

Depression in TM

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Traditionally, Transverse Myelitis (TM) has been thought of as a spinal cord disease, affecting motor, sensory, bowel, bladder and sexual function as a result of a spinal lesion visible by neuroimaging studies. However, TM is an autoimmune neurologic disease of the Central Nervous System (CNS), with activated immune cells seen (by spinal tap) floating in the Cerebro-Spinal Fluid (CSF) that bathes the spinal cord and brain together. TM is probably best thought of as lying on a continuum with recurrent Optic Neuritis (that affects the optic nerves that carries visual signals from the eye to the brain), Neuromyelitis Optica (involving the optic nerves and spinal cord), and Multiple Sclerosis (which can affect anywhere in the CNS). The traditional view of TM as solely a spinal cord disease, which persists today, has eclipsed consideration of the effects of this autoimmune disease on the brain. Multiple Sclerosis (MS), in contrast, has had a fair amount of research into the effect of this autoimmune disease on the brain. A growing body of work has begun to shed light on the impact of this brain involvement in producing depression. In fact, MS has the highest rate of depression thus far described in any major chronic disease, with 20% of patients suffering from depression at any given time and a lifetime prevalence of depression over 50%. Work done at

the Johns Hopkins TM Center in collaboration between the Departments of Neurology and Psychiatry has begun to shed light on the prevalence of depression as a reflection of autoimmune disease activity in TM. Before reviewing the findings of this preliminary research, we must first differentiate demoralization, which is a psychological state of overwhelming sadness appearing as a consequence of adverse circumstances, from clinical depression, which we view as a disease of the brain.

Demoralization

There is no despair so absolute as that which comes with the first moments of our first great sorrow, when we have not yet known what it is to have suffered and be healed, to have despaired and have recovered hope.
George Eliot (1819-1880)

Sadness is an understandable and predictable response to suddenly finding oneself thrust against one's will into a life under altered circumstances, in which there is a need to accept losses of desired abilities and confrontation with unwanted struggles. Thus is the case with all chronic diseases. In addition to the potentially dramatic disability that can afflict patients with TM, this disease has certain aspects that make it particularly difficult for many patients to endure. It is more difficult to adapt to acute rather than gradual changes, and TM begins without warning and evolves over hours to days. Moreover, the fact that TM is an uncommon ailment has two troubling consequences for those affected. First, physicians are not often familiar with the diagnosis, prognosis and management of TM, and, as a result, patients commonly go undiagnosed, inadequately educated and under-treated. Second, many patients affected with TM have no contact with anyone else in their area with this disease, and

with whom to compare experiences, and so feelings of isolation are all too often the norm.

Sometimes an individual's capacity to adapt is overwhelmed by the stresses with which he is confronted, and he becomes discouraged, bewildered and overwhelmed. This is a state called demoralization. Demoralization has been defined (Frank JD 1991) as a state of helplessness, hopelessness, confusion, subjective incompetence, isolation and diminished self-esteem. The subjective experience of demoralization involves feeling incapable of meeting both internal and external expectations, feelings of being trapped and powerless to change or escape, and feelings of being unique and, therefore, not understood. The combined effect usually leads to frustration, bewilderment and isolation.

To combat the feelings of failure, being overwhelmed and a sense of isolation that collectively represent demoralization, people must be taught how to achieve remoralization. Assistance with developing problem-focused coping skills can instill a new sense of progressive mastery. For example, building rest periods into an afternoon schedule can combat fatigue. Shopping at off-peak times can avoid feelings of being rushed and embarrassed publicly because of a disability. Individual and group support and education can help combat hopelessness and isolation. Cognitive reframing can be employed to help examine unfair assumptions. For example, reexamining the beliefs that all of the gains achieved through rehabilitation are insignificant, because they did not result in complete recovery helps dispel unrealistic short-term expectations. Sometimes gaining an appreciation for one's own accomplishments by viewing them through someone else's perspective can be very comforting and inspiring.

