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Patients' Experiences With Cancer-Related Fatigue: A Review and Synthesis of Qualitative Research

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Cancer-related fatigue (CF) is documented to be a highly prevalent condition among patients with cancer and exacts substantial personal and societal costs (Bruera et al., 2006; Cella, Davis, Breitbart, & Curt, 2001; Curt et al., 2000; Iop, Manfredi, & Bonura, 2004; Irvine, Vincent, Graydon, & Bubela, 1998; Minton & Stone, 2009; Stasi, Abriani, Beccaglia, Terzoli, & Amadori, 2003; Stone & Minton, 2008; Wu & McSweeney, 2004). Several studies have reported that patients view CF as the most common and distressing cancer- or therapy-related symptom (Cella et al., 2001; Fulton & Knowles, 2000). Many publications have documented CF's enormous toll on health-related quality of life (HRQOL) (Bower et al., 2000; Bruera et al., 2006; Cella et al., 2001; Fulton & Knowles, 2000; National Comprehensive Cancer Network [NCCN], 2005; Stone et al., 2000). Patients with CF have found the condition incapacitating, as it directly interferes with their ability to function physically and mentally, and it leads to rapid HRQOL deterioration. The deleterious effect of CF on HRQOL includes dramatic effects on patients' relationships, ability to work and enjoy life, and hopes of fighting the illness (Stone et al., 2000).

However, CF remains an underreported and untreated diagnosis, in part because of differences in its measurement and definition (Minton & Stone, 2009; Piper et al., 2008). Several professional societies (e.g., Oncology Nursing Society, European Association of Palliative Care) have attempted to clarify its characteristics (NCCN, 2005, 2007; Radbruch et al., 2008). In addition, the Fatigue Coalition, a multidisciplinary group of medical practitioners, researchers, and patient advocates, proposed diagnostic criteria in 1998 for CF for inclusion in the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Clinical Modification*; however, these criteria were not retained in the final published version (Portenoy & Itri, 1999).

Purpose/Objectives: To systematically review published qualitative reports of descriptions of fatigue by patients with cancer and how cancer-related fatigue (CF) affects their lives.

Data Sources: MEDLINE®, CANCELIT®, Cochrane Database of Systematic Reviews, and the Cumulative Index to Nursing and Allied Health Literature.

Data Synthesis: Two researchers conducted independent reviews of 667 patient quotes found in 154 articles published from 1996–2009 to identify concepts and language used to describe CF.

Conclusions: CF is more intense than the tiredness patients recalled from before diagnosis or treatment. Published patient quotes fail to adjudicate whether CF should be approached as a single symptom or a more complex symptom cluster.

Implications for Nursing: Systematic study of patients with different cancer types and stages is needed to identify effective, valid, and reliable self-reported assessments of CF for clinical practice and trials.

Measurement experts do not agree as to whether CF is a single, unidimensional concept that can be summarized by a single score or a multidimensional construct that requires a score for each essential concept of importance to patients (Lai, Crane, & Cella, 2006). Most definitions and measures acknowledge that CF is a subjective phenomenon; however, they each focus on certain aspects of fatigue while excluding others. To add to the lack of clinical consensus, many existing instruments that purport to evaluate CF were developed without direct input from patients with cancer and, therefore, whether all the concepts of importance to patients and central to CF are captured by these instruments is questionable. Given the referenced measurement debates, the numerous instruments purporting to measure CF, and the many definitions of CF, regulators have struggled to interpret clinical trials using existing CF instruments.

In 2008, five pharmaceutical companies, a medical research consulting firm, and reviewers from the U.S. Food and Drug Administration (as observers), as well as academically based key opinion leaders, formed the Patient-Reported Outcomes of Fatigue Consortium (PROOF-C) to bring consensus to the CF field by developing a conceptual framework of CF based on patient input. This framework is intended to specify the essential concepts that define and measure CF so that it can be monitored effectively in clinical trials and in practice. This study reports the results of a systematic review and synthesis of published qualitative studies to examine CF's effects on patients with cancer through verbatim quotations. The objective of this study was to identify sensitizing concepts, those that guide but do not direct, for additional research on the meaning of CF to patients (Bowen, 2006).

Methods

The patient quotes included in this article are a result of a bibliographic search of English-language publications indexed in four comprehensive biomedical databases. Search criteria were adapted for each database using Boolean strategy; search terms were based on the Medical Library Subject Heading term *fatigue* and its synonyms. The methodology used to conduct the literature review included a search strategy (e.g., key words, databases), abstract and article selection, data extraction, qualitative research analysis, and summary of findings.

The search conducted in the summer of 2007 retrieved 95 articles. Of these articles, 11 provided quotations for analysis. The references in reviewed articles identified another 19 potential articles for patient quotes. An additional post-hoc search using the same search terms was conducted in October 2009 to account for current publications; 56 additional English-language articles published from January 2007 to October 2009 were identified. Ultimately, 26 articles with direct patient quotes about fatigue were identified from the published literature. For each article reviewed, the following information was extracted in addition to verbatim patient quotes: citation; patient population characteristics, including sample size; condition (i.e., site of primary cancer, metastases, treatment, gender, ethnicity, and comorbidities); and methodology (i.e., type of interview, method of interview, other information, and additional measures used).

