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## Chronic Fatigue Syndrome: An Investigation into Possible Causes and Understandings of the Illness

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**Abstract:** There has been increasing interest in many fields in examining the effects of social pressures and the lifestyles of individuals on health and illness. Relating such factors to syndromes and other illnesses is an important aspect to understanding the origins of many current problems, including chronic fatigue syndrome (CFS). However, many individuals, both health professionals and lay people, do not appear to put much consideration into psychosocial factors in disease origins. This may be related to the biomedical health model which is prevalent in Western cultures. The biomedical model is known for a number of assumptions, including the Cartesian dualism which places the mind apart from the body (Scheper-Hughes and Lock 1987:6). By persisting in understanding CFS in terms of such a model, certain social advantages to the sufferers can be conferred, including societal acceptance and understanding. Unfortunately, it appears that by ignoring the social factors, such as the many lifestyle similarities of many patients of CFS, crucial considerations are overlooked. This may then prevent adequate understandings of the syndrome.

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In the early 1980s, chronic fatigue syndrome (CFS) came to public attention in Western countries, creating controversy and misunderstandings on the part of clinicians, patients and the general population. Difficulties with the diagnosis and treatment of the syndrome have helped to build a sense of confusion about CFS. However, diverse studies and ideas about the origins of CFS have revealed a number of similarities in the lifestyles and values of many individuals diagnosed with the syndrome. This has suggested to some that CFS is influenced by the ethics, values and pace of current Western society. Current ideas about the believable causes of disorders have affected how CFS is viewed. Societal attitudes regarding origins and types of illnesses are instrumental in shaping how patients and health care workers view and treat a disease, condition or syndrome. Attempting to understand the underlying pressures and stressors in our current social fabric, along with ideas about health and disease, may lead to a better understanding of illnesses, including CFS.

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In 1984, a clinic in Incline Village, Nevada, began to note a number of individuals complaining of a series of symptoms which had no obvious cause. By November, 1985, over 160 people in the city had presented with these symptoms, which included rashes, dizziness, sore throats, headaches and muscle aches (Showalter 1997: 119). Over time, chronic fatigue syndrome began to be diagnosed by a number of additional factors. Persistent, often incapacitating, fatigue over a long period of time is the main symptom, but according to the 1988 Center for Disease Control (CDC) diagnosis, this major symptom must be accompanied by six to eight minor criteria (McKenzie and Straus 1995:121). These include sleep disturbance, painful lymph nodes, depression and difficulty in concentration (Ray 1991:1), as well as the previously mentioned headaches, muscle aches, rashes, dizziness and sore throats. Other symptoms that have been associated with CFS include fevers, abdominal cramps, weight loss, chest pains, memory loss, nausea and problems with remembering and pronouncing words (Feinden 1990:33-34).

Many similar non specific symptoms have also been linked to a number of viral diseases, including Lyme disease, with which many sufferers of CFS were initially diagnosed. Epstein-Barr virus (EBV) was also originally thought to be a possible causative agent in CFS but viral research has shown this is be unlikely (Folks *et al.* 1993:161). In fact, viral studies have been unable to pinpoint any specific viral link to CFS, even though a number of tests have been conducted on a variety of known human viruses, including EBV, HIV and rubeola (Landay *et al.* 1991:709-10). This suggests that the syndrome may not be linked to a viral infection; that it may be caused by an as yet unknown viral infection; or that a known virus may be present only briefly in the white blood cells being tested (Folks *et al.* 1993:165). Research has also shown that neither structural nor physiological abnormalities in the muscles of CFS sufferers explain the muscular problems experienced (Edwards 1993:115). However, it is interesting to note that patients with CFS usually exhibit immunological disturbances, which suggests that there is some association between CFS and altered immune function, although there is no evidence of a causal link (Lloyd *et al.* 1993:185).

The lack of concrete medical results, in the search for a cause of the symptoms related to CFS, suggests that the syndrome may be connected to the mental state of the individual, rather than the physical state. Therefore, CFS may be a more culturally related illness than a physiologically related one. While the term culture bound syndrome has often been used to describe syndromes in non-Western societies, it is relevant to Western cultures as well (Simons 1985:25). A culture bound syndrome is culture specific and appears to be related to factors within a culture which may create an opportunity for, or help to predispose individuals towards, disorders which can be chronic or temporary (Hughes 1985:9). The general explanation of culture bound syndromes is that the belief systems of a culture help to shape responses to situations which may be difficult (Simons 1985:44). The episodes of syndromes may serve as a means to attain a legitimate sick role; as a way to reduce tension; or as a way to exit a stressful situation. In order to understand a culture bound syndrome, which CFS could be

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described as, it is therefore necessary to examine the cultural context and conceptualization of health and illness surrounding the syndrome (Hughes 1985:4-6).

