

The Cancer Rehabilitation Journey: Barriers to and Facilitators of Exercise Among Patients With Cancer-Related Fatigue

Janine Blaney, Andrea Lowe-Strong, Jane Rankin, Anna Campbell, James Allen, Jackie Gracey

Background. Despite the evidence to support exercise as an effective management strategy for patients with cancer-related fatigue (CRF), many of the general cancer population are sedentary.

Objective. The aim of this study was to explore the barriers to and facilitators of exercise among a mixed sample of patients with CRF.

Design. An exploratory, descriptive, qualitative design was used.

Methods. Purposive sampling methods were used to recruit patients with CRF who were representative of the cancer trajectory, that is, survivors of cancer and patients in palliative care who were recently diagnosed and undergoing treatment. Focus group discussions were transcribed verbatim and analyzed using a grounded theory approach. Lower-level concepts were identified and ordered into subcategories. Related subcategories then were grouped to form the main categories, which were linked to the core category.

Results. Five focus groups were conducted with 26 participants. Within the core category of the cancer rehabilitation journey were 3 main categories: (1) exercise barriers, (2) exercise facilitators, and (3) motivators of exercise. Exercise barriers were mainly related to treatment side effects, particularly fatigue. Fatigue was associated with additional barriers such as physical deconditioning, social isolation, and the difficulty of making exercise a routine. Environmental factors and the timing of exercise initiation also were barriers. Exercise facilitators included an exercise program being group-based, supervised, individually tailored, and gradually progressed. Exercise motivators were related to perceived exercise benefits.

Conclusions. Individuals with CRF have numerous barriers to exercise, both during and following treatment. The exercise facilitators identified in this study provide solutions to these barriers and may assist with the uptake and maintenance of exercise programs. These findings will aid physical therapists in designing appropriate exercise programs for patients with CRF.

J. Blaney, BSc, is Physical Therapist and PhD candidate, Health and Rehabilitation Sciences Research Institute, University of Ulster, Newtownabbey, County Antrim, United Kingdom.

A. Lowe-Strong, PhD, is Senior Lecturer in Health Sciences, Health and Rehabilitation Sciences Research Institute, University of Ulster, and School of Health Sciences, University of Ulster.

J. Rankin, MSc, is Lead Oncology Physical Therapist, Cancer Centre, Belfast Health and Social Care Trust, Belfast, County Antrim, United Kingdom.

A. Campbell, PhD, is Exercise-Based Cancer Rehabilitation Specialist, Institute of Sport and Exercise, College of Life Sciences, University of Dundee, Dundee, United Kingdom.

J. Allen, PhD, is Pro-Vice Chancellor, Health and Rehabilitation Sciences Research Institute, University of Ulster.

J. Gracey, PhD, is Lecturer in Physical Therapy, Health and Rehabilitation Sciences Research Institute and School of Health Sciences, University of Ulster, Shore Road, Newtownabbey, County Antrim, BT37 0QB, United Kingdom. Address all correspondence to Dr Gracey at: jh.gracey@ulster.ac.uk.

[Blaney J, Lowe-Strong A, Rankin J, et al. The cancer rehabilitation journey: barriers to and facilitators of exercise among patients with cancer-related fatigue. *Phys Ther*. 2010;90:1135–1147.]

© 2010 American Physical Therapy Association



Post a Rapid Response to this article at:
ptjournal.apta.org

Cancer-related fatigue (CRF) is defined as “a persistent, subjective sense of physical, emotional, or cognitive tiredness or exhaustion related to cancer and cancer treatment that is not proportionate to activity and interferes with normal functioning.”¹ It is thought to affect between 70% and 100% of patients with cancer² and is commonly acknowledged as the most troublesome side effect of cancer and its treatment,^{3,4} which has a great impact on patients’ global quality of life (QoL).⁵ An interest in and drive to manage CRF have evolved over recent years, likely due to the realization of the scale and burden of CRF and the classification of cancer as a chronic illness⁶ within an aging population.⁷ Recent research has refuted previous recommendations of using rest as a management strategy for CRF due to its detrimental effects on the musculoskeletal system,^{8,9} cardiopulmonary fitness,¹⁰ and functional status¹¹ and has progressed to the opposite end of the continuum by advocating exercise and physical activity. Exercise has been the most studied management modality¹² and has shown positive results in decreasing fatigue^{13–16} and improving physical functioning,^{17–19} cardiopulmonary functioning,²⁰ and QoL status,^{15,21,22} thus counteracting the side effects induced by surgery and anti-cancer treatments.

Despite these positive findings, at least one third of patients with can-

cer decrease their levels of physical activity following diagnosis,²³ which often is not reinstated, even years after treatment has ended.²⁴ Additionally, a recent population-based study showed that up to 70% of patients with cancer were not meeting the US national recommendations for exercise.²⁵

Because many factors may influence this decline in physical activity and progression toward sedentary living, researchers have initiated the groundwork and begun to qualitatively explore the reasons behind this decline. Although existing research in this area provides some insight into this phenomenon, it remains at an early stage for several reasons. First, much of the research has focused on the barriers to and

facilitators of exercise among patients with breast cancer^{26–31} or colorectal cancer³² who were either exercising independently²⁷ or had participated in an exercise intervention trial.^{3,26,30,32,33} Such findings may not be transferable to the general population with cancer, as exercise does not currently appear as an integral part of cancer care.³⁴ Second, although CRF has been reported as one of the main barriers to exercise among patients with cancer,^{35–37} all of the aforementioned studies failed to recruit patients who were experiencing fatigue or failed to report whether they were experiencing fatigue at the time the research was conducted. Furthermore, although it is thought that fatigue intensity may vary by cancer stage,³⁸

The Bottom Line

What do we already know about this topic?

Despite evidence to suggest that participation in regular exercise can help manage cancer-related fatigue, few patients with cancer meet physical activity guidelines. The reasons behind this are not well understood. This study explored the barriers and facilitators of exercise participation among patients with cancer-related fatigue.

What new information does this study offer?

Barriers to exercise participation are interlinked and often stem from the side effects of cancer treatment. Fatigue and physical deconditioning were identified as major barriers that contributed to patients’ lack of interest in exercise and motivation to exercise, as well as their difficulties in exercise participation and in making exercise a routine. Facilitators of exercise included programs that were group-based, supervised, individualized, and gradually progressed.

If you’re a patient, what might these findings mean for you?

Identifying personal barriers and adopting practical strategies to overcome such barriers will aid exercise participation, which may ultimately decrease the experience of fatigue and physical deconditioning associated with a cancer diagnosis.



Available With
This Article at
ptjournal.apta.org

- [The Bottom Line Podcast](#)
- [Audio Abstracts Podcast](#)

This article was published ahead of print on June 17, 2010, at ptjournal.apta.org.

