Exploring patient experiences and self-initiated strategies for living with cancer-related fatigue

by Margaret I. Fitch, Deborah Mings and Alan Lee

Abstract

Fatigue is one of the most prevalent and distressing side effects of cancer for patients. It threatens quality of life and can interfere with daily living. Systematic approaches for assessing and intervening are recommended for implementation in many cancer centres.

Prior to implementing a formal fatigue program, this study was conducted to explore what cancer patients do to cope with fatigue on their own. In-depth interviews were conducted with 31 patients receiving chemotherapy to identify the strategies they used to cope with the fatigue they experienced. Patients were able to identify when they noticed the fatigue and what they had tried to do. Most individuals used resting, sleeping, and decreasing activity. Relatively few tried a range of other strategies. Many perceived the fatigue as a normal part of cancer treatment and something with which they just had to put up. Heightened emotional reactions emerged when the fatigue interfered with an activity that was important to the individual. Clearly, without a systematic patient education program, patients are left to learn through trial and error what could be helpful to them in coping with the effects of fatigue.

Introduction

Fatigue is one of the most prevalent and distressing side effects of cancer. It is the only symptom reported by the majority of cancer patients in all diagnostic groups (Blum, 1997; Curt, 2001). It threatens quality of life and interferes with various activities of daily living (Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003). Often profound, it can influence relationships and adherence to medical therapy. Based on a growing body of evidence about interventions to cope with fatigue, cancer centres are encouraged to implement systematic or programmatic approaches for fatigue management.

Prior to initiating a systematic program to assist cancer patients manage fatigue, an investigation was undertaken to identify what patients did of their own accord to deal with this symptom. This investigation was designed to establish a baseline picture prior to implementing the patient education program, and provide ideas that could be incorporated into the program. It was anticipated that strategies patients found useful in coping with fatigue could be identified and shared with other patients.

Background

Fatigue is as difficult to define and measure today as it was in 1921 when Muscio stated that, “the term be absolutely banished from scientific discussion and consequently that attempts to obtain a fatigue test be abandoned.” Although the meaning of fatigue in common usage is intuitively clear, as an empirical phenomenon fatigue has many different meanings. It can refer to tiredness after physical activity, to concentration problems after mental efforts, to not feeling motivated as a side effect of illness and treatment, and as a mood state characterized by de-activation (Frijda, 1986; Smets, Garssen, Schuster-Uitterhoeve, & DeHaes, 1993). There isn’t one universally accepted definition (Piper, 1993; Tiesinga, Dassen & Halfens, 1996).

However, there are common threads running through the existing definitions. These include the notions that fatigue is subjective and multidimensional (Aistars, 1987; Irvine, Vincent, Grayson, Bubela, & Thompson, 1994; Piper, 1993; Rhodes, Watson, & Hanson, 1998; Smets et al., 1993; Winningham et al., 1994), has different modes of expression (Hickok, Morrow, McDonald, & Bellg, 1996; Smets, Garssen, Cull, & deHaes, 1996), exists along a continuum (Irvine et al., 1994; Jensen & Given, 1993), and involves energy depletion (Irvine et al., 1994; Robinson & Posner, 1985). In cancer circles, fatigue is frequently defined as a condition characterized by subjective feelings of tiredness; loss of strength; endurance or energy that varies in degree, frequency, and duration with different modes of expression (i.e., physical, functional, cognitive, emotional, social and motivational) (Ahlberg et al, 2003).

The prevalence of fatigue in cancer has been well documented. Estimates of fatigue during chemotherapy range from 70% to 100% (Cassileth et al., 1985; Fernsler, 1986; Jamar, Meyerowitz, Watkins, & Sparks, 1983; Nail & King, 1987; Potempa, 1993; Rhodes et al., 1998) while those in radiation range from 80% to 100% (Adams, Quesada, & Guttermann, 1994; Anderson & Tewfik, 1985; Cassileth et al., 1985; Greenberg, Sawicka, Eisenthal, & Ross, 1992; Meyerowitz, Sparks, & Spears, 1979; Nail, 1993; Oberst, Hughes, Chang, & McCubin, 1991). Additionally, the majority of patients with advanced disease experience this symptom (Aistars, 1987; Billings, 1985; Donnelly & Walsh, 1995; Winningham et al., 1994). In studies where comparison groups have been used, fatigue is more of a problem for cancer patients than for the general population (Ahlberg et al., 2003; Glaus, 1993; Irvine et al., 1994; Potempa, 1993). Chen (1986) documented that fatigue is seven times more prevalent in the cancer population than...
in the general population. Additionally, fatigue is qualitatively different for cancer patients than for the general population. Cancer-related fatigue is rarely relieved by rest or sleep (Berger, 1998, Piper, 1993).