The data were organized into an abstraction or summary form and imported into ATLAS.ti, version 5.0, a qualitative research data analysis software package that facilitated the organization and analysis of the data (Muhr, 2004). A coding scheme was developed with concepts that had been used at least once in the CF literature to define CF (e.g., "persistent," "not relieved by rest"), and codes were applied to each quote. Two

coders reviewed each transcript and harmonized their coding scheme when discrepancies arose. At the end of the coding process, the study team used the constant comparison method to examine similarities, differences, and patterns in the data to describe the meaning of fatigue as found in published patient quotes.

Findings

The final database contained 667 quotes retrieved from 26 articles, totaling 19,930 words, with an average of 25 quotes retrieved per article (range = 1–87 quotes per article). Table 1 summarizes the characteristics and methods that the authors described, as well as the number of quotations and the list of concepts reported in each article. Table 1 also includes sample size, clinical characteristics (if available), data collection methods (e.g., face-to-face or phone interview, patient-administered questionnaire, longitudinal study), type of interview (e.g., semistructured, unstructured), theoretic approach (e.g., phenomenology, grounded theory), and types of analyses (e.g., content analysis). Figure 1 provides exemplary quotations describing the concepts and subconcepts of CF. Of the 26 articles identified, 9 (34%) were from the nursing literature.

With the exception of four studies with large sample sizes (exceeding 75 patients), the average sample size was 15 patients per study (range = 4–29 patients per study). Two studies included healthy subjects as well as patients with cancer; one study included patients with chronic fatigue syndrome as well as patients with CF. Most of the patients studied were diagnosed with breast cancer, although colon, lung, and ovarian cancers also were represented in some studies. Many studies included patients with advanced-stage cancer. The studies of patients who were undergoing treatment included those receiving chemotherapy, radiotherapy, surgery, exercise therapy, or complementary therapy (e.g., acupuncture) separately or in combination. Most patients were receiving chemotherapy at the time of interview.

Face-to-face interviews (n = 21), phone interviews (n = 2), focus group discussions (n = 5), and patient-completed instruments (n = 2) were used to collect data. Two studies used face-to-face interviews and focus groups together. Of the 26 studies, 20 employed a semistructured interview guide and the remaining used a structured or unstructured guide. Only seven articles provided the actual interview questions.

Eight studies employed grounded theory, a method using inductive reasoning that emphasizes the generation of theory based on observations of patterns in qualitative data. With grounded theory methods, the meaning of a concept is not discovered by applying a priori theory or concepts but rather emerges from the words and actions of participants (Charmaz, 1995; Strauss & Corbin, 1998). Sampling is done purposefully and iteratively in studies with a

Table 1. Review of Studies With Patient Quotations About Fatigue

Study	Quotes	Sample	Data Collection Method	Type of Interview	Theoretic Approach	Analysis	Concepts Extracted
Adamsen et al., 2004	9	23 patients with colon (n = 6), breast (n = 5), ovarian (n = 2), and testis (n = 2) cancer, and one each of sarcoma, small cell lung cancer, unknown primary, cervix, Hodgkin disease, non-Hodgkin lymphoma, myelomatosis, and acute lymphoblastic leukemia	Fact-to-face interviews	Semistructured	No data available	No data available	Synonyms (n = 6), descriptors, temporal, intensity and severity, unrelieved after rest, physical impact, and coping strategy
Barsevick et al., 2001	18	8 patients with ovarian cancer (n = 2) and one each of breast, prostate, lymphoma, tonsil, lung, and colon cancers	Focus group Face-to-face interviews	Semistructured	No data available	Content analysis	Synonyms (n=2); descriptors; temporal; abnormal; intensity and severity; unrelieved after rest; cognitive, physical, social, and emotional impact; and coping strategy
Bennett et al., 2007	29	16 patients with breast cancer and 12 patients with chronic-fatigue syndrome	Focus groups	Structured	Grounded theory	Content analysis	Synonyms (n = 3), descriptors, temporal, intensity and severity, unrelieved after rest, and cognitive, physical, social, and emotional impact
Cappiello et al., 2007	10	20 patients with breast cancer	Face-to-face interviews Phone interviews	Semistructured	No data available	No data available	Synonyms (n = 2), other impact; and physical, other impact
Chung et al., 2009	38	13 patients with breast cancer	Focus groups	Semistructured	Grounded theory	Content analysis	Synonyms (n = 5); social, other impact; and coping strategy
DeSanto-Madeya et al., 2007	7	84 patients with breast cancer	Activity log	No data available	Feminist theory	Secondary analysis Content analysis	Synonyms (n = 2) and physical impact
Efkors & Petersson, 2004	9	15 patients with lung cancer	Face-to-face interviews	Semistructured	No data available	Content analysis	Synonyms (n = 5); descriptors; temporal; intensity and severity; physical, social, and emotional impact; and coping strategy
Ferrell et al., 1996	55	910 patients with ovarian (n = 152), breast (n = 37), and thyroid (n = 34) cancers and 687 cancer survivors	Focus group Face-to-face interviews	No data available	Phenomenology	Content analysis	Synonyms (n = 5); descriptors; abnormal; intensity and severity; cognitive, physical, social, emotional, and other impact; and coping strategy

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Table 1. Review of Studies With Patient Quotations About Fatigue (Continued)

