

The Symptom Experience of People Living With HIV/AIDS in Southern Africa

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This study describes the symptom experience of 743 men and women living with HIV/AIDS in Botswana, Lesotho, South Africa, and Swaziland. Data were obtained in 2002 by using a cross-sectional design. A survey of participants included 17 socio-demographic items and the 54-item Revised Sign and Symptom Checklist for Persons with HIV Disease. Results indicate a strong correlation between the frequency of reported symptoms and their intensity ($r = .84, p < .00$). Participants who reported having enough money for daily expenses also reported significantly fewer symptoms. There were no significant differences in symptom frequency between men and women or by location of residence. The study showed a complex picture of HIV-related symptoms in all four countries. Because of the high levels of symptoms reported, the results imply an urgent need for effective home- and community-based symptom management in countries where antiretroviral therapy is unavailable to help patients and their families manage and control AIDS symptoms and improve quality of life.

Key words: HIV/AIDS, symptoms, symptom control, symptom management, southern Africa

Living with HIV disease poses tremendous physical and psychological challenges for those who are infected, as well as for their families and health care

providers. The burden of illness often is confounded by a host of factors including caring for children, caring for an HIV-positive spouse, earning a living, fear of disclosure, AIDS stigma and discrimination, and poverty (Grant & De Cock, 2001; Johnson, Stallworth, & Neilands, 2003). The experience of HIV-related symptoms is a significant part of that challenge (Holzemer, 2002). Physical and psychological symptoms are profoundly disruptive and impact almost every aspect of daily life.

Southern Africa has the highest rate of HIV infection in the world. An estimated 29.4 million people are living with the disease, and about 3.5 million new infections were documented in 2003 (Joint United Nations Programme on HIV/AIDS & World Health

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Organization [UNISA & WHO], 2002). Few medications of any type—including palliatives, prophylaxes, or antiretrovirals—are available in Africa and other resource-poor countries, such that people living with HIV infection and their families are left to experience and manage the pain, skin sores, diarrhea, fear, and distress on their own. Whereas Western medications may not be available, families living with HIV use home remedies and traditional healers to treat symptoms (Gilks, 2001). The purpose of this study was to document the self-reported HIV symptoms experienced by a sample of persons living with HIV infection in the southern African countries of Botswana, Lesotho, South Africa, and Swaziland.

Symptom management includes preventing, assessing, and treating HIV-related symptoms, associated opportunistic infections and malignancies, and the side effects of prophylactic and therapeutic interventions (Doerfler, 2002; Lesho & Gey, 2003).

The first step in symptom management is gauging the frequency and intensity of symptoms to get an overall assessment of illness burden. This is complex, because the literature and clinical opinion suggest that the presentation of HIV-related symptoms varies significantly by a host of factors such as age, sex, culture, poverty, genetic variability, severity of illness, available therapies, and use of traditional healers (Doerfler, 2002). For example, pulmonary symptoms may be more prevalent in southern Africa because tuberculosis is the most common cause of death among people with AIDS (Grant, 2002). In the United States, however, tuberculosis is rarely a cause of AIDS-related death, partially because of the wide availability of medications. Exploring the potential relationships between symptom frequency and personal characteristics can shed light on the symptom experience.

HIV Symptom Assessment

Researchers in the United States and other resource-rich countries have widely documented the importance of symptom assessment and management in HIV/AIDS (Fantoni, Ricci, & Del Borgo, 1997; Hurley & Ungvarski, 1994; Janson-Bjerklie, Holzemer, & Henry, 1992; Kalichman, Rompa, & Cage, 2000; Smith & Rapkin, 1995). Poorly controlled

physical and psychological AIDS symptoms may lead patients to delay, reduce, or terminate treatment, which in turn can adversely affect the course of the disease (Antoni, 2003; McMahon & Coyne, 1989). Valente, Saunders, and Uman (1993) reported that the number of HIV symptoms experienced was positively correlated with both depression and change toward unhealthy self-care behaviors. Bing et al. (2000) emphasized the importance of perceived physical symptoms for psychological functioning among HIV-infected adults.

Mathews et al. (2000) studied the prevalence of symptoms of 4,042 HIV-positive adults in a national, probabilistic U.S. sample. The following symptoms were reported: fever/night sweats, 51.5%; diarrhea, 51%; nausea/anorexia, 49.8%; dyspnea, 48.9%; severe headache, 39.3%; weight loss, 37.1%; vaginal symptoms, 35.6%; sinus symptoms, 34.8%; eye trouble, 32.4%; cough/dyspnea, 30.4%; thrush, 27.3%; rash, 24.3%; oral pain, 24.1%; and Kaposi's sarcoma, 4%. Symptoms were more frequent in women and injection drug users and in persons with low education levels and low income. A strength of this study was the large national probability sample that showed significant illness burden; nearly one-half of the sample experienced fever and night sweats, diarrhea, nausea/vomiting, and body pain. A criticism of the study was its sole focus on physical symptoms to the exclusion of psychological symptoms such as fear and anxiety.