The severity of fatigue in cancer has been described as ranging from mild to moderate and severe, but is not directly related to type of cancer, cancer stage, size of tumour, number of nodes involved or the presence or site of metastases (Servaes, Verhagen, & Bleijenberg, 2002). Winningham et al. (1994) stated that the pattern of fatigue over the illness and treatment regimen varies with disease type, site and regimen. For many patients, fatigue tends to increase over the course of treatment and dissipate once treatment has finished (Chen, 1986; Hickok et al., 1996; Irvine et al., 1991; 1994; Nail & King, 1987). However, for some patients, fatigue has been reported to persist after the treatment has finished, sometimes for several years (Berglund, Bolund, Forndander, Rutqvist, & Sjoden, 1991; Devlen, McGuire, Phillips, Crowther, & Chambers, 1987; Fobair, Hoppe, Bloom, Cox, Varghese, & Spiegel, 1986).

Fatigue becomes significant when it reaches a level that adversely affects an individual’s quality of life (Aistars, 1987; Fernsler, 1986; Jamar, 1989; Kurtz, Kurtz, Given, & Given, 1993; Skalla & Lacasse, 1992; Walker, Katon, & Janelka, 1993). Fatigue has been reported to interfere with employment, leisure and social activities, activities of daily living and the ability to care for one’s self (Pearce & Richardson, 1996). Fatigue can precipitate or aggravate discord in family relationships. The burden of caregiving can induce fatigue in family caregivers as they assume roles previously performed by patients (Carter, 2002). Fatigue can also impact on a person’s ability to understand and use information. In a convenience sample of 910 men and women with cancer, fatigue was observed to have an impact on all four dimensions of quality of life: physical, psychological, social, and spiritual (Ferrel, Grant, Dean, Funk, & Ly, 1996).

It is almost universally accepted that the measurement of fatigue needs to be subjective and multi-dimensional. Over the years, several instruments have been developed to measure fatigue in cancer populations across its multiple dimensions from the patient’s perspective (Skalla & Lacasse, 1992; Smets, Garssen, Cull, & deHaes, 1996). Piper’s scale is one of the most popular and measures fatigue using the characteristics of temporal, intensity, affective, sensory, evaluative, associated symptoms and relief patterns (Piper et al., 1989). A recent addition to the collection of fatigue measures is the Fatigue Pictogram (Fitch, Bunston, Mings, Sevean, & Bakker, 2003). It was designed to measure two dimensions of fatigue and be used as a screening or triage device. By using a screening instrument, patients who are experiencing difficulties with fatigue can be identified. An in-depth assessment of fatigue can then be conducted by a health care provider and appropriate interventions offered.

Assessing the nature and pattern of fatigue increases the likelihood of linking interventions to an underlying etiology and selecting the appropriate intervention. Changes in the patients’ drug regimen, reversal of anemia or metabolic abnormalities, or treatment of sleep disorders or depression are potential avenues for intervention (Portenoy & Itri, 1999). Psychostimulants (e.g., methylphenidate, pemoline and dextroamphetamine) and selective serotonin-reuptake inhibitors are being used empirically to counteract debilitating fatigue. However, there are no controlled trials demonstrating their efficacy in cancer-related fatigue (Cleeland, 2001). The nonpharmacologic approaches for the management of cancer-related fatigue are receiving more attention and are showing great benefits to some patients. These include walking or exercise programs (Berger, 1998; Dimeo, 2001; Schwartz, 2000), educating patients about fatigue (Grant, Golant, Rivera, Dean, & Benjamin, 2000), and individual counselling by professionals (Fawzy, 1999; Gaston-Johansson et al., 2000). Magnusson, Moller, Ekman and Wallgren (1999) noted that some patients cope with fatigue by distraction (e.g., reading, listening to music), resting more frequently, exercise by walking, and preparing ahead for various activities during the day.