Study	Quotes	Sample	Data Collection Method	Type of Interview	Theoretic Approach	Analysis	Concepts Extracted
Gibson et al., 2005	15	8 patients with cancer, including leukemia (n = 4), brain (n = 2), sarcoma (n = 1), and other (n = 1)	Face-to-face interviews	Semistructured	Phenomenology	Content analysis Moustakas modification of the Stevick- Colaizzi method	Synonyms (n = 2); descriptors; temporal; abnormal; intensity and severity; unrelieved after rest; physical, emotional impact; and coping strategy
Glaus et al., 1996	70	20 patients with cancer, including 14 different tumor types, 20 other patients, and 20 healthy subjects	Face-to-face interviews	Unstructured	Grounded theory	No data available	Synonyms (n = 8); descriptors; temporal; abnormal; intensity and severity; unrelieved after rest; cognitive, physical, social, and emotional impact; and coping strategy
Gledhill, 2005	38	24 patients with cancer, including breast (n = 5), digestive (n = 4), lung (n = 4), renal (n = 4), leukemia or myeloma (n = 3), sarcoma (n = 2), gynecologic (n = 1), and other (n = 1); 24 other patients; and 24 healthy subjects	Face-to-face interviews	Semistructured	Grounded theory	No data available	Synonyms (n = 6); descriptors; abnormal; intensity and severity; unrelieved after rest; cognitive, physical, social, and emotional impact; and coping strategy
Holley, 2000	31	16 patients with cancer, including breast (n = 3), colon (n = 2), non-small cell lung (n = 2), melanoma (n = 2), and one each for head and neck, non-Hodgkin lymphoma, pancreatic, gastroesophageal, acute lymphocytic leukemia, squamous cell of perineum, and squamous cell of tonsil	Face-to-face interviews	Semistructured	Symbolic interactionism	Content analysis	Synonyms (n = 4); temporal; intensity and severity; unrelieved after rest; cognitive, physical, social, emotional, and other impact; and coping strategy
Kennedy et al., 2007	3	29 patients with cancer, including breast (n = 24), non-Hodgkin lymphoma (n = 2), uterus (n = 2), and larynx (n = 1)	Focus group Face-to-face interviews	Semistructured	No data available	Content analysis	Synonyms (n = 4), intensity and severity, and cognitive, social, and emotional impact
Krishnasamy, 2000	14	15 patients with cancer, including breast (n = 5), prostate (n = 4), lung (n = 2), non-small cell lung (n = 2), ovarian (n = 1), and mesothelioma (n = 1); and 22 other subjects, including relatives or friends (n = 11) and healthcare providers (n = 11)	Face-to-face interviews	Semistructured	Grounded theory	Content analysis Glaser and Strauss constant comparative method	Synonyms (n = 3); descriptors; temporal; abnormal; intensity and severity; cognitive, social, and emotional impact; and coping strategy
Lindqvist et al., 2004	8	4 patients with cancer, with one each of breast, prostate, kidney, and abdominal	Face-to-face interviews	Semistructured	Phenomenology	No data available	Synonyms (n = 3); descriptors; intensity and severity; physical, social, and emotional impact; and coping strategy

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Table 1. Review of Studies With Patient Quotations About Fatigue (Continued)

Study	Quotes	Sample	Data Collection Method	Type of Interview	Theoretic Approach	Analysis	Concepts Extracted
Magnusson et al., 1999	41	15 patients with cancer, including lymphoma (n = 5), breast (n = 3), gastrointestinal (n = 2), ovarian (n = 2), and one each of myeloma, pancreatic, and malignant melanoma	Face-to-face interviews	Unstructured	Grounded theory	No data available	Synonyms (n = 4); descriptors; temporal; abnormal; intensity and severity; cognitive, physical, social, and emotional impact; and coping strategy
Messias et al., 1997	77	127 patients with cancer, including breast (n = 55), lung (n = 19), ovarian (n = 11), bladder (n = 8), and others (n = 34)	Face-to-face interviews	Semistructured	Grounded theory	Content analysis	Synonyms (n = 6); descriptors; temporal; abnormal; intensity and severity; unrelieved after rest; physical, social, and emotional impact; and coping strategy
Pearce & Richardson, 1996	20	6 patients with cancer	Face-to-face interviews	Semistructured	Phenomenology	No data available	Synonyms (n = 6); descriptors; physical, social, emotional, and other impact; and coping strategy
Polley et al., 2007	1	782 patients with breast cancer	Patient-administered questionnaire	No data available	No data available	Content analysis	Synonyms (n = 2)
Porock & Juenger, 2004	29	10 patients with renal cell carcinoma or melanoma	Face-to-face interviews	Semistructured	No data available	Content analysis	Synonyms (n = 4), descriptors, temporal, intensity and severity, unrelieved after rest, and cognitive, physical, social, and emotional impact
Potter, 2004	13	6 patients with cancer, including kidney (n = 2) and one each of colon, cervix, lung, and pancreas	Face-to-face interviews	Semistructured	Phenomenology	Content analysis	Synonyms (n = 5); unrelieved after rest; cognitive, physical, social, and emotional impact; and coping strategy
Ream et al., 2006	10	21 patients with cancer, including eight in treatment, six off treatment for one to two years, and seven off treatment for five years or more	Face-to-face interviews	Semistructured	Phenomenology	No data available	Synonyms (n = 5); descriptors; intensity and severity; physical, social, and emotional impact; and coping strategy
Ream & Richardson, 1997	11	9 patients with cancer, including breast (n = 5), non-Hodgkin lymphoma (n = 2), colon (n = 1), and rectal (n = 1) as well as six patients with chronic obstructive airway disease	Face-to-face interviews	Semistructured	Phenomenology	Content analysis Moustakas modification of the Stevick-Colaizzi method	Synonyms (n = 3), descriptors; temporal, and cognitive, physical, social, and emotional impact