Table 1.
Interview Guide

Social Cognitive Theory Constructs ^a	Explanation of Constructs	Questions Based on the Social Cognitive Theory Constructs
Behavioral capability	Knowledge and skill required to take part in physical activity	What type of exercise or physical activity (eg, walking, cycling, swimming) did you enjoy in the past or at present? Do you think you could carry out this type of exercise or physical activity if having a bad day with fatigue?
Environment	External factors influencing physical activity	What do you feel are the main issues that would prevent you from exercising or taking part in a physical activity? Can anything be done to overcome these issues?
Self-efficacy	Confidence in a person's ability to take part in physical activity	If an exercise program were designed to suit your preferences and needs, how confident would you be in participating? Think back over the period from when you were diagnosed, through treatment, and up until now. When do you feel would be the ideal time to take part in an exercise program, if at all?
Expectations	Anticipatory outcomes of physical activity	What do you think the benefits of exercising would be?
Expectancies	Value of the outcome	What would be the most important exercise benefit for you personally?
Self-control and performance	Goal-directed behavior or performance	What exercise goals, if any, would you set for yourself at present? Why would these goals be important?
Reinforcement	Responses to a person's physical activity behavior that increase or decrease the likelihood of reoccurrence	How would you feel if you achieved your exercise goals? How would you motivate yourself to reach your goals (eg, rewards, benefit to health)?
Observational learning	Occurs by watching the outcome of others' behavior	What do you think could be gained through group exercise?

^a Social cognitive theory constructs adapted from Glanz et al.⁴¹

many of the aforementioned studies did not identify the staging of their samples.^{3,27,28,31}

Therefore, the aim of the current study was to address these important methodological issues by exploring the barriers to and facilitators of exercise among patients who were experiencing CRF and were representative of the cancer trajectory. We also aimed to elicit information that would assist oncology physical therapists and researchers with the future design and delivery of exercise programs for individuals with CRF.

Method

The data reported in this article were part of a broader qualitative study

that explored the overall experience of CRF and its impact on QoL.³⁹ This article, however, addresses the specific issues surrounding the barriers to and facilitators of exercise for patients with CRF.

To address the aims of the study, an exploratory, descriptive, qualitative design was undertaken, using focus groups as a data collection strategy. To ensure participants were representative of the cancer trajectory (ie, patients recently diagnosed with cancer, survivors of cancer, and patients in palliative care) and to gain multiple viewpoints, purposive sampling methods were used across 3 sites. Patients who were recently diagnosed and undergoing treatment

were recruited through the Regional Cancer Centre in Belfast. Survivors of cancer were those who had completed treatment and were members of a local supportive care charity. Patients in palliative care were recruited through a local hospice at a day therapy unit that provided multidisciplinary palliative care services. Eligible participants were those over 18 years of age, with a previous or current diagnosis of cancer, and who were identified as having CRF as defined by the National Comprehensive Cancer Network (NCCN).¹

Participants were asked to score their fatigue on the Oncology Nursing Society (ONS) Fatigue Scale. The ONS Fatigue Scale is a number or

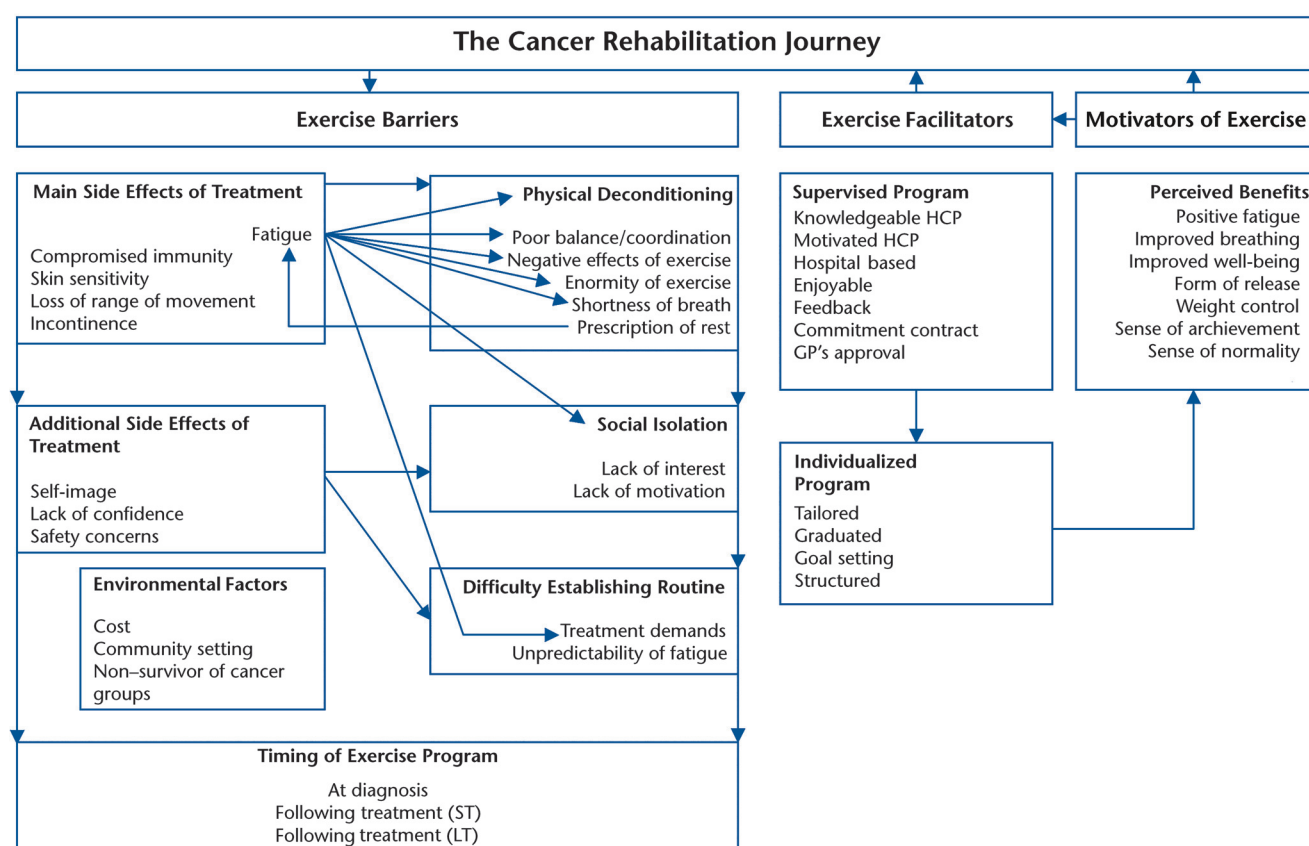


Figure.

