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Chronic Fatigue Syndrome: New Hope from Psychoneuroimmunology and Community Psychology

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Chronic Fatigue Syndrome is a baffling disease potentially affecting millions of Americans. New insights and developments in the fields of psychoneuroimmunology and community psychology may offer promising new leads in helping people recover from this debilitating illness. The experiences of a CFS-afflicted person in struggling to overcome this disease are used to illustrate the usefulness to recovery of concepts in the fields of psychoneuroimmunology, community psychology, and primary prevention.

KEY WORDS: Chronic fatigue; psychoneuroimmunology.

In the last 10 years, thousands and perhaps millions of Americans have become afflicted with a puzzling and debilitating disease called Chronic Fatigue Syndrome (CFS) (Fisher, 1987; Goldstein, 1990). The most prominent symptom is persistent fatigue, with at least a 50% reduction of activity level for at least 6 months.[2]

At first, it was believed that CFS was caused by the Epstein-Barr virus that also causes infectious mononucleosis; however, 95% of the population have antibodies to the Epstein-Barr virus. Later, it was believed that the

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[2] In addition, 6 or more of the following symptoms are also present: mild fever, sore throat, painful lymph nodes, muscle weakness, muscle pain, prolonged fatigue after exercise, headaches, joint pain, neuropsychological complaints, sleep disturbance and acute onset of symptoms. Two of the following three physical criteria should also be documented: low grade fever, nonexudative pharyngitis, and tender cervical or axillary lymph nodes. Other clinical conditions that may produce similar symptoms must be excluded from consideration (Holmes et al., 1988).

HHV-6 virus might be the culprit, but again this virus did not turn up exclusively in people with the illness (Bell, 1991). Recently Dr. Elaine DeFreitas found 77% of CFS patients to have a piece of genetic material found in HTLV-2, a retrovirus (none of the normal control sample contained this viral gene), and Dr. John Martin has found a foamy virus in half of CFS sufferers. Even if these findings are replicated, it is possible that this virus does not cause CFS (Palca, 1990).

Perhaps the most promising theory is that any of a number of infectious agents might damage the immune system in genetically vulnerable people. With the immune system damaged, other viruses that are normally controlled begin to replicate. In an attempt to attack these viruses, the immune system produces cytokines (e.g., interleukin-2) and these substances cause side effects such as fatigue and muscle aches. The immune system stays in high drive attempting to combat a continuing viral infection (Feiden, 1990). Several investigators have found chronic activation of the immune system in CFS patients (the CFIDS Chronicle, 1991). Landay, Jessop, Lennette, and Levy (1991) found in CFS patients that the CD8 CD11b suppressor cell population was reduced, and the CD 38 and HLA-DR markers were raised. This suggests that decreased suppressor cells lead to a hyperimmune response of the remaining CD8 cells. The activation might lead to increases in other cytokines that are associated with fatigue and other signs of viral infections. Demitrack et al. (1991) recently found low levels of cortisol in CFS patients, which might be due to a deficit of corticotropin-releasing hormone. Deficits in cortisol have been linked to lethargy and fatigue, and this deficit might be contributing to the overactive immune system.

If a viral culprit is found, it might take years to find an effective antiviral drug. If it is the immune system that has gone awry, perhaps due to genetic vulnerability and a variety of insults to the immune system (e.g., stress, inadequate diet, emotional traumas, and physical injury), then a promising approach might involve strengthening this protective system through a multi-modal approach involving proper diet, rest, exercise, yoga, and vitamin supplements (Steinman, 1990; Stoff & Pellegrino, 1988; Weil, 1990; Weiner, 1986). Even herbs could be used, particularly those like echinacea that have been shown to stimulate macrophage activity and to act as a mild antibiotic (Mowrey, 1988). In addition, psychological strategies from the emerging field of psychoneuroimmunology might offer new hope for patients suffering from CFS.

Psychoneuroimmunologists propose that the nervous, endocrine and immune systems are in constant communication with each other (Kiecolt-Glaser & Glaser, 1989). In the early part of this century, the effects of negative thoughts, emotion, and expectations on health and behavior were convincingly documented (e.g., voodoo spells have caused the deaths of numerous people who believed that the spells are real; Cannon, 1935). In the mid-70s, Ader and Cohen's (1975) pioneering work indicated that the immune system can be conditioned, suggesting that our thoughts and surroundings can cue immune enhancement or suppression. Cousins (1989) believed that everything influences the immune system: "The immune system is a mirror of life, responding to its joy and anguish, its exuberance and boredom, its laughter and tears, its excitement and depression, its problems and prospects" (pp. 35). Locke and Colligan (1987) have summarized the work of investigators (e.g., Kiecolt-Glaser, Garner, Speicher, Penn, & Glaser, 1984) who have found that under conditions of stress, depression, loss of control, learned helplessness, high anxiety, bereavement, loneliness, or high inhibited power motivation, there have been reductions in disease fighting immune cells, whereas support and relaxation training have led to enhancements in the immune system.

