4-2024

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James Petropulos

Recommended Citation

Petropulos, James, "WARRIOR VOICES: A NARRATIVE INQUIRY INTO THE EXPERIENCES OF MEN LIVING WITH MULTIPLE SCLEROSIS" (2024). *Dissertations*. 819.
https://digitalcommons.nl.edu/diss/819

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James M. Petropulos

EDD in Teaching and Learning:
Curriculum, Advocacy, and Policy

Submitted in partial fulfillment
of the requirements of
Doctor of Education

National College of Education
National Louis University
April 04, 2024

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James M. Petropulos
EDD in Teaching and Learning:
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Approved:

Chair / Co-Chair, Dissertation Committee

Director of Doctoral Programs

Vito M Dipinto

Co-Chair / Member, Dissertation Committee

Carolyn Theard-Griggs

Dean, National College of Education

Shaunti Knauth

Dean's Representative

April 4th, 2024

Date Approved

Abstract

This narrative inquiry delves into the lives of six men, including the researcher, who have multiple sclerosis (MS). Through in-depth interviews, the researcher asks participants to describe their life before diagnosis, the diagnosis process, and the construction of a “new normal” after diagnosis. This research provides insights into how participants make sense of the disease, how they cope with the ongoing changes to their bodies, their relationships, their careers, and their perceptions of their masculinity. Analyzing the narratives provides insight into the variability of MS types and symptoms, and various coping mechanisms. It supports the idea that each participant should adjust to the ever-changing nature of their disability. Drawing on the “warrior” metaphor, the researcher conceptualizes life with MS as a battle and expands the metaphor from a physical struggle to a spiritual battle to accommodate the changes the disease wrought.

Acknowledgments

I remember my first course, Cultures of Schools & Communities. It was so overwhelming to me. I was surrounded by students beyond my capabilities, speaking with a foreign academic vocabulary, confirming that I did not belong there. I walked out of the Wheeling classroom in a state of confusion.

At that moment, a student must have recognized the overwhelmed look on my face. I do not remember her name, but she was able to ease my anxiety by simply saying to a stranger, "You will be fine; it will be okay." Her kindness brought me back to the next class, the next, and so on. This story exemplifies the wonderful classmates I have been fortunate to know during my doctoral journey. I am incredibly thankful to my colleagues for their guidance.

Thank you to all my excellent professors who shared their knowledge, wisdom, and patience. Dr. Efron pointed me in the right direction in telling me to follow my passion. Dr. Vito Dipinto agreed to accept me as a single student in the Core II and to be part of my dissertation committee. Dr. Terry Smith for her inspirational instruction during the latter part of my coursework for providing guidance, instruction, and infinite patience during the dissertation process, and for agreeing to become the chair of my dissertation committee. Dr. Shaunti Knauth offered her time and guidance within my dissertation committee. A special thank you to the participants who were willing to share their stories. Without them, this dissertation could not have happened. My family and friends provided support throughout the dissertation process.

My wife Denise provided love and support, and my daughter Rachel started my dissertation journey with her class project.

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Chapter One

"Even in times of trauma, we try to maintain a sense of normality until we no longer can. That, my friends, is called surviving. Not healing. We never become whole again, we are survivors. If you are here today, then you are a survivor. But those of us who have made it through hell and are still standing? We bear a different name: warriors." (L. Goodwin, https://www.goodreads.com/quotes/797581-even-in-times-of-trauma-we-try-to-maintain-a)

Introduction

The purpose of this study is to examine the unique experiences of the male participants who have acquired multiple sclerosis (MS) and how they have been able to manage the psychological trauma that accompanies living with this disease. Narrative inquiry offers a glimpse into the human intellect of men with MS. And how they have designed the means to construct a new meaning for their lives.

The initial neurological diagnosis confirms and supports that the patient has multiple sclerosis and discusses an outline of how to combat the disease, but often fails to accommodate the patient's accompanying emotional trauma.

This research fosters the ability to take back the life stolen from those who are living with MS. It will examine if the participants can make sense of their new life with multiple sclerosis. Understanding the changes in the participants' lives is paramount to the overall study.

The dissertation title, Warrior Voices, was chosen for two reasons. First, all participants in this research design are engaged in their battle; they decide to fight to maintain a new way of life and construct new normalcy. Furthermore, collecting the participants' stories or voices can enable a sense of solidarity among other participants who share a common thread of living with multiple sclerosis.

Life with multiple sclerosis has infused the disposition of the warrior. Fighting daily battles with a disease that has taken residence within the body, the fight is with an unseen adversary from within.

Without warning, multiple sclerosis, like a thief in the night, stole my life as I knew it. Life as I knew it crashed, leaving behind shattered remnants. This adversarial relationship with this disease has created a personal struggle with the uncertainty and the anxiety of the continuous battle to overcome the obstacles in life with this disease.

A new life is causative of episodes of deep personal reflection. The principal question of who I am within this new construct of living requires acknowledgment of who I was before life with multiple sclerosis and the reevaluation of the new self.

I have lived with multiple sclerosis since my diagnosis in 2005. As evidenced within my narrative, I did not understand what multiple sclerosis was and the magnitude this disease would have upon changing my life. The eighteen years of experience with living with this disease has left profound physical and emotional difficulties.

The initial attempts to deny the diagnosis were living a lie, blaming past injuries from football, blaming the falls on plausible failures of uneven footing, and eventually realizing that acceptance of fate was inevitable. Rather than accepting self-loathing and self-pity, I opened up to the world and began talking and fighting MS. This study is my agreement in trying to become a positive force for others who need support with their struggle with living with MS. The personal narratives share how they adapted and reconstructed a new meaning to their lives.

The Beginning

My story of living with multiple sclerosis began in the fall of 1995. What was unbeknownst to me then was that events were about to begin. A fall was just the beginning of the experience with MS. On that auspicious day, returning home from work, I found the cars of both my mother and father in the driveway.

Having my parents at the apartment simultaneously was odd and uncommon. They had divorced for several years. Several scenarios were present before stepping out of the car: either someone had passed away or they had won the lottery. Upon entering the apartment, my mother had been crying, and a solemn expression upon my father's face.

My wife at that time paralleled the somber expression of both parents, and I immediately asked, who had passed away? My mother said that no one had passed and further explained that the MRI exam taken weeks earlier for chronic headaches showed evidence of scar tissue within my brain. The interpretation from the radiologist stated that this was consistent with that of multiple sclerosis.

After the explanation, the sadness was understood. Is multiple sclerosis a form of cancer? Am I dying? My mother then tried to clarify what the radiologist had told her about multiple sclerosis. It was a disease that could result in a crippling effect on my body. The tears and somber expressions began to make sense.

I struggled to understand the severity of the situation and what they were saying. Within the past thirty years, I have been an athlete, playing baseball and football, and I have been very active. I was a high school teacher, coaching football and baseball for many years, spending countless hours on the play fields. How could this be true? I did not feel any different. I was a young man, a football, baseball, and wrestling coach, so how could I have this disease.

The radiologist had to be wrong. After all, he is just a radiologist, not a doctor. I appeased my wife and parents by agreeing to see a neurologist. The neurologist examined the M.R.I. film and concluded that he could not offer a conclusive diagnosis without further evidence. He wanted to prescribe a spinal fluid test to gain conclusive medical data.

I was hearing nothing but horrible stories about a spinal tap exam that, at times, patients could develop a disability. I genuinely feared the exam and would not have that test done. The neurologist explained that although there were no immediate symptoms of MS, the evidence established from the M.R.I. remained, and there was the potential of acquiring the disease later in life.

Later in life, it happened. It was ten years later that the very first symptoms arrived. The first symptom was the loss of balance. I fell several times without any justifiable cause. I was falling over backward. The falls occurred while coaching football.

The second and most convincing symptom was the development of optic neuritis affecting the vision in the left eye. The vision in the eye was comparable to seeing through a smeared lens: blurry glow without contrast and clarity. The optometrist explained that she believed the blurred vision could result from optic neuritis. She further explained that optic neuritis is one of the symptoms of multiple sclerosis.

The combination of falling and the optic neuritis prompted a visit to another neurologist. He urged the conclusive spinal test. I succumbed and had the test done. The spinal examination concluded that it was MS.

I have always addressed previous challenges in life. I was able to understand and formulate a plan to overcome any adversity. MS presented a challenge that was beyond understanding, and therefore, there was no real plan of attack. All I can do is live with this. Like a warrior or a prizefighter, pick yourself up when you fall and get back on your feet.

Living within the premise that this disease will miraculously disappear or wake up, believing it was a bad dream was not an option. My family, especially my sisters, believe that a cure for this disease is close. There is always hope that a cure for this disease will be found. However, I must live in the present, not someday.

Reflecting on my life with MS, I see that two years have been fundamental to change. 1995 was the beginning, and 2005 was when life suddenly changed. 2005, my marriage ended, and my teaching career was in jeopardy.

Life with multiple sclerosis and its accompanying physical and emotional difficulties began slowly. Its evolution was a steady progression of increased hardship. In 2005, life began to change. I cannot blame MS as the sole cause of the failing marriage; however, there is no denying that it played its part.

I recognized that my ability to teach had begun to be a struggle. I started to become easily fatigued. I could have done better for the students. In coaching, physical fatigue became overbearing. I could no longer perform the coaching responsibilities as before. I began to lose my balance and experienced what doctors referred to as exacerbations or flare-ups. The flare-ups increased in occurrence. Within the same year, I sought medical assistance from Rush Presbyterian Hospital in Chicago.

A new neurologist discussed new treatment options. I wanted to be as proactive with the treatment as possible. I was participating in a medical study examining the effect of the medicine used to combat diabetes on those who have multiple sclerosis. The two-month research consisted of numerous MRIs and cognitive motor skills tests weekly. The study's conclusion was shared years later without conclusive evidence of any benefit to combat multiple sclerosis.

New Self

My stepdaughter asked me a complicated question: Who are you? At that moment, I was unable to answer. It was not a deep inquiry into the meaning of life; however, the question caused a personal reflection of who I was before living with MS and the man who existed amid the disease.

What defines the man I have become? Multiple sclerosis? Or is there more? She conceded and acknowledged that the experience of living with this disease was beyond her understanding and that her inquiry may have been inappropriate. I am no longer hiding that m.s. has substantially impacted my life. It has been stated, within circles of people who are living with multiple sclerosis, that unless you are living with this disease, you will never truly understand. To some extent, the statement is true.

Early after the initial diagnosis, trying to hide this disease and making every effort to conceal what was happening from friends and family was the intent. When falling in front of my daughter, I blamed the sidewalk or my shoes. Our visits to the health club pool caused difficulty in disguise. It was only a matter of time until I would have to tell the truth. I was living with m.s. caused the acceptance of a new usual way of life.

Some activities are no longer accessible, which is becoming a stigma to me. I have created a sense of inferiority within my perception of myself. I tended to shy away from social interactions, believing they may cause potential physical difficulties.

A new home in Florida allows escape from weather not conducive to a new normal. Life with the snow and ice of Chicago land would cause difficulty I can no longer maintain. There are beautiful beaches that I would love to visit, but the difficulty of walking on the beach causes anxiety. It is a continual battle to accommodate life activities with multiple sclerosis.

I am fifty-eight years old and should have a pretty good idea of who I am in midlife. Life with m.s. has changed that assumption. Life is a continual journey, never stagnant, and we all live within the middle of our narrative. After more than a half-century of life, I have a conclusion: We, as human beings, are perfectly imperfect. We are the creation of perfectly imperfect parents.

My mother and father gave me strength of character, compassion, empathy, and the desire to seek the morally right way to conduct ourselves. A paradigm of respect and Christian morality was instilled within me as a young boy and continues to guide me throughout my life. As a man, I possess their strength of character.

The confronting problem for me and others who have unwillingly embarked on the journey of living with this debilitating disease is struggling with the question of who they are at this moment of our life’s narrative. It is a perplexing problem. With certainty, the answer to the question of who I am has changed with age. Life with MS has complicated the personal discovery of the self. Multiple sclerosis has its agenda; it has an underlying life, affecting self-identity.

I must recognize that I can no longer be the athlete, the coach, or the active participant in strenuous physical activities, which is a vital component of self-identity. I no longer have the level of energy that was essential to my teaching career and coaching. Mobility, such as going to places like ball games, has become increasingly difficult. Fatigue has now become part of the daily struggle of life.

Laughing whenever I see commercials from pharmaceutical companies stating, "Don't let MS dictate your life." Here is some bad news: MS does and will dictate life. I accept the premise of being a warrior. Rather than deny the significance of MS in my life, I fight back.

I take a proactive stance, going to physical therapy to support the goal of walking better and speech therapy to support better communication. Both walking and speech are principal to my career and a more fulfilling life.

Multiple sclerosis has become part of who I am. It triggered a quest to establish a new self-identity and the establishment of the new normal. I must accept the daily obstacles that present as uninvited, inexpiable nuances as part of life’s additional challenges.

The mundane, routine activities that at one time were accomplished without thought and minimal effort are now challenging. Walking, for example, requires a cognitive plan of surveying the surroundings for the most straightforward path without potential falling or injury.

A cane accommodates and assists with walking at work or other longer distances. This disease has affected my ability to walk freely and comfortably. Walking around the shopping malls is no longer an option.

I began this study to share my story with others fighting the same battle with m.s. and creating a common pathway in making sense of our lives. Together, we wear the warrior tag. Every day since the diagnosis, I am waking with the same adversities: the same walking difficulty as the day before, the same fatigue, the same anxiousness, the same helpless feeling, and the same anger about the loss of the life I had before multiple sclerosis. The anger leads to finding the strength to persevere and to overcome any adversities presented by the diseases.

