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## **FATIGUE IN CHRONIC FATIGUE SYNDROME: A DISCOURSE ANALYSIS OF WOMEN'S EXPERIENTIAL NARRATIVES**

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Chronic fatigue syndrome (CFS) is a debilitating condition. Approximately 75% of sufferers are women. The etiology of CFS is debated, but remains inconclusive. "Fatigue" is ill defined and conceptually problematic. The international multidisciplinary literature on CFS reveals a paucity of studies on women. Qualitative research to analyze women's discourses on CFS is virtually absent. Eleven New Zealand women of European descent with experience of CFS were interviewed in depth. Within the complex facets of CFS, this article reports specifically on an analysis of discourses on "fatigue." The predominant theme that emerged was that fatigue is articulated as "lack" or absence, which is not representable as an identifiable entity in biomedical terms. Parallels with chronic pain are briefly drawn. We conclude that approaches to CFS must respond to the diverse and complex constructions of the experience of fatigue evident in women's narratives.

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Chronic fatigue syndrome (CFS), postviral fatigue syndrome (P.V.F.S), myalgic encephalomyelitis (ME), "yuppie flu," or Tapanui flu are some of the many names coined to identify what can be a chronic and debilitating

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illness with a plethora of symptoms. In this article we analyze the way women employ the concept of fatigue in their narratives of CFS. What is fatigue? What role does fatigue play in women's experience of CFS? In the context of analyzing talk about fatigue, we consider discourses on the body and the way in which energy is mobilized as a concept through which the women interviewed for this study convey their meaning of fatigue.

## BACKGROUND

In New Zealand CFS has a prevalence of approximately 127 per 100,000, and approximately three quarters of CFS sufferers are women of working age suffering from a chronic and debilitating illness with a wide variety of symptoms causing financial problems, problems at work, and domestic problems (Murdoch, 1987). Buchwald et al. (1995) estimate that the prevalence of CFS in their Pacific Northwest U.S. study had a well-defined lower bound of 75 cases per 100,000 and a probable upper bound of 267 cases per 100,000. In a review of the international literature on CFS, Shafran (1991) claims that "[r]eports of CFS have emerged from the United States, Canada, the United Kingdom, Australia, New Zealand, Israel, Spain and France" and there seem to be an increasing number of reports on CFS emerging from Japan (Hashimoto et al. 1992; Minowa & Jiamo, 1996; Ogawa, Toyama, & Matsutomo, 1992), Australia (Lloyd, Hickie, Boughton, Spencer, & Wakefield, 1990), the United States (Buchwald et al., 1995), Russia (Artsimovich et al., 1994), and Czechoslovakia (Fucikova & Petanova, 1993).

In the foreword to Vayda's (1991) book *Chronic Fatigue*, Dobie comments that "fatigue is one of the commonest symptoms heard by any health practitioner" (p. 6). According to Showalter (1997), writing in the North American context, approximately 10% of those subjects who present with fatigue are diagnosed with CFS (see also David et al., 1990).

An analysis of the relevant literature relating to women with CFS (including that found within sociology, psychology, psychiatry, psychotherapy, medicine, and the self-help literature) reveals, first, the extent to which CFS is a women's health problem, second, the complexities of providing adequate treatment and patient "management," and third, the absence of reference to women's experiences of both CFS and their consultations with the medical profession in this literature.

It appears that "fatigue" is a particularly difficult symptom in the context of a medical consultation. Fatigue is difficult to define because it can result from numerous varied causes and might in itself be expressed through a variety of different symptoms. Where CFS is intertwined with the more general literature on chronic fatigue, it is considered to be an exacerbated case or development of chronic fatigue. In the nursing liter-

ature, Ream and Richardson (1996) respond to these problematic characteristics of fatigue with the following definition: "Fatigue is a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals' ability to function to their normal capacity" (p. 527).

