

Self-Care for Fatigue in Patients With HIV

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Purpose/Objectives: To identify when fatigue is reported as a problem by people who are HIV positive, what the perception of fatigue is, and which self-care behaviors are used and with what efficacy.

Design: Multisite descriptive study.

Setting: University-based AIDS clinics, community-based organizations, and homecare agencies located in cities across the United States, in Norway, and through a university Web site.

Sample: Convenience sample of 422 self-identified people who are HIV positive.

Main Research Variables: Symptom description, symptom relief, symptom help, and self-care strategies.

Findings: The sixth most reported symptom in this study, fatigue, was treated with a variety of self-designed strategies. In only three instances was consultation with a healthcare provider (i.e., physician) or an injection (medication not defined) mentioned. The most frequently used interventions were supplements, vitamins, and nutrition followed by sleep and rest; exercise; adjusting activities, approaches, and thoughts; distraction; and complementary and alternative therapies. In addition to self-designed strategies, the media and friends and family were sources of information.

Conclusions: Fatigue was reported less frequently in this study than in other HIV-, AIDS-, or cancer-related studies. This may be an artifact of the study design. The use of informal networks for assistance, let alone the prevalence of unrelieved fatigue, indicates the need for more attention to this problem among people with AIDS.

Implications for Nursing: Careful assessment of the pattern of fatigue and its onset, duration, intervention, and resolution is required if the varied types of fatigue are to be identified and treated successfully.

Key Points . . .

- ▶ Patients with HIV, AIDS, cancer, or other chronic diseases commonly report experiencing fatigue.
- ▶ Healthcare professionals often overlook fatigue.
- ▶ Fatigue is treated with a variety of strategies.
- ▶ Participants' reported sources of care were self-designed and obtained from their informal support networks, not their healthcare providers.

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With the advent of more effective therapies, HIV and AIDS, which once were imminently fatal, now are chronic. This change has increased the attention given to the management of symptoms, particularly those symptoms of greatest concern to patients living with HIV or

AIDS and the healthcare community. Fatigue is a symptom common to individuals with or without chronic diseases. The critical question is whether rest resolves fatigue. In the latter instance, fatigue is considered transitory. Fatigue occurring in those with HIV or AIDS that was not alleviated by rest and the self-care strategies used were the focus of this study. Specifically, individual perceptions of fatigue, self-care strategies, and the efficacy of those strategies in resolving fatigue as it occurs in those with HIV or AIDS were studied.

Background

Fatigue has been defined in various ways. Piper, Lindsey, and Dodd's (1987) definition of fatigue in patients with cancer addressed their lived experiences. They stated "fatigue, from a nursing perspective, is defined as a subjective feeling of tiredness that is influenced by circadian rhythm. It can vary in unpleasantness, duration, and intensity" (p. 19). In contrast to this subjective definition, Lee, Hicks, and Nino-Murcia (1991) defined fatigue from a physiologic perspective as "the end result of excessive energy consumption, depleted hormones, or diminished ability of muscle cells to contract" (p. 291). Breitbart, McDonald, Rosenfeld, Monkman, and Passik (1998), quoting from the work of Hays, Turner, and Coates (1992), noted the positivist or "simple definition (e.g., 'persistent or frequent fatigue [feeling tired all the time] for at least two weeks')" (p. 165). This definition operationalizes fatigue as tiredness that persists for a given length of time—in this case, greater than two weeks.

Breitbart et al. (1998) contrasted this simple definition with definitions that contain multiple and interactive components, including cognitive, behavioral, and emotional aspects. Rose, Pugh, Lears, and Gordon (1998), who referenced Piper et al. (1987) when they observed "most definitions of fatigue include aspects of work decrement, physiological effects, and feelings of tiredness" (p. 296), highlighted the continuum from tiredness to exhaustion. Cleary et al. (1993) found fatigue a strong predictor of the limitations in daily activities among patients with AIDS. Specifically, Darko, McCutchan, Kripke, Gillin, and Golshan (1992) found that fatigue affected employment and activities of homosexual men who were HIV seropositive. Capalini (1998a) described physical fatigue but also noted other types, such as psychological, depression, hypogonadism, and morning fatigue. These types represent fatigue secondary to other phenomena, as well as the time of day when fatigue occurs.