Holzemer, Hudson, Kirksey, Hamilton, and Bakken (2001) have conducted several studies of symptom prevalence in people with HIV/AIDS in the United States. A sample of 207 hospitalized AIDS patients (87% male and 51% non-White) reported that their common symptoms were shortness of breath with activity, 68%; fatigue, 62%; cough, 60%; weakness, 59%; and dry mouth, 56% (Reilly, Holzemer, Henry, Slaughter, & Portillo, 1997). A sample of 420 HIV-positive adults visiting an outpatient clinic reported that their most frequent symptoms were anxiety/fear, 17.3%; diarrhea, 16.6%; neuropathy, 11.6%; nausea/vomiting, 9.7%; depression, 8.1%; and fatigue, 7.3% (Hudson, Kirksey, & Holzemer, 2004). A sample of 176 HIV-positive Taiwanese adults reported that the most frequent symptoms were dry mouth, 65.3%; fatigue, 64.2%; thirst, 54.5%; weakness, 53.4%; loose stool, 51.7%; and

difficulty concentrating, 50% (Tsai, Hsiung, & Holzemer, 2003). Variation in symptom frequency in these studies can be attributed to several factors, including the presence of various pathogens in the local environment, sample characteristics, stage of illness, age, sex, and availability of medications (Holzemer, 2002). The three studies used the same instrument and captured both physical and psychological symptoms, and all participants reported significant symptom burden. Participants reported a broad array of physical symptoms such as diarrhea, psychological symptoms such as anxiety and fear, and combined physiological and psychological perceptions of illness such as fatigue and weakness.

Psychological symptoms represent a significant burden of HIV disease. Anxiety is a universal symptom in people with HIV/AIDS (Kemppainen et al., 2003). Indeed, anxiety, fear, and depression are some of the most prevalent HIV symptoms, with estimated rates of up to 39%, depending on a wide range of factors including stage of disease and time since notification (Ickovics et al., 2001). Neidig, Smith, and Brashers (2003) reported that 20% to 35% of their sample ($n = 60$: 13% female and 18% Black) reported significant levels of depression symptoms at the outset of the study. This work suggests that although people in the early course of HIV disease may be physically asymptomatic, they may be experiencing extreme psychological distress.

There is some evidence regarding differences in the reporting of symptoms by personal characteristics. Farzadegan et al. (1998) reported that, although HIV-positive women experienced the same number of symptoms as their male counterparts, their viral load was 50% lower. Among injection drug users with HIV, significantly more women reported fatigue compared with the same cohort of men (Spijkerman, Langendam, van Amerijden, Coutinho, & van den Hoek, 1998). Zingmond et al. (2003) reported that in their sample, older non-Whites were less likely to report having experienced symptoms than were younger Whites. They concluded that age is a determinant in the reporting of HIV symptoms.

There are few published studies that report data on the HIV/AIDS symptom experience in Africa. Elmir et al. (2002) cited the symptom experience of 12,981 Moroccans during the years 1991 to 1999. Forty-two percent of this sample reported weight loss, fever,

and diarrhea. It is not clear if this large-scale assessment focused only on physical symptoms. Gilks, Katabira, and De Cock (1997) reported on the challenge of providing effective care for HIV/AIDS in Africa. Because of limited diagnostic facilities in many African settings, the authors discuss the "management of specific HIV associated syndromes"—in particular, care management strategies based on the presenting clusters of symptoms, although they did not directly address the signs or symptoms themselves.

Aims

This study had two main aims: (a) to describe the frequency and intensity of HIV-related symptoms in an outpatient sample of HIV-infected adults in southern Africa, and (b) to determine if personal characteristics such as gender, place of residence, and adequacy of income were correlated with the number and intensity of HIV-related symptoms experienced by that sample.

Method

Design

A cross-sectional, descriptive design was used to gather demographic and self-reported data on the presence or absence of symptoms and the intensity of any current symptoms. The survey included 17 sociodemographic items and the 64-item Revised Sign and Symptom Checklist for Persons with HIV Disease, which measures the frequency and intensity of a respondent's signs and symptoms.

Adults living with HIV/AIDS in Botswana, Lesotho, South Africa, and Swaziland were the target population. A convenient community-based, purposefully selected sample ($n = 743$) was obtained in 2002 in face-to-face interviews. Each country used a somewhat different procedure to access participants. In some areas, home care nurses approached families to determine if they would be interested in participating. In other areas, outpatient clinics provided referrals. Institutional review boards at the University of California–San Francisco and each university

in Botswana, Lesotho, South Africa, and Swaziland approved the study protocol.

