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*Oncologist* 2000;5;353-360  
DOI: 10.1634/theoncologist.5-5-353

**This information is current as of December 12, 2007**

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 AlphaMed Press

# Impact of Cancer-Related Fatigue on the Lives of Patients: New Findings From the Fatigue Coalition

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**Key Words.** *Asthenia · Cancer · Chemotherapy · Fatigue · Fatigue Coalition · Quality of life*

## ABSTRACT

**Purpose.** This survey was designed to confirm the prevalence and duration of fatigue in the cancer population and to assess its physical, mental, social, and economic impacts on the lives of patients and caregivers.

**Patients and Methods.** A 25-minute telephone interview was completed with 379 cancer patients having a prior history of chemotherapy. Patients were recruited from a sample of 6,125 households in the United States identified as having a member with cancer. The median patient age was 62 years, and 79% of respondents were women. Patients reporting fatigue at least a few times a month were asked a series of questions to better describe their fatigue and its impact on quality of life.

**Results.** Seventy-six percent of patients experienced fatigue at least a few days each month during their most recent chemotherapy; 30% experienced fatigue on a daily basis. Ninety-one percent of those who experienced fatigue reported that it prevented a “normal” life, and 88% indicated that fatigue caused an alteration in their

daily routine. Fatigue made it more difficult to participate in social activities and perform typical cognitive tasks. Of the 177 patients who were employed, 75% changed their employment status as a result of fatigue. Furthermore, 65% of patients indicated that their fatigue resulted in their caregivers taking at least one day (mean, 4.5 days) off work in a typical month. Physicians were the health care professionals most commonly consulted (79%) to discuss fatigue. Bed rest/relaxation was the most common treatment recommendation (37%); 40% of patients were not offered any recommendations.

**Conclusions.** Cancer-related fatigue is common among cancer patients who have received chemotherapy and results in substantial adverse physical, psychosocial, and economic consequences for both patients and caregivers. Given the impact of fatigue, treatment options should be routinely considered in the care of patients with cancer. *The Oncologist* 2000;5:353-360

## INTRODUCTION

Patients with cancer commonly report a lack of energy during the course of their disease and treatment [1]. Fatigue may result from the disease itself, antineoplastic therapies, and/or a broad range of physical and psychologic comorbidities. Fatigue is multidimensional and can be described in terms of perceived energy, mental capacity, and psychologic status [2, 3]. It can

impair daily functioning and lead to negative effects on quality of life [4-7], self-care capabilities [8], and desire to continue treatment [9]. In some cases, fatigue is the most significant barrier to functional recovery in cancer patients with stable disease who are undergoing chemotherapy [10].

The incidence and severity of cancer-related fatigue appear to be influenced by characteristics of the patient

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[9, 11-13], primary malignancy, and type/intensity of treatment [2]. Fatigue has been reported in 80% to 99% of cancer patients who undergo treatment with chemotherapy, radiotherapy, or both [5, 12, 14, 15]. Although the relative importance of physical (e.g., anemia, cachexia), psychological (e.g., depression, anxiety), and situational (e.g., sleep deprivation) factors is usually unclear [2, 9, 10, 14, 16, 17], these and other factors appear to be important in the pathogenesis and may be predominant in some cases.

Interest in characterizing the epidemiology and pathogenesis of cancer-related fatigue has intensified in recent years [2]. Research on this subject has been limited, however, and evaluation of data from previous studies is complicated by variations in defining and assessing fatigue and its relatively high prevalence in the general population [10, 17]. Recent acceptance of cancer-related fatigue as a diagnosis in the International Classification of Diseases 10th Revision-Clinical Modification (ICD-10) should help ensure a standardized diagnosis in research settings and clinical practice [2, 3].

The Fatigue Coalition, a multidisciplinary group of medical practitioners/researchers (oncology, HIV/AIDS, palliative care, psychiatry, psychology) and patient advocates, was formed to study the incidence, prevalence, and functional impact of fatigue in patients with cancer and to develop diagnosis and treatment guidelines (Appendix). In 1996, we conducted the first large-scale, population-based survey to characterize the epidemiology of cancer-related fatigue and its impact from the perspectives of patients, primary caregivers, and oncologists [6]. Data from that tripart survey confirmed that fatigue is highly prevalent, causes substantial functional and psychological impairment, and is rarely discussed or treated [6]. In an effort to better understand the nature of cancer-related fatigue in patients receiving chemotherapy, we conducted a second survey specifically designed to A) confirm the conclusions of the first survey concerning the prevalence and relative importance of fatigue as a side effect of cancer treatment; B) clarify the experience of fatigue in patients; C) further explore the impact of fatigue on the daily lives of both patients and caregivers, and D) develop insights into how physicians can better communicate with their cancer patients. Unlike our first survey, the present survey evaluated the duration of fatigue and the economic/occupational impact of fatigue on both patients and caregivers.