Current practice guidelines by the National Comprehensive Cancer Network indicate that a systematic (programmatic) approach is required to screen, assess, intervene and manage fatigue appropriately. Prior to implementing such a program at our cancer centre, we wanted to gain an understanding of how patients did of their own accord about fatigue. How did patients manage their fatigue when there was no systematic approach in place at the cancer centre? Did patients have strategies they used and found helpful? It was anticipated that learning more about what patients did to cope with their fatigue could help with the design of the patient education program and would also provide a baseline for our work.

**Purpose**

The purpose of this investigation was to gain a better understanding about what cancer patients do to cope with the fatigue they are experiencing. We hoped to gain insights into what strategies patients initiated on their own to manage their fatigue, which ones they found useful, and what made it difficult to deal with the fatigue.

**Methods**

This study made use of in-depth interviews with cancer patients receiving either radiation or chemotherapy treatment for their disease. Following ethics approval by the hospital research ethics committee, a convenience sample of 31 patients was accrued in a comprehensive cancer centre. The nurse caring for patients told them the study was being conducted once having identified the patient as a potential candidate for the study using the following criteria: 1) a definitive diagnosis of cancer, 2) more than 18 years of age, 3) able to understand and speak English, and 4) mentioned to their nurse that they were experiencing fatigue. If the patient was interested in hearing about the study, the nurse contacted the research assistant (RA) who informed the patient about the study purposes and participation and obtained the consent. For patients who were interested in participating, an informed consent was signed and a time scheduled for the interview.

All interviews followed the interview guide developed for the study. The guide contained open-ended questions for use by the interviewer to gather information about the experience with fatigue and what individuals did to cope with it. Once several demographic questions had been posed (i.e., age, marital status, education level, work status, cancer type, diagnosis date), participants were asked to describe the events surrounding their diagnosis and treatment decision-making, their awareness of when the fatigue started, the impact of the fatigue on their daily lives, what strategies they used to cope with the fatigue, which strategies were helpful, whether they talked with anyone about their fatigue, and suggestions about what a cancer centre could do to help patients who were experiencing fatigue. We wanted to understand their awareness of their own fatigue, its impact on them, and their subsequent actions to cope within their experience. Probes were used only as encouragement (i.e., tell me more about that) or for clarification (e.g., did that happen before or after the treatment?). The interviews were conducted by the skilled research assistant in the clinical setting, were audiorecorded, and lasted between 30 and 45 minutes.

The interview audiotapes were transcribed verbatim and any identifying features were removed. A content analysis was performed (Silverman, 2000). Each team member independently read the
transcripts and made marginal notes about the content for each interview. Team members discussed their impressions of the content and, working together, designed a categorization scheme (set of topic categories) for the content analysis. One team member then completed all the coding according to the agreed-upon scheme (MF).

The primary content categories included talking about the fatigue, the impact of the fatigue on the person, and strategies to cope with the fatigue experienced. The content within each category was then reviewed and summarized, and the key ideas were identified. These key ideas will be reported below.

**Findings**

A total of 31 cancer patients participated in this study. The 15 men and 16 women ranged in age from 30 to 78 years (average 56.3). Nineteen were married or living with a partner and six were continuing to work at reduced hours throughout their treatment. A cross-section of cancer types was included (see Table One) and eight participants were living with recurrent disease. All were currently receiving treatment for their disease at the time of the interview.

**Describing the fatigue/Talking about the fatigue**

Without exception, all participants described feeling shock and dismay when they learned they had cancer, and the disruption and upheaval they experienced in their daily lives because of the treatment regimens. All were able to pinpoint when the fatigue invaded their lives and they could isolate its effect on them. For most, the fatigue began after their cancer treatment was started. The few who had experienced fatigue prior to the diagnosis now thought about it in terms of being a sign they had had cancer before it was diagnosed.

When asked to describe the fatigue, participants elected to talk about it using a range of words (e.g., tired, fatigue, no energy.) Their descriptions provided wonderful illustrations of what the experience of being fatigued was like for them.