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Table 1. Review of Studies With Patient Quotations About Fatigue (Continued)

Study	Quotes	Sample	Data Collection Method	Type of Interview	Theoretic Approach	Analysis	Concepts Extracted
Rhodes et al., 1988	31	20 patients with cancer	Phone interviews	Semistructured	Phenomenology	Content analysis	Synonyms (n = 3); temporal; intensity and severity; physical, social, and emotional impact; and coping strategy
Westerman et al., 2007	62	23 patients with small cell lung cancer	Face-to-face interviews Longitudinal study	Semistructured	Grounded theory	No data available	Synonyms (n = 4); descriptors; temporal; abnormal; intensity and severity; cognitive, physical, social, and emotional impact; and coping strategy
Wu & McSweeney, 2007	43	10 patients with cancer	Face-to-face interviews	Semistructured	Phenomenology	Content analysis	Synonyms (n = 6); descriptors; temporal; abnormal; intensity and severity; unrelieved after rest; physical, social, and emotional impact; and coping strategy

grounded theory approach, and sample size is determined by the achievement of saturation (Lasch et al., 2010). Nine studies used phenomenology, a qualitative approach that aims to understand the participants' experiences as they perceive and interpret them; that is, in the context of their own "life world" (Crabtree & Miller, 1992). This approach typically requires a limited number of participants, sometimes only one or two, usually no more than 10 (Creswell, 1998). One study was identified as being guided by feminist theory, which emphasizes that "women think, act, and feel differently than men," and provided "the lens through which women's activities of daily living were viewed" (DeSanto-Madeya, Bauer-Wu, & Gross, 2007, p. 842). The remaining studies did not report their theoretic approach. Content analysis was the primary analytic method in the studies (n = 17).

Patients' Experiences of Fatigue

Fatigue descriptors: Of the 667 words or phrases coded, fatigue was used by patients (and coded as such) 107 times. Tired was used 247 times, references to energy level (n = 61), and being weak (n = 20) or exhausted (n = 21) also were reported. In addition, patients referred to being worn out (n = 6), listless (n = 5), finished (n = 4), or sluggish (n = 3). Sleepiness and feelings of lethargy also were reported. Publications frequently noted colloquialisms, imagery, or metaphors patients used to describe the sensation of fatigue. Patients, for example, reported feeling "just deathly hung over" (Messias, Yeager, Dibble, & Dodd, 1997, p. 45) and "being very slow, very sickly" (Ferrell, Grant, Dean, Funk, & Ly, 1996, p. 1544). Patients used imagery and metaphors, such as

When I get up, my legs feel like spaghetti (Messias et al., 1997, p. 45).

I was a carpet (Barsevick, Whitmer, & Walker, 2001, p. 1367).

I relate that to a tire, that the rubber is wearing down and you just don't bounce back (Barsevick et al., 2001, p. 1367).

[I feel] out of gas (Porock & Juenger, 2004, p. 358).

Like your battery just ran dry (Porock & Juenger, 2004, p. 358).

I was like a zombie (Porock & Juenger, 2004, p. 359).

You're really drained, as if you want someone to pump some blood into you . . . you know, like a clock-work person you want to be wound up again (Ream & Richardson, 1997, p. 48).

Like a wet fish flopped out . . . just like a rag doll . . . like I had been run through a ringer (Wu & McSweeney, 2007, p. 120).

I feel like someone let the plug out somewhere and all my energy drained out (Messias et al., 1997, p. 45).

Fatigue sensations: Patients described CF as “overwhelming” or “all-encompassing.” CF was seen as abnormal or qualitatively different from the tiredness patients had experienced prior to their cancer diagnosis. Some patients implied that this abnormality was simply because of the intensity or pervasiveness of the tiredness, whereas others believed unique aspects distinguished it from ordinary exhaustion.

Fatigue severity was described by some patients as “extraordinarily severe”; others said CF was being “very, very tired,” “really tired,” “extremely tired,” or “terribly tired” (Glaus, Crow, & Hammond, 1996, p. 13). Patients also described the intensity of fatigue using colloquial phrases such as “sick-tired” or “tired like mad” (Glaus et al., 1996, p. 13). To convey symptom severity, some patients referred to simple actions of daily living that they could no longer accomplish. For example, patients reported,

I’m too tired to get out of bed in the morning (Messias et al., 1997, p. 45).

When I’m tired . . . even chewing food can make me tired (Potter, 2004, p. 18).

I didn’t have the strength to even turn on the TV (Ferrell et al., 1996, p. 1546).

Tired means that you can hardly put one foot in front of the other (Westerman et al., 2007, p. 859).

Once I started becoming active again, I would find that by noon or one o’clock, I was just spent (Chung, Cimprich, Janz, & Mills-Wisneski, 2009, p. 242).

Patients also noted that CF persisted after adequate rest (i.e., no matter how much they slept, their feelings of tiredness persisted), distinguishing it from exertion-induced or sleep deprivation-related fatigue. Others reported that CF was caused by their inability to sleep or to obtain adequate sleep, whereas others claimed that any amount of sleep or rest was unable to provide adequate rest when they were fatigued.

Patients described fatigue as “constant,” “unrelenting,” and following certain patterns (e.g., particularly after a cycle of chemotherapy). For some patients, CF was unpredictable; it had a sudden onset rather than gradually building up over the course of a day. They could feel fine at one moment and be completely exhausted the next moment without warning. Other patients felt they could predict CF. These patients associated their fatigue with treatment; CF was related to how recently they had received chemotherapy or radiotherapy. Many patients could identify specific cycles and actual weeks they would feel tired. Others felt their CF to be a cumulative treatment effect (i.e., each successive treatment worsened fatigue).