## PATIENTS AND METHODS

Wirthlin Worldwide Research (New York, NY) was commissioned by the Fatigue Coalition to conduct a quantitative survey to further assess the effects of cancer-related fatigue during and after chemotherapy. The survey was conducted from July to August 1998 in accordance

with methods prescribed by the Council for American Survey Organizations. Patients were recruited from a nationally representative panel comprised of 575,000 households in the United States, which consisted of individuals who had previously indicated they would be willing to be contacted for research purposes. Attempts were made to contact by telephone a randomly selected subset of households identified as having a member diagnosed with cancer (6,125 households). Only individuals in these households who identified themselves as having cancer and who had undergone treatment with chemotherapy alone or with radiotherapy were eligible to participate in a 25-minute interview, which included approximately 50 questions. No monetary or other incentives were offered or provided to the participants.

Initially, patients were asked background questions about their current condition and medical history (e.g., type of cancer, side effects experienced during and after chemotherapy) and how often they had experienced fatigue (defined as a general feeling of debilitating tiredness or loss of energy). Patients who reported they "hardly ever" experienced fatigue were asked only a few additional demographic questions for statistical purposes. Those who experienced fatigue at least a few days each month were asked a series of questions aimed at describing fatigue, its impact compared with the other common chemotherapy-induced side effects of nausea, pain, and depression, and the level of communication with health care professionals. Additional questions examined the impact of fatigue on daily functioning, including physical, mental/emotional, behavioral/social, and occupational/economic effects. Patients also were asked questions that examined the occupational/economic effects of their fatigue and chemotherapy regimen on primary caregivers. Types of questions addressing the impact of fatigue consisted primarily of open-ended questions and lists of statements, which were read to patients and answered with "yes" or "no" responses.

Descriptive statistics were used to summarize demographic variables. Differences in responses by demographic variables (e.g., gender, age) were tested for significance using two-tailed *t*-tests. *p* values <.05 were considered statistically significant.

## RESULTS

### Patient Population

A total of 406 contacted households had a cancer patient who received chemotherapy alone or with radiotherapy and was willing to participate in the survey; 379 (93%) patients completed the interview. The sampling error was  $\pm 6\%$ .

Table 1. Patient profile (n = 379)	
Demographic	Percent
<b>Gender</b>	
Male	21
Female	79
<b>Age (years)</b>	
≤44	8
45-54	19
55-64	26
65-74	29
≥75	17
<b>Type of cancer*</b>	
Breast	62
Genitourinary	12
Leukemia/lymphoma	11
Gastrointestinal	7
Gynecologic	7
Other	13
Don't know/refused	1
<b>Type of treatment</b>	
Chemotherapy	53
Chemotherapy and radiotherapy	47
<b>Education</b>	
Less than high school	6
High school graduate	32
Some college	30
College graduate	18
Postgraduate	13
<b>Household income</b>	
Less than \$15,000	13
\$15,000-\$24,999	17
\$25,000-\$49,999	28
≥\$50,000	24
Don't know/refused	18

\*More than one type of cancer was an acceptable answer.

Table 2. Side effects affecting ≥2% of patients the most after completing chemotherapy (n = 379)	
Side effect	% of patients
Fatigue	25
Nausea	13
Hair loss	6
Diarrhea and/or constipation	2
Weight loss and/or gain	2
Hot flashes/menopause	2

Patient demographics for the 379 patients are shown in Table 1. The median patient age was 62 years. Fifty-three percent of the interviewed patients received chemotherapy only, whereas the remainder (47%) had a history of chemotherapy and radiotherapy. Forty percent of patients had their last chemotherapy treatment within the past two years, whereas 60% had been treated with chemotherapy more than two years previously.

