

Mellen Center Approaches: Initial adjustment to the diagnosis of MS

Framework: The initial diagnosis of MS can have a profound psychological effect on both the patient and the family. The unpredictability of MS may add layers of complexity to the ordinary challenges of life. For example, individuals are faced with decisions on career, intimate relationships, social activities, domestic routines, parenting, financial planning, and aging. At times, the diagnosis itself may not be certain, adding further to the emotional challenges. Behavioral medicine is often an important and necessary component in the interdisciplinary treatment of MS patients to help patients and family members manage the emotional adjustment to the disease, including adjustment to the diagnosis

Although it may seem implausible, patients and family members can live a life full of meaning, despite having a chronic condition, as they use their struggles as a way to redefine their lives, develop deeper relationships, a greater purpose and meaning. A difficult situation can often serve as a springboard for relational, emotional and spiritual growth.

What are the emotional challenges of a chronic illness?

Patients and family members might find the disease difficult to fathom, as they may feel that hopes, dreams, and goals for the future will drastically change. Individuals and family members may react in a number of different ways, including, but not limited to: grief, anxiety, anger, depression, fear, numbness, denial, hopelessness, and in the worst case suicidal ideation or intent.

Several challenges related to MS frequently present in therapy: 1) Dealing with the “invisible symptoms.” Among the most common symptoms of MS are fatigue, subtle cognitive impairment and

depression, which may be largely invisible. Patients find explaining this complicated and frustrating. 2) Making difficult treatment decisions, such as what medications to take, benefits vs. harm of newer disease modifying drugs, etc. 3) Making disclosure decisions in career, relationships, etc. 4) Dealing with the reactions of others once the decision to disclose has been made. 5) Identifying and communicating limitations and needs (e.g., asking for help, deciding to participate or withdraw in events, etc.). 6) Arguably the most difficult is planning, given the uncertain disease severity and future disease course. Specifically, family and relational responsibilities, financial and estate planning, disability insurance policies, SSDI. The difficulty of reaching these decisions is compounded by the present unsettled state of the medical care financing system and of the uncertain societal approach to support for disabled or retired individuals.

Appropriate delivery of the diagnosis:

Rabow and McPhee developed a practical and comprehensive model, synthesized from multiple sources, that uses the simple mnemonic ABCDE:

A - Advance Preparation: Be prepared for basic info on outcomes and prognosis. Bring patients into the office to be able to respond to the emotions that come with the news.

B - Build a Therapeutic Relationship: See “how should physicians manage early emotional reactions” below. When possible, involve the family members. Deliver the news softly and acknowledge the emotional reaction. Normalize the emotional reaction. Build trust with patient, by telling them that you and s/he will become a team and find the best way to manage xyz. Assure patients that you will be available to them (within reason).

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C - Communication: Ask what the patient has heard and understands about their condition. Speak frankly but compassionately. Have the patient paraphrase their understanding, knowing that they will likely not hear what was said after you deliver the news. Be prepared with a notepad or sketches for the patient to increase their understanding and take with them

D - Deal with the patient and family reactions: Assess and respond to emotional reactions of family. Be aware of cognitive coping strategies (e.g., denial, blame, intellectualization, disbelief, and acceptance). Be attuned to body language. With subsequent visits, monitor the patient's emotional status, assessing for despondency or suicidal ideations.

E - Encourage and Validate Emotions: Offer realistic hope. Even if a cure is not realistic, offer hope and encouragement about what options are available. Discuss treatment options at the outset, and arrange follow-up meetings for decision making. Explore what the news means to the patient. Inquire about the patient's emotional and spiritual needs and what support systems they have in place. Offer referrals as needed.

Use interdisciplinary services to enhance patient care, but avoid using these as a means of disengaging from the relationship.

Attend to your own needs during and following the delivery of bad news. Issues of counter-transference may arise, triggering poorly understood but powerful feelings.

What are common emotional reactions to a new diagnosis?

The diagnosis of a chronic condition generally provokes a strong emotional response, but not all individuals respond alike. Emotions may be related to many different things such as the stressors and challenges created by this chronic, unpredictable illness, symptoms of MS itself (e.g. depression and fatigue), and family members reactions. In addition, the range of emotions varies from person to person and over the course of the disease (e.g., with initial symptoms, diagnosis, relapse, disability progression, loss of working ability, etc.). No two individuals or situations are alike.

Common emotional reactions include, but are not limited to: denial, shock, fear, anger, guilt and relief are all normal and predictable reactions to any difficult news.

