Multiple Sclerosis: Finding Health Within a Chronic Illness

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Abstract

Multiple sclerosis (MS) is a chronic neurological disease that slowly destroys the conduction of the Central Nervous System. Its symptoms are progressive and debilitating and often leave the patient in a state of chaos, where he/she is forced to place his/her life on hold in order to manage the symptoms. Using Moch's theory of Health-Within-Illness, there is a way to foster a sense of insight within diseases that are debilitating. Using cognition, perception and regulation as the points of reference for this theory and the disease, we see the positive changes Moch's theory can make on a very negative situation. This theory was applied to a patient experience as well as to an aesthetic one, to emphasize the positive spiritual and physical journey of MS.

Traditional Views of Illness

Healthcare has consistently viewed chronic disease as something to "fight." Healthcare providers encourage patients to wage war with an invisible invader that is battling to take over their bodies, and they foster the idea of teamwork to beat it. However, in chronic illness, this war can only be fought for so long before the patient's body shuts down completely due to progression. So how does one find meaning in something so debilitating? In Susan Moch's developing theory of Health Within Illness, she explores the idea of "getting in touch" with the illness as an opportunity for spiritual and emotional growth, suggesting that perhaps the time the patients are with disease is the best opportunity for them to facilitate desired change (Moch, 1988). I will explore this theory using the altered life process of Multiple Sclerosis, and give case evidence of how one woman came to embrace her disease process in a very positive way.

Multiple Sclerosis : An Altered Life Process

Multiple Sclerosis (MS) is a chronic autoimmune disorder that affects the central nervous system (CNS), particularly in the brain, spinal cord and optic nerves (Holland & Madonna, 2005). In this process, the myelin sheath, which insulates the nerves of the CNS, is destroyed in certain areas by the body's immune system, leading to inflammation and lesions forming in those areas, causing many of the symptoms that have become so identifiable with the disease. Paresthesias, or numbness and tingling and increased sensitivity of the face or extremities of the body, as well as visual clouding and gaze paralysis are usually the first manifestations of the disease in otherwise healthy people (Porth, 2005). These symptoms can manifest as acute episodes that last for weeks before they resolve themselves, leading many patients not to get medical attention for the signs before the next, more serious batch of symptoms appear.

As the disease progresses, symptoms such as gait disturbance, fatigue, bladder dysfunction or even Lhermette's Symptom, an electric-shock-like tingling down the back and into the legs when the neck is flexed, appear (Porth, 2005). Many of these symptoms will last for days to weeks before they are completely or partially resolved. It is after this time, when function appears to be normal, that new symptoms manifest, leading to the diagnosis of relapsing–remitting MS, where there are defined periods of symptom expression followed by periods of normalcy, where the symptoms are fully or partially resolved. The disease process can progress over time, making the times between symptom expression and remission almost non-existent (Holland & Madonna, 2005).

Relapsing-remitting MS usually follows the disease path to secondary-progressive MS, where there is progression of symptoms with or without occasional relapses and remissions (Holland & Madonna, 2005). Secondary-progressive MS usually shows the signs of "plateau," in which the symptoms stay in a holding-pattern if you will, without regression or progression. There are two other classifications of MS, primary-progressive and progressive-relapsing, but this paper will focus on relapsing-remitting and secondary-progressive, the main disease processes of my patient.

According to Holland (2005), 50% to 60% of people with MS report fatigue as their most disabling problem. This crippling, unrelenting fatigue often affects people in the most drastic of ways: they find their cognition is altered through inability to focus their attention or be alert to the world around them. These exacerbations of hypersomnia can come from many pathological processes in MS, but much of the research has linked this phenomenon to the demylenation and damage to the reticular formation area of the brain (Zifko, 2004). There are medications to help treat this hypersomnia in MS patients, namely Modafinil, a non-amphetamine drug that was approved for the treatment of narcolepsy (Karch, 2006). This drug has shown promising efficacy in the MS population and has become part of the regular drug therapies for those who are crippled with excessive daytime sleepiness.