By mentioning depression, Capalini (1998b) drew attention to a major debate in the literature—the association between depression and fatigue. Perkins et al. (1995) and Walker, McGowan, Jantos, and Anson (1997) saw a close relationship between depression and fatigue. Perkins et al., in a six-month follow-up of 82 homosexual men infected with HIV and 64 uninfected homosexual men, noted that "complaints of fatigue and insomnia in otherwise asymptomatic HIV-infected patients were likely to be related to psychological disturbances and possibly major depression" (p. 1776). Breitbart et al. (1998) and Ferrando et al. (1998) disagreed and observed that although associated with depression, fatigue makes an independent contribution to morbidity in HIV disease. In a recent double-blind, placebo-controlled study, Breitbart, Rosenfeld, Kaim, and Funesti-Esch (2001) found that psychostimulants (i.e., methylphenidate and pemoline)

were effective in decreasing fatigue with minimal side effects and improving quality of life. Fuhrer and Wessely (1995) came to a similar conclusion with a sample of 3,784 participants examined for fatigue as a presenting complaint in a primary care study of patients in a general practice. Fatigue also has been associated with pain (Burrows, Dibble, & Miaskowski, 1998). Finally, Blesch et al. (1991) cited Aistars (1987) who viewed fatigue as the endpoint of the stress related to physiologic, psychological, and situational factors involved in disease and treatment.

Before a further explication of the causes and correlates of fatigue in those infected with HIV, fatigue in patients with cancer has been observed to be complex, multicausal, and multidimensional (Curt, 2000). Fatigue also is the most frequently reported symptom by patients with cancer (Magnusson, Moller, Ekman, & Wallgren, 1999; Nail, Jones, Greene, Schipper, & Jensen, 1991; Piper et al., 1998; Sarna, 1998; Simon & Zittoun, 1999; Winningham et al., 1994; Wyatt & Friedman, 1998; Yarbrough, 1996), occurring in 40%–84% of patients (Carlson, 2001) and 100% of patients with breast cancer during radiation therapy (Mock et al., 1997). Fatigue was the second most frequently occurring symptom for patients undergoing chemotherapy (Foltz, Gaines, & Gullatte, 1996).

Irvine, Vincent, Graydon, and Bubela (1998) tracked fatigue in patients receiving radiation therapy for breast cancer and found that fatigue increased during treatment and receded to pretreatment levels three months post-treatment. Bower et al. (2000) found that only a minority of women with early-stage breast cancer had persistent fatigue after the conclusion of therapy. This finding may be related to disease stage and the types of therapy experienced. In contrast to these results, Harpham (1999) discussed the profound tiredness that many patients feel even after therapy has been completed. In another study, patients reported that fatigue was a continuing problem (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Walker, Nail, Larsen, Magill, and Schwartz (1996) emphasized that fatigue was the most frequently reported continuing problem.

In addition to the experience of fatigue at the conclusion of therapy, Berger (1998), in a study of women undergoing chemotherapy, found a roller-coaster pattern of fatigue intensity. Richardson, Ream, and Wilson-Barnett (1998) identified a similar cyclic pattern. Woo, Dibble, Piper, Keating, and Weiss (1998) noted that women receiving combination therapy had the greatest fatigue. However, these patients also were at the most advanced disease state. Sarna (1998) found fatigue the most severely rated symptom over a six-month period by participants with advanced lung cancer, and it was the most persistent symptom over a year in patients with breast cancer (Hoskins, 1997). These studies identify multiple patterns of fatigue in patients with cancer depending on disease status, cell type, and course of therapy.

