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Defining Fatigue: The Experience of Patients with Cancer Receiving Radiation Therapy

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This research was sponsored by a research grant from Cephalon, Inc.

Significance of Cancer-Related Fatigue

- Most common symptom of cancer
- Most distressful symptom of cancer
- Interferes with daily activity
- Impacts quality of life
- Affects 40-100% of patients receiving radiation therapy



Ashbury et al. (1998). *J Pain Symptom Manage*, 16, 298-306.
Curt et al. (2000). *Oncologist*, 5, 353-360
Portenoy & Miaskowski. (1998). *Principles and Practice of Supportive Care*. Pp109-118.
Schwartz et al. (2000). *Cancer Invest*, 18, 11-19.
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Poirier et al. (2007). *Oncol Nurs Forum*, 34, 827-824.

Fatigue is the most common symptom of cancer and is most frequently rated as moderate or severe by patients.

Because it is the most common symptom and because there are few effective treatments, it is more often reported to cause distress than any other symptom of cancer.

At moderate and severe levels it interferes with usual daily activities and impacts quality of life.

The incidence is reported to be between 65-100% in patients receiving radiation therapy depending on the primary cancer, the dose of radiation, and the area radiated both in terms of volume and location.

Problems in Cancer-Related Fatigue Assessment

- No widely accepted definition of fatigue
- No clear, well-developed theoretical framework for fatigue
- Complex defining characteristics of fatigue



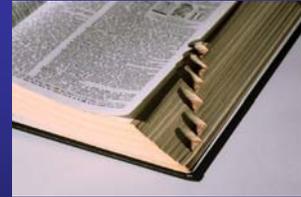
Tiesinga et al. (1996). *Nurs Diagn*, 7, 51-62

Defining the patient's experience of a symptom is critical to assessing and managing the symptom. The assessment and management of symptoms, including fatigue, is a primary role of oncology nurses.

There is not a single, agreed upon definition for fatigue or a clearer, well-developed theoretical-framework. Many of the defining characteristics that have been suggested for fatigue are complex concepts. These factors complicate discussions about fatigue and make comparing results of fatigue research difficult because measurements are not equivalent.

Current Measurement of Fatigue

- Intensity/Severity
- General/Global
- Behavioral/Interference with Activities
- Affective Meaning/Motivation
- Physical/Sensory
- Cognitive/Mental
- Duration/Timing



Aaronson et al. (1993). *J Natl Cancer Inst*, 85, 365-376
Hann et al. (1998). *Qual Life Res*, 7, 301-310.
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Rhoten. (1982). *Concept Clarification in Nursing*. Pp. 277-300.

Schwartz. (1998). *Oncol Nurs Forum*, 25, 711-717.
Smets et al. (1995). *J Psychosom Res*, 39, 315-325.
Stein et al. (1998). *Cancer Practice*, 6, 143-152.
Tack. (1990). *Arthritis Care Res*, 3, 154-157.
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Because of differences in definitions, methods to measure fatigue are sometimes unidimensional and sometimes multidimensional.

Unidimensional scales usually are a single item that measures the intensity or severity of fatigue globally or multiple items that report a single mean fatigue score based on the intensity or severity of several aspects of fatigue, such as behavioral, affective, physical, cognitive, or temporal.

Multidimensional scales measure between 2 and 5 dimensions of fatigue. These dimensions often include some of the aspects that unidimensional scales combined. While there is some overlap in dimensions between scales, multidimensional scales do not agree on what dimensions should be measured.

Purpose of Research

- Develop a detailed description of the experience of cancer-related fatigue during radiation therapy to guide fatigue assessment.
- Addresses the content area of Research in Cancer Symptoms and Side Effects of the ONS 2005-2009 Research Agenda.



In order to try to bring some clarity to the understanding and measurement of fatigue, particularly in clinical trials measuring the efficacy of interventions, this research sought to develop a detailed description of the experience of cancer-related fatigue during radiation therapy based on patients' reports of their experience of fatigue.

It is hoped that by understanding fatigue from the patient's perspective, we will be able to select or develop a measurement tool that will capture the aspects of fatigue most essential to patients.