Sample

Data from a community-based sample of 743 HIV-infected adults were obtained during 2002 in Botswana ($n = 97$, 13.1%), Lesotho ($n = 76$, 10.2%), South Africa ($n = 420$, 56.5%), and Swaziland ($n = 150$, 20.2). More than half of the participants were from South Africa because that country is much larger than the other participating nations.

The participants were 61.2% female ($n = 455$) and 38.8% male ($n = 288$), with a mean age of 34.05 ($SD = 9.59$) and an average 7.7 years of education ($SD = 3.87$). Only 7.9% ($n = 59$) of participants had any health insurance. The distribution by location of residence was 30.3% urban, 34.3% peri-urban (outskirts of a city), and 34.6% rural. Peri-urban is a term used in Africa to refer to the area surrounding a city. Peri-urban areas differ from suburban areas in that they often have poorer access to transport, health services, and public sanitation services.

Each country developed a purposive sampling strategy that recognized cultural differences in terms of language, geography, and urban, peri-urban, or rural populations. Each country accessed participants somewhat differently. In some areas, home care nurses approached families to determine if they would be interested in participating in the study. In other areas, referrals were received from outpatient clinics, hospital associations, and organized groups of persons with AIDS.

The Committee on Human Research at the University of California–San Francisco and participating universities in Botswana, Lesotho, South Africa, and Swaziland approved the study protocol.

The survey was translated into seven languages, including Sesotho, Setswana, Siswati, Tswana, Venda, Xhosa, and Zulu. The survey was administered in the local language of the participants, and then the results were then translated to English by the research team.

Instruments

The survey booklet, consisting of a sociodemographic data form and The Revised Sign and Symptom

Checklist for Persons with HIV Disease (Holzemer et al., 2001), was translated into seven languages, including Sesotho, Setswana, Siswati, Tswana, Venda, Xhosa, and Zulu. The instrument was translated by the appropriate language departments at the collaborating authors' respective institution. Country project leaders reviewed the translations to ensure their accuracy. The checklist is composed of 64 items that capture the frequency and intensity of HIV signs and symptoms that the participants were experiencing on that day. After providing informed consent, each participant completed a survey booklet.

The symptom-related survey items are rated on an ordinal, 3-point Likert scale: 1 (*mild*), 2 (*moderate*), 3 (*severe*). Calculations included the total number of symptoms (with a range of 0-64) and the mean intensity of symptoms (with a range of 1-3). Validity and reliability of the instrument previously have been reported for a U.S. sample (Holzemer et al., 2001). Each country-level team that consisted of experts in HIV/AIDS care, nurses working directly in home-based care, and university faculty reviewed the sign and symptom checklist for its relevance to their community. Content validity was confirmed for the instrument by each participating country-level team of expert AIDS clinicians.

Data Analysis

The data were analyzed using Statistical Package for the Social Sciences for Windows software (SPSS Inc, Chicago, IL). The responses to the questionnaire were coded, and descriptive statistics were used to characterize the sample and symptom intensity. The average number of symptoms rated was computed, and symptom frequency and intensity were correlated. Student *t* tests and *F* tests enabled comparison of demographic variables with symptom frequency. Demographic data are presented in Table 1.

Results

The participants were relatively ill. Sixty-two percent ($n = 458$) reported they had received an AIDS diagnosis. Very few participants were having either their CD4 count or their viral load monitored. A total

Table 1. Descriptive Data for Personal Characteristics and Severity of Illness (*n* = 743)

Personal Characteristics		
Sex		
Female	61.2%	<i>n</i> = 455
Male	38.6%	<i>n</i> = 287
Transgender	.2%	<i>n</i> = 1
Age (yr)		
Mean	34.05	
<i>SD</i>	9.59	
Years of education		
Mean	7.70	
<i>SD</i>	3.87	
Where do you live?		
Urban	30.3%	<i>n</i> = 225
Peri-urban	34.3%	<i>n</i> = 255
Rural	34.6%	<i>n</i> = 257
Missing	.1%	<i>n</i> = 6
Country		
Botswana	13.1%	<i>n</i> = 97
Lesotho	10.2%	<i>n</i> = 76
South Africa	56.5%	<i>n</i> = 420
Swaziland	20.2%	<i>n</i> = 150
Do you have children?		
Yes	70.3%	<i>n</i> = 522
No	28.1%	<i>n</i> = 209
Are you pregnant?		
Yes	2.86%	<i>n</i> = 13
Do you have enough money to cover your daily expenses?		
Yes	40.5%	<i>n</i> = 301
No	52.1%	<i>n</i> = 387
Do you have health insurance?		
Yes	07.9%	<i>n</i> = 59
No	87.2%	<i>n</i> = 648
Severity of Illness		
Year known HIV-positive		
1980-1984	4%	<i>n</i> = 3
1985-1989	4%	<i>n</i> = 3
1990-1994	2.6%	<i>n</i> = 19
1995-1999	30.6%	<i>n</i> = 227
2000-now	59.1%	<i>n</i> = 439
Missing	6.9%	<i>n</i> = 52
Have you been given an AIDS diagnosis?		
Yes	61.6%	<i>n</i> = 458
No	33.8%	<i>n</i> = 251
Missing	4.6%	<i>n</i> = 34
Is anyone monitoring your CD4 count?		
Yes	15.7%	<i>n</i> = 117
No	59.1%	<i>n</i> = 439