This narrative is my story; this is how I deal with life with multiple sclerosis. Adapting to a new life approach has been a continuous emotional struggle. I wondered how other men who are living with multiple sclerosis have constructed a new life. How did they emotionally adapt to a new approach to life? What hardships did they encounter in their journey with this life?

Study Rationale

I was diagnosed with this life-changing disease in 2005, and since that time, I have been struggling with restructuring a new life with MS; I often wondered how other men who have acquired multiple sclerosis managed the sudden change in their lives. Although each has a unique journey, the struggle has many similarities. Shared lived experiences can help others learn how they might overcome some of the hardships accompanying the disease.

When diagnosed, doctors will give an in-depth rationale of the medical ramifications of the disease and the different types of medications available to keep the disease from further progression, and they may discuss potential complications. However, they cannot tell how to recover from the emotional trauma. Ultimately, this is a journey that is yours alone.

This inquiry will initiate a personal journey of advocacy for those who suffer from both the physical hardships and the emotional stress of life with multiple sclerosis. When diagnosed, life as you knew it will change, and you must renegotiate, reconstruct, and reinvent a new sense of personal normalcy.

Conceptual Framework

My experiences of life with multiple sclerosis have instilled a curiosity about other journeys along the same pathway. Therefore, this research will focus on understanding those journeys through in-depth interviewers. The overarching research questions are:

- How did the participants, after the diagnosis of multiple sclerosis, manage their lives with new normality?
- How do the participants reevaluate and reconstruct a new meaning within their lives?
- How do men living with multiple sclerosis adapt to the physical and psychological stress?
- How do they cope with the challenges related to their physical stamina and masculinity?

Methodology

This narrative study will examine the lived experiences of men who have acquired the life-altering disease of multiple sclerosis. The narrative approach used within this inquiry will enable an authentic approach to gain insight into the human struggle of the participants. By implementing a conversational approach to interviewing, the participants can share their experiences.

Because I share experiences with the participants, this can lead to a deeper dialogue about how we have been able to make some sense of what happened to our lives after the diagnosis. Through mutual conversation, we can share how we can reconstruct a new purpose and construct a new self-identity or a new nature of being.

Narrative stories of personal experiences shared with others through the eyes of the storyteller become powerful windows into people's lives. Shared experiences can facilitate a deeper understanding of how they have shaped a new sense of who they are.

Goals of the Study

This study will facilitate a deep inquiry into the unique experiences of the male participants who are living with multiple sclerosis and the methods constructed to manage the psychological trauma that accompanies living m.s. You begin with their lives before the diagnosis and the participant's initial medical diagnosis through how they accommodate for the emotional trauma.

According to the National Multiple Sclerosis Society (2017), each diagnosis is unique to each person. Multiple sclerosis initiates symptomatic hardships that include fatigue, decreased visual perception, bladder and bowel dysfunction, sexual dysfunction, Paresthesia, tingling, numbness, burning, and emotional disturbances. (MS, Symptoms & Signs of MS)

The struggle of life with multiple sclerosis and adapting to the psychological stress imposed is often lacking. The medical experts cannot explain how to approach a new life. The National Multiple Sclerosis Society offers valued support, but it is a path that each person must follow alone.

Contextualization

I have been living with MS for eighteen years since the initial diagnosis, and for much of the years, I was in denial. Family and friends were aware that I had MS; however, I tried to hide my disease from my daughter and others.

I attempted to portray an image in the best possible interpretation to maintain status in social interaction. Adopting a lie about our true selves by presenting ourselves intending to become accepted in the social setting

Through my experiences, I have learned that I am a terrible actor. The premise that the world is a stage and we are merely actors may be true within specific social interactions; however, it is a failed performance. I may have initial success, but over time, my true self begins to sabotage and spoil the management of the portrayal.

Within my career as a teacher, I have encountered many false identities. I am encountering people who present themselves in a false reality. They play the role that a particular social situation demands. They are happy to do so, hoping to move their status to a higher social station.

As my physical capabilities began to deteriorate with the progression of the disease, I was no longer able to keep up with the demands of my coaching career. Disguising the disability was no longer an option.

I began to realize that I was not alone. Others around the social environment were struggling with living with this disease. I started to seek to identify with others who had this disease. I conducted a qualitative inquiry pilot with an acquaintance living with multiple sclerosis. I wanted to know more about how she lived with this disease.

I wanted to learn and understand how she could allocate her hardships. This narrative inquiry began with the desire to know how others were able to find themselves living with multiple sclerosis.

Chapter Summary

As stated earlier within the rationale of the study, I was diagnosed with this life-changing disease in 2006. Since then, I have struggled to restructure a new life with MS. This chapter provides an overview of the proposed research. The dissertation title, "Warrior Voices," points to the significance of the voices of each participant sharing the unique story of their lives with MS.

The purpose and the primary focus of this inquiry will be the investigation of how the male participants can reconstruct a new purpose in their lives after the thief, MS, stole from their lives. Through research and reflection on my struggle with living with MS, I concluded that this disease stole my life, a happy life encompassing what I believed to be necessary to my life's social station—established within an excellent teaching and coaching career, a house, wife, and a beautiful daughter. MS crushed that normality. The victim persona has established itself.

Fact: you have MS. It is here to stay. It is going to change your life forever. New challenges will present themselves daily. The time for self-pity and loathing has played an early role. You are now in a fight for your life. Rise above the need to be the victim. Yes, this disease is of no fault of yours. You are now a warrior.

Chapter Two Literature Review

Introduction

There is nothing more powerful than a good story. Stories begin with spoken words, and oral stories start with the ancient mythologies that profoundly shaped our written history. The life stories within this narrative inquiry illuminate the shared stories of living with the life-changing disease of multiple sclerosis.

Chapter two examines books and academic literature that help provide background theory, research, and information related to this inquiry's emphasized narrative life stories.

Multiple Sclerosis Research

Understanding the nature of this debilitating disease is necessary to understand the narratives in the research. A brief informative explanation of the disease creates a foundation for this narrative inquiry. The research discussed within the literature enlightens the reader about the necessary, however short, overall process of this disease's history and scientific context.

According to Murray (2005),

> Multiple sclerosis is a common neurological disease that usually affects young adults, most often beginning with episodic attacks of neurological symptoms but entering a progressive phase years later. It usually starts between 15 and 50 (average age 30) and occurs in about 1in 500 individuals of European ancestry living in temperate climates. There appears to be a complex interaction between a genetic predisposition and an environmental "trigger" that initiates the disease. (p.9)

Multiple sclerosis is the scarring caused by inflammatory attacks at various sites in the central nervous system. Multiple sclerosis lives and thrives within my body. Like the monster under the bed or in the closet, awakened a childhood nightmare and given the free rein of the body.

According to Compston (2005), the neurological disease known as multiple sclerosis was first portrayed one hundred and sixty years ago with the study of an unnamed French patient. Within sixty years after the initial study, French and German physicians gave a logical, clinical, pathological account of the disease.

In the early 20th century, theoretical validation began to isolate the causes of the disease. Continued research conducted within the mid-twentieth century began to clarify the means of tissue injury and gave the first accurate descriptive depiction of the human brain.

Multiple sclerosis is one of the most common diseases affecting the human nervous system. The disease affects people of all ages. Neuroscience research concludes that m.s. has a genetic predisposition but is not directly inherited. It causes neurologic symptoms, including vision loss, paralysis, numbness, and walking difficulties. These symptoms can be sporadic and confusing, often coming and going without any noticeable pattern.

Rolak (2016) stated that these symptoms occur when the nerves in the brain and spinal cord lose their ability to transmit signals. Myelin, a complex substance that surrounds and insulates nerve fibers, is essential for nerves to conduct electricity and function. The myelin is damaged.

> The disease attacks when the natural process of the cells and proteins of the body’s immune system, which normally defend the body against infections, leave the blood vessels serving the central nervous system, decant into the brain and spinal cord, and destroy myelin. However, the specific activating instrument that

> releases the immune system to attack its healthy tissue remains unknown, and the cause of MS is still its biggest mystery. (pp.1-2

Before the 19th century, doctors relied on hearsay and delusion to care for the sick. Scientifically tested data did not support the medical ideas. Despite the lack of medical knowledge, doctors were often good observers, and we can look back today and identify the patients who undeniably had this disease from the descriptions written as long ago. Once physicians began to analyze illnesses scientifically, multiple sclerosis was among the first diseases described. Drawings from autopsies done as early as 1838 clearly show what we now recognize as m.s. Rolak (2016)

Rolak (2016) states that within the last decades of the 19th century, the leading physicians understood that multiple sclerosis was a specific disease. “The disease gained recognition in England by Dr. Walter Moxon in 1873, and the United States by Dr. Edward Seguin in 1878.” Rolak, (2016, p.2)

According to Brochet (2015), Neuropsychiatric Symptoms of Inflammatory Demyelinating Diseases provide a more clinical approach to understanding the disease. "Multiple sclerosis is, by far, the most common inflammatory demyelinating disease of the central nervous system.” Brochet, (2015, p.2)

Brochet (2015) states that multiple sclerosis is a disease in which myelin (protecting casings encompassing the nerve cells of the brain and spinal cord) is attacked and destroyed. The affected nerve cells can no longer transfer signals from one brain area to another. The nerve damage and demyelination caused by MS may lead to many problems, which include muscle weakness, blurred or double vision, difficulty with balance, uncontrolled movements, and depression.

Preissner and Baumgartner (2015) stated within the abstract of their exploratory study of self-identity and self-reevaluation that people living with multiple sclerosis continued to struggle to overcome the common disabling symptoms of the disease. Fatigue and physical disabilities are prominent issues that people with the disease struggle to overcome.

People with MS have looked to alternative methods to battle fatigue. Adding and using a cane to support walking, avoiding going to places that are difficult to overcome, and reinventing ourselves is an ongoing process. Each of us must find our way to move on with life.

The shared stories and voices of the participants are genuine, authentic, personal accounts of their struggles and hardships manifested from living with the disease. We witness their power as we listen to their stories, drawing us into the narrative with empathy and compassion for the human struggle. This research intends that the stories can support and guide others starting their new life journey with MS.

They highlight how they have balanced life's challenges that multiple Sclerosis provides—within the role of the researcher, wondered how others have been able to live with this disease. I looked to the published stories, or the narrative research, of those living this challenge.

Ken Jones, Life Sentence

The title, Life Sentence, immediately drew my interest in his story. At first, Living with m.s. is exactly a life sentence. Those who have multiple Sclerosis have the disease for the rest of their lives. We must find a new way of living life, a new life with impediments. They are creating a new normal. Ultimately, there is no choice. With multiple Sclerosis, we must find a new meaning to life. We must replace those parts with new ones, and we must accept the new parts to move forward.

Ken Jones begins his story with the quote, "This book is a book about me…just a regular guy next door that unfortunately was diagnosed with a course of relapsing multiple Sclerosis (RRMS). It is about how it affected my life, family, and friends." (Jones 2015, p.15)

He provides a timeline within his narrative of his life experiences before his diagnosis to the beginning of what would later be his diagnosis of multiple sclerosis in 1998. His experiences and struggle of living with this disease with commonplace activities now became difficult and tiresome. Descriptive accounts of weakness and fatigue accompanied by occasional falls and brief periods of normality occurred.

His first experience of physical weakness took place as a volunteer at a fundraiser for his son's school. He oversaw the food as a school board member and the chairman of the fundraising event. He spent the early moments of the event setting up the folding tables and chairs without incident. It was a full day of preparing, and he began to experience a sense of "tiredness."

His legs felt extremely weak and heavy. Standing and walking became difficult. Dismissing the event is a symptom of old age. Within the following weeks, he played golf with his wife; as often, the weakness returned. The round of golf increasingly became difficult. His legs became heavy and weak as they had done at the fundraiser.

His first fall took place at the next round of golf. In search of his golf ball, he fell. Without any warning, he just collapsed. His experience was eerily familiar. The first falling episode was the same falling for no responsible reason. The falling events led to further experiences that became symptoms of multiple sclerosis.

He then describes an active life before his diagnosis, involving active participation around his kids and family. A life of happiness engaged around family and community. He states how he grew up in Waterford, Connecticut, building a successful life insurance brokerage business working for twenty-five years. He enjoyed his family life, participating in all the activities fatherhood bestowed upon him.

The explanation of the worsening of blurred vision, accompanied by visual examples, clarified what the author was experiencing. It was not until he visited the eye doctor that he became familiar with optic neuritis.

The experiences discussed in this narrative highlight the stress and anxiety of the tests that he had to endure to conclude his diagnosis of MS. The M.R.I. exams were uncomfortable for the author, resulting in a terrible headache. He shares the results of numerous scarring (plaques) of the brain tissues. He illuminated within the text his stress and anxiety of undergoing the test of the eventual lumbar puncture or spinal tap.

The four little words "you have multiple sclerosis" were the transformative words that would change the author's life. The book's title, "Life Sentence," summarizes the eminent reality of those four little words. It means that life is now about to change. Things we take for granted now enter a realm of uncertainty. (Jones, 2010, p.29)

The narrative of Ken Jones describes in detail how the physical difficulties brought on by the progression of the disease ended his participation in any physical activities with his children and assaulted his masculinity.

