The Psychological Impact of Vestibular Disorders

This document is a transcript of an informal talk given in 1987 by Garfield DeBardelaben, PhD, at a support group meeting. For the sake of brevity, some parts of the lecture have been omitted.

Introduction
This morning my presentation is going to be basically anecdotal. Over the last month, I’ve been canvassing some of my patients to find out what the issues are that are most important to them. As Dr. (Alar) Mirka pointed out, we’re at the early stages of research relative to the treatment of vestibular disorders. I can only say that goes doubly true for the psychological treatment. To my knowledge, prior to the last three or four years there hasn’t been much attention to the psychological aspects.

Organic brain syndrome
With several vestibular patients that I’ve seen over the years, I’ve come to believe that what I see is an organic personality syndrome that these patients are manifesting. Now, there may be some argument with that, because ordinarily organic personality syndromes are associated with things like strokes, and some neoplasms, which are brain tumors. But oftentimes I see patients who come in and they’ll start describing things to me that indicate that the day before they had their fall or the day before they were hit in the head, they were different people. The day after, all of a sudden something has changed. They can’t always put their finger on it, but you better believe the family members or anybody close to them can recognize a difference. They are different people, they say.

I label these syndromes that I see as organic personality syndromes, and the essential feature of an organic personality syndrome is a marked change in personality that is due to a specific organic factor—an organic factor that is anything other than another organic brain syndrome. Now these are usually due to some structural change or damage to the brain. Oftentimes I see patients who are seen because they were in an automobile accident or they had fallen on the job. This head trauma can cause a post-concussion syndrome, which can lead to this organic brain syndrome—this marked change in personality.

Now a common pattern of behavior seen in organic personality syndrome is emotional lability, which means that people can vacillate in emotional states. One moment they may be happy, smiling, and without notice they can break into tears. Obviously this can cause great concern and consternation for family members or friends who are in the same room with these people. Of the symptoms that vestibular patients have, this one symptom is the major cause for my getting calls at home on the weekends.
Along with emotional lability is an impairment of impulse control, social judgment. People who are ordinarily considered to be reasonable and rational people oftentimes start doing things that even they cannot explain. People who are ordinarily very calm, considerate, placid people can become somewhat belligerent, combative, demonstrating temper outbursts at the drop of a hat with little or no provocation. Under extreme conditions there’s often socially inappropriate behavior and sometimes sexual indiscretions. Those are relatively extreme situations. There’s oftentimes apathy and indifference, which wreaks havoc on marriages. There’s no interest in hobbies or usual activities, which causes some concern for friends and family members.

Some associated features of the organic personality syndrome are depression and irritability. This depression has along with it changes in appetite.

The person can lose appetite, or their sleep can be disturbed. They can start feeling guilty about things. They can start obsessing about all the negative aspects in their lives. The one difficult aspect about treating depression that is secondary to the adjustment to a vestibular disorder is that oftentimes the complications that could arise from being prescribed an antidepressant medication preclude the prescription of an antidepressant. It makes it very difficult when people are saying, “I can’t stop crying, I can’t stop feeling so sad, I feel as though I never want to get out of bed,” but then they cannot be helped by the introduction of a medication that has been demonstrated throughout the medical community to be extremely helpful in diminishing the degree of depression.

Along with this, [there may be] mild cognitive impairment—an impairment in a person’s ability to think, to judge. Some specific cognitive impairments are in the areas of concentration—[for example], if a person has a decreased ability to concentrate, to sustain attention on tasks that they are about to do, decreased short-term auditory memory. It’s difficult to remember phone numbers, for example. It’s really difficult to read a novel. I mean, I hear people whose prime passion in life was reading, but after this disorder, they cannot tolerate reading. Number one, they can’t keep track of what they read on the previous line, if they can tolerate looking at the lines. People become nauseous just glancing at a page. You can have a pretty grim life at that thought.

There’s also a reduced behavioral efficiency. In other words, the coordination is off. They can’t put things together. Filling out forms, for example, requires being able to track, requires being able to remember what the previous line was all about, and some visual motor coordination is often off with patients with vestibular disorders.

Now the degree of impairment is extremely variable depending upon the particular type of the vestibular disorder. Also, oftentimes it varies with the time of the day, whether or not a person is fatigued. Oftentimes people are a lot more on the ball in the morning than they are in the afternoon, especially more so than they are in the evening at times.
Sometimes the impairment in judgment that’s associated with this cognitive impairment can be so difficult that it would require that the person have constant supervision and sometimes even custodial care. Those are more extreme circumstances.

**Grief**

Along with organic personality syndromes, what strikes me most is that people with vestibular disorders are experiencing grief. We usually associate grief with a physical loss, such as a death. But I’m here to tell you today—and I’m sure that once I begin to explain this, I’ll get a lot of head nods on this one too—that people with vestibular disorders are experiencing a grief process.

