



Symptoms and Quality of Life in Women

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Symptoms occur across the trajectory of HIV disease and can diminish the quality of life of women living with the virus. Untreated symptoms may also influence medication adherence and lead to complications of HIV and coexisting illnesses. Symptom management can address these concerns. A variety of self-care approaches should be incorporated into any plan of treatment, which ideally should be based on a partnership between the woman with HIV and her health-care providers. This article will address a range of issues concerning symptoms in women with HIV both in the U.S. and worldwide.

Symptoms and Quality of Life

Women with HIV experience a constellation of symptoms, many of which arise early in HIV infection. Symptoms are defined as any perceptible change in the body or its functions. Symptoms of disease are subjective (perceived by the person with the condition), whereas signs of illness are objective (perceived by another person). The experience of the affected individual is the most important index for understanding symptoms and approaching their management.

Symptoms vary according to the stage of HIV disease and any coexisting illnesses. The essential use of highly active antiretroviral therapy (HAART) and side effects related to the drugs also contribute to their occurrence. Symptoms may affect functional status (ability to perform basic activities of daily living) as well as psychological well-being.

Quality of life (satisfaction with the conditions under which one lives) is also influenced by symptoms and is a frequent outcome measure in research. Several studies have shown that HIV symptom control can improve quality of life for women living with the virus. While quality of life is often assessed in HIV clinical trials and in practice

settings, evaluation across the course of disease and in relation to medication regimen is infrequent.

What Symptoms Do Women Experience?

Symptoms in women with HIV may differ from those experienced by HIV positive men. For example, women with lipodystrophy or body fat changes are more likely than men to experience breast enlargement and abdominal fat redistribution, whereas men are more likely to have a dorsocervical fat pad (“buffalo hump”). Women are more likely to have headaches, which are usually poorly identified and poorly managed (see “Headache and HIV” on page 47). Women tend to have more fatigue, which can be related to disease or stress (such as due to childcare), and more abdominal and pelvic complaints that can mimic “normal” female complaints in healthy women. In addition, gynecological symptoms arise early and are often a marker for advancing infection.

Symptoms experienced by HIV positive women in developing countries are remarkably similar to those that affect women in the U.S., although their intensity may be greater. Fatigue, pain, and abdominal problems can be markedly more severe in areas where women lack access to over-the-counter remedies, and where HIV disease tends to advance earlier and progress faster.

Symptoms may be categorized as either physical or psychological; however, the two often overlap. For example, depression in HIV disease is a psychological symptom. Yet experts suggest that brain chemistry and neurotransmitters are linked to depression, so the condition can be considered both a psychological and a physical symptom. Anxiety and sleep disturbances are other examples of symptoms that likely involve both psychological and physical dimensions.

In HIV positive women, psychological symptoms (some of which overlap with physical symptoms) may typically include anxiety, depression, insomnia/sleep disturbances, and changes in body image. Physical symptoms may include diarrhea, nausea and/or vomiting, cough, fever, pain, neuropathy, weight loss, lipodystrophy or body fat changes, rash or other skin problems, and gynecological disorders.

A study published in the September 1, 2004 edition of *Clinical Infectious Diseases* analyzed the prevalence of clinical symptoms associated with antiretroviral therapy in the Women's Interagency HIV Study (WIHS). Michael J. Silverberg, PhD, MPH, and colleagues from Johns Hopkins University in Baltimore reviewed data collected beginning in April 2000 from 1,256 HIV positive women and 364 HIV negative women at several U.S. sites. In the six months before a study visit, 69% of HIV positive women on HAART, 67% of HIV positive women not on HAART, and 49% of HIV negative women reported having at least one clinical symptom. Symptoms reported by the participants included abdominal pain, diarrhea, anorexia, nausea and/or vomiting, fatigue, fever, body fat changes, body image disturbance, dizziness, headache, paresthesias (numbness or tingling sensations), xerostomia (dry mouth), kidney stones, and skin rash.

The researchers found that women who changed their HAART regimens were more likely to experience any symptom—particularly diarrhea, nausea and/or vomiting, body fat changes, muscle pain, and paresthesias—compared with women who remained on stable HAART. The authors concluded that the high prevalence of symptoms in HIV positive women not on therapy and in HIV negative women suggested that antiretroviral drugs were a contributing but not exclusive factor in the development of symptoms.

See the sidebar on page 34 for a comprehensive, though not exhaustive, list of symptoms in women. The list is alphabetical rather than arranged by system (see below).

A Systems Approach

Control of symptoms involves interventions to remove their cause as well as palliation (bringing relief without curing). Symptoms in women are often addressed via a systems approach. Affected body systems include the cardiovascular; respiratory; gastrointestinal; gynecological; genitourinary (genitals and urinary tract); dermatological; ear, nose, and throat; hematological (blood and blood-forming tissues); musculoskeletal; and neurological systems. Psychosocial factors, or the influence of social conditions on mental and physical health, may be considered an additional system in terms of management.

