

ABSTRACT

The Process of Healing in Multiple Sclerosis: The Roles and Experiences of the Patient, Physician, Family, and Peers

Kyrie K. Cameron

Director: Dr. William D. Hillis

Patients who suffer from multiple sclerosis are faced with the reality that this disease, which causes such tremendous physical and emotional distress, simply cannot be cured. Though medical researchers have not yet been able to find a cure, multiple sclerosis patients may certainly experience healing during their struggle. To cure one from disease is a permanent eradication of all physical symptoms that the body experiences, whereas healing is the retaining of a sense of personal integrity and self-worth in spite of the physical manifestations of illness. Healing is experienced by the patient, but is also an experience in which the physician, family members and peers play significant roles. In cases of incurable disease, such as multiple sclerosis, it is important that every patient is provided with an opportunity for healing. In order for each patient to have this chance, it is beneficial for each of the individuals involved in the healing process to recognize those practices and attitudes that contribute to healing.

APPROVED BY DIRECTOR OF HONORS THESIS:

Dr. William D. Hillis, Department of Biology

APPROVED BY THE HONORS PROGRAM:

Dr. Andrew Wisely, Director

DATE: _____

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THE ROLE AND EXPERIENCES OF THE PATIENT, PHYSICIAN, FAMILY
AND PEERS

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PREFACE

The Process of Healing in Multiple Sclerosis

Though the words are often used interchangeably, there is a significant difference between the meanings of healing and curing. The most notable distinction is that not every person can be cured, but there is a possibility for every person to be healed. It must also be noted that it is indeed very possible for one to be cured, and not healed.

To cure one of disease is a physical restoration of the body to its healthy, non-diseased state. For example, a patient may be cured from pneumonia. To cure pneumonia, the patient would be prescribed or administered antibiotics or anti-viral medications. In the case of MS it is very possible for patients to experience bouts of remission from certain symptoms that are common in multiple sclerosis, but it is, at this point, impossible for a patient to be cured of the demyelinating process in the central nervous system of this neurological disease. Science has made tremendous strides in the efforts to cure many diseases. However, there has been no sure-fire way to remedy multiple sclerosis in its totality.

In contrast, the idea of healing “relates to whole person care, to the preservation or restoration of a sense of personal well-being, dignity, and integrity” (Toombs 2). For example, a patient could experience healing from MS if he or she retains a sense of wholeness that was experienced before the onset of the disease. Healing could be likened to the overcoming of a disease, not a physical overcoming,

but it is the point at which the patient has learned to live well in the face of illness. The word “healing” shares the same root as the word “whole” and healing relates to the preservation of personal not bodily wholeness. Healing is a meaningful experience that can bring the patient a great deal of empowerment and renewal of self-purpose. While a person can be healed and not cured, it is important to note that a person can be cured and not healed. For example, “a cancer patient whose disease is cured but for whom the radical alterations of her body causes a deep sense of loss of integrity and continued suffering” (Toombs 3).

In a society in which we are constantly striving towards but not always being able to discover cures for the many diseases, such as multiple sclerosis, cancer, heart disease, arthritis, strokes, AIDS and Parkinson’s Disease, that affect the global population, it is important that we always pursue healing. This is particularly the case because the majority of patients who seek health care are suffering from diseases that cannot be cured. The healing process is not a solitary endeavor, but it is a process that is best achieved by the patient when the physician, family and friends are also committed to the goal of healing. If each of these individuals works together to promote healing, the patient will feel a sense of well being that is sometimes not even attainable from a cure.

Multiple sclerosis (MS) is “a demyelinating disease marked by patches of hardened tissue in the brain or the spinal cord” (Merriam-Webster Medical Dictionary). The symptoms are incredibly vast and can range from paralysis, to loss of vision, to loss of sensation, to muscle tremors, to sensory disturbances that cause

pain, to loss of bladder and bowel control. These symptoms are not only physically painful and debilitating, but can be degrading to one's self esteem as well because their onset is not easy to predict and the duration is widely variable. Many patients who are diagnosed with MS initially feel as though they have had their lives taken away, though the disease is not clinically considered terminal. Patients are faced with the reality that from the diagnosis on, life will be different and they will always live with MS. However, there is a great deal of hope for all patients of incurable diseases. It is not necessary to be cured in order to be healed.

In my own personal experience, I have had the opportunity to watch the healing process occur in my father's life. My dad was diagnosed with multiple sclerosis in the same year that I was born. The illness was not only physically taxing on my dad, but mentally and emotionally taxing as well. My father was determined to remain whole and to live well in the face of illness (to experience healing) in his struggle with multiple sclerosis and was fortunately surrounded by physicians, family, and friends who also wanted to promote his experience of healing in the face of the disease. Though he was never cured of multiple sclerosis, there is no doubt that my dad was healed. Multiple sclerosis did not declare victory in his life, because with the help of doctors, family, and friends, my dad was convinced that the disease would not define him.

If healing is to occur, the patient must recognize that healing (and not just curing) is the goal for which he or she may strive. As should be expected, the patient

plays the largest role in the healing process, because he or she must be willing to submit and dedicate themselves to efforts and attitudes that will ultimately lead to healing. It is not an endeavor that should be experienced alone. Communication with physicians, family members and peers is very important at every step along the journey. True healing can be found when patients realize that their disease does not define them; in fact, they can live a meaningful life despite the disease. In the first chapter we will discuss the roles, experiences, and healing practices of the patient in his or her journey with multiple sclerosis.