I’ve had patients that are obsessed, preoccupied with the fact that they’re no longer athletes, they are no longer able to care for their families, they’re not able to work any longer. Obviously, that has a dramatic effect on their self-image and their self-confidence. It can cause all kinds of somatic distress, sleep disturbances as well as effects on their appetite. There is often preoccupation with the image of what was lost. Again, oftentimes that image is that of an independent person. Guilt is often associated with this. What I hear more often than not is the guilt associated with not being the breadwinner in the family or not being able to handle the children without assistance. Upon facing this fact, oftentimes hostility arises. The person becomes hostile, secondary in my estimation to the frustration and the sense of loss of control over their particular situation. Finally, there’s a loss of patterns of conduct. In other words, the normal life pattern has been disrupted.

Grief is the process of psychological, social, and somatic reactions to the perception of a loss. The loss can be physical or symbolic or psychosocial. In other words, with vestibular patients the particular loss that they’re coping with is that of who they were, which includes what they were capable of doing. It’s the same with the person who has lost a loved one. When you lose who you used to be, it’s just as devastating. The loss of the idea that you were once independent, able to care for yourself, can be overwhelming.

Grief is the process that allows us to let go of that which was and be ready for that which is to come and to adjust to what is here and now.

What the person needs when they’re grieving, what they need most, is acceptance and nonjudgmental listening, which will facilitate the expression of their emotions, their fears regarding this disorder, giving them what’s necessary to review how they’re envisioning their lives henceforth. The patient needs to have assistance in integrating their images of who they were with who they are now.

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We have to be present physically as well as emotionally to render the person, the patient, security and support—emotional support, financial support. As I alluded to earlier, oftentimes they cannot work anymore, especially if they’re on bed rest or an extremely restricted activity schedule.
Give the person permission to grieve, to recognize that things are different. Because oftentimes I see people who are not given that permission. As a matter of fact, they are being ostracized on some level for not being able to do the housework or not getting up to make lunch, which is ludicrous. Do not allow the person to be isolated. If there’s one thing that I’ve heard from every person that I’ve ever seen, it’s the fear of being abandoned—the fear that their symptoms are driving friends and loved ones away. Without exception, that’s the fear.

**Disability**
To be sure, people with vestibular disorders are disabled, as far as I’m concerned, in every sense of the word...psychologically as well as physically disabled. One, if you ask them, they’re no longer able to work, oftentimes; secondary to that is a decrease in ability to concentrate or to make appropriate judgments at times or to sustain attention.

Besides those things, oftentimes they are experiencing panic attacks that are brought on by the anticipation of becoming disabled or debilitated through dizziness or nausea. So what happens is that some forms of agoraphobia develop. They don’t leave the house. Sometimes they break into sweats during the panic attacks. They are disabled.

A lot of insurance companies don’t want to buy that, and employers don’t want to buy that. They’re always questioning, well, you tell me how this person is disabled. I’ll tell you how they’re disabled. When you don’t want to get out of bed for fear that you’re going to fall or you’re going to have anxiety attacks because you’re afraid that it’s going to happen to you on the way to work in the car, you’re disabled, as far as I’m concerned. And that needs to be addressed.

Some of the additional factors that impinge upon patients with vestibular disorders besides the dizziness and nausea are feeling as though “I’m someplace else”—now, can you imagine if somebody were to explain to a friend, “I feel as though I’m someplace else?” They’re going to think they’re bananas, right?

These are what vestibular patients have to deal with all the time. Because not only are lay people thinking they’re bananas, but all too often people in the medical community are thinking they’re bananas.

What do you do when you go to a physician who you thought you trusted and who is knowledgeable, and you give him or her these symptoms, and they tell you, “Well, I think you need to see Dr. So and So, who is a psychiatrist friend of mine.” What do you do? Well, you do what a lot of my other patients have done—you shop around for another physician! Their hope plummets when they recognize that something is wrong with them and their physician cannot find the problem and then suggests that something is wrong mentally with them. They now not only have to deal with the balance problem but also with the frightening thought that they might be going crazy! That makes it even worse. They start doubting themselves, which makes them even more incapacitated because they don’t know where to turn.
**Impact on family**

How can vestibular disorders affect family and friends? The introduction of a vestibular disorder in any family is analogous to throwing a rock in a pond, because those ripples are far-reaching and ever-widening. Family members need to receive emotional, psychological treatment just as much or even more so than the patient with the vestibular disorder.

Those behaviors [to compensate for the dizziness] can lead to a rapid decrease in tolerance of the patients by family members and friends. It can lead to an eventual disintegration of the family. I’ve seen people whose families were afflicted with separations and/or divorce because they couldn’t handle the new person, the change in personality. But I think some of that may have been avoided had the family members come in to gain some kind of understanding of what they’re really dealing with.

I’ve seen teenagers as well as younger children who didn’t understand what was going on with Mom or Dad. Consequently, I’ve seen these students become non-students, start acting out in school because they’re feeling the stress of this whole situation … Mom and Dad not being able to understand each other anymore, not being able to pay attention to them anymore. Maybe you’re getting the picture. It’s not just the patient’s problem. It’s everybody’s problem. Everybody needs an opportunity to have their concerns voiced and to try to get some answers … at least to have somebody help them sort some things out.