The cancer rehabilitation journey. HCP=health care professional, GP=general practitioner, ST=short-term, LT=long-term.

picture visual analog scale ranging from 0 (“no fatigue”) to 10 (“the worst fatigue”) and categorizes fatigue as mild (1–3), moderate (4–6), or severe (7–10). To ensure participants were purely experiencing CRF, individuals diagnosed with a fatigue-related comorbidity (eg, multiple sclerosis, fibromyalgia, chronic fatigue syndrome) were excluded. Once interested individuals were screened for their eligibility, procedures of informed consent were undertaken. Those individuals who consented were invited to attend a focus group at the site from which they were recruited.

Prior to the focus group commencing, participants completed a short, investigator-developed questionnaire that gathered information on fatigue

intensity (ONS Fatigue Scale), frequency, demographic and medical information, and physical activity levels before and after diagnosis. For the duration of the focus groups, participants were seated in a circular format. Each focus group was conducted by an experienced and independent facilitator and audiorecorded. The first half of the discussions explored participants’ experience with CRF and its impact on QoL. Participants were asked “If you were to describe CRF to someone who knew nothing about it, what would you say?” and probing questions were used to elaborate on the important points raised. However, the focus of the current article is concerned with the second half of the focus groups, which used an interview guide (Tab. 1) to investigate the barriers to and facilitators of exercise. The

interview guide was based on social cognitive theory (SCT)⁴⁰ constructs as defined by Glanz et al⁴¹ and advocated by Rogers et al.³¹ Social cognitive theory is based on a model of triadic reciprocity in which behavioral, cognitive, and personal factors and environmental events all act as determinants of each other,⁴⁰ whereby self-efficacy is the central concept.⁴² Five focus groups were conducted to reach saturation: 2 with survivors of cancer, 2 with patients in palliative care, and 1 with patients who were recently diagnosed and undergoing treatment. Each focus group discussion lasted an average of 76 minutes (range=69–84), with 3 to 8 people in each group.

Data Analysis

Questionnaire data were input into the Statistical Package for the Social Sciences for Windows (version 14),* and descriptive statistics were generated. All audio recordings were transcribed verbatim and validated by a second researcher through direct comparisons of the audio recordings and the transcriptions. To add methodological rigor to the study and reduce researcher bias, independent analysis was carried out by both the first author and the focus group facilitator, and a consensus was reached. Data were analyzed manually using the constant comparative analysis of grounded theory, which involved the continual questioning of what was occurring in the data.⁴³ Such questioning allows the objectivity and sensitivity of the data to be upheld and reduces researcher bias.⁴³ During the initial process of open coding, transcripts were analyzed line by line, allowing the data to be fractured and identifying emerging lower-level concepts.⁴³ These concepts were highlighted and labeled within the text. Memos were used to record initial thoughts and ideas surrounding lower-level concepts as their properties and dimensions materialized. Axial coding (Figure) then allowed the data to be reassembled,⁴³ whereby lower-level concepts were extracted and conceptually grouped into subcategories and then categories. Following these procedures, selective coding was undertaken to examine the existing categories and their subcategories and arrive at a central theme or core category that provides a refined and integrated meaning to the relationships between the categories and the core category.⁴³ A summary of the findings was mailed to the participants, along with supporting quotations for their validation and comments. All participants who

Table 2.
Participant Demographic and Medical Information

Variable	Patients in Palliative Care (n=10)	Survivors of Cancer (n=12)	Patients Recently Diagnosed (n=4)	Total (N=26) n (%)
Occupation				
Clerical	1	5	2	8 (30.8)
Customer service	3	1	0	4 (15.4)
Managerial	1	2	0	3 (11.5)
Educational	0	2	1	3 (11.5)
Homemaker	2	1	0	3 (11.5)
Domestic service	2	0	0	2 (7.7)
Manual	1	0	1	2 (7.7)
Unemployed	0	1	0	1 (3.9)
Work status				
Retired	7	3	1	11 (42.3)
Long-term sick leave	2	3	3	8 (30.8)
Part-time	0	3	0	3 (11.5)
Full-time	0	2	0	2 (7.7)
Homemaker	1	1	0	2 (7.7)
Marital status				
Married	6	11	4	21 (80.9)
Single	2	1	0	3 (11.5)
Divorced	1	0	0	1 (3.8)
Widowed	1	0	0	1 (3.8)
Oncology Nursing Society Fatigue Scale				
Mild (1–3)	1	0	1	2 (7.7)
Moderate (4–6)	3	9	1	13 (50.0)
Severe (7–10)	6	3	2	11 (42.3)
Frequency of fatigue				
Every day	9	11	1	21 (80.9)
Every other day	1	0	2	3 (11.5)
Weekly	0	1	1	2 (7.7)
Cancer diagnosis				
Breast	4	6	2	12 (46.3)
Prostate	2	3	0	5 (19.3)
Colorectal	1	0	0	1 (3.8)
Cervical	1	0	0	1 (3.8)
Non-Hodgkin lymphoma	0	1	0	1 (3.8)
Lymphoma	1	2	0	3 (11.6)
Bladder	0	0	1	1 (3.8)
Leukemia	0	0	1	1 (3.8)
Information missing	1	0	0	1 (3.8)

(Continued)

* SPSS Inc, 233 S Wacker Dr, Chicago, IL 60606.

Table 2.

Continued

Variable	Patients in Palliative Care (n=10)	Survivors of Cancer (n=12)	Patients Recently Diagnosed (n=4)	Total (N=26) n (%)
Staging				
I	0	1	0	1 (3.8)
II	0	3	0	3 (11.5)
III	2	5	3	10 (38.5)
IV	7	1	0	8 (30.8)
Information missing	1	2	1	4 (15.4)
Treatment received				
Chemotherapy alone	1	1	1	3 (11.5)
Radiotherapy alone	2	3	0	5 (19.2)
Chemotherapy and radiotherapy	6	6	3	15 (57.7)
Information missing	1	2	0	3 (11.5)
Completion of treatment (mo)				
Undergoing treatment	3	0	4	7 (26.9)
<6	1	4	0	5 (19.2)
6–12	0	1	0	1 (3.8)
13–24	2	1	0	3 (11.5)
25–36	2	1	0	3 (11.5)
>48	1	3	0	4 (15.4)
Information missing	1	2	0	3 (11.5)

responded (n=14) agreed with the proposed findings.

Role of the Funding Source

This study was supported by the Department for Employment and Learning, Northern Ireland.

