Just health

Immune dysfunction — Part 2

A layperson's report on a disturbing medical syndrome. What is it telling us?

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Last month in Part 1, I reported on a controversy currently raging in the medical journals over an immune dysfunction syndrome recently named Chronic Epstein-Barr Virus syndrome (CEBV), characterized primarily by incurable, severe, and in some cases, debilitating, fatigue. It has been featured in the past few months on television's *20/20*, in *Newsweek*, and on the Phil Donahue show.

Ironically, as suggested in the conclusion to Part 1, the CEBV "breakthrough," the discovery that many chronic fatigue patients show a high number of antibodies to the Epstein-Barr virus, may in fact be diverting medical attention from more important co-factors in the chronic fatigue syndrome and as a result, may be clouding public understanding of this and other immune dysfunction illnesses.

I have been involved personally and professionally in the world of immune dysfunction for the past several years in handling the legal affairs of a good friend and neighbor who fell ill in 1984 with what has since been diagnosed as Environmental Illness (EI), an immune dysfunction syndrome even more controversial than CEBV and characterized by multiple chemical sensitivities causing varying combinations of symptoms, some of which are also reported by CEBV patients (i.e., fatigue, pain and mental debilitation).

Environmental Illness books and community newsletters indict the organic chemistry revolution of the 1940s for introducing thousands upon thousands of previously nonexistent substances to the air we breathe in our homes, in the workplace, and out of doors. These now ubiquitous manmade hydrocarbons, says the EI literature, provide a constant challenge to our immune systems, and some of us are not up to it, and eventually suffer an immunological "breakdown," becoming chronically ill. The only known treatment for EI is diet change and avoidance of environmental toxins.

I first learned about CEBV in the fall of 1985 when the chronic fatigue syndrome was named for the Epstein-Barr virus. My EI friend and I noted with interest that CEBV and EI were similar in several respects:

- Most CEBV and EI people had allergies as children, and many CEBV and EI people suffer from food allergies and yeast problems as adults, all of which doctors seem to agree indicates a somewhat vulnerable immune system.
- Many CEBV people report they were exposed to a product containing tung oil prior to falling ill (of which there are in excess of 300 resins, laquers, etc.). Virtually all EI people have toxic reactions to thousands of volatile organic substances, including tung oil products, perfumes, household cleansers, fabric softener, paints and plastics, etc. The most-used synonym for Environmental Illness, in fact, is Chemical Sensitivity.
- Informal surveys of CEBV patients indicate that the vast majority of them are intelligent, self-motivated, achievement-oriented people. CEBV is also reported to strike more women than men by a ratio of three to one, and is said to be particularly noticeable in the health and teaching professions. My personal observation is tht EI people, even with their limitations, tend to be articulate, positive-thinking, self-reliant types. My own EI friend, for example, is helpless, humiliated and totally disabled, yet he rarely complains about his pain or his desperate situation.

A couple of observations can be made about the current medical research on these nonfatal immune dysfunction syndromes. First, research on these diseases is, understandably, presently overshadowed, in terms of funding and media coverage, by the search for a vaccine and cure for AIDS. (In fact, as discussed in Part 1, the relation of the Epstein-Barr virus to chronic fatigue was a windfall of an early AIDS research project.) Second, and again, perhaps in part because of AIDS, medical research on CEBV and similar illnesses seems primarily directed toward finding an etiologic agent, isolating one viral culprit.

The search for a virus has resulted in some interesting ideas, one so interesting that it actually resulted in a press restriction (broken by *Village Voice*) — the idea was that a common newly isolated virus, HBLV, might be the cause of not only what is now called CEBV but also of the initial flu-like symptoms of AIDS victims. *(Just an idea.)*

Even a lay person fumbling through the medical literature quickly finds that at least some of the viruses being discussed as possible factors in nonfatal immune dysfunction are common viruses — for instance, HBLV, discussed in the preceding paragraph, supposedly resides in thirty percent of us. This could mean that even if "the" viral agent were identified, certain people would continue to fall ill until and unless a safe, economical and effective vaccine were developed, no simple matter.

It seems to me that serious research should also be conducted on the possibility of non-germ co-factors, such as pre-illness exposure to toxic chemicals and psychological makeup. If there are such preconditions to viral immune dysfunction, then information about them is as important to prevention as the name of the virus.

It is heartening to know that a new branch of medicine called psychoneuroimmunology is already giving serious attention to apparent psychosocial factors in the cause of certain diseases. Interestingly, two of the first studies reported related to the most common Epstein-Barr disease, infectious mononucleosis.

In the first study, in 1959, 38 undergraduates at the University of Wisconsin were tested for ego strength and this was correlated with the length of time it took them to recover from infectious mononucleosis. The strong ego group recovered faster than the weak ego group.

Twenty years later a larger study was done of 1400 West Point students. The study tracked all students whose first exposure to the Epstein-Barr virus occurred after entering West Point, comparing those so-called "eroconverters" who actually came down with infectious mononucleosis to those who did not become ill in spite of being attacked by the virus. It was found that the following factors significantly increased the risk of coming down with clinical infectious mononucleosis after expsoure:

1) having a father who was an overachiever;
2) having a high level of motivation;
3) doing relatively poorly in school.

In another study, it was found that students who showed greater evidence of role crisis, personal failure, depression, hostility, and anxiety had far more respiratory illnesses for which they sought treatment than happier students.

These studies are intriguing to anyone reading about the mystery of immune dysfunction; perhaps we can hope for a more complete understanding of these illnesses and some new approaches to prevention and cure before too long. •

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