**Lethargy:**

It was not the fatigue so much as feeling lethargic. You are not feeling your normal zip, the get up and go, that kind of stuff... it’s a monumental task to do anything. (2)

I didn’t realize, really realize, how tired I would get... how lethargic... it was almost like running into a brick wall... you keep thinking if you have a couple of good night sleeps it will get better... but you do feel exhausted for awhile. (7)

**Exhaustion:**

It’s like you are totally exhausted... like when you’ve worked hard and you are tired, it’s not like that. It’s like you are wearing, say like metal, full body metal [armour] like you just can’t go on... like you go to bed, you wake up and you’re tired. (9A)

I’m not going around and falling asleep all day. I just have no energy, you know, the body is like a dead zone... I haven’t got what it takes to make [my arms and legs] do things. Everything I do is a thinking process. Now get up. Now move yourself, you know. It’s not like you get up and do things naturally. (1A)

It’s like having someone sitting on your shoulders. Your muscles aching and you’re working in slow motion. The extent of your travel is really from the bed to the chesterfield if you can get away with it. (23)

**Overwhelming tiredness:**

It is like nausea, or maybe headachy, so you slow right down. (2A)

It’s a tiredness to the point of nausea, almost. It’s hard to explain. You don’t actually feel nauseous per se, but you, it’s a form of tiredness that just leaves you feeling, or maybe it’s a form of, maybe nausea can make you feel tired, too... I get this feeling if I don’t sit down I’ll pass out... it’s just a sense of no energy and, ah, it’s like the muscles won’t work. There’s no energy in your body and there’s no energy in your mind. (1A)

Although most participants talked about noticing physical aspects of the experience, some described others such as the mental, emotional, and motivational aspects of their experiences with fatigue.

**Mental:**

It is hard to think about anything. I don’t want to think of anything. And my body tells me I am exhausted, lie down, you know, take it easy. (5)

It’s both physical and mental. Like you can’t concentrate on anything for a prolonged period of time. I read a newspaper article and then I have to close my eyes, just close them for a while. (9)

I haven’t felt... I don’t have the mental energy anymore. I guess I don’t know whether it was the stress and trauma or whether it’s the age plus the chemo. I don’t know, but I just don’t have the energy to think, to worry about things, you know. I’m kind of in a zombie sort of state, that sort of twilight zone. Tho’ I’m not totally comatose! (1A)

**Emotional:**

I am depressed more. I never was before... it’s like feeling very sad. That’s it, just sad. (7A)

<table>
<thead>
<tr>
<th>Table One. Selected demographic characteristics (N=31)</th>
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<tbody>
<tr>
<td>Gender</td>
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<td>Age (in Years)</td>
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<td>Marital Status</td>
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<td>Work Status</td>
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<td>Time Since Diagnosis</td>
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<td>Type of Cancer</td>
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Motivational:
I find that I really have to push myself to do stuff... I really have to psych myself up to do it. And I do find I have a lot of trouble concentrating and focusing and stuff and getting myself motivated to do things. (22)

Impact on aspects of living
These participants noticed the fatigue had an impact on various aspects of their daily life. The focus within the descriptions was often one of not being able to do something they used to do before their treatment began. Given the nature of the sample (i.e., number of retirees), the specific examples they offered were frequently oriented around leisure and housework-related activities. Those who were working during their treatment had all made adjustments to accommodate the fatigue.

Decreased activity:
...the activity, that’s the main sort of impact on me. And I cannot walk too well. Everything is slowing down at this point... I just have less energy. (3)

Even tho’ I am pretty sick, I drag myself out of bed, I drag myself to work. And I force myself... you get so tired that you just don’t want to do anything. You just want to go home and just hit the couch... I was just so tired... I lay on the couch. I couldn’t move... I try to get up, but I can’t... it literally knocks you off your feet... I had no energy whatsoever. I didn’t eat. I didn’t want to do anything... It kept me from doing my exercise. I missed shows... it just puts my life on hold to the point it sets me back... I can’t be myself since cancer. I cannot get up and go and do whatever I want to do at times. I have to plan everything around my treatment because of how I feel... my whole life has changed. (6A)

Difficulty with daily tasks:
...I just haven’t been able to do so much. I can’t vacuum. I can’t clean the bathtub, that scrubbing, you know. I can clean the toilet or the sink, but the big scrubbing jobs I can’t do. I have to do things in bits and pieces now, and I only hope it will improve. (2)
I’m great as long as I am sitting. So it’s basically the walking about that bothers me... it’s hard to do anything like go shopping or anything like that. I mean, standing in line I thought I’d pass out! (4A)

Curtailed social activities:
I haven’t been getting anything much as far as social. I really don’t want to. You just sort of want to be by yourself, just curl up and sleep or whatever. That is all you want. I mean, you really can’t maintain a conversation with people for a very long time. (9)