Results

A total of 26 participants with CRF (16 female, 10 male) took part in the study: 12 were survivors of cancer, 10 were patients in palliative care, and 4 were patients who were recently diagnosed and undergoing treatment. All participants were of Caucasian ethnicity, with a mean age of 55 years (range=39–83). Table 2 details participants' demographic and medical characteristics and the intensity and frequency of CRF experienced. Most participants had worked in a clerical (30.8%) or customer service (15.4%) environment

and were either retired (42.3%) or on long-term sick leave (30.8%). In terms of medical characteristics, there was a range of diagnoses and staging; however, most of the sample had been diagnosed with breast cancer (46.2%) and had either stage III (38.5%) or stage IV (30.8%) disease. The majority had been treated with a combination of chemotherapy and radiotherapy (57.7%), and the mean time since completion of treatment was 19.09 months (range=0–92). In terms of CRF, the mean score on the ONS Fatigue Scale was 6.23 (range=2–10), with most participants experiencing either moderate (50.0%) or severe (42.3%) fatigue on a daily basis (80.8%).

As detailed in Table 3, there were considerable changes in participants' physical activity levels pre-diagnosis to post-diagnosis. Before diagnosis,

61.5% of the participants were engaging in exercise 3 or more times per week, which is a stark contrast to after diagnosis, as only 19.2% of participants were managing this amount of activity. Similarly, 50.0% of the participants perceived themselves as "very active" before diagnosis, whereas none of the sample felt "very active" after diagnosis. The majority felt they were either "not active" (38.5%) or "a little active" (34.6%). These findings notwithstanding, 65.4% had managed to reinstate some level of physical activity.

From the qualitative data, 3 major categories emerged: (1) exercise barriers, (2) exercise facilitators, and (3) motivators of exercise, each linked to the core category of the cancer rehabilitation journey (Figure).

Quotations are provided in the text to highlight findings. The quotations are labeled with codes and identification numbers to ensure anonymity of the participants. Thus, patients in palliative care are coded as PC, survivors of cancer are coded as CS, and patients who were recently diagnosed and undergoing treatment are coded as RD.

Exercise Barriers

As an overview, the main barriers that participants reported generally could be linked back to the side effects of treatment (Figure). Fatigue and physical deconditioning were major exercise barriers that contributed to participants' feelings of social isolation and difficulty making exercise a routine and strongly influenced participants' opinions as to the most appropriate time to begin an exercise program following diagnosis. Other barriers were related to environmental factors such as cost and the lack of exercise facilities tailored to patients with cancer.

Table 3.

Pre-diagnosis and Post-diagnosis Physical Activity Levels of Patients

	Physical Activity Status	Patients in Palliative Care (n=10)	Survivors of Cancer (n=12)	Patients Recently Diagnosed (n=4)	Total (N=26) n (%)
Pre-diagnosis	Perceived activity				
	Not active	0	0	0	0
	A little active	0	1	0	1 (3.8)
	Average	2	4	0	6 (23.1)
	Above average	2	4	0	6 (23.1)
	Very active	6	3	4	13 (50.0)
	Frequency of activity (per week)				
	None	1	2	0	3 (11.5)
	1–2	3	4	0	7 (26.9)
	3–4	3	3	2	8 (30.8)
	5–7	2	3	2	7 (26.9)
	>7	1	0	0	1 (3.8)
Post-diagnosis	Perceived activity				
	Not active	4	5	1	10 (38.5)
	A little active	3	4	2	9 (34.6)
	Average	3	1	1	5 (19.2)
	Above average	0	2	0	2 (7.7)
	Very active	0	0	0	0
	Frequency of activity (per week)				
	None	5	3	1	9 (34.6)
	1–2	3	7	2	12 (46.2)
	3–4	0	1	1	2 (7.7)
	5–7	2	1	0	3 (11.5)
	>7	0	0	0	0

Main side effects of treatment.

The main side effects of surgery and anticancer treatments were fatigue, compromised immunity, skin sensitivity, loss of range of movement, and incontinence. Side effects of surgery mainly were associated with loss of range of upper-limb movement in the case of survivors of breast cancer and with the incontinence issues that surround survivors of prostate cancer after surgery or treatment. These incontinence issues were inferred by the male participants in the group rather than being spoken about openly, which likely was due to their embarrassment at female participants being present. Such findings suggest that certain exercise barriers may be

cancer- and sex-specific. Some participants also suggested they were limited in the type of exercise they could choose, in particular swimming, due to skin sensitivity following radiotherapy and a compromised immune system as a result of chemotherapy. The main barrier to exercise, however, was the overwhelming and debilitating physical sensation of CRF, which the participants described as “a complete shutdown,” “weakness,” “exhaustion,” “unrelenting,” and “uncontrollable.” Although the participants could identify the enjoyment and benefits attached to exercise, they quickly emphasized the limitations that fatigue had placed on them in terms of physical activity. The follow-

ing excerpts demonstrate that these limitations were apparent across all subgroups.

You say to yourself, “Well, I should be doing this [exercise]” . . . you see to get up out of the chair and do it (puffs). (PC2)

I walked continually, all of the time. . . . I loved walking, and I went to Curves (female-only gym) 2 or 3 times a week. . . . I could hardly walk 5 minutes now. (CS5)

. . . the energy you know it takes to even get up and get ready in the morning. (RD1)

Additional side effects of treatment. Many participants expressed a lack of confidence regarding their self-image and identity following surgery. Survivors of breast cancer were particularly self-conscious about wearing prostheses in public, which they felt also limited their choice of exercise (eg, swimming, aerobics, gym). This was a similar situation for survivors of prostate cancer, as incontinence issues imposed both social and physical limitations regarding exercise. Lack of confidence also was apparent with regard to safety and fear of falling. This lack of confidence was inherently linked to physical deconditioning and was particularly evident among patients in palliative care, many of whom described difficulties with their mobility and balance, experienced shortness of breath, or simply lacked confidence to exercise independently.

I find now that I'm not really having the confidence to walk *on my own*. (PC2)

Across all subgroups, there was a lack of motivation, which also was associated with fatigue and physical deconditioning. For some participants, this was a battle between the mind and body, as there was a desire to be active but also an urge to give in to the overwhelming sensation of fatigue.

Well, the heart is willing [to exercise], but the flesh is weak, so that's really what it boils down to. (PC3)

This lack of motivation, coupled with the existing aforementioned barriers, made the thought of exercising a daunting task. Some participants even found it difficult to have an interest in anything, particularly things they would have previously enjoyed, making it more difficult to instigate new and even old exercise behaviors.

You knew what you were like [before having fatigue], you were active, you

were into things, you had a bit of a particular interest, a particular hobby. Now, you find . . . you can't be bothered. (PC3)

Physical deconditioning. All participants in this study experienced some form of physical deconditioning, which most likely was a result of their experiences of fatigue and decline in physical activity (Tab. 3). Physical deconditioning was highlighted through their comparisons of their previous and current physical abilities and their descriptions of low exercise tolerance levels. This physical deconditioning was further emphasized as even the simplest of activities proved extremely difficult, and engaging in these activities often had repercussions.