The HIV and AIDS literature is underdeveloped compared to that of cancer-related fatigue. This symptom is prominent for those with HIV or AIDS. In studies of people infected with HIV, the incidence of fatigue ranged from 55%–98%. Fatigue was present in 43 (98%) women (van Servellen, Sarna, & Jablonski, 1998), 428 (85%) ambulatory patients (Vogl et al., 1999), 91 (77%) hospitalized patients, and 75 (64%) ambulatory patients who were HIV positive (Fontaine, Larue, & Lassauniere, 1999). Breitbart et al. (1998) found that 363 (85%) ambulatory patients infected with HIV described a "lack of energy" during the preceding week and 235 (55%)

participants felt tired “all the time.” In a comparison of patient and nurse ratings of HIV-related signs and symptoms, fatigue was mentioned by 62% of the 207 patients (Reilly, Holzemer, Henry, Slaughter, & Portillo, 1997).

Various causes of HIV-related fatigue have been noted, including anemia, impaired liver or thyroid function, malnutrition, wasting, AIDS dementia, HIV myopathy, immunosuppression, hormonal deficiencies, depression, lack of exercise, pain, infection or fever, nutritional deficiencies, excessive inactivity or rest, and growth hormone dysregulation (Adinolfi, 2001a, 2001b; Barroso, 1999; Breitbart et al., 1998, 2001; Darko, Mitler, & Miller, 1998; Groopman, 1998; Lee, Portillo, & Miramontes, 1999, 2001; “More Awareness Needed in Treatment of Fatigue,” 1996). McDonnell, Gielen, O’Campo, and Burke (1999) found viral load and energy were inversely related in 273 women who were HIV positive. Lee et al. (1999) also found that lower CD4 counts in women who were HIV positive were related to higher morning and evening fatigue. For women in general, fatigue is a major issue (Stewart, Abbey, Meana, & Boydell, 1998).

Factors unrelated to fatigue include hemoglobin, hematocrit, albumin, total protein, altered muscle metabolism, and treatable anemia (Barroso, 1999; Cosby, Holzemer, Henry, & Portillo, 2000; Miller et al., 1991; O’Dell, Meighen, & Riggs, 1996). O’Dell et al. noted that their data indicated a stronger association of fatigue with psychosocial factors rather than with physiologic factors. Messias, Yeager, Dibble, and Dodd (1997) urged nurses “to listen carefully to patient’s own description of being tired” (p. 47).

Conceptual Framework

The current study used the symptom management model developed by the University of California, San Francisco (UCSF) School of Nursing Symptom Management Faculty Group (“A Model of Symptom Management,” 1994). This model emphasizes the subjective aspect of the symptom experience. Symptoms are considered to reflect changes in biopsychosocial function, sensation, or cognition. For effective symptom management to occur, attention must be given to the three interrelated aspects of the model, namely, symptom experience, symptom management, and symptom outcomes. In the current study, this focus translates to the individual’s perception of fatigue, self-care strategies, and the efficacy of those strategies in resolving fatigue as reflected in the symptom management outcome.

Piper et al. (1989) proposed a model of fatigue in patients with cancer. Characteristics distinguishing acute and chronic fatigue include purpose or function, population at risk, etiology, perception, onset, duration, pattern, relief dimension, and impact on activities. Two of the characteristics of this model, onset and resolution, which are components of the relief dimension, will be used as part of the framework and analysis of this study. Descriptors of fatigue and self-care strategies will be evaluated as to the acute or chronic nature of both onset and resolution.

Methods

Design

The data for this analysis were obtained in a survey of the symptom management strategies used by people with HIV.

The study questions were “When fatigue is identified as a problem, what is the individual’s perception of fatigue? What self-care behaviors are used, and with what efficacy? What are the sources of information for the self-care behaviors utilized by people experiencing fatigue?”

