The impact and management of cancer-related fatigue on patients and families

by Joan Hamilton, Lorna Butler, Hieke Wagenaar, Terry Sveinson, K. Anne Ward, Leslie McLean, Donna Grant, and Florence MacLellan

Abstract

Fatigue has been identified as both a chronic and recurrent problem for individuals diagnosed with and treated for cancer, yet there is little information on how to manage the impact of fatigue. Describing what happens to individuals and their families as a result of fatigue and identifying what individuals do to manage or reduce the impact of fatigue are essential elements in determining multidimensional nursing interventions. The purpose of this pilot study was to examine the impact of fatigue on individuals with cancer of the lung and their families, and explore how they managed as a result of the fatigue. A semi-structured interview guide was used with 22 lung cancer patients and 14 family members six weeks post completion of radiation therapy.

Results indicated that fatigue was not reported as a major concern by many of the participants in this study. For those who did experience fatigue, it was considered an inconvenience and a frustration that had to be dealt with for a limited time period. Some patients appeared to gradually adjust and accommodate to the fatigue and were not really aware of the changes that took place over time. Over half of the family members felt more of the impact of fatigue than did their loved ones. Family subtly assumed or took over responsibilities and activities the patient could no longer perform.

The symptom of fatigue has been well documented in the cancer experience as both a chronic and recurrent problem for individuals diagnosed with and treated for cancer. The emphasis of previous work has been on deriving a conceptual definition of fatigue, achieving consensus on a definition, and developing theoretical frameworks to guide further study of this complex construct. Fatigue has been conceptualized as a multidimensional phenomenon, attributable to multiple causes and having a negative effect on quality of life (Piper, 1993; Tiesinga, Dasson, & Halfens, 1996). Describing what happens to individuals and their families as a result of fatigue and identifying what individuals do to manage or reduce the effects caused by the fatigue are essential elements in determining multidimensional nursing interventions.

Fatigue in chronic illness

Fatigue has been documented in chronic illnesses other than cancer. The major focus of this existing research has centred on determining the severity, duration (acute/chronic), frequency, and associated symptoms of fatigue (Hait, 1978; Packer, Foster, & Brouwer, 1997; Srivastava, 1989), identifying correlates of fatigue (Belzar, Henke, Yelin, Epstein, & Gillis, 1993; Crosby, 1988; Krupp, Larocca, Muir, & Steinberg, 1990), and describing the relationship between fatigue and depression (Cardenas & Kutner, 1982; Jamar, 1989; Krupp et al., 1990; Krupp, Larocca, Muir-Nash, & Steinberg, 1989; Pickard-Holley 1991; Srivastava). Although beginning work has been done to relate the severity of symptoms experienced to the effect of fatigue on activity levels, the trend has been to use traditional performance status measurements rated by health professionals, predominantly in institutional settings (Packer, Sauriol, & Brouwer, 1994). This approach has limited relevance today, and the narrow focus of these indicators on the basis of daily tasks negates the social and role responsibilities of daily life. Fisk et al. (1994) reported that the self-rated impact of fatigue was related to the amount of time per day patients were fatigued. Furthermore, the impact of fatigue was not related to disease classification and had little relationship to the clinical

ABRÉGÉ: L'IMPACT, SUR LES PATIENTS ET LES PROCHES, DE LA FATIGUE ASSOCIÉE AU CANCER ET SA GESTION

Il est reconnu que la fatigue est un problème à la fois chronique et récurrent chez les personnes diagnostiquées d'un cancer et suivant un traitement, mais il existe peu d'information sur la gestion de l'incidence de la fatigue. La description des répercussions de la fatigue chez les personnes atteintes et leurs proches et la détermination de ce qu'ils font pour en gérer et en réduire l'incidence *représentent des éléments essentiels de l'élaboration d'interventions* infirmières multidimensionnelles. Cette étude pilote visait à examiner l'incidence de la fatigue chez les personnes atteintes de cancer du poumon et chez leurs proches et à explorer les façons dont ils s'adaptaient à cette fatigue. On a utilisé un guide d'entrevue semistructurée auprès de 22 patients atteints de cancer du poumon et de 14 proches six semaines après la fin du traitement de radiothérapie. Les résultats indiquaient que les participants à l'étude étaient peu nombreux à signaler la fatigue en tant que préoccupation majeure. Chez ceux qui indiquaient l'avoir éprouvée, la fatigue était perçue comme une complication et une frustration auxquelles ils ne devaient faire face que durant une période de temps limitée. Certains patients semblaient s'adapter graduellement à la fatigue et ils n'étaient pas vraiment conscients des changements qui étaient survenus au fil du temps. En revanche, plus de la moitié des proches avaient éprouvé l'incidence de la fatigue plus que ne l'avaient les patients. C'est de manière subtile que les membres de la famille assumaient les responsabilités et effectuaient les activités que les patients étaient obligés d'abandonner.