Philosophical Framework

Story Theory

- Narrative process
- Listener and storyteller
- Intentional dialogue
- Share the experience of a complicating health challenge
- Clear and understandable



Smith & Liehr. (2003). *Middle Range Theory for Nursing*. Pp. 167-187.

In order to develop a patient-driven description of cancer-related fatigue during radiation therapy, the study was guided by the philosophical framework of Smith and Liehr's Story Theory. Story Theory is a narrative process that can be used for research or practice where a listener gives a storyteller the opportunity to engage in intentional dialogue to share the experience of living a complicating health challenge in a clear and understandable way. In this study, fatigue was the complicating health challenge and a research interviewer gave patients undergoing radiation therapy the opportunity to share their current and past experiences of fatigue.

Methods

- Descriptive, exploratory qualitative study
- Scientific and human subjects approvals
- Cross-sectional, single audio-recorded interview
- Descriptive, exploratory content analysis
- Themes confirmed by 2 other researchers



This was a descriptive, exploratory, qualitative study. Institutional scientific and human subjects approvals were obtained prior to the initiation of the study. It was cross-sectional with subjects participating in a single, open-ended, digitally –audio recorded interview that was transcribed verbatim by a professional transcriptionist.

All interview transcripts were verified prior to analysis.

The primary researcher initially analyzed the interviews to identify themes using a descriptive, exploratory content analysis method described by Parse.

Two additional researchers with experience in qualitative research and symptom assessment, confirmed the themes.

Sample Characteristics

- Purposive sample
- Large comprehensive cancer center, south central United States
- ≥ 18 years of age; English speaking
- Breast, head and neck, or prostate cancer
- Radiation therapy as part of initial treatment; no concurrent chemotherapy
- 21 and 25 doses of radiation, each dose 1.8-2.5 Gy (Total dose 37.8-62.5 Gy)
- Experiencing fatigue
- Informed consent

Purposive sample that came from a large comprehensive cancer center in the south central United States

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Experiencing fatigue

Informed consent

Now on to the study findings

Sample Demographics

N = 21

Age	54.3 years (sd=12.0)
Female Gender	12 (57%)
Married	13 (62%)
Caucasian	16 (76%)
Completed College	12 (57%)
Currently Not Employed	14 (67%)
Type of Cancer	Breast = 7 (33%) Head and Neck = 7 (33%) Prostate = 7 (33%)



The average age of the participants was 54.3 years

57% were women

62% were married

76% were Caucasian, 14% (3) were Black, 5% (1) were Hispanic, and 5% (1) were Asian

57% had completed college and of those 58% (7) had done post-graduate work, Only 5% (1) had not completed high school and 10% (2) had no education past high school. 28% (6) had some college but had not graduated. The average number of completed years of formal education was 15.1 years (sd = 2.1)

67% were currently not employed. Of those 29% (4) were retired, 57% (8) were on a medical leave of absence, and 14% (2) were unemployed. 14% (3) of the participants were employed fulltime, 14% (3) were employed part time, and 5% (1) was a fulltime homemaker.

Patients Reporting No Fatigue

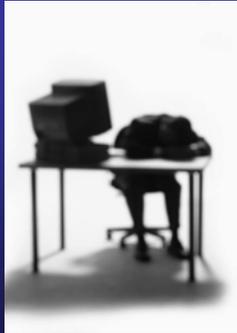
Breast Cancer	25% (16/37)
Head and Neck Cancer	43% (3/12)
Prostate Cancer	62.5% (15/24)



One of the eligibility criterion for this study was participant acknowledgement that they were experiencing fatigue. Patients were pre-screened prior to study entry by being asked, “Are you experiencing fatigue?” No further definition of fatigue was given by the recruiter. Of the patients we approached for this study, 25% of breast cancer patients denied that they were experiencing fatigue, 43% of patients with head and neck cancer denied fatigue, and over 60% of patients with prostate cancer denied fatigue.

Main Themes

- Loss of Strength or Energy
- Major Effects of Fatigue
- Sensations Associated with Fatigue



Three main themes were identified.

Loss of Strength or Energy

A loss of strength or energy includes feelings of tiredness or weakness, which may progress to exhaustion, and lack of energy and stamina.