Psychosocial Impact and Long Term Adaptation

MS, being more common, has been investigated more extensively than TM. A study of MS patients whose average time since diagnosis was nine years, examined their subjective experiences and the psychosocial consequences of their disease (Mohr, Dick et al. 1999). The results of this study are very instructive, in that they demonstrate that even though autoimmune neurologic diseases can be difficult to adapt to acutely, most patients appreciate, over time, the beneficial as well as detrimental effects of their illness on their lives. In this study, the minority of patients (20%) reported that MS had led to a deterioration in their relationships, most often characterized as concerns that they were not as good a mate or that their partners were angry or irritated more often. There were 30% who reported feeling demoralized, with feelings of sadness, loss of independence, or uncertainty about the future. The majority of patients (60%) endorsed finding benefit as a result of contracting their disease: their relationships seemed closer, they felt they were more compassionate and communicative, and they gained a better appreciation of, and perspective on, life. Thus, over time, as the body and mind adapt to life under altered circumstances, unrelenting sadness is usually tempered by adaptation, appreciation and growth. Depression is among the reasons that individuals find themselves incapable of coping with their disease and moving on with their lives, even after many months or years.

What is Depression?

The sadness that accompanies demoralization is not equivalent to clinical depression (which will subsequently be referred to as Depression). Sadness is a symptom whereas Depression is a clinical syndrome; a constellation

of several symptoms that cluster together in affected individuals. Sadness is to Depression what cough is to pneumonia; cough can be an indicator of pneumonia, but not every cough is the result of pneumonia and sometimes pneumonia can present without a cough. If the cough is productive of green mucous and accompanied by fever, rapid breathing and evidence of infection in a lung by examination or x-ray, we call this the syndrome pneumonia. What then is the syndrome of Major Depressive Disorder (as Depression is referred to in the medical literature)? The cardinal features are a fixed and unresponsive low mood, poor self-attitude or self-esteem and decreased vitality. How can these features be translated into straightforward diagnostic criteria?

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) is the main diagnostic reference of Mental Health professionals in the United States. The DSM-IV criteria for Major Depression require the presence of at least five of the nine following symptoms: 1) decreased interest (or pleasure) and/or; 2) low mood; 3) increased or decreased sleep; 4) increased or decreased appetite; 5) feelings of guilt or worthlessness; 6) subjective sense of fatigue or low energy; 7) poor concentration; 8) feeling/appearing as though one's thoughts and actions are either slowed down (e.g., *dragging*) or sped up (e.g., *agitated*); and 9) thoughts of death or suicide.

Because the minority of individuals suffering from depression seek treatment, and those that do often conceal their diagnosis from friends because of the stigma that surrounds mental illness, the prevalence of Depression is often unappreciated. In the general population, Depression affects 5% of individuals at any given time, and 17% of individuals will suffer from

Depression during the course of their lifetime. Depression is a very debilitating disease. Compared to the leading medical causes of chronic disability, Depression is second only to heart disease in terms of its impact on daily functioning. Depression is also a lethal disease, resulting in suicide in up to 15% of those severely affected. In the United States, suicide is the third leading cause of death in those 1-24 years of age, and the fourth leading cause for young adults aged 24-44. In MS, suicide is the third leading cause of death overall, after pneumonia and cancer, and occurs at a rate 7.5 times that of the general population. Compared to other common causes of death in MS, suicide tends to occur in relatively younger individuals who have milder disability, making the years of life lost particularly tragic.

