

What My MS Has Taught Me About Severe Mental Illnesses

William A. Anthony, Ph.D.

I was first given the diagnosis of multiple sclerosis (MS) in the 1990s. This diagnosis explained mild but worsening symptoms that have been occurring for the past 30 years. Currently, I am diagnosed as having secondary progressive MS. My diagnosis has launched me into the “MS community,” an assembly of MS consumers, families, providers, and advocates that has helped me to redefine my personal life. MS and all that comes with the diagnosis have also stimulated me to think about what should be happening in the field of severe mental illnesses, a field that has up until now defined my professional life.

I have learned that we people with MS are more fortunate in our dealings with society and the health care community than people with severe mental illnesses—a field in which I have functioned as a researcher, educator, administrator, clinician, and consultant. As is the case with severe mental illnesses, the diagnosis of and prognosis for MS are still perplexing; the course is episodic and unpredictable; employment and family life are affected, and self-esteem suffers; symptoms are numerous; comorbidity with other long-term diseases is a concern; a cure is nonexistent; and recent developments in medication have occurred that promise to alleviate more of the symptoms with less of the side effects. Unlike people with severe mental illnesses, however, people with MS are

typically treated like people; we are usually helped to feel empowered and hopeful, drug companies are our allies, and education about the illness is easily obtainable from both other consumers and professionals. Is this a vision to which the field of severe mental illnesses can aspire? I think it can be but only with a very significant change in practice and policy.

What is MS?

In my role as a consumer of MS services, I have learned that MS is a progressive neurological disorder that results in the demyelination of the nerve fibers of the central nervous system. Simply explained to me, it is similar to electrical wires (the nerves) losing some of their insulation in multiple spots, resulting in the inefficient transmission of electrical energy. Symptoms are wide ranging and can include loss of muscle strength in arms and legs; tremor; loss of vision; loss of balance and coordination; bladder, bowel, and sexual dysfunction; pain; and cognitive and mood dysfunction. Many symptoms of MS are not visible to the casual observer; the majority of people with MS do not use a wheelchair.

Only a metaphor

Using the field of MS as a metaphor for understanding what needs to happen in the field of severe mental illnesses is just that, a metaphor. No one-to-one relationship is implied. Obviously the conditions are different in some important ways. Two of the most significant differences are that people with MS never fully recover in the sense that the disease disappears forever and that the prejudices and discrimination toward people with MS are relatively minor compared with those toward people with severe mental illnesses.

The personhood vision

As a consumer of MS services I feel so fortunate compared with people who have severe mental illnesses in terms of what is happening in the MS field today. I think the progress in how we “MS people” are now treated can inform the field of mental health about new ways of thinking and acting. Increasingly, people with MS are treated in ways that educate, empower, and encourage hope about our MS, despite the functional losses we routinely experience. Similarly, I believe that the educated, empowered, encouraged mental health consumer is a vision worth working toward and that the field of MS has something to teach the field of severe mental illnesses about attaining that vision.

That was then, this is now

Fifty years ago, my uncle essentially died of MS. The death certificate may have said pneumonia, but when he died he was totally bedridden as a result of MS. He could travel only in a stretcher and by ambulance. At the time of his diagnosis there was no medication to reduce the severity and frequency of symptom relapse. Like most people with MS, he was told that there was nothing the medical field or he could do about it. He wasn't physically segregated, as were his counterparts with severe mental illnesses, and did not experience forced medical treatments, but he was psychologically isolated and restricted. He had no role in his care. There was no societal interest in his predicament; he could go home and wait to die, as the disease gradually compromised almost all of his functions.

Now people with MS experience a different health care system and a different societal response. Medications

Dr. Anthony is executive director and professor, Center for Psychiatric Rehabilitation, Sargent College of Health and Rehabilitation Sciences, Boston University, 940 Commonwealth Avenue West, Boston, MA 02215 (e-mail: wanthon@bu.edu). Jeffrey L. Geller, M.D., M.P.H., is editor of this column.

are available that can reduce the frequency and duration of symptom relapse and the degree of progressive disability. We are educated about these medications and their side effects, so that we can choose whether or not to use MS medications and which drug to use. Education about managing MS is easily available through Web-based seminars, educational lectures, and readable magazines, such as *InsideMS*. Each educational experience routinely includes a person with MS speaking about how he or she manages the illness. We learn from each other and professionals about exercise, diet, management of fatigue, bladder control, and so forth.