Cohen and Williamson (1991) have reviewed many studies that have found a relationship between stress and increased illness behavior. Infectious diseases, caused by common germs such as streptococcus bacteria, have been related to both acute and chronic stress (Meyer & Haggarty, 1962). Kasl, Evans and Niederman (1979) studied mononucleosis infection among cadets who were not immune to the disease. Those who contracted mononucleosis had fathers who were described as overachievers, the cadets were very committed to a military career, and they performed poorly academically. Manuck, Cohen, Rabin, Muldoon, and Bachen (1991) found that only individuals who showed heightened catecholamine and cardiovascular reactions to stress showed suppression in their immune function in response to a twenty minute laboratory stressor. These studies suggest that there might be many factors, including stress, susceptibility, and coping styles, making people candidates for infectious diseases. Recent evidence does suggest that social support, stressful events, and coping style influence immune function; however, some investigators feel we need to temper our enthusiasm for this new field because there is no definitive evidence linking psychological states to specific immune diseases (Bower, 1991).

Given the impairment of the immune system in CFS affected people, it is possible that strategies pioneered in this emerging field of psychoneuroimmunology could be employed to boost and enhance the functioning of impaired immune systems. Relaxation training, meditation, and other strategies that are useful in reducing despair and depression (Kabat-Zinn, 1990), and enhancing commitment, faith, hope and joy (Locke & Colligan, 1987), might be particularly worthy of further investigation for helping people with CFS.

Whereas the psychoneuroimmunology approach emphasizes internal strengths, ideas within the fields of community psychology and primary prevention focus on support systems and external strengths (Gesten & Jason, 1987), and these concepts could also be employed for helping CFS affected individuals. Community psychology posits that some environments can help people heal by providing them sanctuary from the stressors and conflicts of everyday life (Felner, Jason, Moritsugu & Farber, 1983). On the other hand, some environments can interfere with the body's efforts to resist disease (Jason, Hess, Felner, Moritsugu, 1987). For example, higher relapse rates are found for schizophrenics, who are excessively sensitive to the effects of stress, when the emotional climate in their homes is characterized by high levels of criticism, hostility and emotional overinvolvement (Hooley, 1985). The following passage from Morgan (1942) illustrates the importance of the community where one lives:

> In normal primitive life men commonly had periods of stimulated living alternating with periods of quiet vegetating. The nervous and physiological reserves consumed during periods of stress were renewed during quiet periods. This was the general condition of primitive village life. Under city influences, especially under modern conditions of constant over-stimulation, there is small opportunity for renewing these reserves. There is reason to believe that periods of intense urban life may consume the reserves of human energies to such a degree as to bring about general decadence. Can development of small community living add to its stimulus and interest and yet give opportunity for renewing these reserves, and might such an achievement be a major factor in lengthening the period of vital life of a people? (pp. 110-110)

Individuals who suffer from CFS are overwhelmingly tired, sometimes finding even brief conversations energy draining. In an effort to conserve energy, particularly during the worst phases, many isolate themselves from friends, family and work. Because of difficulties maintaining employment, many CFS-affected individuals have fewer financial resources, and thus they may be forced to seek less than desirable housing. Feeling ill, isolated, and with few resources, it is not surprising that many CFS affected people find themselves confronted with an escalating, downward spiral of negative emotional and physical stressors. For many CFS-affected people, a one-hour monthly support group is all that is available. Clearly, for individuals confronted with this debilitating condition, community psychologists would recommend the creation of behavior settings or environments with ongoing supportive caring and fellowship, where individuals could feel accepted and appreciated, and where there exists opportunities to begin redeveloping physical capacities that had withered (Tolan, Chertok, Keys, & Jason, 1990). Although few ideal settings like this exist, in theory, incorporation of more environmental strategies into comprehensive efforts to aid CFS-affected people seems to be especially warranted.

The approach alluded to above would also have important implications for the field of primary prevention. If supportive environments were established for CFS-afflicted individuals, these settings could become places where other at-risk individuals might learn how to strengthen their immune systems through a variety of psychological, medical, nutritional, and environmental strategies. In addition, other non-afflicted people might volunteer as aids at such settings. These helpers could benefit from learning about the devastating impact of this disease, and in the process, they might obtain a richer appreciation of what many people take for granted; that is, having energy and feeling well.

The traditional medical establishment was initially skeptical of the existence of CFS. Some physicians believed that CFS patients were just depressed; however, some studies have not found a higher than expected incidence of past depression in CFS afflicted people, and a substantial portion lack any identifiable DSM-III-R psychiatric disorder (Krupp, Mendelson, & Friedman, 1991). With increasing media attention (e.g., CFS was the cover story of *Newsweek* in November 1990), some medical personnel are beginning to accept this disease as a real syndrome. Recommended treatment, however, often focuses on symptomatic relief (e.g., medications to reduce fatigue, pain, and sleep disorders)[3], and, more recently, drugs (e.g., ampligen, Adenosine Monophosphate, gamma globulin, kutapressin, and acyclovir) that attempt to eradicate viruses or to strengthen the immune system (the CFIDS Chronicle, 1990, 1991; Goldstein, 1990). If one accepts the premise that the best hope for recovery from CFS lies in enhancing immune functioning, the fields of psychoneuroimmunology and community psychology (Kelly, 1990) might offer promising new treatment approaches.