Impact of Fatigue

Quotes more often described the impact of fatigue on patients’ lives rather than the sensation of fatigue itself

(403 quotes were coded as impact; 259 quotes were coded as sensation). With the exception of “impact on cognition,” the impact codes (i.e., emotional, physical, and social impact) appeared in more than 95% of the articles. Patient quotes specifically describing emotional, physical, social, and cognitive effect of fatigue are detailed in this article.

Emotional impact: Quotes containing descriptions of the emotional impact of CF were more common than those about any other concept. Patients’ feelings of anger or frustration because of the physical and social limitations placed on them by fatigue were quoted commonly. For example, one patient described the inability to do things as a loss that saddened her greatly (Gledhill, 2005). Patients also reported feeling depressed or unable to hold back tears. The emotional impact of CF is depicted in patient quotes, such as

I eventually lost all ability to function well and “hit the wall” emotionally. I felt I couldn’t go on—very uncharacteristic for me (Ferrell et al., 1996, p. 1543).

I’m a bit depressed, when it [fatigue] does stop, if it doesn’t stop it would be better if my life was over (Westerman et al., 2007, p. 859).

My body has let me down. Sometimes that makes me angry and I feel frustrated because I can’t do the things I want to do (Wu & McSweeney, 2007, p. 122).

Physical impact: The physical impact of CF was apparent in the comments from patients describing physical sensations associated with CF and the functional limitations CF caused. Patients’ quotes described physical sensations, such as “I am out of breath from just going up the stairs to the first floor” (Adamsen et al., 2004, p. 366).

These sensations were associated in their quotes with functional limitations: “The fatigue is so debilitating that there are days that to turn the pages of the newspaper was more than I could do” (Barsevick et al., 2001, p. 1367). Many patients also reported that tiredness prevented them from performing basic activities (e.g., chewing food, brushing hair, brushing teeth). Quotes describing the physical impact of CF included

At work, I have to force myself to stay awake (Bennett, Goldstein, Friedlander, Hickie, & Lloyd, 2007, p. 130)

I have problems in walking. I need to rest in between (Glaus et al., 1996, p. 14).

I don’t do anything. I’m too tired to get out of bed (Messias et al., 1997, p. 45).

I am having trouble keeping up with my housework (DeSanto-Madeya et al., 2007, p. 844).

Social and familial impact: Publications reported that fatigue had an effect on patients’ social and family life. In addition, CF caused patients to feel isolated.

Concept: Sensations of Fatigue

Abnormal sensation (n = 14)

- "It is not exhaustion. I've been exhausted. I've never had fatigue like this. It's not work fatigue or emotional fatigue. It's very different. It's incredible. It's like rubber knees. All of a sudden everything's fine. And you just start sinking. You're like rubber knees. There's nothing to hold you up" (Ferrell et al., 1996, p. 1543).
- "I was tired then, but now . . . I didn't know what tired was until now" (Messias et al., 1997, p. 45).
- "Normal tired feels like you're tired. There's a reason for it . . . if you get a pretty good night sleep . . . or if you take a nap, you're going to be fine. It's not anything that's going to happen. Fatigue seems to be bigger. It encompasses so much more because more things feed into it. Depression or the medicine, or I'm taking eight pills a day, just kind of, it all feeds into it. It's not just being tired. It's the whole emotional gamut; there are not words for that" (Wu & McSweeney, 2007, pp. 119–120).

Descriptions of fatigue (n = 18)

- "After my chemo[therapy], I am also tired but it feels more like I have the flu or a hangover" (Adamsen et al., 2004, p. 366).
- "You feel like a block of concrete, there's this heaviness in your body and this tired feeling that makes you feel sleepy" (Magnusson et al., 1999, p. 228).
- "I was just drained, just listless. Like a wet fish flopped out . . . just like a rag doll. . . . Like I had been run through a ringer or something like that" (Wu & McSweeney, 2007, p. 120).

Intensity and severity (n = 19)

- "The only word that you can describe is extreme . . . fatigue, where you just don't have the energy to get up" (Kennedy et al., 2007, p. 22).
- "Sometimes the fatigue can become so strong you just almost feel like you've been drugged and you need to go lie down and sleep and it can come over you very suddenly" (Wu & McSweeney, 2007, p. 120).
- "I couldn't overcome it. I couldn't force myself . . . the fatigue was overwhelming . . . there would be times when you might be tired but you can make yourself do it anyway. I couldn't make myself do things anyway during certain phases of it. So it was just overwhelming" (Wu & McSweeney, 2007, p. 121).

Temporal descriptions of fatigue (n = 15)

- "There are periods when you get really tired but . . . when it's over, then you feel fit again" (Ekfors & Petersson, 2004, p. 331).
- "You can't see it coming. Suddenly you're down and out and don't know how you got there" (Holley, 2000, p. 91).
- "After the third or second night [post-therapy], I start getting weak . . . It takes me up to 10 days to two weeks to sort of feel like getting up" (Messias et al., 1997, p. 45).
- "Constant" (Porock & Juenger, 2004, p. 358).
- "I felt good, let's say, for about a week [out of every three-week administration]. I felt half-way decent about a week before I had my chemo[therapy] again" (Rhodes et al., 1988, p. 191).