The Water Dance

This film study's relevance can mirror living life after a life-alerting event. The main character, Joel Garcia, becomes a paraplegic from an accident resulting in a broken neck, creating a struggle to adjust to all the personal, psychological, and traumatic experiences that accompany people as they begin constructing a new life.

Joel encounters others within the rehabilitation hospital who share the exact consequences of their journey. All suffer from a life-altering deniability from a violent accident or event. Raymond Hill became a paraplegic resulting from a violent confrontation with a rival gang. Raymond was married with one daughter. He struggles to maintain his family life; however, his wife divorces him, and he loses the ability to maintain a relationship with his young daughter.

The character of Bloss is also a paraplegic resulting from a drunk driving accident while driving his motorcycle. Bloss tries to be a dominant force within the hospital rehab floor. He uses racist overtones and projects disgust on many of the rehab floors to accommodate his lack of control of his new life. Both Raymond and Bloss continually argue over their masculine dominance.

If we compare living with Multiple Sclerosis to the struggles highlighted in the film, they share similarities. Both undergo the classic conceptual ideas of denial, depression, and anger. However, the result over time is that in both examples, life continues. Life-changing events, whether brought on by a horrific accident or disease, bring forth the question of how to move on. Each must undergo a soul-searching journey of how to live.

The drama film is a semi-autobiographical study of a young professional writer paralyzed in a hiking accident—this young man experiencing success professionally and personally. The accident becomes a life-changing event. He will be paralyzed for the rest of his life without any aspirations of a return to his life as he knew it. The relevance of this story to this narrative inquiry mirrors the idea of the life-changing event that alters the trajectory of life. It embodies the struggle of the construction of a new perspective of self.

The people living with m.s. are equitable to the struggle of the main character, Joel Garcia, in "The Water Dance." Within the film's opening scene, the audience witnesses Joel on the back of a gurney, with his head bolted to a neck harness, seeing only the fluorescent lights of the rehab hospital. The feeling of helplessness is stifling. We can feel and see with his eyes the surreal helplessness now confronting him. The initial m.s. diagnosis shares a sense of vulnerability.

Initially, Joel experiences a sense of denial of the seriousness of his paralysis. Denial initially is part of his defense mechanism. Within days and weeks, Joel begins to experience the difficulty of his new life of the rehabilitation of his body and mind. His love affair with a married woman, Anna, will slowly end. Joel becomes angry and anxious because of the loss of his ability to carry on any sexual recourse with Anna.

The title, The Water Dance, is derived from a patient within Joel's ward. Ray Hill, like Joel, experienced a life-altering event that paralyzed him. Ray was thrown into a dry water duct after a confrontation with a rival gang. Like Joel, Ray was experiencing a tragic conclusion with his wife losing his marriage and his daughter. From Ray, we are exposed to his dream, dancing on the lake to avoid sinking and drowning. The dream becomes the metaphor for the necessity of the continual coping needed to live within this new world.

Disability and Masculinity

Masculinity is defined as the qualities or attributes regarded as characteristic of men: handsome, muscled, and driven; he is a prime example of masculinity. New Oxford Dictionary (2010)

The vision of the ancient Greek male body is as lasting and pertinent now as it was in 500 BC. The ideal image of man, chiefly found in Homeric legend, still exists and creates the foundations of our ideas of masculinity.

According to Germaine (2016), disability and depression, particularly as they relate to masculinity, have devastating effects on the male self-identity. The social complication of disabilities has a disastrous impact on the identification of the self. Social stigmatization affects the personal emotional perception of the self.

Physical limitations, loss of power, autonomy, ability, stamina, and the shame associated with failure are all components of the construction of the self. Acceptance of a new identity is essential to the composition of the new self. It may take a great deal of time to accept and move forward to the new self, but it is essential to move forward emotionally.

The emotional appearance is the result of initial trauma from the disability. The immediate emotional shock accompanying the disability is difficult to explain and requires support from others. The physical component of the disability can and often is corrected by physical therapy or prostheses. Of course, both physical and emotional trauma are equally difficult to overcome.

As young men and in many cultures, men must be strong, compete, and rise to challenges that may befall us. In our communities and groups of friends, we have learned the social tools to survive within the social group—the more assertive, dominant, and competitive to a more prominent social status. With the occurrence of a disability, the appearance of social dominance is often absent. Emasculation and disempowerment are the results of loss of power and control. Germaine (2016)

According to Scott (2014), the analysis of personal narratives of masculinity of physically disabled men highlighted a sense of vulnerability within a social context. The absence of conventional physical norms within the experiences of the narratives emphasizes the conveying of cultural distinctions of masculinity. It examines what it means to be human.

Societal norms of masculinity and femininity accept acquired social differences between the sex classes. "Every society seems to develop its conception of what is essential to, and characteristic of, the two sex classes, this conception embracing both praised and dispraised attributes." (Goffman, 1977, p.303)

> Masculinity is not a natural character type, behavioral average, a norm but is simultaneously a place in gender relations, the practices through which men and women engage that place in gender, and the effects of these practices on bodily experience, personality, and culture. (Connellas, as cited in Scott, 2014 p.71)

“The physically disabled male body absent of the operative normality may result in emphasized differences. The noticeable differences may cause the struggle with self-perception of masculinity in daily performances of personified identity." (Thomson 1997, p.24) With disability comes the need to reevaluate personal self-identity. Challenges for men is the struggle to maintain or create a new norm without physical masculinity. Scott, (2014)

According to Butler (1990), The physically disabled body, in its abnormality from society’s norms, gendered roles that are vital to how we come to know ourselves. Disability and masculinity are how we create our identity.

Body image and social perception interpret femininity and masculinity. In the case stated within the essay, Gouverneur Morris compensated for the loss of his leg through sexual competition, trying to better the exploits of his female partners and trying to prove his masculinity.

Goffman (1977) stated that in contemporary civilization, sex is at the center of a central system that is in harmony with social interactions and structures. A code establishes the conceptions individuals have concerning their human nature. Societal norms of masculinity and femininity accept acquired social differences between the sex classes. “Every society seems to develop its conception of what is "essential" to, and characteristic of, the two sex classes, this conception embracing both praised and dispraised attributes.” (Goffman,1977, p.303)

Social stigma

Goffman (1959) states that within social situations, people seek to present themselves in the best way to create the impression to observers of the desired respect and serious consideration. "We take upon ourselves the role of the performer. The performer presents to the observers information about their socioeconomic status, conceptions about the self, competence, and attitudes toward others and themselves. Like a Shakespearean play, we become actors within the social dynamic, presenting our best self. (Goffman,1959 pp.1-)

Within social interaction with others who are unfamiliar or threatening social comfort, we present to the observers the desired compliance to the social norms—even attempting to acquire their language and dress, resulting in the spoiled identity of the true self. Looking back at that social dilemma, why would I have worn a multicolored vest?

The New Oxford Dictionary defines stigma as "a mark of disgrace associated with a particular circumstance, quality, or person: the stigma of having gone to prison will always be with me." (New Oxford American Dictionary,2015) From a historical context, according to Erving Goffman, the ancient Greeks originated the term stigma, referring to body signs designed to expose something unusual and wrong about the signifier. The signs burnt into the body advertised that the bearer was a slave, a criminal, a traitor, or a defective person.

A cane has become part of my life for the past decade. MS has gifted issues with balance. The cane has prevented falling on countless occasions. It provides a valuable purpose in life. The cane also creates social stigmatization. Within public occurrences, the cane tells the world that I am disabled, a man who is unable to negotiate himself within the everyday world. When walking with a cane, people offer their assistance with doors. Their empathy was an act of kindness, not pity.

Social stigma encompasses both the physical and social. For example, a person who committed a legal felony will no longer be accepted in society, forfeiting all political, social, and legal rights. A man or woman who breaks the religious covenant may also forfeit religious acceptance. Within modern Catholicism, divorce becomes a stigma that denies the signifier the right to the ritual of communion.

For those unfortunate people who have acquired Multiple Sclerosis, social stigmatization may become normative. Disabilities caused by the disease become a signifier of abnormalities within normal social society. According to Goffman (1977), a man/woman who uses a cane to assist in their walking becomes stigmatized and viewed as outside the norm. From the male perspective, it can be perceived as a threat to their masculinity—a lessened position in their social status within social culture.

Chapter two summary

The literature review provides a framework for the research necessary to support this study. An understanding of the fundamentals of the disease, multiple sclerosis, is required to inform those who are unaware. The information provided within this study is relevant; however, it is limited in its scope. The literature discussed within the review provides the academic background for this inquiry. It is important to provide background into what a diagnosis of multiple sclerosis means and the ramifications the disease brings.

Each participant discusses how their life was before the diagnosis of multiple sclerosis, how they handled and reacted to the diagnosis, how they managed and responded to the diagnosis, and how they can live with the disease. Each narrative is unique, as each diagnosis is unique. All five narratives share similarities in their experiences with multiple Sclerosis; however, their journey is theirs alone.

The film "Water Dance" reflects a life-changing event. The main character “Joel Garcia” suffers from a broken neck from a hiking accident and becomes paralyzed from the waist down. He will be paralyzed for the rest of his life without any aspirations of a return to his life as he knew it. The relevance of this story to this narrative inquiry is mirrored in the idea of the life-changing event that alters the trajectory of life. It embodies the struggle of the construction of a new perspective of self.

People who suddenly, unexpectedly, are forced to find a new pathway in life to circumnavigate the new obstacles that confront them. Those who have had accidents like that of Joel go through a process similar to mourning a loss, in this case, the loss of their life as they knew it. So is the case with those who have been diagnosed with multiple sclerosis.

Although the story is not from the academic sphere, it allows the viewer to empathize with the pain and suffering of the characters. We acknowledge the difficulty of returning to a familiar way of life. Joel is paralyzed, and he can no longer do things that are pretty natural and easy to achieve. Although he is paralyzed, Joel can continue his career as a writer. We, the unlucky few who live life with MS, can still live a productive life despite losing some physical activities.

Yes, there are physical challenges, but teaching is still accessible. I am finding ways to participate in life. I can attend events with the understanding of the need to use a cane to walk, a wheelchair to go long distances, or to have special seating at a baseball game.

Chapter Three Methodology

Research

This narrative inquiry promulgates the narrative of the participants and the stories of the warriors encompassed within the research of this study. Through the critical analysis of each participant's response, the examination of how each participant adjusted to the physical and psychological trauma of the loss of some sense of masculinity will ultimately provide support for others who are struggling with life with MS.

This study is about how this disease affects those forced to embark on the journey of living with MS. It examines how men adjusted to a new way of life and how they have fostered a new meaning within their lives. Their stories tell the tale of how multiple sclerosis changed their path in life.

This research study's methods consist of a qualitative narrative inquiry to ensure a deeper understanding of the complex human struggle of maintaining a new approach to life with MS. Narrative inquiry will examine how the participants can endure the physical and social barriers brought on by this disabling disease. The personal stories are necessary for a deep understanding of how the participants can construct a new approach to life.

Each participant discusses how their life was before the diagnosis of multiple sclerosis, how they handled and reacted to the diagnosis, and how they can live with the disease. Each narrative is unique, as each diagnosis is unique. All five narratives share similarities in their experiences with multiple sclerosis; however, their journey is theirs alone.

This analysis will consist of following the themes of life before multiple sclerosis, multiple sclerosis diagnosis, and living with multiple sclerosis. The research questions (theoretical framework) will initiate and set the analysis parameters for the chosen themes' relevance. For each participant, a set of different questions will be highlighted within the analysis.

Research questions

- How did the participants, after the diagnosis of multiple sclerosis, manage their lives with a new normality?
- How do the participants reevaluate and reconstruct a new meaning within their lives?
- How do men living with multiple sclerosis adapt to the physical and psychological stress?
- How do they cope with the challenges related to their physical stamina and masculinity?

Qualitative research design

Creswell states: “Qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem." (Creswell, 2007, p. 3). Qualitative researchers use the approach of collecting data from interpersonal communication and dialogue to produce an inductive analysis.

> Qualitative methods allow the researcher to study issues in depth with data collection often occurring through open-ended questions permitting one to understand and capture the points of view of other people without predetermining those points of view through prior selection of questionnaire categories. (Patton, 2002, as cited in Butina, 2015)

This narrative research project embodies the study of participants diagnosed with multiple sclerosis. Conversations between the participants and the researcher will create a more meaningful, authentic shared dialogue. The conversations and experiences will exemplify their experiences of living with multiple sclerosis and how such experiences can be inspirational and empowering.

Narrative inquiry as research

My daughter and I were going through a box filled with saved memorabilia and artifacts in the room that is to be an office. Each artifact within the storage box is a component of a personal story, a narrative of individual experiences that together create a story. A collection of personal experiences of the events that helped shape who I am.

A football in the box is just that, a football. It was the only time I scored a touchdown in the fifteen years of playing football without the story of how it came to be in the box. Without the story, it is just a football.

Narratives become a collection of experiences and stories that allow the researcher to explore the personal stories of individual people. It enables the researcher to construct an approach to carefully designed guided questions investigating the human struggle of living with multiple sclerosis.

The emotional trauma encountered and the means of overcoming them. The combination of participant interviews and analysis defines a broader perspective toward answering questions specified by the researcher.

Who am I within this narrative inquiry? Clandinin (2016) asked her students about this as they embarked on their narrative inquiry journeys. Reflections upon this question, several additional questions surfaced. Why pursue this inquiry? What is my role in the investigations? What social significance could be achieved from this inquiry?