A PERSONAL CASE HISTORY

In the remainder of this paper, I will describe my efforts to overcome CFS. I will illustrate, whenever possible, how I tried to incorporate some

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[3] It is possible that drugs can be used to decrease symptoms, and less pain or more sleep could lead to better mood and enhancements in the functioning of the immune system. On the other hand, inappropriate use of drugs can lead to longer-term adverse effects. For example, sleeping pills rapidly lose effectiveness and can bring about drug-dependent insomnia (Davison & Neale, 1986). Small doses of tricyclics have been found to lessen symptoms in some patients possibly due to their immunomodulatory or antihistamine effects (Bell, 1991). Tricyclics block the reuptake of norepinephrine and serotonin, thereby making them more available, and these increases have been shown to alleviate episodes of depression. However, continuous use of these drugs can actually decrease the amount of norepinephrine (Costin & Draguns, 1989).

of the mind-body and environmental notions that have been discussed. But, first, I will describe some of the contributing conditions that made me vulnerable to becoming sick initially.

In many ways, I fit the typical profile of highly achieving people susceptible to CFS. At age 26, I was an Assistant Professor at DePaul University, and for the next fifteen years, I published about ten research articles and presented about ten papers at psychological conventions each year. In the last five years, I had devoted an increasing amount of time to grant writing, raising over 3 million dollars for research. By late 1989 there were about 40 people working for me on three large research projects. I was also working with about fifteen graduate students on masters theses and dissertations. In addition to working on five books, I was regularly reviewing research articles for ten journals. Three to four times each year, I reviewed research grants in Washington for the National Institute of Mental Health. I had also just been elected President of the Division of Community Psychology of the American Psychological Association. In addition to these academic responsibilities, I had many outside involvements, including sitting on the human subjects committee at the Illinois Department of Alcohol and Substance Abuse and serving as the chairperson of the Board of Directors of the Illinois Self-Help Center. I was also writing a play with several friends and was writing a patent on a device to help parents reduce their children's television viewing. I loved each of these activities, but when taken together, they placed an enormous strain on my immune system.

Even though I swam about a quarter of a mile three times each week, and ate a generally adequate diet (I was a vegetarian), I had noticed that for the past few years, I was getting colds and sore throats more often and was having more difficulty getting over them. Clearly, my immune system was giving me warning signs, but rather than slowing down, I was actually expanding the number of activities in which I was involved. I absolutely felt that I needed to do more as there were so many areas that I felt needed my energy and attention. At some level, I knew there was a problem because in addition to the colds, at the end of the day, I was beginning to feel more drained, but again I tried to dismiss these feelings from my consciousness.

The first week of October, 1989, I was very stressed attempting to finish a grant that had a Friday deadline. I remember waking up on Thursday at 4:30 a.m. to work for a few hours on the grant. Then I drove to Evanston to give a lecture on prevention for the psychologists at Evanston Hospital. I then worked for another hour on the grant. This was followed with a noon lunch meeting in downtown Chicago with my patent attorney. Following this, I attended a two-hour meeting of the committee on human subjects at the Illinois department of Alcoholism and Substance Abuse. I then drove for two hours in rush hour traffic to a Chicago suburb to address a town's legislative body on reducing children's purchase of cigarettes. It had begun to get colder and was drizzling. By the time I got home, to finish working on the grant, I noticed that I had a sore throat. At the time, I had no idea what this symptom would mean for my life as I knew it.

My life was full. My time was consumed very productively. I had not taken a vacation in years, because I had no time for such "trivial" activities. Although I had many friends, at age 40 I was still unmarried, and this was again due to my unwillingness to devote time to nonacademic pursuits. It's not difficult to see that my life was unbalanced, but it is also true that I was stimulated by my intellectually rewarding lifestyle.

During the month of October, my head felt hot and I had a sore throat. My physician prescribed antibiotics, but my health continued to worsen. I was now functioning with less energy, but continued my demanding work schedule, with three out-of-town trips that month. Finally, at the beginning of November, I realized that this illness was different from anything else I had ever had. After a particularly stressful trip to Washington, I decided to stay home and get well.

In November, my physician confirmed that I had mononucleosis, and he suggested I continue working and rest when I felt tired. At that point, I had been home for 2 weeks and was beginning to feel somewhat better. But I noticed that when I was on the telephone for two or more hours, I was much weaker the next day. Because of the doctor's suggestion, on the weekend before Thanksgiving, I went to my office for the first time in three weeks. I worked for about 1 1/2 hours and then felt tired, so I came home. On Monday and Tuesday, I spent more time on the telephone, and after about four hours on Tuesday talking to students and research associates, I experienced my first significant relapse. I stayed in bed the whole next day.

After that first relapse, it became apparent to me that my energy level was depressed at a qualitatively lower level. By late November, I could not work for ten minutes. Other troubling symptoms began to emerge. At night I began to sweat and develop insomnia. There were some nights in December where I stayed up the entire night. Even though my body was tired, it was as if my mind was wired at night.