Unrelieved by rest (n = 11)

- "I wake up and think—I've got nothing out of this sleep at all" (Bennett et al., 2007, p. 130).
- "I was a total wreck. However much I rested, I couldn't manage to shake off my tiredness. Even if I slept 8 or 10 hours at night, I still woke up in the morning totally exhausted, as though I had run a marathon" (Gledhill, 2005, p. 310).
- "I just keep falling asleep all the time but sleeping doesn't help. The tiredness is there all the time it's really strange" (Potter, 2004, p. 21).

N = 26 studies

- "I wake up maybe every three or four hours or so and, when I do get up, I spent the hours in the bed, but I'm still tired. The sleep doesn't refresh me" (Wu & McSweeney, 2007, p. 121).

Concept: Impact of Fatigue

Cognitive impact (n = 13)

- "My brain's gone. . . . I have no memory" (Bennett et al., 2007, pp. 129, 131).
- "It is in the limbs, but also in the head, one is listless to read a newspaper or to watch television, it is 'total tiredness'" (Glaus et al., 1996, p. 14).
- "I've been tired from work, but mentally I could still get up. With this kind of fatigue, you can't even form it in your mind to do it" (Holley, 2000, p. 92).
- "You can't concentrate; when my wife asks what I've been reading, I don't know, I can't remember" (Magnusson et al., 1999, p. 228).

Emotional impact (n = 20)

- "Tiredness feels like depression, it makes me feel listless, one has to fight against it" (Glaus et al., 1996, p. 14).
- "After about two weeks I became very tearful, I wasn't doing my job properly and I was forgetting things . . . I realized that I, well, I couldn't cope really, I was just really struggling" (Kennedy et al., 2007, p. 22).
- "When I feel so dull and tired I can't go on anymore, then I always start crying; there's no stopping the tears" (Magnusson et al., 1999, p. 228).
- "I'm much more tired than before and that makes me frustrated" (Messias et al., 1997, p. 46).
- "My body has let me down. Sometimes that makes me angry and I feel frustrated because I can't do the things I want to do" (Wu & McSweeney, 2007, p. 122).

Physical impact (n = 22)

- "You have to shave . . . you have to shop and get your hair cut, but, no, I haven't been able to do that, and I don't care that much" (Ekfors & Petersson, 2004, p. 331).
- "I have to take my time going upstairs now or I become breathless. The slightest effort puts me out" (Gledhill, 2005, p. 299).
- "Everything is too much effort. It is ridiculous. Just to comb your hair, I mean I haven't got any hair, but just to put my wig on, I just couldn't be bothered . . . even to get dressed is too much effort . . . it is as much as I can do to get out of bed and go to the loo" (Ream & Richardson, 1997, p. 49).
- "I could not get out of bed and walk into the bathroom and I would have to sit down, go to the shower, take a shower, but then I would have to sit down, put on my clothes, then I would have to sit down—I would have to rest in between each activity. If I just walked out to my car, I would have to sit in the car for a few minutes and rest because I had no energy left" (Rhodes et al., 1988, p. 191).
- "It's so bad that I know I'm hungry, but I'm too tired to get up and go to the kitchen and fix it. And if I fix it, I'm too tired when I sit back down to eat it. I don't even feel like chewing . . . it's hard to describe, it's not like anything else. It's horrible" (Wu & McSweeney, 2007, p. 121).

Social impact (n = 21)

- "I want to take my loved one dancing and can't do it, and that bothers me. We try to plan at least one day a weekend to do something not physically straining" (Holley, 2000, p. 92).
- "It got to the point that I didn't answer the phone because it was work to talk. I'd go to church on Sunday morning, for an hour and a half or so, then I'd go home. Mostly I just wanted to stay home" (Holley, 2000, p. 93).

(Continued on the next page)

Figure 1. Quotations Describing the Concepts and Subconcepts of Cancer-Related Fatigue

Concept: Impact of Fatigue (continued)

Social impact (n = 21)

- “You know that’s what makes me regret, watching myself give things up, feeling too exhausted to enjoy the people who have given me such pleasure” (Krishnasamy, 2000, p. 408–409).

Concept: Coping Strategies

Coping strategies (n = 19)

- “Mostly the only thing that helps the fatigue is giving into it” (Ferrell et al., 1996, p. 1544).
- “When you’re ill and tired physically, every bit of energy you have becomes precious. You can’t afford to disperse it indis-

N = 26 studies

criminally right and left. You have to reserve it for essential activities” (Gledhill, 2005, p. 299).

- “You have to force yourself to get up in the morning, force yourself to eat, force yourself to meet people” (Gledhill, 2005, p. 303).
- “It’s all about attitude really . . . in altering what you can, accepting what you can’t” (Pearce & Richardson, 1996, p. 114).
- “So I’ve learned to pace myself differently and learn how to interpret the cues of my own body . . . like, I knew that I needed to take a rest” (Wu & McSweeney, 2007, p. 122).
- “For a while during chemotherapy treatment, I had to accept fatigue as reality one out of every three weeks and just expect to rest and stay home that week” (Ferrell et al., 1996, p. 1543).

Figure 1. Quotations Describing the Concepts and Subconcepts of Cancer-Related Fatigue (Continued)

Some quotes show that patients attribute restrictions in their social lives to physical limitations related to CF. Tiring quickly or feeling the need to go to bed early keeps some patients housebound. Being housebound, in turn, isolated them from anyone other than the people living with them, even from their families and closest friends. Patients described being “too tired to talk” or frustrated when they could not spend time with or relate to family or friends as they did before their disease. “You don’t feel like doing anything; you don’t call people up; you get unsociable” (Magnusson, Moller, Ekman, & Wallgren, 1999, p. 228). One particularly poignant quote makes clear the cost of CF on family relationships.

