

Keep Moving: Patients With Myeloma Talk About Exercise and Fatigue

Sharon K. Coon, PhD, RN, AOCN®, and Elizabeth Ann Coleman, PhD, RNP, AOCN®

Purpose/Objectives: To learn about the feelings, beliefs, and experiences of patients with multiple myeloma implementing an exercise program in the context of an aggressive tandem peripheral stem cell transplant protocol.

Research Approach: Qualitative naturalistic (constructionist).

Setting: International referral center for the treatment of multiple myeloma.

Participants: Purposive nonprobability sample of 12 men and 9 women with multiple myeloma aged 38–70 enrolled in the exercise arm of a randomized trial of epoetin alfa with or without exercise as an intervention to decrease cancer-related fatigue.

Methodologic Approach: Verbatim transcripts of tape-recorded, in-depth interviews analyzed for thematic content using content analysis and constant comparison.

Findings: Themes included (a) belief systems, which encompassed participants' beliefs about exercise and epoetin alfa, philosophy, and self-concept, (b) social context, which included life before cancer, social environment, and social system congruence, and (c) intersection between belief systems and social context, which were participants' experience appraisals. All participants believed that exercise could be helpful and would recommend exercise to other patients with cancer in a similar situation. Most believed that lack of activity contributed to decreased energy.

Main Research Variable: Patients' experience of implementing exercise in the context of treatment for multiple myeloma.

Conclusions: Complex interactions between participants' beliefs and social context and experience appraisal influenced their ability to adhere to an exercise program during aggressive treatment for multiple myeloma.

Interpretation: Through careful assessment, clinicians can capitalize on belief and social systems that support adherence to exercise as an intervention to ameliorate fatigue for patients with cancer who are undergoing prolonged aggressive treatment.

Multiple myeloma is a B cell malignancy of the plasma cells of the immune system. Approximately 45,000 Americans are living with the disease (Multiple Myeloma Research Foundation, 2002) and 15,270 are expected to be diagnosed in 2004 (American Cancer Society, 2004). In multiple myeloma, aberrant plasma cells make large numbers of monoclonal antibodies that crowd out normal immune and blood-forming cells in the bone marrow, leading to frequent infections and anemia. These abnormal antibodies also cause increased osteoclastic activity in the bone that leads to the most common presenting symptoms of bone pain and fractures (Lokhorst, 2002).

Patients with multiple myeloma undergoing conventional treatment have a median survival of less than three years (Barlogie et al., 1997). Tandem autologous peripheral blood stem cell transplantation (PBSCT) significantly improves the chance for partial or complete remissions and longer survival with the possibility that some patients may be considered cured (Tricot et al., 2002). This is a remarkable advance in

Key Points . . .

- ▶ Patients with multiple myeloma can safely carry out a home-based exercise program aimed at reducing cancer-related fatigue.
- ▶ Commitment to keeping their promise to exercise helped participants to continue their exercise program during times when they were not feeling well.
- ▶ Encouragement from family and healthcare professionals facilitates adherence to an exercise program.
- ▶ Many participants avoided taking time off from exercise because they had experienced dramatic declines in their strength and stamina after interruptions to their exercise program. However, most patients needed to reduce the exercise intensity or take time off from exercise immediately following chemotherapy.

the outlook for a disease that until recently was considered incurable. However, the aggressive phase of the treatment lasts nearly a year, and maintenance therapy, which includes interferon α , continues for another year. All patients undergoing such an aggressive treatment protocol can expect to experience cancer-related fatigue (CRF); therefore, early intervention and management are important in maintaining patients' functional status and quality of life.

Cancer-Related Fatigue

Fatigue is widely regarded as one of the most pervasive and distressing consequences of cancer and cancer treatment. CRF can affect virtually all aspects of patients' lives (Curt, 2000). For patients undergoing bone marrow or stem cell transplants for hematologic malignancies, studies suggest that

Sharon K. Coon, PhD, RN, AOCN®, is a clinical assistant professor in the College of Nursing and Arkansas Cancer Research Center, and Elizabeth Ann Coleman, PhD, RNP, AOCN®, is a professor in the College of Nursing and College of Medicine, both at the University of Arkansas for Medical Sciences in Little Rock. Funding from an American Nurses Foundation; Ada Sue Hinshaw, RN, Scholar Award; American Cancer Society Doctoral Scholarship in Cancer Nursing; and Cornelia Beck Gerontology Research Award supported this study. The Arkansas Cancer Research Center at the University of Arkansas for Medical Sciences contributed partial salary support. (Submitted June 2003. Accepted for publication October 1, 2003.) (Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Forum or the Oncology Nursing Society.)

Digital Object Identifier: 10.1188/04.ONF.1127-1135

CRF can last months or even years beyond recovery (Neitzert et al., 1998). Coleman, Coon, Mattox, and O'Sullivan (2002) conducted a retrospective chart review of 87 patients with multiple myeloma who had received autologous PBSCT as outpatients. They found a significant association ($F = 4.35$, $p = 0.017$) between patients' reports of fatigue (as a percent of usual energy) and unplanned hospital admission. This finding is of particular interest because high fevers and positive blood cultures, although present, failed to show a significant association with unplanned admission.

CRF emerged as a research priority in the early 1990s. Since then, a plethora of literature has addressed the issues of etiology, definition, and measurement. Because of the multidimensionality of CRF, a core etiology, a single definition, or a gold standard for measurement is unlikely to be forthcoming in the near future, if ever (Nail, 2002; Varricchio, 2000). In the absence of a single definitive cause, interventions aimed at specific contributing factors have been incorporated into guidelines for assessment and treatment of CRF. The nonpharmacologic intervention that has received the most attention and evidence-based support is exercise (National Comprehensive Cancer Network [NCCN], 2004).