Table 1. Continued

Personal Characteristics		
Don't know	19.8%	<i>n</i> = 147
Missing	5.4%	<i>n</i> = 40
Is anyone monitoring your viral load?		
Yes	14.5%	<i>n</i> = 108
No	62.6%	<i>n</i> = 465
Don't know	16.7%	<i>n</i> = 124
Missing	6.2%	<i>n</i> = 46
Have you been hospitalized during the last year?		
Yes	50.1%	<i>n</i> = 372
No	47.9%	<i>n</i> = 356
Missing	2.0%	<i>n</i> = 15
Are you receiving home care to help you with your disease?		
Yes	37.0%	<i>n</i> = 275
No	59.5%	<i>n</i> = 442
Missing	3.5%	<i>n</i> = 26
Do you spend more than 80% of the day in bed?		
Yes	24.9%	<i>n</i> = 185
No	72.7%	<i>n</i> = 540
Missing	2.4%	<i>n</i> = 18
Total number of symptoms being experienced today		
Mean	17.58	
<i>SD</i>	13.74	
Total number of gynecological symptoms experienced today (women)		
Mean	2.64	
<i>SD</i>	1.90	

of 50% (*n* = 372) reported that they had been hospitalized during the previous year, 40.5% (*n* = 301) were receiving home care, and 24.9% (*n* = 185) reported they spent more than 80% of the day in bed. The participants reported that on the day of the interview, they were experiencing an average of 17.58 symptoms out of a possible 64.

The frequency and intensity of the reported symptoms are presented in Table 2; fatigue, weakness, concern over weight loss, fear and worries, and painful joints were the top five. Participants reported high levels of both physical and psychological symptoms.

A Spearman rank order correlation was calculated to estimate the relationship between the rank of fre-

Table 2. Symptom Rank Order, Frequency, Percentage, and Mean Intensity ($n = 743$)

Symptom	Rank	Frequency	Percentage	Mean Intensity ^a
Fatigue	1	414	55.7	2.02
Weakness	2	400	53.8	1.99
Concern over weight loss	3	349	47.9	2.23
Fear/worries	4	337	45.4	2.08
Painful joints	5	335	45.1	2.09
Coughing	6	334	45.2	2.03
Lack of appetite	7	330	44.4	1.93
Headaches	8	312	42.0	1.90
Muscle aches	9	312	42.0	1.93
Night sweats	10	302	40.6	2.17
Depression	11	299	40.2	1.93
Dry mouth	12	262	35.3	1.97
Numbness/tingling of feet	13	257	34.6	1.98
Thirsty	14	255	34.3	1.96
Itchy skin	15	251	33.8	1.88
Rash	16	244	32.8	1.90
Fever	17	240	32.3	1.82
Insomnia/cannot sleep	18	234	31.5	1.98
Shortness of breath with activity	19.5	229	30.8	2.12
White spots in mouth/thrush	19.5	229	30.8	1.91
Numbness/tingling of legs	21	228	30.7	1.98
Dizziness	22	227	30.6	1.86
Diarrhea	23	221	29.7	1.96
Difficulty concentrating	24	212	28.5	1.81
Nausea	25.5	208	28.0	1.67
Chest pain	25.5	208	28.0	1.90
Abdominal pain	27	202	27.2	1.90
Memory loss	28	200	26.9	1.79
Anxiety	29	199	26.8	2.02
Mouth ulcers	30	195	26.2	1.91
Numbness/tingling of hands, fingers	31	194	26.1	1.88
Swollen glands	32	191	25.7	1.83
Skinny arms and legs	33	187	25.2	2.23
Shortness of breath at rest	34	180	24.2	1.82
Burning with urination	35	178	24.0	1.94
Vomiting	36	177	23.8	1.81
Swollen feet	37	176	23.7	1.91
Sore throat	38	172	23.1	1.76
Loose stools	39	164	22.1	1.68
Painful swallowing	40	162	21.8	1.85
Day sweats	41	160	21.5	1.83
Numbness/tingling of arms	42	159	21.4	1.69
Blurred vision	43	145	19.5	1.73
Chills	44	137	18.4	1.83
Constipation	45	131	17.6	1.76
Sores or lumps on genitals	46	130	17.5	1.85
Heart racing	47.5	122	16.4	1.80
Sore/bleeding gums	47.5	122	16.4	1.67
Gas/bloating	49.5	113	15.2	1.68
Rectal itching	49.5	113	15.2	1.65
Prominent leg veins	51	87	11.7	1.90