## PREVALENCE AND DURATION OF FATIGUE

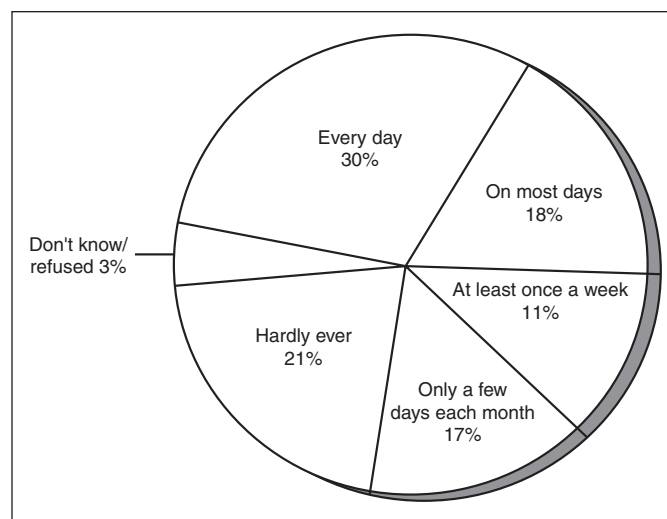
When patients were asked what side effect affected them most during chemotherapy, nausea was most commonly identified (34%), followed by fatigue (18%) and hair loss (11%). The side effect with the greatest impact after completion of chemotherapy was fatigue (reported by 25% of patients; Table 2). Of the interviewed patients, 301 (76%) reported experiencing fatigue at least a few days each month during their most recent chemotherapy (Fig. 1), compared with 54% reporting nausea, 23% reporting depression, and 20% reporting pain. Thirty percent of patients reported experiencing fatigue on a daily basis; women tended to be more likely than men to report experiencing daily fatigue (33% versus 22%, respectively;  $p > .05$ ).

Of those who experienced fatigue during and after their most recent chemotherapy regimen, 62% and 33% said it lasted for longer than four days and two weeks, respectively. Patients aged 55-64 years were more likely than younger patients (55% versus 36%, respectively;  $p < .05$ ) to experience fatigue that lasted longer than one week during and after their most recent chemotherapy. When patients who experienced fatigue and pain, nausea, or depression ( $n = 198$ ) were asked which of their symptoms lasted the longest, 54% identified fatigue (Table 3).

## IMPACT OF FATIGUE

### Physical

The majority (90%) of respondents who reported fatigue considered themselves very or somewhat active



**Figure 1. Prevalence of fatigue in cancer patients (n = 379).** [While undergoing your most recent treatment, how often did you feel fatigue, that is, a general feeling of debilitating tiredness or loss of energy? Would you say you felt this way every day, on most days, at least once a week, only a few days each month, or hardly ever?]

**Table 3.** Duration of fatigue relative to other side effects/symptoms<sup>a</sup>

	Symptom rank	% Rank 1st <sup>b</sup>	Mean score <sup>c</sup>
Fatigue	1st	54	1.6
Nausea	2nd	27	2.1
Depression	3rd	12	2.5
Pain	4th	6	3.1

<sup>a</sup>Question: Which of these side effects or symptoms lasted the longest: pain, nausea, fatigue, or depression?

<sup>b</sup>Patients who experience(d) fatigue and pain, nausea, or depression ( $n = 198$ ).

<sup>c</sup>Rank based on a scale from 1 (longest) to 4 (shortest).

**Table 4.** Impact of fatigue on daily living relative to other side effects/symptoms<sup>a</sup>

	Symptom rank	% Rank 1st <sup>b</sup>	Mean score <sup>c</sup>
Fatigue	1st	60	1.5
Nausea	2nd	22	2.1
Depression	3rd	10	2.6
Pain	4th	6	3.1

<sup>a</sup>Question: Which of these side effects or symptoms do you think affects/affected your everyday life more: pain, nausea, fatigue, or depression?