Joan Hamilton, RN, BN, MSc(A), is a Clinical Nurse Specialist in Cancer Care at the Queen Elizabeth II (QEII) Health Sciences Centre in Halifax, Nova Scotia. Lorna Butler, RN, PhD, is an Associate Professor in the School of Nursing at Dalhousie University and QEII Health Sciences Centre. Hieke Wagenaar, RN, MN, practises in Ottawa, Ontario. Terry Sveinson, RN, BN, CON(C), is an Oncology Staff Nurse at the QEII Health Sciences Centre. K. Anne Ward, RN, MN, is a Nurse Educator at the QEII Health Sciences Centre and an Adjunct Lecturer at Dalhousie University. Leslie McLean, RN, BScN, works in Oncology Services at the QEII Health Sciences Centre. Donna Grant, RN, BScN, CON(C) is an Oncology Nurse Educator at the QEII Health Sciences Centre. is a Patient Educator at the Patient and Family Learning Centre, QEII Health Sciences Centre.

CONJ: 11/4/01

variables of neurological impairment and the time since selfreported onset of disease symptoms. The disruption in one's life was not symptom-specific, but was related to the ability to accommodate the fatigue and the resulting effect on mental wellbeing regardless of the degree of physical impairment. This finding was also supported by the work of Wagenaar (1995). Absent in the fatigue and chronic illness literature was the perceived effect of fatigue on the family.

Fatigue and cancer

Recognition of fatigue as one of the major components for study in quality of life research has been accomplished through the development of theoretical frameworks to understand the concept (Piper, Lindsey, & Dodd, 1987; Winningham et al., 1994), and the development of psychometric instruments for testing theory and identifying influencing factors of fatigue (Graydon, Bubela, Irvine, & Vincent, 1995; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Piper, 1989). Fatigue in individuals with cancer has been studied by examining levels of activity (Glaus, 1993; Pickard-Holley, 1991), energy conservation and restoration (Pickard-Holley; Piper et al.), the influence of various treatment modalities on the severity of fatigue (Christensen & Kehlet, 1993; Nail & King, 1994), the negative outcome for quality of life (Irvine, Vincent, Bubela, Thompson, & Graydon, 1991), ability to maintain self-care (Rhodes, Watson, & Hanson, 1988), and the effect on depressive states (Pickard-Holley). Changes in biological and psychological patterns have also been reported as factors which influence the signs and symptoms of fatigue (Piper, 1988; Piper et al.). Cancer-related fatigue increases over the course of treatment with both radiation therapy and chemotherapy and also along the disease trajectory (Bruera & MacDonald, 1988; Graydon, 1994; Irvine et al., 1994; Jamar, 1989). Fatigue after surgery is particularly relevant to cancer patients who receive adjuvant therapy, as they may not have completely recovered from surgery when the next therapy begins. The possible cumulative effects of sequential treatments may increase fatigue.

The impact and management of fatigue

There is scant literature to assist nurses in improving their understanding of the impact of fatigue on the lives of patients with cancer and their families. Fatigue has been identified as either one of the worst or the worst symptom by patients with systemic lupus erythematosus (SLE) and multiple sclerosis (MS) (Fisk et al., 1994; Krupp et al., 1990; Wagenaar, 1995), and is consistently described by cancer patients as one of their most distressing symptoms (Knobf, 1986; McCorkle & Quint-Benoliel, 1983; Munkres, Oberst, & Hughes, 1992; Nail & King, 1994). The nature of the distress experienced due to fatigue in cancer patients is unknown. The most common fatigue management efforts are aimed at restoring and conserving energy and taking one's mind off fatigue through distraction. Winningham et al. (1994) have recommended that fatigue management include education, attention-restoring activities, and exercise.

Purpose of study

The purposes of this pilot study were to examine the impact of fatigue on individuals with cancer of the lung and their families, and to explore how fatigue was managed.

Conceptual framework

The study was guided by a conceptual model of symptom management comprised of three interrelated dimensions: the symptom experience, symptom management strategies, and symptom outcomes (Larson et al., 1994). This model assumes that symptoms need to be managed and such management should be aimed at influencing the symptom experience, not just the outcome. Symptom experience refers to the dynamic interchange among perception of symptoms which includes personal, environmental (social, physical), and health/illness status; evaluation of the meaning of a symptom including one's judgment about that symptom and the threat imposed and the response to symptoms which may be physiological, psychological, or behavioural. Symptom management strategies require a patientfamily-health provider partnership that is complementary and encourages patient and family management of the symptom. Symptom management is often fluid, with strategies changing over time to maintain effectiveness.

Method

Design

A content analysis methodology (Downe-Wamboldt, 1992) was used to systematically describe the experience of cancer-related fatigue for patients and family members.

Participants

The sample consisted of two groups, the individual with lung cancer and a designated family member. Patients were asked to identify an individual who lived with them and who they considered to be a close family member, and who could best represent the family's experience of the impact of the cancerrelated fatigue. In the event that the person lived alone or with a friend, the identified family respondent was whomever was considered most familiar with the impact the fatigue had on the person's life and home.

A purposive sample of individuals diagnosed with primary, nonsmall cell inoperable lung cancer without distant metastases, i.e., Stage III disease (CTRF, 1996), and who were receiving radiation to their thorax only, was accrued for the study at the completion of radiation treatment. This was done through the radiation department and the follow-up clinics designated for lung cancer at the Nova Scotia Cancer Clinic in Halifax. A mutually convenient time for the interview was arranged with the individual and their family member six weeks post completion of radiation therapy. Patients had to be between 18 and 70 years old and have a family designate who would agree to participate.