### The Social Context of CFS

It has become increasingly clear, not solely in the case of CFS, that insight into the world of the illness sufferer is necessary to fully understand an illness. Factors outside of the physiological realm can have an impact on the health status of an individual. Moreover, shared interpersonal experiences in the family, the community and the workplace are all aspects that should be taken into consideration when examining the health status of an individual (Ware 1993:63). A common aspect of CFS is the lifestyle that many patients led prior to developing the syndrome. Many people diagnosed with CFS felt that, prior to becoming ill, they were "involved in a million things at once" (Ware 1993:69), often being intensely active in the community, workplace and family. Multiple responsibilities, including careers, social lives, child rearing, volunteer work and exercise were generally exhibited by CFS patients (Showalter 1997:127). A sense of being overextended was usually expressed by these individuals, who often identified these feelings with idioms such as 'superwoman,' 'supermom,' and 'workaholic' (Ware and Kleinman 1992:551). One individual explains:

*I was an extremely energetic sort of person. Physically, I was in very, very good shape. I was working 12-13 hours a day, including weekends, going to school nights, and teaching. I had a husband, children, kept up with the laundry, cooked on weekends for the week. Until recently, I hadn't had a vacation in years (Ware 1993:64).*

In addition to high standards for personal performance, it has also been noted that CFS patients have often experienced other sorts of high stress situations shortly before the onset of the symptoms. Such situations may include the death of a loved one, personal injury, a divorce and other negative events (Ware 1993:65). While this may suggest to some that CFS is related to depression, not all CFS patients fit into the category of major depression according to diagnostic criteria (Mckenzie and Straus 1995:134-137). While depression is a symptom of CFS, it may arise in patients as a result of other physical and emotional problems associated with the syndrome, as can occur in the case of other illnesses which severely disrupt the lives of individuals (Ray 1991:3). It should also be noted that while CFS has affected children to individuals in their 70s, most patients range in age from the mid 20s to the late 40s (Feinden 1990:12). This is a period when many individuals may be experiencing multiple roles and consequently, multiple areas of stress in the home, workplace and volunteer realms.

An additional critical factor with CFS is that a disproportionate number of the sufferers are women. It has been suggested that women outnumber men in CFS diagnosis 3-4 to 1 (Showalter 1997:127). A number of possible reasons have

been suggested for this difference, including that women appear to be more prone to autoimmune disorders such as lupus, multiple sclerosis and rheumatoid arthritis. This view is based around the belief that CFS is also linked to autoimmunity. However, the disparity in diagnosis may also be linked to the reporting behaviour of women. It has been noted that women are more likely to seek help for complaints that are less concrete, such as stress and fatigue, and this may help to contribute to an explanation for differences in the numbers of men and women diagnosed with CFS (Feinden 1990:14).

A parallel can be drawn between modern day CFS and the popular diagnosis of neurasthenia in the nineteenth century. Recorded in 1869 by Beard, the diagnosis of neurasthenia shared many similar symptoms and characteristics with CFS. Also affecting primarily women, neurasthenia gained popular interest during this period, becoming an almost fashionable illness. As well, both neurasthenia in the 1880s and CFS today have received much popular attention, with CFS having been discussed on television shows, popular magazines, self help books and even cartoons (Showalter 1997:124-125). As a result of the physical similarities between CFS and neurasthenia, an interesting point can be raised, in that at this time in history, Western society was undergoing a considerable change in the roles of women. A desire to work, have access to higher education, vote and attain equality with men was increasingly important to women, and yet many such ambitions were thwarted by a society that was not yet able or willing to accept the aspirations of the 'new woman'. It has been postulated that frustration and anxiety with these changes helped lead to the frequent symptoms and diagnosis of neurasthenia (Abbey and Garfinkel 1991:1643).

