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Does “Asymptomatic” Mean Without Symptoms for Those Living with HIV Infection?

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Abstract

Throughout the history of the HIV epidemic, HIV-positive patients with relatively high CD4 counts and no clinical features of opportunistic infections have been classified as “asymptomatic” by definition and treatment guidelines. This classification, however, does not take into consideration the array of symptoms that an HIV-positive person can experience long before progressing to AIDS. This short report describes two international multi-site studies conducted in 2003–2005 and 2005–2007. Results from the studies show that HIV-positive people may experience symptoms throughout the trajectory of their disease, regardless of CD4 count or classification. Providers should discuss symptoms and symptom management with their clients at all stages of the disease.

Keywords

HIV infection; symptoms; asymptomatic

BACKGROUND

In untreated HIV disease, more than ten years can elapse from initial infection to the first occurrence of an opportunistic infection (OI), an indicator that the disease has progressed to AIDS (Panel on Antiretroviral Guidelines for Adult and Adolescents, 2006). This period of time does not mean, however, that people infected with HIV who have not yet progressed to AIDS are symptom free. Existing definitions and care guidelines that categorize patients as “asymptomatic” may lead clinicians to ignore symptoms that are not directly related to opportunistic infections, but that do require attention.

In 1986, the Centers for Disease Control (CDC) (“Classification system for human T-lymphotropic virus type III/lymphadenopathy-associated virus infections,” 1986) provided an early description of HIV disease, which included two main categories: symptomatic and asymptomatic. For two decades, these definitions have been incorporated into treatment guidelines that have informed clinicians in the United States and other countries in their care for patients.

In the mid-1990s, with the ability to treat HIV itself, many clinicians began focusing solely on CD4 counts and symptoms directly related to OI (e.g. diarrhea, night sweats, fever). There has been growing evidence, however, that HIV-positive people experience many symptoms that are not directly related to OI or CD4 counts, particularly fatigue, depression, muscle aches, and fear/worries (Corless, Nicholas, Davis, Dolan, & McGibbon, 2002; Corless et al., In Press; Eller et al., 2005; Kemppainen et al., 2006; J. Voss, Portillo, Holzemer, & Dodd, 2007; J. G. Voss, 2005). These symptoms often go unrecognized and untreated by health care providers (Hughes, 2004), either because care providers do not ask patients about their symptoms or because they consider the symptoms to be “sub-clinical”.

Siegel and colleagues (1999) reported that having symptoms, as well as their intensity, influenced decisions to seek care and have contributed to reduced adherence to medications, thereby increasing the likelihood of resistance to medication regimens and exacerbating symptoms. These factors may also reduce the physical and mental aspects of a person’s quality of life (Abel & Painter, 2003; Ammassari et al., 2001; Corless et al., 2002; Hudson, Kirksey, & Holzemer, 2004; Lorenz, Cunningham, Spritzer, & Hays, 2006).

The aim of this study is to determine whether there are differences in the frequency and intensity of self-reported HIV symptoms among three levels of CD4 count (<200 cells/mm³, 200–350 cells/mm³, >350 cells/mm³), regardless of use of ARVs.

METHODS

This study is a secondary analysis of two studies conducted under the auspices of the UCSF International Nursing Network for HIV/AIDS Research (www.ucsf.edu/aidsnursing) (Table 1). The first study, “Self-Care Symptom Management in HIV/AIDS” (Study A) (Reynolds et al., 2007) was a descriptive cross-sectional study examining self-reported symptoms and self-care behaviors in 1,217 HIV-infected men and women from Colombia, Norway, Puerto Rico, Taiwan and the United States. The second study, “The Efficacy of the HIV/AIDS Symptom Management Manual” (Study B) (Wantland et al., in press), was a three-month, repeated measures randomized controlled trial of 775 participants in Kenya, Puerto Rico, South Africa, and the United States. Only the baseline data are used in this analysis.

INSTRUMENTS

A *Demographic Survey* booklet was used to collect information on personal and environmental characteristics (eg. age, gender, whether participants had adequate income). Data on biological/physiological factors (eg. whether participants had received an AIDS diagnosis, had comorbidities) were also collected.

The Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev) (Holzemer, Hudson, Kirksey, Hamilton, & Bakken, 2001) was used to capture the frequency and intensity of 72 common HIV signs and symptoms experienced by the participant on the day the checklist is completed. Items were rated on a 3-point Likert scale of 1 (mild), 2 (moderate), or 3 (severe). Reliability and validity of the instrument have been previously reported for a U.S. sample (Holzemer et al., 2001). A Chinese version has been tested with a Taiwanese sample (Tsai, Hsiung, & Holzemer, 2003). Slightly different Spanish versions were used in Texas, Puerto Rico, and Colombia. In Africa, the English version was used. Researchers at each site confirmed the content validity of the versions.