Loss of strength or energy included feelings of tiredness or weakness that could progress to exhaustion as the fatigue worsened, and a lack of energy or stamina. Tiredness and lack of energy were the terms that were almost universally used by this group of patients to describe fatigue while weakness, lack of stamina, and exhaustion were used less frequently.

Participant Quotes

- I don't have a body part that is tired. My whole body is tired.

Woman with breast cancer

- I just have a weak feeling . . . pretty well all over.

Woman with head and neck cancer

- Fatigue to me is just a feeling of no energy.

Woman with breast cancer

- (When I realized I couldn't push myself, it was) shocking, because I don't know if we were going to get through to this or not.

Man with prostate cancer

Major Effects of Fatigue

The major effects of fatigue are a lack of motivation or inability to perform usual activities, decreased interest in social interactions, and an overwhelming need to rest at times.



Three major effects of fatigue were identified by the participants:

Interference with usual activities because of lack of motivation or inability to perform the activities.

Decreased interest in social interactions.

An overwhelming need to rest. that had to be attended to immediately. For some participants this need to rest occurred at a regular time every day but for others it would come on unexpectedly.

Participant Quotes

- Your energy is going to be gone quickly, so it's kind of like why bother.

Man with head and neck cancer

- You cannot do what you have normally done all your life.

Woman with breast cancer

- It tires me out just having people around. It tires me out.

Woman with breast cancer

- I wanted to take a nap right after my radiation, like I would be sleepier than usual.

Woman with head and neck cancer

An example of fatigue leading to a lack of motivation is the man with head and neck cancer who said:

A woman with breast cancer described that she could not:

Another woman with breast cancer noted the effect that fatigue had on her social interactions:

Finally a woman with head and neck cancer described her overwhelming need to rest:

Sensations Associated with Fatigue

Sensations associated with fatigue included both physical and mental sensations.

Physical sensations were malaise, aching, feelings of heaviness or weight, slowness of movement, and lack of appetite. Mental sensations were psychological distress and difficulty thinking or concentrating.



Most of the sensations associated with cancer-related fatigue were physical. Women reported more physical sensations, while men reported more psychological sensations. Other physical sensations reported by a small number of patients were dizziness and shortness of breath.

Psychological distress is often frustration or sadness over the loss of ability to perform or enjoy certain activities.

Participant Quotes

- I guess I could compare it to when you feel like you're about to get a virus or the flu, . . . and you get achy like that.

Woman with breast cancer

- A feeling, a very heaviness . . . heaviness, weight.

Man with prostate cancer

- I know I move a lot slower. I do everything a lot slower.

Woman with head and neck cancer

- Along with this fatigue comes lack of appetite. . . . You just don't want to even get up and eat.

Man with head and neck cancer

Physical sensations

Participant Quotes

- I just felt myself dragged out, just tired, and it was distressing to me because that's not my norm. I don't like to feel like that.

Man with prostate cancer

- It's just difficult to think about complex issues, complex tasks, analysis.

Man with prostate cancer

Mental sensations

Cancer-Related Fatigue During Radiation Therapy

Fatigue during radiation therapy is defined as tiredness and lack of energy which may progress to exhaustion as it becomes more severe over the course of therapy. Because of fatigue, patients may be unable to perform usual activities and may become frustrated or sad.



Definition

Implications for Practice

- Regular assessment of fatigue during radiation therapy
- Measure fatigue severity and interference with normal activities
- Monitor need for assistance with daily activities, mood, and nutritional status



The results of this research have several implications for practice:

Assess fatigue regularly during radiation therapy as it changes over the course of the treatment.

Fatigue measurement should include both severity and interference with activities.

Patients needs should be monitored, especially needs for assistance with daily activities, help in coping with the frustrations associated with fatigue, or help with maintaining adequate nutrition. As fatigue worsens, patients may be unable to shop for or prepare food.

Implications for Research

- Describe cancer-related fatigue in other patient populations
- Identify minimum requirements for cancer-related fatigue so that a standard definition can be agreed upon
- Investigate mechanisms of cancer-related fatigue and interventions that may be effective



Other patient populations – chemotherapy, biological therapy, different cancers, stage of disease, and survivors

Understanding why fatigue occurs more or less frequently in different patient groups may suggest mechanisms of fatigue production. Identification of mechanism may suggest interventions that will be effective in preventing or decreasing fatigue



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