Setting and Sample

Data were collected for this multisite, descriptive study in person or by mail at various agencies and institutions that provide services to those infected with HIV or over the Internet at www.hivsymptoms.ucsf.edu. The Web site was developed by the UCSF International HIV/AIDS Nursing Research Network. A convenience sample of people who were HIV positive ($N = 422$) was recruited from university-based AIDS clinics, private practices, public and for-profit hospitals, residential and daycare facilities, community-based organizations, and homecare agencies located in Boston, MA ($n = 52$), New York, NY ($n = 49$), Oslo, Norway ($n = 20$), Paterson, NJ ($n = 52$), the San Francisco Bay Area ($n = 87$), and through the UCSF Web site ($n = 162$). The Web site accounted for 38% of the study responses, followed by the greater San Francisco Bay Area (21%), Paterson (12%), Boston (12%), New York (12%), and Oslo (5%).

Participants, self-identified as being HIV positive, volunteered to participate in the study. Informed consent was implied by participation in the study (Boston) or given by written consent (New York, Paterson, San Francisco Bay Area, and Norway sites). Web participants were informed about the study with the following introduction: “You are invited to take a few minutes to complete this survey designed to help us gather information on how people living with HIV or AIDS manage the symptoms related to their illness and its treatments.” The Web site clearly identified the study as research and stated that individuals were free to participate as they wished, but that participation would help the researchers understand the nature of the self-care strategies used by the respondents. To maintain anonymity, names were not requested.

Instruments

The demographic questionnaire included questions about age, gender, race, education, current living arrangements, adequacy of income, perceived adequacy of insurance coverage, CD4 lymphocyte count, AIDS diagnosis, history of injection drug use, and antiretroviral medication use. Adequacy of income and insurance coverage were categorized as “enough,” “barely possible,” and “totally inadequate.”

The participants were asked to name and describe a physical or psychological symptom or problem they frequently experienced. Once participants named a symptom, they were asked to describe the symptom and answer the following questions. What do you do to help relieve this symptom? Where did you learn this strategy? How does it help? Participants then had the option of naming another symptom and repeating the process for the next symptom identified or ending the interview. A panel of expert HIV and AIDS clinicians and researchers established face validity. Instruments were pretested with people with HIV or AIDS; no modifications were made to the instruments.

Data Analysis

Data were analyzed using both quantitative and descriptive techniques. Statistical Packages for the Social Sciences—Personal Computer Version 10.0 was used to organize and analyze

the demographic and descriptive data about symptoms. Data were aggregated by the symptom mentioned. For example, in addition to fatigue, such related concepts as tiredness, loss of energy, exhaustion, weakness, and chronic fatigue also were mentioned as symptoms. Participants who discussed fatigue and the related concepts constituted the sample for this study.

Results

Sample

A comparison of all participants of this symptom management study and those who reported fatigue is given in Table 1. The demographic characteristics for the fatigue sample and the total sample were similar except in regard to ethnicity, education, and living arrangements. The fatigue sample was less racially diverse, more educated, and less likely to live alone than the totality of the participants of the symptom management study.

Fatigue Descriptors

Fatigue was the sixth most frequently reported symptom (10%, n = 31) in the symptom management study, with anxiety or fear (25%), diarrhea (23%), neuropathy (16%), nausea and vomiting (14%), and depression (11%) reported more frequently. Other symptoms categorized by the participants as fatigue included exhaustion, tiredness, weakness, and loss of energy.

Fatigue was attributed to discontinuation of antiretroviral drugs and “not having enough blood.” As one participant said,

[I’m] often able to be up for four to six hours in a day. This has been getting worse since my doctor took me off antiretrovirals in February of 1999 because my liver enzyme levels were dangerously high.

Fatigue was associated with depression and a difficulty in concentration. “Fatigue leads to depression and sadness or is it the other way around, I wonder sometimes?” As another participant said, “[The fatigue] comes and goes during the day

and makes it difficult for me to concentrate and participate in long meetings or long lectures.” Other respondents described having fatigue as “[being] tired, even when just waking up,” “[being] extremely tired, weak, achy, sleepy,” “extreme fatigue that is not affected by the amount of sleep,” and “I have just no energy; I’m weak and tired. It’s hard to do anything or to get motivated.”