In the sociology and social work literature<sup>1</sup> chronic fatigue in women is connected to sexual abuse (Craine, Henson, Colliver, & MacLean, 1988) and identified as an issue for the occupational health of women (Costello, 1980). CFS is associated with chronic fatigue (Barshay, 1993; Burke, 1992; Schmaling & DiClementi, 1995). Given the magnitude of this problem the paucity of social work and sociological literature on CFS is striking.

Within the psychology, psychiatry, and psychotherapy literature<sup>2</sup> CFS is described as a modern form of neurasthenia. Individuals with CFS disproportionately suffer from sleep disorders and mood disorders and they often are reported to concurrently suffer from seasonal affective disorder or a disorder which has features of both conditions (Abbey & Garfinkel, 1991; Lam, 1991; Saltzstein, Gurwitt, Webster, & Barrett, 1992; Stone et al., 1994).

CFS is also attributed to the somatization of distress in childhood and, according to a number of authors, appears to occur in conjunction with various psychiatric and neuropsychiatric disorders (Deale & David, 1994; Garralda, 1992; Hawton & Cowen, 1990; Lawrie & Pelosi, 1995; Rusconi, Rubeo, Bernabei, & Valesini, 1994). In a recent study (Pelcovitz et al., 1995), psychosocial factors in adolescent girls, such as an overly protective relationship with the father, mothers who are not attuned to the psychological components of the illness experience, and family dynamics operating within the construction of the illness that tend toward labelling psychological symptoms as physical or tend to omit psychological aspects of the child's illness experience, are seen as contributing factors to CFS, which in turn is considered to be closely related to anorexia nervosa and bulimia nervosa.

Within this literature CFS is often characterized as being a disorder most prevalent in white, middle or upper class, well-educated, previously successful, and often perfectionistic women and is predominantly considered to be due to psychosocial factors. However, Barrows (1995) states "The CFIDS<sup>3</sup> population is incorrectly stereotyped as upper-middle class, white, female hypochondriacs; consequently symptoms are often belittled

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<sup>1</sup>Sourced through the Sociofile, Social Sciences Index, and the Social Work Abstracts databases.

<sup>2</sup>Sourced through the PsycLit and Medline databases.

<sup>3</sup>Chronic fatigue and immune deficiency syndrome.

or ignored' and that "this population has severe physical and cognitive disabilities that affect their professional, familial, and social lives" (p. 327). Gracious and Wisner (1991) state that "Research is needed to elucidate whether CFS is an organic psychiatric illness secondary to chronic infection, or an affective/anxiety disorder that produces immunologic dysfunction and secondary viral reactivation" (p. 405).

There is clearly a debate within this literature over the etiology of CFS, which tends to be premised on the dichotomous construction of either psychogenic or organic etiology. CFS is considered either to result from the somatization of distress and therefore be psychogenic in origin, or to result from organic dysfunction such as a viral or chronic organic illness. Grace (1998) makes a parallel observation in the case of the medical literature on "chronic pelvic pain without organic pathology" where, in the absence of organic pathology,

the debate in the medical sphere tends to open onto the question of whether the pain is in fact caused by organic pathology, or whether there is a psychogenic component to the cause of the pain. This dichotomy of either an organic or a psychogenic etiology has been challenged only in recent years. (p. 127)

The only paper identified through our literature search which focuses specifically on CFS in women (Wheeler, 1992) appears in the psychology literature; it is also the only research using a qualitative methodology. It is written from a feminist perspective and focuses on the highly specific issue of self-blame in women CFS sufferers in California.

The medical literature on CFS provides epidemiological, clinical, and biomedical accounts of the disorder. Within this literature, however, the only attempts at measuring women's disability due to this disorder involve research on issues such as reduced functional capacity, for example, reduced cardiovascular fitness and stamina (Cordero et al., 1996; Riley, O'Brien, McCluskey, Bell, & Nichols, 1990; Sisto et al., 1995; Sisto et al., 1996), or measuring women's information processing efficiency (Barrows, 1995; DeLuca, Johnson, & Natelson, 1993). The only articles that look at women's subjective experiences of CFS on the above topics are Riley et al. (1990) and Barrows (1995), which very briefly attempt to quantitatively assess self-reported degrees of fatigue and reduced functional capacity.