Fatigue just, it seeps into every part of your life. I, it doesn’t just affect one thing or two things. It affects my relationship with my kids, my relationship with my husband, my relationship with my friends (Wu & McSweeney, 2007, p. 123).

Cognitive impact: Quotes mentioned cognitive effects of fatigue as interfering with patients’ ability to think, concentrate, or be creative. Patients most often related the inability to think to difficulty working, and the inability to concentrate (or form thoughts) was so severe for some patients that it made working at their jobs impossible. Some quotes provided insight into dramatic and even frightening limitations in cognitive ability that patients experienced with CF.

My brain’s gone . . . (Bennett et al., 2007, p. 129).

I have no memory (Bennett et al., 2007, p. 131).

I have difficulty finding right away a solution to even quite simple problems (Gledhill, 2005, p. 303).

You can’t concentrate; when my wife asks what I’ve been reading, I don’t know, I can’t remember (Magnusson et al., 1999, p. 228).

The thing that went with it [the fatigue] was having poor concentration . . . my ability to connect ideas somehow, to sort of synthesize things, wasn’t good

and I really got panicked (at work) (Ream & Richardson, 1997, p. 49).

Coping strategies: In 18 of the 23 articles containing verbatim quotes, patients spoke about different coping strategies for living with fatigue, such as increased exercise, modifying their diets by eating “healthy” foods, planning ahead to ensure enough energy for things that were important, sleeping more, and cutting back on activities. Patients commented that CF forced them to rely more on family, relatives, and friends, and to learn to let others do things for them. The following quotes describe different coping mechanisms.

I made no plans for three days each time I got chemo[therapy], and then after that I would be fine (Barsevick et al., 2001, p. 1367).

I have arrived at my own set of priorities, things that are important to me. I try not to waste mental energy on things I cannot change (Ferrell et al., 1996, p. 1546).

I compensate the lack of physical stimulation by intellectual stimulation. Of course, if I’m feeling tired physically, I take things easy, but as soon as I’m feeling better I read, go to classes, I continue to learn. In that way I can plan my days, my time, and look forward to the future (Gledhill, 2005, p. 310).

Eating makes fatigue better (Holley, 2000, p. 93).

Accept walks as my only form of exercise (Holley, 2000, p. 93).

I treat myself to a nap if I need it (Chung et al., 2009, p. 239).

The most frequently quoted coping strategies were to learn to live with fatigue and to rely on willpower to overcome the feeling; patients pushed themselves to do things. Others simply learned to limit themselves to their most important activities. Some described this process of learning to live with fatigue as adjusting their expectations of what they could accomplish, whereas others reported that they had to give in to CF. Together,

the quotes suggest that, overall, patients accept fatigue and learn to scale back their level of activity to accommodate its limiting effects.

The following observations summarize results of this review of patient quotes from research with patients with cancer experiencing fatigue. Patient quotes suggest fatigue in cancer is different—more intense, less predictable, longer lasting, more problematic—from tiredness experienced prior to cancer and its treatment. Patient quotes indicate physical, emotional, cognitive, and social issues may be caused by or associated with CF. Patient quotes describe various coping strategies used to deal with CF, including adjusting expectations for what they can achieve and relying more on others for assistance.

Discussion

The most striking finding in this review is that, although fatigue is one of the most commonly reported symptoms of cancer and a universally reported adverse event of cancer treatment, so few articles have published reports of how patients actually describe CF. Patients, at least in their published quotes, attribute emotional, cognitive, and social issues to CF. As patients often will describe illness metaphorically, their quotes were rich with metaphors to describe the severity of their fatigue or how it makes them feel (Sontag, 1978). The publications seldom provided further insight into the meaning of colloquial or metaphoric phrases to patients; however, these quotes seem to imply that the patients feel completely depleted. Whether patients can further characterize these sensations and what effect the sensations have will need to be determined in future studies to ensure that the interpretation of patients' experience is not driven by the researchers' biases or perspective. Given the paucity of verbatim quotes from patients experiencing CF, additional research with an adequate sample can fill an enormous gap in the understanding of CF from the patient perspective. Limitations of this approach were recognized prior to launching the study because this method could entice other researchers under time constraints to use a similar method. The intention was to show what could and could not be gained from analyzing and synthesizing patient quotes and the characteristics of articles that reported them.

The objective of this study was to identify sensitizing concepts to develop future research to understand how patients with cancer talk about CF, what they consider it to be, and how they experience the sensations and effects of CF. To fully understand what should be measured to monitor CF or to assess efficacy of its treatments requires documentation of what sensations and experiences patients label as "fatigue." Despite the evocative nature of some of the similes and metaphors

patients used, the patients' intentions remain unclear when they described CF with phrases and words such as "being punched," feeling "like a zombie," "drained," or a "wet fish flopped out." A better understanding of these colorful descriptions is essential if healthcare professionals are to identify accurate and comprehensive measures of CF for clinical trials or patient monitoring. In addition, the relative frequency of metaphors versus simple statements may reflect the authors' reporting bias for the imagery of metaphor and not patient language trends. Metaphors are more evocative and may more dramatically convey the effect of fatigue on participants.