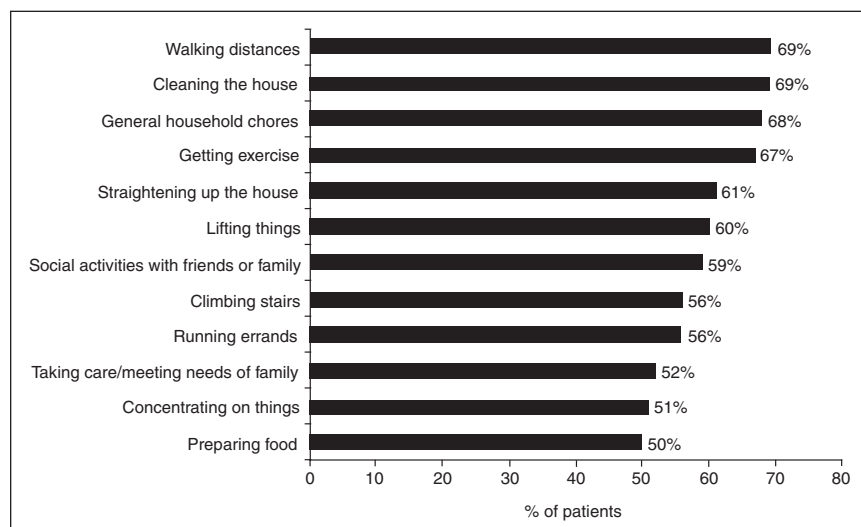
<sup>b</sup>Patients who experience(d) fatigue and pain, nausea, or depression ( $n = 198$ ).

<sup>c</sup>Rank based on a scale from 1 (greatest) to 4 (least).

prior to being diagnosed with cancer. Physical manifestations of fatigue were most commonly described as a significantly diminished energy level (81%), a need to slow down from a normal pace (81%), a general sense of sluggishness or tiredness (79%), and an increased need for sleep or rest (78%). When fatigue was experienced, an average of 2.8 additional hours of sleep/rest were required per day.

Of the 301 patients who reported fatigue, 275 (91%) said it prevented them from leading a “normal” life, and 266 (88%) indicated an alteration of their daily routine due to fatigue. Sixty percent of patients who experienced fatigue and pain, nausea, or depression ( $n = 198$ ) reported that fatigue affected their daily lives the most (Table 4). Specific daily activities identified as being more difficult when experiencing fatigue

**Figure 2.** Daily activities that were “a lot” or “somewhat” more difficult in  $\geq 50\%$  of cancer patients ( $n = 301$ ) when experiencing fatigue.

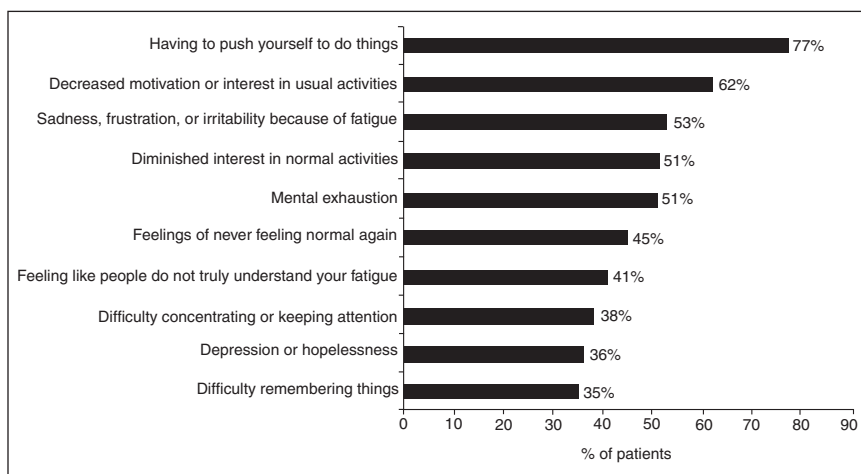


included walking distances, general household chores, cleaning/straightening up the house, social activities, and food preparation (Fig. 2). On average, when feeling fatigued, patients reported an ability to accomplish only 55% of activities normally performed. Subsets of patients more likely to have their daily routine significantly affected by fatigue included those who were aged 55-64 years (60% versus 44% of younger and older patients;  $p < .05$ ) or active prior to diagnosis (58% versus 39% of those less active;  $p < .05$ ). Patients who experienced fatigue on a daily basis were significantly more likely to have been experiencing pain (32%) than those who experienced fatigue less frequently (17% of patients who experienced fatigue at least once a week or on most days and 8% of patients who experienced fatigue only a few days per month;  $p < .05$ ). Patients who experienced fatigue on a daily basis were also significantly more likely to have reported depression (32%) than those experiencing fatigue only for a few days each month (14%;  $p < .05$ ).