Others have suggested that neurasthenia was a type of hysteria, part of a symptom pool of acceptable methods to express distress for the era (Showalter 1997:50). Recently, Elaine Showalter has hypothesized that chronic fatigue syndrome, along with other phenomena such as Gulf War Syndrome and recovered memories, is a type of modern day hysteria. She suggests that such phenomena are culturally acceptable symbols of anxiety and stress in current society. Like neurasthenia in the past, Showalter believes that CFS is part of a symptom pool of currently permissible ways for individuals to express worry and stress with certain lifestyles, as well as to express anxiety about possible changes in the future (Showalter 1997:15).

When looking at more recent history, it becomes apparent that similar stressors to those of the late nineteenth century may be occurring for women today. The definition of a 'successful' woman is changing in Western society. During the 1980s, when CFS first began to appear, the societal attitude for both men and women was one where harder work was required to do well in a competitive job market. Women, however, were generally expected to balance a successful career with a good marriage and a rich family life (Ware and Kleinman 1992:554). Additionally, women tended to work more than men, and continue to do so today. Career women could be expected to come home from a job, and continue to work in the house, sometimes looking after children and the household work. Studies have shown that in the United States, husbands or male partners of employed

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women actually contribute less time to the household chores than do partners of women who stay at home: approximately an hour and a quarter of help a day for women who do not have a job outside the home, compared to thirty-six minutes a day for women who are employed in the workforce (Wolf 1990:23-24). While some women work as much outside of the home as men, they are less likely to be rewarded as well financially, with pay rates for women continuing to lag behind those of men in the same field (Wolf 1990:49). Although changes continue to occur, in the interim such issues can be frustrating and potentially stressful, contributing to a sense of personal overload.

It has also been stated that the modern American woman has conflicting expectations placed on her. While she is expected to be fun loving and sensual, she should also be thin and attractive, with a sense of self discipline (Scheper-Hughes and Lock 1987:25). Additional central values include being tough, strong and healthy, something the individual is expected to work hard to achieve (Scheper-Hughes and Lock 1987:26). These expectations, coupled with the stresses of multiple roles and increasing responsibilities may contribute to a feeling of being overwhelmed, manifest in physical consequences. Like neurasthenia, CFS seems to be linked to an overload of the body's resources. The individual is overtaxed as a result of lifestyle factors which may include a fast paced life, changing roles and difficult life events.

### **Disease Models, Stigma and Validation**

It appears that somatization plays an important role in the development of CFS, with physical symptoms perhaps being linked to the psychological stressors that patients experience in their lives. Somatization is an idiom for personal distress, a way for individuals with psychological disturbances to illustrate their problems physically (Gureje *et al.* 1997:989; Kleinman 1995:10). Since somatization blurs the borders that have been constructed between psychological and physical health, it has been suggested that it can be used as a defense against the acknowledgement of psychological distress (Gureje *et al.* 1997:989). Somatization is identified by the existence of unexplained somatic symptoms, non specific physical complaints. Such symptoms are shaped by and linked to the social, cultural and political situation by which each individual is surrounded. This includes the traditional views of illness and cultural attitudes surrounding psychological and physical problems (Gureje *et al.* 1997:989-990). There is some evidence that somatic complaints differ cross culturally, since cultures express physical problems and pain in different manners (Gureje *et al.* 1997:994).

Some CFS patients use a biopsychosocial model of illness to explain their symptoms. A high stress lifestyle, some believe, helped lead to a weakened immune system, in turn creating the opportunity for a viral infection to cause the physical symptoms experienced (Ware 1993:66). However, many other CFS patients view their symptoms as purely a physical problem, perhaps attributing them to a virus, but without the consideration of personal distress and stress (Abbey 1993:242). Why is it so difficult for members of Western society to

accept that illness may be related to both sociocultural and psychological factors as well as physiological ones? One important idea in current biomedical institutions is the mind-body illness dichotomy, where illness is viewed as either a mental/psychiatric problem, or a physiological disturbance (Ware 1993:69). As a result, it can perhaps be difficult to accept that both the body and the mind can contribute to a condition like CFS.