As individuals progress through the grief model, several considerations arise at each step that are noteworthy. **Denial** is a common first coping skill, as individuals might assume that the doctor may have made a mistake in diagnosing the illness and a person may not believe that they have this diagnosis. Denial may get in the way of important early decision making on treatment and self-care strategies, as individuals may not follow-up with their physician or may not follow the treatment protocol. Next a person might experience **shock**. For some individuals, the news is so startling that they simply can not absorb it. Thus, it may take several days to weeks for them to be able to think about the next steps in their treatment. Individuals also commonly experience **fear**. Patients may panic. They may assume the worst case scenario about their health, life, future or possible disability. It is not uncommon for a person to experience **anger**. The anger can be directed towards self, others, including their physician, or God. Many react with resentment to the unfairness of being diagnosed. This can cause problems in significant relationships, job, and in appropriately managing the disease. **Guilt** is also a common occurrence. Patients assume that their family, work, significant relationships will suffer because of the disease. **Relief**, albeit difficult to understand, is common, as some individuals have had to wait months and even years to understand their symptoms. Other people have been told there is nothing wrong with them, it is all in their head, and so being diagnosed is a welcome relief.

Denial, shock, fear, anger, guilt and relief are all normal and predictable reactions to any difficult news. Each of these feelings are important to explore with your patient and eventually with their therapist. In therapy, our goal is to progress not only to accepting that an individual has a chronic illness, but adapting their lives and learning that even though life will change, they can learn to adapt and still experience joy, purpose and meaning.

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How should physicians manage the early emotional reactions?

- 1) The above reactions may occur at anytime throughout the initial adjustment phase; expect this.
- 2) Normalize their emotional reaction, this will go a long way in building rapport and trust with your patient and will allow the patient to feel more comfortable in following your treatment plans/goals
- 3) Early identification of a psychological condition is imperative. Treatment outcomes are much higher when a psychological condition is treated in the beginning stages.
- 4) Understand the connection between the above reactions, depression/anxiety and the disease. It is important to treat a psychological condition because a patient will do better physically and emotionally
- 5) Utilize your basic listening skills :
 - A) Take 5 minutes to have an emotional interchange
 - B) Turn to the person, look at them and STOP TYPING
 - C) Allow silence and tears- avoid your own discomfort by jumping in and rescuing.
 - D) Encourage an emotional response- "It sounds as if you are saying you are scared, sad, etc." Nod your head occasionally.
 - E) Reflect and Paraphrase-
 - i. "I hear you saying..." "It sounds like you were..."
 - ii. "It sounds like you were saying..."
 - iii. Summarize responses
 - F) When an individual tears up, do not give them a Kleenex, instead have a Kleenex within arms reach. Providing a Kleenex immediately shuts down emotional interchange, and gives a message that you would prefer for them to stop the emotion. Instead, encourage the patient to continue by adding verbal cues such as "uhh huh" or reflections such as "I can tell that this provokes a feeling of fear, sadness, worry etc..."

- G) If you feel comfortable, appropriate touch (a hand on their hand) is a way of connecting.
- H) Watch your body language- do you tense up with an emotional response?
 - i. uncross your arms
 - ii. sit facing the person
 - iii. soft, warm facial expressions
- I) Normalize the emotional experience
- J) Encourage the person to continue with cues such as "uhhuu, really, tell me more"
- K) Defer judgment

What are common psychological conditions in patients diagnosed with MS?

One of the most common, yet treatable symptoms of MS is depression. The frequency of depression varies depending on the targeted population, the measure used, and the time frame evaluated. In general, 50% of MS patients will experience a depression at some point over the course of the disease. In large population studies the prevalence of major depression varies between 26 and 51%. There have been consistent results showing a very high prevalence in the MS population. Best estimates of the 30 day prevalence of major depression in the general population are about 3% (Wilhelm), and in rheumatoid arthritis patients depression appears in about 15%. Depression is therefore common and of significant interest in patients with MS and is 3-4 times as high than in the general population.

Depression differs from normal grieving, as it is a pervasive disease, whereas grieving has a time frame. We find that depression is more common in females than in males, however, the strength of depression is much greater in the male population.

Although depression has the highest prevalence, anxiety disorders are also very common. As a general rule of thumb, when one sees a mood disorder, it is always important to look for an anxiety disorder as mood and anxiety are comorbid in 2/3 of all cases. Clinicians should look closely for substance abuse in those with anxiety and mood disorders, as patients commonly learn to self medicate with benzodiazepines and alcohol. In addition to the above, anger, irritability, dysphoria, pseudobulbar

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affect, bipolar disorder and relational problems present as diagnosable conditions.