#### PSYCHOSOCIAL

The mental/emotional effects of fatigue reported in  $\geq 30\%$  of patients are summarized in Figure 3. Most patients reported a need to push themselves to do things (77%), decreased motivation or interest (62%), and feelings of sadness, frustration, or irritability (53%) during their experiences with fatigue. In addition, fatigue affected typical cognitive tasks, such as concentrating (38%), remembering things (35%), and keeping dates straight (34%). Younger patients (i.e., aged  $\leq 54$  years) were almost twice as likely as older patients to have felt that people did not understand what their fatigue felt like (60% versus 33% of those older;  $p < .05$ ), reported feeling depressed or hopeless (51% versus 29% of those older;  $p < .05$ ), and indicated that they occasionally felt like they wanted to die (28% versus 15% of those aged  $\geq 65$  years;  $p < .05$ ).

**Figure 3. Mental and emotional effects reported in  $\geq 30\%$  of cancer patients (n = 301) when experiencing fatigue.**



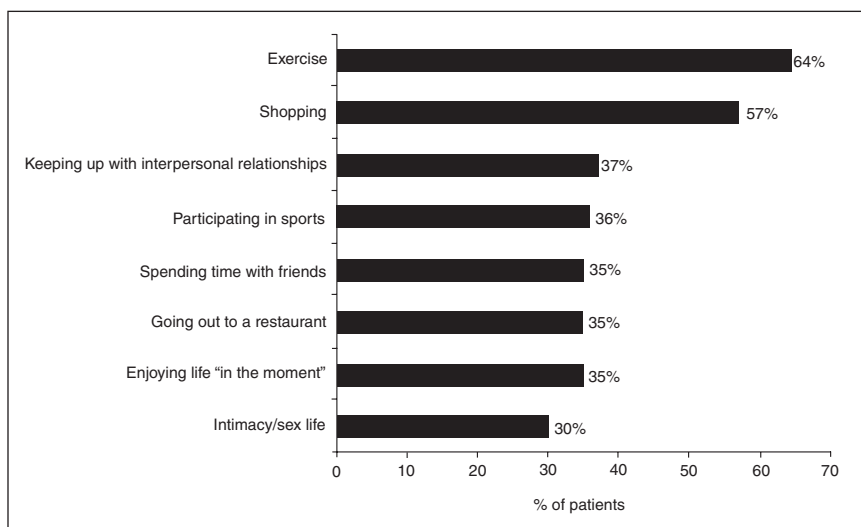
The social/behavioral activities that were more difficult in  $\geq 30\%$  of patients when experiencing fatigue are summarized in Figure 4. Exercise and shopping were more difficult during episodes of fatigue in 64% and 57% of patients, respectively. Fatigue also made it more difficult to participate in social activities, such as going to a restaurant (35%), keeping up with interpersonal relationships (37%), and spending time with friends (35%).

#### ECONOMIC/OCCUPATIONAL

Most (59%) of the 301 patients who experienced fatigue were actively working at the time of cancer diagnosis. The occupational impact of fatigue on patients and the occupational impact of the patient's cancer treatment on primary caregivers are summarized in Figure 5. Of the 177 patients who were employed, 75% changed their employment status as a result of fatigue. The mean number of sick/vacation days typically used as a result of fatigue was 4.2 per month (during and immediately after treatment). In extreme cases, patients discontinued work altogether (28%), went on disability (23%), or used unpaid family and medical leave (11%) because of fatigue (during or immediately after treatment); men were more likely than women to stop working altogether because of fatigue (43% versus 24%, respectively;  $p < .05$ ). Additionally, patients needed to hire help to take care of daily chores, such as cleaning (22%), yard work (18%), and cooking (5%).

Patients reported that, while they were undergoing chemotherapy, their primary caregivers took more time off work (20%), accepted fewer responsibilities (18%), or reduced worked hours (11%).