Some systems are more likely to be affected by HIV-related symptoms. For example, the gynecological and dermatological systems are often disturbed in women with HIV. Women may also experience symptoms that are not easily classified using a systems approach. Fatigue, depression, and pain are examples of common symptoms in women with HIV whose etiologies (causes) are often complex and may be related to several body systems.

Self-Assessment and Self-Care

Self-assessment and self-care are often vital for women living with HIV. For many women, self-care is the first or only approach to dealing with symptoms. Because women are frequently caregivers, issues related to childcare may limit their ability to focus on their own HIV-related health needs. Several studies of women with children have examined the difficulties these women face in keeping clinic appointments and addressing their symptom management needs. In addition, stigma remains a major barrier to care for women, particularly in southern Africa and Asia.

Some women use a variety of self-care strategies, including complementary therapies, as well as treatments advised by their health-care providers. In many countries where HIV prevalence rates are over 30%, the sole resource may be home remedies. In resource-limited countries, women may use both antiretroviral medications and traditional remedies to cope with symptoms. Although little evidence exists to support the use of traditional or complementary therapies in HIV/AIDS, more data suggesting their importance for symptom control are becoming available.

Marge Miles, PhD, RN, of the University of North Carolina at Chapel Hill and colleagues developed an intervention to assist African American women with symptom management that included education about self-care and medications, as well as regular home visits. Their study, published in the November/December 2003 issue of *Nursing Research*, showed that women with the intervention had fewer feelings of stigma, higher levels of physical functioning, and less depression and anxiety than women who received standard care.

Symptom Screening and Management

Research-based assessment tools may be helpful not only for routine clinical use by health-care providers, but also for people to comprehensively assess their own symptoms. These self-assessment tools can then be shared with providers to monitor HIV-related symptoms, effects of antiretroviral treatment and complementary therapies, self-care strategies, and progression of illness.

Several valuable symptom assessment and management guidelines exist, including those developed by Lisa Capaldini, MD, of the University of California at San Francisco (UCSF) and published in July 2004 on the HIV InSite web site (see www.hivinsite.org). [Ed. note: Dr. Capaldini is also a member of BETA's Scientific Advisory Committee.]

William Holzemer, PhD, RN, also at UCSF, has developed assessment tools such as the Sign and Symptom Check-List, which covers both signs and symptoms related

symptoms in women with HIV

Anorexia	Fever	Shortness of breath
Anxiety	Forgetfulness	Skin conditions
Cough	Lipodystrophy/ body fat changes	Sleep disturbances
Delirium	Nausea	Swelling of extremities
Dementia-type symptoms	Neuropathy	Vaginal symptoms
Depression	Night sweats	Vomiting
Diarrhea	Oral symptoms	Weight loss
Dizziness	Pain	
Fatigue	Sexual dysfunction	

web sites for symptom assessment and management for women with HIV

- www.aidsnursingucsf.org
- www.hivinsite.org
- <https://statepiaps.jhsph.edu/wihs>
- www.thebody.com/quality.html
- www.thebody.com/Forums/AIDS/SideEffects/index.html

to HIV and their intensity (mild, moderate, or severe). Holzemer's work has led to the development of a web site (www.aidsnursingucsf.org) that includes HIV Self-Care Symptom Management Guidelines, which were produced with UCSF faculty and students, members of the HIV/AIDS Nursing Research Network, and colleagues in four southern African countries (Botswana, Lesotho, South Africa, and Swaziland). This symptom instrument is available in four languages—English, Afrikaans, Sesotho (Lesotho), and Siswati (Swaziland)—so that people living with HIV/AIDS, their formal and informal caregivers, and organizations working with these individuals can manage their illness and related symptoms. Although developed for use with both women and men, the manual addresses many symptoms that occur solely in women (e.g., vaginal symptoms) or are more prevalent in women (e.g., anxiety, depression, fatigue, sleep disturbances).

As a self-care tool for *BETA* readers, a quick reference catalogue of symptoms occurring in women, their causes, and strategies to minimize them is available on the following pages. Also, see the sidebar on this page for a list of web sites providing more information on symptom screening and control in women with HIV.

Summary

Because HIV is an illness that requires ongoing, routine management and evaluation, women must be vigilant about cues to their health. Women often lack a clear understanding of why symptoms arise or the likely course they may take. Some symptoms may be subtle and require careful follow-up and communication between the woman and her providers to track changes over time. For women as well as men, developing a partnership and sharing observations about symptoms with health-care providers is an important aspect of HIV self-care.