There are alternatives to this mind/body dichotomy, including the mindful body approach in medical anthropology. The mindful body approach attempts to surpass biological fallacies in the field of the anthropology of the body, rather assuming that the body is symbolic as well as physical, as much a product of culture as it is of nature (Scheper-Hughes and Lock 1987:6-7). The approach examines the relationships and connections between three bodies: the individual body, referring to lived experiences on a personal level; the social body, where the body is a symbol for nature, culture and society; and the body politic, involving the control and regulation of the body within a society (Scheper-Hughes and Lock 1987:7). It is through the interaction of these three bodies that ideas of health and illness are produced and communicated (Scheper-Hughes and Lock 1987:31). This approach also highlights some of the key differences between Western biomedicine and many non-Western ethnomedical systems. While biomedicine tends to place the body and the self (mind) as distinct entities, as well as separating social relations from health status, this is not so with all health and illness models. Rather, alternative models may not distinguish the mind from the body, and social relations are often viewed as key to the health or illness of an individual (Scheper-Hughes and Lock 1987:21).

The origins, or perceived origins, of a disorder or a disease can have repercussions on how a specific problem is viewed by society (Kleinman 1980:126). Until a sickness or a disorder is given a name and is described in terms of the effects on the sufferer, treatment and the cause of the illness, society cannot analyze the problem in terms of disease and illness (Kleinman 1980:126). Additionally, as a result of these classifications, a series of moral and ethical connotations can be attached to a type of illness.

An example of moral attachments to a disease can be seen with HIV/AIDS. Initially viewed as a disease that affected only the homosexual community, which some today still believe, heterosexuals who contracted the virus were and are often afraid to let others know of their diagnosis for fear of being morally judged and stigmatized. Many infected haemophiliacs suffered from what was termed homophobia-phobia - the fear of having homophobic acts directed at them. This caused an attempt to separate infected homosexuals from infected haemophiliacs (Picard 1995:81).

In industrialized nations, stigma has often been attached to psychogenic illnesses, which may be viewed as less legitimate and more suspicious in nature (Showalter 1997:117). The social stigma of psychiatry and the general aversion to undergoing psychiatric treatment is an important factor to consider when

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examining the issue of illness attribution (Abbey 1993:248). The fear of being labeled as a hysteric, with emotions dismissed as unimportant, may be a contributing factor in the refusal to consider a non-physiological origin to illnesses such as CFS. Many hold the assumption that an illness with a psychological cause is an imaginary illness, rather than a true, tangible problem, and it is therefore possible that the self esteem of an individual may be partially dependent on creating and accepting a biological cause for his or her illness (Showalter 1997:117,129).

These attitudes about illness causation can be compared to beliefs in Chinese culture, where there is a very large stigma attached to mental illness. As a result, minor psychiatric problems are often given a medical diagnosis of neurasthenia, with the label of mental illness being reserved for extremely serious problems. Traditional Chinese doctors may take note of psychological complaints but refer to them as though they are a physical ailment (Kleinman 1980:125,128).

In Western culture, attributing CFS to a viral agent may similarly validate the feelings of ill health that the patient experiences, legitimizing the illness complaint. The attribution of CFS to a physical problem rather than a psychological one has repercussions for both the patient and the clinician. For the patient, it is no longer necessary to worry that he or she will be perceived as weak or attention seeking. The blame for the illness no longer lies with the sufferer but with an uncontrollable extrinsic factor. In the case of the clinician, suggesting a viral aetiology reinforces a sense of social authority (Aronowitz 1992:155). This is not to say that clinicians are inventing a condition and its cause in order to maintain a sense of authority. Rather, it suggests that they are responding as best they can to the social pressures of the patient who expects them to name the illness as a part of recovery. It may also be that clinicians are responding to CFS symptoms with the tools that the biomedical viewpoint provides for them. During training, clinicians may not have been equipped with the tools, ways of thinking and vocabulary to effectively bridge the gap of the mind-body illness dichotomy.

Diverse medical systems share a number of similarities, including the normalization of health and illness diagnosis, and the synthesis of health complaints into culturally meaningful syndromes (Kleinman 1995:21-22). Biomedicine, the dominant medicine in the West, emphasizes a reductionist orientation towards ill health, which dehumanizes the person, and tends to overlook the experience of suffering (Kleinman 1995:25-31). Biomedicine searches for objective causes of pain, which means that there should be a concrete and identifiable cause for pain and suffering to be viewed as legitimate (Kleinman 1995:32). Symptoms are due to a disease, which is a tangible and natural process.