We suggest, given that CFS has been characterized as asthenia, neurasthenia, and neuromyasthenia and is associated with premenstrual syndrome, somatoform disorders, mood disorders, anxiety disorders, panic and sleeping disorders, depression, multiple chemical sensitivities, hyperventilation, and pyrexia, that there is a need for qualitative approaches

to understand women's experience of this debilitating condition. The literature to date has not used a qualitative approach to develop such an understanding.

## RESEARCH AIMS

The current research is concerned with developing understandings of a range of issues apparent in women's experiences of CFS, including understanding etiology, issues surrounding diagnosis and treatment, or "management," and conceptualizations of CFS in relation to discourses on the body. This paper focuses specifically on understanding the issues generated by a discourse analysis of women's narratives on "fatigue."

## METHOD

The method chosen for this project was to recruit a number of women who have, or have had, CFS to participate in open-ended, in-depth interviews. Eleven "Pakeha"<sup>4</sup> women, ranging in age from mid-20s to late 60s from a variety of occupational backgrounds and at various points through the illness, were interviewed. Four participants were recruited through a Christchurch ME Support group. Four participants were recruited through Christchurch general practitioners (GPs). Three participants who had recovered from CFS were recruited through contacts recommended by other participants.

I (BH) asked very general questions, noting any key words, themes, ideas, or issues as they arose in the interviewees' responses. These key words or ideas were used to further prompt women to enlarge on their experiences. The interview guideline provided a checklist of questions which the interviewer reviewed at the end of the interview to ensure that a number of previously identified areas of concern were covered. This guideline was adapted to fit each individual interview and the concerns raised by the interviewee.

Sections of the interview tapes were identified which conveyed, or related to, the theme of "fatigue." These included sections in which the participants used the word *fatigue* or a synonym for fatigue (such as *tiredness*), or narrated experiences of being fatigued. The resulting text is referred to below as the "text on fatigue." The text on fatigue was scanned for key words and phrases, which were then grouped according to themes

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<sup>4</sup>Non-Maori New Zealander, usually of European descent.

that arose from this material. Several themes emerged, the most prominent of which are analyzed in the discussion below.

Several quantitative analyses were performed on the text on fatigue to assist in developing a focus for the qualitative analysis of fatigue. These analyses confirmed numerically the emphasis placed on particular key words and phrases and highlighted common grammatical constructions in the interviewees' narratives:

- Tables containing a list of all the words that occurred in the text on fatigue and the number of occurrences of each were produced, sorted both by number and alphabetical order for ease of reference.
- A similar list grouped by parts of speech was generated.
- A table of common adjacent word pairs was extracted.
- From the above, significant words, parts of speech, and phrases were identified and lines of text containing these were individually extracted from the text on fatigue. This generated lists of all the lines containing: modal and modal auxiliary verbs such as "can" or "would" which are used with a main verb to express ideas such as possibility, intention, or necessity; w-words such as "what," "who," "when," "how," "where," and "why" and "that," "which," and "whatever," which are used to ask or express questions; "fatigue" and its synonyms; "it" and its forms "just," "can" and "can't," "was," "but," and "like."

## DISCOURSE ANALYSIS

After several trial runs it became evident, based on identifying passages containing key words such as fatigue and tiredness, that there was an *absence* of fatigue within this text, as a positively identifiable discursive construct. The women seemed to be expressing the experience of feeling fatigued, for instance, through examples of things one could and couldn't do or by describing symptoms which were a result of the fatigue, but there seemed to be a real absence of passages which directly referred to fatigue. It was not possible to identify a specific or positive "thing," that could be called fatigue.

