Some Thoughts on Managing Mood and Multiple Sclerosis

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Multiple sclerosis (MS) is a chronic disease with an unpredictable course and living with it poses multiple physical and emotional challenges to the patients who have it. How successfully they cope with these challenges is influenced by unpredictable factors that are unique to each patient. It is also strongly influenced by the quality of the relationship they have with, and the guidance they receive from, their health care provider.

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The Newly Diagnosed MS Patient. The emotional impact of MS is different at different stages of the disease. It can be especially intense and difficult to manage at the time of diagnosis because patients are often quite disorganized and traumatized by the sudden loss of control of their health. How the diagnostic phase is managed can strongly influence how a patient faces the future challenges of MS.[1]

The emotional impact of the diagnosis depends on many factors. For some people receiving the diagnosis is a relief. Especially if the patient already suspected MS, if the diagnostic process has been very long and confusing, or if the diagnosis rules out even more horrible sounding problems, a confirming diagnosis can be, at least initially, reassuring.

For the majority, however, receiving a diagnosis is anything but reassuring. It is psychologically traumatic and can cause the patient to experience fear, helplessness and a sense of being out of control. The magnitude of the trauma is can be influenced by the way the news is delivered. Some patients still harbor intense resentment, years later, about the way they were told they had MS. This is especially true, for example, when the diagnosis is delivered via voicemail. A face-to-face conversation is essential, especially when the diagnosis is sudden and unexpected.

Some patients immediately have thousands of questions about MS, many of which are really impossible to answer. It is not usually helpful to provide extensive information about MS immediately following the diagnosis because patients tend to be in a highly emotional state, cannot absorb very much, and often hear only part of what is said. The choice of words can be important here. To say that "MS is a chronic illness" or to say "There is no cure for MS" is to say essentially the same thing. However, to a frightened, newly diagnosed patient, "chronic illness" can sound far less frightening than "incurable disease."

Multiple sclerosis is not a common illness and prior to diagnosis many people have only a very vague ideas about what it is. Inaccurate information and pre-existing, outdated notions about MS can strongly influence patient response to the diagnosis. Asking a patient what his previous experience with MS has been can help identify and clarify inaccurate information.

It is helpful to provide limited, concrete, reassuring information and to stress MS is rarely fatal and doesn't necessarily result in disability and is usually slow moving, Most patients need some time to absorb the shock of diagnosis before they can be very receptive to much information. Schedule a follow-up appointment in a few

weeks to provide more extensive education. Provide the patient with information about community resources so they can begin their own research, should they be so inclined. Every month the Rocky Mountain MS Center offers a two-hour education program, MS101, for newly diagnosed patients and their families. The National MS Society Information and Referral Center can also provide extensive and excellent literature.

Health care providers and patients respond differently to a confirmed diagnosis. For healthcare providers, a diagnosis answers the question and signals a move to issues about treatments. For most patients, however, the diagnosis is a shock and it creates many more questions than it answers. Because their timing can be so different, the physician may be ready to talk about treatments while the patient is still reeling from the trauma of learning that she has an unpredictable, chronic disease.

The newly diagnosed patient needs to regain a sense of control and safety, manage anxiety and fear, and begin to develop a working knowledge of the disease. The more traumatic and unexpected the diagnosis, the more time it may take someone to come to terms with the diagnosis and to be ready for the next stage of treatment.

Depression and MS. During the diagnostic phase, the focus of treatment is largely on medical issues. Successful management of MS over the long haul requires a flexible focus and the ability to expand attention to the rest of the patient's life. Long-term management requires a focus on psychological well-being, relationships, support systems, and all the activities that comprise the rest of life.

A significant problem in the long-term management of MS is depression. The prevalence of major depressive disorders in MS is many times greater than in the non-MS population and is high even when compared to other groups with chronic illness.[2] There are multiple reasons why this might be so.

Depression can be a primary MS symptom caused by demyelination in the brain. It appears to be associated with greater neuropathology in the left anterior/parietal region.[2] Depression appears to be less common in patients who have purely spinal cord disease.

The nonspecific effects of a chronic illness can certainly contribute to depression. Changes in self-image, loss and chronic uncertainty about the future are among the more draining aspects of life with MS. Depression does not appear to correlate with degree of physical disability and occurs throughout the disease course. It may be more acute at certain times — following the diagnosis, after a significant change in function, or following a change in the support system (for example, following a divorce, or after leaving employment) — but is often present at lower levels at other times.