The question of why this inquiry is pursued originates within a reflection of a personal paradigm. I was diagnosed with multiple sclerosis in the spring of 2006. Life has changed within the fourteen years, from the diagnosis in 2006 until today. Personal experiences can be described as a fourteen-year journey as a passenger on a train ride. The engineer of the train is the thief; multiple sclerosis stole my life.

The train travel agenda is temporal, changing continually; the journey encounters many speed bumps, offering only new hardships to overcome. Each bump requires a new adjustment within the new normal of life living with this disease. The train ride is a personal reflective metaphor for living with MS.

What is my role within the inquiry? This question requires a deeper understanding of narrative inquiry. According to (Webster & Meritova, 2007), narrative inquiry allows the researcher to explore participant experiences through an all-inclusive perspective, enhancing the story. The story developed through understanding the connection of all facets of the experience. Researchers can examine the implication of each experience to the value of the story in its entirety.

Clandinin(2006) defines narrative inquiry as a research approach to studying human experiences devised through human lives. It is a way of valuing lived experiences as a springboard of critical understanding and knowledge.

What is my role within the inquiry? The role serves as both researcher and active participant. In the introduction, I share my lived experience with MS. Thus, I take on the role of an active participant. Participants in this narrative inquiry will share their personal stories.

Stories are humanist. They address the human struggle within the anxieties and hardships people encounter as they tell their own stories. The power resides with the battle.

Our own stories are temporal within the process of being storied. We change our story as life presents itself to us. It builds itself upon the past, present, and future. Understanding the past allows us to understand who we are in the world. As human beings, our stories with our past shed light on who we are. They highlight the experiences that shaped our ontology or perception of our being. They are heuristic in the sense that they enable self-discovery of ourselves.

Although our past stories are a powerful way to gain insight and understanding of how the past events within our lives have shaped our stories, the past is static; it cannot change. We cannot live within the past events of our story. They are essential to our story. We may reflect on how and why events occurred within our story, but they are past events. The present becomes the temporal component of our story.

It is changing daily. Our story lives within a state of flux and continuous change. Our human struggle adapts to all the hardships we may encounter. The adaptations will adjust our stories. They will tell the story of the how and why within the personal struggle. These personal struggles provide insight into the nature and value of experiences and power behind the story, illuminating our sense of self.

According to Connely & Clandinin (1990), “Narratives are the illuminated stories of experiences. Although the narrative inquiry is about people’s experiences, to understand everyone’s experience, one must understand the individual shapes the social, cultural, familial, linguistic, and institutional narratives. The social significance within this inquiry begins with its purpose.” (pp. 2-14)

The significance of this inquiry is to examine the unique experiences of the male participants who have acquired multiple sclerosis and how they have been able to cope with the psychological trauma, and physical trauma that accompanies living a new life with MS. Within the role of both the researcher and the participant, I will become part of the narrative. Conversations of shared experiences living with MS become intertwined with the narrative.

The resulting inquiry will become a shared narrative with others who have encountered similar struggles with living with this disease. Within the shared stories, others may find hope, emotional support, and guidance to assist with their struggles.

According to Connelly (1990), narrative inquiry studies human lives and how they experience the world. Understanding the experiences told by the participants and the researcher's analysis shape the study's significance. Everyone has a story to tell. A story is unique and authentic, as in the storytellers themselves. Each story is an experience. Collecting stories within the same context can provide insight into an understating of a complex question. According to Squire & Andrews and Tamboukou (2013),

> Narrative research is free of overall rules about suitable materials, modes of investigation, or the best level at which to study stories. It does not tell us whether to look for stories in recorded everyday speech, interviews, diaries, photographs, TV programs, newspaper articles, or the patterned activities of people’s everyday lives, whether to aim for objectivity or researcher and participant involvement, whether to analyze stories particularity or generality; or what epistemological or ontological significance to attach to narratives. (p.1)

Narrative inquiry enables gathering stories that share in the human struggle of life. A glimpse into experiences defined by one's unique story, a moment constructing how they survived and lived, how they overcame the adversity and hardships encountered from life with m.s. From the collection of stories, researchers can analyze and create theoretical conceptualizations of how interview participants constructed their lives.

"Narrative might be the term assigned to any text or discourse, or it might be the text used within the context of a mode of inquiry in qualitative research with a specific focus on the stories told by individuals." The text within this research will attempt to search the emotional state of men with multiple sclerosis. (Chase, 2005 and Polkinghorne, 1995, cited in Creswel, p. 53, 2007)

In essence, this research will expose the emotional trauma of the participants from their perspectives and stories. It will attempt to provide a personal timeline of how the participants were able to overcome their traumatic events of life with MS. In addition to the acknowledgment of the experienced trauma, how can the participants overcome the trauma caused by the life experience of living with MS?

Warrior narratives provide a personal perspective through the voices of those fighting the thief every day of their lives. It is a glimpse of the reconstruction of a new self-identity and a vision of how they can move forward from the life-changing event. Narrative stories provide a very personal dynamic of how their lives were taken from them and how they adjusted to the reality of a new self and normality.

Assumptions

Several research articles highlight society's views on disability and the loss of masculinity. They discuss how male masculinity edicts men's self-esteem through nature and culture. The personal perception of the self affects the very disposition of the individual and may cause changes in social status. According to Scott (2014), the analysis of personal narratives of masculinity of physically disabled men highlighted a sense of vulnerability within a social context.

Scott (2014) States that men who are disabled suffer from self-perceived inadequacy from their sense of faltering masculinity. Simple physical actions can no longer be accomplished. The inability to perform physical tasks becomes demeaning and leads to a decreased sense of self-esteem. The effect of living with MS upon men can lead to a feeling of low self-esteem and a sense of physical vulnerability, assaulting masculinity.

Data collection methods

The interview questions enable conversational responses. “All narrative inquires begin with an autobiographical inquiry about who the researcher is concerning the phenomenon under study, which helps to set personal practical, and theoretical/social justifications and shapes the emerging research puzzle.” (Clandinin, 2013, p. 191)

“Those undertaking qualitative studies have a baffling number of choices of approaches. Qualitative approaches of inquiry are diverse and can be numerous depending upon how they are classified as some classification schemes include 20 plus approaches.” (Creswell, 2013, cited in Butina, 2015)

The study will utilize in-depth interviews of approximately 3 to 5 men with m.s. Within this narrative inquiry, the researcher is a middle-aged male who was diagnosed with multiple sclerosis in the spring of 2006 and has been living with this disease for 15 years. The physical, emotional, and psychological trauma contingent on the effects of the disease has been experienced, to some extent, by the researcher.

Because we share the same diagnosis, the interview approach will reflect an understanding of the hardships the participants may be experiencing. Through becoming part of the narrative, the results will engage a deeper conversation about how the participants have been able to construct coping mechanisms to live with MS.

The steps taken within the data collection process will begin with the purpose of the narrative inquiry. As stated earlier, within the rationale, this study aims to examine the unique experiences of the male participants living with multiple sclerosis—initial essential questions that generate further exploration and provide in-depth responses. The vital questions become the foundation for the interview process.

Interview Questions

1. Please describe your life experiences before the multiple sclerosis diagnosis.

Your life in early childhood years? Your life experiences as a young adult?

2. Please tell me about your experiences when you first learned of your diagnosis of multiple sclerosis. Describe your experience with the medical process that led to your diagnosis. What was your experience with the doctor? Did the doctors offer any insight into dealing with the immediate emotional trauma?

3. Please share how you began to process the challenges MS brought to your life emotionally. How did you start making sense of what happened to you?

4. Once you were diagnosed with multiple sclerosis, who provided emotional support?

Who was most impacted by your diagnosis, and how did they react to it? How did your family react to your diagnosis? Did some people distance themselves and withdraw because of your diagnosis?

5. Please explain the changes related to your life after the diagnosis.

How did your diagnosis affect your work or career? What changes have occurred as a result?

6. Describe the experienced progression of MS that you have encountered.

What lived experiences have occurred over time? Can you describe how MS has impacted your daily life?

7. Have you experienced anxiety and depression because of your disability? If so, please describe how you can handle and maintain emotionally.

8. What physical changes did you encounter because of your diagnosis? How did your physical well-being change after your diagnosis? How have you adapted to physical labilities after your diagnosis?

9. Have you experienced challenges to your masculinity resulting from the physical changes of MS.? If so, how has your life changed from a decreased sense of masculinity? How have you been able to adapt physically and emotionally from a loss of masculinity?

10. Is there anything you might want to discuss further that was not covered in the questions?

Participants

This narrative inquiry design examines and inquires about the human persona engaged in the struggles of living with multiple sclerosis. The participants will be men of various ages ranging from twenty to eighty. Their personal stories and answers to the prescribed questions will provide an authentic and honest narrative, becoming the foundation of this study. Members within the m.s. support group will likely become active participants in this study.

Ethical consideration

Creswell (2007) states, “Regardless of the approach to qualitative inquiry, a qualitative researcher faces many ethical issues that surface during data collection in the field and in analysis and dissemination of qualitative reports.” (p.41,) This research study will observe the ethical program of the code of ethics of the American Educational Research Association. The, (AERA) program expresses a standard set of principles upon which education researchers build their professional and scientific work. The code provides both the principles and the rules to cover professional situations encountered by education researchers. (AERA, 2016)

Each participant will remain anonymous; they will have alternate names and identities to maintain anonymity, securing ethical standards provided by the American Educational Research Association.

Creating a conversational approach to the inquiry enables both the participants' stories and the researcher to play essential roles within this narrative inquiry. The nature of this study delves into each participant's sensitive emotional responses. Before the interview, each participant can end the investigation as they see fit. Each education researcher's responsibility is to aspire to the highest possible standards of conduct in research, teaching, practice, and service.

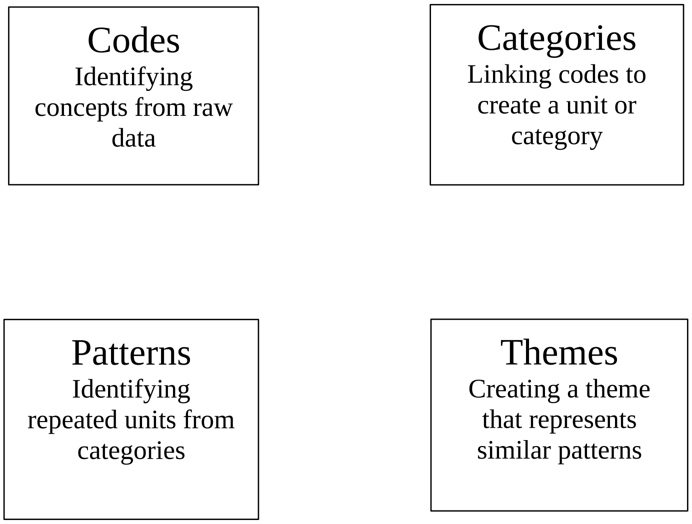
Data analysis

According to Creswell (2007), the data collected within a narrative study needs to be examined for the story they must tell, a timetable of events of the reveling experiences, and potential points of turn within the narrative. Three steps: Data analysis in qualitative research entails preparing and organizing data for analysis, then condensing the data into themes through coding and condensing the codes, and finally, representing the data in figures, tables, or a discussion.

The research of the personal stories, as told by the study participants, can be considered individual ingredients to the narrative recipe of how to live with MS. Each participant shared how they reconstructed value and meaning to their new identity. Like many recipes, each cook must make their own, draw on the ingredients they can access, and hone the recipe to their taste and resources. This formula, collected from the participants, essentially becomes a recipe book for overcoming the obstacles presented in life with MS.

According to Kim (2016), understanding the qualitative research process is the first step in directing narrative data analysis. Data analysis in qualitative research generally involves examining raw data collected from the interview process, then reducing the raw data into themes through the coding process and presenting the coded data within the final research text. The reduced complex qualitative data analysis comprises four essential elements: codes, categories, patterns, and themes. (p.189)

Figure 1 Basic Elements of Qualitative Data Analysis



Pilot study

The initial narrative inquiry research project occurred in the spring 2016 semester of coursework. Having been diagnosed with multiple sclerosis in 2006, I wondered how other people who have acquired a disabling disability managed the sudden change in their lives. How did they adjust and reconstruct a new meaning of their self-identity? I wondered if I could make a difference in the lives of people who are going through similar emotional and physical trauma.

This study explored the human reaction to acquiring a life-changing disability. The research design exemplified the personal experiences of the researcher as a participant with an acquaintance who also had acquired the disability of multiple sclerosis. The rationalization of this research and the concluding results may provide emotional support to others who are dealing with an acquired disability.

Others like me have to go through the same every day, and providing support is a way to advocate for others. I belong to the m.s. support group in Fort Myers, Florida, offering support to those in need.

The pilot narrative inquiry allowed for the experience of developing the qualitative and narrative inquiry methodology to sustain the research. To begin, the task of the inquiry was overwhelming. Supporting research literature, Creswell’s Qualitative Inquiry and Research Design were paramount to understanding the methodology design process. Creating the design process became less daunting as the research puzzle began to take shape.

The process of constructing the research questions and the interview guide was complex. Making sure the questions facilitated the desired responses was a meticulous experience. Significant understanding that the process was a continual endeavor. Continued research instituted an ongoing process of revision and change within the dynamic of the inquiry.

Chapter three summary

The works of Creswell (2007), Clandinin (2013), and Kim (2016) were of vital importance to the framework of this methodology. The most essential guide to understanding the methods of narrative inquiry was the guidance of Clandinin (2016). The structure of the stories' and narratives' power was discussed within the context of Engaging in Narrative Inquiry. Clandinin (2016).