Table 2. Continued.

Symptom	Rank	Frequency	Percentage	Mean Intensity ^a
Ncsebleed	52	81	10.9	1.57
Wheezing	53	78	10.5	1.67
Blood in spit/sputum	54	73	9.8	1.51
Easy bruising	55	72	9.7	1.69
Weight gain in stomach area	56	68	9.2	1.66
Concern over weight gain	57	64	8.6	1.59
Flushing	58.5	60	8.1	1.60
Rectal bleeding	58.5	60	8.1	1.67
Hump on back of neck/shoulders	60	52	7.0	1.67
Seizures/tremors	61	50	6.7	1.52
Breast pain/changes	62	44	5.9	1.64
Rectal discharge	63	42	5.7	1.67
Nipple discharge	64	32	4.3	1.47

a. 1 (mild), 2 (moderate), 3 (severe).

quency of a reported symptom and the intensity of that symptom. The Spearman rho correlation was .84 ($n = 64$, $p < .00$), suggesting a strong relationship between frequency and intensity.

Comparisons were made between and among symptom frequency, personal characteristics, and severity of illness. There were no differences in symptom frequency between men and women or by location of residence (urban, peri-urban, or rural; see Table 3). However, there were significant differences between the symptoms of those who reported they had children and those who reported they did not. Individuals with children had significantly higher symptom frequency than those with no children ($t = 2.28$, $df = 650$; $p < .02$). In addition, those who reported having enough money for their daily expenses indicated they had fewer symptoms ($t = 3.62$, $df = 629$; $p < .00$; see Table 3).

Interestingly, in comparing symptom frequency by country, Lesotho participants reported significantly fewer symptoms than did participants in Swaziland and fewer, although not significantly fewer, than did participants in either Botswana or South Africa (see Table 2). Further analysis indicates that patients in Swaziland had more advanced disease than did those in other countries. This could explain the high frequency of reported symptoms in Swaziland. The country-level differences must be cautiously interpreted because each country-level team selected a convenience sample based on their ability to access

participants. It seems that the nurse data determiners in Lesotho inducted subjects who were less ill than those in the other countries.

There were no differences between symptom frequency in those who reported having received an AIDS diagnosis and those who had not. However, the three other severity-of-illness measures showed significant differences. Participants who had been hospitalized ($t = 2.56$, $df = 669$; $p < .01$), those who were receiving home care ($t = 2.58$; $df = 658$; $p < .01$), and those who spent more than 80% of the day in bed ($t = 4.18$, $df = 666$; $p < .00$) reported significantly higher frequencies of symptoms (Table 3).

Discussion

This is one of the first reports from southern Africa on the full spectrum of symptoms experienced by a sample of HIV-positive adults. The sample reported a total of 64 different symptoms with a mean of 17.58 symptoms per person ($SD = 13.74$). Participants in this study were extremely ill. They reported constitutional, neurological, digestive, pulmonary, cognitive, musculoskeletal, genitourinary, and gynecological symptoms involving most major organ systems. They also reported severe psychological distress.

Assessing symptom frequency and intensity is extremely important in resource-poor areas where di-

Table 3. Tests of Mean Differences of Symptom Intensity by Personal Characteristics and Severity of Illness ($n = 743$)

