A Qualitative Analysis of Cancer-Related Fatigue in Ambulatory Oncology

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The purpose of this study was to describe patients’ perceptions of the causes, relief, related symptoms, meaning, and suffering secondary to cancer-related fatigue (CRF). In total, 252 patients with breast, lung, colon, and prostate cancers were enrolled in a quasi-experimental study to test the effects of a clinical intervention on reducing barriers to symptom management in ambulatory care. Analysis of data reported in this article was derived from the Piper Fatigue Scale–Revised. Using qualitative research methods and content analysis, written statements related to the impact of CRF were coded using the following themes: patients’ perceptions of CRF, causes, relief, related symptoms, meaning, and suffering. Comments were categorized and reviewed for content. Overall, CRF had a significant impact on physical, psychological, social, and spiritual well-being. CRF limited the ability of participants to function, socialize, and participate in enjoyable activities. Emotional issues as a result of CRF were common. The negative impact of CRF on patients’ overall well-being alters the meaning and suffering related to the cancer experience. The assessment of personal meaning and suffering related to CRF is an important component of the multidimensional assessment of CRF and will enable nurses to better understand the suffering related to CRF.

Cancer-related fatigue (CRF) is one of the most common and distressing symptoms experienced by patients with cancer (Berger, 2009; Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007). Many patients experience fatigue as a presenting symptom prior to their diagnosis of cancer, and about 70%–100% of patients with cancer experience CRF at some point during diagnosis and treatment (Berger, 2009). Prevalence rates vary from 25%–99%, depending on the type of treatment, dose and route of administration, type and stage of cancer, and the method and timing used to assess CRF (Mitchell & Berger, 2008). CRF can negatively affect all aspects of patients’ quality of life (QOL) and can limit their ability to fully engage in activities that give meaning and value to their lives (Berger, 2009). Despite its frequency and its negative impact, CRF remains under-reported, underdiagnosed, and undertreated (Berger, 2009).

In patients receiving chemotherapy (CT), 80%–90% report CRF, and its prevalence rates and patterns over time may vary by the specific CT agent, its route of administration, and the frequency and density of treatment cycles. For example, a “roller-coaster” pattern of CRF over time is reported in women with early-stage breast cancer receiving 3–4 week CT cycles (Berger, 1998). Less is known about CRF’s prevalence rates and patterns prediagnosis (Hofman et al., 2007). During radiation therapy (RT), CRF is an almost universal occurrence, with 70%–100% of patients experiencing a gradually increasing, cumulative pattern of CRF over time that usually peaks and plateaus at 4–6 weeks and gradually declines thereafter over time (Berger, 2009). Most RT studies address CRF in patients receiving external beam RT. Increased levels of CRF are reported when different therapies, such as RT and CT, are used as combination therapy (Woo, Dibble, Piper, Keating, & Weiss, 1998). Although...
studies have described the prevalence and characteristics of CRF for patients with cancer receiving treatment or follow-up in ambulatory care settings, few have addressed patients’ perceptions of CRF, its meaning, and related suffering. The understanding of suffering and the promotion of patients’ search for meaning is an important goal of oncology nursing (Ferrell & Coyle, 2008). This article examines patients’ perceptions of the meaning of CRF and its related suffering through qualitative analysis of patient comments obtained through the Piper Fatigue Scale-Revised (PFS-R).

Literature Review

The most commonly used definition for CRF is found in the National Comprehensive Cancer Network’s (NCCN’s) evidence-based CRF guidelines, where CRF is defined as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning (NCCN, 2012). Patients may describe CRF as being more of a severe or overwhelming sense of tiredness that is unusual for them and that differs from the usual sense of tiredness they previously experienced when they were healthy. Studies consistently support that patient distinction by demonstrating that CRF is much more severe and distressing and much less likely to be relieved by rest or by a good night’s sleep when compared to the fatigue experienced by healthy individuals (Jean-Pierre et al., 2007; NCCN, 2012). Additional descriptors may include having no energy, lacking in endurance, feeling mentally fatigued (i.e., not being able to concentrate or focus), and not being able to perform activities that one used to be able to do.