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Symptoms, Symptom Etiology, and Self-Care Strategies* for Women with HIV

* *Consult with a health-care provider, if possible, when any symptoms develop. Self-care strategies ideally should be used together with approaches recommended by health professionals.*

ANXIETY

Causes: worry about HIV infection, anti-HIV medications, mental health issues (including depression), substance use (stimulants)

Self-Care Strategies: relaxation exercises (including meditation, tai chi), anti-anxiety medications

COUGH

Causes: infections (e.g., bacterial pneumonia, *Pneumocystis carinii* pneumonia [PCP], tuberculosis [TB], viruses)

Self-Care Strategies: over-the-counter medications (acetaminophen, cough remedies); drink fluids

DEPRESSION

Causes: brain chemical changes, fatigue, stress, family history of depression, past or current substance use, history of trauma, HIV-related dementia or other organic brain disorders

Self-Care Strategies: psychotherapy/counseling, antidepressant medications, St. John's wort (over-the-counter) [Note: this can interact with anti-HIV medications and should be avoided unless approved by a clinician]; avoid isolation

DIARRHEA

Causes: infections (protozoal, viral,

bacterial), anti-HIV medications (protease inhibitors)

Self-Care Strategies: antidiarrhea medications including over-the-counter agents (acidophilus, Metamucil, Lomotil), acupuncture; drink plenty of fluids and energy drinks (e.g., Gatorade); avoid alcohol, caffeine, fast food, fried foods, dairy products (except yogurt); make dietary changes in consultation with a health-care provider

DIZZINESS

Causes: anemia, dehydration, anti-HIV medications

Self-Care Strategies: if dizzy upon waking, sit up slowly and remain sitting for several minutes before standing up to walk; drink plenty of fluids; eat a healthy diet; consult with a health-care provider about medications and laboratory blood values (hematocrit/hemoglobin)

FATIGUE

Causes: HIV disease progression, anti-HIV medications, anemia, depression, pain, low testosterone, chronic viral hepatitis coinfection

Self-Care Strategies: complementary therapies (e.g., massage, reflexology, acupuncture); get enough sleep every night (8 hours); take frequent rest breaks during the day; exercise in moderation (e.g., walking); eat plenty of fruits, vegetables, and cereals; avoid alcohol, caffeine, substance use, high sugar and high carbohydrate foods; consult with a health-care provider about medications and labora-

tory blood values (hematocrit/hemoglobin)

FEVER

Causes: HIV disease, progression of HIV disease, anti-HIV medications, infection in any of the body systems, coexisting health problems

Self-Care Strategies: drink plenty of fluids without caffeine or alcohol (8–10 glasses of water, juice, ginger ale daily); rest to avoid using up energy; take acetaminophen as directed by a health-care provider; take all anti-HIV drugs and other medications as prescribed; take a full course of antibiotics if prescribed; check temperature with a thermometer and call a health-care provider if higher than 101° F or if elevated for more than 24 hours

FORGETFULNESS

(may be related to early symptoms of delirium or dementia)

Causes: HIV disease, progression of HIV, anti-HIV medications, brain infection (e.g., toxoplasmosis), depression, coexisting health problems

Self-Care Strategies: get enough sleep every night (8 hours); take frequent rest breaks during the day; avoid alcohol and substance use; seek assistance to develop a schedule of daily events; ask for cues and reminders from family/friends; ask family/friends/providers to organize anti-HIV medications and use medication reminders; take all anti-HIV medications but consult with a health-care provider about any other medications

GYNECOLOGICAL SYMPTOMS

Causes: HIV disease, infection (yeast, bacteria, viruses), cervical dysplasia or cancer

Self-Care Strategies: for white, curd-like vaginal discharge use prescription or over-the-counter medications; to avoid vaginal yeast infections eat yogurt and acidophilus each day; wear cotton underwear and change daily; avoid tight clothes and nylon clothing; do not use tampons; do not douche since this disturbs the vaginal flora; use condoms during sex whether or not vaginal symptoms are present; for women with HIV, more careful monitoring to avoid gynecological symptoms is recommended; more frequent Pap smears may be necessary

LIPODYSTROPHY/ BODY FAT CHANGES

(fat loss in the extremities, abdominal fat accumulation, dorsocervical fat pad [buffalo hump], increased breast size, lipomas [benign fat cell tumors], increased prominence of veins)

Causes: unclear; associated with anti-HIV drugs, especially certain PIs and NRTIs (e.g., d4T [stavudine, Zerit], alone or in combination; longer duration of HIV infection; longer duration of anti-HIV drug use

Self-Care Strategies: exercise (especially aerobic); avoid refined carbohydrates in foods and beverages; increase intake of healthy fats (omega-3 and monounsaturated fats); increase fiber intake to at least

