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

Lucy Nthabiseng Makoae, PhD, RN
Naomi Mmapelo Seboni, PhD, RN
Kgoroletso Molosiwa, MPH, RN
Mary Moleko, MA, RN
Sarie Human, PhD, RN
Nonhlanhla A. Sukati, PhD, RN
William L. Holzemer, PhD, RN, FAAN

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 sociodemographic items and the 64-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

Lucy Nthabiseng Makoae, PhD, RN, is at the National University of Lesotho. Naomi Mmapelo Seboni, PhD, RN, is at the Department of Nursing, University of Botswana. Kgoroletso Molosiwa, MPH, RN, is at the AIDS/STD Unit, Gaborone, Botswana. Mary Moleko, MA, RN, is at the Democratic Nursing Organization of South Africa. Sarie Human, RN, PhD, is in Advanced Nursing Science at the University of South Africa. Nonhlanhla A. Sukati, PhD, RN, is at the University of Swaziland. William L. Holzemer, RN, PhD, FAAN, is Professor and Associate Dean for International Programs at the School of Nursing, University of California, San Francisco.

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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%; dysesthesias, 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

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