The rather counterintuitive idea that exercise would help to relieve CRF has gained support since Aistars (1987) published one of the early conceptual models of CRF. Aistars conceptualized exercise as an energy conservation strategy based on the idea that physiologic and psychological adaptations occur in response to exercise and improve activity tolerance. However, Aistars noted that rest was still the dominant recommendation for managing fatigue because clinicians and families assumed that patients with cancer could not tolerate exercise and, even if they could, it would increase rather than decrease fatigue. Unfortunately, using rest as the primary intervention strategy for dealing with fatigue can lead to physiologic deconditioning that, in turn, can lead to decreased activity tolerance, which can result in even less activity. Unless reversed, this downward cycle can end in functional disability (Winningham, 1996). Winningham's fatigue inertia spiral model (see Figure 1) portrayed well-established concepts from exercise physiology (Greenleaf & Kozlowski, 1982) and rehabilitation medicine (Valbonna, 1982) in a way that fits the emerging idea that exercise might ameliorate CRF.

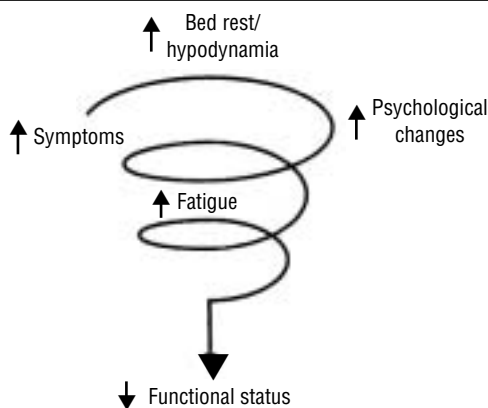


Figure 1. Fatigue Inertia Spiral

Note. Copyright © 1991, 1994 by Maryl L. Winningham. Reprinted with permission.

Researchers have studied the relationship between CRF and exercise in patients receiving various treatment modalities. The majority of these studies involved convenience samples of patients with breast cancer undergoing conventional treatments with surgery, chemotherapy, or radiation therapy (Courneya & Friedenreich, 1999; NCCN, 2004). Dimeo, Fetscher, Lange, Mertelsmann, and Keul (1997) studied the effects of supervised exercise on physical performance parameters and treatment-related complications in a randomized study of 70 patients receiving high-dose chemotherapy and PBSCT. The majority of the sample for this study also was patients with breast cancer, and study outcomes were physical performance parameters. The investigators reported a positive effect on fatigue and mood, but they did not formally assess or measure these aspects. Later, Dimeo, Stieglitz, Novelli-Fischer, Fetscher, and Keul (1999) studied the effects of exercise on fatigue and psychological status in 59 subjects receiving high-dose chemotherapy and PBSCT. Nearly half of the subjects in this study were patients with breast cancer, and no patients with multiple myeloma were included. Eligible patients recruited on odd weeks received a supervised exercise intervention ($n = 27$), whereas patients recruited on even weeks served as controls ($n = 32$). The subjects' scores on the Profile of Mood States, the Revised Symptom Checklist-90, and clinical interviews confirmed the investigators' previous observations. The exercise group did not show a significant change in fatigue scores ($p = 0.28$) or vigor ($p = 0.10$) but showed a significant decrease in global psychological distress ($p = 0.03$), whereas control subjects showed significant increases in fatigue scores ($p = 0.02$), decreases in vigor ($p = 0.05$), and no change in global psychological distress ($p = 0.68$). No change in fatigue or vigor for the exercise group was a positive result in this context.

In a feasibility pilot study, Coleman, Hall-Barrow, Coon, and Stewart (2003) showed that patients with multiple myeloma without fractures could implement a home-based exercise program while receiving aggressive chemotherapy and PBSCT. Published studies to date have indicated that exercise has a positive effect on physical performance indicators and CRF in other populations. Dimeo et al. (1997, 1999) found that high-risk patients receiving PBSCT for diagnoses other than multiple myeloma could exercise safely with supervision. Further, several studies (Mock et al., 1994, 1997, 2001; Schwartz, 1999) have shown that patients with breast cancer undergoing standard therapy can participate in home-based exercise during treatment. Still unconfirmed are the risks and benefits of home-based exercise for patients with bone lesions or for patients undergoing regimens that include high-dose chemotherapy and PBSCT. Also unknown is how patients implementing home-based exercise programs during treatment appraise the experience of participating in such programs.

Purpose

The purpose of this naturalistic study was to ascertain how patients with multiple myeloma appraised the experience of participating in a home-based exercise intervention as part of a randomized controlled trial of prophylactic epoetin alfa with or without exercise. The focus of this article is the research question, "What were the participants' feelings, beliefs, and experiences related to the risks and benefits of exercise as an intervention for CRF?"

Conceptual Orientation

Kleinman's (1980) theory of explanatory models served as a sensitizing framework for this study. Kleinman (1978) viewed disease as a disturbance of biophysical processes but characterized illness as "personal, interpersonal, and cultural reactions to disease or discomforts" (Kleinman, Eisenberg, & Good, 1978). The experience of illness is shaped by the cultural and social context in which it occurs. This context influences expectations; when, where, and from whom treatment is sought; the perception and interpretation of symptoms and symptom distress; appraisal of the desirability and effectiveness of remedies; and adherence to recommended treatments (Kleinman, 1978, 1980). The participants in this study were from across the United States. Their occupations and lifestyles were diverse, but they all had sought treatment at an international referral center specializing in their uncommon form of cancer.