**Figure 4. Social and behavioral activities that were "a lot" or "somewhat" more difficult in  $\geq 30\%$  of cancer patients (n = 301) when experiencing fatigue.**

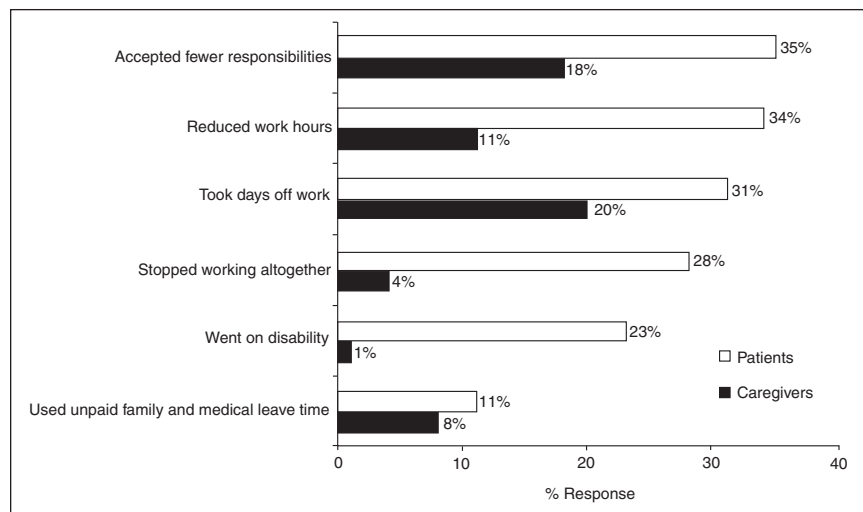


(Fig. 5). Twelve percent of primary caregivers had to use unpaid family leave or were forced to stop working completely. Furthermore, 65% of patients indicated that their fatigue resulted in their primary caregivers taking at least one day (mean, 4.5 days) off work in a typical month.

#### PATIENT-PHYSICIAN COMMUNICATION

Physicians were the health care professionals most commonly consulted to discuss fatigue (79%), followed by nurses (28%) and physicians' assistants (5%). Eight percent of patients indicated that they had never discussed their fatigue with a health care professional. Reasons for not discussing fatigue with a health care professional most often included assumptions that it was an expected outcome of their cancer treatment (79%), would not persist much longer (61%), or was caused by cancer (49%). Furthermore, 45% of patients believed that nothing could be done to relieve or reduce fatigue. Patients aged 65 years or older were least likely to discuss fatigue with health care professionals (3% versus 16% of those younger;  $p < .05$ ).

**Figure 5. Occupational effects of fatigue reported in  $\geq 10\%$  of cancer patients working at the time of diagnosis (n = 177) and the occupational impact of the patient's cancer treatment on primary caregivers (n = 301).**



## MANAGEMENT OF FATIGUE

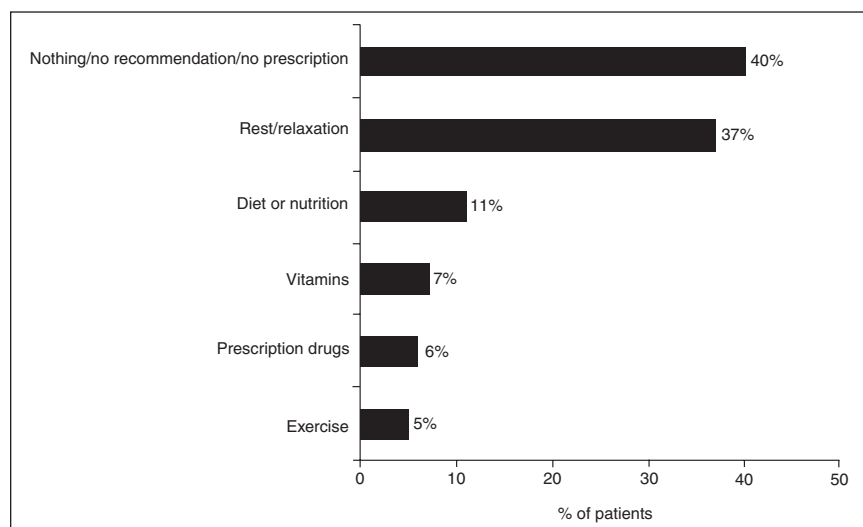
When asked what was recommended or prescribed for reducing fatigue, 40% of patients stated that nothing was offered (Fig. 6). Bed rest/relaxation (37%) was most commonly recommended for reducing fatigue, followed by diet or nutrition (11%), vitamins (7%), and prescription drugs (6%).

