A Multimodal Approach in Dealing with Chronic Epstein-Barr Viral Syndrome

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Chronic Epstein-Barr Viral Syndrome (CEBV) is a puzzling and controversial disease with a variety of symptoms that frequently include depression and emotional debilitation. The following article describes CEBV, offers some diagnostic signs, and suggests a possible treatment strategy based on the multimodal approach.

I am writing this letter in an attempt to try and explain the way my life has changed due to an illness called Chronic Epstein-Barr Viral Syndrome, or CEBV. I was not diagnosed at first. . . . I saw doctor after doctor and (had) test after test before being diagnosed . . . all of this began three years ago. I started getting weak, fatigued, headaches, swollen glands, sleep disturbances, light-headed and having pain and weakness in my joints. I soon was unable to perform at work or in my various sports activities. I sought help medically . . . he (the physician) put me in the hospital and ran numerous tests, all showing normal . . . this did not help either, I was still sick.

Thus began my introduction to John, a bright 22-year-old man from a small suburb of Huntington, West Virginia. His letter was part of the evidence in his case file that John had prepared, along with his family and attorney, in his plea for the recognition of his "disability" status by the Social Security Administration's Office of Hearings and Appeals. I was called on as an expert witness by the administration to comment on both the vocational and psychological implications of not only CEBV but also of the various other physical and psychological diagnoses offered for this individual. I was also asked the possible vocational implication of each condition, if deemed credible by the Administrative Law Judge. John's ordeal, unfortunately, was not uncommon; in fact, his condition is amazingly similar to that of thousands of others who report the debilitating effects of a somewhat mysterious and elusive (in terms of diagnosis) chronic viral infection that infects most of us (Straus, Tosato, Armstrong, Lawley, Preble, Henle, Davey, Pearson, Epstein, Brus, & Blasey, 1985). In developed countries, the classic manifestation of primary Epstein-Barr virus infection is infectious mononucleosis, which occurs primarily in adolescents and young adults (Straus et al., 1985). Yet, in recent years, many are developing these flulike symptoms that persist for months and even years. These symptoms are frequently accompanied by severe depression, broken marriages, ended careers, and even suicide ("ABC News," 1986). The condition has been called *the Yuppie disease* or *the Yuppie flu*, since so many of its sufferers have been young, White, mobile professionals. It also seems to strike women at a rate of two to three times that of men and in the literature has been called CEBV, chronic mononucleosis, neuromyasthenia, and chronic fatigue syndrome, although not all chronic fatigue is attributable to CEBV.

As mental health professionals, we are increasingly coming into contact with these individuals either to treat the frequently accompanying depression or, unfortunately, to misdiagnose a

purely psychological problem when there seems to be an actual viral culprit. This article attempts to inform counselors of the signs and symptoms of Chronic Epstein-Barr Viral Syndrome and suggests how a comprehensive multimodal or holistic approach for the management and treatment of this complex syndrome may be of help.

SYMPTOMS AND DIAGNOSIS

John's ordeal parallels that of many CEBV patients. A local examining psychologist had labeled him "an immature personality," yet at age 22, he was vice-president of a thriving family corporation, with a personal line of credit at local banks that few his age could hope to attain. John had had mononucleosis in the ninth grade. He recovered and through placement in accelerated classes graduated six months ahead of his peers. In 1984, before his illness, John essentially ran the tri-state business for his ailing father. In an attempt to deal with his persistent symptoms and fatigue, he turned to alcohol and later to cocaine for energy. This caused him to earn the psychiatric footnote of "adjusting poorly to his Epstein-Barr virus" (from the medical/psychiatric records and used with John's permission). Several examining physicians found nothing physically wrong with John and a few suspected malingering.

Susan Michaud, a patient interviewed on ABC's "20/20" ("ABC News," 1986) stated: "They thought that I had a thyroid problem or a blood sugar problem, premenstrual syndrome" (p. 2). Darrell Anderson on the same program stated that his diagnosis was multiple sclerosis, while Brenda Longworthy's symptoms were attributed to "nervous stomach" (p. 3). Longworthy was treated with tranquilizers, since "they thought it was mostly psychological" (p. 3).

Dr. Paul Cheney began treating nearly 200 cases of suspected CEBV in a strange outbreak of the disease in Incline Village, Nevada, in the early 1980s. He was among the first to recognize a perhaps unique syndrome with a physiological basis and to begin the plea for assistance and research. Cheney had to battle with the Centers for Disease Control in Atlanta for an objective study of CEBV patients in Incline Village. He also met resistance from local civic and businesspersons for bringing "bad press" to the trendy resort area (Boly, 1987).

Recently, Robert Gallo and his colleagues at the National Cancer Institutes Laboratory of Tumor Cell Biology have identified a novel herpes virus, which they named HBLV (human B lymphotropic virus). Cheney feels that this newly discovered virus may be related to the Incline Village epidemic (Boly, 1987). Gallo stated in *Hippocrates*, "My feeling is that HBLV is a very hot candidate to be involved in a portion of what is now being called chronic Epstein-Barr virus syndrome" (Boly, 1987, p. 38).