I used to be active all day long... I led quite an active life... golf, running, working... 40 hours a week... Scottish dancing and so on... now I am really cut off from those folks, the friends that we had with those activities... we haven’t really been travelling. (5A)

We don’t entertain as much as we used to... and my wife has to do more around the house now. I have this strength limitation. (3A)

...just basically your life is not as lively because lots of times you’re not quite well enough to go out and see people and that sort of thing. But you do the best you can and go out when you can... I’ve had to stay close to home. I normally travel quite a bit and I have not been out of the city since last year... you don’t often feel quite brilliant... I get fatigued and I don’t feel 100% quite a lot of the time. (4A)

Emotional responses to the situation
The emotional response or distress for the person experiencing the fatigue was often linked to how much of an issue it was for the individual to be unable to do something that was of importance to them. The emotional responses ranged from minimal to frustration.

Yes, it can be frustrating, because you want to do things... but you find you want not to start projects... not do as many things, especially creatively... as far as going out and doing things, you don’t have the gumption to get up and go out and have more of a social life. (15)

Whether or not the fatigue and its impact were perceived as a problem for the person was embedded within their attitude or perspective about managing it. For some, if they had to adjust, but could still do important activities to some degree, the fatigue was not as much of an issue for them. Others, who found themselves rather limited in doing what was important to them, were more upset about the fatigue.

My walks are shorter... the amount of time I spend swimming lanes is less. I am good for a golf game... It’s a question of degree more than the activity. I’m probably down to 25% in terms of what I used to do. My stamina is pretty good. I don’t have trouble getting up and going to work. I don’t have to push myself... relatively mild side effects. But, as we go down the road, who knows? (3A)
I haven’t really considered it a real problem. It doesn’t stand in the way of getting things done... it takes a bit longer... I have to space things out a lot more than I did... sort of wish you would get more done. Sometimes. (19)

Some participants were very clear that, as long as the fatigue was temporary, and they thought it was, they could cope for now. They could make the necessary adjustments on a short-term basis.

You know, I know it’s something I have to do for now and so I am OK with it, as long as it is not a permanent thing. (6A)
I don’t feel frustrated because I know that in a month or so it’ll be back to normal, I hope. It is annoying, actually, but not too bad. (23)

For some participants, the fatigue was clearly a problem for them and a source of frustration and distress.

It’s a drag. There’s no other way to put it. I am usually, like, an active kind of go-go-go kind of person. So, to me, that’s the worst part of having cancer—even this, the crappy chemo, everything, whatever—to me, the hardest part is the fatigue. You want to do things and you can’t. That’s the hardest emotionally for me. The toughest thing. (22)
I still worked every day... I think maybe that is why I was exhausted after. Because I didn’t want to look weak or unable. And I wanted my life to be as normal as possible. There is something about it, especially if you are younger and going through cancer. If you have a job it is part of the normal world, the healthy world. So you try to pretend nothing is wrong. (2)

