

## RESEARCH BRIEF

# Representations of Fatigue in Women Receiving Chemotherapy for Gynecologic Cancers

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**Purpose/Objectives:** To describe women's representations of fatigue and fatigue-related coping efforts by women receiving chemotherapy.

**Design:** Descriptive, correlational.

**Setting:** Outpatient gynecologic oncology clinic.

**Sample:** Women receiving chemotherapy for gynecologic cancers. Fifty-four women were recruited; 49 (91%) completed measures. This report focuses on the 27 women who identified fatigue as one of their "most noticed" symptoms and subsequently completed the fatigue representations measure.

**Methods:** Women completed measures of key research variables at home seven days after receiving chemotherapy.

**Main Research Variables:** Representations of fatigue (identity, cause, timeline, consequences, cure or controllability, and emotional representation), fatigue-related coping efforts (communication with healthcare provider, adherence, and self-directed coping strategies), and overall symptom interference with life activities.

**Findings:** Women reported a mean of 13.44 different symptoms. They reported a mean fatigue identity (severity) score of 6.48 on a scale of 0–10. On a 0–4 scale, women reported mean fatigue consequences of 2.21, cure or controllability of 1.58, and emotional representations (distress) of 2.16. A majority (59%) had not communicated with their healthcare providers about fatigue at their last appointments, and 56% reported never receiving recommendations for managing fatigue. Sleep or rest was the most common strategy used for managing fatigue.

**Conclusions:** Fatigue is a prevalent, severe symptom that is perceived as distressing and uncontrollable by women receiving chemotherapy for gynecologic cancers. These perceptions may be reinforced by a lack of recommendations from healthcare providers for managing fatigue.

**Implications for Nursing:** Nurses must make extra efforts to ask patients about fatigue and to provide self-care suggestions for coping with fatigue. Research efforts must continue to evaluate the efficacy of nursing interventions aimed at decreasing cancer-related fatigue.

**F**atigue is the most prevalent, distressing symptom associated with cancer and its treatment (Stone et al., 2000; Winningham et al., 1994). Cancer-related fatigue is a multidimensional, subjective experience with physiologic, psychological, functional, and social consequences. Understanding patients' perceptions of fatigue is essential to developing interventions to improve management of this complex symptom. Studies have demonstrated that many patients consider fatigue to be an inevitable and unmanageable consequence of cancer and that these perceptions contribute to patients' reluctance to discuss fatigue with their healthcare providers (Curt et al., 2000; Stone et al.).

### Key Points . . .

- ▶ A majority of women receiving chemotherapy for gynecologic cancers identify fatigue as one of their "most noticed" symptoms.
- ▶ Many women perceive fatigue as severe, uncontrollable, and emotionally distressing.
- ▶ Fatigue identity (severity), consequences, and emotional distress all were associated significantly with symptom interference with life activities.
- ▶ Despite the significance of fatigue in their daily lives, most women had not discussed fatigue with their healthcare providers at their last appointments, nor had they previously received recommendations for managing their fatigue.

Leventhal's Common Sense Model (CSM) serves as an excellent framework for assessing individuals' perceptions of fatigue. The CSM is a theory of self-regulation that proposes that individuals have commonsense understandings (representations) of health problems that guide how they cope with a problem. Representations consist of cognitions about the identity, cause, timeline, consequences, and cure or controllability of a health problem, as well as emotional responses to a problem (Leventhal & Diefenbach, 1991; Leventhal, Nerenz, & Steele, 1984; Ward, 1993). According to the CSM, understanding patients' representations of health problems is critical because representations influence patients' coping strategy choices, their goals for the coping strategies, and the extent to which they persist in using the strategies (Leventhal, Leventhal, & Cameron, 2001). A great deal of research supports relationships between illness representations and

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coping, but very little research has been conducted in the area of symptom-specific representations and coping with symptoms. One exception was a recent qualitative study demonstrating that women's descriptions of cancer-related fatigue could be classified into the proposed dimensions of representations as described in the CSM (Barsevick, Whitmer, & Walker, 2001). To further explore relationships between symptom representations and symptom-related coping efforts, the Symptom Representation Questionnaire (SRQ) was developed and tested to be used for a wide range of cancer-related symptoms. The purpose of this article is to describe initial pilot-study findings related to representations of fatigue and fatigue-related coping efforts for women receiving chemotherapy for gynecologic cancers.

## Methods

### Sample and Procedures

Following institutional review board approval, 69 women receiving chemotherapy for gynecologic cancers and with good performance status (Eastern Cooperative Oncology Group [ECOG] score  $\leq 2$ ) were invited to participate and 54 (79%) consented to do so. Women were recruited from an outpatient gynecologic oncology clinic on the day they received chemotherapy and instructed to complete the survey seven days following chemotherapy. Women were asked to complete the symptom representation and coping questionnaires for three symptoms they "noticed most in the past week." Twenty-seven women identified fatigue as one of these symptoms. They had a mean age of 58.19 (SD = 10.12) years and 14.04 (SD = 2.86) years of education. All but one participant were Caucasian. The mean time since diagnosis was 18.81 (SD = 16.72) months. Ovarian cancer was the most common diagnosis (74%), followed by cervical (11%) and uterine cancers (7%). Paclitaxel was the most common chemotherapy agent received by women, either alone (29%) or in combination with carboplatin (21%).