The side effects of some medications used in MS symptom management, for example Klonopin and Baclofen, can mimic depression. The interferon class of disease modifying drug was initially thought to cause depression in some patients but the research has not confirmed this. The most recent studies suggest that, although they might intensify an underlying depression, the best predictor of depression in patients on interferon therapy is a pretreatment history of depression.

Depression can be a symptom of other common MS problems. There is the MS terrible triumvirate, an often-confusing tangle of fatigue, depression, and cognitive

1. Johnson, J. On receiving the diagnosis of multiple sclerosis: managing the transition. *Multiple Sclerosis.* 2003; 9: 82-88.
2. Siegert, RJ, Abernethy, DA. Depression in multiple sclerosis: a review. *J Neurol Neurogurg Psychiatry.* 2005:76: 469-475
3. Mohr, DC, Hart, SI, Fonareva, I, Tasch, ES. Treatment of depression for patients with multiple sclerosis in neurology clinics. *Multiple Sclerosis.* 2006;12:204-208.
4. Steinbeck, J. Travels with Charlie. 1960: 481. Johnson, J. On receiving the diagnosis of multiple sclerosis: managing the transition. *Multiple Sclerosis.* 2003; 9: 82-88.

problems that overlap, augment and complicate each other. For example, it can be impossible to determine whether fatigue is causing depression, depression is causing impaired concentration, or, perhaps, impaired concentration is causing fatigue. Physical symptoms, for example, the loss of mobility in a patient who was previously quite active, are another problem that can contribute to depression.

In short, there are numerous aspects of MS that can cause or contribute to depression. It is, therefore, very surprising that depression is one of the most under reported, under diagnosed and under treated problems related to MS.[2, 3]

There are several reasons that it is under reported by patients. For many people, there is still a stigma associated with depression. Some patients view it, not as a symptom of MS, but as a sign of character weakness, failure of will, and an indication that they are not trying hard enough. They do not report it because they are embarrassed about it.

Some patients know they are distressed and unhappy, but see this, not as the predictable and treatable problem of depression, but almost as a prerogative and an inevitable companion of chronic illness. They may respond defensively to questions about mood with, “Of course I’m depressed. It’s natural, under the circumstances. Wouldn’t you be?”

Frequently, though, patients do not report depression because they do not have the subjective sense that they are depressed. The stereotype of depression suggests a tearful, sad, slowed down, perhaps suicidal persons and that does not describe them. They do not report feeling especially sad and they often do not have vegetative signs of depression. They do report feeling exhausted, overwhelmed, irritable and close to the end of the rope.

They deny depression but do acknowledge feeling very irritable and depleted from the chronic stresses, worries and adjustments that MS demands. Because the stresses accumulate so gradually, their significance does not register, until they are perilously close to overwhelming. These depleted patients are usually willing to try antidepressant medication and often have a very positive response to it, especially when the problem is described as depletion or irritability rather than depression.

There are also many reasons why MS is under treated by health care providers. MS is a complicated disease and patients commonly arrive for a 30-minute appointment with 60 minutes of concerns. Problems with mood may not be a priority until they are severe or unless they become evident during the appointment. Some patients may want to focus exclusively on neurological issues and will rebuff questions about mood. Some health care providers do not invite, or actively rebuff discussions about these issues.

Major depressive disorder is often successfully treated with antidepressant medication and with psychotherapy, especially psychotherapy that focuses on the development of coping skills. When left untreated, depression in MS patients often worsens.

It is important to remember that not all sadness is depression. It is healthy and appropriate to experience grief and sadness in response to bad new, loss and traumatic life events. It can be difficult to distinguish between sadness that is healthy and necessary, and the corrosive, depressive process that can undermine long-term coping. When discussing these issues with

patient's, the choice of words can again be very important. Asking questions about "mood" may yield better information than asking about "depression." Regularly inquire about mood in the review of systems. Provide patients with information about depression and MS before they need it. Be alert to circumstances that may impact mood (for example, using a mobility aid for the first time) and help patients anticipate this change. If significant mood disturbance has persisted for more than a month, consider medication and a referral to a mental health professional.

Conclusion. The emotional challenges that confront MS patients change over the course of the illness. They can be subtle and hard to identify, and may seem minor when compared with the many physical problems that accompany MS. They are important issues to recognize and treat, however, because patients who are struggling emotionally will be less able to manage all the other challenges of the disease. It is especially true with chronic illness, that "a sad soul can kill you quicker, far quicker, than a germ."[4]

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