Patient-initiated strategies to cope with fatigue
No one reported they did not try to do something about the fatigue. Most of the patients reported using several strategies to try to deal with it. A small proportion described using more than 10 different types of strategies while the majority focused on three to four. The strategies described in Table Two are presented in descending order of frequency reported by the participants (i.e., those reported most often by the participants are described first). All participants described using the strategies of sleeping, resting, and taking naps. Many described stopping an activity or adjusting their activities. Few used exercise. Patients often elected to try strategies they had used in the past to deal with feeling tired. Sometimes the strategies patients used were helpful but, other
Table Two. Patient-reported strategies to cope with fatigue (reported in descending order of frequency)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency</th>
<th>Reported by</th>
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<tbody>
<tr>
<td><strong>Sleeping/Taking Naps</strong></td>
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<tr>
<td>• Sleep, rest, not doing active stuff. Just like sitting down and watching TV...and I guess maybe those two-hour naps in the day help. (Marg, 40)</td>
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<tr>
<td>• Any fatigue I have, I deal with it as I always have. I take cat naps. (Ian, 60)</td>
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<td>• I do normally take a rest every day. I try to take a nap every day. Sometimes I sleep. (Mary, 60)</td>
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<td>• Sometimes just close my eyes and thrash around a bit, try to relax. (Mark, 70)</td>
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<tr>
<td><strong>Lying Down/Resting/Relaxing</strong></td>
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<td>• If I am standing [and I feel overwhelmed] I feel I have to sit down. If I sit down, I am fine. Other times, I realize the only way I am going to get out of this sort of situation is to go and lie down, you know. (John, 75)</td>
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<td>• ...when I am home, I lie down and I think that helps. I don’t lie in bed. I lie on the couch. I don’t go upstairs. I turn on the TV or read a book. (Jackie, 58)</td>
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<tr>
<td><strong>Stopping an Activity/Doing it in Stages</strong></td>
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<td>• I had to stage it all out. Like clean the bathroom, do the laundry...make the pie crust. Rest. Fill it later. I can’t do it all at once any more. (Nancy, 58)</td>
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<td>• Sometimes, I have to drag my keister, but I will drag it. I will cut the grass at the lake, you know. It will take me maybe twice as long to cut it, but it will be cut... I take little rests... I will cut half and go take a little drink and sit down. (Mark, 70)</td>
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<tr>
<td><strong>Adjusting (reducing) Activities</strong></td>
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<td>• ...you would want to empty your dishwasher, so you sit down to do it. If you want to do any cooking or anything like that, you have to sit... walking from the parking lot to here, I had to keep sitting down. (Mary, 60)</td>
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<td>• If I feel tired or I know there’s something, say for example, that I have to do like in the evening, I will kind of make sure I take it easy in the daytime and in the morning, so I can rest in preparation for that. (Marg, 40)</td>
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<tr>
<td><strong>Organizing Daily Activities/Planning Around Fatigue (and Chemo/Radiation Cycle)</strong></td>
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<td>• I don’t make elaborate plans to do things and I would say to people, I have a window of opportunity of one week in which we can go to the movies or we can go out to dinner or go out for a walk or whatever. And the other three weeks, I’d have people come in to me. (Mary, 60)</td>
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<td>• I can do almost everything that I normally do... I have been able to arrange my life so the fact I have fatigue doesn’t get in the way. And if I get tired, then I sit down and don’t do anything. (Alex, 59)</td>
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<tr>
<td><strong>Accepting Help from Family and Friends</strong></td>
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<td>• It’s lack of physical and mental energy... I have days when things are a lot lower... the energy level’s quite low... and then my husband has to jump in and do the daily chores more or less. (Sally, 42)</td>
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<td>• Without the support of family and friends, I don’t think I could have made it... they will come and make dinner, you know. Clean the house and say, “Don’t you worry”... my brother comes over and cooks and my husband does the grocery shopping... the laundry and stuff like that. (Sue, 48)</td>
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<td>• My wife... we talk about it. We talk about what’s happening... We devise strategies to deal with it... try a division of work that fits the pattern of how I am feeling. (Ian, 60)</td>
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<td><strong>Keeping Busy/Finding Something to Do</strong></td>
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<tr>
<td>• As long as you are doing something, something that keeps your mind off it. (Gale, 58)</td>
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<td>• I find reading helps me... it keeps your mind going and it keeps my mind off the fact that I am tired. Therefore, there is something else in the forefront. (Norman, 48)</td>
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<td>• I keep busy. I like to try to keep busy. There’s a lot to do. It keeps your mind off your problems. (Liz, 51)</td>
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<tr>
<td><strong>Exercising/Walking</strong></td>
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<td>• I try a little walking... I try to go to work, if I can, and do all the things... I like to keep active... I keep walking. (Don, 67)</td>
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<td>• I try to exercise regularly to see if that will help. And it sometimes does. (Ian, 60)</td>
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<td>• I find that throughout the day, if I’m really tired, instead of just going and lying down, I’ll often get down on the floor and do some stretches and even just doing the stretches really helps getting over being incredibly tired. (Fran, 30)</td>
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<td><strong>Eating a Balanced Diet</strong></td>
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<td>• I’ve changed my diet. There’s certain things I’m doing that I didn’t do before... no alcohol, no caffeine... and those heavy carbs; cut back on pasta and breads, stick to proteins and fruit and vegetables. A lighter diet... and I take Noni juice and coral calcium. (Sally, 42)</td>
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<td>• You can be tired if you don’t eat, if you don’t eat like you are supposed to... I think the best vitamins you get are from eating fresh vegetables and the fruits. (Bob, 64)</td>
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<td><strong>Other (mentioned only once)</strong></td>
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<tr>
<td>• Removed all deadlines</td>
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<tr>
<td>• Focusing on one goal a day</td>
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<tr>
<td>• Telling myself it’s okay to slow down</td>
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<td>• Get a cleaning lady</td>
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<tr>
<td>• Organize a quiet spot for oneself</td>
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<tr>
<td>• Don’t fight it</td>
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<tr>
<td>• Break things into stages</td>
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<tr>
<td>• Don’t dwell on it</td>
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<tr>
<td>• Don’t look too far ahead—deal with today</td>
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<tr>
<td>• Tell others when I need to rest or sit or lie down</td>
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times, they were not. These participants talked about believing they were doing the best they could in the circumstances and trying to find what worked best. All recognized fatigue was part of the cancer experience.