Perceptions of losing control are also a growing issue in the population of people with MS. Within this group of people, their bodies are ever-changing and their symptoms can evolve to something new within weeks. Because of this inability to anticipate what will happen next physically in their lives, many feel a crippling loss of control and symptom devastation (Courts, 2004). As one patient described it in the Courts (2004) article, "You have to plan your days a lot better than you used to . . . it slam dunks you. . . . And it does . . . it puts you in your place" (p. 44). People with this condition are then forced to work their lives around the disease and what new symptoms may occur in the next few months, making them slaves to the disease process.

There are some treatments to retard the symptom progression of the disease, namely Betaseron and Copaxone, two agents that reduce the average relapse rate in people with relapsing-remitting MS (Karch, 2006). The mechanisms of action in these medications are not well-known; with Copaxone it is thought because it mimics a protein in myelin, that the disease is "drawn" to the breakdown of the medication rather than the myelin itself, but scientists are no longer fully sure of that theory (Karch, 2006). Betaseron, the older medicine of the two, is used as a cellular immune enhancer, because it mimics the beta-interferon produced when cells are invaded by viruses (Karch, 2006).

Regulation within MS is severely damaged by this altered life process. Almost all bodily function is altered by the disease process, leading to chronic physical abnormalities that need medical intervention. One of the most common regulatory systems that is changed by this process is that of bladder function. Dysfunction of this system affects as many as 90% of all MS patients, in different ways (Holland, 2005). Because there are many different dysfunctions of this system, the main focus will be on the regulatory dysfunction of my patient, the phenomenon known as "failure to empty." In this condition, when the bladder attempts to empty, the external sphincter also contracts, leading to uncoordination between the sphincter of the detrusor muscle and the external sphincter (Holland, 2005). This leads to a sense of urgency, increased frequency of urination and a postvoid residual urine level of more than 100mL. Due to this residual urine in the bladder, calculi from mineral precipitates develop, as well as recurrent urinary tract infections from the bacterial proliferation in the residual urine (Holland, 2005). Catheterization becomes commonplace in this condition and many who are at home have to intermittently catheterize themselves twice a day to prevent the complications from "failure to empty" syndrome. Another treatment used to aide in the regulation of this altered process is Ditropan XL, a medication that relaxes the detrusor muscle sphincter to relieve urgency and incontinence (Karch, 2006).

Nursing Theory

The theory chosen to examine this patient's life experience with MS was Susan Moch's Health-within-Illness theory, a concept that, while still in its infancy of development, is still very applicable to the interaction with this patient. In this theory, Moch explores a conceptual definition of health-within-illness as "an opportunity which increases meaningfulness of life through connectedness or relatedness with the environment and/or awareness of self during a state of compromised well-being" (Moch, 1998, p. 305). The theory focuses on four key areas that need to be developed in order for the concept to be actualized in a patient:

- The patient must be faced with an *opportunity for change*. Moch (1998) defines this opportunity as the recent discovery or sudden intensity of illness. This opportunity provides a circumstance for positive change in one's life, if the next three areas are developed fully.
- *Increasing meaningfulness* is the ability for the person, once faced with the opportunity, to re-define his/her priorities in life. People in this stage of actualization often hold more value for the things in their lives they once took for granted (Moch, 1998). Patients may even have a greater sense of purpose in their lives.
- *Connectedness/relatedness* is viewed as more of a spiritual experience by Moch (1998), as the patient communicates more with others in his/her life, nature, and a personal spiritual guide.
- The last component, *thorough awareness of self*, includes self-knowledge (Moch, 1998). This concept is more in line with the idea of listening to what one's body is trying to tell him/her in regards to the disease process and physical health.

The patient, when experiencing these four levels of actualization, is able to see that his/her health is more than just the absence of disease. This concept becomes very important when a person is living with a chronic condition, like MS, that has no cure. Constantly seeing oneself as a "sick" person may lead to a spiritual failing that accompanies the breakdown of one's body, in essence a failure to thrive (Moch, 1998).