I developed extreme sensitivity to light such that I couldn't watch television, and even the light coming in from the window seemed to evoke a stress response in my system. Next I began to feel nauseous after eating, and I began losing weight (20 pounds in two months). I also experienced discomfort in my liver and spleen. My tongue turned white, and my lymph nodes enlarged.

Besides the general discomfort I was in, I felt completely cut off from my work and friends. I hired a former employee to bring me food, and all my energy was consumed in getting up and making meals. I spent my days lying on the floor listening to the radio (the reason for lying on the floor was that I had developed a sore back from lying on my bed). I could only speak to two or three people for five to ten minutes on the telephone, and if I extended that time, I would be completely exhausted.

I had never felt so alone in my life. As weeks passed, and no improvement were noticed, I realized that I had an illness that was more serious than anything I had ever imagined. I was getting increasingly desperate for some possible solutions. I felt tense, I was slowly becoming depressed, and I had no idea of what to do to improve my condition. I tried meditating, I tried humor, I tried listening to spiritual tapes, but these strategies only provided temporary relief. There were no hospitals to which to go and my physician continued to reassure me by saying that I would get better with rest. I knew I was not getting better as I continued to see more signs that my body was breaking down.

By late December, I had not left my 500-square foot apartment for a month, as it was severely cold outside. One day, lying on my couch, with several painful welts on my arm due to food allergies, I began experiencing breathing difficulties, and I actually thought I was going to die. I knew I had to leave my isolated environment, but where could I go? I called a close friend, and he said I could stay with his family. I was also invited to stay at my parents' house and with my sister's family. I was also considering going to Florida. It was during this planning time that a friend brought me a book by a physician who had treated hundreds of cases of CFS with a reported 90% success rate. I wondered how he obtained this success rate, as no data were presented in the book, but at this point I was desperate and most willing to try anything.

During the second week of January, 1990, I spent five days with ten other CFS-afflicted people, attending the program described in the book by the physician. What impressed me the most about the staff was their overwhelmingly positive attitude. When I had contacted self-help groups, many members were resigned to accepting their condition, but this was not the case at this program. While enrolled in this program, I talked with a nutritional biochemist, a counselor who had completely recovered from CFS and the physician in charge of the program. I tried meditation, acupuncture, and eurythmy (a form of dance therapy). Finally, I had people with whom to talk who understood my condition. Although it seemed as if I was the weakest person in the group of ten, I was able to do more than I had done in several months. I felt hopeful even though I was constantly feeling tired after completing different activities. I was very sad about leaving this program, but I felt that through weekly telephone contact with my therapist, and contact with the program's physician and nutritional biochemist every few months, I would continue to make progress. I was rather skeptical about some of the treatment components (e.g., homeopathic remedies[4]), but overall the positive philosophy seemed exactly what I needed to guide me in my recovery.

Coming back to Chicago was rather difficult. I tried to develop a stronger support system. Several friends began giving me weekly polarity massages, another close friend taught me how to hypnotize myself, I borrowed biofeedback equipment, and I hired a macrobiotic cook to make all my meals. For a few weeks I began getting outside each day for five to ten minute walks. I was still having many of the physical problems, and by the end of February I began feeling worse again. By the end of March, I was once again becoming very isolated. I felt increasingly hopeless about my physical condition and problems occurring at work (e.g., two of my favorite graduate students had left the program, and I felt very responsible). The hope that I had in early January was quickly dissipating. I wondered if I would ever recover.

In early April, two close friends asked if I would move into their home. With my immune system continuing to deteriorate (e.g., Tinea versicolor was beginning to appear on my shoulders), I agreed to spend a few days with them. Although initially very fearful, my first visit of a few days proved extremely beneficial. They ate healthy foods, were very supportive and loving, and welcomed me completely. I began eating more, talking more, and feeling better. Over the next few weeks, I visited my friends on two other occasions for a few days. I began spending some time outside, I felt I was part of a family, and I began to feel more hopeful. In addition, I had a new physician in Chicago who was treating my strep throat with antibiotics and the growth on my shoulder with an anti-fungal drug. I was ready to move into my friends' house, but the father of one of my friends developed cancer, and she had to attend to his needs. I felt crushed, but at least I had experienced what a change in my environment could mean for my overall spirits and health.

During the next two months, the weather became warmer and I spent some time each day outside. I even went to work for an hour at a time, a couple of times a week. I felt that I was slowly getting stronger, but the progress was very erratic. If I was too active, for example, not resting at

[4] Homeopathy is a form of healing that involves administering minute doses of substances that in healthy people would cause symptoms of the disease being treated. However, the ratio of water to medicine may be as great as a million parts of water to a single part of the medicine. Remedies are chosen that rebalance the physical body by supplying subtle energy which supposedly moves the person to a new equilibrium of health (Gerber, 1988).

least four to five hours, then I would collapse the next day. I was still under tremendous work-related pressure, as I was trying to work on a book, several articles, one grant renewal, and hire personnel for one new grant. I felt that if I completely got away for a period of time, my energy would return.

I also had found another physician in Chicago who suggested that my progress would be facilitated by working for 30 minutes each day and exercising daily. In addition, he told me it would take a few years to completely recover. Part of me believed this assessment, but part of me felt I would recover more quickly if I could find a peaceful place to rest.