Procedure

Ethical approval to conduct the study was obtained from the Queen Elizabeth II Health Sciences Centre Research and Review Committee. Potential participants were identified by the clinic staff who approached the patients, informed them of the study, and invited interested individuals to meet the researcher. Informed consent was obtained by the researcher. The interviews were conducted by one of three interviewers from the research team at a mutually agreed upon time either at the clinic or in the participant's home.

Semi-structured interview guide

A semi-structured interview guide was developed by the research team specifically for use in this study. The content of the questions reflected the clinical experiences of the research team members (six with many years of oncology nursing experience), recent graduate work completed by a member of the team which involved indepth interviews of a different patient population experiencing fatigue (Wagenaar, 1995), and the literature on fatigue in chronic illness, specifically cancer. The development of the interview questions was guided by the conceptual framework. As well as asking about the changes they had experienced physically, and in their day-to-day activities, the scope of the questions went beyond role responsibilities to include participants' feelings, relationships with family and friends,

intimacy issues, and social changes. The questions sought to explore how patients and family adjusted to the impact of the experience rather than just the actual symptom of fatigue. Patients were asked how the fatigue affected their relationship with others, and how they would describe their feelings about being fatigued. They were asked what they did to keep these changes from affecting their lives in these ways, and, what or how they found the approaches helpful. For example, questions included, "Fatigue can influence your mood and feelings. How would you describe your feelings about being fatigued? How do you manage/control these feelings? Of the things you do, what do you find helpful?"

Family members were interviewed separately. They were asked about the changes they had experienced because of their loved one's fatigue, what they (the family members) did to keep these changes from affecting their lives, and if they found it helpful. For example, "How has your mother's fatigue affected your relationship with others? What do you do to keep your mother's fatigue from affecting your relationship with others? Of the things you do, what do you find helpful?"

The interview guide was pilot tested for content validity with five oncology nurses working in lung cancer care, five patients with lung cancer, and a support group of individuals with SLE available to the research team. The interview process was conducted in the same manner for both the person with cancer and the family designate. All interviews for the pilot testing and the study were taped and transcribed verbatim. Interviews took from 10 to 40 minutes.

Data analysis

Content analysis was used to analyze the findings of the semistructured interviews. Data were analyzed using phrases, sentences, or paragraphs that referred to the fatigue experience. The data were searched for themes or ideas contained within the respondents' answers which determined and defined mutually exclusive categories for our category system. Information obtained from one particular question was accepted to answer other research questions when applicable. The unit of analysis was coded in its content category regardless of where in the transcript it occurred. Sentences or phrases that included the words 'because' or 'but' were analyzed as a complete thought. When a sentence contained 'and/or,' it was considered a separate unit of analysis. Category frequencies were tabulated using all responses. Each unit was counted only once. The categorization system was developed by three of the investigators. Throughout the analysis, samples of the text were tested to determine if the rules and classifications were clear and distinct. Categories were reworked as needed. Ninety-five per cent reliability agreement was achieved for coding of the data.

Results

Sample

The sample consisted of 22 patients with non-small cell lung cancer; 12 males and 10 females between the ages of 46 and 80, with an average age of 66 years. Of these 22 patients, 13 were married, five were divorced, three were widowed, and one was single. Three had completed their high school diplomas and four had university degrees. Fifteen lived with a spouse (partner) and six of these patients still had children living in the home. Three lived alone, three with a friend/roommate, and one lived with children.

No patient was actively working, although two stated that they were on sick leave. All patients had smoked prior to their diagnosis and just over half continued to smoke at the time of the interview. Of the 15 people who consumed alcohol pre-diagnosis, nine had stopped post-diagnosis. Symptoms did not appear to be a concern for these participants, as less than 10% experienced pain and 81% reported that they were not experiencing any symptoms.

Twenty-three family members were accrued into the study, but four were not interviewed because their scheduling would not permit it. The 18 family members who completed the interviews were comprised of wives (n=6), husbands (n=4), daughters (n=5), son (n=1), nephew (n=1), and close friend (n=1). Four transcripts were deleted from the analysis because the respondents were unable to answer the questions about the patient (i.e. did not know patient well enough), resulting in a total sample of 14 family members.

The impact of fatigue on patients

Patients discussed a variety of aspects of their lives which were impacted by fatigue (see Table One).