Self-Care Behaviors

The respondents to this survey utilized various self-care behaviors to address fatigue. Ninety-four different behaviors were mentioned, and those responses were listed and grouped (see Table 2). The most frequently reported self-care strategies included supplements, vitamins, and nutrition (n = 29, 31%); sleep or rest (n = 21, 23%); adjustments to activities, approaches, or thoughts (n = 16, 17%); and exercise (n = 14, 15%).

Sources of Information

Participants reported 41 sources of information for these self-care behaviors, including self-designed interventions (n = 15, 37%), media reports (n = 13, 32%), friends and family (n = 7, 17%), physicians (n = 3, 7%), and other (n = 3, 7%).

Efficacy of Self-Care Behaviors

Strategies utilized by this sample were helpful to varying degrees from “not at all” to “it helps a lot.” Seventy one percent of the strategies were considered helpful, 12% “not at all,” and the remainder helped “sometimes,” “somewhat,” “very little,” and “not much.”

In this study, a distinction was not made *a priori* as to whether the fatigue was acute or chronic. Using the Piper et al. (1989) model of fatigue, the descriptors of fatigue given by this study’s participants were differentiated as to whether onset and resolution were described as acute or chronic. Piper et al. (1989) described acute onset as rapid, whereas chronic onset is gradual and cumulative. Acute resolution is quick, alleviated by rest, diet, exercise, or stress management techniques. Chronic resolution requires a combination of methods and does not resolve readily. Using these distinguishing characteristics, Table 3 was developed with four different patterns of onset and resolution: acute-acute, acute-chronic, chronic-acute, and chronic-chronic.

If patterns of onset were observed alone, 15 participants were acute and 14 were chronic. Similarly, if only patterns of resolution were examined, 17 participants were acute and 12 were chronic. Ten respondents were divided almost equally into mixed patterns of onset and resolution of acute-chronic (n = 4) or chronic-acute (n = 6). Further investigation of the use of self-care strategies by the participants may elucidate treatments that were more effective for one pattern than another.

Table 4 lists the interventions by onset and resolution pattern. The major distinction in the categories depicted in Table 4 is that although all groups used sleep and rest, the acute-chronic group mentioned sleep more frequently (as a percentage of total mentions). Indeed, 44% (n = 4) of the acute-chronic group, 33% (n = 5) of the chronic-chronic group, 26% (n = 10) of the acute-acute group, and 6% (n = 2) of the chronic-acute group described sleep. Nevertheless, more participants in the acute-acute group described sleep and rest than in any other group. Fifty-three percent (n = 17) of the chronic-acute group, 26% (n = 10) of the acute-acute group, 22% (n =

Table 1. Demographic Profile: Fatigue Sample and Total Sample

Characteristic	Fatigue Sample (n = 31)	Total Sample (N = 422)
Age (years)	41.72	43
Range = 15–79		
Male	77%	78%
Nonwhite	29%	46%
Greater than high school education	80%	64%
Inadequate income	16%	16%
Does not live alone	77%	63%
No history of injecting drug use	68%	64%
HIV, not AIDS	42%	48%
Mean CD4	379.2 (SD = 312.45)	409.38 (SD = 267.48)
Range = 0–1,488		
Inadequate insurance	13%	18%
Taking antiretroviral drugs	71%	75%

Table 2. Activities Used to Relieve Fatigue

Type of Activity	Number of Times Mentioned	Examples
Supplements, vitamins, and nutrition	29	Vitamins, minerals, herbs, ginko biloba
Sleep or rest	21	Sleep, rest, nap, take it easy
Adjustments to activities, approaches, or thoughts	16	Adjusting social agenda, planning, not getting stressed out, believing activities will help
Exercise	14	Exercising, walking, light weight-lifting
Distraction	5	Movies, gardening, housework, watching television, reading
Complementary and alternative therapies	5	Acupuncture, prayer, meditation
Medications	2	Amitriptyline, shots
Healthcare provider support	2	Seeing/talking with a physician
Total	94	