Regardless of whether the virus is CEBV, HBLV, or something else, there are symptoms the counselor can look for and others the counselor will want to refer for consultation with a physician. An elevated titer count for the Epstein-Barr virus antibody

or other similar viruses is one possibility for suspicion of a viral cause for the clients' complaints, but this is far from a definitive test. Other symptoms may include chronic fatigue, low-grade fever, swollen lymph glands, flu-like body aches, mild sore throat, headaches, depression, and confusion (Houck, 1988). Cheney's current thinking is that the CEBV may be an effect rather than the cause. Perhaps subtle changes in a person's immune system allow the virus to become activated. We know that the virus is present in the bloodstreams of 90% of all Americans and is thought to be the cause of the common form of infectious mononucleosis, a disease similar to CEBV but milder and shorter lived (Houck, 1988). Cheney's thesis seems plausible. The chronic persistence of the disease syndrome is another hallmark of the diagnosis. As Boly (1987) noted, "AIDS kills; chronic mono . . . just makes you wish you were dead" (p. 32). The comparison to AIDS is often made, since both seem to strike at the immune system, both produce a complex and varied range of symptoms, and both are relatively new, at least as far as diagnosis. As noted, CEBV seems to strike women about twice as frequently as men, prefers adults in the prime of life, and through its chronicity helps to destroy careers, relationships, and the premorbid quality of life. After Nomi Antelman suffered through 5 years of illness and one misdiagnosis that led to the removal of her spleen, she said, "I couldn't face another doctor saying, 'You're suffering all of this, you're doing it to yourself, think positively, you're crazy, you're neurotic,' whatever they had to say. And one day I simply decided that I had to be released from the pain that I was suffering, and the only release that I could see was suicide" ("ABC News," 1986, p. 4).

Unfortunately, this vague, hard-to-diagnose disease has brought out the full array of healers. As Johnson (1987) noted in *Rolling Stone*: "CEBV has been a boom to healers in and out of the realm of orthodox medicine, including orthomolecular physicians, who attempt to treat the disease through megavitamin therapy, as well as psychiatrists, psychologists, psycho-immunologists, herbalists, hypnotists, homeopaths, nutritionists, acupuncturists, accupressurists, faith healers and even purveyors of snake venom" (p. 45).

Straus et al. (1985) profiled 23 patients referred to the National Institutes of Health (NIH), whose serologic and immunologic studies suggested CEBV. In a 2-year follow-up a relatively homogeneous group was described. All were Caucasian adults, with ages ranging from 21 to 48, all except two had college degrees or were in college, one was a physician, one was a nurse, and two had Ph.Ds. Thirteen had an onset of the chronic illness within one year of a mononucleosislike disease that was characterized by prolonged fever and adenopathy (seven of these episodes are known to be associated with a positive heterophil test). In ten instances the patients never fully recovered from acute infectious mononucleosis. In three other instances, the onset of chronic fatigue was associated with clinical relapse within one year of apparent resolution of acute heterophil-positive infectious mononucleosis. Six patients had a mononucleosislike illness more than one year before the onset of current symptoms, and four patients never had a mononucleosislike illness before the onset of the current symptoms (Straus et al., 1985, pp. 8-9).

COUNSELING APPROACHES

CEBV patients have done an excellent job in spreading their stories to the public and in pressuring the U.S. Congress for research funds. Self-help groups have emerged. The National Chronic Epstein-Barr Virus Syndrome Association of Portland, Oregon, enrolled 11,000 members in its first year (Boly, 1987, p. 36). Local support groups are springing up in the larger cities across the country, especially on the coasts.

The persistent fatigue and chronic illness of those with CEBV, coupled with their ordeal in receiving a correct diagnosis, is

frequently associated with major depression, dysthymic disorder, and suicidal gestures or attempts. Once a medical diagnosis is confirmed or strongly suspected, the mental health professional working in concert with the physician should consider a holistic or multimodal approach (Lazarus, 1981).

Although the syndrome itself currently is "incurable," it is subject in some cases to spontaneous remission, at least for certain indeterminable periods. The multimodal, interdisciplinary approach seems to be the best model for helping the client or patient to deal with both the physical and psychological effects of the disease.