The current oncology nursing literature contains descriptions of the meaning of illness and symptoms in cancer. Meaning in illness has been described as an important process where patients derive meaning from the suffering related to their illness (Borneman & Brown-Saltzman, 2010), and often is referred to as the search for an existential meaning (Thompson, 2007). Faced with a serious illness, patients tend to search for meaning in that experience (Ferrell & Coyle, 2008; Steeves, 1992; Taylor, 2005). Studies have shown that the search for meaning in cancer can be transforming for patients, and that a greater sense of meaning may be associated with better social, psychological, and emotional adjustments (Ramfelt, Severinsson, & Lützén, 2002; Taylor, 2000; Thompson, 2007).

Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000). Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2002; Taylor, 2000).

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Suffering related to an illness such as cancer is an intensely personal one. Suffering impacts all aspects of a person’s being. Physical symptoms such as fatigue can have a negative effect on the psychological and spiritual well-being of patients (Ferrell & Coyle, 2008). Cassell (1999) published a seminal paper in which he described suffering as “experienced by persons, not merely bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychologic entity,” (p. 17). He went on to say that the way to understand human illness and suffering is through the recognition of personal meaning.
(Cassell, 1999). Recognizing the trajectory of cancer, Reich (1987, 1989) described the experience of suffering through the metaphor of language by describing the sufferers’ struggle to discover a voice that would express the search for the meaning of suffering in three phases: mute suffering, expressive suffering, and new identity.

Although research has focused increasingly on the meaning of illness for patients with cancer, few have focused on patients’ perception of CRF, its meaning, and related suffering. The physical dimensions of CRF also have been the focus of the majority of the research on CRF, but few studies have focused primarily on the psychological, social, and spiritual dimensions of CRF. The current study contributes to current knowledge of meaning in cancer through a qualitative analysis of patients’ perceptions of the causes, relief, related symptoms, meaning, and suffering related to CRF.

Methods

The data consisted of responses to seven open-ended questions from the PFS-R, a 22-item self-report scale that measures four dimensions of subjective fatigue (behavioral or severity [6 items], sensory [5 items], cognitive or mood [6 items], and affective meaning [5 items]) (Piper et al., 1998). Each item is measured on a numeric rating scale, from 0 (not at all) to 10 (a great deal). Items are summed and divided by the total number of scale items to keep scores on the 0–10 scaling. Higher scores indicate more fatigue. Mild (1–3), moderate (4–6), and severe (7–10) PFS-R total score levels have been validated with declines in physical functioning (Medical Outcomes Study SF-36® physical functioning subscale) (Piper et al., 1998). Five additional items, not included in the scale’s scoring, assess perceived causes, relief measures, additional fatigue descriptors, presence of other symptoms, and duration of fatigue (Piper et al., 1998). Patients completed the PFS-R at baseline. Evidence for moderate to strong concurrent and discriminant validity estimates exist. Internal consistency (Cronbach alpha) reliabilities remain strong (0.83–0.97) for the PFS-R and its subscales across various cultural samples, languages, and diagnostic groups, and were 0.89–0.97 in the current sample.

Study participants were recruited from the Medical Oncology Adult Ambulatory Care Clinic at an NCI-designated comprehensive cancer center. Institutional review board approval was obtained prior to patient accrual. Patients with breast, lung, colon, or prostate cancers were recruited and enrolled in the study if they met the following eligibility criteria: (a) time since diagnosis of at least one month, (b) expected prognosis of six months or more, and (c) subjective fatigue rating of 4 or higher (moderate to severe fatigue) on a numeric scale of 0–10 (0 = none, 10 = worst imaginable).

Data Analysis

All original data from the seven open-ended questions of the PFS-R were obtained and grouped under the corresponding themes (cause, relief, other symptoms, meaning, and suffering). Responses for each theme were tallied. The data were read by two researchers to bracket significant responses that could be useful for written analysis. The data then were analyzed using content analysis techniques in which responses relevant to

<table>
<thead>
<tr>
<th>Code</th>
<th>Sample Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer or medical condition</td>
<td>My present diagnosis of cancer mets to my liver.</td>
</tr>
<tr>
<td>Cancer treatment</td>
<td>Fatigue seems to come about two weeks after receiving chemo[therapy]. The treatment is so strong.</td>
</tr>
<tr>
<td>Emotional issues</td>
<td>I feel depressed and tired. I have noticed changes like wanting to be alone and cry. Stress that my daughter may go [through] life with no mother</td>
</tr>
<tr>
<td>Inactivity</td>
<td>Not active, unable to go out Limiting amount of weight-bearing exercise</td>
</tr>
<tr>
<td>The unknown</td>
<td>The “not knowing” is what I think causes my fatigue.</td>
</tr>
<tr>
<td>Work</td>
<td>My work is a very stressful place to work.</td>
</tr>
</tbody>
</table>