As a result, chronic illnesses such as CFS, which have little in the way of definitive physical causes, may be regarded with suspicion (Kleinman 1988:17). It is therefore possible that by framing CFS as an illness of viral aetiology,

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clinicians and researchers may be able to combat their skepticism about the disorder. This skepticism can be frustrating for CFS sufferers, who may find that clinicians can equate 'not known' with 'not real' (Aronowitz 1992:168). By allowing that there is an underlying biological problem, even if it has yet to be pinpointed, it might be that physicians are able to accept an illness that they do not understand and are, therefore, able to address their patients' needs for reassurance, understanding and treatment. However, while medicalizing CFS may serve to allow the individual the sick role, it may also obscure the roots of complex problems (Kleinman 1995:38). By searching for a physical cure, the social and economic aspects that influence illnesses like CFS can be overlooked, thus inhibiting effective treatment for the individual.

As noted previously, before CFS patients became ill, most had been engaged in a high stress lifestyle, in which a debilitating illness was not supposed to occur. However, the development of CFS has allowed many sufferers to undergo positive changes in their lifestyle. It has been postulated that CFS is a method of reasserting control over one's life. In Chinese culture, when a patient with relatively minor psychiatric problems such as depression, receives a physical diagnosis, he or she also receives the right to live the sick role - to be relieved from work, stay at home, be passive and seek out the help and understanding of family members (Kleinman 1980:125).

In the United States and other countries affected by CFS, it is possible that similar factors are at work. In order for an individual to remove him or herself from a life which is increasingly complex, a legitimate reason is required. A diagnosis of CFS legitimizes the fatigue and the emotional distress that sufferers endure, and they can therefore withdraw from situations which are difficult and stressful. They are able to do so as a requirement for recovery from an illness, not of a conscious desire (Abbey and Garfinkel 1991:1644). In this way, individuals are able to regain some control over their lives, without appearing as though they are selfish or weak. Some sufferers have expressed frustration, a feeling of being cheated out of their goals and ambitions due to the limits and suffering involved with CFS. However, others became relieved over time, pleased at having an opportunity to change the lifestyle that they were engaged in. An ability to focus on the needs of the self, often neglected before CFS set in, arose out of the necessity for recovery. Decreasing activities in the family and workplace, by reducing work hours and responsibilities, relieved some of the hectic pace of their lives and allowed many patients to relax and regain some management over a life that had increasingly been moving out of control (Ware 1993:67). As some CFS patients have noted:

*...but in some ways I'm sort of glad it got me out of all these problems...I hate to say the word 'grateful', but in some ways I am (Ware 1993:67).*

*It's been a very frightening experience, but I am a better person for it. Not worse, no. Much better (Ware 1993:68).*



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## Conclusion

When the available literature on CFS is reviewed, it seems important to recognize the impact that sociocultural factors have on the sufferers of the syndrome. While various medical tests have failed to reveal a specific viral cause for the illness, an examination of the backgrounds of patients has revealed a number of common factors in the pre-illness lifestyles and goals of the sufferers. The problems that CFS patients endure may be linked to a discontentment with a societal ethos in which core cultural values such as multiple responsibilities have become inflated, unfulfilling and ultimately destructive of personal well being (Ware and Kleinman 1992:556).

With CFS being reported with increasing frequency in Western countries in such as the United States, Australia and England (Landay *et al.* 1991:707), it appears clear that this disorder is an important one in Western industrialized nations. The increasing awareness and response to the illness has resulted in such endeavours as the CIBA Foundation Symposium in 1993 to address CFS, as well as the creation of the *Journal of Chronic Fatigue Syndrome*. Research into previously overlooked areas such as CFS in children is also being undertaken. There has increasingly been a call for an examination of non-physiological causative agents in CFS as the syndrome gains more attention. This bodes well, since at the present time, there appears to be little evidence that a full understanding of the illness will be found solely in biological studies.

In considering views of CFS, as well as causative factors, it is important to remember to also take into account sociocultural factors in the lives of the sufferers. The reactions to diagnosis and treatments of CFS could be considered a wider example of the Western medical system in general, with respect to how illness is regarded and treated within such a system. Biomedicine, which is historically rooted in materialism and empiricism (Kleinman 1995:25, 29), cannot be considered outside of this historical context, which helps to shape our understandings and views of illnesses. Similarly, neither can a specific illness be considered outside of its historical and cultural contexts if a complete understanding is desired. Therefore, while CFS could be called a culture bound syndrome, it is important to remember that our biomedical response to it is also culture bound (Hughes 1985:8). Perhaps CFS could be better understood if the responses to it were not based on a health model that separates the mind from the body by default.

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