I’ve seen where the patient’s inability to work can cause horrendous financial hardships in the family. And, as we know, excluding vestibular disorders, marriages can go crashing on the rocks when there are financial problems, as well as difficulties in communications. And with vestibular disorders, I’ve seen communications break down within families. This, on top of financial problems because the person isn’t able to work—here we go again. More reasons for psychological intervention to assist the family in coping with this.

Patients can often feel guilty and feel overwhelmed because family and friends expect more of them than they’re capable of giving because they still look relatively normal. There are no broken limbs, no observable pathology; there’s no tumor that can be viewed. So oftentimes they are asked to behave normally: “You don’t look sick.”

I’m going to reiterate this one point because friends and oftentimes family members cannot identify with or relate to what the patient is experiencing internally. They often think that the patient is experiencing some kind of mental disorder. Oftentimes they stay away because they’re feeling uncomfortable. They don’t know what to expect. They don’t know what to say. They don’t know what to do. Sometimes the opposite happens. They act toward the patient as though nothing is wrong at all. Now this really makes a lot of the vestibular patients that I’ve seen livid! They say, “How dare they be that insensitive? I’m telling them that something is wrong with me, and I can’t function like I used to function, and they’re acting as though today’s just another day.”
I’ve often had family members who are sensitive, who are feeling the overwhelming effects of this type of disorder, call me up or come in to see me and ask, “What can I do? What can I say to make things better? How can we get through this?” The fact that you came in asking these questions is going to help you get through this because you’re going to be looking for solutions. You are going to be looking for ways to make this easier on all of you. It’s a family problem.

Patient’s perspective
I’m going to just give you some comments that some of my patients have mentioned over the last month or two, just to give you an idea. You know, whenever you walk into a room with a vestibular patient, and you’re a family member, and they’re startled? That makes you not want to do it anymore, even though you’re coming in to surprise them with something nice, like a birthday cake. Makes you just not want to do things anymore.

My practice basically deals with people with chronic conditions: cancer, diabetes, spinal cord injuries, etc. But of all the disorders that I’ve ever worked with, vestibular disorders tend to be some of the most overwhelming [for patients]. You know why? Because they don’t see an end to it. I heard that time and time again. And I’ve heard vestibular patients say, “You know, if I had cancer, I’d know one day it would probably be over. You know, there would be some relief in death.” They say, “You know, it’s like somebody coming in and saying, ‘you’re it,’ and there’s no getting away.” I’ve had people say, “You know why I continue with these treatments, even though nobody has said it can be cured? I’m afraid to stop. I’m afraid to get off of this treadmill because around the next corner might be the cure. And I don’t want to deny myself that opportunity.” And I can appreciate that. There’s one thing that has to be maintained in dealing with this type of disorder, and that’s hope. Hope. Because without it you won’t get out of bed. You have to believe that what you’re doing is going to make a difference.

Treatment
Treatment includes support and assistance in coping with the change in lifestyle, and to lower the expectations that people have of themselves, which, as I’ve alluded to earlier, can lead to guilt feelings and depression because their expectations are still high. Guilt stems from not being able to be the breadwinner or to be the effective parents or the worker that they used to be. A lot of us get a lot of self-respect out of the work that we do. And if we’re not able to do it anymore, it can really erode away our self-image, our self-confidence.

Oftentimes I use relaxation treatment, and I’ve had pretty good results, especially with people who were phobic regarding being in shopping centers, shopping malls, and feeling that they were going to become dizzy. Oftentimes it’s controlled breathing and just controlling the overall stimuli that are affecting them. For example, oftentimes vestibular patients, even with their eyes closed, feel dizzier. Sometimes, though, what’s really triggering the dizziness is all the peripheral stimuli. Like when you’re walking down the aisle in the supermarket, and all the rows of colors can make you feel a little woozy. I’ve
found that oftentimes in situations like that the fear is that of falling. So I’ve found that if I can get a person to sit down, close the eyes—sitting down, they’re eliminating the fear of falling because they’re already down. Closing the eyes, they’re eliminating all that peripheral stimuli that’s causing what’s triggering the dizziness and the nausea. And then just taking a breath, allowing the oxygen just to kind of loosen up and diminish the tension in the body. That’s helpful.

Then, oftentimes I use a technique called systematic desensitization to lower the anxiety associated with the fear of experiencing what I just described.

Oftentimes just having family members come in to work out some of the financial arrangements will lower the amount of tension within the patient, too. As I said, it’s a family situation, and it calls for just reducing the amount of responsibilities in terms of raising the kids, caring for the kids, getting somebody else in there to take care of them, getting Grandma or Grandpa in to help to provide some respite. It requires having the kids come in to learn that it’s not OK to slam doors anymore or to move the furniture around with the screeching on the floors. There’s a need to demonstrate that there is some hope, that there can be some optimism, and there can be assurance or reassurance that they will not be abandoned by the ones who care for them.

Let me point out that the several times that I’ve heard patients of mine consider suicide, it was from the fear that they were going to be abandoned. Every time the term has ever been mentioned in my presence with a vestibular patient, it was because they felt that “I’m driving them away, and they are going to abandon me.” But, if we can assure them that that’s not going to be the case, we can at least lower that anxiety level to the point that they can start dealing with the other factors in their lives.

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