This chapter discussed the methodological framework: qualitative research design, narrative inquiry as research, rationale, assumptions, ethical considerations, research questions, inquiry participants, data collection, and analysis of collected data of the human struggle of life with multiple sclerosis. The lives of others who share the same battle will discover that they are among others who endure.

Chapter Four Participant Narratives

"They carried all they could bear, and some, including a silent awe for the terrible power of the things they carried"(O'Brien,19)90

This analysis will consist of following the themes of life before multiple sclerosis, multiple sclerosis diagnosis, and living with multiple sclerosis. The research questions and conceptual framework will initiate and set the analysis parameters for the chosen themes' relevance. For each participant, a set of different questions will be highlighted within the analysis.

- How did the participants, after the diagnosis of multiple sclerosis, manage their lives with a new normality?
- How do the participants reevaluate and reconstruct a new meaning within their lives?
- How do men living with multiple sclerosis adapt to the physical and psychological stress?
- How do they cope with the challenges related to their physical stamina and masculinity?

The original questions were changed and adjusted to fit the depth of the participants' responses during the interview. The interview process evolved into a conversational experience, sharing experiences between participants and interviewees.

Each participant has provided a lens into their lives and experiences with multiple sclerosis. The stories they shared were easy to tell for some but difficult for others for various reasons. The questions are designed to foster some emotional response. The idea of revisiting an event that inspired a profound emotional reaction created some resistance. For any questions the participants found challenging, it was their right not to answer. Some participants viewed the interview process as a positive way to reflect upon how they could move forward with their new lives.

According to Clandinin (2013), narrative inquiries begin with the autobiography study of who the researcher is and what the experiences under study are. Within this study, the researcher has lived with multiple sclerosis for 18 years. The study's guiding purpose is to understand how others have been able to live with this disease/phenomenon. (p.19)

Creswell (2007) states that the data collected within a narrative study needs to be examined for the story they must tell and a timetable of events of the reveling experiences. The themes from the conversations gathered through the interview process create the timetable of experiences that governed participants' lives.

The following narratives are, in essence, the voices of the participants. They are the true stories of those who have been stricken with a debilitating disease and are fraught with pain and anxiety. They carry these burdens with them as they navigate their new life journey with multiple sclerosis.

Living with multiple sclerosis has challenged the lives of the five participants in this study. They have renegotiated their life purpose, accommodating this disease's overwhelming demands. Their vignettes are the true stories told by men who have multiple sclerosis. They offer glimpses of their lives before multiple sclerosis and the moment it changed forever.

The stories the participants tell are derived from interviews reviewed and rewritten in narrative form within this study chapter. Each participant shares a unique perspective on their life with multiple sclerosis in this study chapter. They will have different names to secure anonymity. Each narrative is formatted with three themes: life before the diagnosis of multiple sclerosis, the diagnosis, and living with multiple sclerosis.

The interview process became overwhelming to some of the participants. It was challenging to discuss and relive the process of living with multiple sclerosis and returning to the scene of the crime if you will. Sometimes, the lived experiences trigger emotional reactions, resulting in shortened responses. While some participants offered limited responses, others gave deeper insights within their responses.

The interview process offered a more rewarding experience than the preceding chapters. The foundation of the study is the personal narratives of the participants. I wanted to learn from all of them. I wondered how they overcame the initial diagnosis and created a new life with multiple sclerosis compared to my experience.

Did they have the same anxieties, and how could they overcome them? Did they experience denial and depression? What were the tools they used to reconfigure a new normal within their lives? What do our shared experiences exist?

The conversations that took place during the interview process were enlightening. It provided a strong connection between the investigator and the participants. Through sharing similar experiences, a genuine bond was established. A kinship. Like the bond between war veterans and the struggle for survival or past teammates who shared the battle on the athletic field. The bond survives, although distance and time may have lost the relationship.

The interview process established more than the collection of data. It was the means of establishing friendships. With each interview, a shared bond was created beyond the goals of this study. We all spoke of our cherished past and how we adapted to our new lives with multiple sclerosis. Perhaps the participants feel the same after the experience.

What was a difficult and daunting process in the beginning of finding five participants who were willing to tell their stories became more manageable with each interview. The narrative became more authentic as the participants became more comfortable with the interview process. They began to open up and share their struggles freely. Conversations began to transcend the interview process. The conversations developed a lasting bond.

Theme One: Life Before Multiple Sclerosis

Examining the participant's life story facilitates an understanding of life before the diagnosis of multiple sclerosis. It sheds light upon who the participant was. Although it is a brief window into their background, it becomes an essential foundation for the overall impression of the participant.

This theme begins a timeline of the narrative. It tells of who the participant was before the life-changing event of life with multiple sclerosis, highlighting a life that once was. A life that was filled with all the trappings life offers. Some had successful careers and families and were married, while others struggled. A common thread is that life changed with the onset of multiple sclerosis. Some encountered difficulty transitioning from the loss of the normality of life. Some could handle the new life with this disease with relative ease and grace.

A few participants could not return to a sense of normality and continued to struggle with everyday existence. Multiple sclerosis has changed their lives forever. They had to find a new purpose in life. They were adjusting to a new normal.

Theme Two: The Diagnosis

The diagnosis captures that moment in their lives when those four words are stated by their doctors, "you have multiple sclerosis." After the endless doctor visits and tests, those words will change their lives as they know it. Forever serving as an overlord to their futures and forcing them to give homage to the Lord.

Each participant underwent this moment, an experience every m.s. patient suffers through. Each is unique as to their diagnosis. The diagnosis varies from Four disease courses that have been identified in multiple sclerosis: the clinically isolated syndromes include relapsing-remitting MS, primary progressive MS, and secondary progressive MS.

> Relapsing-remitting MS is characterized by experiencing symptom flare-ups, also known as *relapses, exacerbations,* or *attacks.* When someone experiences a relapse, they may be having new symptoms or an increase in existing symptoms. These usually persist for a short period (from a few days to a few months) and afterward may remain symptom-free for months or years. (Multiple Sclerosis Society of America (**https://mymsaa.org/ms-information/overview/types/**)

Theme Three: Living With Multiple Sclerosis

Theme three illuminates how each participant lives with multiple sclerosis. It highlights how each participant picks up the pieces of their former life and finds a new path. The new normal elicits the creation of a new purpose in their lives. It is not a death sentence. It is a regeneration of life for them. It is the way people move forward.

It is how people approach their lives with all the changes m.s—forced upon them. It is all the changes and adjustments made to accommodate this new normal. It is understanding what you can and cannot do and creating new ways to approach life without giving up.

Life Before Multiple Sclerosis

Jerry's story

Jerry began life in Westchester Count, New York, where Jerry grew up. He and his family lived in a three-bedroom apartment shared with his brother and parents. "There were four of us there, and it was a little tight."

Jerry lived an active life before his diagnosis; playing golf with his three children and later grandchildren was one of the things he enjoyed. Maintaining the household through daily chores such as cutting the grass and working on minor repairs was part of his life.
He served in the Navy for six years on the ship the U.S.S. Boston and two years within the Navy reserve.

The service was part of a tour of combat service with the 7th Fleet and was part of Naval Gunfire Support Task Unit 77.8.9 and Sea Dragon operations off North Vietnam. Jerry was a manager for I.B.M. for 37 years in networking services and communications, including the physical installation of telecommunications equipment.

Upon retirement from I.B.M., he worked part-time for a Toyota dealership, driving cars from one dealership to another. Driving became difficult after several hours; his right leg became numb. Driving his car with his left foot became dangerous.

The Diagnosis

The initial experience that led to the idea that something was wrong occurred in the early 1990s in Las Vegas. "We were walking, and all of a sudden, I kinda like tripped and fell." The sidewalk had cones set up to order, but "there was the real reason for me to fall, and I was dizzy." He looked at this experience, saying it was "clearly a sign that something was wrong with him."

Jerry anticipated the diagnosis of multiple sclerosis. "It was not a shock; I knew I had something." Although the diagnosis was difficult and took a long time with several doctors, what bothered him the most was that his legs were becoming weaker. "My fear of winding up in a wheelchair for the rest of my life" was at the forefront of his mind.

He was officially diagnosed with multiple sclerosis in 2015 after several months and numerous visits to several doctors. Multiple MRIs each confirmed lesions in the spine and the brain, and further testing examining the neurologic signaling between the brain and his feet exposed faulty connections.

He suffers from other autoimmune diseases: Ankylosing spondylitis, an inflammatory disease that, over time, can cause some of the bones in the spine to fuse, and uveitis, an inflammation inside the eye. Uveitis is an inflammation that usually happens when the immune system is fighting an infection, but it can also occur when the immune system attacks healthy tissue in the eyes. Doctors were able to treat the uveitis with steroid injections, elevating the uveitis over time.

With his multiple sclerosis diagnosis, he and the doctors discussed his medical options in detail. Jerry and his doctor, Dr. Krieger, from Mt. Sinai Hospital in New York City, decided to prescribe Ocrevus to treat relapsing forms of multiple sclerosis in adults. Relapsing-remitting M.S. describes that within the patient, there are experiences of flare-ups or exasperations characterized by inflammation in the central nervous system that causes damage to the myelin and slows or blocks the transmission of nerve impulses.

Living With Multiple Sclerosis

When first diagnosed with depression, aggravation was one of the emotional experiences encountered with not being able to help around the house, something he was always able to do.

The irritation of being unable to do anything was part of his existence before m.s. The inability to walk freely and the frustration of not being able to physically help and support his wife led to a sense of depression. "Well, you know, just basically understanding what I can and cannot do." Referring to what he can no longer physically do became challenging.

He knows his wife must do the physical activities he can no longer accomplish. "That bothers me. It is just horrible." He notices the things he can no longer do anymore. The physical demands of life before his diagnosis that he was not able to complete anymore. His wife, now having the task of maintaining the household, hurts him.

His life with MS has given way to a new approach to life. To support walking, he now relies heavily on using a rollator walker. "I'm joined at the hip with one of those rollators, which I'm not a fan of, but it helps me get around." He maintains a regiment of vitamins to support his health. Vitamin B12 and D12 are prescribed to combat fatigue. His sleeping patterns have changed. "I don't sleep well at all." Because of the changes in sleep, he is fatigued throughout the day.

Jerry's life with multiple sclerosis has been a struggle. Suffering from hardships of both Ankylosing spondylitis and MS is a daunting task. He can live his best life with the support of his wife, whom he describes as "his rock."

Life Before Multiple Sclerosis

Bob’s story

Bob's life begins with growing up on a farm in Virginia's Roanoke area of Blue Ridge Mountains. Life on the farm enabled the development of a strong work ethic that continued throughout his life. His parental role model, his mother, lost a leg when she was 16 and managed to have nine children—his development of a robust ethical character derived from the resiliency of his mother.

At age 12, he was diagnosed with Sydenham chorea or Saint Vitus dance disease, a neurological disorder characterized by irregular and involuntary movements of various muscle groups. This diagnosis forced him to be bedridden, missing a year of school. “Which was kind of the worst thing for at the time, I had seizures between the age of eleven and fifteen.”

He spent the next twenty-seven years living in the state of Maryland in the Washington D.C. area. Bob was "athletic, running five to ten miles a day in college." He earned a bachelor's degree in theology and social work that enabled him to organize a group of socially at-risk young men to assist in building and remodeling projects. After college, he was a private contractor building homes and various construction jobs.

For 11 to 12 years, Bob created and administered a nursing home ministry. "I wanted to use his theology degree and social skills to help people." When COVID came along, they locked down the nursing home to bring his ministry to an end.

The Diagnosis

The start of m.s. symptoms were the sudden uncertainty of balance that prompted appointments with doctors in Maryland. After testing and E.E.G., an electroencephalogram that records brain activity concluded that he had bordering multiple sclerosis symptoms.

“I thought, well, I didn't know what MS was then. So, over the years, I've discovered how devastating it can be." He continued to maintain his running routine and lost his balance more frequently.

Bob then moved from Maryland to southwest Florida in 1999. When he came to Florida, he obtained a new Neurologist, and “treatment was more structured down here in terms of attacking the disease.” The latest diagnosis stated that he had secondary progressive multiple sclerosis.

Bob had no idea what multiple sclerosis was or the potential life-altering experiences he would encounter upon his diagnosis. Stated, "I'm a driven person; if somebody tells me that I can't do something, I'll be damned if I'm not going to sit back and not do it." He does not acknowledge having any emotional trauma at the time.

“Well, I’m intelligent enough to realize what I can and cannot do and know the symptoms.” M.s. affected the left side of his body more than anything else, so his left leg is much weaker than the right. “So, when I feel like the left side of my body is getting weaker, and I'm having trouble walking and keeping my balance, particularly, then I just ease up, I take a break.”

Living With Multiple Sclerosis

Multiple sclerosis has had minimal impact on his emotional well-being. "I'm very realistic about it." His neurologist and the MS support group have provided support. Both have led to a clear understanding of the disease and how it affects his body. "I'm just thankful that the Lord has given me the strength to get up and do what I can. Well, I talk to the Lord every morning, every night, and throughout the day. And I ask him to give me the strength to do the things I need for the day and keep me through the night. I rely on the Lord constantly.”

MS caused some physical challenges in his life. Bob experiences a pronounced weakness within his left side, affecting his legs. "So, my left leg is weak." The drawback becomes challenging to manage on various days. “I could hardly leave the car and finally reached the house. I could come in, sit in my chair, and rest for about a day. And you know, as I say, every day, it's different. You don't know how you'll be from one day to the next; you must roll with the punches.”