Drug companies routinely sponsor educational events and advertise in the journals that are targeted to consumers. Drug company funding is an important source of support for these presentations and publications. The MS community assumes that I can make decisions about my treatment—just as I can decide what food to buy—and that such advertisements and sponsorships are not inherently evil. I feel more educated, empowered, and encouraged since becoming an active participant in the MS community.

Why not in mental health?

The never-ending flow of information from professionals and other consumers, the empowerment to make our decisions based on up-to-date information, and the constant encouragement from other consumers and professionals are routine and expected in my personal health care field of MS. Will this ever be the case in my professional health care field of severe mental illnesses?

Certainly progress has been made in this direction. Consumer and family advocates are now a strong force, self-help programs exist, and recovery from severe mental illnesses is an accepted outcome. But where are the drug company-sponsored seminars for consumers? Where are the popular journals written by and for consumers that are supported only in part by drug advertisements? Where are joint meetings for the purpose of fostering the respectful give-and-take between professionals, consumers, and consumer advocates? Why are

our belated attempts at educating consumers offered under the stigmatizing term “psychoeducation”?

The bottom line is that my experience in the MS community has enlightened me to the fact that we in mental health are fooling ourselves if we think that we can attain a people-first treatment system without changing the role that force and the threat of force play in our system. The dream of an educated, empowered, encouraged consumer cannot be our vision when medications and medicine play a role in locking people up, when we use demeaning terminology, and when we force treatment on the people we are trying to help. A people-first vision can simply not occur in a health care environment that condones the use of force. Such a vision can be approximated, but the vision of personhood can never be realized fully.

How can consumers trust advertisements and lectures sponsored by the company whose very products can be forced upon them? How can a natural give-and-take occur when one person has the power to lock another up? How can an adult feel good about being “psychoeducated”? How can consumer magazines be trusted as a source of information if they contain advertisements from drug companies that cannot be trusted?

A counterpart to the highly informative and credible consumer-targeted magazines, such as *InsideMS* and *Neurology Now*, can simply not happen in the field of severe mental illnesses. I get the information I need to help me lead a healthier life with my MS from columns written by experts; personal accounts of people's management strategies; articles on nutrition, exercise, and alternative treatments; and advertisements by all the major drug companies. Drug company support is vital, and the magazines are very specific in stating that they do not endorse the products advertised and that the wording of all advertisements is guided by Food and Drug Administration regulations. It is assumed that I am an adult and am free to make informed choices, with input from my health care provider if I choose. In short, I am helped to feel educated, empowered, and encouraged.

Achieving the vision

Where might we begin in order to move closer to the vision of treating mental health consumers as people and full partners in the health care system? The first step in achieving the people-first vision in our field is to acknowledge that such a vision simply cannot be achieved in an atmosphere of force. If we continue to assume that we health care providers must use force as part of our health care delivery system, then we need to stop talking about a people-first vision. The abolition of force in the severe mental illness community needs to be achieved, and acknowledging the vision-limiting effect of forced interventions is a good place to begin. Perhaps one major drug company could state that it is opposed to any use of its products against the will of the patient. Perhaps individual practitioners and groups of practitioners could state up front that they will not participate in any “forced treatment” decisions, a phrase that in itself seems like an oxymoron, unless the client has a specific advanced directive condoning it.

We need to use our best minds to figure out how to extricate ourselves from being society's purveyors of involuntary interventions. It is not a role that fits us well, nor should we want it to fit. Vision change will start in the way that most change starts, one company, one individual, one group at a time until it can no longer be stopped and progress toward the vision becomes inexorable. But start somewhere it must, if we really want to interact as people with the people we are trying to help. It can make a difference to our consumers, and it can make a difference to our field. I challenge us to develop ways to get us out of the forced treatment business. Force has no place in a helping profession. When we finally eliminate force in the name of helping, we will have moved closer to a people-first vision, and the result will be that more good things will happen to consumers of mental health services.

I am thankful that I have not been forced to take particular MS medications or to undergo a particular treatment for my own good or the good of society. Being treated as a person first has helped me deal with MS and still feel like a person—no matter the incredible vagaries of this condition.