field of HIV care.

Instruments

1) Socio-demographic Questionnaire. Data related to participant characteristics (age, race, gender, education, income, work status, years with HIV, CD4 count, viral load, medical conditions) and their experience with alcohol use, drugs, tobacco and violence were collected.

2) HIV/AIDS Targeted Quality of Life Instrument (HAT-QoL) (24). This 34-item quality of life instrument is a disease-specific quality of life measure assessing nine dimensions: overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust, and sexual function. All dimensions are scored so that the final dimension score is transformed into a linear 0 to 100 scale, where 0 is the worst score possible and 100 is the best score possible. Multi-trait, multi-item assessment indicated correct correlations (> 91%) for eight of the nine dimensions. Construct validity was determined through various self-reported HIV disease markers and self-reported socio-demographic variables (17). In a multi-site, multi-country study, including Puerto Rico, with HIV-positive individuals (n=1217), internal consistency reliability coefficients ranged from 0.83 to 0.88 for all nine dimensions (18).

3) The Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev). The SSC-HIVrev has three parts: Part I consists of 45 items and eleven factor scores, along with a total score, with reliability estimates ranging from 0.76-0.91; Part II consists of 19 HIV-related symptoms that do not cluster into factor scores, but may be of interest from a clinical perspective; and Part III consists of eight items related to gynecological symptoms for women that are not reported in the other two parts. These eight items were submitted to a principal components factor analysis with Varimax rotation (n = 118 HIVpositive women) and a one-factor solution explained 71.8% of the variance. The Cronbach's alpha reliability estimate for the total scale was 0.94 (19).

Data analysis

The data were analyzed using Statistical Package for the Social Sciences (SPSS) for Windows software version 13. The responses to the instruments were coded and descriptive statistics such as frequencies, percentages, and measures of central tendencies, and standard deviation were performed to compare the characteristics of the sample. T-tests were calculated to explore differences and r Pearson correlations were performed to analyze the associations among variables.

Results

Data were collected using a convenience sample of 44 men (n=22), women (n=21), and one transgender person (n=1) living in a community housing project located in an urban area in San Juan, Puerto Rico (Table 1). Participants ranged in age from 25 to 59 with a mean age of 42.08 years (SD=8.89). Fifty-seven percent (57%) of the participants had grade school or high school education. Sixty-six percent (66%) of the participants reported having children, while ninety-five percent (95%) of the participants relied on Medicaid or the government health care reform insurance. Only 18.2% reported currently working for pay. Income adequacy was reported between barely adequate (47.7%) or totally inadequate (31.8%) to meet their needs. At the time of the study, fifty-nine percent (59%) of the sample reported currently taking HIV medications. Seventy-seven percent (77%) reported that, in addition to HIV infection, they were also dealing with other health conditions, including depression (22.7%), asthma and anemia (22.7%).

The coexistence of violence and drug use was also identified among the study sample. Forty-one percent (41%) of the sample reported having been physically abused by a partner or other person. Sixty-six percent (66%) of participants reported being hit, slapped or kicked and 27.3% of the sample reported forced sexual activity. Current tobacco use was 55%, alcohol use was 32%, and marihuana and cocaine use were reported by 66% of the respondents. Forty-five percent of the sample formerly used heroin. Twenty-two percent (22%) of the sample also reported other comorbidities including asthma, anemia, and depression.

The top ten symptoms reported by the sample are presented in Table 2. The top five symptoms included: muscle aches (81.8%), depression (77.2%), weakness (70.5%), fear/worries (70.5), and difficulty concentrating (65.9%). Overall symptom frequency was significantly related to four dimensions of quality of life, including overall function (r=-0.58), life satisfaction (r=-0.59), health worries (r=0.32) and HIV medication worries

Table 1. Demographic Characteristics of Study Sample (N=44)