DATA ANALYSIS

Responses to the questionnaires were entered into Statistical Package for the Social Sciences (SPSS) for Windows Version 13.0 software (SPSS, 2005). Descriptive statistics (i.e., means, standard deviations, frequencies, and percents) were used to examine demographic characteristics of the samples and the frequency and intensity of the symptoms. For the purposes of this analysis, gynecological signs and symptoms were excluded. The individuals' self-reported CD4 values were stratified into three groups: 0–200, 201–350 and >350 CD4 cells/mm³. In Study A, 26.8% of reporting participants had CD4 counts of 0–200 cells/mm³; 19.5% had counts of 201–350 cells/mm³; and 53.7% had counts greater than 350 cells/mm³. In Study B, 24.7% had CD4 counts of 0–200 cells/mm³; 21.1% had counts of 201–350 cells/mm³; and 54.1% had counts greater than 350 cells/mm³. Analysis of covariance (ANCOVA) compared the mean number and intensity of symptoms reported by the three groups, controlling for taking ARV medications at the time of the survey.

FINDINGS

Symptom Rankings

In both studies, the most frequently reported symptoms included both physical and psychosocial symptoms: fatigue, depression, and muscle aches. Table 2 shows the ranking of the twenty most frequently reported symptoms for both studies, with a frequency range of 33% to 60%.

Symptoms by CD4 Category

For Study A, the mean self-reported CD4 count was 433 (SD=413) and the average symptom frequency was 18.3 (SD=16.8) (Table 3). The mean number of symptoms by CD4 category was: 0–200 cells/mm³ = 19.9 (SD=17.5); 201–350 cells/mm³ = 17.5 (SD=15.6); and >350 cells/mm³ = 17.9 (SD=16.9). Of those reporting (n=820), 21.3% (n=175) were not taking ARV medications. No differences were noted as to whether or not the participant was taking ARV medications and the frequency or intensity of symptoms reported. ANCOVA revealed a nonsignificant main effect of CD4 category on the frequency of reported symptoms ($F(2,820)=2.43$, $p = 0.12$). There were no differences in the number of symptoms among the three levels of CD4 counts. There was a significant lower report of symptom intensity for those presently taking ARVs compared to those not taking ARVs ($F(1,718)=7.42$, $p=0.007$), however similar to symptom frequency, there was no significant difference between the CD4 categories in either ARV group ($F(2,718)=0.44$, $p=0.64$).

For Study B, the mean self-reported CD4 count was 407 (SD=268) and the average symptom frequency was 20.9 (SD=18.3). The mean number of symptoms by CD4 category was: 0–200 cells/mm³ = 21.0 (SD=17.7); 201–350 cells/mm³ = 21.7 (SD=20.3); and >350 cells/mm³ = 20.4 (SD=17.8). Of those reporting, (n=477), 27.6% (n=132) were not taking ARV medications. Again, there was no effect on whether or not the participant was taking ARV medications and the frequency of symptoms reported. ANCOVA revealed a nonsignificant main effect of CD4 category on the frequency of reported symptoms (F(2,479)=0.20, p = 0.82). There were no differences in the number of symptoms among the three levels of CD4 counts. The interaction between taking/not taking ARV medications and CD4 category was not significant with similar results (F(2,479)=0.46, p=0.63). In Study B, there was also no significant difference in the report of symptom intensity for those presently taking ARVs compared to those not taking ARVs and, similar to Study A, there was no significant difference between the CD4 categories in either ARV group (F(2,448)=0.47, p=0.62). Results from both studies show that the symptom frequency and intensity for those taking ARV medications and those not taking ARVs were similar by CD4 category (Table 3). Intensity of symptoms in both studies demonstrates a wide SD. This indicates a broad variation in how patients perceive and rate their symptom experience.

DISCUSSION

The data from these studies demonstrate that the term “asymptomatic” HIV disease is not a valid term, as patients do experience symptoms regardless of their CD4 count or lack of OIs. The data also reveal that self-reported symptoms are present in individuals regardless of whether they are taking ARVs. Clearly, there are symptoms associated with all levels of CD4 classification.

Based on developments in HIV treatment and care, and the findings reported here, the authors recommend that clinicians no longer use the term “asymptomatic” to define their HIV-positive clients’ treatment needs. Clinicians should carefully interview patients as to the presence of symptoms regardless of CD4 count and should address symptom management. The wide variability of symptoms’ intensity lends credence to further interview of the patients to explore their illness experience and seek methods to improve quality of life. The danger of labeling someone living with HIV infection as “asymptomatic” is the failure to recognize the constellation of symptoms they are experiencing, on or off ARVs, across the spectrum of CD4 counts. Clinical practice guidelines have been shown to be an effective means of improving the way clinicians manage patients, and it is important for HIV clinical practice guidelines to reflect the fact that HIV-positive people may experience symptoms throughout their disease, and that these must be managed to improve quality of life.