In the second chapter, I will address the physician's experience in dealing with patients who suffer from multiple sclerosis, as well as the doctor's possible role and contribution to the healing process. The physician plays a significant role in the healing process. As I will show, many doctors find this task difficult, but it is imperative for the doctor to help his patients along their journey to healing. Due to the high regard placed on physicians by society, they are some of the most influential people involved in the healing process. Historically however, there is "a great gulf that exists between the way we think about disease as physicians and the way we experience it as people" (Baron 606). In an effort to promote healing, the physician must make the effort to bridge this gap and try to understand the patient's experiences with the disease. When the physician understands the patient's experience, he or she can better relate to the patient, address specific problems and challenges in the patient's life, and help in protecting the patient's self-worth and emotional well being.

In the third chapter, I will discuss the roles and experiences of the family and friends of MS patients in the healing process. It is often difficult for MS patients to feel comfortable relating to the family members and friends with whom they were closest before the diagnosis. Patients can feel isolated and as though no one can understand what they are going through. However, family members and peers have a vital role to play in facilitating healing. Though it is impossible for each family member and friend to feel exactly what their suffering loved one is feeling on a physical level, it is possible that they can share in the fears, trials, anxieties, and discomforts that are associated with multiple sclerosis. Family and friends must themselves perceive the patient as a person of worth in spite of the effects of the illness. When they treat the individual as they always have, while being sure to acknowledge and be patient with his or her limitations, then the patient will regain a sense of normalcy and self-worth and come to realize that the illness does not negatively define who he or she is or diminish self-esteem. Although life will be different, it is still possible for the patient to live well and retain a place of value with family, friends and others. When peers and loved ones can experience the healing process together, the relationship can be brought to new heights because that is an incredible journey to share.

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Dr. Hillis, you have not only taught me a great deal about the human body and its biological processes, but you have also taught me the importance of the patient-physician relationship. Most importantly, you have always showed me, by example, the significance of being a Christian leader and role model within the community. I know that I will apply the lessons I have learned from you to my future for years and years to come.

Dr. Toombs, I cannot fully express my appreciation for your willingness to help me with my thesis along every step of the way. I am forever grateful for the tremendous amount of time you sacrificed to meet with me and edit each and every page that I had written. I have learned so much from you and your life's experiences. You are such an inspiration and I know that I will cherish the experience of working with you for years to come.

DEDICATION

I would like to dedicate this thesis to my dad, whose bravery-filled experience with Multiple Sclerosis will forever inspire me.

CHAPTER 1

The Roles and Experiences of the Patient

Part 1: The Patient's Experience

Medical Overview of multiple sclerosis

Before we can begin to discuss and understand the patient's lived experience of multiple sclerosis, it is important that we have general knowledge of the disease process itself and its physical disturbances to the body. "Multiple sclerosis (MS) is a nervous system disease that affects [the patient's] brain and spinal cord. It damages the myelin sheath, the material that surrounds and protects your nerve cells. This damage slows down or blocks messages between [the patient's] brain and [the patient's] body" (MedlinePlus). There exists a myriad of symptoms characteristic of multiple sclerosis; the most commonly observed symptoms include fatigue, visual disturbances, muscle weakness, troubled or non-existent coordination and balance, sensations of numbness or prickling, and functional problems associated with thinking and memory. Other symptoms of multiple sclerosis include constipation, frequent and or difficult urination, blindness, depression, dizziness, hearing loss, loss of sexual drive, and speech impediments, just to name a few. The autoimmune disease plagues women more often than men, and its onset usually occurs when

patients are between the ages of 20 and 40 (MedlinePlus). Globally, “MS is thought to affect more than 2.1 million people” (National MS Society).

There are various forms of multiple sclerosis. The most widely accepted forms of the disease are Relapsing-Remitting Multiple Sclerosis, Secondary-Progressive Multiple Sclerosis, Primary-Progressive Multiple Sclerosis, Benign Multiple Sclerosis, Progressive-Relapsing Multiple Sclerosis, and Malignant Multiple Sclerosis. Relapsing-Remitting Multiple Sclerosis (RRMS) patients experience periods of symptom flare-ups followed by recovery; during the period between flare-ups patients are stable. Secondary-Progressive MS (SPMS) patients are considered to be within the second phase of RRMS. These patients experience a progressive worsening of symptoms and may or may not experience intermittent relapses. This form may be delayed using various medical treatments. Primary-Progressive MS (PPMS) patients experience gradual and steady accumulation of neurological problems from the onset of the disease. Benign Multiple Sclerosis is rare. These patients experience few attacks and have little to no disability after 20 years. Progressive-Relapsing MS (PRMS) patients undergo a progressive course from the onset of the disease, however they may experience occasional flare-ups during which their symptoms become even more acute. Malignant MS is the most rapidly progressive course of the disease (MSAssociation.org).

Disruption of Life

The clinical definition of multiple sclerosis does not convey the life disruption that the patient experiences. The life disruption that occurs with the illness is not limited to the physical disturbances experienced by the body because the impact of a particular symptom will depend upon the unique circumstances of the individual patient's life. For example, loss of the ability to walk will be different for someone who wakes up each morning to go on a walk with their friends than for someone who doesn't participate in a daily walking group. Each patient's clinical experience (and resulting symptoms) is unique. Also, the symptoms of multiple sclerosis are vast and affect each person differently. It would be difficult, if not impossible, to establish a list of physical symptoms that every patient of multiple sclerosis suffers. However, given the global experience of life disruption that the illness necessarily causes, all patients generally experience the feeling of a loss of wholeness. In thinking about this loss of wholeness, it is important to note that there are some common characteristics associated with this experience. In her Case Study, Kay Toombs, enumerates many of the characteristics of the loss of wholeness; these include illness as it destroys the taken-for-granted-ness of the body, loss of mobility, loss of function, oftentimes a loss of self-esteem, as well as a loss of certainty. The implications of these common experiences are dependent on the life context of the individual. In the following paragraphs, each of these characteristics will be addressed and examples of each will be provided using the lives of multiple sclerosis patients. In the latter portion of this

chapter, attention will be given to the healing practices that address each of these characteristics of the loss of wholeness.