I walked everywhere, I loved walking, you know. I pay for it [now], if I go [for] a walk one day, the next day I'm in bed. (CS1)

Many participants used rest and sleep as a means of coping with fatigue, and others had been advised to rest by a health care professional. Furthermore, the recommendation of rest would have presented itself as an additional exercise barrier. As outlined in the previous quotation (CS1), some participants reported having negative side effects following exercise, such as increased levels of fatigue and muscle soreness. Such side effects were handled predominantly by taking further rest, which would have had a counterproductive effect on any health gains obtained, or for some participants, would have created fear-avoidance behaviors.

I think that's what puts me off exercise, [be]cause I know how I am going to feel afterwards. (CS3)

There was a general consensus among patients in palliative care as to the enormous challenge that exercise presented. For some of these participants, exercise was classed as

walking "from the back to the front door" (PC6). Other participants summarized it as "a battle, sounds like a whole day's work" (PC7), that they would not contemplate: "I know at times . . . I know how I feel, you wouldn't even consider it [exercise]" (PC3).

Environmental factors and difficulty establishing routine. As many of the participants in this study were either retired or on long-term sick leave, the cost of using facilities at a leisure center posed as an additional barrier, in particular for those patients who were recently diagnosed. The participants further expressed that such leisure facilities were not tailored toward patients with cancer. Additionally, they emphasized the possibility of not being able to routinely avail themselves of a gym membership, due to fatigue and its unpredictability and their physically deconditioned state.

I couldn't afford to join a gym and . . . not only to use half of the equipment but, there's days that I just couldn't go, I might be weak. (RD4)

What you can achieve one day, you might not the next, you know every day could be different. (CS2)

Such statements highlight the difficulty patients with CRF may face in initiating and maintaining exercise. Furthermore, recently diagnosed patients and some survivors of cancer expressed that the acute side effects of treatment and attending treatment appointments, in particular consecutive radiotherapy sessions, could interfere with an exercise regimen.

Timing of introduction to exercise. There were conflicting views across subgroups as to the ideal time to initiate an exercise program. Most of the patients who were recently diagnosed and some survivors of cancer suggested that during and up to a year following treatment would be

an inappropriate time to initiate or commit to exercise. This view was mainly attributed to their fatigue and physical deconditioning.

It definitely would've been a good year before I'd of been fit for any exercise at all. (CS6)

In contrast to this view, the remaining survivors of cancer and some of patients in palliative care tended to advocate an earlier start, either at diagnosis or in the shorter term following treatment, with emphasis placed on the physical and psychological benefits they felt could be gained from exercise.

Exercise Facilitators

Supervised, individualized, group-based exercise program. Almost all participants emphasized that an exercise program should be supervised by a trained health care professional, whereby they could avail themselves of the health care professional's knowledge, guidance, and feedback, and in particular the professional's motivational support.

I think it's hard to do on your own. . . . I suppose you need somebody to give you a prod or you need somebody to tell you, "Yes, you're right," and "Yes, you should be doing this" and to work with you maybe. (CS3)

These facilitators seemed to offer assurance that they would not be prescribed exercise that would prove detrimental to them. This assurance of their well-being echoed through to their ideal exercise setting, as many participants advocated a hospital-based exercise program. Most participants stated they would prefer to exercise with other patients with cancer, as they would have undergone a similar path since diagnosis and treatment and be of similar fitness levels. These factors would provide an opportunity for peer support, shared experiences, a sense of belonging, and subjective norms.

If I went to a normal class, I would feel very peculiar . . . and I think you need to feel that you are surrounded by people that at least have some idea . . . of what you are going through. (CS2)

Conversely, due to the aforementioned incontinence issues, some survivors of prostate cancer indicated that group exercise would not be appropriate for them. Exercising was something they preferred to do at home, but with some professional input and support. Participants across all subgroups placed great emphasis on the need for an exercise program to be tailored to the individual according to his or her abilities, age, and medical or treatment variables. They also added that any exercise should be gradually progressed and include realistic goal setting. Additionally, some survivors of cancer suggested that setting up a patient/professional commitment contract would oblige them to regularly attend an exercise program.

Motivators of Exercise

Perceived benefits of exercise. All participants could identify the potential benefits of exercise, from both previous and current experiences. Due to the many side effects of treatment, but in particular fatigue, participants wanted to gain a sense of achievement and regain a sense of normality. They recognized exercise as a potential way of delivering these benefits and a progression away from their illness and toward recovery.

That feeling of achievement when you do something like that, like walk half a mile to the petrol station or cycle round the block, it's an enormous sense of achievement when you're sick like this. (RD2)

I loved walking, I mean that was always my . . . one escape from everything . . . I suppose it was *being normal* you know, like you want to be normal again. (CS5)

Interestingly, although participants earlier identified the negative side effects of exercise and endorsed them as exercise barriers, they could identify the positive side effects of exercise and associated them with being motivational. Many participants discussed the positive impact previous exercise had on their physical and mental well-being and viewed the fatigue associated with exercise as a pleasant and more "normal" or natural experience, compared with that of CRF.

Many participants across all subgroups had gained weight since being diagnosed with cancer. Interestingly, they attributed their weight gain to being a side effect of chemotherapy, as opposed to a decline in their physical activity levels. The participants, however, expressed that exercise could act as a means of losing weight and thus give them the motivation to exercise. Additional exercise motivators were improved breathing, improved well-being, and decreased stress or form of release.

Discussion

Exercise Barriers

This qualitative study gives a unique insight into the barriers to and facilitators of exercise from the perspective of patients who were recently diagnosed and undergoing treatment, survivors of cancer, and patients in palliative care, all of whom had CRF. It is evident from our findings that the main barriers to exercise can be attributed to the side effects of treatment, in particular fatigue, which supports previous research findings.^{3,27-29,31,35}

Few of the exercise barriers described by the participants in this study can be isolated from each other; rather, they are interlinked and can have a ripple effect (Figure). Fatigue was at the center of the majority of barriers experienced by the participants; this finding was partic-

ularly evident within the subcategory of physical deconditioning. The combination of fatigue and participants' feeling physically deconditioned undoubtedly contributed to the decline in their physical activity levels from before diagnosis to after diagnosis. This decline in physical activity may have contributed to the negative side effects of exercise, breathlessness, and balance problems experienced by the participants. The experience of fatigue, physical deconditioning, and the decline in physical activity levels can become cyclical events,⁴⁴ exacerbated by the fact the participants used or were advised to use rest and sleep as a management strategy. Prolonged rest and sleep can contribute to muscle deconditioning and disuse atrophy,⁸ causing increased effort and sensations of fatigue.⁴⁵ Winningham et al¹¹ summarized this relationship through their psychobiological-entropy model, whereby a combination of pre-existing conditions, environmental influences, and cancer and its treatment can lead to decreased activity, secondary fatigue, and decreased functional status, which ultimately can lead to disability. The fact that none of the participants in this study had been given any appropriate advice on how to manage fatigue highlights how such events could easily become a reality for patients with CRF.