2) of the acute-chronic group, and no participants in the chronic-chronic group mentioned supplements, vitamins, and nutrition. Those with a chronic resolution described sleep more frequently, whereas those with an acute resolution to their fatigue described supplements, vitamins, and nutrition more frequently. Although participants in all groups described sleep, the chronic-chronic group did not mention supplements, vitamins, and nutrition.

These same strategies were used with very different effects. For the acute-acute group these strategies increased energy, “helped a lot,” resulted in “rejuvenation,” and left participants “rested enough to handle things,” “more relaxed and less intense,” and “less tired.” In the chronic-chronic group these same strategies helped “somewhat,” “sometimes,” “some,” “often not,” “just a little,” “very little,” “it doesn’t seem to,” “no,” or “not at all.” The difference between the two mixed groups was, by definition, if the intervention helped, the resolution was characterized as acute. Those in the chronic-acute group stated “it seems to help,” “[it] takes my mind off it,” “it helped me,” “somewhat,” “yes,” and “at least I have some life now.” In contrast, those in the acute-chronic group were not helped by the intervention as indicated by “doesn’t help,” “not much,” “it doesn’t help,” and “rest and time seem to be the only solution.”

Discussion

In this study of self-care strategies used for symptoms by people infected with HIV, fatigue was the sixth most frequently cited symptom. This differs from other reports cited earlier, as well as Barroso (1999), who found a 20%–60% prevalence of fatigue in the literature, and Bormann, Shively, Smith, and Gifford (2001), who viewed fatigue as among the

most frequently reported symptoms. Given this literature, fatigue may have been underreported in this study. The design of the study may have affected this outcome. Participants were invited to name and describe a physical or psychological symptom that frequently occurs instead of all of their symptoms, the most troublesome, or the one of longest standing. Thus, the fact that fatigue was less prominent in this study may be an artifact of study design. Collection of data via the Internet is fraught with a new problem, the potential for multiple entries by the same individual. An inspection of the demographic data led the researchers to believe this was not a problem in this study.

Descriptors of fatigue in this study overlap with those noted by Messias et al. (1997) for patients undergoing cancer chemotherapy, with the exception of feeling cold. The latter was indicated by patients with cancer and may reflect a low hematocrit level. In a study of the psychometric properties of a fatigue assessment tool study, Schwartz (1998b) organized fatigue descriptors under physical, emotional, cognitive, and temporal subscales. Descriptors listed under the emotional subscale include loss of ability or being overcome, stuck, listless, frustrated, helpless, and vulnerable. The descriptors listed by the participants in the current study were physical, cognitive, and temporal descriptors, but not emotional ones. Similarly, the descriptors do not contain the sensory subscale in the four subscales of the Piper Fatigue Scale (i.e., behavioral/severity, affective meaning, cognitive/mood, and sensory) (Piper et al., 1998). These differences may be the result of sampling variations or may reflect a difference between patients with cancer and those with HIV or AIDS.

The interventions described in the literature are medications directed at physiologic causes (“Fighting Fatigue Requires Battle on Many Fronts,” 1996; “More Awareness Needed in Treatment of Fatigue,” 1996). Potential treatments mentioned in the literature, but not specifically by these respondents, include dextroamphetamine (Capaldini, 1998a; Wagner & Rabkin, 2000), peptide T (Doob & MacFadden, 1992), hyperbaric oxygen therapy (Reillo, 1993; Reillo & Myers, 1992; Steinhart, Montoya, & Kaiser, 1994), and testosterone (“Testosterone Therapy Can Improve Mood, Energy,” 1999; Wagner, Rabkin, & Rabkin, 1998). Whether the participant who mentioned getting “shots” was referring to B₁₂ or testosterone, which is available in patches and gels, is unclear.