Loss of Bodily Taken-for-granted-ness

Healthy individuals go about the day without ever having to think about how the body works. For example, most people do not have to worry about the next step they are going to take or about being able to control urination. Over time, we take all of our body's normal processes for granted. It is not until these mundane processes become flawed that we recognize their importance and incredible efficiency in our healthy states of living. Also, changes in bodily function make us aware of how dependent we are upon our bodies for health. Incurable illness "brings [patients] face to face with the fact that [their] most cherished assumptions about personal indestructibility and the absolute control we have over our lives are illusions" (Toombs 7).

In recalling her experience with MS, Kay Toombs says, "My body could no longer be trusted. Nor could it be ignored. I needed to be on my guard to watch and listen to my body's rhythms, its sensations, its movements" (Case Study 7). Due to the symptomatic loss of sensation and numbness, patients with multiple sclerosis may also at times feel alienated from their bodies in the sense that the affected body parts appear to be separate or absent. The limbs and other parts of the body are not

physically absent but instead seem to become foreign, they appear to be “lifeless, object-like, but are no longer one’s own” (Case Study 8).

This loss of bodily taken-for-granted-ness causes a forced attention to the disabled body because the patient must address the myriad of symptoms associated with multiple sclerosis in an effort to alleviate many of the pains and discomforts that he or she experiences. For example, many patients, like Kay Toombs, living with multiple sclerosis find that periodically they lose control of their body’s ability to control urination. At these times, these patients are forced to insert a catheter into their body to help maintain regular urination and to offset possible embarrassment that would ensue if one were to lose control of urination in a public setting. Though this treatment is being used to address this specific symptom effectively, it serves as a constant reminder that the patient’s body is diseased and not working as it previously had.

Montel Williams recalls that one of his most challenging symptoms of MS was the constant fatigue he experienced. The former marine, boxer and member of the Naval Academy at one time could tape his show all day long, never once having to stop for a break. He had so much energy that he often followed up his busy days of taping with an evening workout. He was, in his healthier times, very energetic and always busy, never stopping to think about how blessed he was to have such vigor all of the time. At the onset of multiple sclerosis, Montel Williams began to notice how extremely tired he was. Taping his shows became exhausting, and often he simply

could not continue. He was forced to ask for breaks from taping, and many times had to end taping for the day altogether because his body simply could not go on. Montel, along with the producers, was forced to take his body and its tiredness into account when planning the taping and appearance schedules for every day.

In my father's experience with multiple sclerosis, he became quickly aware that the heat was a great aggressor of his symptoms. My father, along with the rest of the family, loved the beach. We spent countless summer days building sand castles, swimming at the country club, and crabbing off the boat deck. As my father's disease progressed, these joyous activities had to be shortened, and on some days eradicated from our daily plans because the heat would exacerbate his symptoms to painful and unbearable extremes. Though my father was strong and steadfast in his battle with MS, these small constant reminders of the disease's effects on his body were degrading to his sense of wholeness and disruptive of his way of life and interactions with friends and family.

Loss of Mobility

Multiple sclerosis patients experience a vast array of symptoms, however many of these symptoms can contribute to the individual's loss of mobility. Some of the characteristic symptoms associated with MS that contribute to a loss of mobility are poor balance, gait disturbances, fatigue, dizziness, and numbness in the extremities.

For some patients even the most mundane of tasks, such as getting to the grocery store, require the patient to pay attention to his or her illness. Patients “need to consider such things as fatigue and weakness but [they] must constantly be aware of the limitations imposed by loss of mobility” (Case Study 8). For example, a Baylor student who is in a wheelchair would need to make special arrangements and plans when preparing his course schedule. This student would need to make certain that all of the classrooms in which he will be studying are wheelchair accessible and must also plan in advance for the time and means that he will need to get from class to class throughout the day. In my own father’s illness, a trip to the store was not as easy as it once had been. Where he used to simply hop in his car and drive to the store, he was suddenly dependent on the Metro Lift program for transportation. These trips needed to be planned hours in advance so that he was ensured a seat on the bus. Every day tasks, that to healthy individuals are so routine, can be aggravating to MS patients because they serve as constant reminders that the body is currently in a diseased state.

In thinking about the significance of bodily disruption it is important to recognize the difference between “objective” and lived space. “Objective” space is the distance calculated by object measurements (e.g. 15 feet). Lived space is surrounding space, as we experience it in negotiating space in our daily activities. Patients with MS also experience a change in the meaning and experience of lived “space.” Distances that were “formerly regarded as “near” are now experienced as

“far”” (Case Study 9). For Kay Toombs, the distance from her office to her classroom had “always been short”, but after experiencing the symptoms of MS this walk “began to be far”, because, after lecturing in class for forty five minutes, her return journey to the office was nearly impossible due to exhaustion. Because of her loss of mobility she began to see the world through the lens of the disordered body. For example, when she visited the Lincoln Memorial, her first impression of the landmark “was not one of awe of its architectural beauty but, rather, dismay at the number of steps to be climbed” (Case Study 9). Her loss of mobility gave her yet another reason to be aware of her body’s disabilities.

The loss of mobility experienced by many patients is often one of the most frustrating aspects of this disease because it can make frivolous errands and trips daylong outings that require great amounts of pre-planning. The disordered body must always be taken into account.

Obviously, the significance of loss of mobility will depend on the life context and values of the patient. For Kay Toombs in her life as a college professor the inability to walk had a different meaning than it did for her friend who was a marathon runner and who defined her self worth by this activity.