This absence of fatigue began to raise significant issues with regard to the definition of fatigue and the role it plays in CFS. What amounts to fatigue, for the layperson, the GP and for women with CFS seems to be unclear. We concluded that fatigue is not a positive, identifiable thing but rather a way of expressing a subjective, negative absence or lack. Conceptualizing fatigue as lack prompted consideration of fatigue in much broader terms than is typical of the lay or medical concepts. How does this lack express itself?



## Communication

Women with CFS experience various communication difficulties, many of which they describe through references to talking.<sup>5</sup> They find themselves unable to talk or hold conversations and they claim this is due to both short- and long-term memory problems. One woman commented that “the neurologist who **tested** me said I’d **lost** my long-term, short-term, and recall paths, so right across the spectrum of **memory everything was gone.**” Another commented that: “I would **totally forget** what we were **talking** about,” and a woman who has recovered from CFS described it as “1, 2, 3, 4, I’d **forget** by the time I’d got to 4 that I’d counted 3.”

These communication difficulties sound similar to dyslexia and arise in both speech and writing. They are often accompanied by difficulties with enunciation such as slurs. One woman said “I **can’t talk** straight.” When asked for an example of her communication difficulties another woman responded that: “This very interview, trying to **express in words** what I’m **feeling** and what I **want to say**. It’s there in my head but it, I **can’t** get it into **words.**” It is as if Mai<sup>6</sup> could not grasp suitable words or even a suitable medium for expressing herself. She found this to be a significant and frustrating aspect of her CFS. It seems obvious that these women, who often appear to be very expressive and proficient verbally, are experiencing a significant breakdown in communication.

These women report that they are too **tired** or **lack the energy to talk**. For example the women commented: “I was **too tired** to even **talk** to anybody” and

They sat at the end of the bed and G had a hold of my feet and while he had a hold of my feet I **could talk**, when he took his hands away I had **no energy**, it’s like I can get **energy** from people and when they go they **take my energy**, they **take their energy** that I was using with them.

Comments such as these not only describe the **talking** difficulties, the **fatigue**, and the lack of **energy** but also offer insight into the way the interviewees connect ideas together and try to make **logic** out of it all. They intertwine a myriad of often conflicting discourses in order to describe their experiences. This can include drawing on concepts from Western medicine, traditional Chinese medicine, homeopathy, and naturopathy. They often combine and reshape concepts such as **energy flow** and the **immune system** to more adequately represent their experiences.

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<sup>5</sup>In this section we have placed key words or phrases that the interviewees used in bold text.

<sup>6</sup>All names are pseudonyms chosen by participants.

## The Whole Body

We would like to consider the role of the body in women's experiences of CFS and their sense of self by first considering a link between talking and the body.

Women with CFS **talk** to their **bodies** and their bodies **talk** to them: "I **tell my body** that you're going to eat" or "My **body was telling me** what to do, **rest . . . my body was saying, stop stop stop.**"

They **listen** to their **bodies**: "You just have to **listen** to your **body,**" and sometimes this is how they work towards **wellness**. At other times, this is not so successful either because communication is not good ("I don't **listen** to my **body** very well like that so that's why I've been **sick so long**") or because their body does not respond.

Nowhere in this text on fatigue is there a sense that their bodies **listen** to them. Bodies do not **listen**; they respond or improve. Such bodies are positioned in the passive. Yet these bodies very actively **hurt**. Interviewees' phrases included: **wrack** with **pain, ache, collapse, tingle**, and feel **weak**. Other phrases used here: "**every bit** of my **body hurt,**" "**whole body just wracked with pain,**" "**just every muscle** in your **body just ached,**" "**whole body has collapsed,**" "this quarter of my **body** was all pins and needles," "it was just a **complete** and utter **lack** of any **strength** in my body."