In multimodal therapy, (Lazarus, 1981, 1984) clients are initially interviewed by asking questions that relate to the seven modalities of the acronym BASIC ID: Behavior, Affect, Sensation, Imagery, Cognition, Interpersonal Relationships, and Diet/Drugs (or Biology). Corey (1986) notes that this preliminary questioning usually brings out some central and significant themes that can be productively explored (p. 194). Corey continues:

... The preliminary questioning is followed by a life history questionnaire. Once the main profile of a person's BASIC ID has been established, the next step consists of an examination of the interactions among the different modalities. This second phase of work intensifies specific facets of the person's problem areas and permits the therapist to understand the person more fully as well as devise effective coping and treatment strategies. (p. 194)

The therapist would then treat the selected modalities using various approaches. "... they are willing to teach, coach, train, model, and direct their clients. They provide information, instruction, and feedback. They challenge self-defeating beliefs, offer constructive feedback, provide positive reinforcement, and are appropriately self-disclosing. It is most essential that therapists start where the client is and then move into other productive areas for exploration. Failure to apprehend the client's situation can easily lead the client to feel alienated and misunderstood" (Lazarus, 1984; Corey, 1986, pp. 194-195).

The therapist would use a selective or technical eclecticism (Lazarus, 1984) and borrow from the whole range of psychotherapeutic techniques. This flexibility and holistic attitude of the therapist make the multimodal approach ideal for the CEBV client.

CASE STUDY

Let us examine the case of "Jan" (a composite client). Jan is a 26-year-old White woman, college educated, who was working as a real estate salesperson until 17 months ago, when she was forced to resign due to her fatigue and symptoms. At first, she thought that she had a simple case of the flu. As her symptoms progressed and her energy waned, she was forced to request a leave of absence from her fast-track, successful real estate job. Initially this was a blow to her self-esteem, but Jan was confident that with proper rest and medical treatment, she would soon rebound. Since she was only minimally sexually active, she did not fear that these were the early symptoms of Acquired Immune Deficiency Syndrome (AIDS), as other CEBV patients have, but was troubled by the lack of a definitive medical diagnosis.

As Jan's financial reserves ran low, she was dismayed to discover that she was denied both social security and private disability benefits from her personal insurance carrier. To make matters worse, several of the professionals that she came into contact with suggested various psychiatric conditions ranging from dysthymic disorder to conversion reaction.

Finally, after several additional tests an internist diagnosed CEBV. This alone was a turning point for Jan. Confirmation that she was really "sick" and not "crazy." But, by now, the psychological and physical factors had interacted and taken their toll.

The physician and mental health specialist working in tandem and realizing that the disease syndrome is, at least as of now, "incurable" (but sometimes subject to spontaneous remission or recovery) agreed to try the multimodal approach. A thorough history yielded the following for the seven BASIC ID modalities:

Behavior—Jan has "good days" but also stretches of a week or more where she is too tired to dress and leave the house. Some days, she does not eat or even get out of bed. On "good days" or during periods of brief remission, she tends to overdo things and quickly experiences a return of symptoms.

Affect—Jan presents as severely depressed. She dwells on her disability and has noticed an increase in both the frequency and intensity of her depression.

Imagery—Jan's self-image is at an all-time low. Her appearance has declined, over and above what would be expected from her physical symptoms. She imagines a future of chronic illness, financial ruin, and a premature death.

Cognition—Jan has progressed (or actually regressed) from telling herself that "I can beat this thing with proper treatment" to "I'll never get any better" and "I'm going down and no one or nothing can help me."

Interpersonal Relationships—Jan has gone from an outwardly oriented social and enterprising type of personality to a near recluse. Her relationship with her boyfriend has ended, but she still relates to her immediate family and a very few close friends.

Diet/Drug/Biology—Jan enjoyed better-than-average health prior to her CEBV. She exercised to videotapes two to three times per week and has had no prehistory or posthistory of alcohol or drug abuse and no chronic illnesses. Naturally her current "disabled" status is a major area of concern.

TREATMENT

Using a multimodal approach, the counselor would complete a history for all modalities. Next, the counselor would begin to work with altering some of Jan's maladaptive and nonproductive behaviors. Through behavioral contracting, Jan could set goals to get out of bed, get dressed, and set reasonable daily objectives for both "good" and "bad" days. She could learn to pace herself so that she did not overdo things, thus draining her energy during times of remission and hastening a relapse.

The rational approach of Ellis might be used to help Jan to eradicate her self-defeating thoughts. She would begin by telling herself that "I can cope with CEBV; I can live with CEBV and still be a success." She might also enroll in a weekly CEBV

support group. As treatment progressed, Jan would begin to imagine herself as a strong person, one whose will to live with and overcome CEBV was strong. Through role playing she could practice applying for part-time real estate work and re-establishing previous relationships. In consultation with her physician, her counselor could help her to develop a high energy diet to maximize her physical strength and endurance. Various drug regimens would also be tried by the physician.

In real life, John's struggle continues. He was denied social security benefits and continues his daily battle with CEBV, while his case works through the appeals process. But at least John has the benefit of what he and his physicians believe to be a correct diagnosis, while hundreds or even thousands more still struggle to find out what has affected them.

Although research and experimental drug studies are being conducted, CEBV remains a puzzling and controversial illness. We do know that the pain and suffering of CEBV victims are real and suggest that counselors, with their wide range of coping and treatment skills, can be of help. By working with the physician and patient, counselors can be effective partners in the treatment of this syndrome, at least until an effective cure is found.

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