Loss of Function

Loss of function occurs in numerous ways in the life of a patient with MS. For instance, some patients experience constipation because their gastrointestinal tract has

lost its functionality in the conducting and eventual passing of stool from the intestines. Other patients, for example Montel Williams, find their vision to be impaired. It was just before his graduation from the Naval Academy that Montel Williams did not pass his standardized vision tests during his final physical. His eyes were beginning to fail him and eventually lost all color vision, which returned 18 years later out of the blue. The loss of functionality of Montel's eyes eventually led to a loss of purpose for his life because he was no longer able to achieve his goal of becoming a pilot for the Navy. His vision problems, caused by MS alone, prevented him from being allowed to attend Flight School.

In addition, with loss of function many patients find that everyday objects become problematic. For example, my father found that he struggled to brush his teeth every morning and evening. He could no longer hold onto his toothbrush with a constant grasp and his hand would violently shake to the point that toothpaste would go everywhere, on the mirrors, on the sink, on the wallpaper, but not in his mouth and on his teeth. His toothbrush had become a problem to be solved. He had lost the ability to brush his own teeth, without great difficulty.

Loss of Self-esteem (The Sense of Diminishment)

In a society in which “a person's worth is judged according to the capacity to produce or the ability to achieve a certain professional status,” it can be a devastating

and frustrating realization that such an ability to “do” will be affected upon the diagnosis of multiple sclerosis (Toombs 17). This emphasis on one’s ability to perform often contributes to the patient’s sense of diminishment and loss of self-esteem. Whether it is a television personality, like Montel Williams, who suddenly feels complete exhaustion and cannot fulfill his everyday show tapings and appearances, or a football player who can no longer fulfill his duties on the field, patients feel a loss of control and a depletion of self-worth. Multiple sclerosis ultimately “disrupts social roles” such as being a husband, mother, or friend which causes the patient to feel that “he is failing to fully contribute in areas of family and social life” (Toombs 17). In order for a patient to be healed, this loss of self-worth must be addressed by healing practices that are conducive to rebuilding that individual’s sense of purpose.

Permanent Uncertainty

As noted, there are different forms of MS. Patients can experience either the relapsing-remitting or progressive forms of the disease. The relapsing-remitting form of multiple sclerosis is very unpredictable. These patients will have periods of time in which their bodies are in remission, and then suddenly they will experience a period of acute attacks. For these patients, symptoms appear and then dissipate significantly or even completely and then reappear; the cycle is ongoing and often because the symptoms don’t disappear completely the disability increases over time. Primary

progressive MS is best described as a form of the disease in which “patients tend to have symptoms that gradually progress without typical relapses” (ClevelandClinic.org). According to the National MS Society, about 85% of MS patients are diagnosed as relapsing-remitting, but within ten years it is confirmed that they are in fact experiencing the progressive form of the disease.

This erratic nature of the multiple sclerosis causes patients to experience a sense of permanent uncertainty. Because there is not a designated course, that the disease will take and every individual’s experience is different, patients are constantly unsure about what the future holds. As Kay Toombs said, “Every M.S. patient has a different story to tell” (Case Study 4). The disease is unpredictable, as evidenced by Montel Williams’ rapid deterioration of color vision followed up 18 years later by complete restoration in his ability to see colors. Though the patient will almost certainly ask, “What does this illness mean for ME in the future,” neither patients nor physicians can predict the course that the disease is going to take (Toombs 5). A patient with MS cannot possibly know whether tomorrow will be a day filled with energy or a day in which he or she feels extreme fatigue or what the future holds in terms of possible disability. This characteristic sporadic nature of MS makes it difficult for patients to plan ahead for future endeavors.

In addressing the uncertainty of life with Multiple Sclerosis, many patients fear the future threat of the disease on their lives. For example, if a patient experiences or has experienced a reduction in vision as a symptom of their MS, they

may constantly worry that this symptom will present itself again and possibly in a more acute manner. This symptom could potentially threaten their career and ability to do many things in the future. On other occasions patients have expressed a fear of the future threat that the disease imparts on marital relationships. Individuals fear that MS will lead to such disability or bodily brokenness that their spouse may not be able to care for them any more at some point in the future. These future threats associated with the uncertain nature of multiple sclerosis are very disruptive to the healing process.

*Part 2:
The Patient's Healing Practices*

There are many ways to approach the disruptions that contribute to a loss of wholeness experienced by patients with multiple sclerosis. The following approaches are suggested as healing practices, where such practices involve the effort to restore personal integrity in the face of illness. The most effective and beneficial healing practices will be different for each patient. It must be noted that the physician, family and friends of the patients play a significant role in helping the patient to regain his or her sense of self-worth. However, these roles will be examined further in the later chapters.

Reclaiming Life

As discussed, multiple sclerosis is a disease that diminishes a patient's self-worth and sense of purpose. Ultimately, the disease disrupts the expectations of normal every day living. As a result of this life disturbance, the initial steps towards healing begin when the patient takes the stance of reclaiming his or her life from the disease. For Kay Toombs, her reasons for deciding to reclaim her life from the disease were unclear. Perhaps it was her realization that she "would not become immediately disabled" or maybe it was because she "found living in constant fear unbearable" (Case Study 13). In her life, she found it important to change her way of thinking and planning into short-term rather than long-term goals.

In the life of Montel Williams, it wasn't until a point of desperation after considering ending his own life that he declared his pursuit for healing from his battle with multiple sclerosis. He recalls this experience as the moment in which he decided "[he] was going to live, period," and he "started to think of MS as a blessing" (Williams 22). As a result of his being a public figure, he was provided with an opportunity for a platform to spread awareness of MS and its effects on the lives of individual patients.