The participants of this study used self-care interventions that were nonspecific and germane to chronic disease in general. Skalla and Lacasse (1992) developed a patient-education

Table 3. Frequency of Acute and Chronic Onset and Resolution of Fatigue

Relief Dimension: Resolution	Onset		Total
	Acute	Chronic	
Acute	11	6	17
Chronic	4	8	12
Total	15	14	29 ^a

^aMissing data = 2

Table 4. Intervention by Onset and Resolution Pattern

Onset-Resolution	Self-Care Strategy	%	n
Acute-acute (n = 38)	Supplements, vitamins, and nutrition	26	10
	Sleep and rest	26	10
	Adjust activities	24	9
	Exercise	18	7
	Complementary and alternative therapies	3	1
	Distraction	3	1
Acute-chronic (n = 9)	Sleep and rest	44	4
	Supplements, vitamins, and nutrition	22	2
	Exercise	11	1
	Adjust activities	11	1
	Distraction	11	1
Chronic-acute (n = 32)	Supplements, vitamins, and nutrition	53	17
	Exercise	13	4
	Distraction	9	3
	Complementary and alternative therapies	9	3
	Sleep and rest	6	2
	Healthcare provider support	6	2
	Medications	3	1
Chronic-chronic (n = 15)	Adjust activities	40	6
	Sleep and rest	33	5
	Exercise	13	2
	Complementary and alternative therapies	7	1
	Medications	7	1

Note. Because of rounding, not all percentages total 100.

tool that suggests that patients with cancer sit or lie down often and take naps. These suggestions were the same as those used as self-care by the participants of this study. Similarly, 84% of patients with cancer in a study by Ream and Richardson (1999) employed resting and napping, taking things easy, modifying activities, and walking and gardening as self-care strategies. These are the same strategies used by the participants with HIV in the current study.

Schwartz (1998a) reported that 76% of the participants in her study exercised to relieve cancer-related fatigue. Less frequently used were being with friends and family, eating, watching television, or reading. Ninety percent of the sample reported using a combination of rest and exercise to reduce cancer-related fatigue. Mock et al. (1994) found a structured exercise program of walking combined with a support group to convey benefits for those undergoing adjuvant chemotherapy. Aerobic exercise also was beneficial for patients with cancer (Dimeo, Rumberger, & Keul, 1998).

Self-care activities devised by Nail et al. (1991) addressed both fatigue and nausea faced by patients undergoing chemotherapy. Fatigue interventions included taking naps, going to bed earlier than usual, sleeping later than usual, and keeping busy to keep the mind off fatigue. These are the same as those used by the participants who were HIV positive in the current study.

Self-care interventions for patients with multiple sclerosis or myasthenia gravis are similar to those used by the current study's participants and include energy conservation, stress reduction, and an increase in rest and sleep (Grohar-Murray, Becker, Reilly, & Ricci, 1998; Stuifbergen & Rogers, 1997). A study by van Mens-Verhulst, van Dijkum, Lam, and van Kuijk (1999) indicated that for individuals with a moderately severe chronic disease, focusing on symptoms, maintaining activity, and accommodating the illness were the most effective approaches. Irvine et al. (1998) found the most frequent self-care strategies used by women undergoing radiation therapy for breast cancer were sitting and sleeping. Foltz et al. (1996) also found that inpatients undergoing chemotherapy used sleep and rest most frequently in self-care for fatigue.

As in the current study where healthcare providers were listed very infrequently as sources of information (7%), only 14% of patients with cancer-related fatigue had any intervention prescribed or recommended by their providers (Stone, Richards, Ream, et al., 2000).