Relief of Cancer-Related Fatigue

<table>
<thead>
<tr>
<th>Code</th>
<th>Sample Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better diet</td>
<td>Finding something to eat to bring up my energy level</td>
</tr>
<tr>
<td>Distraction</td>
<td>Distracting myself with reading, knitting, crossword puzzles, etc. Listening to music, meditation</td>
</tr>
<tr>
<td>Exercise or more activity</td>
<td>Moving around Continu[ing] to work has given me a purpose, reason to get up and get moving</td>
</tr>
<tr>
<td>Ignoring it</td>
<td>Trying to ignore it and push forward</td>
</tr>
<tr>
<td>Prayer</td>
<td>To pray always to our Lord and to shower more of His blessing to me</td>
</tr>
<tr>
<td>Rest or relaxation</td>
<td>Rest for a couple of days, and I feel much, much better</td>
</tr>
<tr>
<td>Sleep or sleep medication</td>
<td>Sleep and more sleep Medication to help me sleep</td>
</tr>
<tr>
<td>Slowing down or less activity</td>
<td>Reducing work hours Rest for short periods of time during the day and being active when feeling up to it</td>
</tr>
<tr>
<td>Think positive</td>
<td>Friends and family interaction and keeping a positive attitude Being in a bright place</td>
</tr>
<tr>
<td>Treatment of symptoms</td>
<td>Unfortunately, it’s the pain medication.</td>
</tr>
</tbody>
</table>

Description of Cancer-Related Fatigue

<table>
<thead>
<tr>
<th>Code</th>
<th>Sample Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spurts of energy followed by fatigue</td>
<td>It fluctuates during the day. I’m able to complete a project like gardening and then I am tired for a couple of days.</td>
</tr>
<tr>
<td>Weakness or exhaustion</td>
<td>On bad days, it could be described as comparable to participating in a triathlon. I am not the same energetic person I used to be.</td>
</tr>
</tbody>
</table>

(Continued on the next page)
I don’t feel like getting out of bed. Usually active with my grandchildren; now. Fatigue can be depressing because of inability to work full-time. Depression from not being able to accomplish different tasks.

Social impact

Impatient with others The effects it has on loved ones/family

Meaning of Cancer-Related Fatigue

Inability to function

Inability to function normally at all levels Slow me down—I tend to overdo all day and then, by day’s end, I’m tired.

Loss of enjoyment

Usually active with my grandchildren; now they seem reluctant to ask me to play Loss of everyday enjoyment of just being alive

Emotional impact

Makes me feel useless It makes me feel vulnerable.

Loss of control

It is unpredictable.

Deterioration of condition

Seems sickness is getting worse Feels like if I were dying

Less independence

More dependency on others. I was strong; my family doesn’t understand how I feel.

Suffering From Cancer-Related Fatigue

Inability to do enjoyable activities

Yes, it limits my ability to do the things I enjoy. I was unable to fly to Colorado for the birth of my youngest daughter’s first child.

Impact on social well-being

Job unsupportive of work from home after chemo[therapy] Too fatigued to interact with anybody

Emotional impact

I don’t feel like getting out of bed. It has kept me from living with hope.

Sense of loss

I miss my hair, eyelashes, and body. I have lost so much of me . . . I want my life back!

PFS-R—Piper Fatigue Scale—Revised

each theme were identified. All aspects of the bracketing and coding were validated by the researchers, who have extensive experience with qualitative data analysis.

Results

A total of 280 participants were accrued and completed the PFS-R. Out of the total sample, 252 participants provided responses to the seven open-ended questions. Mean age was 60.4 years (see Table 1). Importantly, about 36% of patients were racial or ethnic minorities and 46% had colon or lung cancer. Functional status, as measured by the Karnofsky Performance Status, ranged from 70–80 on a scale from 0–100 (0 = dead, 100 = no symptoms), suggesting that some patients were unable to carry on with normal activity.