Bridging the Space

Though the loss of mobility experienced by individuals with MS is discouraging, it is an effect of the disease that can be positively addressed. For example, there are many mobility aids available to patients dealing with the immobilizing effects of MS. These mobility aids are canes, walkers, wheelchairs, and motorized scooters. When using these aids, it is important for patients to see these aids as a means of expanding space rather than as a symbol of disability. In the case of my father, though he was disappointed in the fact that he could legally no longer drive a car, he began to appreciate and enjoy riding on the MetroLift vans available through the Houston Metro System. At first he was easily frustrated because he had to plan his weekly trips and travel arrangements in advance, but over time he began to love his time spent on the vans. He had regular drivers who he developed friendships with, as well as other passengers who were often on the same van schedule. The rides that at one time seemed so discouraging and diminishing to his self-esteem became rides that brought him great joy and fun conversation. Eventually it became habit for my dad to plan his shopping trips, haircut appointments, and work schedule in advance so that he could make sure to arrange his transportation.

Being vs. Doing

Pivotal to the healing process is an understanding of the distinction between being and doing. In our society, “a person’s worth is judged according to the capacity to produce (to be useful) or the ability to achieve a certain professional status” (Toombs 17). This being the case, it is easy for patients who suffer from MS to feel that they do not have worth because they cannot “do” everything that is expected of them. An example of this loss of “being” is seen in the life of Kay Toombs’ friend who was a marathon runner. She defined her very being by her ability to run in marathons. Multiple Sclerosis prevented her from being able to run in these marathons and simultaneously stripped her of her sense of worth.

In my own father’s life, he underwent the same struggle with feeling as though he wasn’t able to be himself; because he could no longer do the things he was accustomed to doing. One example of this was my father’s love to dance and goof around with his friends. Upon my father’s death, almost all of my father’s friends told me that I should always remember that he was “the life of the party.” He loved to have fun and make others laugh. When MS began to visibly debilitate my father and forced him to walk with a cane, walker and eventually sentenced him to a wheelchair, my father felt as though he could no longer be himself. He feared that he couldn’t be the life of the party or the friend that made everyone smile because he couldn’t get up and dance or throw the football with his friends. It was a hard time for my father, as well as the rest of my family. However, with the help of family and friends, my father was quickly reminded that he wasn’t loved for his goofy dance moves or his

ability to play sports, he was loved for his fun loving spirit, contagious joy and strong faith in the Lord. Those personality traits and morals weren't things that could be taken by multiple sclerosis. When my father realized that MS may lessen his ability to "do" certain things, but it couldn't take away his personality or soul, he began again to live fully and "be" an active member of society.

As Kay Toombs recalls, a woman with Parkinson's once told her, "I always imagined that when I became a grandmother, I would do a lot with my grandchildren. Then I got Parkinson's. However, now I realize that I can *be* for my grandchildren" (Toombs 18). This realization was very empowering for her. As evidenced by my father and the woman living with Parkinson's, realizing the distinction between doing and being is imperative to healing.

Reducing Uncertainty

Though it seems that it would be difficult to find a healing practice conducive to eliminating the uncertainty that accompanies MS, patients find that "focusing on the present is a valuable means of learning to live with the uncertainty of incurable illness" (Toombs 25). Rather than imagining problems that might occur in the future, it is imperative that patients in pursuit of healing focus on developing concrete solutions to concrete problems. If patients can learn to deal with problems on a daily basis, they will not have to feel constantly "paralyzed with fear" (Toombs 26). In reality, no single individual knows what the future holds. Thus, uncertainty of the

future is a feeling that can be shared by the patient and peers. Though the future for a diseased individual may seem more daunting, healthy individuals must also come to live with the understanding that we cannot possibly predict exactly what the future holds.

Healing as an Ongoing Pursuit

The battle with multiple sclerosis is an ongoing experience that endures for life. Since the disease is incurable, it is vital that the goal is healing. Healing can be defined as the ability to accommodate to life in a way that enables the patient to live well. The determination, attitudes and life contexts of each patient play a large role in their healing experience. Healing is an extremely individualized experience that allows the patient to live life as fully as possible in the face of symptoms.

CHAPTER 2:

The Roles and Experiences of the Physician

Part I: The Physician's Role

Physician's Role

The physician is one of the most influential people in the healing process for multiple sclerosis patients. He or she is responsible for diagnosing the ailment and then treating its symptoms in a way that brings the most relief for the patient. We live in a society in which doctors are thought to be some of the most knowledgeable individuals. However, we also live in a society that treats medicine as a business, thus physicians are constrained by commercial enterprise to see an incredible number of patients in the day. To put it simply, physicians often do not have the time necessary to build relationships with the patients. Patients trust in their doctors to help them find relief from their symptoms, but they should also be able to confide in their physicians and feel that the physician is understanding the experience of the illness. It is important for patients to “feel comfortable with [their] doctor when [they’re] struggling with the unknown” (Williams 11). Not only should the physician address the physical manifestations of disease, but he or she should also take interest in the experience of the patient, as this is necessary to the patient’s healing process.

The Meaning of Illness to Patient vs. Physician

There is “a great gulf [that] exists between the way we think about disease as physicians and the way we experience it as people” (Baron 606). In other words, illness means something different to the physician than it does to the patient. In the context of modern scientific medicine, physicians are trained to focus almost exclusively on the disease process. In addition, due to the way clinical medicine is now practiced, it has become necessary to decrease the average time spent with each patient. It has been observed that many doctors are expected to see a new patient every fifteen minutes (Weed). This short period for patient interaction time has made it almost impossible for physicians to investigate the individual patient’s experience of illness. Consequently, because they are concerned with only the medical aspects of the disease, physicians are often unable to understand the total effects of multiple sclerosis on the patient’s everyday life. As Richard Baron notes, the patient and physician come to “inhabit different universes, and medicine, rather than being a bridge between them, has actually become one of the major forces keeping them apart” (Baron 606). For example, in the story of Montel Williams’ battle with MS, his initial interaction with a physician was the hardest part of coming to terms with his diagnosis because he and his initial physician were interested in very different aspects of the disease. When asking his physician if he could continue his exercise routines in a modified way, Montel became frustrated because, rather than

understanding his need to continue exercising as a means of maintaining a sense of purpose, his physician simply said no because it wasn't conducive to his medical regimen. Ultimately, this patient-physician interaction was harmful to Montel's healing because his doctor had no respect for the symptoms' effects not only on Montel's body but also on his sense of self-worth (Williams 8-9).