Personal Characteristics	Mean	SD	<i>t</i> or <i>F</i> test	<i>df</i>	<i>p</i> value
Gender					
Female	17.73	14.16	$t = .44$	680	.66
Male	17.25	12.98			
Where do you live?					
Urban	17.02	14.06	$F = .18$	2,674	.84
Peri-urban	17.71	14.86			
Rural	17.70	12.02			
Country					
Botswana	15.95	8.95	$F = 7.56$	3,679	.00 ^a
Lesotho	12.25	6.42			
South Africa	15.81	10.01			
Swaziland	19.45	16.05			
Do you have children?					
Yes	18.30	13.83	$t = 2.28$	670	.02
No	15.63	13/19			
Do you have enough money to cover your daily expenses?					
Yes	15.47	10.07	$t = 3.62$	629	.00
No	19.50	15.96			
Do you have health insurance?					
Yes	15.40	14.82	$t = 1.21$	646	.23
No	17.80	13.69			
Severity of Illness					
Have you been given an AIDS diagnosis?					
Yes	17.31	13.04	$t = .72$	650	.47
No	18.13	15.13			
Have you been hospitalized during the last year?					
Yes	18.91	12.96	$t = 2.56$	669	.01
No	16.21	14.40			
Are you receiving home care to help you with your disease?					
Yes	19.52	13.56	$t = 2.58$	658	.01
No	16.67	13.89			
Do you spend more than 80% of the day in bed?					
Yes	21.26	12.10	$t = 4.18$	666	.00
No	16.27	13.94			

a. Bonferroni post hoc comparisons: Lesotho has a significantly lower mean score than Swaziland; there are no significant differences among the other comparisons.

agnostic and disease-progression tests for HIV, CD4 count, and viral load are not available. The Centers for Disease Control and Prevention and the World Health Organization have developed a method to stage HIV illness on the basis of the presence and intensity of HIV-related symptoms. Constellations of symptoms also are used to qualify HIV-infected individuals for disability claims when the traditional biomarkers are not available. In such persons, symptom clusters are thought to be predictive of progression to death (Grant, 2002; Grant & De Cock, 2001).

Participants reported high levels of fear, worries, depression, and anxiety (Table 2). This constellation of psychological symptoms suggests that people living with HIV/AIDS experience significant distress. It also suggests a great need for counseling services and psychological support. The high frequency of psychological distress reported by the respondents suggests that nurses and home-based care providers need strong training in counseling to be effective care providers for patients who are experiencing such high levels of distress.

Nearly 90% of the participants reported they had no health insurance (Table 1), and of those who were insured (8%), only 4% indicated that coverage was adequate. This result shows that most people living with HIV/AIDS rely on the public health sector for care. As the largest provider of HIV services, the challenge for governments is to formulate policies that include access to medications.

There is growing recognition of the link between HIV/AIDS and poverty. Poor nutritional status is known to be reflected in signs and symptoms related to HIV infection. The United Nations Development Programme recently estimated that more than one-third of residents of southern Africa, a famine region, are undernourished (Patel & Delwiche, 2002). In 2002, after 2 years of bad harvests, the area's rampant hunger crossed the official threshold for famine. Yet malnutrition plagued southern Africa even before the current food crisis. Two countries in this sample, Lesotho and Swaziland, are among those hardest hit by the famine (UNISA & WHO, 2002). These results suggest that adequate income, as a marker for poverty, is a significant determinant in the presentation of HIV-related symptoms. This is not surprising in view of the extraordinarily high HIV prevalence rates in the four countries represented in our sample (20%-39%) and the region's longstanding food crisis. That crisis and the HIV/AIDS epidemic are inextricably linked. With limited access to medication and health services, adequate nutrition and intake of sufficient calories become even more critical to stabilize symptoms and prevent disease progression and early death. The food emergency affects all aspects of daily living.

As Patel and Delwiche (2002) note, famine is caused not by a shortage of food, but rather by poverty. The markets in Lesotho, for example, are not lacking food, according to the World Food Programme. Yet two-thirds of the population live below the poverty line and half are destitute. Fully 75% of the annual food needs of Lesotho's poor are cereals they purchase, but more than 70% of households classified as very poor have no cereal in reserve. Rapidly escalating prices and vanishing incomes are a lethal combination. The people of Lesotho cannot afford to buy available food (Patel & Delwiche, 2002). The downward slide of national economies in the region has thrown many individuals, families,

and communities into poverty, thus exacerbating their HIV disease.

The paucity of symptom prevalence data about HIV-positive persons in southern Africa presents an opportunity to develop a better understanding of what it is like to live with HIV/AIDS in such resource-poor environments. It also presents a challenge for care providers, because once they are aware of the severity of symptoms being experienced, they will be challenged to assist individuals and families to manage these symptoms. Self-reported symptom data provide a clinical picture of people living with HIV infection who do not have access to antiretroviral medications or medications for managing opportunistic infections.

The reported signs and symptoms seem to reflect a significant prevalence of tuberculosis and opportunistic infections, particularly in the enteral tract. Data suggest that the systemic impact of HIV causes weight loss, diarrhea, fatigue, and weakness. People who have HIV/AIDS often must cope with the 10 most common symptoms (see Table 2) as a constellation or cluster without the benefit of medications.