## DISCUSSION

This survey was designed to characterize the prevalence and duration of cancer-related fatigue and its impact from the perspective of cancer patients treated with chemotherapy alone or with radiotherapy. The fatigue prevalence rate of 76% is consistent with results of our initial survey [6] and previous studies that assessed the prevalence of fatigue in patients with cancer [1, 5, 12, 14, 15, 18-21]. The high prevalence of fatigue in cancer patients may be due in part to the evolution of more intensive treatment strategies, including combined modality approaches and high-dose chemotherapy [17]. In this survey, fatigue was more prevalent and was associated with a longer duration than other chemotherapy-induced side effects. More than 50% of patients reported that fatigue lasted longer than nausea, depression, and pain, and one-third reported a duration of more than two weeks.

Experience indicates that evaluation of fatigue in cancer patients is difficult due to the subjectivity of this measure of functional performance [22]. Therefore, explicit questions concerning common daily activities were asked in

**Figure 6. Strategies for fatigue reduction that were recommended or prescribed for  $>1\%$  of cancer patients (n = 301). [What, if anything, did your doctor prescribe or recommend to help reduce your fatigue?]**



attempts to improve the objectivity of our survey. The reported effects of fatigue on daily physical and psychosocial functioning of cancer patients were substantial and consistent with results of previous studies [4, 7, 8, 15, 23, 24]. Most patients who reported fatigue said it prevented them from leading a normal life and conducting their daily routine. Social activities, such as going to a restaurant and spending time with friends, became more difficult. Fatigue was also associated with a wide range of symptoms consistent with psychological impairment, including a lack of motivation, depression, and disturbances in mood and cognition. Although cancer-related fatigue can occur independently of physical performance level [22], the present survey suggests that patients with low physical performance levels were more depressed, anxious, and socially insecure. In addition, pain or depression was more likely to occur in patients experiencing fatigue on a daily basis than in those experiencing it less frequently. Available evidence suggests that these symptoms are correlated with fatigue in cancer patients [4, 12, 21].

The cause-and-effect relationships among pain and psychological distress and the physical manifestations of cancer-related fatigue remain unclear, however, and require further investigation [13, 15, 18, 22, 25].

The ability to work is considered a concrete indicator of quality of life [26]. The reported impact of fatigue on the abilities of patients to continue working normally was substantial in the present survey. More than 75% of patients admitted changing their responsibilities because of fatigue. Furthermore, more than 20% of patients stopped working completely or went on disability. An interesting finding of our survey was the high occupational impact of the patients' cancer treatment on primary caregivers. Twelve percent of cancer patients reported that their primary caregiver was forced to take unpaid leave or stop working completely.

Our initial fatigue survey showed that fatigue was undertreated and seldom discussed among patients, caregivers, and oncologists [6]. Similarly, 40% of patients with fatigue in the present survey indicated that they were not offered any recommendations for reducing possible contributing factors or achieving symptomatic relief. The rate of discussion with health care professionals (92%) was encouraging; however, it is important to note that 45% of patients did not discuss fatigue more often because they believed nothing could be done to relieve it. As in our initial survey, bed rest/relaxation was the most common recommendation for relieving fatigue despite the potential physical and psychologic benefits of exercise in cancer patients [22, 27-30]. Although patients may benefit from correction of potential etiologies and comorbidities (e.g., pain, depression, anemia, and metabolic/nutritional abnormalities), these strategies were not pursued [2, 3, 16]. Further education for cancer patients, caregivers, and health care professionals on the availability of effective strategies and the development of individualized treatment plans targeted at alleviating fatigue is warranted. In addition, the importance of discussing fatigue with health care professionals should be emphasized to patients [2].

## CONCLUSION

Cancer-related fatigue is common among cancer patients receiving chemotherapy with or without radiotherapy. A high percentage of these patients suffer debilitating fatigue that affects their physical and psychosocial well-being and ability to work. Given the substantial effect

of cancer-related fatigue on quality of life, evaluation and treatment options for this symptom should routinely be considered to alleviate this condition [3].

## APPENDIX

The Fatigue Coalition is a multidisciplinary group of medical practitioners, researchers, and patient advocates formed to develop educational and research initiatives designed to help patients, physicians, and other practitioners better understand the onset, duration, and progression of fatigue in patients with cancer or AIDS and provide successful interventions. The Fatigue Coalition received support for this project from Ortho Biotech Products, L.P., a biotechnology subsidiary of Johnson & Johnson.

### The Fatigue Coalition

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## ACKNOWLEDGMENTS

Presented at the Thirty-fifth Annual Meeting of the American Society of Clinical Oncology, Atlanta, GA, May 15-18, 1999.

*N.J.V.* represents The Fatigue Coalition.

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