He experienced physical deficiencies that affected his sex drive. MS affects his Bladder, forcing him to self-catheterize. "I have been doing that for about 12 years now." Suffering from constipation, he relies on linzess and amitiza to accommodate. "I think the physical things that I used to do. However, mentally, I am still adept." He continues to do the physical things that he can.

Cleaning the house is one of the daily routines he can do. He has a collection of birds that have become essential to his life. Eighteen cockatiels, parakeets, African greys, and McCall's have been residents within his life.

Although Bob has dealt with the complications presented by living with multiple sclerosis, he, at times, has suffered from mild episodes of depression. He stays busy at home, helping out around the house the best he can, and his birds can alleviate depression.

Life Before Multiple Sclerosis

Ron’s story

Ron's story begins in Oakland, New Jersey, where he had a career in the family business of electrical contracting and spent 35 years of his life. Oakland is a borough in Bergen County, New Jersey, and a suburb of New York City. He describes his job as having been in a family electrical contracting business with my brother and father for 35 years. His career came to a halt, "I just had I had to stop after my last relapse. I just could not work anymore. It was awful."

Before his diagnosis of multiple sclerosis, Bob was living an active, fulfilling life. He led an active lifestyle, including playing golf and tennis and participating in softball leagues. As was the case of his career in an electrical contracting business, the relapses with multiple sclerosis began to weigh heavily on his life.

The Diagnosis

The first exacerbation or attack of MS was in the year 1992. "It was a long time ago. Trying to remember, "I am pretty sure I was out landscaping around the house, and suddenly, my arm just went numb." He was getting sporadic exacerbations. "Back then, I struggled with optical neuritis in my left eye." The pain in his left eye was excruciating. "You know, the pain behind your eye was incredible. I did not know what it was, so I did not. I did not do anything." Weeks later, the pain subsided, and it seemed to get better.

The following year, he encountered a relapse as he was working. "I remember I was behind some air conditioning units. I was wiring them up, and the same thing happened; I lost my right arm and became numb, and I could not move my hand ." Ron finally went to seek help and answers to the neurological attacks. His doctor sent him to a neurologist, and he was pretty sure what it was. "So, he sent me to get an M.R.I. When he got the results back, he said, yes, this is MS oh my god.

His doctor was supportive. Thirty years ago, doctors' understanding of multiple sclerosis was limited, and there was not much they could do back then. They did not have certain drugs that you can take nowadays. "I would get the relapses, and then I recovered fairly well; I could still go back to golfing and tennis and everything else, and working was not a problem, so he just did not start me on anything back then." "So, trying to stop relapsing was one of his new normal of living with MS are the worst things for me because they get worse every time. As far as that is what I have been experiencing."

Living With Multiple Sclerosis

After he was diagnosed with multiple sclerosis, he tried to take many vitamins. I remember doing that. He took the vitamin supplements for about a year, stopped thinking that the relapses were secured, and everything was fine. Despite the occasional relapses, there was nothing else wrong with him.

He did not experience another exacerbation (relapse) for a couple of years. He remembers starting to slow down in the early 2000s. The effect of MS was getting much worse. Work was becoming difficult. It was hard to get through a day trying to keep awake. "

Fatigue became his main problem. "It's just awful." In the early 2000, he started getting hit again with relapses and small attacks, and he began to develop a limp. "My whole right side was bad, my leg became very sore, and my right arm was so weak. I just lost all the strength on my right side. It was terrible."

Ron was able to handle the sporadic exasperations and got married to his second wife. His first marriage did not work out; however, he was willing to do it again. "She was a great girl." Unbeknownst to Ron, his second wife had bipolar disorder, and their son developed bipolar as well. I do not know if you know anything about bipolar. "That awful disease. It's unbelievable." He adds, "My wife can be the kindest person to other people, but when it comes to me, I'm the person she's going to pick on and try to destroy."

He spent 22 years married to his second wife. He and his second wife had two children, a son and a daughter. "I know it is a postpartum depression that kicked off her bipolar, and It has just been a nightmare for the last 22 years. I do not know how I survived that.” The marriage ended, allowing him to move on. "We are finally selling the house and going our own way. "I am going my way; the kids go on their way." The children are young adults who have enough money for a college education. "My son is doing very well in college. So, he will stick with it, and my daughter is just graduating this year and going off to college."

The problem with my ex-wife being bipolar was causal to overwhelming personal stress. "My big problem is stress. When I get stressed out, I know that is what brings on attacks." The medication doctors prescribed him was Copaxone. "That just did not help me at all." He lost his insurance, and proper drugs were not available. "Luckily, I go to the m.s. center at Holy Name Hospital. So, the doctor does many trials, and the doctor paced me into a trial for millennia."

The drug was controversial because it may lead to a dangerous drop in blood pressure. "I got into a trial where I took it to show that it's not a problem you're monitored for when taking the drug. It's not like there are no problems with taking the drug." Ron could get into that trial for two and a half years.

Ron lives on his own. "I'm all by myself. When I go back to New Jersey when I live there, I have no help with anything. Nobody helps me." He has become alienated from his family. The toxic relationship with his wife has caused an emotional divide. "My whole family hates me. That's because his wife has turned the kids against me."

The emotional stress and anxiety of the relationship with his wife left a sense of a loss of masculinity. "I'm less than a man. My wife has taken all that out." "I have E.D. I mean, I lost all sensation in that area. I haven't had sex for three years. So, it doesn't matter to me."

He remains physically active. He can still move freely and can get the tasks of everyday life. "Luckily, I can still move around and get things done, but I'm weak. You have a tendency not to be able to do things. They're mundane things you've done before in a lifetime." Ron's frustration is one that many must endure when living with multiple sclerosis.

Ron sums up his difficulty in working. "I have worked with my hands all my life. I was an electrician, and all you do is work with your hands. They have to be able to pull wires. They have to be able to do this. I could not do it anymore. I was just so weak. Moreover, you cannot do the job if you are not strong. Really. It is not possible. Well, I still did. I still try to get much work done around the house. I do my work as much as I can. However, it is hard."

Life Before Multiple Sclerosis

Phil's story

Phil grew up about three miles west of Chicago, Illinois. He attended Kalamazoo Valley Community College in Michigan to study in their paramedic program. "I was going to be a paramedic. To go to school, you must get vaccines. So, my sister was good friends with a doctor from the city." One of the vaccines was for malaria. He believes the vaccines triggered M.S. "That's when I started to experience multiple sclerosis issues."

He was diagnosed with multiple sclerosis in 2008; however, he believes his first experience with MS was in 1996. "I think I had optic neuritis since I couldn't see very well, and my eyes were darting all over the place, and that went away on its own in about five, six weeks." Optic neuritis is one of the symptoms of multiple sclerosis.

His experience of the progression of multiple sclerosis was a slower process. "I could not run, play baseball as much as I used to, or play softball. I was playing in softball leagues and was very active with them." He was forced to adopt a new role as a spectator rather than an active participant. "I realized I was more of a spectator or coach than a player."

The Diagnosis

Phil was diagnosed through involvement in clinical trials. He was officially diagnosed in 2008, and the doctor was very supportive. "Listen, you went through a lot. It could be a lot worse." His doctor supported maintaining a cheerful disposition toward the new life with multiple sclerosis. "We will take care of this. We will handle this. We will get it under control." The positive approach taken by his doctor established a trusting relationship; he told me about the aggressive form of m.s. and said he suggested medication for me, Tysabri."

Regarding his family medical history, no one else had an MS before. "It's shocking. My mother began to question what she had done wrong. Why is my son diagnosed with MS and my daughter has cancer."

Living With Multiple Sclerosis

“The motivational factor was my kids. I wanted to be around for them. My children count on me, and I wanted to live a healthy lifestyle as much as possible, quitting smoking in 2005. His friends were and are very supportive. You know, but everybody's supportive.”

Phil tells me, “I'm single now and have been dating." He approached dating with complete honesty about his condition. " I enjoyed riding bikes and mountain climbing, and the activity tired me out.” He concluded that he had to give up on some of his activities. Dating also became challenging. “So that's pretty much all that it's affected me.”

Phil shared an example of how life with MS—changed his approach to physical activities—having an active lifestyle before his diagnosis made it difficult to accept his inability to participate in some physical activities. He was active within his son's travel baseball team, often accompanying his son on trips to play in baseball tournaments.

"A good example of how MS changed my life was when I was in Tennessee with my son for a baseball tournament. Some other parents wanted me to accompany them to the Great Smokey Mountains. I can't do that. So, my son went with other parents." I missed that because of m.s., which made me feel bad. What did I do to deserve missing out on this trip with my son?

When the Chicago White Sox played in the World Series in 2005, he owned season tickets to all the games. “My Tickets were located down in row 12 close to the field. The ballpark doesn’t have railings, so I had to beg someone to exchange his seats closer to the concourse. So, I got rid of my tickets, and my sister took my son."

He began to search for MS support groups for answers on approaching his new life routine. "In the beginning, I was involved in MS on Facebook. It has a lot of groups, and I met up with some people locally in my area, and I met some great people who offered personal support."

Life Before Multiple Sclerosis

Bill's story

Bill's self-described life before his diagnosis is "fairly regular…I was extremely active and involved with sports; I went to a Southside school in Chicago, where I played baseball, football, and golf." He led a very social existence, having many friends from high school and college, and he attended the University of Iowa. "I held a job locally on campus as a bartender, so I had a chance to meet and develop new relationships."

"I've always been somebody who has taken fitness seriously. I think everybody would agree it's good for mind and body." I think it supported me and allowed me to live probably one of the most ordinary lives I could have post-diagnosis.

He was always active, "I was always working out. I was physically fit. So overall, I took care of care of my body, and I never really had any, you know, underlying health issues that I was aware of. So, you know, for me to think that I had any type of, you know, long-term, you know, untreated Well, I guess, uncurable disease at that point was like just totally out of this world; I couldn't even conceptualize what that might mean."

He graduated college, and roughly two years later, he began his career selling business-dependent business software in a corporate sales job. "I am in the cloud technology space.” I was walking around one day at work, and my initial MS experience occurred. I thought something was potentially wrong as these pins and needles were at the bottom of my feet. The pins and needles sensation accompanied by some of the numbness that occurs, I think, is consistent with some people who have these initial symptoms."

Over the next three to four days, the sensation of pins and needles ascended from the bottom of his to his ankles, knees, and waist. "Essentially, at the end of day three and day four, I couldn't feel anything below my waist whatsoever… now, weirdly enough, it didn't affect my ability to move or be physical. I could still walk around, push myself in my routine, kind of go to the gym, and still lift, you know, lower body weights and all that stuff. But again, there wasn't a lot of sensation there."

The Diagnosis

Bill was not very proactive when making an appointment with a doctor. He was living at home then, and his mom had identified the lack of sensation as abnormal. His mother made an appointment with his primary care doctor in LaGrange, Illinois. His doctor asked him why he was there. "I was kind of doing some research. And at the time, I thought it could be one of two things. It could be neurological, or it could be vascular. It could be a potential issue with overall blood flow or something larger from a nervous system standpoint."

Bill communicated his symptoms to the doctor and his staff within 10 to 20 minutes of the back-and-forth discussion. He could convey his feelings, what he was going through, and how it progressed over the past few days. His doctor and the staff essentially left the room, and they came back. "They had told me, Hey, we just called the emergency room, we need you to go there for a stat M.R.I., and we need to do some more tests. So shocking, I went to the hospital and reviewed their overall testing procedures.”

Bill continues, "I had numerous M.R.I.s of my brain and my spine, lumbar and all that, and at the time, I think they saw, this number is not going to be accurate, but I would say anywhere between 30 and 50 different lesions all scattered throughout my brain and then also my spinal cord. So, predominantly, it was in my brain and the upper part of my spinal cord. So, you know, obviously, at that point, they thought it was clear that I had multiple sclerosis."

He was diagnosed at the hospital, and he was there for several days. “So it was not a quick diagnosis." However, essentially, he spent time trying to make sense of the new life he was about to endure. A few days after the diagnosis, he was able to begin seeing a neurologist who he still sees today. Dr. Christopher Simon: "he has been a phenomenal physician over the past ten years and somebody who quickly began treating me with my first medication, which was Rebif, an interferon inflammatory medicine to treat multiple sclerosis."

"I'm not exactly sure about the medication, but it was like a prednisone that more or less suppressed the flare-up that I was experiencing, which, of course, was kind of challenging because the side effects that make you inherently very much anxious and kind of like, you know, accelerate any kind of depressive kind of thoughts that you might have."

He initially began trying to figure out multiple sclerosis because he did not know much about the disease.

"So, I thought, potentially, am I going to die?" What are the potential issues he needed to understand? At that point, it was me being curious and trying to understand, you know, what this disease was. Is it treatable? How do I treat it? And then, most importantly, who do I work with to receive the best treatment in my area?"

“Overall, I think the biggest thing for me when I first got diagnosed was, hey, how do I share this? Do I share this story, more or less? Has it felt like you’re not embarrassed? Still, you feel that if you tell people this, they might think differently of you, or it might appear as a weakness, or it might appear as maybe you have a vulnerability, and people might, you know, approach or interact with you differently.”

Living With Multiple Sclerosis

From the beginning, his approach was proactive in talking about his diagnosis. "I talked about it very openly. "I was, at times, probably sharing too much information with people. Whenever somebody asked about it, I would tell the story as we discussed it. Furthermore, weirdly enough, I found a lot of Power Support and healing throughout that process.