Moch's theory emphasizes the development of positive perception in one's life, in order to "expand human potential" (Moch, 1989). By viewing one's illness as an opportunity to make positive change and control in their lives, people leave themselves open to all they can learn from this experience. Instead of defining themselves by the diagnosis they have been given, they open themselves to a new sense of "aliveness" and all they can learn about themselves and their priorities. In qualitative research cited by Moch (1989) in her article, 22 patients who were diagnosed with advanced cancer were studied: "[They] have a greater appreciation of time, life, people, and interpersonal relations. They are more relaxed and less concerned about the non-essentials of life" (p. 26). These patients faced the illness along with their potential mortality, and found that there was more to their world than this word "cancer" could ever define. Their perceptions were ever changed and their priorities shifted. They now found the increased meaningfulness outlined by Moch (1998) in her conceptual definition.

When viewing cognition as a way to interpret data, we can see that this theory, when applied, helps patients to problem solve and reason differently. They are now open to the new "opportunity" they have been given through the illness to change their lives in a positive way; they have taken the first step to health within illness. Patients who subscribe to the theory are able to embrace their mortality and make decisions. Though this perspective does not necessarily prolong life, patients are able to view the illness as a quality learning experience, without fear of whether or not they were making decisions that would put them closer to death.

Because this experience involves the patient's support system as a main component, the family would have to align with this philosophy of embraced mortality as well. As Moch (1989) states, "Feelings of overwhelming grief at a friend or family member's diagnosis of serious illness would be replaced by feelings of empathy with the difficulty and excitement of anticipated learning. . . . the response [to death] would not be one of despair or failure" (p. 28). There would be no feelings of failure, because the patient had the ability to learn all he/she could about themselves and his/her priorities during this time with his/her illness. He/she would have felt more alive at that point, on the way to death, than they ever could have experienced trying to fight death.

The primary emphasis in this theory is that by finding the experience of health within illness, the patients stay regulated and in control. There is no way for them to physically take control back from the illness that is ravaging their bodies, but spiritually and mentally they are still in control. They no longer see every new symptom as another marker to death or healing as a way to win; rather they stop keeping tally because they have full control over their spiritual development. They are able to regulate the one aspect that they have control over: their learning experience on this spiritual journey.

Health-within-Illness Applied to Patient Care

The patient, who had been diagnosed with relapsing-remitting MS close to 24 years ago, is a 47 year old woman. At the time I met her, her disease had progressed to the secondary-progressive stage, which she has experienced now for 7 years. She was hospitalized for a severe urinary tract infection that had caused systemic discomforts of fever, overall weakness and malaise. Upon my assessment of her, her WBC level was 18.7 x 10^3 / mm^3, compared to the normal range of 4.3 to 10.8 (Fischbach, 2004). She didn't have a fever, and experienced no other discomforts other than some lower back pain from the severity of her infection. She had a Foley catheter in place, and her urine appeared dark yellow with a bloody tinge. Because of her MS, she was unable to shift herself in bed, and so she was on a turn schedule every two hours. She had severe contractures of her lower extremities, and only limited movement in her arms, providing only reading, some writing and the ability to brush her teeth and hair as her main activities of daily living. However, her grip was weak due to the progression of MS, and her hands would involuntarily shake when she tried to grip onto the brush and work with it.

This patient had a small group of devoted friends and a sister who was with her for most of the day. The support group, as well as the patient, were willing to teach me about living with this disease, when I admitted that I knew nothing of what the patient was experiencing. However, instead of explaining the physical symptoms that seemed so obvious to me, the patient and her support group went on to tell me of her spiritual journey living with MS.

My patient was open in telling her perceptions of how it was to be diagnosed with secondary-progressive MS. She told me that at first, she was upset with the diagnosis because she felt it brought her "closer to death." Before this opportunity for growth, my patient had held the hope that her disease would never progress. She has been injecting Betaseron since she was first diagnosed, and was continuing to manage her symptoms with Copaxone, and thought that would be the key to retarding her disease into remission. Now she felt that she had to face death before she was ready to die, and it made her hopeless. My patient stated that she found her life meaning in her spiritual relationship with God that helped her to see that her spirit was greater than her body, that death was not the end of life. She stated that this embrace of mortality was not overnight and it took hours of prayer and reflection to fully accept that this progression was just a "second part to the journey," that she would "find her [physical] health in Heaven." When faced with an opportunity, she was able to see the learning experience in her advancement, and unbeknownst to her, the health within her illness.