Methods

The research approach for this study was naturalistic (constructionist) inquiry as put forth by Lincoln and Guba (1985) and amended by Guba and Lincoln (1998). They contended that people construct the meaning of their experiences and can hold conflicting beliefs simultaneously. They also recognized that in qualitative studies that employ in-depth interviews, the participant and investigator have a personally constructed view of reality. In naturalistic inquiry, the investigator's reflections, impressions, beliefs, and biases are acknowledged and become part of the data for analysis. This method was particularly suited to this study because experience in the setting led the principal investigator to believe that many participants would hold complex and contradictory views of their health and illness experience. When the study was planned, the principal investigator, who is a coinvestigator on the parent exercise study, had little contact with potential participants. However, a personnel change put the principal investigator in the study coordinator position where she had close contact with the participants before the interviews. Because of this situation, the principal investigator believed that examining and accounting for her biases was especially important.

Participants and Setting

The study setting was a university-based, international referral center for the treatment of multiple myeloma located in the southeastern United States. All participants in this naturalistic study were enrolled in the same aggressive tandem transplant protocol, with or without thalidomide, for the treatment of multiple myeloma (see Table 1). In addition, they had been assigned to the exercise arm of a randomized, controlled trial of a home-based exercise program as a proactive intervention for CRF. The home-based exercise prescription included daily stretching exercises and endurance exercises (usually walking) alternating with strengthening exercises for the upper and lower extremities. Enrollment for the exercise study took place immediately after enrollment in the multiple myeloma treatment protocol. The initial phase of the exercise study continued through stem cell mobilization and harvest. All patients in the exercise study received prophylactic epoetin alfa. Patients who met criteria for response to epoetin alfa and complied with data submission were invited to continue in the exercise study through discharge from their first transplant

Table 1. Treatment Regimen

Chemotherapy ^a	Acronym	Purpose and Timing
Vincristine, doxorubicin, and dexamethasone	VAD	Induction Enrollment
Dexamethasone, cyclophosphamide, etoposide, cisplatin	DCEP	Induction Five weeks after VAD
Cyclophosphamide, doxorubicin, and dexamethasone	CAD	Mobilization or stem cell harvest Five weeks after DCEP
Dexamethasone, cyclophosphamide, etoposide, and cisplatin	DCEP	Consolidation Five weeks after CAD
Melphalan 200 mg/m ² followed by stem cell reinfusion	Mel 200 T-1	Transplant 1 (T-1) Five weeks after DCEP
Melphalan 200 mg/m ² followed by stem cell reinfusion	Mel 200 T-2	Transplant 2 (T-2) Three months after T-1

^a In addition to the listed drugs, half of the patients were randomized to receive thalidomide.

episode. All but two of the participants in this qualitative study were among those who continued in the exercise study through their first transplant.

The first interviews for this naturalistic study took place approximately 10–12 weeks after participants enrolled in the exercise study. The principal investigator used purposive, non-probability sampling from the exercise study population. She sought participants who were willing to discuss their experiences candidly. A research assistant, not connected with any studies involving patients with multiple myeloma, contacted potential participants and obtained verbal consent for the investigator to contact them about the study. The university's institutional review board and the protocol monitoring and review committee of the cancer center approved the study.

Methodologic Approach

The principal investigator conducted the face-to-face tape-recorded interviews, which took place in a small conference room or office in the college of nursing. To protect the participants' privacy, the tape recordings of the interviews did not contain identifying information and the investigator labeled the tapes with a number that had no meaning outside the context of the study. After obtaining written informed consent and demographic data, the principal investigator opened the interview with the grand tour question (Spradley, 1979), "What was your life like before you were diagnosed with multiple myeloma?" followed by "How has that changed?" Additional probe questions helped to elicit answers to the study questions (see Figure 2).

At the time of the first interview, participants had implemented their exercise program while undergoing two courses of induction chemotherapy, usually administered by their local oncologist, and were returning to the institute for stem cell mobilization and harvest (see Table 2). Two participants' first interviews took place after their recovery from stem cell collection. Vincristine, doxorubicin (Adriamycin[®], Pfizer Inc., New York, NY), and dexamethasone; and dexamethasone, cyclophosphamide, etoposide, and cisplatin (Platinol[®], Bristol-Myers Squibb, New York, NY) typically result in moderate neutropenia and anemia, but cyclophosphamide, Adriamycin, and dexamethasone (CAD) for stem cell mobilization result in

Grand tour question for first interview

“What was your life like before the diagnosis of multiple myeloma?” followed by “How has that [your life] changed since diagnosis?”

Original probe questions

What did you believe about the relationship between exercise and fatigue at the time you enrolled?

How did your experiences affect your beliefs as time passed?

Do you have any safety concerns about exercising?

Added probe questions

How did that [your beliefs] fit with the beliefs expressed by your family or friends?

How did the advice you were getting from others change?

Did you get any conflicting advice? If so, how did you deal with it?

Figure 2. Examples of Probe Questions

pancytopenia with profound neutropenia. Melphalan 200 mg/m² given in preparation for stem cell reinfusion is myeloablative. Both CAD and melphalan typically cause significant fatigue.

Initial and confirmatory interviews elicited the participants' experiences of trying to exercise while progressing through this treatment continuum. In most cases, the confirmatory telephone interview took place after participants returned home following recovery from their first transplant and no longer were participating in the exercise study.