Physical, cognitive and behavioural impact. The greatest impact that fatigue had on patients was the physical, cognitive, and behavioural changes that they experienced. "*I just was more quiet*" (when fatigued). Patients reported having to take naps or rests, and sleeping throughout their day, all of which were changes from previous patterns. "*I don't have any problem going in and lying down on the bed and having an hour's sleep, be it 10 in the morning or two in the afternoon*." Other changes included the inability to do usual household activities, limitations in walking/climbing stairs, and having to move and think more slowly. "…you can't do things like if *I wanted to vacuum I just am physically unable to get the vacuum cleaner out and do it, that, or if I do it then I would get so tired*." "*I just slow down a bit.*"

Emotional impact. Participants described the emotional experience of being fatigued in negative tones. Many reported being frustrated, apathetic, unhappy, or upset. "*It wasn't moody as much as frustrating*." "*I didn't care if I did anything, so I didn't care if I was tired*." "*It was hellish for about four weeks; you aren't as joyful.*" "*...it upset me a little bit.*"

Changes in family life and relationships. Patients reported a range of changes involving loved ones due to their fatigue. "*The help that they gave me was more important than money*." Patients described how family respondents had to "*take over*" household and yard duties normally performed by the patient. "...he does most of the bull work or heavy work now." "Lying around the house…bothers the wife I think." Some patients reported that as a consequence of fatigue, they felt closer to loved ones, and although sexual intercourse was not occurring, intimacy had improved. "It's like we are in this together,...but the intimacy has been great…a lot more closeness and hugging and touching and

Table One: Impact of fatigue on patients (n=22)*				
Patient	Number	Frequency		
Impact	of patients	impact reported		
Personal				
 Physical, cognitive 				
and behavioral	18	65		
 Emotional 	16	82		
No Impact	3	4		
FamilyFamily life and relationshipsNo impact/no changes	11 8	52 15		
Social • Activities, friendships, leisur • No Impact	e 9 8	24 10		
* numbers do not always add up to 22 because not everyone answered every question				

affection." Patients reported that family members were performing some of the patients' personal hygiene, driving them instead of "letting" the patient drive themselves, and family members were not letting them be alone. Eight patients reported that there was no change in or impact on family life when they were initially asked. Three of the patients who responded in this category indicated that family understood the fatigue, "...he knows that I'm sick and that I just couldn't do some of the things that I wanted to do or needed to do." Three others indicated that family did not understand, "They just say, you should phone up and find out what's wrong."

Changes in social activities, friendships and leisure activities. Fatigue impacted people's ability to maintain a normal social life. Patients talked about no longer feeling able to go to dances or parties or to play bingo. "*I used to go to my bridge club and go to an exercise, which I couldn't do.*" Patients reported that socialization with friends and family in bars or restaurants was either discontinued or decreased. "*I used to be there every night because I knew the crowd.*" Patients reported that friendships had changed because they could no longer play their usual sports with friends, or go to sports events with buddies. "*We had plans for going camping; that's on hold.*"

No impact. Ten of the 22 patients who participated in the study initially stated that they had not experienced fatigue in any aspect of their lives and, therefore, had not experienced any changes or consequences from it. With further probing, however, seven of these 10 individuals began to talk about changes they had experienced, which they then attributed to the effects or consequences of fatigue.

Patients' fatigue management strategies

Patients described a variety of fatigue management strategies to help them manage or live with their fatigue. Some activities focused primarily on fatigue prevention and energy restoration, while others described strategies used to reduce the emotional and social impact of fatigue (see Table Two).

Table Two: Patients' fatigue management strategies (n=22)*				
Patient strategies	Number of patients	Frequency strategy reported		
Energy conservation	8	17		
Energy restoration	9	14		
Health maintenance	6	11		
Fighting spirit	9	21		
Acceptance of fatigue	13	38		
No strategies identified	3	4		

* numbers do not always add up to 22 because not everyone answered every question

Table Three: Impact of fatigue on families (n=14)*

Family impact	Number of family members	Frequency impact reported
Picking up the slack	8	28
Caregiver fatigue	5	8
Worry and concern	4	8
Helplessness	3	5
Closeness	4	13
Family/social life	7	30
No impact/no changes	7	12

* numbers do not always add up to 14 because not everyone answered every question

Energy conservation. Eight patients discussed managing fatigue by conserving their energy. People described pacing themselves and slowing down their thoughts, movements, and activities. "*I got to pace myself with everything I do.*" "Everything slow, and don't just do it...think it, think slow...", "go down to the basement with the laundry and stay there."

Energy restoration. Nine of the 22 patients described activities they used to re-energize themselves. Five people reported that taking a nap was helpful. "You get an hour or so (nap) under your belt and then you get up and you aren't as fatigued as you were when you went down." "I sit down for a few minutes and everything will come back." Others noted that taking a break from different activities or relaxing for a time, such as in a hot bath, restored some of their energy.

Health maintenance. Six patients reported that leading a healthy lifestyle was helpful in managing their fatigue. Exercising, eating "good food" because "I didn't want my health to deteriorate," and using vitamin supplements were described as helping to keep fatigue from affecting their lives. "I have to get some good food in me."

Fighting spirit. Just under half the patients approached fatigue as a challenge (n=9). Patients described how they did not want fatigue to "get the better of them." "I just said I'm not going to do this (sit around), so I get up every morning and I have my shower and I put on my makeup, and I get dressed as if I'm going somewhere or someone's coming." "I don't think, I just do it." "Just keep going the way I always do, even when I'm tired, it does wear off after a while."

Acceptance of the fatigue. Over half the patients indicated that it was helpful to acknowledge that the fatigue was present, to understand it, and to accept it (n=13). "If the floors don't get vacuumed every week, well, so they don't, we'll do that when I get better." "Why dwell on it?" Patients acknowledged their fatigue and then described their adjustment tactics. "Just go out, play cards, play something." "I go to Tim Horton's and talk to everybody."