25 grams daily and increase soy consumption to reduce cholesterol; increase consumption of beans, fruits, vegetables, nuts, whole grains, and rice

NAUSEA

Causes:

anti-HIV medications, infections, coexisting health problems (e.g., diabetes, alcoholism, chronic hepatitis, reflux esophagitis)

Self-Care Strategies:

medications, both over-the-counter and prescription (e.g., prochlorperazine, metachlopramide); acupuncture; medical marijuana or dronabinol (Marinol), in consultation with a health-care provider; drink enough fluids to avoid dehydration

NEUROPATHY

Causes:

anti-HIV medications (especially d4T, ddI [didanosine, Videx], ddC [zalcitabine, Hivid]), HIV disease, coexisting health problems (e.g., diabetes, alcoholism, chronic viral hepatitis)

Self-Care Strategies:

massage, acupuncture, reflexology, meditation, vitamins, rest, ice (in consultation with a provider), creams/lotions for feet (both over-the-counter and prescription), medications (gabapentin, lamotrigine, tricyclic antidepressants, anti-seizure medications such as phenytoin, carbamazepine, valproate)

NIGHT SWEATS

Causes:

HIV disease, menopause (vasomotor symptoms, hot flashes)

Self-Care Strategies:

avoid extreme temperatures; have a change of clothes and

bed linens available; drink plenty of fluids (8–10 glasses of water daily); take OTC pain reliever after consulting with a health-care provider

ORAL SYMPTOMS/ MOUTH SORES

Causes:

candidiasis (thrush), herpes simplex virus infection, progression of HIV disease

Self-Care Strategies:

eat soft or liquid foods (e.g., mashed potatoes, soup, yogurt, instant breakfast, Ensure, Sustecal); avoid salty, spicy, or acidic food and drinks (e.g., orange juice, pineapple juice, grapefruit juice); use a straw for beverages to minimize liquids' contacting mouth sores

PAIN

Causes:

HIV disease, anti-HIV medications (abdominal pain, neuropathy), infections (bacterial, viral, protozoal), coexisting health problems (e.g., bowel problems, gynecological problems may cause abdominal pain)

Self-Care Strategies:

identify the source and location of the pain if possible; if pain is mild, take OTC pain reliever as directed; if the pain is acute in onset, call a health-care provider

SEXUAL DYSFUNCTION

Causes:

HIV disease and other chronic illnesses, fatigue, depression, body image issues, coexisting health problems (e.g., gynecological problems, vaginal infections, herpes simplex infection)

Self-Care Strategies:

get plenty of rest if decreased libido is due to fatigue; psychotherapy/counseling may improve sexual functioning and body image and limit depression

SHORTNESS OF BREATH

Causes:

respiratory infections (e.g., bacterial pneumonia, viral pneumonia, TB), anemia, fatigue, anti-HIV medications, asthma/emphysema

Self-Care Strategies:

check for fever; watch for respiratory secretions or productive cough (coughing sputum); check breathing rate and notify a health-care provider

SKIN CONDITIONS

Causes:

HIV disease, anti-HIV medications, other medications (e.g., antibiotics), viral infections (e.g., herpes simplex, herpes zoster), bacterial infections (e.g., *Staphylococcus aureus*), yeast infections of skin (under breasts or in groin), Kaposi's sarcoma (KS); sun exposure

Self-Care Strategies:

monitor the skin condition as to size, changes in appearance, drainage from lesions; evaluate whether the skin condition is accompanied by pain or fever; avoid excess sun exposure; use sunscreen as directed; report sudden onset of rash

SLEEP DISTURBANCES

Causes:

HIV disease, anti-HIV medications, anxiety, depression, reduced estrogen level due to menopause, substance use

Self-Care Strategies:

over-the-counter and prescription medications; keep a sleep diary; drink warm milk before bed; avoid large meals before bed; sleep in a darkened room without noise if possible; seek counseling/psychotherapy, with a sleep specialist if possible

SWELLING OF EXTREMITIES

Causes:

HIV disease, lymph system problems

Self-Care Strategies:

rest with legs elevated on pillows, avoid constrictive socks and shoes

WEIGHT LOSS

Causes:

HIV infection, anti-HIV medications, depression, fatigue, infection (e.g., TB), coexisting health problems (e.g., diabetes, hepatitis)

Self-Care Strategies:

use a scale to keep track of weight every week; eat high-protein, high-calorie foods; eat small, frequent meals (6–8) each day; eat yogurt; drink liquid supplements such as Ensure, Sustecal, or instant breakfast; take vitamin/mineral supplements in consultation with a provider; have high-calorie snacks available between meals; exercise may improve appetite