In July, I traveled to New Jersey to stay with my sister and her family for a couple of weeks. Although her family had many activities going on, I was finally able to reduce my school-related work and time on the telephone. I stayed for an entire month because I felt that I was able to relax more than I had been able to in Chicago. I remember after the first week being somewhat discouraged because my energy level continued to be so low. Progress was slow and erratic, but by the fourth week I was able to swim an easy breast stroke in my sister's outdoor pool for five minutes.

I know that my strength improved because when I got back to Chicago in early August, I had more energy (I was able to catch up on work-related networks, working about 2 1/2 hours one day). In a few days, I flew to Montana to be with some friends I had met the previous January in the treatment program.

When I arrived in Montana, I was overwhelmed with the beauty of the land. My friends had a ranch, with sheep, horses, and cows, and with mountains in the background, the view was absolutely spectacular. For the next ten days, joined by another CFS-afflicted individual, we talked, read, played, made sculptures, face masks, had bonfires, and just had fun. For the first time in many months, I was with people who knew exactly how I felt. The community that we formed for a brief period of time gave me a tremendous amount of hope. I could actually be with people again, be somewhat active, and feel like I had rejoined the human race. Although I overdid it a few days, and got very tired, for the most part, I did more and had more energy than in months. I was very sad to leave this community at the end of the ten days, but at least I now knew that in a healing community, I would not only feel better but also continue to gain more energy.

I came back to Chicago for a few weeks, and spent this time trying to find a place to go for the fall. As much as possible, I wanted to duplicate the conditions I had experienced in Montana. Some friends told me about the Camphill movement, where mentally retarded and normal people live together in a supportive community. After talking to several people who lived in one of these communities in Minnesota, I was informed that a couple wanted to start a Camphill community for people undergoing stressful periods in their lives. The couple lived on a 300-acre farm a little north of Minneapolis and invited me to stay in their house. I jumped at the opportunity to be part of this new community.

At the beginning of September, I found a person to help drive me to this farm. I arrived in better health, after a summer of considerable healing. I had gained about 10 pounds, my stomach and intestinal problems were beginning to clear up, I was not allergic to any foods, and my liver and spleen discomfort was reduced. My two principal problems now were insomnia (it took me about an hour to fall asleep, and I often woke up during the night) and low energy (I could be active for only a couple of hours each day). However, I was confident that these problems would fade in the upcoming months.

The intent of the community was to establish a place where people could learn about growing crops, become reacquainted with the beauty of the land, and heal, and I was to be one of the first members. This was a Rudolph Steiner-inspired community[5], based on the same philosophy that was used by my physician. As with any farming community, there was a tremendous amount of work that needed to be done at all times. Although the people associated with this community were compassionate and idealistic, I often felt depressed and tired in doing my assigned chores (cleaning all the dishes, watering plants, burning the garbage, making breakfast, putting wood in the fires). I began spending time at several parks, and when I left the house for most of the day, I would often feel a bit stronger. By late October, each day I was able to either swim for ten minutes or walk for 15-20 minutes.

Unfortunately, the temperature dropped, a person with a cold came into the house, and I overdid it a few days as a result of my intense good mood and positive expectations for getting well. In November I nursed a sore throat and saw my new-found energy quickly disappear. After a few weeks of struggling with not feeling well, a friend drove me to Madison, and I drove from Madison to Chicago. That short trip in my weakened condition set me back even further. I then had a sore throat, insomnia, stomach problems, and Tinea versicolor on my shoulders. I started on antibiotics to deal with my strep infection and other medication to combat the fungus. I then flew to New Jersey to spend a few weeks with my parents.

[5] The anthroposophic movement, which was founded by Rudolph Steiner, has been the inspiration for Waldorf School, Bio-Dynamic Agriculture, as well as the Camphill Community. Although I was not able to accept many of this movement's ideas on spirituality (Shepherd, 1954), there is no question that the Camphill communities (Konig, 1981) are refreshing, positive, and vital settings where healing and fellowship can occur.

My plan was to spend a few weeks in New Jersey and then find a place in Florida to continue my recovery. My parents were extremely supportive, but they are late-night people, often watching television into the early morning hours. The noise kept me up, and this further eroded my strength. This was a rather discouraging period. I had now been sick for over a year, and I felt as weak as I had in the beginning. For 2 1/2 weeks I stayed in and tried to rest, and gradually I began feeling somewhat better.

On Christmas Day, I flew to an inexpensive resort a little north of Tampa. For the next three months, I stayed at a 2 1/2 acre resort that served about ten guests. This setting was extremely restful as I had no responsibilities or obligations. I found that I was able to regain some of my strength. I was able to work for about an hour, practice 20 minutes of gentle yoga exercises, and walk 20-25 minutes or swim 10 minutes, each day. If I exceeded these energy boundaries, for example, walking or swimming beyond these limits, I would be depleted for a couple of days. I kept pushing myself to always do a bit more, but it seemed that my body would only allow a certain amount of energy expenditure before I encountered a punishing setback. The guests were interesting, and I found myself relatively content most days, particularly when I was feeling well, which was about 70% of the time. Even in Florida my throat continued to be red, with an occasional sore throat, indicating the presence of a continuing viral infection. I noticed that when the weather was warm enough to sit outside, I generally felt better and had fewer respiratory problems.