Implications for Practice

Many studies focus on the need to manage pain and control diarrhea and on skin rashes. People living with HIV/AIDS do experience these physiological symptoms, but they more frequently report psychological symptoms: fear, weakness, fatigue, anxiety, and confusion. The challenge for care providers is to build an aggressive care plan that not only moderates distress but also meets physiological needs (Holzemer, 2002).

Nurses must help individuals and families develop strategies for managing and controlling symptoms. Home- and community-based symptom management is especially urgent in countries where antiretroviral therapy is unavailable. Such an approach also shifts the burden of care from an overtaxed health services infrastructure and vests patients and their families with a modicum of responsibility and control. In this way, those living with and closest to the disease are empowered to make decisions that enhance their well-being. Even after antiretroviral therapy does become available, symptom management will con-

tinue as a key component of HIV management because of its relationship to the side effects of medication, medication adherence, and quality of life.

Conclusion

These data lead to three conclusions. First, the most frequently reported symptoms represent a cluster of the signs and symptoms of living with HIV disease without the benefit of any medications, including antiretroviral agents and prophylaxis for opportunistic infections. These symptoms are not the side effects of medications, because very few participants were taking medications. The data document high levels of disease, comorbidities, pain, distress, and suffering.

Second, health professionals and family members who provide care should be aware that people living with HIV/AIDS experience significant psychological symptoms, including fear, distress, and anxiety. In fact, such symptoms are reported more frequently than are physiological symptoms. Strategies to help clients manage fear and anxiety are as important as developing strategies to manage their pain or diarrhea. Such strategies might include creating opportunities for persons living with HIV/AIDS to participate in support groups. It is possible that outreach workers or community workers can be trained to provide support such as TASO (The AIDS Support Organization) model in Uganda (Fleischman, 1995; "TASO: 'Caring is Sharing,'" 1995).

Third, because people living with HIV describe their lives holistically in terms of both significant psychological distress and physiological signs, their concerns do not solely fit a medical or biological model of disease. Professional care providers and family members cannot assume they understand the signs and symptoms a patient is experiencing without asking. Health care providers are also reminded that families seek alternative care for symptoms through their use of traditional healers. Incorporating the psychological support, from traditional healers is important to enhance the quality of life for people living with HIV/AIDS.

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References

- Antoni, M. H. (2003). Stress management and psychoneuroimmunology in HIV infection. *CNS Spectrum*, 8(1), 40-51.
- Bing, E. G., Hays, R. D., Jacobson, L. P., Cher, B., Gange, S. J., Kass, N. E., et al. (2000). Health-related quality of life among people with HIV disease: Results from the Multicenter AIDS Cohort Study. *Quality of Life Research*, 9(10), 55-63.
- Doerfler, E. (2002). Sweetening the Toxic cocktail: Managing the side effects of HIV medications. *Advance for Nurse Practitioners*, May, (10)5, 52-54, 57-58, 103.
- Elmir, E., Nadia, S., Ouafae, B., Rajae, M., Amina, S., & Rajae, A. (2002). HIV epidemiology in Morocco: A nine-year survey (1991-1999). *International Journal of STDs and AIDS*, 13(12), 839-842.
- Fantoni, M., Ricci, F., & Del Borgo, C. (1997). Multicentre study on the prevalence of symptoms and symptomatic treatment in HIV infection. Central Italy PRESINT Group. *Journal of Palliative Care*, 13, 9-13.
- Farzadegan, H., Hoover, D. R., Astemborski, J., Lyles, C. M., Margolick, J. B., Markham, R. B., et al. (1998). Sex differences in HIV-1 viral load and progression to AIDS. *Lancet*, 252, 1510-1514.
- Fleischman, J. (1995) HIV-positively. *Africa Report*, 40(3), 57-59.
- Gilks, C. F. (2001) HIV care in non-industrialized countries. *British Medical Bulletin*, 58, 171-185.
- Gilks, C. F., Katabira, E., & De Cock, K. M. (1997). The challenge of providing effective care for HIV/AIDS in Africa. *AIDS*, 11(Suppl. B), S99-S106.
- Grant, A. (2002). Clinical features of HIV disease in developing countries. *Leprosy Review*, 73(2), 197-205.
- Grant, A. D. & De Cock, K. M. (2001). ABC of AIDS. HIV infection and AIDS in the developing world. *British Medical Journal*, June 16, 322, 1475-1478.
- Holzemer, W. L. (2002). HIV and AIDS: the symptom experience. What cell counts and viral loads won't tell you. *American Journal of Nursing*, 102(4), 48-52.
- Holzemer, W. L., Hudson, A., Kirksey, K. M., Hamilton, M. J., & Bakken, S. (2001). The revised sign and symptom checklist for HIV (SSC-HIVrev). *Journal of the Association of Nurses in AIDS Care*, 12, 60-70.
- Hudson, A. L., Kirksey, K., & Holzemer, W. L. (2004). The influence of symptoms on quality of life among HIV-infected women. *Western Journal of Nursing Research*, 25, 9-23.
- Hurley, P. A., & Ungvaski, P. J. (1994). Home healthcare needs of adults living with HIV disease/AIDS in New York City. *Journal of the Association of Nurses in AIDS Care*, 5, 33-40.