We are no more accustomed to thinking about how our brains regulate our moods, much as thermostats regulate the temperature within our homes, than we are to considering how our brains facilitate our use of language to communicate. Although it can result from a combination of genetic predispositions and environmental stressors, a number of medical diseases are known to predispose to Depression. Neuropsychiatric diseases that cause insults to the brain are known to be associated with extremely high rates of Depression. Diseases such as strokes, brain tumors, Alzheimers and Parkinsons disease are associated with rates of Depression between 30-50%. Importantly, studies have shown that Depression in such diseases is not simply an inevitable reaction to severe adversity. For example, Amyotrophic Lateral Sclerosis (also known as ALS or Lou Gehrig's Disease) is a selective motor neuron disease resulting in the paralysis of all skeletal muscles, which follows a relentless course and usually results in death from respiratory failure or aspiration in three to five years. There is no general insult

to the brain and there is no increase in the rate of Depression seen in patients afflicted with this devastating illness. Thus, Depression should not be assumed to be an inevitable or even common outcome of misfortune alone.

Of all the medical conditions reported to date, MS is believed to have the highest rate of associated Depression, with a lifetime prevalence following diagnosis of 50-60% (Patten and Metz 1997). Evidence for a role of the immune system's effects on the brain as a contributor to Depression in MS includes the following three findings: 1) patients with MS who become depressed do not have a greater likelihood of having depressed relatives than non-depressed MS patients, suggesting an insult, and not a genetic predisposition, plays the key role, 2) Depression increases during periods of immune-system activation resulting in disease exacerbation, and 3) there is no correlation between the degree of disability and occurrence of Depression in MS patients.

TM and Depression

Work done in the Johns Hopkins TM Center in collaboration between the Departments of Neurology and Psychiatry has begun to examine the rates of Depression in patients with TM. Only a summary of the initial findings will be presented here. Evidence was obtained for rates of Depression in TM patients exceeding those seen in comparably disabled MS patients. As in previous studies of MS patients, there was no correlation between severity of Depression in TM patients and motor, bladder or sexual dysfunction. There was a modest correlation between Depression and sensory disability (predominantly symptoms associated with prickling, tingling or numbness). Whether this represents a lowered tolerance for these symptoms in patients with Depression or, alter-

natively, an effect of sensory symptoms on patient's mood cannot be determined from these findings. It may be fair to suggest that of the known ongoing chronic symptoms of TM, sensory symptoms (including chronic pain) may be among the most distressing and difficult to accommodate. An additional association was found between rates of Depression and history of IV steroid treatment. Patients who received IV steroids did not appear to differ with respect to the severity of symptoms at presentation or level of ongoing disability following recovery. The possibility cannot yet be excluded that those patients who appeared most distressed because of Depression at the time of presentation were more likely to be treated with IV steroids. Because steroids are known to cause Depression in numerous other patient populations, the finding of higher rates of Depression in TM patients who received steroid treatment suggests that it would be prudent to closely monitor the patient's mood, if they receive such treatments.

We found high rates of Depression in TM reminiscent of what had been described previously in MS. We wondered whether this Depression was a marker for brain involvement due to immune-activation in the CNS. In addition to high rates of Depression, patients with MS also suffer from elevated rates of cognitive impairment manifesting as difficulties with certain tasks of concentration, short-term recall of details and processing speed. When we examined mental processing in TM patients, we found preliminary evidence that they excelled at many cognitive tasks. There were subtle paper-and-pencil tests, however, on which some TM patients performed worse than expected, and these were the same tests that often were difficult for MS patients. Clinically, we

have noted that a minority of TM patients, even those without depression and on no medications, report that following the onset of their neurologic disease, they could no longer remember as many details without writing them down, and required additional time to complete complex mental tasks.

Special Considerations in TM Depression

The importance of making the diagnosis of Depression in TM cannot be overestimated. Often what is most debilitating is not the requirement for assistance with walking or the chronic pain that must be endured, but the Depression that leads to difficulty getting out of bed, social isolation and lowered pain tolerance. Routinely for patients with TM and Depression, the majority of their disability is due to the Depression and treatment leads to a dramatic increase in their function. Depression, despite its often devastating impact on patients, is a treatable disease with the majority of patients who receive adequate treatment able to make a complete symptomatic recovery. What is required to achieve this result is often the same level of aggressive management that TM patients routinely invest in managing other aspects of the effects of their disease, such as physical therapy and rehabilitation to enhance ambulation, or urologic consultation for bladder management. Before Depression can be managed, however, it must be properly diagnosed.