Overcoming barriers such as fatigue and physical deconditioning presented an enormous challenge to participants that obviously could have had a negative impact on their interest and motivation to exercise. Lack of motivation to exercise has been previously reported as an exercise barrier among patients with cancer.^{27,29} Smets and colleagues⁴⁶ recognized reduced activity and reduced motivation as 2 of the 5 dimensions of CRF (ie, general fatigue, physical fatigue, reduced activity,

reduced motivation, and mental fatigue).

Further complicating the scenario, participants felt that they would find difficulty in making exercise a routine part of their lives, especially due to the unpredictability of fatigue and the variability of its intensity from day to day. Additionally, participants who were undergoing treatment and some survivors of cancer felt that initiating and maintaining an exercise regimen would prove too difficult while coping with the side effects of treatment and attending regular treatments and review appointments.

Taking these barriers into consideration then poses the question as to the most appropriate time for patients to initiate exercise. A systematic review carried out by Cramp and Daniel⁴⁷ showed that there was statistically significant reduction in fatigue with patients both during and following treatment. Considering the participants' varied opinions surrounding this timing issue, the most obvious resolution is to offer an exercise program to patients in all phases of care, which can be accessed when they feel it is appropriate. This approach has been advocated by the NCCN,⁴⁸ whose guidelines recommend that physical activity enhancement should be available to patients from the commencement of treatment to end of life.

Environmental factors such as the cost and feasibility of exercising in local leisure centers, plus the fact that the participants felt there was a lack of specialized exercise services available to them, raise additional barriers to exercise initiation and maintenance. Cost has been reported previously as an exercise barrier³¹ and presents itself as a major issue. Like many participants in this study, patients who have been re-

cently diagnosed, survivors of cancer, and patients in palliative care within our society may be forced to take long-term sick leave or retirement, which can have a direct impact on their financial situation. Bennett et al⁴⁹ conducted a questionnaire survey with survivors of cancer to assess their changes in employment and household income following a diagnosis of cancer. They found that 40% of the respondents reduced their working hours or quit working as a result of their cancer diagnosis or side effects of treatment. Furthermore, a decrease in household income was reported by 37% of the respondents. These findings make explicit the barriers associated with the cost of joining a gym or using leisure center facilities, and they further support the recommendation of the NCCN guidelines⁴⁸ that exercise programs for patients with CRF should be routinely available as part of their package of care.

Exercise Facilitators

Taking into account the aforementioned barriers to exercise for patients with CRF, it is interesting, yet not surprising, that participants' exercise facilitators were the polar opposite of their barriers. Participants felt strongly that an exercise program should be delivered by a specially trained health care professional and held within a hospital setting. These findings have been reported in previous studies^{3,28,31} and indicate that such requirements would assist participants with overcoming the barriers associated with the side effects of treatment, physical deconditioning, and environmental factors and allay fears surrounding safety issues. Furthermore, participants suggested these exercise programs should be tailored to the individual and gradually progressed. These factors may help avoid the negative side effects of exercise that many participants had experienced previously and would ensure fear-avoidance be-

haviors did not develop. Because participants felt that lack of motivation and the additional side effects of treatment such as lack of confidence and self-image issues were major barriers, they required a program to be conducted with other patients with cancer, of similar abilities and with whom they could share their experiences. Group support has been reported as an exercise facilitator, as it generates friendship, solidarity,^{26,30,33} and feelings of belonging and subjective norms.³⁰

Overall, the facilitators of exercise described suggest that patients with CRF require much support and guidance when it comes to initiating exercise and changing behaviors. Physical therapists working in oncology and palliative care are ideally placed and have the core skills to design and deliver exercise programs to help patients manage their fatigue and thus improve their functional status and QoL. Donnelly et al⁵⁰ recently conducted a survey of UK physical therapists working in oncology and palliative care to establish physical therapists' knowledge and management of CRF. The authors found that although physical therapists recognize CRF as a major problem and many therapists are using exercise as a management strategy, physical therapists themselves face barriers in prescribing exercise. The main barriers reported were: a lack of exercise guidelines for patients with CRF, patients' family and friends advising rest, poor exercise adherence among patients, limited time with patients, and a lack of patient referral for physical therapy. These findings suggest that both patients with CRF and physical therapists would benefit from the development of exercise guidelines.

Motivators of Exercise

The motivators of exercise that were identified by the participants were encouraging, as these were actually

their perceived benefits of exercise. Realizing that exercise provides a means of escapism and induces feelings of physical and mental well-being that would assist them in achieving a sense of normality and progression from illness are important factors in the promotion of exercise among patients with CRF. Previous studies^{32,33} have shown that the perceived benefits of exercise, such as managing fatigue, were the main reasons for initiating exercise programs. As a result, we propose that although patients with CRF have many unique barriers to exercise, these barriers could be dispersed if their exercise facilitators were in place. Furthermore, such exercise facilitators could help patients achieve the benefits of exercise identified by the participants in this study, and knowledge of the benefits of exercise could act as an exercise motivator.

Disease and Sex-Specific Issues

Using a mixed sample of cancer diagnoses and staging proved beneficial within this study, as it highlighted variations in the side effects of treatment. This finding raises several issues regarding exercise programs for patients of mixed sexes and mixed diagnoses. First, research carried out by Adamsen et al³³ detailed the benefits of sex-specific exercise groups among male patients, as they allow the development of comradeship, "male trust," and action-oriented togetherness. The issues surrounding incontinence for survivors of prostate cancer in the current study support the findings of Adamsen and colleagues.³³ The barrier of decreased range of movement, which was specific to the survivors of breast cancer, further supports the fact the barriers often may be disease specific. Second, patients who had received chemotherapy had additional barriers of immunosuppression; whereas those who had radiotherapy raised issues

of skin sensitivities that they felt would place restrictions on the use of certain exercise modalities.

The lack of confidence regarding self-image or identity reported by the survivors of breast cancer may further suggest the need for disease- or sex-specific exercise groups. Emslie and colleagues²⁶ reported that setting up a specialized exercise program specifically for survivors of breast cancer helped to dismantle sex-related barriers and empowered patients to exercise without feeling self-conscious. Perhaps this is the only realistic option to obtain patient satisfaction and produce an effective exercise program that is, in the first instance, appealing to patient subgroups, and in the longer term, maintainable. Pragmatically, although this option creates major challenges, considering the spectrum of cancer diagnoses and those that are indiscriminate of sex. Further complicating the situation, group exercise is not suitable or appealing to every individual.