Data Analysis

Demographic information was entered into SPSS® version 10.1 (SPSS Inc., Chicago, IL) statistical software to obtain mean ages and frequencies of demographic characteristics of the sample. Verbatim transcripts of the in-depth, face-to-face interviews, confirmatory telephone interviews, and the principal investigator's field notes provided the qualitative data for this study. The transcripts were imported into QSR NVivo® version 1.1.146 (QSR International, Cambridge, MA) computer software program that is designed specifically to facilitate analysis of non-numerical data. It allows the user to assign codes to words, phrases, sections, or linked documents that relate to the project. The user can expand, collapse, rename, or reorganize coded units of meaning into hierarchical arrangements to discover linkages and themes. Coded sections can be viewed separately or within their original context.

The principal investigator performed content analysis by reading each verified transcript several times while listening to the tape recording of the interview. During the first two readings, the investigator listened carefully to develop a sense of the participant's global experience. With the third reading, she began assigning codes to each unit of meaning. Through constant comparison of the interview transcripts, the investigator refined the coding and identified linkages and themes

that described the participants' experiences and addressed the research question. Trustworthiness of the investigator's interpretations was established through confirmatory telephone interviews with the participants. An expert in naturalistic inquiry independently coded a sample of the transcripts and compared the results with those of the principal investigator. The few discrepancies in coding were discussed until consensus was reached.

Findings

Participants

Twenty-one of 24 consecutive exercise study participants returning to the institute for stem cell mobilization and harvest were willing and able to discuss their experiences candidly and consented to the interviews. The sample demographics reflect the makeup of the exercise study and are consistent with historical demographics of patients treated in the myeloma institute. Fifty-seven percent of the participants were male. Most of participants were Caucasian, from out of state, well educated, relatively affluent, and had a previous history of fitness program adherence at some time in their lives; more than half were employed at the time of the first interview (see Table 3). Eighteen participants had documented bone lesions. At the time of enrollment in the exercise study, participants' baseline fitness ranged from being unable to stand without assistance to being able to perform strenuous workouts that included weight lifting.

Themes

Three overarching themes emerged from the data: (a) belief systems, which encompassed the participants' beliefs about exercise or epoetin alpha, philosophy, and self-concept; (b) social context, which included life before cancer, social environment, and social system congruence; and (c) experience appraisal, which included participants' assessments of the meanings of their experiences.

The definitions that follow explain the underlying data clusters that came together to develop each theme. Belief systems included the participants' beliefs about the benefits and risks of exercise or epoetin alfa in their situation and participants' personal moral or ethical philosophy concerning keeping their promise to exercise, taking responsibility for their health, and contributing to society by participating in research. Lastly, belief systems encompassed participants' views of themselves and their abilities to exercise within the context of their disease and treatment.

For the purpose of this study, social context was a circumscribed aspect of culture. It included participants' views of their lives before the diagnosis of cancer, their social support system of family and friends, and social congruence or the

Table 2. Study Timeline Relationships

Event	Weeks							
	1	~1	~5	~10	~15	~20	~24	~32
Treatment protocol	Enroll	VAD	DCEP	CAD	DCEP	T-1	Rest	T-2
Exercise study	Enroll			Finish or continue		All finish		
Qualitative interviews				Initial interview			Confirmatory interview	

CAD—cyclophosphamide, doxorubicin, and dexamethasone; DCEP—dexamethasone, cyclophosphamide, etoposide, and cisplatin; T—transplant; VAD—vincristine, doxorubicin, and dexamethasone

Table 3. Demographic Characteristics

Characteristic	Regular Exercisers					Total (N = 21)
	Current ^a (N = 4)	≤ 1 Year Ago ^b (N = 8)	Remote ^c (N = 2)	Never ^d (N = 7)		
Age (years)						
\bar{X}	48	51	47	57	52	
Range	41–55	36–66	45–50	48–70	36–70	
Characteristic	n	n	n	n	n	n
Gender						
Male	2	4	2	4	12	
Female	2	4	–	3	9	
Race						
Caucasian	3	6	2	7	18	
Black	1	2	–	–	3	
Residence						
Local	–	1	1	4	6	
Out of state	4	7	1	3	15	
Education						
High school or less	–	–	1	2	3	
> High school but < baccalaureate	1	6	–	4	11	
Baccalaureate or higher	3	2	1	1	7	
Household income						
< \$30,000	–	2	–	2	4	
\$30,000–\$49,000	–	–	–	2	2	
\$50,000–\$100,000	1	2	1	2	6	
\$101,000–\$250,000	2	3	1	–	6	
> \$250,000	1	–	–	1	2	
Not sure	–	1	–	–	1	
Employment						
Full-time	3	3	2	–	8	
Part-time	–	–	–	3	3	
Not employed	1	5	–	4	10	

^a Current—Participant was engaged in an exercise program at the time of enrollment in the exercise study.

^b ≤ 1 year—Participant had engaged regularly in a fitness activity within one year of enrollment.

^c Remote—Participant had engaged regularly in a fitness activity at some time but not within one year of enrollment.

^d Never—Participant had never engaged regularly in a fitness activity.

extent to which those in participants’ support systems agreed with participants’ exercise beliefs, goals, and actions. Social context also included social environments such as shopping malls, health clubs, work, home, travel, temporary housing, and hospitals as well as information sources such as the Internet and various forms of media.

Experience appraisal was the meaning that participants assigned to their experiences. It included participants’ assessment of and feelings about the outcomes of trying to exercise during aggressive chemotherapy and PBSCT.

Figure 3 depicts the reciprocal relationships among the themes and their placement as precursors to participants’ behaviors, exercise decisions, and advice they would give to other patients in similar circumstances. The relationship of these themes to specific exercise decisions will be reported elsewhere. Table 4 provides an audit trail that shows the decisions of the investigator as she combined raw data into clusters and finally into more global themes. The raw data in the table is separated artificially from its context to clearly show the data clusters. In reality, the clusters and themes were intricately interwoven.