As in the case of many medical or neurologic diseases, recognizing Depression in TM patients can be challenging because of the overlap of symptoms between these psychiatric and neurologic diseases. Fatigue and poor concentration, for example, occur in many patients with TM making reliance on these symptoms difficult in making a diagnosis of Depression.

Certain clues that can help differentiate symptoms of TM from those of Depression can be recommended. Feelings of self-blame, guilt and self-recrimination are not common reactions to a medical illness, but are almost always found to some degree in Depression. The pervasiveness of symptoms can also suggest Depression. Low mood most of the time or loss of pleasure in activities that require skills that are made more difficult because of neurologic deficits can occur commonly in TM, particularly during the first few weeks of adjustment to this disease. But low mood all of the time, and lack of pleasure in all activities should raise suspicion for Depression. Similarly, a failure to progress beyond the acute shock of being afflicted with TM after many months or years should raise questions about a supervening Depression. The statement "He/She is not the same person since the disease hit," many months after the disease onset, should also raise suspicion for a Depression. If an individual was progressing well, initially, in terms of their recovery from their neurologic deficits, but suddenly stopped progressing and, in fact, began to lose ground, the possibility of Depression should be entertained as a possible cause. Finally, suicidal thoughts are the result of Depression until proven otherwise, and should prompt an urgent assessment by a trained physician or Mental Health professional. This is because the rate of suicide in TM Depression appears at least as great, if not greater, as that found in other medical conditions.

Ultimately, the diagnosis of Depression can best be made by an individual, usually a physician, with extensive training and expertise in mood disorders, such as a psychiatrist. Just as individuals afflicted with TM could not rely on their own knowledge or that of their loved ones to make the neurologic diagnosis, only a

trained professional can confirm and assist with the treatment of Depression. If there is any question about whether a person is afflicted with Depression, an evaluation should certainly be requested.

Barriers to Seeking and Accepting Treatment for TM Depression

Rehabilitation and recovery from TM is often a painstaking and laborious journey. Adjusting to life under altered circumstances when neurologic deficits become long-term can be dramatically taxing. Unfortunately, symptoms of Depression, such as hopelessness and loss of interest, are often first interpreted as "giving up" and equated with being "weak" or "lazy." Moreover, many people equate Depression with being "crazy" and so avoid seeking treatment for this reason. Recognizing that Depression is a chemical imbalance in the brain that is treated with a class of chemicals called antidepressants, rather than a character flaw or personal failure, can sometimes prove helpful in combating this stigma.

Preconceptions and myths about antidepressants also represent common barriers to accepting treatment for Depression. Antidepressants specifically target and treat changes in the brains of patients who are suffering from Depression, but they have no mood elevating effects on individuals who are not depressed. As a result, antidepressants are not addicting, like drugs that induce euphoria, and they have no street value. And antidepressants do not give people "fake" feelings or make them feel things they would not normally feel. Instead, antidepressants restore the normal cycle of ups and downs, in response to life's rewards and stresses, that is lost in individuals suffering from Depression. Finally, individuals occasionally refrain from using antidepres-

sants based on a perception that they do not want to "end up like a zombie" based on knowing or having heard of someone who was not the same once they started taking medication. The fallacy in this argument is that Depression is far more likely to make someone appear impaired than is the medication that is started to treat his mood disorder. While it is true that medications that are used to treat other mental disorders, such as schizophrenia, can produce noticeable side effects such as over-sedation and stiffness, the judicious use of antidepressants by trained psychiatrists results in a return to previous functioning in patients in whom Depression has made their behavior different. The goal with antidepressant therapy is to return an affected individual to the helm of their own ship, and allow them better to chart the course of their thoughts, emotions and behaviors as they regain control of the direction their life is taking. Rather than develop noticeable side effects that suggest a person is being treated for depression with medication, the only thing that other people notice is that the person being treated seems "more like their old self."