- Ickovics, J. R., Hamburger, M. E., Vlahov, D., Schoenbaum, E. E., Schumar, P., Boland, R.J., et al. (2001). Mortality, CD4 cell count decline, and depressive symptoms among HIV-seropositive women: Longitudinal analysis from the HIV Epidemiology Research Study. *The Journal of the American Medical Association*, 285(11), 1466-74.
- Janson-Bjerklie, S., Holzemer, W. L., & Henry, S. B. (1992). Patients' perceptions of pulmonary problems and nursing interventions during hospitalisation for *Pneumocystis carinii* pneumonia. *American Journal of Critical Care*, 1, 114-121.
- Joint United Nations Programme on HIV/AIDS & World Health Organization. (2002). *AIDS epidemic update: December 2002*. Retrieved July 1, 2003, from <http://www.unaids.org/worldaidsday2002/press/Epiupdate.html>
- Johnson, M. O., Stallworth, T., & Neilands, T. B. (2003). The drugs or the disease? Causal attribution of symptoms held by HIV-positive adults on HARRT. *AIDS Behavior*, 7(2), 109-117.
- Kalichman, S. C., Rompa, D., & Cage M. (2000). Distinguishing between overlapping somatic symptoms of depression and HIV disease in people living with HIV-AIDS. *The Journal of Nervous and Mental Disease*, 188(10), 662-670.
- Kempainen, J. K., Holzemer, W. L., Nokes, K., Elier, L. S., Corless, I. B., & Bunch, E. H. (2003). Self-care management of anxiety and fear in HIV disease. *Journal of the Association of Nurses in AIDS Care*, 14, 21-29.
- Lesho, E. P. & Gey, D. C. (2003). Managing issues related to antiretroviral therapy. *American Family Physician*, 68(4), 675-686.
- Mathews, W. C., McCutchan, J. A., Asch, S., Turner, B. J., Gifford, A. L., Kuromiya, K., et al. (2000). National estimates of HIV related symptom prevalence for the HIV Cost and Services Utilization study. *Medical Care*, 38(7), 750-762.
- McMahon, K. M., & Coyne, N. (1989). Symptom management in patients with AIDS. *Seminars in Oncology Nursing*, 5, 289-301.
- Neidig, J. L., Smith, B. A., & Brashers, D. F. (2003). Aerobic exercise training for depressive symptom management in adults living with HIV infection. *Journal of the Association of Nurses in AIDS Care*, 14, 30-40.
- Patel R., & Delwiche A. (2002). *The profits of famine: Southern Africa's long decade of hunger*. Oakland, CA: Food First. Retrieved July 3, 2003, from http://www.thirdworldtraveler.com/Africa/Profits_Famine.html
- Reilly, C. A., Holzemer, W. L., Henry, S. B., Slaughter, R. E., & Portillo, C. J. (1997). A comparison of patient and nurse ratings of human immunodeficiency virus-related signs and symptoms. *Nursing Research*, 46, 318-323.
- Smith, M. Y., & Rapkin, B. D. (1995). Unmet needs for help among persons with AIDS. *AIDS Care*, 7, 353-363.
- Spijkerman, I. J., Langeveld, M. W., van Amerijden, E. J., Coutinho, R. A., & van den Hoek, A. (1998). Gender differences in clinical manifestations before AIDS diagnosis among injecting drug users. *European Journal of Epidemiology*, 14, 213-218.
- TASO: "Caring is sharing." (1995). *World AIDS Day Newsletter*, (2), 12.
- Tsai, Y-F., Hsiung, P-C., & Holzemer, W. L. (2003). Validation of a Chinese version of the sign and symptom checklist for persons with HIV disease. *Journal of Pain and Symptom Management*, 25, 363-368.
- Valente, S. M., Saunders, J. M., & Uman, G. (1993). Self-care, psychological distress, and HIV disease. *Journal of the Association of Nurses in AIDS Care*, 4, 13-25.
- Zingmond, D. S., Kilbourne, A. M., Justice, A. C., Weenger, N. S., Rodriguez-Barradas, M., Rabeneck, L. et al. (2003). Differences in symptom expression in older HIV-positive patients: The Veterans Aging Cohort 3 Site Study and HIV Cost and Service Utilization Study experience. *Journal of Acquired Immune Deficiency Syndrome*, 33(2), S84-S92.