Advice to health care professionals

Participants in this study, for the most part, did not talk with health care professionals about the fatigue they were experiencing. Most did not raise the topic with their care providers, nor did the health care professionals raise it with them, as far as they could recall. For those few who did raise the topic, the main message they received from the health care professionals was that fatigue was normal and to be expected with cancer treatment. They did not receive a strong indication that interventions existed to help them cope with the side effects.

I talked to the doctor, but I don’t think there is much that you can do… I think the thing about being tired is that it is expected from the chemo treatment. (5)

Not really [talked to the doctor or nurse about it]. It’s all part of the course. It’s expected. We read up on it and it’s all part of the chemo and radiation. It makes you tired. (24)

They seem unsympathetic… they don’t have much to offer in the way of helpful advice. Because they say always it’s just the side effects of chemotherapy. (5A)

I just think it’s a whole parcel of this thing… what’s to talk about? (4A)

...the doctors, the nurses, the technicians didn’t tell me as much about how tired I would be. I asked about side effects of radiation, “Oh, you might feel a little tired.” But they kind of, I wouldn’t say pooh-poohed it, that is probably unfair, but downplayed it. (2)

Participants indicated it would have been more helpful to receive information about how to handle the fatigue. They thought this was a role health care professionals ought to perform, particularly cancer nurses.

It would be helpful if they could give you a more detailed outline about what to do about it. Maybe a pamphlet on how to deal with your fatigue. (6A)

Discussion

This study was undertaken to identify strategies cancer patients use on their own to cope with fatigue. We wanted to understand what cancer patients do about the fatigue they experience in the absence of a structured program for fatigue management. Most qualitative work in the past has focused on patient experiences regarding the impact of fatigue. However, these studies have not linked the experiences to patient-initiated strategies for coping with fatigue (Chan & Molassiotis, 2001; Harden et al., 2002; Magnusson, Möller, Ekman, & Wallgren, 1999; Pearce & Richardson, 1996). We anticipated this work would provide a baseline description prior to mounting a fatigue management program in our cancer centre.

A convenience sample was used in this work and, as a result, relevant populations have been omitted (i.e., ovarian, lung, etc.). A qualitative methodology was used to garner the patient perspective withoutcolouringtheirviewpointsbyprovidingapredetermined checklist of possible strategies from the investigator. However, in future work, a checklist of strategies could be provided as a stimulus to discussion with the person. Our approach may have led patients to describe only those strategies they used with conscious intent.

The participants in this study provided rich, detailed descriptions about the impact of fatigue and how they tried to deal with it. The physical impact was described most often, although many individuals also described other dimensions of the phenomenon. Clearly, the fatigue had a profound impact on daily living for some of these individuals. The nature of this impact has also been reported by other investigators (Ferrel et al., 1996; Harden et al., 2002; Kurtz et al., 1993; Walker et al., 1993).

The participants also described how their emotional reaction to the impact of the fatigue was linked to whatever activity they could no longer do and how important that activity was to them. If they were unable to do something that was important to them, the emotional reaction (i.e., anger, frustration, resignation, etc.) was heightened. This emotional response pattern has been described in the literature on appraisal of stressful life events (Lazarus & Folkman, 1984). The emotional reaction emerges as a result of perceiving that important values and commitments cannot be fulfilled.

In terms of strategies they used to cope with the fatigue, these participants described using strategies they had found helpful in the past to cope with being tired. One is left with a sense they engaged in a process of trial and error to find out what was helpful, rather than having been instructed in appropriate and relevant (evidence-based) interventions. In particular, concerns could be raised about how all individuals select rest and sleep activities as their primary strategy to cope with fatigue with the emerging evidence regarding the effectiveness of exercise and more proactive approaches (Schwartz, 2000). Yet, at the same time, it is not surprising individuals selected rest or sleep based on their past experience of being tired or fatigued, as this is a common-sense approach (Graydon, Bubela, Irvine, & Vincent, 1995).