The biggest barrier to seeking and accepting treatment for depression, bar none, is the effects of depression itself, which makes people hopeless, unmotivated and unable to imagine that things could get better. Ironically, it is these same symptoms of Depression that are among the important reasons an individual requires treatment, yet they interfere with his ability to get the help he needs. The following three points can help overcome the inertia of such situations. First, successful treatment of Depression requires an individual be compliant with his treatment, not that he believe he will return to being well. Second, in light of the fact that what has been tried has clearly not succeeded in changing the situation, accepting treatment for De-

pression is often the only reasonable course of action. Even if treatment were to fail, the person will certainly be no worse off for having tried something new. And third, sometimes we must all accept the advice of our loved ones, knowing that it is offered in good faith and with an objectivity that may elude us for the moment, especially in situations where our own judgment may be compromised by an illness. To this end, caregivers often play a critical role in persuading patients to seek and accept treatment for their Depression.

Who Cares for the Caregivers?

There are both positive and negative aspects of being a caregiver; in reality, being able to care for the people whom we love, in their time of need, is both a privilege and a burden. A full consideration of the impact of TM on caregivers goes beyond the scope of this article. It is necessary to point out, however, that caregivers are dramatically impacted by both TM and Depression in the people whom they love. Despite this fact, caregivers, care recipients and health care providers usually focus virtually all of their attention on the well being of the patient with TM and Depression, often to the neglect of concerns for the caregiver. In general, the caregiver's health status is often compromised because of neglect of their own health. This occurs despite the fact that the wellbeing of the care recipient is often vitally dependent on the continued efforts and support from the caregiver, which can best be furnished by a healthy individual. Studies have shown that the care recipient variables associated with increased caregiver burden include an unstable course, increased physical disability, pain and depression. Since Depression exacerbates all of these variables, caregivers often have a very real personal stake in whether a care recipient receives adequate treatment for their

mood disorder.

Four issues can be recommended for caregivers to keep in mind in caring for their loved ones without neglecting themselves. First, caregivers should enhance their problem-focused coping skills. This usually involves recognizing what can and cannot be changed, and trying different solutions to the problems that arise until the right one is found. Both caregivers and care recipients must avoid entrenchment in failed solutions that only serve to increase distress. Second, information is crucial because what caregivers don't know about TM and Depression will increase their anxiety and prevent them from being able to efficiently problem solve. Peer education opportunities are often invaluable for both information and support. Third, caregivers must remember to periodically ask themselves "how am I doing?" Taking care of their own needs should not be viewed as being in conflict with the care recipient's needs. Caregivers are no good to their care recipients if they are burnt out, and knowing how to get additional help is often critical to the wellbeing of both parties. And fourth, caregivers and care recipients must not lose sight of the obvious fact that they are in this together. Coping strategies must therefore be complimentary. There are often multiple solutions to the same problems, so a premium should often be placed on maintaining enough flexibility to maximize the benefits for both care recipients and caregivers.

Conclusion

Sadness and demoralization are commonly the result of the acute hardships that people afflicted with TM are made to undergo. Time to adjust and strategies to achieve remoralization are the keys to recovery from these acute situations. Depres-

sion, on the other hand, is a disease that appears to be at least, in part, a direct result of the effects of the activated immune system in TM patients on their brain. Depression is not a character flaw or sign of personal weakness, anymore than is diabetes or hypertension. Like other medical illnesses, Depression is a disease that is associated with considerable morbidity and mortality, and, therefore, must be aggressively identified and treated. Fortunately, Depression is also one of the most treatable consequences of TM, with the expectation that individuals will make a complete recovery with proper management. Finally, it is imperative to consider the impact that TM and Depression have on both patients and their loved ones, because success will ultimately be measured in how well individuals are functioning in the context of their families.