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Table 1

Study Demographics

STUDY A (n=1,217)				STUDY B (n=775)			
Mean (SD)	Percentage (n)	Range		Mean (SD)	Percentage (n)	Range	
Age (years)							
41.7 (9.1)		20–84		42.8 (9.6)		20–72	
Gender							
Male	67.5 (821)		Male		59.2 (455)		
Female	31.4 (382)		Female		38.5 (296)		
			Transgender		2.2 (17)		
Education							
			Grade School		29.1 (223)		
Less than high school	29.2 (355)						
High school	33.1 (403)		High school		41.5 (318)		
			Tech/vocational school		18.6 (143)		
Greater than high school	37.5 (456)		College		7.7 (59)		
			Master's/Doctorate		3.1 (24)		
Race/ethnicity							
African-American/Black	37.9 (461)		African National & American/black		43.6 (335)		
Hispanic/Latino	26.0 (316)		Hispanic/Latino		27.8 (214)		
White/Anglo (non- Hispanic)	22.7 (276)		White/Anglo (non- Hispanic)		21.2 (163)		
Asian/Pacific Islander (including residents of Taiwan)	10.4 (126)		Asian/Pacific Islander		1.4 (11)		
			Native American Indian		1.0 (8)		
Other	2.7 (33)		Other		4.8 (37)		
AIDS diagnosis							
Yes	40.7 (493)		Yes		42.0 (322)		
No	56.4 (682)		No		53.2 (408)		
Don't know	2.9 (35)		Don't know		4.8 (37)		
Taking HIV Meds now							

STUDY A (n=1,217)				STUDY B (n=775)			
	Mean (SD)	Percentage (n)	Range		Mean (SD)	Percentage (n)	Range
Yes		72.5 (879)		Yes		70.4 (537)	
No		27.1 (328)		No		29.6 (226)	
Years known HIV-positive							
	9.8 (5.5)		1-20		9.1 years (6.6)		0-26
CD4 (Recent CD4 count, if known)							
	433 (413)		0-1580		407 (268)		0-1200
Co morbidities							
Yes		53.8 (655)		Yes		62.7 (470)	
No		45.3 (551)		No		37.3 (280)	
Years on ARV medications							
					6.7 years (5.2)		0-20
Symptom frequency							
	18.3 (16.8)		0-64		20.9 (18.3)		0-64
Symptom intensity							
	33.6 (32.0)		0-192		39.6 (36.1)		0-192

Table 2

Twenty Most Frequently Reported Symptoms (percentage of participants reporting each symptom)

Symptom	Study A (N=1,217)		Study B (N=775)	
	Frequency %	n	Frequency %	n
Fatigue	60	630	57	446
Depression	58	706	56	432
Muscle aches	56	681	55	425
Weakness	53	643	53	408
Thirst	52	635	52	389
Worry	50	605	50	388
Difficulty concentrating	50	610	51	392
Memory loss	49	591	49	376
Dry mouth	48	583	50	387
Insomnia	45	551	48	371
Joint pain	44	578	50	386
Diarrhea	41	501	38	291
Shortness of breath with activity	41	503	42	326
Night sweats	39	473	39	299
Gas/bloating	39	475	41	314
Headaches	37	446	41	319
Abdominal pain	36	434	38	297
Numbness/tingling of hands/fingers	34	408	39	303
Numbness/tingling of feet/toes	33	400	44	339
Numbness/tingling of legs	33	403	37	286

Table 3
Symptom Frequency and Intensity of Participants by DHHS category and Taking ARVs

Taking ARVs now	CD4 (cells/mm ³) - DHHS category	Study A						Study B					
		N in group	% in group	Symptom Frequency Mean (0-64)	SD	Symptom Intensity Mean (0-192)	SD	N in group	% in group	Symptom Frequency Mean (0-64)	SD	Symptom Intensity Mean (0-192)	SD
No	0-200	38	21.7%	21.2	20.1	46.2	53.2	29	22.0%	18.7	17.5	40.0	41.1
	201-350	22	12.6%	23.8	18.2	37.7	40.7	31	23.4%	20.4	20.2	39.4	33.2
	351 and higher	115	65.7%	19.7	19.2	37.0	39.2	72	54.5%	19.3	16.9	37.0	30.7
Total No		175		20.5	19.2	38.5	39.8	132		19.4	17.7	38.2	33.5
Yes	0-200	182	28.2%	19.7	17.0	31.0	29.8	89	25.7%	21.9	17.8	44.4	37.5
	201-350	138	21.3%	16.4	15.0	32.5	33.9	70	20.2%	22.2	20.6	43.5	39.7
	351 and higher	325	50.3%	17.2	16.0	30.1	30.0	186	19.7%	20.8	18.2	40.6	35.4
Total Yes		645		17.8	16.1	32.2	31.4	345		21.4	18.6	42.2	36.8
Combined	0-200	220	26.8%	19.9	17.5	33.48	34.9	118	24.7%	21.0	17.7	42.9	38.1
	201-350	160	19.5%	17.5	15.6	33.22	34.9	101	21.1%	21.7	20.3	42.3	37.5
	351 and higher	440	53.7%	17.9	16.9	31.8	32.3	258	54.1%	20.4	17.8	39.8	34.4
Total Combined		820		18.3	16.8	33.7	33.8	477		20.9	18.3	41.1	36.0