Cancer-Related Fatigue

Table 2 provides coded qualitative data from participants regarding their perception of CRF. For causes of CRF, several themes emerged. Participants frequently described sleep disturbance related to other symptoms, such as pain. In terms of emotional issues as the cause of CRF, participants used descriptors such as “depressed and tired” as they attempted to communicate the intensity of the psychological effects of CRF. Many participants also reported their cancer treatment as a cause of CRF. The trips taken to and from treatment also were reported to contribute to CRF. Some participants also believed that inactivity was a cause of CRF.

Overall, participants provided many insights into their perception of CRF relief. Both rest and relaxation and exercise and more physical activity were described as helping with CRF. Some participants described rest for more than one day as helpful, whereas others found exercise and physical activity provided a reason to get up and get moving. Participants also reported better diet and less activity as helpful in relieving CRF. For participants who were suffering from other symptoms such as pain, pain medication was helpful in relieving CRF. Several participants described the use of distraction, such as reading, knitting, and meditation, as helpful in relieving CRF. Some participants reported prayer and blessings from God as an effective method to relieve CRF.

The descriptors provided by participants for CRF were mainly negative. CRF was described as a fluctuating symptom, where participants would have spurts of energy followed by a prolonged period of exhaustion. The weakness and exhaustion attributed to CRF also was described as comparable to being in a triathlon. CRF was described as “never-ending” despite sleep and rest. CRF also was described as emotionally labile and depressing. Participants described feeling lethargic, worthless, and losing interest in enjoyable things. Finally, CRF was described as having tremendous social impact, particularly with loved ones or family members.

Because little research in CRF has focused on its meaning, that was of particular interest during data analysis. The themes that emerged provided significant insight into the meaning of CRF as related to function and emotional well-being. Many participants attributed CRF to an inability to function at normal levels. CRF limited the ability of participants to take part in activities, and led to less enthusiasm to engage in physical activities. Participants described that effect as leading to poor QOL. Another significant theme was the loss of enjoyment that was attributed to CRF. Having CRF meant that participants lost the everyday enjoyment of just being alive. Again, participants described the emotional impact of CRF, which led to depression, vulnerability, and worthlessness.

As expected, participants’ descriptions of suffering related to CRF were related to their descriptions of the meaning of CRF. Participants suffered from the inability to do enjoyable activities, including dancing and participating in important family events.
such as the birth of a granddaughter. As a result, participants described that they were unable to live a productive life. Having CRF also meant suffering from its social impact, including employment issues, lack of interaction with others, and even failure of marriage. Emotionally, participants described suffering related to lack of hope, depression, and losing a sense of mission or purpose in life. Finally, participants described a profound sense of loss related to body changes or the loss of time.

Table 3 presents tallies of comments regarding other symptoms related to CRF. Not surprisingly, pain or neuropathy was the most common symptom that participants experienced in conjunction with CRF. Other common symptoms included nausea or dizziness, emotional changes, and gastrointestinal issues.

Discussion

The aim of this qualitative analysis in a cohort of patients with cancer in an ambulatory oncology setting was to describe participants’ perceptions of CRF. The findings underscore the importance of assessing CRF as a multidimensional concept. In busy clinical settings where time dedicated for patient assessment may be limited, the assessment of CRF intensity often is not enough to obtain an understanding of the personal suffering related to CRF. Cognitive appraisals, such as perception, may be important components of understanding how patients derive meaning and suffering from cancer and its related symptoms. To fully assess the impact of a specific symptom on patients’ overall well-being, it may be necessary to also assess personal meaning and suffering related to debilitating symptoms such as CRF. As nurse researchers test interventions for fatigue, such as psychoeducational approaches, outcomes should include evaluation of all domains of QOL. Interventions are needed that include physical approaches, such as exercise, combined with psychosocial therapies to treat the whole-person experience of fatigue.