I wondered if this patient made decisions differently since this personal epiphany, and she and her support group were able to give me a resounding "yes." As my patient's sister described it: "We no longer talk about what is going to cure her, but rather what is going to make her feel better." My patient even went on to say that she spends more freely on the things and services that she really wants, because it just makes her feel "good" to do that for herself and others. Her cognition was changed forever, because her desires to problem-solve her illness away no longer existed. To many this would seem like loss of hope, because she no longer acted towards the future for positive outcomes (Fryback, 1993). She was living in the present, and keeping only a conservative eye on the future. However, when applying Moch's theory, we see that the decision to be in the moment and learn from the illness at that exact moment doesn't mean a loss of hope or a decision to die. Instead, it means being in tune with how the disease is shaping her world, day by day, and how to make the most of that day. She was increasing her connectedness to her family and friends, and increasing her meaningfulness through appreciation of the world around her.

Regulation to my patient was being able to have the little control that she had over her spirituality and her care. Midway through my time with her, my patient called me to her bedside when her support group was gone for coffee. She pulled me close and asked me about Copaxone, an injection that she received every day for the management of her MS symptoms. She informed me that she had been in the hospital for two days and no one had given her the shot, and she was concerned about missing it. She was regulating her care at this point, and exerting the control she had to make sure her care was at her standards. She was exemplifying Moch's (1998) fourth component of health-within-illness, awareness of self, and it helped her to be strong and voice her concerns over her care. In traditional medicine this vocalization may be deemed as the call of another "needy" patient (Fryback, 1993). The patient saw, however, that this was her way to have a stake in her care and regulation over a chaotic disease process.

Aesthetic Experience

I chose Jackson Pollack's "Shimmering Substance" (see Appendix) as a beautiful representation of my client's experience with MS. At first glance the painting just seems like chaos: splatters and smudges that have no reasonable connection or discernable shape, colors that barely seem represented among an overpowering of white. However, the white isn't even pure or complete; it is scattered here and there with no sense of the purity or simplicity that we so often associate with the color. However, I took a closer look. I let my gaze follow the smudges in their fluidity and I saw that there was more to this painting than what appears. I saw a yellow circle, a shimmering substance if you will, that caught my eye and gave me a sense of peace: there is order within the chaos. There is something beautiful within these smudges of blue, gray and white. There is a purpose and meaning to this whole experience, found by surrendering my will to the painting and letting it show me what I was to learn, rather than forcing my own desire.

What I have always loved about Pollack's work is that it takes one surrendering his/her idea of beauty in order for him/her to see the value within it, much like disease. When one is first diagnosed with something that is more complicated than a cold, all that is seen is chaos, much like what this patient experienced when she found that her disease progressed to secondary-progressive MS. Her perception was altered at that point, and she was focused on the chaos of it all and the ugliness of the overall picture. This disease was going to lead her to death, of that she was certain.

Then she surrendered to the experience. She followed the lessons, or brush strokes if you will, to find her shimmering substance: a relationship with God that gave her meaning beyond this world. Her cognition was now changed because she no longer needed to apply her desire to "fight the disease" to this process. She saw her shimmering substance and it was meaningfulness, connectedness and awareness of self. Her perception saw that death was not the final answer, and that this process does not have to be chaos. It doesn't have to follow a certain order, but it does have meaning.

With this understanding, she became able to regulate and control how she reacted to her disease. She became more aware of herself and her needs, and made sure that they were being met on every level. Because she has that control, every chaotic-looking situation now has a beauty that not every one sees. She can go from this Pollack painting to another, and still get the same meaning and understanding. That is the beauty of health-within-illness: once you get it and once you accept it, it applies to every other aspect of one's life and future health. It becomes a lifestyle choice rather than just a credo to live by.

Conclusion

As nurses, we don't always get the chance to learn from the spiritual growth of our patients; most of the time we are catching them right at the beginning of a new fight with a disease, when they are at their most vulnerable. Moch (1998) states that within the health-within-illness model, we can facilitate a spiritual re-birth for the patient by being available for the patient's spiritual needs. A patient doesn't have to enter this chaos without someone on the outside giving him/her perspective and that is what is most fascinating about this theory. We can use our holistic roots in healthcare to spiritually feed a patient and nurture him/her to grow in the harshest of conditions. In this case, I was taught more from my interaction with this patient than I was able to teach her, but I was left inspired by her health to foster that health within myself and others as well.