Because the more you share with people, the more I get similar stories back. It is incredible how many people have been affected by MS, some other type of autoimmune disease, or other progressive illness. I think inherently, people are very reluctant to share this type of, you know, significant, monumental life experience because ultimately, you know, as I said, it just seems like a kind of weakness or vulnerability.

Bill decided early on that sharing his story would be one of his strengths. He agreed that although people will react differently, some positively and others negatively, he would continue sharing his story. "I'm sure people have, you know, a variety of different emotions that come out of the experience."

Deciding that early in his diagnosis, he was optimistic; he was still growing in his career. He had very high career aspirations. "This could not slow me down if I was going to align and follow through with everything I was trying to accomplish. So that was that was that was reassuring. I think that being open and honest about it was positive."

He was more conscious of his overall health. In college, I was partying and going out drinking a lot, all that stuff. I am still social. I will still go out and be a social drinker and stuff like that. However, I pulled those things back. I think I was very aware of what was good for me and what was bad for me. "I like to work out and stuff like that. I will still go out and be a social drinker and stuff like that."

He has become much more mindful of being active; he tries to be in the gym daily. He focuses on good foods and limits any bad or processed foods. "So, I kind of take more of a holistic approach, but I also can't discount my current medications. “Talking about his medications: Rebif, Tecfidera, and Ocrevus, prescription medicines used to treat relapsing forms of multiple sclerosis. "So, I'm doing infusions every six months, which, at this point, has seemed really effective and very efficient. I have I've had no new lesions or no new, noticeable clinical progression through M.R.I.s for the past, you know, since I've been on that drug, which is good."

Chapter Summary

Chapter four is the compilation of all the shared stories of the participants. The stories consistently proved authentic dialogue in response to the prescribed interview questions. The men openly told of their anxieties, frustration, hardships, and emotional stress during the process of living with MS.

Each story tells about the human struggles of living with this disease. The emotional strain, the physical pain, and their ability to adjust and modify to cultivate new meanings within their lives. The will and courage to construct a new life have been illustrated in their stories.

Living with multiple sclerosis requires adjustments and modifications to live the best possible life. Some of the men have difficulties walking. Their adjustments can be simple or more complex. Using a cane, for example, is a relatively simple solution. Others have to use a walker or the rollator device that assists both walking and a seat if fatigued. At first, Jerry used a cane, but it became a rollator. Jerry found a way to continue to be mobile.

Some of the men were able to adjust by other means. Bob chose the spiritual way of looking, relying upon his faith to support him. He established a ministry providing spiritual guidance to others within his community. His day begins with prayer and the upkeep of his birds, allowing a sense of peace in his life.

Multiple sclerosis support groups have provided a social outlet for others who are living with this disease. The group offers support by sharing stories about reconstructing a life. News is shared about new medications and research toward a cure for MS.

Others who may not be as disabled found it hard to continue to live an active life. They continue to live a very social life. Going to events or gatherings with simple modifications allows for a complete way of life. Modifications may be simple, allowing for rest periods and doing as much within the activity as possible. They have found a way to coexist with multiple sclerosis.

Chapter Five Narrative Analysis

"How do you go on when you begin to understand in your heart... there is no going back? There are some things that time cannot mend. Some hurt that go too deep."

Tolkien, J. R. R. (1991)

Introduction

The participants within this narrative inquiry have shared their journeys of living with multiple sclerosis for all to benefit. The narratives are stories shared by the five participants who are living with multiple sclerosis, examining how the participants have found a way to coexist with this devastating disease.

The warrior metaphor will be reinterpreted to examine and include the psychological stamina required to adapt and overcome the emotional stress accompanied by the diagnosis of multiple sclerosis.

The original interview questions changed with the depth of the participants' responses during the interview process, evolving into a conversational experience, sharing experiences between the participants and the interviewer. Each participant has provided a lens into their lives and experiences with multiple sclerosis. The stories they shared were easy to tell for some but difficult for others for various reasons.

The idea of revisiting an event that inspired a profound emotional reaction created some resistance. For any questions the participants found problematic, it was their right not to answer. Some participants viewed the interview process as a positive way to reflect upon how they could move forward with their new lives.

This analysis examines the responses across all five participant narratives for similarities and differences in how multiple sclerosis affected their lives. Each participant had to adjust to the challenges presented with life with this debilitating disease. Each created a new approach to living with m.s. They drew upon the strengths that served them well before the diagnosis and adapted them to the new normal of their lives.

This analysis will return to the research questions and examine how each participant responded, which will be compared and contrasted among the groups. The research questions that frame this study are:

- How did the participants, after the diagnosis of multiple sclerosis, manage their lives with a new normality?
- How do the participants reevaluate and reconstruct a new meaning within their lives?
- How do men living with multiple sclerosis adapt to the physical and psychological stress?
- How do they cope with the challenges related to their physical stamina and masculinity?

In addition to answering each of the research questions. I will add two more themes to this analysis: life before the disease and stigma. These themes are necessary to get a complete picture of men's experiences with MS.

Cross Narrative Analysis

Life Before Multiple Sclerosis

The first questions I asked each participant focused upon their lives before the diagnosis of m.s. To comprehend how the men have modified and adapted to a "new normal" of life with m.s., I needed to understand what their normal was before the diagnosis. It is essential to establish how these men lived before their diagnosis of multiple sclerosis. It creates a lens of who these men were and how they lived, establishing a timeline of their lives.

The most consistent theme in their narratives involved having an active life in which sports played a vital role. Each of the men described having an extremely active life before their diagnosis. Jerry described playing golf with his kids and grandkids. Ron described his life before m.s. as an active, fulfilling life. He played golf and tennis and participated in softball leagues. Phil also explained a life where he actively participated in softball and baseball leagues.

Bill stated, "I was extremely active; I was very much involved with sports," including baseball. He said, "I've always been somebody who has taken fitness seriously." While Bob describes a time in his college years when he ran five to ten miles a day and a career in construction, he is the only participant who experienced a disabling disease before his diagnosis.

He told me that he was diagnosed with a neurological disorder when he was 12, which forced him to be bedridden and miss a year of school. He had seizures between the ages of eleven and fifteen. Jerry explained he was diagnosed with an autoimmune disease called Ankylosing Spondylitis, an inflammatory illness that potentially could cause bones within the spine to infuse. Jerry is the only participant who had experience with a debilitating disease before being diagnosed with MS. He also had the experience of having a parent with a disability who had adapted to her disability and continued her whole life. Jerry is the only participant whose life before the disease had experiences with adapting his life due to illness. In addition, he had a robust role model. For the other participants, learning to adjust to a disability was a new experience that stood in stark contrast to their activities before diagnosis.

Concerning their careers before diagnosis, all participants participated in professional careers. Jerry was a technology manager for I.B.M., and Bob was an independent construction contractor. Ron had a successful electrical contracting career with his family. Phil had a successful career as a truck driver in technology sales using "cloud" services.

Each participant had to make some changes in their career after diagnosis. I also had a successful career as both a teacher and coach. Although coaching is no longer an option, I have maintained my teaching career for thirty-five years with minimal modifications.

The Diagnosis

Jerry knew that there was something wrong with him after he tripped and fell on a trip to Las Vegas. He experienced a dizziness that he had experienced before. After several years and several doctor visits, Jerry has received a diagnosis. After experiencing uncertainty about his balance, Bob sought guidance and advice from his doctor. After a series of tests, the conclusive evidence prompted his diagnosis of MS.

He didn't know the extent and how devastating the disease would be on his life. He began to understand the severity of multiple sclerosis and modified his daily routine to accommodate for the fatigue.

In 1992, Ron experienced his first symptom. He describes that his arm went numb while landscaping his yard. Ron felt excruciating pain in his left eye. Doctors confirmed that he had optic neuritis, which is a symptom of multiple sclerosis. His neurologist confirmed that his illness was MS. He was devastated by the diagnosis. Through a series of clinical trials, Phil was diagnosed with MS. His doctor was very supportive, "We will take care of this… you went through a lot." His doctor supported him by maintaining a cheerful disposition of his new routine. He began to live healthier, giving up all his bad habits. His children were the motivation for him to move on.

After experiencing numbness and sensations of pins and needles in his feet, Bill embarked on his research. He was able to realize what he was experiencing was not expected. After discussions with his mother, Phil saw a neurologist. He communicated to his doctor all of the symptoms he was experiencing; he had an M.R.I., discovering lesions in his brain and spinal cord.

He spent time trying to make sense of what happened to him. He didn't know much about the disease. He was concerned with sharing this news. Will it create a perception of vulnerability or weakness? Preceding the appearance of being vulnerable or weak, Bill decided to share his story. Through his story, he met others who also lived with MS. Sharing became a source of power and strength for Bill.

My experience has striking similarities with some of the participants. The initial symptoms were dizziness and loss of balance. I also experience optic neuritis in my left eye. The optometrist was concerned that the optic neuritis was a symptom of multiple sclerosis, which prompted a visit with a neurologist. After more M.R.I. tests and the spinal tap exam, it was conclusive that a diagnosis of multiple sclerosis was correct.

My initial response was denial. I kept the diagnosis to myself and my close family and friends for more than ten years. I realized that sharing my story more broadly was part of my acceptance of the new reality and routine.

Each participant began this journey with various symptoms, from dizziness, loss of balance, falling, numbness, sensation of pins and needles, and optic neuritis. Given that these symptoms could be symptoms of other diseases, they each had to endure a long process to the final diagnosis. For each, the final diagnosis was a life-changing

Living With Multiple Sclerosis

Living with multiple sclerosis requires each person to reflect deeply on the new everyday demands and adjustments and recognize that some of the tasks efficiently completed now need a new approach. Accepting how the disease affects us and finding ways to accommodate it is the first step to life in the new normal.

Ron is an example of a deep commitment to the Christian faith. He was a Christian minister before Hurricane Ian devasted Fort Myers, Florida. He is reliant upon his faith to support his life with multiple sclerosis.

Both Jerry and Bob have the support of their wives. Much to their frustration, they take care of the physical demands of the household. Jerry has accommodated his difficulty with walking by using a cane and then a rollator. Bob has given up working in construction. Bob has found spirituality as a means of support.

Multiple sclerosis support groups have provided additional support to them. The support group gives social support to others who have MS. It is a safe place to share their stories and exchange new ideas about medicine and the latest research.

Ron has lived a tough life. Multiple sclerosis is part of his life. He continues to take care of his home and yard. He also belongs to a support group.

Living a better life through healthy decisions and being part of the lives of his children is how Phil maintains his life with MS. Phil accommodates his new normal by learning to change from participant to observer. He still supports his son in travel baseball.

Bill approached his new life by being proactive. Bill continues to share his story with others, gaining strength from its power. He decided early in his diagnosis to be optimistic. He realized he had a growing career and that MS may slow him down, but it wouldn't interfere with his goal.

Multiple sclerosis has forced much self-reflection within my approach to a new normal. I continue to struggle with frustration, fatigue, and physical demands. Walking has become an issue. To overcome this, I use a cane outside and at work. At times, a wheelchair at sporting events or airports. I have a handicap sticker to support parking. My teaching career is the best it's ever been. The accommodations of being less mobile have only created new avenues to explore.

I have become closer to my wife and family by sharing the obstacles I may face. I have learned to accept help from others, even without asking. At first, I was defiant about accepting help and support. I realized that receiving support was not a weakness. I've only become acceptable to the support in the last five years.

Masculinity

Multiple sclerosis can affect the physical capabilities of some men. Because life with this disease is unique for each person, the physical capabilities vary from extreme to tolerable. Each must construct their understanding of how to manage both the societal perception and their conception of the self. Because physical strength and stamina are often associated with masculinity, as men come to terms with the disease, they inevitably must reassess what it means to be a man. Shuttleworth et al., (2012) sum it up:

> A much-cited point by those who study the intersection of gender and disability is that masculinity and disability conflict with each other because disability is associated with being dependent and helpless, whereas masculinity is associated with being powerful and autonomous, thus creating a lived and embodied dilemma for disabled men. (Shuttleworth & Russell & Wedgwood & Nikki & Wilson and Nathan 2012, pp. 174-194)

Disability is viewed through the eyes of society as being dependent and helpless, challenging the idea of manhood—the ideal concept of autonomous, independent, and virile. The extent of this perception varies with the limitations of the disability. Asch & Fine., (1988) The conflict resides within the perceptions of masculinity before the disability and the acuities of the after struggle to create a new version of masculinity.

Life with this disease ultimately forces recognition of the parts of their past lives that are lost, things they can no longer do. Those losses often connect with notions of masculinity. Jerry lived an active life before his diagnosis; playing golf with his three children and later grandchildren was one of the things he enjoyed. Maintaining the household through daily chores such as cutting the grass and working on minor repairs was part of his life; some things he could no longer do caused emotional pain.

Jerry stated, "Well, understanding what a can and cannot do became difficult." It was difficult for him to accept. Knowing that he can no longer physically support his wife is hard for him; "that bothers me; it is just horrible." His inability to walk freely and knowing that he was no longer physically able to help his wife led to a sense of depression.

Phil explained, "I'm single now and have been dating." He approaches dating with complete honesty about his condition. However, many activities he might have done with a date, like riding bikes and mountain climbing, tire him out." He concluded that he had to give up on some of these activities. Dating became more challenging.