Limitations

Although this study addressed some of the methodological issues of previous qualitative studies, there are several limitations. First, the participants were a convenience sample of patients with CRF, and when the sample was separated into the trajectory subgroups, the sample sizes were relatively small. Second, the majority of the sample were patients with stage III or stage IV breast cancer, with minimal representation of other cancer diagnoses and staging. Furthermore, all participants were white, with no representation from other ethnic groups. As a result, the findings of this study may not be transferable to the general population with cancer. Future qualitative studies should aim to include a wide range of cancer diagnoses and stages and include participants with varied ethnic backgrounds. Finally, taking

into account the aforementioned limitations, the sex-specific issues raised in this study should be handled tentatively. Participants did not state explicitly that they would prefer sex-specific exercise groups; this was more implied by the participants and is an interpretation on the part of the authors. However, these issues warrant further exploration with both sexes.

Conclusions

The findings of this study highlight the barriers that patients with CRF may face in initiating and maintaining exercise. These barriers are mainly attributed to the side effects of treatment, in particular fatigue; however, most barriers are not experienced in isolation, and many can cause a ripple effect, creating additional exercise barriers. On a positive note, however, the participants in this study could identify the benefits of exercise, which may well act as an exercise motivator. Furthermore, the participants offered solutions to their own barriers in the form of exercise facilitators. Physical therapists have the core skills required to deliver the exercise facilitators described by the participants, especially tailoring an exercise program to an individual's ability and level of functioning, graduating an exercise program according to the progress made, and setting short-term and long-term goals, thus giving patients structure, targets, and the sense of achievement and normality that many desired. When designing exercise programs for patients with CRF, physical therapists and researchers in this area should be mindful of variables such as stage of disease, treatment protocols, side effects of treatment, exercise tolerance, and physical abilities, as well as sex-specific issues, personal exercise barriers, facilitators, and motivators.

Ms Blaney, Ms Rankin, and Dr Gracey provided concept/idea/research design. Ms

Blaney, Dr Lowe-Strong, Ms Rankin, Dr Campbell, and Dr Gracey provided writing. Ms Blaney provided data collection. Ms Blaney and Dr Gracey provided data analysis. Ms Blaney, Dr Lowe-Strong, and Dr Gracey provided project management. Dr Lowe-Strong, Prof Allen, and Dr Gracey provided fund procurement. Ms Rankin provided participants. Ms Rankin and Dr Gracey provided facilities and equipment. Ms Rankin, Dr Campbell, and Dr Gracey provided institutional liaisons. All authors provided consultation (including review of manuscript before submission).

The authors thank the staff at all 3 sites for their assistance with recruitment and the participants for giving so freely of their time and experiences.

Ethical approval was granted by the Research Governance Office at the Regional Cancer Centre and the Office for Research Ethics, Northern Ireland (April 2007).

A poster presentation was given at the annual international symposium of the Multinational Association of Supportive Care in Cancer; June 26–28, 2008; Houston, Texas.

This study was supported by the Department for Employment and Learning, Northern Ireland.

This article was submitted August 24, 2009, and was accepted April 18, 2010.

DOI: 10.2522/ptj.20090278

References

- 1 National Comprehensive Cancer Network (NCCN). NCCN clinical practice guidelines in oncology: cancer-related fatigue V.1; 2006. Available at: http://www.nccn.org/professionals/physician_gls/PDF/fatigue.pdf. Accessed October 12, 2006.
- 2 Alberg K, Ekman T, Gaston-Johansson F, Mock V. Assessment and management of cancer-related fatigue in adults. *Lancet*. 2003;362:640–650.
- 3 Coon SK, Coleman EA. Keep moving: patients with myeloma talk about exercise and fatigue. *Oncol Nurs Forum*. 2004;31:1127–1135.
- 4 Ganz P. Monitoring the physical health of cancer survivors: a survivorship-focused medical history. *J Clin Oncol*. 2006;24:5105–5111.
- 5 Hartvig P, Aulin J, Hugerth M, et al. Fatigue in cancer patients treated with cytotoxic drugs. *J Oncol Pharm Pract*. 2006;12:155–164.
- 6 Patrick DL, Ferketich SL, Frame PS, et al. National Institutes of Health State-of-the-Science Conference Statement: symptom management in cancer: pain, depression, and fatigue, July 15–17, 2002. *J Natl Cancer Inst Monogr*. 2004;32:9–16.

- 7 Yancik R. Population aging and cancer: a cross-national concern. *Cancer J*. 2005;11:437–441.
- 8 Germain P, Guell A, Marini JF. Muscle strength during bed rest with and without muscle exercise as a countermeasure. *Eur J Appl Physiol*. 1995;71:342–348.
- 9 Greenleaf JE, Kozlowski S. Physiological consequences of reduced physical activity during bed rest. *Exerc Sport Sci Rev*. 1982;10:84–119.
- 10 Levine BD, Zuckerman JH, Pawelczyk JA. Cardiac atrophy after bed-rest deconditioning: a nonneural mechanism for orthostatic intolerance. *Circulation*. 1997;96:517–525.
- 11 Winningham ML, Nail LM, Burke M, et al. Fatigue and the cancer experience: the state of the knowledge. *Oncol Nurs Forum*. 1994;21:23–36.
- 12 Manzullo E, Liu W, Escalante C. Treatment for cancer-related fatigue: an update. *Expert Rev Anticancer Ther*. 2003;3:99–106.
- 13 Dimeo F, Schwartz S, Wesel N, et al. Effects of an endurance and resistance exercise program on persistent cancer-related fatigue after treatment. *Ann Oncol*. 2008;19:1495–1499.
- 14 Mock V, Dow KH, Meares CJ, et al. Effects of exercise on fatigue, physical functioning, and emotional distress during radiation therapy for breast cancer. *Oncol Nurs Forum*. 1997;24:991–1000.
- 15 Mock V, Pickett M, Ropka ME, et al. Fatigue and quality of life outcomes of exercise during cancer treatment. *Cancer Pract*. 2001;9:119–127.
- 16 Pinto BM, Frierson GM, Rabin C, et al. Home-based physical activity intervention for breast cancer patients. *J Clin Oncol*. 2005;23:3577–3587.
- 17 Windsor PM, Nicol KF, Potter J. A randomised, controlled trial of aerobic exercise for treatment-related fatigue in men receiving radical external beam radiotherapy for localized prostate carcinoma. *Cancer*. 2004;101:550–557.
- 18 Mock V, Frangakis C, Davidson NE, et al. Exercise manages fatigue during breast cancer treatment: a randomised controlled trial. *Psychooncology*. 2005;14:464–477.
- 19 Segal R, Evans W, Johnson D, et al. Structured exercise improves physical functioning in women with stages I and II breast cancer: results of a randomized controlled trial. *J Clin Oncol*. 2001;19:657–665.
- 20 Kim CJ, Kang DH, Smith BA, Landers KA. Cardiopulmonary responses and adherence to exercise in women newly diagnosed with breast cancer undergoing adjuvant therapy. *Cancer Nurs*. 2006;29:156–165.
- 21 Knols R, Aaronson NK, Uebelhart D, et al. Physical exercise in cancer patients during and after medical treatment: a systematic review of randomized and controlled trials. *J Clin Oncol*. 2005;23:3830–3842.
- 22 Mutrie N, Campbell A, Whyte F, et al. Benefits of supervised group exercise programme for women being treated for early stage breast cancer: pragmatic randomised controlled trial. *BMJ*. 2007;334:517.