In mid-March I left Florida and returned to Chicago. I had been gone for almost a year, and although I had healed considerably, I was unsure how I would respond to the new stressors and responsibilities in Chicago. My intention was to try to work in my office for 1 1/2 hours each day. I was so thrilled to actually be back at work that the 1 1/2 hours usually stretched to three hours, seven days a week. Within a month, I had caught up on old correspondence, manuscripts, and other organizational matters. Because I appeared to be relatively healthy, it was difficult for other to completely appreciate my limited energy reserves, and numerous small requests frequently depleted my stamina. I was most encouraged by my ability to work about 20 hours a week, although this new, high level of activity forced me to rest for most of the remainder of the day. In effect, during the first few months in Chicago, I had to greatly limit contact with friends and restrict my exercising in order to have the energy to complete job responsibilities.

After returning to Chicago, I found that four friends with CFS who had been functioning at a rather high levels before I left Chicago had experienced serious relapses due to exceeding their energy boundaries. The message to me in modifying my behavior was clear.

Clearly, establishing a balance was essential. I slowly learned how to divide my limited energy into both work and social arenas. This is the task I am presently confronted with, to learn to manage my time efficiently and effectively (Servan-Schreiber, 1988). Over the next year, as I slowly began feeling stronger, I began participating in activities and events that I had been deprived of for so long, and this higher level of activity often pushed me to the limits of my energy boundaries. In the fall of 1991, I began teaching at DePaul University once again; I had been away from the classroom for two years. I tried to continue limiting my academic work to 20 hours a week, but I often exceeded these limits.[6]

DISCUSSION

The most debilitating symptom of this illness is the profound weakness and fatigue. For months I had only enough energy to perform the most basic tasks. Even brief conversations with friends left me depleted for hours. It is possible that having mononucleosis and the stress involved with being isolated and anxious depleted my reserves of vital chemicals needed for normal body activities. As mentioned in the introduction, deficiencies of corticotropin-releasing hormone and cortisol have been found in CFS-afflicted people, and these deficiencies are associated with lethargy and fatigue. Drained of these important chemicals, I lacked the physical capacity to respond. Finally, it is also possible that by not succeeding in eradicating the virus from my system, my body was in a continual state of arousal, with my immune system producing substances (e.g., cytokines) causing side effects such as fatigue.

At the same time that my body was so fatigued, I was in a state of overstimulation. The battle ongoing in my immune system probably increased brain electrical activity (Besdeovsky, Sorkin, Felix, & Hass, 1977). I often felt that there was a buzz of an electrical charge throughout my body, and if I was stressed, this tingling feeling became so prominent that I might not be able to sleep for an entire night. My body had also become more sensitized to stress, and life events that I had formerly tolerated easily now seemed to produce a stress response (e.g., even thoughts began to elicit a feeling of overstimulation). Goldstein (1990) suggests that the brain becomes hypersensitive to stress because cytokines reduce the threshold for neuronal excitability. The most consistent remedy, for me, was complete rest for hours, and this had the effect of toning down my overactivated

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[6] By the Spring of 1993, I had slowly gained more strength, and I was able to work an average of 35 hours each week.

system. Exercise, which is so critical for long-term recovery, often exacerbated my symptoms. Exercising might cause interleuken-1 to enter the bloodstream and raise the body temperature (Locke & Colligan, 1987). However, in CFS-afflicted individuals, the interleuken-1 might precipitate extreme achiness and fatigue.

Shepherd (1990) has presented evidence from England concerning muscle abnormalities in CFS-afflicted people. Unfortunately, many of the findings in this area are either inconclusive or have not been replicated (Shafran, 1991). David, Wessely and Pelosi (1991) have suggested the presence of viral RNA might be having an adverse effect on muscle metabolism, without showing evidence of cell damage (Archard, Bowles, Behan, Bell & Doyle, 1988). Because of possible impairments in muscle systems, exercise should be approached with caution in order to stimulate recovery and to prevent further damage.

Interleukin-1 promotes deep sleep, and Moldofsky (1991) has found dramatic increases in this cytokine when people go to sleep. In addition, Moldofsky reports that when normal, healthy individuals have their deep sleep disturbed for three nights, they often begin to complain of aching and fatigue. Because interleukin-1 might already be elevated in CFS-afflicted individuals, there might be a connection between normal increases of this substance at night and some of the sleep disorders that are typically found in CFS, and these sleep disorders might contribute to some of the fatigue and achiness that are also frequently reported.

At the recent American Society for Microbiology meeting, William Carter discussed the findings of a trial of Ampligen for CFS patients (Cotton, 1991). While normal levels of interleukin 1 are less than 1 pg/ml, 42% of CFS patients had elevated levels (96 pg/ml in the treatment group) of interleukin 1 at the beginning of the study. Those patients most likely to respond to the ampligen treatment had markedly elevated levels of interleukin 1. These findings add more support to the possible role of interleukin 1 in causing many of the symptoms in CFS-afflicted individuals.