However, the fascinating aspect of this study was the capacity to observe, on a case-by-case basis, what individuals actually tried to do (i.e., the strategies they had used) about the fatigue within the context of living with it. The complexity emerged by looking at the interplay among their perceptions about the fatigue (e.g., it is normal, not much can be done about it, it is not permanent), the impact on their lives (e.g., slowed them down, stopped them doing an activity), their doing something intentionally to cope with the fatigue (e.g., resting, adjusting their pace of activity), and their finding out whether or not the strategy they tried actually worked. If it did have some effect, the strategy was used again. If it did not, the perspective of fatigue being something one could actually do something about was questioned by participants. In some cases, this stopped any more experimenting with other strategies. The notion of just putting up with the situation and waiting until it’s over emerged. However, if the predominant issue for the person was not being able to do something that was rather important, the effort was often renewed to find another strategy to cope with the fatigue. A fundamental issue for these participants, however, was that the menu of strategies they knew about was rather short. Additionally, being unfamiliar with the patterns of fatigue and not making use of systematic assessment or monitoring schemes/tools, participants may have judged a strategy to be ineffective – but, if it had been used at a different point in the fatigue experience, it may have been helpful. For example, what would be an effective strategy during the three or four days following a chemotherapy dose might not be an effective strategy at the point a week or so following the dose when a person is apt to be more mobile and engaged in activities.

Based on these observations, clearly tailoring interventions to the nature and pattern of fatigue, as well as the individual is essential. The same specific strategy may not have the same effect for everyone. The practice challenge, then, is to determine which strategies to use at what point for which individual patient. This will necessitate that health care providers have a) a solid knowledge base about fatigue/fatigue interventions, b) skills in assessing/monitoring, communication and patient education, and c) positive attitudes about working in partnership with patients to cope with fatigue.
Implications for practice
Cancer nurses need to be proactively asking patients who are receiving treatment about their experiences with fatigue. They need to listen acutely and identify accurately the nature of the fatigue and whether the patients want help with it. Appropriate guides for triage and assessment are available (National Comprehensive Cancer Network website). Cancer nurses also need to be prepared to assist patients in learning about appropriate strategies to combat the impact of the fatigue (Skalla & Lacasse, 1992; Servaes et al., 2002). They need to link the strategies or interventions to the relevant dimension (i.e., cognitive, physical, motivational, emotional) and pattern of fatigue. User-friendly patient education resources (e.g., the brochure, Your Bank to Energy Savings: How People with Cancer Can Handle Fatigue, 2004) are available for use by nurses.

Above all, the communication needs to occur in such a way that patients not only realize the fatigue is normally part of the cancer treatment experience, but also realize there are potentially ways to combat the impact. Cancer patients must know they do not have to fight fatigue alone, or feel they “just have to live with it.”

In light of the proposed program for fatigue management, several important aspects—related to knowledge, skill, and attitudes—have emerged from these study results that should be incorporated and emphasized.

- Cancer-related fatigue is real, is important to manage, and has a pattern that can be described.
- Fatigue is a part of cancer and cancer treatment, but its impact can be reduced (i.e., interventions are available).
- Cancer-related fatigue may impact a person’s life in different ways at different times and the strategies to cope with it need to be matched with that impact (i.e., physical, cognitive, etc.) for the individual and changed as necessary.
- Systematic assessment and routine monitoring of fatigue are useful to sort out what type of strategy is needed and what is working once it is implemented (i.e., use of patient diaries).
- The notion of a team approach is helpful with good communication exchange among members (e.g., patient and nurse working together to monitor effectiveness of fatigue strategy).

Concluding remarks
In an environment without a formalized education program about fatigue, patients are left to devise their own strategies to cope with this side effect and are likely to utilize common sense approaches based on past experiences. These may or may not be effective. In this study, patients were acutely aware of the impact of fatigue but, on the whole, made use of few strategies. There is a critical need for a structured or organized approach to patient assessment and education in the self-management of fatigue to enlarge the menu of options with which the person can select, reduce the emotional distress patients’ experience, and enhance their capacity to carry on with important daily activities. When individuals are diagnosed with cancer, they may have to develop a new set of skills and knowledge to help them cope with the side effects of the disease and its treatment. Cancer nurses have a responsibility to assist them in this learning.

References