Impact of fatigue on families

Family members believed that the impact of fatigue was experienced not only by the individual being treated for cancer, but also by various members of the family. The family members who were interviewed described personal accounts of how their loved one's fatigue had directly impacted their lives. These changes, and the resultant consequences of fatigue, are categorized in Table Three.

Picking up the slack. Over half the family respondents described taking on more household and yard responsibilities as a consequence of their loved one's fatigue (n=8). Family members reported having to complete or be entirely responsible for chores or activities normally done by the patient.

Caregiver fatigue. Just over one-third of family members experienced personal fatigue as a result of their loved one's fatigue (n=5). Reasons varied for the family member's fatigue. Getting up to keep their partner company, juggling caregiving, extra household duties, and making extra trips to check on their loved one were all described. "*I think I'm over compensating because I'm trying to stay with him or whatever*." Two husbands commented that they developed a greater understanding and appreciation of their wife's role in the family and with the domestic affairs.

Worry and concern. A consequence of the patient's fatigue was the worry and concern it created for family members. Four family respondents specifically commented that they were stressed due to worry about their loved one's weakened state:

I worry about him, he knows that at certain times, that I usually call him and if I don't hear from him...so he's constantly on my mind. Is he all right? Did he get to sleep? Has he fallen? ...because I find he's tired. Although other respondents described being worried, the general sense of their conversations was that it was the cancer as a whole, or concerns about the future or mortality, rather than the specific symptom of fatigue that was the source of their worry.

Helplessness. Feeling helpless was another consequence of patient fatigue for three family members. Even when asked, family members could not separate feeling helpless because of not being able to do anything about the patient's fatigue, from feeling helpless about the disease and the situation that arose from it. "You feel like you want to do something to change it, but you know you can't, you feel helpless."

Closeness. A few family members reported a positive change as a result of their loved one's fatigue, that of a strengthened relationship. Four family respondents indicated that there was an increased closeness between them and their loved one, or between them and siblings. Most descriptions of closeness centred on the new behaviours of the person with cancer, such as being more considerate of their spouse. One woman noted that this emotional intimacy took the place of a sexual relationship:

At this point in our life, we've had sex all these years, so what, I find this much nicer now, to come home and find a note or come home and find a card from him, have him phone me from the highway and say 'look I really missed you, let's go to dinner or something,' those things mean more, it's like being courted all over, so that's nice.

In the discussions of intimacy and closeness, it appears that fatigue was not the primary causative factor for changes. Each of the four respondents who discussed their sexual relationship gave reasons other than fatigue for their lack of a sexual relationship. In two cases, sexuality had been an ongoing problem. Another felt it was inappropriate when the spouse was ill and still recovering, and in another case symptoms other than fatigue precluded sexual contact.

Family and social life. Half of the family respondents commented that their loved one's fatigue had impacted family and social life (n=7). The majority of the respondents were retired, and the greatest impact of their loved one's fatigue was on their ability to socialize or partake in their usual recreational pursuits as a couple. The resulting feeling was one of loneliness. This loneliness was not necessarily the result of a loss of social contact, but of missing the usual events with their spouse.

Families' fatigue management strategies

Family members were asked what they did to keep their loved one's fatigue from affecting the various aspects of their lives, and how they managed the feelings that came from any changes that did occur. Family members described a variety of fatigue management strategies to help them manage or live with their loved one's fatigue. Some strategies were directed at protecting or helping their loved one. Helping the patient indirectly helped them (see Table Four).

Smoothing the way. Over half of the family members indicated that making life easier for their loved one helped themselves. Eight family respondents assisted patients in their energy conservation and energy restoration by "*smoothing the way*." These activities were undertaken to make life easier, reduce stress, protect, and reduce demands on their loved one. "*I think that maybe we are overprotective, but we try to shield him from any stress or need to feel obliged to do things.*" Another person said:

I didn't let things become a problem, like he didn't drive, so when mom had a doctor's appointment or he had a doctor's appointment I would say, "Well I'm going to ...anyway I will just take mom in ...she might as well come with me, so therefore he wouldn't have to make the effort to go.

Other protective activities included ensuring their loved one was not alone during periods when they themselves were not present, and that they obtained the rest they required by curtailing visitors and keeping things peaceful and quiet.

Working around fatigue. Family members talked of having to be flexible. Again, just over half the family respondents managed changes in social and day-to-day activities (n=8). "If I have to go out I make sure that everything is all right. I'm scared she might fall... so when she is in there lying down I go out." "But we work around it...if he's having a good moment we'll go for a walk or we'll go for a beer or supper or something like that." "What we've done the last few weeks is every Sunday we go up to the flea market and we walk because it's flat, there's no hills, there is no effort, he can walk." "... you can't start supper right away because 'did he just go to sleep or is he ready to wake up?' so your whole life just depends on when and how he's sleeping."

Keeping busy. This category described the approach of distraction to the event. Two female family respondents commented that they felt keeping busy helped them cope by reducing the time to "*think about things*." Whether this is a strategy used to reduce the impact of fatigue or one that was used to not think about the cancer and its implications is not clear.