Variables	**M**	**SD**
Age	42.1	8.9
Years HIV +	9.8	6.1
Years on HIV Meds	8.9	5.8
	N	**%**
Race		
African	6	14%
American/Black	32	73%
Hispanic/Latino	6	14%
White/Anglo	3	7%
Gender		
Male	22	50%
Female	21	49%
Transgender	1	1%
Highest Education		
Grade School	14	32%
High School	11	25%
Tech./vocational	9	21%
College	8	18%
Postgraduate	2	4%
Acquired HIV*		
Sex with man		47.7%
Male	6	
Female	15	
Sex with woman		27.2%
Male	12	
Shared needles		29.5%
Male	9	
Female	4	
Blood transfusion/other		6.8%
Male	1	
Female	2	
Frequency & Percentage "Yes"		
One or more children at home	10	22%
Work for pay	8	18.2%
Physically abused by partner	18	40.9%
Physically hit, slapped, kicked	29	65.9%
Forced sexual activity	12	27.3%
AIDS diagnosis	7	15.9%
Know most recent Viral load	21	36.4%
Knows if Undetectable	16	47.7%
Ever taken HIV Meds	38	86.4%
Taking HIV Meds now	26	59.1%
Other Medical Conditions	34	77.3%
Asthma &Anemia	10	22.7%
Depression	10	22.7%
Unhealthy behaviors		
Tobacco	24	55%
Alcohol	14	32%
Marijuana	29	66%
Cocaine	29	66%
Formerly used heroin	19	45%

*Some participants answered more than one type of risk behavior

Table 2. Frequencies and rank order for ten top symptoms (n=44)

Symptoms	n	%	Rank Order
Muscle aches	36	81.8	1
Depression	34	77.3	2
Weakness	31	70.5	3
Fear/worries	31	70.5	4
Difficult concentration	29	65.9	5
Joint pain	29	65.9	6
Memory loss	28	63.6	7
Anxiety	28	63.6	8
Fatigue	27	61.4	9
Blurred vision	25	56.8	10

Table 3. Descriptive statistics for symptoms and HAT Quality of Life scales (N=44)

Scale	Mean	SD	Correlations: Symptom Frequency with QoL scores
Symptom Frequency	43.61	28.86	
HAT Quality of Life Scores			
Overall function	103.05	20.10	-0.58**
Life satisfaction	13.68	5.39	-0.59**
Health worries	5.00	4.70	0.32*
Financial worries	5.82	4.22	0.17
HIV medication concerns	4.15	4.79	0.59**
Worries over being HIV positive	2.55	2.98	0.26
Disclosure worries	4.68	5.64	0.25
Feelings about your doctor	35.40	5.74	-0.07
Sexual functioning	7.09	1.94	0.01

*p <0.05; **p<0.01

Table 4. Symptom frequency by selected demographic variables (n=44)

	Symptom Frequency					
Variable	**Yes**		**No**			
	Mean	**SD**	**Mean**	**SD**	**T**	**p**
Every physically abused	23.61	13.114	23.69	16.79	0.83	0.99
Taking ARVs now	18.27	10.97	31.44	17.35	3.06*	0.00
Other medical conditions	24.12	13.57	22.10	20.71	5.47	0.78
	Male		**Female**			
Gender	26.59	17.53	20.52	12.49	1.45	0.20

*p< 0.01

(r=0.59) (Table 3). The symptom experience was not related to financial worries, disclosure worries, or sexual functioning.

Individuals who reported taking HIV medications had significantly fewer symptoms than did those not taking HIV medications (t=3.061, df=42, p<0.01) (Table 4). There were no differences in symptom frequency among those who self-reported abuse or had other health care conditions.

Discussion

These results provide important data on the wide variety of symptoms being experienced by people living with HIV infection in Puerto Rico, and their relationship with perceived quality of life. This profile of symptoms is similar to what has been reported in the literature including muscle aches, depression, weakness, fear/worries, difficulty concentrating, memory loss, anxiety, fatigue, and blurred vision (8, 10, 13). Both physical and psychological symptoms ranked high among this sample documenting the complex nature of the HIV symptom experience, a finding that is supported in the literature (19).