Participants’ stories illuminated the complex reciprocal interactions among belief systems, social context, and ex-

perience appraisal. Following are examples that represent the different themes and interactions. Examples that did not have at least some element of interaction with other thematic elements were difficult to find. The examples are listed by the dominant theme.

Beliefs

The most overwhelming and pervasive theme that emerged from the data was the participants’ beliefs systems. All 21 participants believed that exercise would be good for them while they were going through treatment. The belief was present regardless of participants’ exercise history.

Participants’ beliefs, philosophy, and self-concept were intertwined to build their belief systems. One 50-year-old man’s comments about himself in relation to the exercise prescription illustrate his belief system that encompassed his self-concept of being young and healthy and of being more able than people who were older to carry out the exercise prescription.

I feel as though, for multiple myeloma, I’m still pretty young. [I’m] pretty active and in pretty good health, and that’s why I say it, it probably affects the older people a little bit different than it does me. I’ve been capable of doing these exercises, probably better than some people.

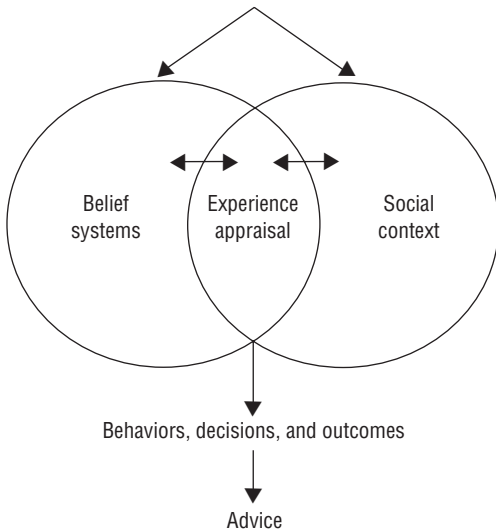


Figure 3. Exercise Implementation Model

Note. Copyright © 2003 by Sharon Coon. Reprinted with permission.

All participants were receiving prophylactic epoetin alfa. Participants expressed their beliefs about the effect of the epoetin alfa in relation to their ability to exercise. This participant had consistently implemented the exercise prescription. His comments illustrate how his belief about its effect influenced his retrospective appraisal of his ability to exercise.

... [It is] kind of hard to say if you haven't gone through it without [epoetin alfa]. But ... red [blood cell] counts, supposedly have such a big influence on energy levels that, you know, you can't do one without the other, you can't exercise without any energy, so, assuming that's what kept my energy level up, and I'm sure it is, that's probably the only way I could've exercised with any kind of consistency.

Prior to enrolling in the treatment program for multiple myeloma and the exercise study, one participant had a strenuous exercise program and active lifestyle that included strenuous outdoor chores. This lifestyle was interrupted when sudden back pain caused him to seek medical attention that resulted in his diagnosis of multiple myeloma. Before he started treatment, he had decreased his exercise for a time because of a painful lesion in his back. His belief system included a strong positive association between exercise and decreased fatigue as well as the deleterious effects of becoming sedentary. His comments about sports and weight lifting alluded to his social environment as a context of his belief system.

Not just because of [epoetin alfa] or whatever the study is, but the more you exercise, the more you put out, the less fatigued you actually are. I played sports all my life, lifted weights all my life. When you sit around for two months, your energy goes down. You work out; you feel like you're drained; walk out of the gym 30 minutes later you're just, you know, chomping at the bit, you're jumping up and down and it's, you know, it comes with—your energy levels come with exercise, metabolism—all that stuff. It's totally different if you are sitting around than if you're engaging in some kind of activity.

Patients not engaged in a fitness program often mention that they thought they were just getting out of shape. During the interviews for this study, three participants specifically discussed how they had attributed their fatigue to lack of exercise or being out of shape. The following are comments from such a participant with a remote history of exercise. He started a diet and had plans to start an exercise program to help his energy level just prior to his diagnosis of multiple myeloma. His comments illustrate the underlying belief in the relationship of fitness and fatigue held by many of the participants. His comments also illustrate how fatigue had challenged his self-concept. His comparison of his physical abilities to those of his teenage daughter illustrates how his social environment influenced his belief about being out of shape. Once diagnosed, he incorporated the disease process into his belief system.

I commented to my wife years ago that I thought my body was getting weaker; I don't know if that was related to the cancer coming on or not. I could sense something—my level of energy was falling a little bit, I couldn't—when I would go do yard work . . . I feel like I would push the lawn mower the same and it was more hard for me to do . . . you know, I would go through chores around the house. I was like, how could my daughter lift a box heavier than I can, you know, and I wasn't—this was this year actually, and I said this doesn't make sense; I am a man, she is a teenage girl, how can she do this, you know, I should be able to lift as much as she can, and that's why—the whole thing with the diet, and getting on it, I said maybe I have just gotten really out of shape. Actually, it was probably a combination of things; yes, I was out of shape, but I was also having a chronic disease process going on, too.

Another aspect of participants' belief systems was their philosophy of life. Several participants directly addressed the belief that they should be active participants in their treatment, and many more gave the overall impression that they were acting on such beliefs. "I think anything that you can make a decision to do, and then do it, if it's going to help you, I think it just makes you feel that much more a part of your cure or your treatment." Participants already had demonstrated one aspect of being proactive about their health by going outside of their local communities to seek health care.

Many participants' philosophy of life also included their commitment to keeping their word, "I just thought I needed to do it. My, um, my, the fact that I had promised to do this exercise. Some days I wouldn't have exercised if I hadn't said, if I hadn't made this commitment to [epoetin alfa]." Participants also hoped that their participation in research studies would help others in the future.