Up to 80% of CFS-afflicted individuals appear to get better in one to five years, with some of the improvement due to having less severe symptoms, making adjustments in lifestyle, and losing fear about the disease (Bell, 1991). Some of those who get better identify a wide variety of cognitive strategies (Burke, 1992) and medications as helpful, but none of these techniques or substances seem to help the majority of CFS-afflicted people (Butler et al., 1991; Peel, 1988). Several recent books do seem to emphasize that those who get better are able to enhance their immune system through a variety of approaches that include rest, reduction from stress, good diet, exercise, and supplements (Bell, 1991; Bolles, 1990; Feiden, 1990; Wilkinson, 1990).

A key question involves why certain people seem to get better while others do not. It could be that some individuals who do not recover have had more severe damage to the immune system. A variety of the other factors might be influencing immunosuppression, including dysphoric responses (e.g., depressive affect, unhappiness, anxiety), immunosuppressive behaviors (e.g., dietary patterns, sleep habits, licit and illicit drug use), adverse life experiences (e.g., ongoing strains in interpersonal relationships), and pre-existing vulnerabilities (e.g., the absence of interpersonal resources and coping patterns to forestall the impact of negative life experiences) (Kaplan, 1991). Gaining insights into the effects of these factors on chronic illnesses might eventually lead to the knowledge base to prevent the onset of a variety of medical and psychological disorders.

In my own recovery, I focused on two goals: a) slowly gaining strength by avoiding stress, relaxing, and resting and b) challenging my system by having fun, maintaining a positive mood, and engaging in some exercise. The problem for many CFS-afflicted people is that their stress-filled environments are often not places to relax, and when energy levels are so low, it is hard to have fun or exercise when all of one's energy is focused on survival issues.

This last issue has been the most difficult for me to deal with. I've often felt that I was trying to solve a Zen paradox: how to enjoy oneself when feeling exhausted and depleted. Those who are able to resolve this issue have better chances of recovery. The fields of psychoneuroimmunology and community psychology do offer some promising leads for helping deal with this puzzle, and in the remaining parts of this paper, I will try to show the relevance of these fields for helping individuals with CFS.

The field of psychoneuroimmunology posits that communications are ongoing between the mind and body. As an example, high levels of anxiety or depression can impair the immune system's functioning. When extreme restrictions in lifestyle occur due to CFS, it is common to become depressed. In December 1989, I found myself becoming increasingly frustrated, anxious, and depressed as I saw week after week pass with no improvement. My depression lifted when I entered a treatment program that I felt had many reasonable elements. For the first time, I had an explanation of what was going on with me and what I might do to get better. One of the possible reasons that so many different treatments (herbs, antidepressants, acupuncture, etc.) seem to help people is that, to the extent that the person believes in these strategies, his/her negative emotional states begin to lift, giving the person's natural healing systems a chance to win the war against the virus and begin to rehabilitate the imbalanced immune system.

Finding hope and improving the mood of CFS-afflicted individuals seems to be a critical task for recovery. Some individuals claim the potency of particular vitamins and herbs, others find relief in new spiritual beliefs, and still others are able to calm their minds using relaxation and meditation. For some individuals who actively inhibit their thoughts and feelings about current or past traumatic events, the active process of inhibition can exert a cumulative stress on the body. Helping individuals divulge personal or traumatic events can have a positive effect in reducing stress (Pennebaker & Beall, 1986). Misinterpretations of normal anxiety responses (e.g., palpitations, breathlessness, dizziness) can be interpreted in a catastrophic fashion, and this can lead to a vicious cycle of increasing apprehension (Clark, 1986). In order to successfully manage stress, it is critical to differentiate distressing physical sensations from misinterpretations of certain bodily functions. In addition, during the most debilitating times, individuals might need to erect defensive screens against painful perceptions (Layne, 1983). All of these strategies and others might protect the person from the ravages of a flood of immune-depressing biochemicals, and positive emotions might even be able to enhance the recovery of formerly impaired immune functions. For some, this new sense of hope and optimism is enough to allow the person's body to heal. These individuals are now able to begin enjoying life, and as new energy is mobilized, they are able to continue to believe in their treatment plan. Psychoneuroimmunology provides a theoretical reference point for helping understand the powerful influence of the mind on the recovery process.

Although this model might help explain why some people recover, for many people, including myself, this particular model was not enough. In January 1990, I returned from my treatment program with what I believed to be a comprehensive and effective plan. I had a wonderful therapist who served as a role model for me, as she had recovered from CFS. I regularly meditated to calm my mind, listened to a variety of relaxation tapes, and used biofeedback equipment to calm myself. Several friends helped me with self-hypnosis and massage. I had an experienced nutritionist and physician treating me. My belief system was energized, I did feel better for awhile, but by February and March of 1990 I was once again feeling sick, and I became increasingly isolated.