Maintaining contact. The strategy of keeping some normality in life emerged. Two women indicated that they made specific attempts to maintain contact with significant others in order to combat the reduced socialization with family that occurred as a result of fatigue. "I try to force the issue like you know, I'll make a point of getting out once a week, just my daughter and I, we go to Tim Horton's for a coffee or something, go shopping anything like that."

Prioritizing, organizing, and planning. As some family members found it necessary to be flexible, others found it necessary to become very structured. Two men found that they had to plan and organize their daily lives in order to adapt to the increased workload at home as a result of their spouses' fatigue.

Patient and Family Education

At the end of the interview, participants were asked what information patients and families should receive if they are likely to experience fatigue as a result of treatment. Participants felt that all patients and close family members should be told in depth about the possible fatigue experience so that they would know that it was normal, should it occur. Patients (particularly women) indicated that they should be taught not to give up, to "distract yourself," "work with it," and "not to let it consume you." They wanted others to know that "you should not let fatigue get the better of you, you need to keep busy." One man felt strongly that, in order to plan ahead, people should be told that they probably will not be able to perform physical labour for a period of time. Participants concluded that patients and family need to be reminded that fatigue is unpredictable, that they need to rest when their body tells them to rest, and to take care of themselves. People should be reminded that, in most cases, the fatigue will end.

Table Four: Families' fatigue management strategies (n=14)*				
Family strategy	Number of family members	Frequency strategy reported		
Smoothing the way	8	35		
Working around the fatigue	8	41		
Keeping busy	2	52		
Maintaining contact	2	6		
Planning, organizing, priori	tizing 5	6		
No impact	5	6		
* numbers do not always add up to 14 because not everyone				

* numbers do not always add up to 14 because not everyone answered every question

Participants felt that individuals needed to be prepared to ask for assistance from family or others. Some family members felt that being provided information gave them a better understanding and acceptance of fatigue as a consequence of treatment. Other family members did not feel prepared for the fatigue or for how it would impact the different aspects of their life. Three family respondents strongly related nutrition and fatigue, and indicated that they were concerned about their spouses' nutritional state and this was an area in which they could have used more information.

Limitations

Perhaps the biggest limitation of this study was that often patients could not separate responses to fatigue from other aspects of the cancer experience. Their descriptions of feelings or changes may not, therefore, be directly attributable to fatigue. This older sample (average age of 66 years) had few obligations outside the home. All but two were 'retired' before the illness. One wonders if a younger sample would have experienced a greater impact of fatigue with roles, responsibilities, and commitments of children and work. Some participants indicated that they did not think that they would have been able to have worked, even part-time, with this experience. At the time of informed consent, some family members agreed to participate then later declined at the scheduled interview, thus decreasing the number of family members to 14 participants. The sample size of this pilot study was small and therefore generalizing to older lung cancer patients receiving radiation therapy is limited. A final limitation related to the conceptual framework was noted. This framework does not address the cultural context of the symptom. This may or may not have impacted patients' and family members' coping strategies related to fatigue.

Discussion

The conceptual framework for symptom management was beneficial as it allowed for consistency in exploring the symptom of fatigue. In order to have a comprehensive understanding from the patient, we explored changes caused by the symptom and how these changes were judged, as well as exploring the feelings, thoughts, and behaviours that were experienced with the fatigue. Expectations were already set by health care professionals (that the fatigue would occur), so that the symptom occurred in the context that was perceived. Patient and family were highly involved in the management strategies and, thus, involvement of the health care system was low. The perceived experience enabled most participants to maintain a positive emotional status resulting in minimal distress overall, changes in functional status, or quality of life.

Further, findings in this study are consistent with the conceptual framework which indicates that one needs to study all who are closely involved with the experience, so that all perspectives are attained. Within this study, family members seemed to identify fatigue and its impact more than the patient. They noted changes in activities, increased nap taking, and changes in mood. They expressed both positive and negative changes in family activities and relationships that occurred as a result of fatigue. They experienced the impact of their loved one's fatigue as the need to assume role responsibilities when their family member could not manage.

By implementing the framework, an analysis of participants' responses was possible. It became evident that, for many of the patients, fatigue could not be isolated or distinguished from other aspects of the cancer experience. The cancer experience as a whole, shortness of breath, and fatigue were used interchangeably in many of the descriptions. A few patients initially said that they had no fatigue, but on further exploration they expressed changes in their activities that were in fact attributed to the fatigue. It was as if they had slowly accommodated to their fatigue, so gradually that patients did not see the subtle changes that took place over time as a result of the fatigue. Fatigue did not impact these patients to the extent that we had

expected. For those patients who talked about it, fatigue was considered a nuisance and a frustrating inconvenience, but not an incapacitating event.

Furthermore, by drawing upon the framework as a guide, it became evident that patients managed their fatigue by facing it "*head on*," many with a determination to not let it alter their activities. It did not appear that patients had spent a lot of energy worrying about the fact that they were experiencing fatigue. Families indicated that because they picked up the slack, and perhaps because they had compensated for the individual's lack of involvement in activities, patients did not realize the extent to which their day-to-day activities had gradually changed. In terms of strategies to manage fatigue, there did not seem to be any new approaches not previously described in the literature. The approaches of "*fighting back*" and "*not letting the fatigue get the best of you*" seemed to help people physically, emotionally, and socially.