The Meaning of the Diagnosis

The diagnosis is often one of the hardest times for patients in their experience with multiple sclerosis. Thus, it provides the physician with the opportunity to promote healing from the very beginning of the disease experience. The diagnosis of MS is most often accompanied by great fear and depression. In an interview with Dr. Kay Toombs, she recalled her diagnosis of MS as an experience in which she immediately believed her life was sentenced to dependence on a wheelchair (Toombs Interview). In his book, *Climbing Higher*, Montel Williams reveals that he believed his diagnosis with multiple sclerosis to be a death sentence. The connotation of multiple sclerosis is debilitation and a loss of the ability to live fully. The meaning that the diagnosis has for the patient will affect his or her attitude towards the process and possibility of healing for the duration of multiple sclerosis.

*Part 2:
The Physician's Healing Practices*

Bridging the Gap

In an effort to bridge the gap between patient experiences and physician's understanding, it is helpful for the physicians treating multiple sclerosis to adopt the Patient-Centered Clinical Method. Using the patient-centered clinical method with MS patients is particularly helpful because, in the words of Montel Williams, "doctors who treat MS don't have MS" (Williams 25). If patient-centered communication is practiced, the doctor can have a better understanding of the disease's effects on the individual. It is understood that doctors do have to see large numbers of patients during the day. However, though they are limited in the amount of time that they can spend with each patient, it is possible for the physician to maximize the time that is spent in face-to-face interaction. The Patient-Centered Clinical Method was first introduced in the 1980s, but since then it has been revised numerous times to ensure that the patient is treated most effectively in pursuit of total healing. Patient-centered care "explores the patients' main reason for the visit, concerns, and need for information; seeks an integrated understanding of the patients' world—that is, their whole person, emotional needs, and life issues; finds common ground on what the problem is and mutually agrees on management; enhances prevention and health promotion; and

enhances the continuing relationship between the patient and the doctor” (Stewards, Brown, Weston, McWhinney, McWilliam, and Freeman 4).

Example Conversation

In an effort to convey the importance of patient-centered discussions, below is an example of a patient-centered conversation between a multiple sclerosis patient and the physician.

Doctor: Hello (Patient’s Name), How are you doing?

Patient: I’m doing pretty well, except lately I am feeling so tired that I’m finding it hard to make it through a whole day of work.

Doctor: At what point of the day do you start to feel tired? Are you finding that certain activities or dietary items are making you tired?

Patient: I start to feel tired in the mid-afternoon. It’s very hard for me to get all of my work done.

Doctor: What’s that like for you? How does it make you feel?

Patient: Well, it’s frustrating because it makes me feel like MS is taking over my life. I feel like my sense of purpose and ability to do those things that are important is diminishing.

Doctor: What do you think would help maintain your sense of purpose?

Patient: Well, I’m the type of person who likes to “do”. I like to accomplish all that’s

on my to do list for the day. If we could find a way to get my energy level back up so that I could accomplish my daily tasks I think that would help a lot!

Doctor: I can only imagine how frustrating that is for you. Let's try a new approach because the stressful schedule that you are following now is only adding to the fatigue you are experiencing. Why don't you try breaking tasks down into shorter increments of time. For example, if you are sitting at your computer typing a lengthy document, why don't you try taking breaks every 45 minutes or so. Leave your desk, go get a drink of water and put your feet up for 10 minutes. Give your mind and body a rest from that monotonous task.

Patient: O.K. I'll give it a try!

Doctor: I really do think you should see an improvement in your energy levels. I had a patient who tried this before and found that it really helped a great deal. Please keep me updated and let me know if you find that this routine is helping. We will make sure to get you back to the place where you can accomplish those tasks you want to accomplish!

In my own father's battle with MS, his physician, Dr. Victor Rivera, implemented the patient-centered clinical method into his treatment of patients. Not only did Dr. Rivera provide the primary health care to my father, but he also became a friend and confidant to my father and our family. He truly did seek to understand my father's experience of illness in an effort to understand the total effects of the disease.

Active Listening

When the physician accepts the responsibility of actively listening to the patient, he or she can learn a great deal. As noted by Richard Baron, the speech of a patient can be used for more than just contextual analysis; it can give great insight into the experience of the patient. As evidenced by the story of Montel Williams' diagnosis, which will be discussed further in the next paragraphs, an experience with a physician who is listening intently has a significant impact to the healing of the patient.