What is the risk of suicide in the MS population?

The rate of suicide varies between studies, but all are homogenous in showing an excess rate of suicide compared with age matched controls in the population studied. Sadvnick et al (1991) surveyed deaths from 2 MS clinics in Canada, and found that of these 28% were due to suicide. They concluded that there was a 7.5 x greater rate of suicide than in age matched controls. This study is subject to bias since it is based on MS center populations. Brønnum-Hansen (2005) performed a full population study of Danish mortality figures on all patients diagnosed with MS between 1953 and 1966. They showed 115 suicides vs. an expected 54 suicides representing an excess rate of 2.1 with a slightly higher rate in the first year and a steady rate after that over up to 40 years. This second study probably provides a better estimate of population risk of suicide.

Although the suicide rate is high in the MS population, it starts to decline after the first year of the diagnosis and after an individual reaches the age of 40. The best predictor of suicidality remains hopelessness.

How can behavioral medicine help?

Behavioral Medicine is an interdisciplinary field of medicine devoted to the understanding and management of health and illness through: disease prevention, health promotion, diagnosis, treatment and rehabilitation. At the Mellen Center for Multiple Sclerosis the behavioral medicine clinic is intended to help MS patients and their families with MS related psychological conditions, adjustment to the disease and disease management issues. We are in a unique position to offer support to not only patients but also family members affected by MS.

Behavioral medicine services at the Mellen Center are most actively used in the following situations:

- 1) Disease-related education
- 2) Adjustment and coping with the diagnosis and associated fears
- 3) Family and couples adjustment issues including caregiver burnout and communication issues
- 4) Non-compliance to treatment regiment

- 5) Needle phobia
- 6) Anxiety or mood changes
- 7) Fatigue management and energy conservation
- 8) Relationships-socially and romantically
- 9) Family and parenting skills
- 10) Pain management
- 11) Support regarding the unpredictable nature of the disease
- 12) Support for individual's efforts to remain productive as long as they are able
- 13) Wellness principles
- 14) Teaching coping and adaptation skills
- 15) Instilling purpose and meaning.

What principles are employed by behavioral medicine?

Several treatment modalities are employed in the treatment of the above conditions. The effectiveness of Cognitive Behavioral Therapy has been well examined in the literature and thus several of the CBT principles are utilized in our treatment. In addition, behavioral strategies, such as relaxation training, assertiveness training and fear hierarchies are appropriately utilized for pain management, couples therapy, needle phobia and assertiveness. Lazarus and Folkman's coping literature is utilized, Motivational Interviewing, as well as methods from interpersonal theories. The goals of health psychology are appropriate coping and adjustment to MS and the disease process, improved functioning in several domains, and emotionally and physically healthy lifestyles.

In addition to psychological theories and principles, education and group services serve as an important role in a health psychology practice.

When should a referral be made to a Health Psychologist?

Health psychologists are trained in individual, couples, family and group therapies. Because there are so many therapeutic modalities, it is optimal to refer patients to the health psychologist to determine what the appropriate avenue for the patient/and or family might be.

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Referrals to health psychology should optimally be for patients with adjustment disorders, recent depression, and family issues, all of which are more amenable to the presently available therapies. Patients with issues of abuse, long standing depression, severe psychiatric conditions, or concurrent drug and alcohol abuse issues are better served by appropriate referrals to psychiatry and addiction medicine.

When a provider feels that a patient would benefit from seeing a health psychologist it is always better to err on the side of sending the person for an evaluation than sending that person home. Overall patients and family members should remain as active as possible, acknowledging and expressing their emotions in a way that allows them to fully take control of their lives, engage in self-management and focus on the potential positive outcomes of the disease. Those that use self-management skills have the best chance to successfully adjust to the challenges posed by a chronic illness and may even find that a chronic illness propels individuals to have a deeper more meaningful life. This can be assisted through a health psychology practice.

What to look for when referring your patient to a health psychologist:

- 1) Make sure that the provider has a fellowship in health psychology and disease management
- 2) Although it would be preferable for a health psychologist to have a specialty in treating MS patients, a health psychologist who specializes in treating chronic illness would be acceptable.
- 3) The health psychologist should work closely with either a neurologist or a psychiatrist for medication management issues
- 4) The provider should be comfortable in treating family and couples issues, because with a chronic illness, the patient is not the only one affected.
- 5) Be sure that the health psychologist will communicate with your practice
- 6) The provider should be connected to a hospital for emergency situations.

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Key Numbers:

- National Suicide Hotline: 1-800-273-TALK (8255)
National MS Society: 1-800-667-7131