There were significant differences in the frequency of symptoms between the participants who were currently taking medications and those not taking medications. In this sample, participants on ARV medications reported fewer symptoms, which suggest that these have a positive effect on reducing HIV related symptoms as compared to causing side effects on the study participants. Studies have demonstrated that when symptoms are controlled and quality of life improves, people living with HIV infection report higher overall functioning and greater medication adherence (20).

The co-occurrence between violent experiences and unhealthy behaviors such as tobacco and drug use, including marihuana and cocaine, was also documented in this sample. These findings are consistent with other studies, which point to high rates of substance abuse, violent experiences, and unhealthy behaviors, such as drug use among HIV positive men and women (21-23). These co-occurrences are key components of the needs and vulnerabilities of the HIV positive population in Puerto Rico. Asthma, anemia, and depression were also relevant co-morbidities found in this study, which add to the complexity of HIVdisease management and may also play a crucial role in the participants' quality of life. Further research is indicated to examine how combination of co-occurrences and co-morbitities, in the context of other complex interpersonal variables associated with HIV infection, impact quality of life and adherence to ARV

therapies. In summary, the findings of this study indicate that, people living with HIV infection in Puerto Rico experience a broad array of physical and psychological symptoms. Study results, although preliminary, provide important data on the variety of symptoms and their relationship to quality of life. These findings can assist health care providers in the identification of potential areas for designing effective management of symptoms on people living with HIV/AIDS infection. There are three important study limitations. This was a convenience sample, which means it may not be representative of all people living with HIV illness in Puerto Rico. Second, all of the instruments were self-reported scales and may have some limitations including inaccurate recall of sign and symptom, intensity and duration, question comprehension and interpretation, and social desirability bias. Third, although the HIV/AIDS Targeted Quality of Life Instrument (HAT-QoL) and the Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev) have adequate reported validity and reliabilities, they require more testing in the Puerto Rico population with a larger sample size of women, men, and transgenders living with HIV infection.

As the number of people with HIV infection continues to increase in Puerto Rico, understanding the symptom experience, its impact upon quality of life, and developing strategies for symptom management will continue to be an important issue for nurses and health care providers in Puerto Rico. More research is needed to test symptom management interventions in the context of other complex interpersonal variables associated with HIV infection to improve quality of life and adherence to ARV therapies.

Resumen

Las personas que viven con el VIH confrontan síntomas físicos y psicológicos que impactan su calidad de vida. Se exploró los síntomas que experimentan las personas que viven con el VIH en Puerto Rico y su correlación con la calidad de vida. Se utilizó un diseño descriptivo transversal y se encuestaron 44 mujeres, hombres y transgénero que viven con el VIH. Se recogieron datos demográficos, sobre los signos, los síntomas y la calidad de vida. El 50% de la muestra fueron hombres con una edad promedio de 42.1 años. Los participantes llevan, en promedio, 9.8 años viviendo con el VIH. Los cinco síntomas más informados por la muestra incluyen dolores musculares (81.8%), depresión (77.2%), debilidad (70.5%), miedos/preocupaciones (70.5%) y dificultad para concentrarse (65.9%). La frecuencia de los síntomas estuvo significativamente relacionada con las cuatro dimensiones de calidad de vida, incluido funcionamiento general (r=-0.58), satisfacción con la vida (r=-0.59), preocupaciones de salud (r=0.32) y preocupaciones sobre los medicamentos para tratar el VIH (r=0.59). No se encontró relación entre la experiencia de los síntomas y las preocupaciones financieras, las preocupaciones de revelación o el funcionamiento sexual. Los participantes que tomaban medicamentos para el VIH informaron significativamente menos síntomas que aquellos que no los tomaban ($t=3.061$, $df=42$, $p<0.01$). Estos resultados demuestran que las personas que viven con el VIH en Puerto Rico experimentan una variedad de síntomas físicos y psicológicos y éstos exhiben una correlación con la forma en que perciben su calidad de vida. Un manejo adecuado de los síntomas pudiera tener un impacto en cómo las personas perciben su calidad de vida.

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