### Measures

Representations of fatigue were assessed using the SRQ (Donovan, 2003; Weinman, Petrie, Moss-Morris, & Horne, 1996). The first section of the SRQ contains a list of 26 symptoms, including fatigue. Patients are asked to rate the severity of each symptom on an 11-point scale from 0 (did not have it) to 10 (as bad as I can imagine). Fatigue identity is operationalized as the severity of fatigue. The second section of the SRQ contains 14 items, each rated on a five-point scale ranging from 0 (strongly disagree) to 4 (strongly agree). Five subscales address the extent to which an individual believes that (a) cancer is causing fatigue (cause), (b) fatigue will last a long time (timeline), (c) fatigue has negative consequences, (d) fatigue can be managed in effective ways (cure or controllability), and (e) fatigue causes distress (emotional representation). Subscale reliabilities of the SRQ are consistently greater than 0.70. Test/retest reliabilities over a three-day period ranged from 0.65–0.82 (Donovan).

Fatigue-related coping efforts were assessed with five items designed to evaluate three types of fatigue management efforts: communication with healthcare providers, adherence to fatigue-specific treatment recommendations, and self-directed coping efforts. Communication was assessed with one item asking whether the subject had discussed fatigue with a

healthcare provider in the past week. Adherence was assessed with one item regarding adherence to healthcare provider recommendations for fatigue and two items regarding adherence to dose and schedule of medications recommended for fatigue. The response options for these four items are 0 (not at all), 1 (partially), 2 (completely), or not applicable (have not received recommendations). Self-directed coping efforts were assessed with a single open-ended item asking participants to describe everything they did to manage the symptom. Strategies were coded as active or passive.

Symptom interference with life was assessed using the University of Texas M.D. Anderson Symptom Inventory Interference Scale (Cleeland et al., 2000). It contains six items addressing how much all symptoms interfered with different aspects of life during the past week. Participants respond on an 11-point scale from 0 (did not interfere) to 10 (interfered completely). A mean score of the six items is calculated. This scale has been shown to be reliable ( $\alpha = 0.91$  to  $0.94$ ) and sensitive to differences in ECOG performance status and treatment status of patients with cancer.

## Results

Overall, women reported a mean of 13.44 (SD = 5.44) different symptoms with a mean severity score of 4.44 (SD = 1.70) on a scale of 0–10.

### Fatigue Representation

Fatigue representations scores are presented in Table 1. Women reported, on average, having moderately severe fatigue ( $\bar{X} = 6.48$  on the 0–10 fatigue identity scale). Sixteen women (59%) had severe fatigue (severity  $\geq 7$ ). The majority of women did not agree that cancer was causing their fatigue ( $\bar{X} = 1.78$ ). More specifically, 15 women (56%) attributed their fatigue to chemotherapy, 10 (37%) to both chemotherapy and cancer, and 2 (7%) to something other than chemotherapy or cancer. Reliabilities were poor for the fatigue timeline scale, so scores on individual items were evaluated. Although women tended to believe that their fatigue would last a long time, they did not feel it was permanent, and they believed it would improve over time. Mean scores of 2.21 on the consequences scale reflected that the majority of women believed that fatigue had negative effects on their lives. Scores were low on the cure or controllability scale, with 17 (63%) women reporting that neither treatment nor their own actions could control fatigue. Finally, mean scores on the emotional representation subscale

**Table 1. Mean Scores for the Fatigue Representation Subscales**

Fatigue Representation	$\bar{X}$	SD	Range
<b>Cognitive representations</b>			
Identity (severity)	6.48	2.83	0–10
Cause	1.78	1.37	0–4
Timeline			
• Last a long time	2.23	0.91	0–4
• Permanent	1.59	1.11	0–4
• Improve over time	2.93	0.68	0–4
Consequences	2.21	0.98	0–4
Cure or controllability	1.58	0.99	0–4
<b>Emotional representation (distress)</b>	2.16	0.97	0–4

were near the midpoint; however, nine women (33%) scored 3 or higher on this subscale, reflecting high levels of fatigue-related distress.

Bivariate correlations were conducted to evaluate relationships among representation dimensions. The cause and timeline dimensions were related: Beliefs that cancer was causing fatigue were associated with perceptions of fatigue as permanent ( $r = 0.42, p < 0.05$ ). In addition, perceptions of fatigue as a permanent symptom were associated with higher perceived consequences of fatigue ( $r = 0.61, p < 0.05$ ) and higher emotional representations ( $r = 0.45, p < 0.05$ ). A positive association existed between consequences and emotional representations of fatigue ( $r = 0.60, p < 0.05$ ).