Social Context

Social context includes life before diagnosis, social support system congruence, and social environment. Again, isolating social context from beliefs and experience is difficult. Social context could be the precursor or the consequence of participants' beliefs. This retired man described his life before cancer, juxtaposed it against the symptoms that brought him into the healthcare system, and then continued with his description of life before cancer.

Well, I could do just about anything I wanted to in the way of lifting, working, working my cattle, do about anything

Table 4. Examples of Raw Data

Themes	Data Clusters	Raw Data
Belief systems	Beliefs about exercise and epoetin alfa	“[Exercise] raises your endorphins, I think—just makes you feel better.” “I think there is probably, definitely a benefit to me being on [epoetin alfa]. . . .”
	Philosophy	“[Exercise] just felt like accomplishment; I had done what I said I was going to do.” “You know, I felt better. You know, I figured I’d do something positive for myself and, you know, it [exercise] made me feel good.” “Another thing—it makes you think you’re doing something healthy for your body, even though you know that they are pumping chemicals into you and you have to take a fist full of pills every day.”
	Self-concept	“Well, I felt like that I could, you know, that I could handle any kind of exercise that they were going to ask me to do, and I think I have.” “If I was 15 years older and I’d had any stronger complications from the treatment, I don’t think there’s any way I could have been a successful candidate to participate.”
Social context	Life before cancer	“I played golf, sporadically, once a month. . . . Very little of an organized effort from the exercise standpoint. Fairly highly stressful . . . position, I pretty much . . . buried myself in my work.” “And it was a seven-day job because when you had it to do, you had it to do. Everyone was waiting on you. Then in the wintertime, that was when slack time, I might go hunting. . . . I’ve got a boat and take the kids boating and fishing in the summertime.”
	Social support	“Usually when he came home the first question out of his mouth was, ‘How you doing? Everything okay? Have you done your exercises?’” “You know, if you are going to walk, find a partner and talk and chit-chat.” “People at church, my kids, everybody. Everybody encourages me.”
	Social system congruence	“All the doctors and the nurses and everybody told me do what you can, push yourself, make yourself get up and go.” “Yeah, I mean, everybody I told said that I needed to exercise, that it helped fatigue . . . it may not, get rid of all your fatigue but it helps relieve it.”
	Social environment	“I would even go to the mall and do my walking.” “I’ve done a lot of the exercises right there in the job trailer; sitting in the chair, doing the chair pushups and you know, the stand ups, and then the walking, it’s a pretty good-size facility. They’ve got a little lake there, the road goes around the lake and I’ve done a lot of the walking just around the lake.” “I went out to the farm; I walked over the hills.” “Exercising is harder up here [at the cancer center] than it is at home.” “I didn’t do any exercise when I was in the hospital.” “Well I had read that, um, the more you exercise the less you become fatigued. . . .”
Experience appraisal	Assigned meaning	“I don’t know what [anemia] feels like, but the cancer fatigue is quite different from exercise, you know, muscle fatigue.” “[Exercise] really just made me feel better, that I could do it, and that I’m glad that as I got better, you know, my body got more limber and your coordination gets better every morning as you stretch and do those exercises; you’re not quite as puny when you can do [exercise].” “But, with chemo, I found out I’m really, it really knocked me down a lot farther than I expected.” “I think I feel better when I exercise.” “I think there’s a psychological side to the [epoetin alfa] study, you know, ‘cause, whether or not it’s physically made me feel better the day after the shot, it’s making me feel better.”

I wanted to do, I’d done it all my life. Then I just started going down where I couldn’t, I just didn’t have any energy at all. But I was very active, played a lot of golf, did a lot of hunting. Traveled, pheasant hunting, the Dakotas, and just had a full life—enjoyed my grandkids.

The following example of social context includes life before cancer (a regular walking program), social support (walking with a group of friends), and social environment (walking at the mall). “I walked for an hour every morning with four of my friends before I would go to work at least four days a week and usually one day on the weekend.” This woman continued to go with the group even when her ability to participate was drastically reduced. She commented, “I’m a social person. I like being with other people when I exercise. I like walking and chit-chatting and doing that, so

that’s more fun for me. . . . We solve all the world’s problems while we’re walking around the mall.” When she was not able to do the whole hour, she would sit on a bench in the mall and wait for her friends to finish. “That’s it for me, I have to go sit down on the bench, you guys can pick me up when you get done—go finish.” Interestingly, this woman, during her first interview, mentioned a number of benefits that she derived from doing the stretching and strengthening exercises. During the second interview, although she reported that she was still going to the mall and was walking a mile whenever she could, she was not doing the stretching or strengthening exercises and had no plans to restart them. This may point to the influence of social context in that the strengthening and stretching exercises were done at home, alone, whereas the walking was done out in public with a group in a setting she preferred.

A young mother described her life before diagnosis. "Neither one of us were really, were probably real active, most of the stuff we did was [with] our kids." She talked about how she was trying to maintain normalcy for her children in the context of the demands of treatment and a full-time job and how she thought she was succeeding until her young daughter challenged her by asking, "Why are you always lying around on the couch?" This mother said, "Well, I guess I was feeling sick that day but, I mean, I thought I'd really been pretty active, but she didn't see it that way so I guess different perspectives." This lack of social congruence (her daughter did not agree with her assessment of how well she was maintaining her routine) threatened this young mother's self-concept. This young woman related the experience to the broader social context with the statement, "I don't know if other mothers have that problem."