Studies examining fatigue in cancer indicate that it is one of the most distressing symptoms for people (Knobf, 1986; McCorkle & Quint-Benoliel, 1983; Munkres et al., 1992; Nail & King, 1994). The authors of this study conclude that the impact of fatigue on lung cancer patients post treatment was not the serious problem one might have thought. It may be because, as we have stated, the impact was so gradual that patients did not realize the extent of the changes that had occurred. Patients in the study were also well prepared for it as a response to treatment. Rhodes and colleagues (cited in Winningham et al., 1994) suggest that realistic expectations may reduce the distress patients experience and enable them to develop self strategies and coping strategies.

Patients' fatigue management strategies reported in this study are similar to those reported in other studies examining fatigue (Rhodes et al., 1988; Winningham et al., 1994). Scheduling activities, decreasing nonessential activities, and increasing dependence on others for home management have all been previously described. It seems that the findings in all of these studies suggest that patients felt responsible for managing their own fatigue, they did not expect others to come up with solutions for how to cope. The findings of this study support the idea that preparing patients for fatigue may be helpful in how patients perceive the impact of fatigue. In other studies (e.g., Irvine et al., 1994; Johnson, Nail, Lauver, King, & Keys, 1988), researchers have concluded that educating patients about the likelihood of experiencing fatigue may reduce negative perceptions of the fatigue. This would appear to be the case in this study. Most patients felt that they had been informed and prepared for some fatigue. When change occurred, adjustments were made and patients accommodated with minimal distress.

Implications for nursing practice and research

The findings of this pilot study support the need for nurses to assess patients being treated with radiation therapy for lung cancer within the broad context of home and community supports for symptom management post treatment. The study findings also support the need for nurses to educate patients and families about fatigue, its impact, and management options. Many patients in the study had been told to expect to be fatigued, but did not appreciate the subtle changes that occurred. Instead, they expected to feel a sudden and lasting event of debilitating fatigue. Informing patients and families that there is a range of fatigue that may be experienced and the potential timeframe in which symptoms are manifested may help to normalize the experience. Furthermore, nurses need to become more aware of the new and emerging options for managing fatigue in order to assist patients and families in learning these strategies.

This pilot study suggests that fatigue was not the issue health care providers believed it might be for this particular group of lung cancer patients. The need for a larger study with more consistency in identifying the family member as providing support for fatigue management is needed. From a practice perspective, there is a need for intervention research on the management of fatigue. This study has demonstrated that the inclusion of family members is critical, and supports the conceptual model to guide nursing practice related to symptom management.

References

- Belzar, B.A., Henke, C.J., Yelin, E.H., Epstein, V.V., & Gillis, D.L. (1993). Correlates of fatigue in older adults with rheumatoid arthritis. Nursing Research, 42(2), 93-98.
- Bruera, E., & MacDonald, R.N. (1988). Overwhelming fatigue in advanced cancer. American Journal of Nursing, 88, 99-100.
- Cancer Treatment and Research Foundation [CTRF]. (1996). **Treatment guidelines for lung tumor site group**. Halifax, NS: Author.
- Cardenas, D., & Kutner, N. (1982). The problem of fatigue in dialysis patients. Nephron 30, 336-340.
- Christensen, T., & Kehlet, H. (1993). Postoperative fatigue. World Journal of Surgery, 17, 220-225.

Crosby, L.J. (1988). Stress factors, emotional stress and rheumatoid arthritis disease activity. Journal of Advanced Nursing, 13, 452-461.

- Downe-Wamboldt, B. (1992). Content analysis: Method, applications, and issues. Health Care for Women International, 13, 313-321.
- Fisk, J.D., Ritvo, P.G., Ross, L., Haase, D.A., Marrie, T.J., & Schlech, W.F. (1994). Measuring the functional impact of fatigue: Initial validation of the fatigue impact scale. Clinical Infectious Disease, 18, S79-83.
- Glaus, A. (1993). Assessment of fatigue in cancer and non-cancer patients and in healthy individuals. Supportive Care in Cancer, 1, 305-315.
- Graydon, J. (1994). Women with breast cancer: Their quality of life following a course of radiation therapy. Journal of Advanced Nursing, 19, 617-622.
- Graydon, J., Bubela, N., Irvine, D., & Vincent, L. (1995). Fatigue reducing strategies used by patients receiving treatment for cancer. Cancer Nursing, 18, 23-28.
- Hait, L.K. (1978). Fatigue in the patient with multiple sclerosis. **Research in Nursing and Health, 1**(4), 147-157.
- Irvine, D., Vincent, L., Bubela, N., Thompson, L., & Graydon, J. (1991). A critical appraisal of the research literature investigating fatigue in the individual with cancer. Cancer Nursing, 14(5), 188-199.
- Irvine, D., Vincent, L., Graydon, J., Bubela, N., & Thompson, L. (1994). The prevalence and correlates of fatigue in patients receiving treatment with chemotherapy and radiotherapy. Cancer Nursing, 17(5), 367-378.
- Jamar, S. (1989). Fatigue in women receiving chemotherapy for ovarian cancer. In S.G. Funk, E.M. Tornquist, M.T. Champagne, L.A. Copps, & R.S. Wiese (Eds.). Key aspects of comfort: Management of pain, fatigue and nausea (pp. 224-233). New York: Springer.
- Johnson, J., Nail, L., Lauver, D., King, K., & Keys, H. (1988). Reducing the negative impact of radiation therapy on functional status. **Cancer Nursing**, **61**, 46-51.
- Knobf, M. (1986). Physical and psychological distress associated with adjuvant chemotherapy in women with breast cancer. Journal of Clinical Oncology, 4, 678-684.
- Krupp, L.B., Larocca, N.G., Muir, J.M., & Steinberg, A. (1990). A study of fatigue in systemic lupus erythematosus. The Journal of Rheumatology, 17, 1450-1452.
- Krupp, L.B., Larocca, N.G., Muir-Nash, J., & Steinberg, A. (1989). The fatigue severity scale: Application to patients with multiple sclerosis and systemic lupus erythematosus. Archives of Neurology, 46, 1121-1123.