Patients' quotes suggest that the word "tiredness" will not adequately capture the multidimensional nature of the CF experience. Future research is required with a sufficient number of patients in strata defined by gender, age, tumor type, treatment, and disease progression to identify the similarities and differences in the experience of CF within and between strata.

Limitations

Several limitations to this study exist. First and foremost is potential publication bias; this study was constrained in that only published studies were reviewed. Search criteria to identify articles with quotes may have omitted some sources of quotations from patients with CF, such as those in book chapters or posted on Web sites. Unless a book chapter was cited by an article or listed in one of the databases, it was not included. In addition, page count limitations imposed by journals reduce the number of quotations that can be presented in a qualitative research article. Consequently, the meaning patients intended may not have been adequately captured or reported. Qualitative research generates a vast amount of data that cannot be easily summarized in tables and figures without losing the essence of the findings (Sandelowski, Voils, & Knafl, 2009).

This study only reviewed published quotes from other studies, which may reflect a microcosm of the findings from the original studies reviewed. Quotes in publications reflect the statements patients made that were salient for the researcher and the research question addressed in the original study. Direct quotes tend to be colorful, interesting, eloquent, or evocative statements rich in metaphor and poignant insights. The dull, mundane, prosaic, or inarticulate comments that make up the core of most spoken communication generally are summarized or left unmentioned in published study reports.

Second, because the questions asked of patients were seldom available, whether "fatigue" was initially introduced by the patients or by the researchers as a term to describe the patients' experiences is unclear, limiting the ability to determine whether the ques-

tions themselves could have biased the results. When interview questions were transparent, the term fatigue was clearly introduced by the interviewer. In addition, exclusion criteria suggested selection bias either through self-selection or through having their physician diagnose CF. Inclusion criteria also relied on patients' self-assessments of fatigue severity on questionnaires using the term fatigue to elicit information on patients' CF severity (e.g., European Organisation for Research and Treatment of Cancer Quality-of-Life Questionnaire Core 30, visual analog scale for fatigue). In addition, given the sample in some of these studies, knowing if a patient quote came from a patient with cancer was not always possible as some articles reported on studies that included patients with cancer and those without cancer. Together, such limitations prevented the authors from determining whether patients spontaneously referred to their condition as fatigue.

The majority of the patients in these studies were women with breast cancer who were on chemotherapy at the time of the interview. Therefore, the generalizability of these descriptions and the effect of CF to other tumor types, to men, and to patients on other treatments or who are not currently receiving treatment is an important area for further study. In addition, research should explore the temporal dimensions of CF. Why is it that some patients see CF as a cumulative experience and others as waxing and waning with treatment cycles?

The patients' quotes more often describe the effects of fatigue rather than the sensations associated with CF; whether this is because of a greater tendency of patients to talk about effects, a greater willingness of researchers to report quotes referring to effects, or the nature of the research questions to which patients were asked to respond is unclear. Impact statements may be more dramatic or interesting than simple descriptions of a sensation. However, describing the sensation of fatigue also may be unsatisfying for patients because they want to differentiate it from the healthy sensation associated with lack of sleep or prolonged exertion.

Researchers who conducted the cited studies generally were not attempting to identify what was needed to more accurately diagnose CF, to identify a comprehensive CF assessment, or to fully characterize the effect of CF on the life of a patient with cancer. To achieve the PROOF-C objectives, the information from patients about their experiences should be grounded in language the patients use, but the questioning must enable the researcher to detect important measurement questions, such as whether fatigue is simply an experience of tiredness (e.g., more intense, longer lasting) that is extreme because of its consequences (e.g., emotional, cognitive, physical, social effect). If so, is it important to understand whether all of these must be captured to accurately characterize CF severity? If not, can a single

numeric rating scale for tiredness, if coupled with a more complex effect assessment, provide a parsimonious approach to detecting and monitoring CF that is sufficiently comprehensive and accurate to use as a clinical trial end point?

Conclusion

This study was an exploration of the patient's voice describing CF and its effect in published literature. Available research (including this analysis of published quotes from patients with cancer) leaves many questions unanswered that must be addressed if reliable and well-defined end points for clinical research are to be identified to assess and monitor the effects of cancer treatments on CF. Additional research is essential to more clearly delineate patients' experiences of CF and to ensure that one has comprehensively captured the language patients use and the meaning they ascribe to CF and its impact. In addition, research should determine if the CF experience is the same for all cancer types, whether and how treatment histories and comorbid conditions complicate the experience and reporting of fatigue, and, if possible, in what ways CF sensations differ from its effects.

Finally, the conceptualization of CF based on rigorous qualitative research across cancer types and treatments that could lead to a consensually approved case definition awaits additional research. The clinical, quality-of-life, and economic implications of such a case definition are of paramount importance to patients with cancer and their families, as this exploratory work makes clear.

Implications for Practice

Incorporating patient-reported outcome instruments in routine clinical care for patients with cancer will help clinicians track and address specific problems fatigue causes. In addition, this comprehensive synthesis suggests how patients may describe and experience CF, alerting oncology nurses to ask their patients about CF so that a treatment regimen could be planned and recommended. Patient-reported outcome instruments that provide sufficient detail to help target interventions will need to be developed, however, so that interventions and medications can address CF and its effects more comprehensively. Finally, this article highlights the patient's voice concerning CF and this may aid in diagnosing CF as well as, given the gravity of its impact on HRQOL, help provide a rationale to develop standardized diagnostic criteria.

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