Experience Appraisal: The Interaction of Beliefs and Social Context

Complex reciprocal interactions among belief systems, social context, the meaning participants assign to their experiences, and their feelings serve as precursors to subsequent behaviors, decisions, outcomes, and advice. For example, consider the interactions in the experience appraisal of the young mother in the previous example when she was asked what advice she would give to another patient in her situation.

I'd say it would be good for them to get on something regularly, regular, you know, just walking or stretching or something—something to make them feel—I think it lifts your mood, too. I know it would lift my mood when I'd do it—make me feel more—I don't know, like, normal. Does that make sense? Like you could still do things, that you weren't incapacitated. Keep a positive attitude about things.

Her statement contains the belief that exercise can help mood, the confirmation of the belief through experience, and expression of the need for a personal feeling of normalcy as part of her self-concept. All of those factors came together in the advice she would give to other patients.

In the following example, the social context of being in the exercise study, along with the belief that the exercises would be easy, provided the incentive for this woman to initiate an exercise program. Once in the program, her belief system, that included an ethical philosophy of keeping her word, provided a congruent context for successful implementation even though the reality of the chemotherapy side effects challenged her beliefs about the difficulty of the exercise program and her self-concept about her ability to exercise.

I probably wouldn't exercise if it weren't for this study. Even though that the doctors are saying, you need to stay active and do as much as you can. But, I signed on to do it, and I'm going to do it until you don't want me to do it any more. . . . When we first started this and you showed me what the exercise was going to be, I thought this was going to be a snap. . . . I thought, anybody could do this. Well I learned real quick, after about the first treatment, that the fatigue level did go down and it was a little bit harder to stand out of the chair 10 times and push my arms up. And [I'm] still not very good at doing that one; you know, I learned that there was more to that exercise study than what I thought right there at first. A healthy

person wouldn't have any trouble doing it, I don't think. But it was enough to keep someone in my situation—I couldn't have done much more unless I broke it up into two or three different times a day.

This woman's social context and beliefs allowed her to implement the program long enough to incorporate the outcomes into her belief system.

I would have to do something, it wouldn't take two or three days for me to feel that I wasn't doing anything . . . like being in the hospital, you can tell when you get, when you're standing up and whatever; you can tell it's been a couple of days since you've done that [exercise]. So . . . the walking is real important. I don't know that what I didn't implement a little more walking into it. But then, I like to walk, so that may be a factor there.

She continued to exercise after the study and said she would advise other patients to exercise during treatment. Her behavior was consistent with her advice, and new patients have reported that she advised them to take advantage of the opportunity to be in the study.

The exemplars contained in this report pertain to the light-to-moderate aerobic exercise included in the exercise study prescriptions. A subset of participants also engaged in rigorous activities that far exceeded those included in the study. Their experiences related to their more rigorous activities will be reported elsewhere.

Limitations

The investigator found that separating her knowledge of participants' situations gained from interactions before the interviews from the actual interview content was somewhat difficult. Therefore, when coding and interpreting the transcripts, her assessment of the meaning was colored by her other interactions. However, a 94% interrater agreement existed on sample segments independently coded by an expert in naturalistic methods who had no knowledge of the participants or the myeloma treatment program.

Most participants in this study were well-educated, relatively affluent Caucasians who had gone outside of their local communities to seek care at an international referral center that specialized in their uncommon form of cancer. The results of this study may be more indicative of the belief systems, social context, and experience appraisal of patients treated in specialty referral centers than those cared for within their local healthcare systems.

Conclusions and Implications

The thematic content from the interviews, with a sample of 21 participants implementing exercise as a proactive intervention for CRF, gave a sense of the complexity and interrelatedness of issues involved in exercise adherence within the context of treatment. The conceptualization of CRF as a phenomenon with multidimensional feedback loops (Aistars, 1987; Piper, Lindsey, & Dodd, 1987; Winningham, 1996) may extend to encompass the implementation of exercise as intervention for relief of fatigue. Participants' reports of dramatic declines in their ability to complete their workouts after taking days off from their exercise program are consistent with Winningham's fatigue inertia spiral.

Disease can be viewed as a malfunction of biophysical systems, whereas illness is the socially constructed experience of the disease (Kleinman, 1978). Participants in this qualitative study were trying to maintain health in the context of a disease still widely considered incurable. The results of this study suggest that participants maintained separate views of their biophysical disease and their socially constructed beliefs about illness and health within the context of their aggressive treatment. Missing from the participants' accounts was social system incongruence or conflicting advice regarding the desirability of implementing the prescribed exercises. Only a few years ago, the patients at this institute commonly complained that the advice given by institute physicians to stay active conflicted with the advice of their hometown physicians to limit all activity for fear of breaking bones.


To provide a social context that supports exercise and integrates the patient's belief systems, clinicians must care-

fully assess previous experience with exercise. Gathering information about the whole context rather than just current exercise habits can help clinicians to capitalize on such things as patients' motivation to be active participants in their care and beliefs about the benefits of exercise. It might be helpful to introduce an element of commitment by contracting with patients who have strong ethical philosophies about keeping their word.

The authors wish to acknowledge the commitment and generosity of the study participants who shared their stories. Jean McSweeney, PhD, RN, FAHA, an expert in naturalistic inquiry, provided guidance and support for this project.

Author Contact: Sharon K. Coon, PhD, RN, AOCN®, can be reached at coonsharonk@uams.edu, with copy to editor at rose_mary@earthlink.net.