It has been argued in this article that Depression in TM, as has been suggested in MS, can be the result of the immune system's influence on the brain. We are actively pursuing the mechanisms underlying this influence. Recent studies have reported on the effect that treating Depression has on immune system functioning. Preliminary studies have suggested that Depressed MS patients have even more aggressive immune systems, capable of wreaking greater neurologic damage, than their non-depressed counterparts (Mohr, Goodkin et al. 2001). Treatment of Depression in these MS patients led to an amelioration of their immune system, suggesting that treating Depression could be of important benefit to patient's neurologic as well as psychiatric wellbeing.

Many patients with TM suffer greatly, often without timely diagnosis or treatment of their neurologic disease. Importantly, the Depression that can accompany this disease should not similarly be overlooked or inade-

quately treated, because of the tremendous benefits patients and their loved ones can obtain from proper management.

The one law that does not change is that everything changes, and the hardship I was bearing today was only a breath away from the pleasures I would have tomorrow, and those pleasures would be all the richer because of the memories of this I was enduring.
Louis L'Amour (1908-1988)

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The Spiritual Life of Transverse Myelitis

Rabbi Gary A. Huber

Congregation Beth Tikvah

Several months ago I asked my friend Sandy Siegel if I could write an article for the Newsletter regarding spiritual approaches in coping with all of the difficult physical, social and emotional issues surrounding TM. My inspiration for this goes back to the wonderfully happy event of Sandy and Pauline’s wedding, at which I had the great joy and honor of officiating. I officiate at many weddings but I cannot recall in my 25 years as a rabbi a more joyous event. The sanctuary seemed to glow from the happiness of the gathered guests who came to share their love with two very special people. But this event was unique in another regard: many of the guests present had lived many years with TM or were related to someone with TM.

Reflecting back on this, I wondered if there were special issues relating to the spiritual life affecting folks with TM and their families. At Sandy’s encouragement, I interviewed about 15 individuals and families, as well as several medical specialists, as to the role of spirituality and religious faith in their life. And what I discovered is that they have a very special insight into the life of the spirit that is both deeply inspirational as well as profoundly insightful. People with TM and their families have much to teach the world about the role of faith and the meaning of human suffering.

No doubt, the central emotional challenge relating to TM is clinical depression. And the sense of despair often takes on a religious dimension. Dr. Adam Kaplin, professor of psychiatry at Johns Hopkins School of Medicine, told me that “many if not

all of the TM patients I see report struggles with questions such as ‘why did this happen to me?’ A history of past or current religious conviction can be one of my greatest allies as a psychiatrist in attempting to assist my patients with turning away from suicide as an option and finding structure and support for themselves especially during grim times.” Actually, at first I fully expected to hear many tales of how the disease had utterly destroyed any sense of faith in God or even faith in the goodness of life. I was wrong. If anything, my conversations with several individuals point in the opposite direction: a growth in faith and a deepening of faith. But the faith of people with TM is not the same as before their diagnosis. It is a more thoughtful, more profound and a more mature faith. By that I mean a faith that comes after many a “dark night of the soul” and after periods of anger at God.

This bears some comment. As a clergyman, I am never worried about someone being angry at God. Anger at God following a diagnosis of TM is a natural and expected reaction to a life-transforming event. And, in a very real sense, it is a statement of intimacy with God. After all, you can only be angry at someone you believe exists and has an important role in your life. I recall the words of the Nobel laureate Elie Weisel, who alone of his entire family survived the hell of Auschwitz: “I can sometimes be very angry at God and sometimes I can be very much in love with God, but I can never be without God.” I know that many people with TM have felt the same. Anger at God is an expected emotion for folks who suffer from such a difficult illness. The question is: does one get stuck at anger or does one move on in the life of faith? The testament of the people I interviewed is one of very impressive spiritual growth.