



No. 49 – ITP: It's not only about bleeding

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Title: **ITP: It's not only about bleeding**

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When we talk about ITP, we often consider only platelet counts and bleeding. This is appropriate. The function of platelets is to prevent bleeding; low platelet counts in ITP increase the risk for bleeding, and bleeding is the most common problem for ITP patients. Therefore almost all discussions regarding ITP focus on the platelet number, and most treatments for ITP emphasize the need to increase the platelet count. However as physicians, we are taught not to treat numbers but to treat patients, and we have learned from ITP patients that bleeding is not their only problem.

Because many patients with ITP have told us about feeling fatigued, the ITP Support Association surveyed its membership several years ago to document problems of fatigue. This survey was led by Dr. Julia Newton of the Institute for Ageing and Health in Newcastle. Simultaneously, we used the same survey for ITP patients in the US (Oklahoma). The results of these surveys were striking. 585 (31%) of the 1,871 members of the ITP Support Association returned their surveys, 69 (74%) of the 93 members of our Oklahoma ITP Registry returned theirs. This large number of surveys returned confirmed that patients thought that the issue of fatigue was important. In Dr. Newton's survey the results from ITP patients were statistically compared to results from normal adults. The findings were striking. The frequency of fatigue among both the UK and US patients was significantly greater than normal, 37% of patients reporting significant fatigue compared to 2.5% for the normal population. There was no difference between the UK and US ITP patients. The reason for the fatigue was not clear, but its frequent occurrence was striking.

In another survey led by Dr. Newton, the members of the ITP Support Association were asked about minor cognitive symptoms using a standard questionnaire with 25 items concerning problems with things such as memory, concentration, and word-finding ability. 189 patients from the ITP Support Association were also asked to have "a close friend of similar age and sex as a normal control" complete the survey. Again the results demonstrated that cognitive problems described by ITP patients were more frequent than those reported by their friends.

Why are these things happening? It would seem that fatigue and problems with memory and concentration have no relation to platelets or specifically to ITP. But these surveys were undertaken in response to repeated concerns from our patients that fatigue and problems with memory and concentration are common and sometimes bad enough to interfere with daily living activities. We know that ITP is an autoimmune disorder in which autoantibodies that destroy platelets; such autoimmune abnormalities may affect other body functions as well. We have seen these symptoms of fatigue and problems with memory and concentration in other autoimmune disorders in addition to an increased frequency of depression. Depression is clearly associated with symptoms of fatigue, memory, and concentration. Therefore, we are now planning a survey of our ITP patients that will focus on depression.

Depression is a distinct and potentially serious mental illness. It must be distinguished from the common and off-handed use of the term, "depression", which we sometimes use to describe temporary sadness, grief, or disappointment, each of which can be normal and healthy responses to life's difficulties. Major depression on the other hand is a disease, not a normal response, and it is not rare in the general population. In fact its major features -- including feelings of hopelessness, having little interest in doing things, feeling bad about oneself, and other related symptoms -- affect 7% of the US population in any single year. Across a person's lifetime, the frequency of major depression is 17%. In patients with a persistent medical illness, the frequency of major depression in any single year can be as high as 25%. Our interest in depression is that it is a common cause of fatigue as well as memory and concentration problems. More importantly, our interest in identifying depression is that it can be effectively treated. Without appropriate diagnosis and treatment depression is dangerous. For example, depression potentially can lead to suicide, which is currently the tenth leading cause of death in the United States.

So, an important question is whether the frequency of major depression is increased among patients with ITP. Depression can be screened for by use of brief questionnaires. Depression can be subsequently accurately diagnosed by a psychiatric evaluation, and then treated with effective medications. Our goal is to discover if the frequency of major depression is more common among patients with ITP than in the normal population. If this is the case, then screening for depression should become a standard part of your medical care and, with appropriate treatment, its manifestations, such as fatigue and problems with memory and concentration can improve.