Implications for Nursing

Fatigue continues to be a problem for people living with HIV or AIDS and contributes to both morbidity and disability (Darko et al., 1992). Strategies utilized by this sample were helpful to varying degrees from "not at all" to "it helps a lot." Careful assessment of the pattern of fatigue including its onset, duration, intervention, and resolution is required if the varying lineages of fatigue are to be identified successfully. A focus on the four dimensions of subjective fatigue— affective and meaning, behavioral and severity (including disruption of activities of daily living), cognitive and mood, and sensory (physical symptoms)—will add to the precision of the scientific discourse.

Fatigue may be the consequence of a deficiency (e.g., anemia), a biobehavioral factor (e.g., alteration in sleep activity patterns), or some other cause. Development of successful interventions requires a careful assessment of the cause. Remediation of a deficiency or alteration of a biobehavioral pattern, although challenging, may constitute the simple case. Fatigue resulting from the interaction of complex and poorly understood mechanisms will be more difficult to resolve and may receive inadequate attention from healthcare providers. Providers may not be alarmed by what may be construed as the lesser of a series of problems because of their own acceptance of fatigue as a part of their daily lives. Kaasa, Loge, Knobel, Jordhoy, and Brenne (1999) argued that although fatigue, mental health, and pain are connected to psychosocial strain in the general population, fatigue is more related to a decline in physical health in patients with cancer. This study received additional credence by the finding that despite the presence of fatigue in the general population, a significantly greater level of fatigue in patients with cancer was identified (Stone, Richards, A'Hern, & Hardy, 2000). Unfortunately, one study found that 45% of patients with cancer believe nothing can be done to alleviate fatigue (Curt et al., 2000). Those living with HIV or AIDS likely have similar feelings.

Kuuppelomaki and Lauri (1998) found that the suffering experienced by patients with cancer had physical, psychological, and social dimensions. Fatigue and weakness were the most common general complaints observed by these researchers. Thus, to alleviate suffering, healthcare providers

need to address fatigue and other troublesome symptoms. The concept of a side-effects burden proposed by Longman, Braden, and Mishel (1997) is one that needs to be examined with regard to HIV and AIDS therapeutics. In fact, the side-effects burden may become more significant as the pill count and frequency of dosage per day declines. The side-effects burden may predict adherence to medications in that as the burden increases, adherence decreases. As healthcare providers become more effective in reducing that burden, adherence may be facilitated. With particular therapies, such as interleukin-2, fatigue may be increased substantially, which affects quality of life (Grady, Anderson, & Chase, 1998). Fortunately, with the cessation of therapy, fatigue returned to baseline after one month.

The question of quality of life has been mentioned as one of the reasons patients decide to terminate therapies. Side effects have a profound impact on quality of life. As Ferrell, Grant, Dean, Funk, and Ly (1996) observed, "rather than being an isolated physical symptom, fatigue is a force that has an impact on all dimensions of quality of life" (p. 1539). Recognizing the profound impact of symptoms is crucial to comprehensive nursing care.

The most significant implication of this study relates to the importance of routine nursing assessment of fatigue for the relief of suffering. Future research should focus on the effectiveness of the strategies identified in this study with a larger sample of research participants infected with HIV, as well as the measurement of biologic markers of fatigue as related to self-care strategies. Specifically, helpful supplements, vitamins, and nutrition need to be identified and evaluated.

Although the prevalence of fatigue was not as high in the participants with HIV or AIDS in this study as in the literature, the result may be an artifact of questionnaire design that did not necessarily capture all of the symptoms experienced by the participants. Similarly, unless nurses in practice investigate all of the problems patients experience, fatigue is likely to be both unreported and untreated. The importance of using an instrument to measure fatigue in the ongoing clinical assessment of patients to identify and, hopefully, alleviate this distressing symptom cannot be overemphasized.

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For more information . . .

- The Body: An AIDS and Information Resource
www.thebody.com
- National Cancer Institute Physician Data Query: Fatigue
www.cancer.gov/cancer_information/doc_pdq.aspx?viewid=3ED94029-47A4-4DB1-9C21-08B8A506FE35
- Oncology Nursing Society: Fatigue Awareness Campaign
www.cancerfatigue.org

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.