Acknowledgements

The authors wish to acknowledge the contribution of Karyn Colwell for her assistance in data collection and Colleen Clattenburg for the preparation and typing of this manuscript. This research was funded

- by Janssen-Ortho Inc. Fatigue Initiative.
- Larson, P., Carrieri-Kohlman, V., Dodd, M., Douglas, M., Fawcett, J., Froelicher, E., Gortner, S., Halliburton, P., Janson, S., Lee, K., Miaskowski, C., Savedra, M., Stotts, N., Taylor, D., & Underwood, P. (1994). A model for symptom management. Image: Journal of Nursing Scholarship, 26(4), 272-276.
- McCorkle, R., & Quint-Benoliel, J. (1983). Symptom distress, current concerns and mood disturbances after diagnosis of life-threatening disease. **Social Science and Medicine**, **17**(7), 431-438.
- Munkres, A., Oberst, M.T., & Hughes, S.H. (1992). Appraisal of illness, symptom distress, self-care burden and mood states in patients receiving chemotherapy for initial and recurrent cancer. Oncology Nursing Forum, 19, 1201-1209.
- Nail, L., & King, K. (1994). Fatigue. Seminars in Oncology Nursing, 3, 257-262.
- Packer, T., Foster, D., & Brouwer, B. (1997). Fatigue and activity patterns of people with chronic fatigue syndrome. Occupational Therapy Journal of Research, 17(3), 186-199.
- Packer, T., Sauriol, A., & Brouwer, B. (1994). Fatigue secondary to chronic illness: Postpolio syndrome, chronic fatigue syndrome, and multiple sclerosis. Archives of Physical Medicine and Rehabilitation, 75, 1122-1126.
- Pickard-Holley, S. (1991). Fatigue in cancer patients. Cancer Nursing, 14, 13-19.
- Piper, B. (1988). Fatigue in cancer patients: Current perspectives on measurement and management. In Nursing Management of Common Problems [Pamphlet]. American Cancer Society, Inc.
- Piper, B. (1989). Fatigue: Current bases for practice. In S.G. Funk, E.M. Tornquist, M.T. Champagne, L.A. Copps, & R.S. Wiese (Eds.), Key aspects of comfort: Management of pain, fatigue and nausea (pp. 187-189). New York: Springer.
- Piper, B. (1993). Fatigue. In V. Carrieri, A. Lindsey, & C. West (Eds.), Pathophysiological phenomena in nursing: Human responses to illness 2nd ed., (pp. 279-302). Philadelphia: Saunders.
- Piper, B., Lindsey, A., & Dodd, M. (1987). Fatigue mechanisms in cancer patients: Developing nursing theory. Oncology Nursing Forum, 14, 17-23.
- Rhodes, V., Watson, P., & Hanson, B. (1988). Patients' descriptions of the influence of tiredness and weakness on self-care abilities. Cancer Nursing, 11(3), 186-194.
- Srivastava, R.H. (1989). Fatigue in end-stage renal disease patients.
 In S.G. Funk, E.M. Tornquist, M.T. Champagne, L.A. Copp, &
 R.S. Wiese (Eds.), Key aspects of comfort: Management of pain, fatigue and nausea (pp. 217-224). New York: Springer.
- Tiesinga, L., Dasson, T., & Halfens, R. (1996). Fatigue: A summary of the definitions, dimensions and indicators. Nursing Diagnosis, 7(2), 51-62.
- Wagenaar, H. (1995). An exploratory descriptive study of fatigue in women with Systemic Lupus Erythematosus. Unpublished manuscript, Dalhousie University, Halifax, NS.
- Winningham, M., Nail, L., Barton Burke, M., Brophy, L., Cimprich, B., Jones, L., Pickard-Holley, S., Rhodes, V., St. Pierre, B., Beck, S., Glass, E., Mock, V., Mooney, K., & Piper, B. (1994). Fatigue and the cancer experience: The state of the knowledge. **Oncology Nursing Forum, 21**(1), 23-36.