What sort of body is it, then, that these women are talking to? Setting aside those phrases that are specifically concerned with body parts or areas, this material suggests that this **body** is a very specific body. It is almost always a **whole body**, that is always present, and a body within which the women situate themselves. Interviewees' phrases included: "just an **aching all over your body,**" "in my **whole body,**" "**complete fatigue,**" "just your **whole body,**" "**heavy's** like your **whole body,**" "yeah, when my **whole body** has **collapsed, internally and externally.**"

This body has **cycles**: "Your **whole bodily cycle** is completely **turned over.**" It **stops** and **starts**: "My **body stops** but my **brain is saying**, oh no no we've got to **keep going** here," and this **body** is rarely at ease.

It is a body that has **needs, likes, and dislikes**: "hens parties and Christmas barbecues and all those sorts of things which **your body** doesn't particularly **like.**"

It sets **limits**: "If you **overexert** yourself, your **body's** not ready to do those things," "It was really **too much** for **my body** and I spent probably, maybe a month **recuperating** from that," "You'd better **give your body** a chance to, to have a **rest** otherwise you could be in trouble again," "I know that I'm skating on thin ice if I **stress** my **body** out."

This body can feel **trapped**: "like a **body** and a **brain** that's so **disabled** that it can't be set **free** and it can be a little bit **hysterical.**"

This is a difficult body to set up a dialogue with. It has difficulty coordinating its own internal cycles, it **restricts** activity and thinking, it places **limitations** on its occupant that are often scary as they are hard to predict and if infringed can **cost dearly**. It is positioned in both a positive and active fashion and also as a passive object for inspection and measurement. By being a whole body and a body within which the women position themselves it becomes an essential component of the self, and at times even representative of the self in the sense that, when this body **hurts**, “**wracks with pain**,” “**aches**,” “**collapses**,” “**tingles**,” and feels “**weak**,” what is being expressed is less a bodily hurt than a more general pain and the collapse and lack of strength being described here in bodily terms seem to represent a process or illness that “**impacts** everything, don’t underestimate it, it **hits** every area, of anyone’s life.”

Some of the most common ways the interviewees described their fatigue involved their bodies feeling like **heavy** and **weak** objects they had to “**lug around**.” They commented on how unpredictable their bodies were, “**tingling**” and “**shaking**” and finding they could not work because of the “**clumsiness**” and “**jelly legs**” they experienced. Lacking in energy often precipitated general sensations of “**numbness**” and “**withdrawal**.” These sensations of numbness and withdrawal were often accompanied with feeling isolated from people, the environment, the body, and even the self. Commonly this would be described as a feeling of “**foggy-mindedness**.” Interviewees would comment that they felt like they were “in a **cloud**” or “walking through a **mist**.” On the other side of their cloud or on the other side of the mist they imagined everything was clear. Inside the cloud that **hung** around them, everything seemed “**confused**” and “**distanced from reality**.” This fogginess is sometimes quite literally described as dissociation from the body. **Sleeping problems** produced similar feelings of distance from reality, with several interviewees commenting that **oversleeping** sometimes made it difficult to “**distinguish reality from unreality, conscious from unconscious**” and one’s time **awake** from **asleep**. The above in combination with the communication difficulties discussed earlier, memory problems, and the concentration problems that these women describe, appear to contribute to a problematic relationship to their bodies.

## Mobility

There is also an important emphasis in the text on fatigue on movement and problems with mobility. Many of the women in this study reported difficulties with movement. They expressed this principally through references to walking and driving. Difficulties with driving seem to re-

late to concentration problems, memory problems, and sensory problems: “**Driving** it took me a while to **concentrate**,” “Worst thing of all is my **concentration**,” “My **concentration** is just zilch,” “I couldn’t quite **focus**,” “bit **absentminded**,” “**forget** to do things,” “**Can’t** take the light, lights are really really sharp.” As Nora commented, “**lightheadedness**—out **driving** I’m apt to see something coming and **not comprehend** it properly.”