Figure 1 presents a potential model of CRF derived from the current study’s qualitative analyses. This is an early schema and additional research is needed to test this model’s validity and the relationship between variables or causation. The spiraling effects of CRF begin prior to a diagnosis of cancer, when an individual characterizes life as healthy. Individuals are able to function normally with independence and a sense of control. Tiredness is relieved by rest and sleep. The downward spiral of QOL begins when a diagnosis of cancer is given, and treatment is initiated, followed by its severe side effects. As CRF sets in, it becomes more than a symptom; it begins to impact all dimensions of QOL. Physical well-being is negatively impacted by CRF-related symptoms. The tiredness becomes tremendously unreliable, and cannot be relieved by rest or sleep. That physical experience impacts overall psychological well-being. The combination of physical and psychological suffering related to CRF spirals to greater levels of distress. As CRF continues to linger, social well-being is disrupted, and the individual becomes isolated. Dependency and lack of control leads to a sense of vulnerability. As the downward spiral continues, the individual’s spiritual well-being is disrupted by a feeling of uncertainty, hopelessness, and an awareness of death.

This qualitative analysis of CRF provided a poignant investigation into the personal meaning of CRF and its related suffering. Patients with cancer experiencing CRF are burdened with tremendous physical, psychological, social, and spiritual suffering that may alter the meaning of their cancer experience. The current study’s analysis was limited to narrative data from a validated measurement tool for CRF. Because data were derived only from participants’ written responses, this may

<table>
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<tr>
<th>Symptom</th>
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<tr>
<td>Pain or neuropathy</td>
<td>57</td>
</tr>
<tr>
<td>Nausea or dizziness</td>
<td>14</td>
</tr>
<tr>
<td>Emotional changes</td>
<td>11</td>
</tr>
<tr>
<td>Gastrointestinal problems (e.g., constipation, diarrhea)</td>
<td>11</td>
</tr>
<tr>
<td>Headache</td>
<td>10</td>
</tr>
<tr>
<td>Weakness or sleepy feeling</td>
<td>10</td>
</tr>
<tr>
<td>Skin problems (e.g., rash, dryness, itchiness)</td>
<td>6</td>
</tr>
<tr>
<td>Soreness</td>
<td>5</td>
</tr>
<tr>
<td>Hot flashes</td>
<td>4</td>
</tr>
<tr>
<td>Swelling</td>
<td>3</td>
</tr>
<tr>
<td>Throat burning</td>
<td>3</td>
</tr>
<tr>
<td>Vision problems</td>
<td>2</td>
</tr>
<tr>
<td>Heart problems</td>
<td>1</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>1</td>
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N = 138
Note. Not all participants reported other symptoms related to CRF.
limit the interpretation of the findings. Additional studies are needed to further explore the personal meaning and suffering related to CRF in ambulatory oncology settings. Research also is needed to assess the feasibility of including brief assessments of the meaning of cancer-related symptoms for patients who are undergoing active treatments.

Implications for Nursing Research and Practice

The findings of the current study provided preliminary insight into the personal meaning and suffering related to CRF for patients with cancer who are actively receiving treatment. In the process of caring for patients with cancer, nurses must be aware of the unique concerns of patients with cancer who are experiencing CRF. Many patients will be burdened with CRF during and after their treatment; therefore, attention to the understanding of the meaning of CRF and its related suffering will be of particular importance. Nurses should recognize that patients will strive to derive meaning from their cancer experience, and that search for meaning should be encouraged. Nurses also should recognize that the burden of suffering from uncontrolled symptoms such as CRF may negatively alter patients’ efforts to derive meaning from their cancer experience.

The authors acknowledge that assessment of fatigue both in the clinical setting and in research is challenging. Patients may find it difficult to quantify or rate their fatigue as a multidimensional symptom. True assessment of this symptom can be time consuming. Because the experience of fatigue often is overwhelming and distressing, assessment of fatigue often leads to patients’ sharing of other concerns, such as spiritual distress or psychological responses. Increasing fatigue may be associated with worsened disease by patients and may lead to concerns about survival. Therefore, optimal symptom management is of particular importance.

Conclusion

CRF is a complex, multicausal, and multidimensional sensation (Piper et al., 2008). The intensity of CRF and its impact need to be assessed and measured in practice and research settings. Oncology nurse researchers and clinicians serve a vital role in advancing understanding of this important symptom and improving multidimensional care.

References

Ramfelt, E., Severinsson, E., & Lützen, K. (2002). Attempting to find meaning in illness to achieve emotional coherence: The experiences

FIGURE 1. The Spiraling Effects of Cancer-Related Fatigue


For Exploration on the Go

Access the Oncology Nursing Society’s Putting Evidence Into Practice information about fatigue by opening a barcode scanner on your smartphone. Point your phone at the code and take a photo. Your phone will link to the content automatically.

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