References

- Aistars, J. (1987). Fatigue in the cancer patient: A conceptual approach to a clinical problem. *Oncology Nursing Forum*, 14(6), 25–30.
- American Cancer Society. (2004). *Cancer facts and figures 2004*. Atlanta, GA: Author.
- Barlogie, B., Jagannath, S., Vesole, D.H., Naucke, S., Cheson, B., Mattox, S., et al. (1997). Superiority of tandem autologous transplantation over standard therapy for previously untreated multiple myeloma. *Blood*, 89, 789–793.
- Coleman, E.A., Coon, S.K., Mattox, S.G., & O'Sullivan, P. (2002). Symptom management and successful outpatient transplantation for patients with multiple myeloma. *Cancer Nursing*, 25, 529–534, 540.
- Coleman, E.A., Hall-Barrow, J., Coon, S., & Stewart, B. (2003). Facilitating exercise adherence for patients with multiple myeloma. *Clinical Journal of Oncology Nursing*, 7, 129–140.
- Courneya, K.S., & Friedenreich, C.M. (1999). Physical exercise and quality of life following cancer diagnosis: A literature review. *Annals of Behavioral Medicine*, 21, 171–179.
- Curt, G.A. (2000). The impact of fatigue on patients with cancer: Overview of FATIGUE 1 and 2. *Oncologist*, 5(Suppl. 2), 9–12.
- Dimeo, F., Fetscher, S., Lange, W., Mertelsmann, R., & Keul, J. (1997). Effects of aerobic exercise on the physical performance and incidence of treatment-related complications after high-dose chemotherapy. *Blood*, 90, 3390–3394.
- Dimeo, F.C., Stieglitz, R.D., Novelli-Fischer, U., Fetscher, S., & Keul, J. (1999). Effects of physical activity on the fatigue and psychological status of cancer patients during chemotherapy. *Cancer*, 85, 2273–2277.
- Greenleaf, J.E., & Kozlowski, S. (1982). Physiological consequences of reduced physical activity during bed rest. In R. Terjung (Ed.), *Exercise in sport science review* (pp. 84–119). Philadelphia: Franklin Institute Press.
- Guba, E.G., & Lincoln, Y.S. (1998). Competing paradigms in qualitative research. In Y.S. Lincoln (Ed.), *The landscape of qualitative research: Theories and issues* (pp. 195–219). Thousand Oaks, CA: Sage Publications.
- Kleinman, A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. *Social Science and Medicine*, 12, 85–95.
- Kleinman, A. (1980). *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry*. Berkeley, CA: University of California Press.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88, 251–258.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Lokhorst, H. (2002). Clinical features and diagnostic criteria. In H. Mehta & S. Singhal (Eds.), *Myeloma* (pp. 151–168). London: Martin Dunitz.
- Mock, V., Burke, M.B., Sheehan, P., Creaton, E.M., Winningham, M.L., McKenney-Tedder, S., et al. (1994). A nursing rehabilitation program for women with breast cancer receiving adjuvant chemotherapy. *Oncology Nursing Forum*, 21, 899–907.
- Mock, V., Dow, K.H., Meares, C.J., Grimm, P.M., Dienemann, J.A., Haisfield-Wolfe, M.E., et al. (1997). Effects of exercise on fatigue, physical functioning, and emotional distress during radiation therapy for breast cancer. *Oncology Nursing Forum*, 24, 991–1000.
- Mock, V., Pickett, M., Ropka, M.E., Muscari Lin, E., Stewart, K.J., Rhodes, V.A., et al. (2001). Fatigue and quality of life outcomes of exercise during cancer treatment. *Cancer Practice*, 9, 119–127.
- Multiple Myeloma Research Foundation. (2002). About myeloma. Retrieved March 19, 2003, from http://www.multiplemyeloma.org/about_myeloma
- Nail, L.M. (2002). Fatigue in patients with cancer. *Oncology Nursing Forum*, 29, 537–544.
- National Comprehensive Cancer Network. (2004). NCCN practice guidelines in oncology v.1.2004: Cancer-related fatigue. Retrieved September 21, 2004, from http://www.nccn.org/professionals/physician_gls/default.asp
- Neitzert, C.S., Ritvo, P., Dancey, J., Weiser, K., Murray, C., & Avery, J. (1998). The psychosocial impact of bone marrow transplantation: A review of the literature. *Bone Marrow Transplantation*, 22, 409–422.
- Piper, B.F., Lindsey, A.M., & Dodd, M.J. (1987). Fatigue mechanisms in cancer patients: Developing nursing theory. *Oncology Nursing Forum*, 14(6), 17–23.
- Schwartz, A.L. (1999). Fatigue mediates the effects of exercise on quality of life. *Quality of Life Research*, 8, 529–538.
- Spradley, J.P. (1979). *The ethnographic interview*. Philadelphia: Harcourt Brace Jovanovich.
- Tricot, G., Spencer, T., Sawyer, J., Spoon, D., Desikan, R., Fassas, A., et al. (2002). Predicting long-term (> or = 5 years) event-free survival in multiple myeloma patients following planned tandem autotransplants. *British Journal of Haematology*, 116, 211–217.
- Valbonna, C. (1982). Bodily responses to immobilization. In F.J. Kottke, G.K. Stillwell, & J.F. Lahman (Eds.), *Krusen's handbook of physical medicine and rehabilitation* (3rd ed., pp. 963–976). Philadelphia: Saunders.
- Varricchio, C.G. (2000). Measurement and assessment: What are the issues? In M.L. Winningham & M. Barton-Burke (Eds.), *Fatigue in cancer* (pp. 55–68). Sudbury, MA: Jones and Bartlett.
- Winningham, M.L. (1996). Fatigue. In S.L. Groenwald, M. Hansen Frogge, M. Goodman, & C.H. Yarbro (Eds.), *Cancer symptom management* (pp. 42–54). Sudbury, MA: Jones and Bartlett. 

Copyright of Oncology Nursing Forum is the property of Oncology Nursing Society and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.