Particularly in the early stages of their illness these women report that they “could **hardly walk**,” “could **barely walk**,” or “**couldn’t walk**” and that they would be in “**agony** from **walking**.” In extreme cases this was like a kind of paralysis. They claimed they “didn’t have the **strength** to **walk**,” “got **really tired**” from walking and, for instance, that “**walking** always made me **dreadfully fatigued**.” They claimed that their walk was very **slow** and that they often felt like they were “**walking** through **mist**” or described, for example, “a little **cloud** or a little area of **fog**, that you’re **walking** through.” They claimed that they “just wanted **quiet walks**” and to “do a lot more **walking**.” This is in fact one of the few areas in which they clearly expressed a want to move forwards towards wellness, away from illness. The women interviewed find that they lack and crave the sort of peace and quiet and freedom of movement evoked by the image of quietly walking somewhere pleasant.

Difficulties with driving and walking are only two examples of the way in which the fatigue these women experience affects the way their bodies operate, or fail to operate. How do the interviewees articulate their relationship to the illness?

### Women’s Relation to Their Illness

They feel like the illness has “**knocked the stuffing out**” of them, like it “**knocks them down**,” “**hits**” them, “**invades**” them, and “**overwhelms**” them. “**It**” seems to have its own independent agency, which gives it the power to “**take choices away**” from these women, “**bring on**,” “**brings back**,” or **cause** them to “**suffer**” from whatever symptom is affecting them. It “**effects**” and “**affects**” their lives, “**works on**” them, “**comes on**” them, “**stops and comes back**.” It **never** quite **leaves** them and “**goes around their body**.” It is as if it has “**got a hold**” over them such that it “**makes**” them experience illness. These women try to “**fight**” their illness but find that it is “**too much**,” that they “**can’t take it**,” that they “**can’t understand it**,” and they “**can’t go on pushing against it**.”

How do they respond to this predicament? Some of the women interviewed “**just give up**” or “**give in**.” Others, however, “**go with it**,” try and “**stop fighting**,” and instead “**accommodate it**” as a part of

their lives. The three women interviewed who have recovered from CFS seem to have arrived at a turning point in their illness where they made a conscious decision to “**stop fighting** their illness.” The most striking example of this comes from Scotty (who has recovered from CFS):

The most fundamental thing to start was to **surrender**. I **let go**, um, and it’s **scary**. One day I was just **walking** along and it **suddenly came to me** what I **needed to do**. I saw this huge big, like a Samurai warrior standing before me and that was ME. And it had all its armor and the glittering swords and I realized if I **tried to fight it**, it would just **set me up**, I would **die**. If I **surrendered to it**, it’d just completely **vanish** and **let go** and **dissolve**; the **energy** that I was **feeding it** was no longer there.

Scotty claims that this realization was clearly a turning point in her illness. Once she stopped “**fighting**” or “**feeding**” the illness with her “**energy**” she started to recover. We believe it would be reductionist, hasty, and problematic to draw from this the conclusion that, in this case Scotty’s CFS is of purely psychogenic etiology. Rather, Scotty’s insistence on the importance of this conscious “psychological” turning point highlights the need to consider both the organic and psychogenic aspects of the illness. This suggests that approaching CFS as if it is either of organic or psychological etiology will not be successful, as it may not engage with women’s discourses on their understandings or experience of CFS. This same concern emerged from a qualitative analysis of women’s experiences of chronic pelvic pain (Grace, 1995).