The Impact of the Diagnosis

An understanding of the meaning that the diagnosis has for the patient is pivotal to the physician's role in the healing process. In the story of Montel Williams' diagnosis, his first doctor was very matter of fact and unconcerned with Montel's emotional battle upon hearing his diagnosis. When diagnosing Montel he said, "Go ahead and see your Harvard doctor, and he will confirm what I've just told you. You have MS. You will have to learn to live with it" (Williams 8). There was no sense of consolation or hope that would be encouraging to Montel's journey to healing. Montel felt great despair and defeat, as if there was no hope for his future. In contrast, when Montel went to see a different doctor at Harvard, who approached the diagnosis

in a patient-centered manner, he felt dramatically more at ease. This doctor said, “Unfortunately, I have confirmed your diagnosis, so let’s talk about this.” He then went on to show Montel the scans of his brain and explain the symptoms that he should prepare to encounter. The doctor made the diagnosis a very individualized experience and said, “you’re doing things that other people with the same level of disease might not be doing. Therefore, it is not affecting you the same way-sometimes different areas of the brain compensate for other areas that are damaged, as if your brain rewired around it” (Williams 10). After meeting with this doctor, Montel was given a new sense of hope. Similarly, Dr. Arthur Frank, a sociologist who studies the relationship between patient and physician, found that in his own diagnosis of cancer the experience of his diagnosis was significantly affected by the attitude of his physicians. One physician “involved himself in what he was telling [him], while the other physician pronounced his diagnosis like a verdict” (Frank 45). The same diagnosis will have different meanings to different individuals because it depends on the values and life context of the particular person. Further, the same content of a diagnosis can have different meanings, depending on the delivery with which it is given.

The Healing Physician

It has been observed that the physician is a key player in the promotion of healing because he or she has a significant impact on the hopes and expectations of

the patient. Physicians are the people who the patient feels are the primary individuals for assistance. Thus the responsibility placed on them in the healing process is extensive. If the physician uses a patient-centered approach to interactions with the patient, the result will be a better understanding of the difficulties associated with MS and in turn will be more likely to help the patient discover healing practices.

CHAPTER 3:

The Roles and Experiences of Family and Friends

Part 1:

The Experience of Family Members and Friends

One of the first questions that a patient facing the challenges of incurable disease asks is, “What does this mean for me in my relationship with others?” (Toombs 5). The relationships between patient and family or peers have a significant impact on the patient’s healing from disease. As noted from the very beginning of this thesis, “healing is not a solitary endeavor” (Toombs 15). It has been said by many patients battling MS, that the ability to retain meaningful relationships with their family and friends has been pivotal in their experience of healing from the disease. In reflecting on the life of her husband, Dee Toombs, who suffered from incurable cancer, Kay Toombs recalled that Dee was able to be fully himself in the face of cancer “in large part due to the fact that he was surrounded by people who cared for him in a loving and respectful way” (*Living and Dying* 22). The maintenance of meaningful relationships is vital to the healing process. Though any friend or family member can attest to the fact that “bearing witness to another’s pain is not an easy task,” as Toombs notes, “it is at the heart of the healing endeavor,” and

often what the patient needs most is “someone to accompany them on their illness” (*Living and Dying* 29).

As I will show, this idea is reflected in the experiences of Kay Toombs, Montel Williams and my father.

Negative Responses to Disability

In today’s society, disability often subjects MS patients to “cultural attitudes that make it extraordinarily difficult for people with disabilities to maintain a sense of self-worth” (*Living and Dying* 11). In modern times “we place inordinate value on appearance, promoting unrealistic ideals of beauty and physical fitness that inevitably devalue those who do not meet those ideals” (*Living and Dying* 11). With regard to MS, these negative thoughts and ideas associated with disease and disability may also be deepened through documentaries or advertisements that exaggerate symptoms or show patients with the most severe form of a particular disease. Patients, being aware of these negative connotations associated with disease and disability, fear that they will become a burden to those around them. They fear that the disease will cause them to be alone.

Montel Williams was aware of these negative societal connotations associated with disease and upon his diagnosis he found himself thinking, “I’m going to be left alone; my kids are no longer going to want to see me; they’ll have to push me around in a wheelchair” (Williams 13). The immediacy of his thoughts being directed to the

thoughts of his family and friends is very indicative of the impact that these individuals can have on the patient's process of healing.

In the story of Kay Toombs' experience with MS she notes that when one is in a wheelchair, people assume one is totally dependent. As other wheelchair users have testified, she noticed, "strangers tend[ed] to address themselves to [her] husband and refer to [her] in the third person" (Case Study 12). These people surrounding her in everyday life would say things like, "Where would SHE like to go?" "What would SHE like to drink?" "Can SHE walk at all?" (Case Study 12). All of these references to her as if she wasn't able to speak for herself were degrading to her self-esteem.

In my own father's life, he was always known for his people person personality. Thus, as would be expected, he was very concerned with the effect that his diagnosis of multiple sclerosis would have on his relationships with others. It is my belief that for him, the most meaningful part of his healing experience was the preservation of his relationships with others.

As a family member or friend to a patient with MS, it is easy to feel like an outsider who is simply watching the effects of the disease on a loved one. Rather than making an effort to understand the disease and its implications on the life of the patient, it is easy for family and peers to distance themselves emotionally from their friend or family member. Though it is an easy way out for the family members or friends, this distancing in relationships is very destructive to the patient in pursuit of healing.

Generalizations vs. Particularities

Our modern society is guilty of making generalizations about disease and disability. In a world that seems to be so scientifically advanced, we often lose hope when a patient is diagnosed with a disease that is considered incurable. We group individuals who experience disability into categories based on their disease. It is often the case that family members and friends fail to realize that “every MS patient has a different story to tell” (Case Study 4). “Most people who deal with ill persons do not want to recognize differences and particularities because sorting them out requires time” and causes a forced attention to the disability of the person for whom they care greatly about. (Frank 45). It is understandably a difficult task for the peers and family of a person diagnosed with MS to accept the illness and embrace its toll on their loved one. However, it is hurtful to patients who experience MS differently when others make incorrect assumptions about the disease and the person’s prognosis. Dr. Arthur Frank has said, “What makes an experience real is its particulars. One person’s anger or grief may differ so much from another’s that calling them by a common name only obscures what is actually going on for each.” Though it may be difficult for family members and friends of loved ones to accept, and pay attention to, the particularities of a patient’s disease because it means they too will have to acknowledge the person’s disability, doing so promotes meaningful and

individualized relationships. Ultimately we must realize that though “bearing witness to another’s pain is not an easy task, it is at the heart of the healing endeavor” (Toombs 29).