Body image and social perception are fundamental to interpreting femininity and masculinity. Gouverneur Morris (year), whose essay was reviewed in Chapter Two, compensated for the loss of his leg through sexual competition, trying to better the exploits of his female partners and trying to prove his masculinity. However, for many men with m.s., such compensation may not be possible. For example, Bob experienced physical deficiencies that affected his sex drive. Multiple sclerosis affects his bladder, forcing him to self-categorize. "I've been doing that for about 12 years now. I think of the physical things that I used to do. But mentally, I'm still adept."

Some with disabilities may attempt to hide their disability as a means to compensate for potential social scrutiny. As Migliaccio (2001) tells us, in fear of emasculation, many men try to hide or deny those qualities of their lives that result in this being abused, usually a recognized role for women. Being stigmatized in Western society may lead to denial of access to resources, the inability to assume a dominant identity, and the perception by others as a deviant.

Self-perception embodies both the personal and the presentation of the self within society. Both concepts work together to establish one's social identity. At the same time, it is possible to reconceptualize personal definitions of masculinity. Men with MS often need to come to terms with the social meanings of their disability, leading to confronting social stigma.

Social Stigma

How we present ourselves within our small group community and society is fundamental to how we perceive ourselves. Being cast aside as the outsider to the group dynamic can devastate our view of the self. After the diagnosis, men may begin to experience the effect the disease has on their physical capabilities. Some may attempt to disguise what is happening to their physical abilities, or they may embrace the inevitable.

Goffman states that within social situations, people seek to present themselves in the best means to create the impression to observers of the desired respect and serious consideration. "We take upon ourselves the role of the performer. The performer presents to the observer information about their socioeconomic status, conceptions about the self, competence, and attitudes toward others and themselves. Like a Shakespeare play, we become actors within the social dynamic presenting our best self." (Goffman, 1959, Introduction)

In my research, Bill spoke most directly to his fear of social stigma. He said, "Overall, I think the biggest thing for me when I first got diagnosed was, hey, how do I share this? Do I share this story, more or less, if it feels like you're not embarrassed? Still, you feel that if you tell people this, they might think differently of you, or it might appear as a weakness, or it might appear as maybe you have a vulnerability, and people might, you know, approach or interact with you differently."

According to Goffman, stigma is the social construct that ascribes a different and undesirable label to a subject, placing them into a different category. Within the social context, it is necessary to consider the perspective in which stigmatization occurs. Observable physical characteristics defined as a stigma include recognition of a difference based on branding and the subsequent depreciation of a person. Stigma is a negative condition recognized in society and negative postures that lead to discriminatory conduct towards a stigmatized group. (Goffman, 1963, in Int J Environ Res Public Health. 2020 Mar; 17(5)

Society tends, through observation the need to marginalize those who display positions that are outside the norm. Personal recognition and acceptance of being outside the normative disposition can lead to negative cognitions. The conceptual feeling of inadequateness, or the feeling of being "half the man," leads to increased anxiety.

Disability is causal to being branded with societal stigmatization. Walking with a cane gives notice of the disability. They are recognized as inadequate to the populace and in need of assistance. Although it is understood as an act of kindness, there are times that it becomes overbearing.

They reinforce the reality of the disability. Stigmatization occurs within the observation of the social environment and the personal perception of the self. Those diagnosed with m.s. are aware of the changes occurring within their disposition. How each person presents themselves within social environments may reinforce stigma. Any visual disability aids create a source of marginalization.

We can see the participants in the study grappled with using mobility aids. Jerry said that as his legs became weaker, "My fear of winding up in a wheelchair for the rest of my life" was at the forefront of his mind. To support walking, he now relies heavily on using a rollator walker. "I'm joined at the hip with one of those rollators, which I'm not a fan of, but it helps me get around." One can see his ambivalence in this statement as he weighs the stigma of the rollator against the freedom it gives him.

Physical limitations resulting from the progression of the disease upon the body or disabilities may marginalize or deny access to essential societal resources. Walking with a cane or other support tools in the Department of Motor Vehicles alerts the agent that further driving requirements must be addressed before granting a driver's license. A process that may take months or years to complete while you wait under house arrest.

According to Arnett, Frank, and Elliot, People diagnosed with multiple sclerosis are confronted with a lifetime of advancing disability, including pain, fatigue, muscle weakness, and cognitive dysfunction, as well as incontinence, sexual dysfunction, and depression. "From the moment people are diagnosed, they are burdened with the knowledge that they have a chronic illness that will, in some ways, influence how others see them and make them a potential target of stigma." They become the branded outsider to the norm. (Cook et al., 2016)

Cook states multiple sclerosis is frequently linked to both cognitive and temperament distractions in addition to physical disabilities. Some people with M.S. have at least some experiences of social stigma or biased treatment. (Cook et al., 2016).

Analysis Summary

Each participant shared stories of their active life before their diagnosis. Most shared extensive activities, while others were moderate in comparison. Golf and softball were standard in their lives before MS, and playing an active role with their children's families was significant to their lives. Most had little experience with disability before their diagnosis.

They all had successful careers, ranging from blue-collar jobs in the construction and electrical fields to white-collar technology-based positions. The ability to continue careers after the diagnosis of multiple sclerosis presented a challenge.

Some had to deal with physical limitations fundamental to the disease, bringing about early retirement from the construction, and others were able to maintain their careers with limited adjustments.

The men have had to face stigma related to physical limitations. This stigma related to this made them confront feelings of inadequacy and helplessness. At times, this perception brought a sense of depression. Both stigma and masculinity have become vital components of this inquiry. Both have a psychological impact on the visible disposition. Each must find a coping mechanism to control the anxieties presented with living with this disease. Each must construct a pathway to enable a healthy physical, spiritual, and psychological life.

A significant part of the creation of a healthy new life with MS is establishing strong support with family and friends. Communication and open dialogue with loved ones expressing the needs required for living with multiple sclerosis is a vital step in starting a new life.

Honesty with loved ones who provide support is essential in developing trust. There will be times that require empathy and compassion relative to unforeseen predicaments. Part of living with this disease is the acceptance that there are moments in life that require the support of loved ones and friends.

Open and honest conversations within the workplace will foster better work relationships. From day one in a new job or position, talk to colleagues about your limitations in the work environment. Accept new work positions that cater to your needs and constraints. A position that is compatible with your new limitations.

The Spiritual Warrior

Within the first chapter of this dissertation, the warrior, the image of the archetype of the masculine heroes of the ancient Greeks and Romans, was presented. The ideas of the warrior can present themselves in different contexts. Consider the spiritual warrior. According to Ruiz, the spiritual warrior accepts the challenges of dreams of fear, falsehoods, and beliefs that create unhappiness and suffering. They understand that happiness is a choice. Ruiz (2001)

> A Spiritual Warrior learns not to measure progress in the war using the metrics of only one battle. A Spiritual Warrior learns to retreat, rest, recover, learn from

> their actions, regroup, and then stand up again to take another step on his path. Even when losing a battle, much progress is made. (**https://www.toltecspirit.com/2013/03/spiritual-warrior-3/**)

Life's journey with MS embodies retreating, resting, and recovering periods. Some moments within the journey require retreating from actions that may result in potential physical harm. Walking, for example, requires attention to the safest pathway, avoiding obstacles that could impair the movement.

I was resting when fatigue began to affect the body and its physical ramifications. Fatigue is a common symptom of multiple sclerosis, requiring periods of rest and recovery before continuing activity. Bob realized the importance of rest and recovery. "I still have good upper body strength and things like that. I'm cautious. When I feel like the left side of my body is getting weaker, and I'm having trouble walking and keeping my balance, I ease up, take a break, come in and rest, and get into the air conditioning."

Often, diagnosis events force a reevaluation of life goals. The physical ramifications of the diseases are instrumental in life changes. Adapting to new limitations in your career or job leads to regrouping. Bill decided that, early in his diagnosis, he was optimistic and still growing in his career. He had very high career aspirations. "This could not slow me down if I were going to align and follow through with everything I was trying to accomplish. So that was reassuring. I think that being open and honest about it was positive."

The essential tool of the spiritual warrior is awareness and the ability to understand the truth of what is happening, free from interpretations. It is vital to the state of consciousness to discern the facts and reality. Freeing the mind from false beliefs and perceptions. (Ruiz, 2001)

The spiritual warrior develops the discipline, awareness, and emotional strength to overcome confronted obstacles.

> The big difference between a warrior and a victim is that the victim represses, and the warrior refrains. Victims are repressed because they are afraid to show their emotions, afraid to say what they want to say. Refraining is not the same thing as repressing. To refrain is to hold the emotions and express them at the right moment, not before, not later. That is why warriors are impeccable. They have complete control over their own emotions and therefore over their behavior.
>
> **―** Miguel Ruiz, (**ttps://www.goodreads.com/work/quotes/376130-)**

The role of the victim is easy to accept after the initial diagnosis of multiple sclerosis. Why me? This is the profound question of the victim, followed by self-misfortune. It is easy to fall into the trap of self-pity and continue to seek solace within the role of the victim. However, at some point, they choose to fight. Self-loathing is unacceptable, so they seek a new path of acceptance, trying to move forward in their new life.

Warriors are constantly learning and adapting to overcome any hardship and obstacles that multiple sclerosis presents. It takes time to be able to throw away the idea of the victim. However, spiritual warriors must live their lives rather than wallow in the victim's life.

Recommendations

For those who have been diagnosed with multiple sclerosis, get a second opinion. Because multiple sclerosis is difficult to diagnose, it is to your benefit to be sure. Have all the conclusive tests and exams been completed to bring all the conclusive evidence supporting the diagnosis?

For those recently diagnosed with multiple sclerosis and are apart to begin their new life with this life-altering disease, understand you are not alone. Look to your spouse, family, and friends for their emotional support. Join multiple sclerosis groups within your city or join online support groups. A total of 2.8 million people are estimated to live with MS worldwide.
National Institute of Health, (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7720355/)

Choose a specialized multiple sclerosis neurologists who possesses the knowledge of the best way to approach your unique diagnosis and can offer the best medication for your case. When discussing your diagnosis with your neurologist, write down as many questions as possible.

Do your research on multiple sclerosis. Research all the medical therapies and drugs to know what might be best for you. MS therapy and drugs are not all the same. It may take a period of trial and error to find the best solution for you. Conclude that you're in for a fight and acknowledge emotional support is essential.

Sharing your story can be a great way to open dialogue with those close to you. Within support groups, it is often said that here, we all have MS. You are not alone in your struggle. Meetings become a social environment with people who live within your community. Support groups are essential to establish camaraderie and share information on recent research developments and how others have adapted to life with multiple sclerosis.

Find your path to living with this disease. Accept the advice of others who are living with m.s. They are the ones who have the experience. They can offer valuable insights into the best solutions to overcome the problems you may encounter in your new journey.

Final Reflection

Life with multiple sclerosis is a process that each of us who has this disease has to endure. It begins with realizing something is wrong with your body. It may be a loss of balance, an experience of dizziness, weaknesses of limbs, or vision-related occurrences that prompt a visit to the doctor. After several doctor appointments, M.R.I. testing, and other conclusive tests, the result is yes, you have multiple sclerosis. You must begin to figure out and reconstruct a new way of life at this point in the process.

The participants in this inquiry have lived through the process. Each has a unique pathway within their journey. Each story offers a glimpse of their processes. We learn about who they are and the obstacles that confront them. We learn how they could renegotiate a life, overcome anxiety and fear, and live their best life. Each shared their emotional responses to all their experiences living with MS. They gave insight into how they approached each step in the process in a way that would benefit others.

The interview process within this dissertation was a challenging task. Some participants began conversations with difficulty. Jerry, for example, began answering the questions with limited responses. A second interview was needed. Others were more open in their responses. Bob was very talkative during his interview, and Bill provided deep insight into his process.

The participants' stories have provided lenses into their lives with MS. They provide the human emotional perspective of their ordeal. Sharing all of the hardships they encountered has left a deep admiration. They have found a way to establish a new meaning in their lives. Life with this disease is a process. Each step from life before, the diagnosis, and life after each play a role. The participants lived through the process and are still moving forward.

This dissertation is a process. It has a life of its own. It has changed from the original conceptual theory to the final words. With every rough draft along the way, it has moved along. I was told earlier during this process that the work would change with every step. They were correct.

I have been fortunate to have learned the human struggle that these men have endured. The conversations have breathed life into the words. I feel a camaraderie with every one of them. I cherish the time spent with them. Their stories will prove to be beneficial to those who are newly diagnosed with multiple sclerosis. They will realize they are not alone; others have lived through this experience and found their way to a new life.

The journey of life with MS is never-ending. Like the men who willingly participated in this inquiry, the struggle continues. Continuing the advocacy for support of those who have multiple sclerosis has become part of my life. Silence was not the best way to provide help and support for myself and others. Teaching others about multiple sclerosis and its effects on the lives of those who suffer from this disease is a better way to advocate proactively.

Teaching has been my calling for thirty-five years of my life. MS has not taken that away. The classroom has become a sanctuary. The goal has always been to evolve into teaching in higher education. Having reached the goal of finishing the doctoral journey, the question of the next step has to the forefront of my thoughts.

Perhaps continuing to write about my journey with life with multiple sclerosis may be a plausible option. Continuing research from the caregiver’s perspective who supports a loved one who struggles with MS is a valid option. I have always asked others the question, once you have achieved your doctorate, what will you do with your achievement? There is no correct answer to that question. My doctoral journey was mine and mine alone. Of course, I had much help and support, but the cause was mine. Personally, continuing foreword is the best option.

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