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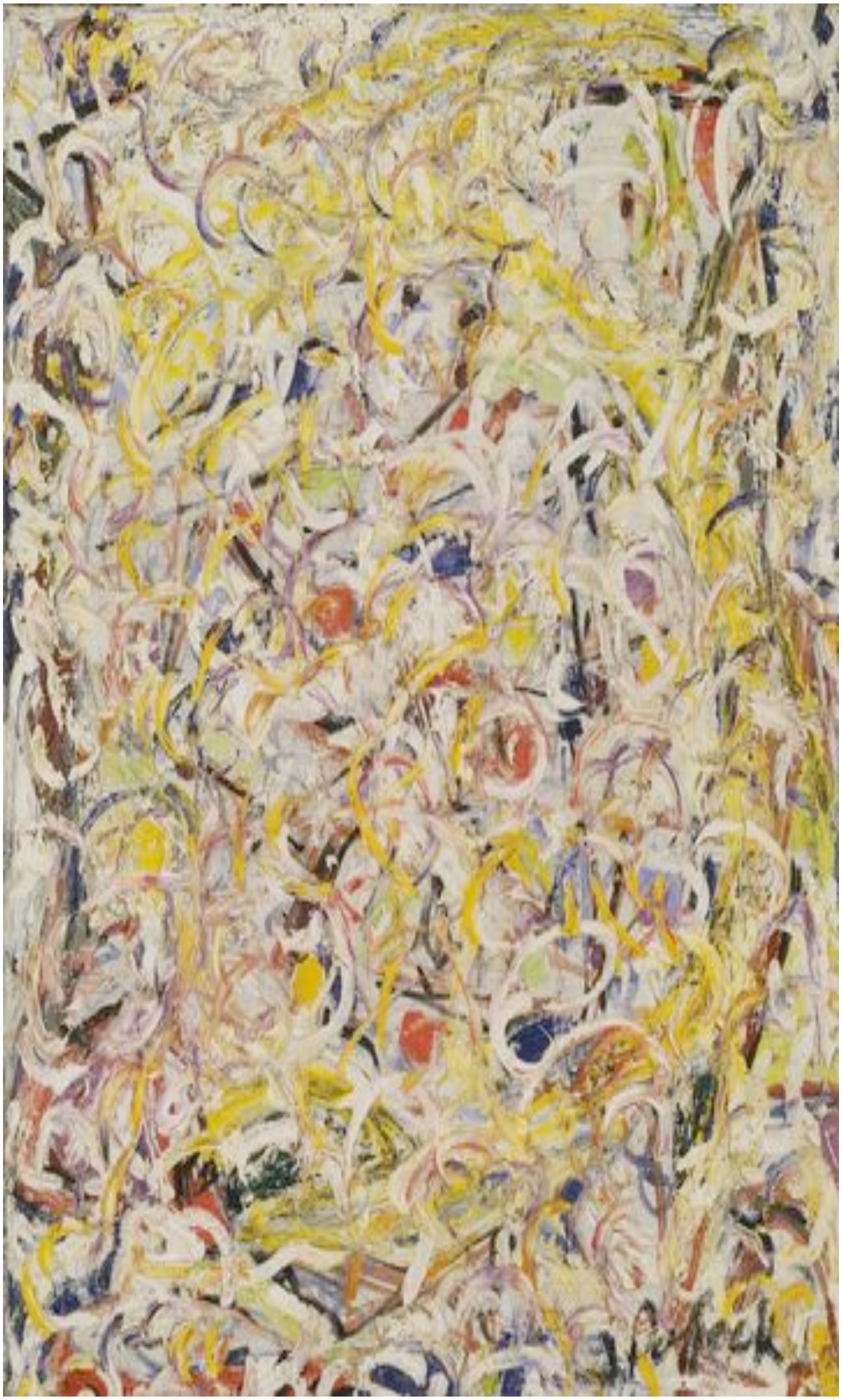
Appendix



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