*Part 2:
Healing Practices Used by Family Members and Friends*

Meaningful Relationships

For the patient to feel whole it is necessary that he or she maintain the relationships that were in place before the diagnosis of MS. It has been observed many times that, “a sense of connectedness and relationship are more likely to retain a sense of personal integrity and wholeness” (Toombs 15). Pivotal to the meaningful relationship is the idea that the family member or friend affirms to the patient that his or her illness does not denigrate him or her as a person (Toombs 22).

A meaningful relationship between the patient and a family member or peer is one that strives to share in the experience of the multiple sclerosis. It is a relationship that takes the individual nature of the disease into consideration, but doesn’t change in dynamic solely because one member of the relationship has been diagnosed with multiple sclerosis. Kay Toombs describes a meaningful relationship as one that demonstrates to her that her illness does not degrade her worth as a person because this type of relationship affirms her in a powerful manner (Toombs 28).

The Reciprocal Relationship

In promoting healing it is important to recognize that the relationship between caregiver and receiver is one that is reciprocal. In other words, both the caregiver and patient have something meaningful to bring to the relationship. If not recognized, patients will assume they are a burden and have nothing to offer, as evidenced by Montel Williams who “didn’t want to be a burden on anybody,” thus he considered ending his own life.

In reflecting on the reciprocal nature of the caregiver/care receiver relationship, Kay Toombs discusses the relationship between herself and her husband, Dee, who suffered from terminal cancer. In this relationship, Dr. Toombs was able to provide her husband with the help he needed to perform certain tasks, for example the task of taking a shower (Toombs 24). In reciprocation, Dee taught his wife the importance of maintaining a courageous and persevering attitude in the face of incurable illness. In observing and caring for her husband near the end of his life, Dr. Toombs noticed that their relationship was strengthened by this shared experience. Each had something to offer the other.

I can attest to the reciprocal nature of the relationship between caregiver and receiver. In my relationship with my father, I provided him with the care and assistance that he often needed and he provided me with lessons of wisdom and bravery that could have not been taught better than by his example. In looking back

on the years I spent learning from the life of my father, I can remember countless times in which I helped him with simple tasks throughout the day. For example, I was able to help him write letters or emails to his friends because his hands were very shaky and he was unable to write. I also provided my father with love and a desire to understand his experiences with multiple sclerosis. Though my father was unable to teach me how to do things, such as ride a bicycle, he was able to show me the importance of living a life filled with joy and love for others. One of the greatest gifts that my father gave me through our relationship was a constant source of encouragement and light-heartedness. I remember one saying in particular that my father constantly used to make me smile; he would say, “Kyrie, you don’t need to worry so much. You are young. Right now the only thing you need to be worried about is what kind of cookie you want for dessert.” Upon utterance of those words, I was immediately reminded that life is too short to be constantly overwhelmed with worry, which was exactly what I needed to remember.

Family members and friends can also learn from the patients in other ways. In accompanying the patient on their journey of illness, they can become more sensitive to the needs imposed by the illness. As a family member or friend who strives to play a role in the healing process, individuals also become caregivers to their friend or loved one. For example, Kay Toombs notices “friends and colleagues who regularly accompany [her] likewise come to view the world through the lens of [her] body” (Case Study 9). Her friends paid attention to wheelchair ramps at the establishments

they were visiting or planning to visit. In my role as caregiver to my father I found that I became much more alert to obstacles along our paths and plans. For example, often I would walk a little bit ahead of my father and check establishments for curb cuts or handicap entrances. Also, when planning for family vacations we were thoughtful of my father's disabilities. If we wanted to go to the beach, we would wake up early and get our beach time in before it got too hot during the middle of the afternoon. After a while, it became second nature for me to notice obstacles and remedies conducive to my father's illness.

Meaningful relationships between the patient and family member or friend are not only pivotal to the healing process in the life of the patient, but they are also beneficial to the family member or friend because they can experience a deeper and more meaningful relationship with their loved one who is battling multiple sclerosis. It has often been noted that meaningful relationships inspire the patient and provide him or her with great hope and assurance for the future, regardless of the future course of disease.

CONCLUDING REMARKS

The Meaning of Being Healed from multiple sclerosis

As evidenced by the lives and works of Dr. Kay Toombs, Montel Williams, and my father, Kenny Cameron, there is great power in the experience of healing from multiple sclerosis. Though it is common knowledge that there is no cure for MS, healing can provide patients with a sense of restoration.

We live in a society in which there is an emphasis placed on “physical wholeness.” This ideal is shallow and only furthers the negative connotations associated with disability. In these modern times it is imperative that we respond to these attitudes and promote healing for patients suffering from incurable diseases, such as MS. The patient feels the firsthand experience of healing, but those surrounding the patient, the physician, family members and peers promote it. When all of these individuals partake in the pursuit of healing, the patient can regain a sense of wholeness and meaning.

The ability of patients to be healed from the many incurable illnesses experienced in our world brings me great hope. Though modern medicine is not yet able to cure all diseases, all patients have the opportunity to experience healing. It is my wish that anyone who is diagnosed with one of these incurable illnesses might read this thesis, or a similar work and be invigorated by the potential for healing in their life.

In the future, I would like to continue my study and reflection on the process of healing in multiple sclerosis. These further studies will most likely include research into the role of Christianity in the process, as I believe religion strongly promotes the experience of healing. I would also like to delve further into the study of the role of children in the healing process, as I was a child of a patient with multiple sclerosis. I truly believe that children have a unique perception of the meaning of being healed and thus serve a unique role in the course of healing.

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