## Coping

With respect to fatigue communication, 16 women (59%) had not discussed fatigue with their healthcare providers at their last appointment. In evaluating adherence, the authors were surprised to find that only 12 women (44%) had ever received recommendations for managing fatigue. Of these, 67% exactly followed and 33% partially followed recommendations. Similarly, only three women had been prescribed medications for fatigue. One of these women reported that she did not take the prescribed medication; the other two women reported exactly adhering to the prescribed medication. Finally, in response to the question regarding self-directed coping efforts, the vast majority of women (85%) identified sleep or rest as their primary strategy for managing fatigue. Pacing or scaling back activities was reported by 37% of women. Less than 15% of women identified the remaining coping strategies (see Figure 1).

In evaluating relationships between representations and coping, only perceptions that fatigue was caused by cancer were associated with communicating with a healthcare provider about fatigue ( $r = 0.53, p < 0.01$ ).

## Symptom Interference With Life

Women reported moderate overall symptom interference with life ( $\bar{X} = 4.09, SD = 2.66$ ). In looking at relationships with fatigue representations, scores on the symptom interfer-

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- Sleep, rest, or take naps when tired ( $n = 23$ )  
"I often take a nap after I come home from work."
  - Pace or scale back activities ( $n = 10$ )  
"I pace my activities; plan things I can handle."
  - Medication or vitamin supplements ( $n = 4$ )
  - Social activities ( $n = 4$ )  
"I have six grandkids—[I] stay very involved in their lives."
  - Spend time outside ( $n = 2$ )  
"Go outside to the park, the lake—that energizes me."
  - Prayer or inspirational reading or listening ( $n = 3$ )  
"Have radio on a Christian station all night."
  - Wait it out ( $n = 2$ )  
"This too shall pass when I'm healthy again."
  - Eating healthy foods ( $n = 2$ )  
"Eat well: lots of fruits, veggies, complex carbohydrates, protein. (It) makes me feel better."
  - Ask for help from family or friends ( $n = 2$ )  
"My husband is doing most of our daily activities, laundry, meals, etc."
  - Protect sleep time ( $n = 2$ )  
"We own our own business and get calls throughout day and night—interrupts rest—use answering machine more."
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**Figure 1. Self-Directed Activities to Manage Fatigue**

ence with life scale were significantly related ( $p < 0.01$ ) to fatigue identity ( $r = 0.62$ ), consequences of fatigue ( $r = 0.40$ ), and emotional representations of fatigue ( $r = 0.53$ ).

## Discussion

Fatigue is a prevalent, severe symptom that is related to interference with life activities for many women receiving chemotherapy for gynecologic cancers. In this study, women's representations reflected fatigue as moderately severe, distressing, and uncontrollable—perceptions that may have been reinforced by a lack of management recommendations provided by healthcare providers. Another indicator of fatalistic attitudes about fatigue is that despite high severity, consequence, and distress ratings, a majority of women in this study had not discussed fatigue with their healthcare provider at their last appointment.

This study had several limitations. The total number of SRQs completed for fatigue was small. Reevaluating these findings in a larger sample is important. Secondly, several measurement issues existed. The timeline subscale of the SRQ was not internally consistent for fatigue, whereas it has been in other samples and for other symptoms. Evaluating whether this is a result of the small sample size or whether it is a problem specific to fatigue is important.

Interestingly, few relationships existed between representations and coping, most likely because of problems with the coping measures that were specific to fatigue. Using adherence as an indicator of coping effort was problematic when only 44% of women had received recommendations and only three were prescribed medications for fatigue. Finally, the scoring protocol for "self-directed coping efforts" was to categorize women's responses into active or passive coping efforts. For all symptoms other than fatigue, the authors achieved an inter-rater reliability of 96%. However, with fatigue, the authors were unable to make clear categorizations. The majority of women identified sleep or rest as their primary strategy, but they were using sleep or rest in different ways. For example, one woman wrote, "I often take a nap after work," and another wrote, "I try to get plenty of sleep at night." Compare those responses to, "I do very little walking or standing. I sit or lay down 99% of the time." The first examples could be categorized as active efforts to manage fatigue, whereas the second example represents a more passive response to fatigue. Unfortunately, most women simply wrote "rest" or "sleep," so the authors were unable to determine whether their use of sleep or rest was an active strategy or a passive response. Further research should explore this important distinction.

## Implications for Nursing

Proactive strategies by nurses to help women anticipate fatigue and minimize its severity and consequences are necessary. Because women seem to be reluctant to initiate discussions about fatigue, nurses must make extra efforts to ask patients about fatigue and to provide self-care suggestions for coping with fatigue. Recent patient and clinician education programs (e.g., ONS, 2003) have promoted self-care strategies for coping with fatigue. These programs emphasize the importance of energy conservation, energy restoration, exercise, good nutrition, and adequate (but not excessive) rest. By initiating conversations about these self-care strategies,

nurses may help women gain a sense of control over their fatigue and reduce fatigue severity, consequences, and distress. However, exercise is the only one of these recommendations that has consistent support from clinical trials (Nail, 2002). Further research is essential to determine the efficacy of these interventions for reducing fatigue associated with treatment for gynecologic cancers.

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