## Energy

An analysis of one full interview transcript reveals that discourses on “energy” are potentially important for analyzing meanings of “fatigue.” **Energy** is a particularly striking key word across the full data set. The main signifier of absence, or lack, is “**energy**,” “**lack of energy**.” The conceptualization of “**energy flows**” and the use of metaphorical understandings of the mechanics of energy flows and blockages emerges as a significant discursive field, as evident in the following key words and phrases identified from a transcript of one complete interview (not from the text on fatigue):

just **energy levels** are **low**; **low energy levels**; **energy levels not good**; **losing energy**; **energy** whether it’s **physical** or **mental**; then it just **flows**; just get **stuck**; it’s just **stuck**; **won’t flow**; not really **energy flowing**; **flows** best when . . . then it will **flow**; literally **feel energy flow**; I can **draw energy** from other people; just seems to be a **reservoir** sometimes; sometimes it’s **used** very **quickly**; having to **draw** on more and more

**reserves** from other areas somehow; get **charged up**; **energy level's not there** anyway; **using** more **energy**—tip me over the edge; **using reserves** that you just **can't afford to use**; you're in **debit**; gone into **overdraft**; you're going to **pay for it**; **high interest** on it; you're given this **energy package**; it's like a **battery**; **plugged in**; it's **taken out**; it **ebbs out** of you; plugs have been **taken out** and it's **flat**; I'm about 60% ... even 80%.

The references to energy flows that dovetail with references to the circulation of money might be characterized as a contrast between a wellness of abundance and an illness of scarcity:

**BH** (in response to interviewee using the key word “normal”): What is normal?

**Int:** It's to have **money in the bank** and **energy to do things**. . .

A fruitful theoretical direction for developing insights into the interconnection of economic and energy metaphors used in relation to CFS may be to examine their use in the light of the work of Susan Sontag (1978, 1989), who has analyzed the key metaphors of political economy in understandings of tuberculosis, cancer, and AIDS.

## CONCLUDING DISCUSSION

There are striking parallels between our analysis of discourses on chronic fatigue and Jackson's (1994) discussion of the characteristics of experiencing chronic pain. Chronic pain, like fatigue, does not present the clinician with symptoms that are readily recognizable, or representable, biomedically or clinically. The problems associated with this crisis of representation are not only very similar across chronic pain and fatigue, but in both cases go beyond clinical communication and “management” issues. Where medical representation hinges on a series of dualisms (psychogenic/organic, mind/body, subject/object), both chronic pain and chronic fatigue systematically confound these dualisms. Jackson claims that chronic pain challenges the notion of the body as object and the self or mind as subject, as the sufferer moves with ease between objectifying the body (constructing a distinct opposition of the body and self) and a “subjectifying” stance whereby the body *is* the self. Parallels are clearly reflected in the analysis of fatigue above.

Such parallels include the way in which both pain and fatigue are expressed as having agency. Pain, like fatigue, is an “it” that acts upon sufferers and, in Jackson's analysis, even comes to possess them. Women with CFS respond to this “agent” in a similar way to those in Jackson's (1994) study. They fight it, become overwhelmed by it to the point where

they almost become it, but, like many of those in Jackson's work, they reach a turning point and accept it, come to "peace" with it, or learn to better control it. A way to move towards this turning point for both sufferers of chronic pain and women with CFS is expressed through the need to "listen to their bodies."

The medical literature on CFS tends to assume that if there is a lack of bodily functioning there must be a specific cause, and this has to be identified before the patient's complaint can be credited with any veracity. The presence of lack is not enough in itself to warrant the status of a definable problem, particularly when this lack is expressed through a myriad of symptoms which, in medical terms, only qualify as "subjective." Often what is made visible, objective, and positively identifiable is prefaced on what is silenced or made invisible. We argue on the basis of this analysis that lack, such as fatigue, is largely about what is silenced in that it is not representable in clinically identifiable terms.

The medical literature that attempts to understand the fatigue women with CFS experience is very fragmented, appearing to pursue numerous avenues of investigation but each only to understand one facet of the problem. This fragmented approach will remain limited without an understanding of the much more complex picture of fatigue expressed by women with CFS as it has emerged in this research. Conceptualizing fatigue in broader terms to encompass the diversity of facets evident in women's narratives on their experience may open the way for new research directions that ask different questions and that attempt to keep the overall picture of CFS more clearly focused, even while investigating specific symptoms.

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