- 23 Blanchard CM, Denniston MM, Baker F, et al. Do adults change their lifestyle behaviors after a cancer diagnosis. *Am J Health Behav*. 2003;27:246-256.
- 24 Courneya KS, Friedenreich CM. Utility of the theory of planned behavior for understanding exercise during breast cancer treatment. *Psychooncology*. 1999;8:112-122.
- 25 Blanchard CM, Courneya KS, Stein K. Cancer survivors' adherence to lifestyle behavior recommendations and associations with health-related quality of life: results from the American Cancer Society's SCS-II. *J Clin Oncol*. 2008;26:2198-2204.
- 26 Emslie C, Whyte F, Campbell A, et al. "I wouldn't have been interested in just sitting around a table talking about cancer": exploring the experiences of women with breast cancer in a group exercise trial. *Health Educ Res*. 2007;22:827-838.
- 27 Hennessey EM, Stevinson C, Fox KR. Preliminary study of the lived experience of exercise for cancer survivors. *Eur J Oncol Nurs*. 2005;9:155-166.
- 28 Leddy SK. Incentives and barriers to exercise in women with a history of breast cancer. *Oncol Nurs Forum*. 1997;24:885-890.
- 29 Milne HM, Guilfoyle A, Gordon S, et al. Personal accounts of exercise and quality of life from the perspective of breast cancer survivors. *Qual Life Res*. 2007;16:1473-1481.
- 30 Midtgaard J, Rorth M, Stelter R, Adamsen L. The group matters: an explorative study of group cohesion and quality of life in cancer patients participating in physical exercise intervention during treatment. *Eur J Cancer Care (Engl)*. 2006;15:25-33.
- 31 Rogers LQ, Matevey C, Hopkins-Price P, et al. Exploring social cognitive theory constructs for promoting exercise among breast cancer patients. *Cancer Nurs*. 2004;27:462-473.
- 32 Adamsen L, Midtgaard J, Roerth M, et al. Transforming the nature of fatigue through exercise: qualitative findings from a multidimensional exercise programme in cancer patients undergoing chemotherapy. *Eur J Cancer Care (Engl)*. 2004;13:362-370.
- 33 Adamsen L, Rasmussen JM, Pedersen LS. "Brothers in arms": how men with cancer experience a sense of comradeship through group intervention which combines physical activity with information relay. *J Clin Nurs*. 2001;10:528-537.
- 34 Markes M, Brockow T, Resch KL. Exercise for women receiving adjuvant therapy for breast cancer. *Cochrane Database Syst Rev*. 2006;4:CD005001.
- 35 Courneya KS, Friedenreich CM, Quinney HA, et al. A longitudinal study of exercise barriers in colorectal cancer survivors participating in a randomized controlled trial. *Ann Behav Med*. 2005;29:147-153.
- 36 Courneya KS, McKenzie DC, Reid RD, et al. Barriers to supervised exercise training in a randomized controlled trial of breast cancer patients receiving chemotherapy. *Ann Behav Med*. 2008;35:116-122.
- 37 Rogers LQ, Courneya KS, Robbins KT, et al. Physical activity correlates and barriers in head and neck cancer patients. *Support Care Cancer*. 2008;16:19-27.
- 38 Hwang SS, Chang VT, Rue M, et al. Multidimensional independent predictors of cancer-related fatigue. *J Pain Symptom Manage*. 2003;26:604-614.
- 39 Blaney J, Rankin J, Lowe-Strong A, et al. Cancer-related fatigue: the barriers and facilitators to exercise across the cancer trajectory. *Support Care Cancer*. 2008;16:648.
- 40 Bandura A. *Social Foundations of Thought and Action*. Upper Saddle River, NJ: Prentice Hall Inc; 1986.
- 41 Glanz K, Lewis FM, Rimer BK. *Health Behaviour and Health Education, Theory, Research and Practice*. San Francisco, CA: Wiley; 1997.
- 42 Marcus B, King TK, Clark MM, et al. Theories and techniques for promoting physical activity behaviours. *Sports Med*. 1996;22:321-331.
- 43 Strauss A, Corbin J. *Basics of Qualitative Research*. London, United Kingdom: Sage Publications; 1998.
- 44 Lucia A, Earnest C, Perez M. Cancer-related fatigue: can exercise physiology assist oncologists? *Lancet Oncol*. 2003;4:616-625.
- 45 al-Majid S, McCarthy DO. Cancer-induced fatigue and skeletal muscle wasting: the role of exercise. *Biol Res Nurs*. 2001;2:186-197.
- 46 Smets EM, Garssen B, Bonke B, de Haes JC. The Multidimensional Fatigue Inventory (MFI): psychometric qualities of an instrument to assess fatigue. *J Psychosom Res*. 1995;39:315-325.
- 47 Cramp F, Daniel J. Exercise for the management of cancer-related fatigue in adults. *Cochrane Database Syst Rev*. 2008;2:CD006145.
- 48 National Comprehensive Cancer Network (NCCN). NCCN clinical practice guidelines in oncology: cancer-related fatigue V.1; 2009. Available at: http://www.nccn.org/professionals/physician_gls/PDF/fatigue.pdf. Accessed June 1, 2009.
- 49 Bennett JA, Brown P, Cameron L, et al. Changes in employment and household income during the 24 months following a cancer diagnosis. *Support Care Cancer*. 2009;17:1057-1064.
- 50 Donnelly CM, Lowe-Strong A, Rankin JP, et al. Physiotherapy management of cancer-related fatigue: a survey of UK current practice. *Support Care Cancer*. 2009 Aug 23 [Epub ahead of print].