To be sure, this illness ebbs and flows, and one needs to accept the many setbacks one will experience. But what happened to me, I believe, happens in different forms to many CFS-afflicted people. When people get sick, they often begin to lose their savings, their jobs[7], and even their

[7] Some social policies interfere with the efforts of CFS-afflicted individuals to become more independent and functional. For example, CFS-afflicted people on social security disabilities

friends. The environment they inhabit can become increasingly stressful. Some individuals are able to keep the levels of stress low, and their bodies gradually do recover. However, for those individuals whose immune systems have been more severely impaired and/or whose environments continue to be stressful, the effectiveness of the various psychological strategies listed above will be limited.

When I was not feeling well in February and March 1990, I continued to use a wide variety of psychological enhancement strategies. They were effective in keeping me from becoming depressed. However, because my energy was at such a low level, I spent most of my time confined to my apartment. I am sure the setting and many of my thoughts became conditioned stimuli for immune suppression. It was clear to me by April 1990 that I needed to be away from job stressors, I needed to be with a family or community, as a buffer against stress and as a nurturing place that would allow my immune system to bounce back.

My efforts in April 1990 confirmed this possibility. When I entered the home of a loving family, I immediately began feeling a lot better. I was still very tired, and I would only walk for five minutes a day, but I began feeling human again. I felt protected, and with fewer negative stressors infringing on me, the psychological strategies I was using were more effective. In a sense, my efforts in the summer and fall of 1990 and winter of 1991 were to be with people, to participate in behavior settings that were supportive, protective, and nurturing. It was during this time that I was best able to save energy each day and to challenge my system by having fun.

The field of community psychology would very much support an emphasis on creating supportive environments where one is protected from stressors and where more profound healing can occur. For many, this might not be necessary, as recovery can occur with purely psychological relief-enhancing strategies and medications to control symptoms. However, for many others, it is clear they need to be away from the daily stressors in order to recover. When sick from CFS, the body becomes so sensitive that even one negative event, which used to be handled easily, can now disturb the person for an entire day. I've talked to many people who have successfully recovered, and I often find that they have been able to have a family or other refuge to which to withdraw for up to several years. I be-

are often discouraged from seeking employment because this might result in a loss of their insurance for medical coverage. Even if they find a well-paying job, it is likely that they could not be insured due to their pre-existing illness. This problem of obtaining insurance is one of a number of factors that deter those on social security disability from becoming more autonomous and independent. Fortunately, during my illness, I was able to slowly increase the number of hours I worked each day, and I was able to keep my job and my insurance.

lieve that people with CFS need both the psychological strategies, medications to control symptoms, and new settings or communities in order to give their bodies a change to recover.

For some CFS-afflicted people, even the use of psychological strategies, medications, and a supportive community that is a refuge from some stressors will not be effective, perhaps because their immune systems are just not able to recover. New biomedical research one day may find the answers for eradicating the virus or improving immune systems (i.e., drugs such as ampligen). Until that day, however, there are probably hundreds of thousands of CFS-afflicted individuals who are terribly isolated, and supportive communities need to be established so that these people can live more decent and high quality lives.

I believe the implications for the treatment of CFS-afflicted individuals are clear. When people become very sick with CFS, they need not only psychological strategies and medications to control symptoms, but often a setting or community to protect them so that their immune systems can heal. At present, there is no setting in the world that affords this type of treatment for CFS-afflicted people (McLaughlin & Davidson, 1986). What is needed, I believe, are families who are willing to take in sick individuals for extended periods of time, or communities emerging in different parts of the country where CFS-afflicted people can heal. This approach represents a different way of extending services, but I believe it is desperately needed for many of those now suffering from CFS. Such an approach—combining strategies that a) strengthen inner resources through instilling hope, confidence, enthusiasm and the will to live, and b) provide a place for people to live that is protected and nourishing—represents a more comprehensive program that could be applied to other problems besides CFS[8]. I expect that these types of more comprehensive approaches[9] will one day be more common, and our effectiveness in helping people will thereby be enhanced.

[8] This type of approach is currently being used with mentally retarded people at Camphill, Innisfree Village, and L'arche. Oxford House for former alcohol and drug abusers is an example of building these types of support systems in urban areas. Wellness communities have been formed in California for people recovering from cancer. Gould Farm provides a secluded retreat and healing milieu for those needing psychiatric treatment and rehabilitation. Gesundheit Institute is building a health care community for helping people with physical and mental illnesses. Open Door Community provides advocacy and housing for the homeless (Intentional Communities, 1990).

[9] Western health care practitioners might also profit from examining alternative healing systems such as rest cures developed by Weir Mitchell, the Japanese Morita therapy, and the Ayurveda Indian therapeutic approach. These traditions place more emphasis on the relational, by attempting to restore harmony between the person and his/her family and community (Kakar, 1982).

There are a number of implications for the field of primary prevention. An increasing knowledge of the different psychological, social, community, and medical factors accounting for chronic illnesses might help the field of prevention develop more sophisticated models and more effective preventive interventions. In addition, we become a more caring and humane society when we invest resources into the establishment of decent living conditions for all our citizens. If we do not decrease the staggering numbers of disenfranchised people in our society, if we fail to develop a sense of community for those who are in need, then our society might become even more conflictual, and then the influence of any of our preventive interventions might be seriously diminished.

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