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A Phenomenological Study of African American Women with Multiple Sclerosis:
Disability Identity and the Superwoman Schema

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Abstract

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A Phenomenological Study of African American Women with Multiple Sclerosis: Disability Identity and the Superwoman Schema

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For African American (AA) women, the conversation regarding the acknowledgment of having a disability is considered a ‘taboo’ phenomenon and rarely associated with the holistic construct of one’s individual identity (e.g., Loveland, 1999). This concept of awareness and acceptance of corresponding impairments from a physical or mental illness is known as disability identity (DI) (Dunn & Burcaw, 2013). Similar to this conversation about the development of a disability identity is the phenomenon known as the superwoman schema (SWS) (Wallace, 1978; Woods-Giscombé, 2010). The principles outlined in theoretical perspective SWS provides rationale to support the hypothesis that historical roles and innate obligations to care for the needs of others (Black & Peacock, 2011; Black, Murry, Cutrona, & Chen, 2009; Beauboeuf-Lafontant, 2008) may overshadow the process of returning to a state of holistic wellness after being diagnosed with an acquired disability.

In general, research suggests that for people diagnosed with acquired disabilities it is a beneficial and critical part of rehabilitation to confront physical, mental, emotional and even spiritual weaknesses in order to improve overall health (Gill, 1997). Together these two phenomenons suggest potential conflict to the commitment surrounding self-care and commitment to the community for AA women. In order to assist AA women
with MS in the process of disability identity development and adjustment to disability after being diagnosed this research investigation was designed to answer the following three questions: 1) Do African American women associate with the superwoman schema?, 2) What is the essence of the lived experience for African American women with MS?, and 3) What challenges do African American women with MS experience in regards to maintaining role obligations of SWS and the development of a disability identity?
Dedication

“Normal is an illusion, what is normal to a spider is chaos to a fly” - Charles Addams. I dedicate this dissertation to all of the Black women in my life who have redefined ‘normal’ in order to triumph over chaos.
Acknowledgments

The successful completion of this dissertation would not have been possible without my amazing dissertation chair/doctoral advisor, Dr. Mona C. Robinson. This journey could not have been possible without your support and encouragement. Thank you for believing in me. You are a “Superwoman”! I would also thank my amazing dissertation committee for their devotion to helping me construct a document that I could be proud of. Special thank you to Dr. Adah Ward Randolph, Dr. Nikol Bowen and Dr. Valerie Martin-Conley. An additional thank you to Dr. Renée A. Middleton for leading and paving a path before me as a future leader within the halls of the academy.

I would like to acknowledge my family for being the supportive force behind my success; I consider it nothing less than a blessing to have parents (Dwight and Brenda Henry) who have prayed for my healing, health and prosperity since I was in the womb. Thank you and I LOVE YOU! To my sisters (biological, sisters in Christ, and members of Delta Sigma Theta, Sorority, Inc.) thank you all for making me laugh when I wanted to cry and smile when you noticed a frown on my face. Your support has been amazing, thank you! I love you all and promise to make you proud!

Finally, and most importantly, I give all the praise, honor and glory to God who bared a cross for me so that I would have this opportunity. Being a woman with MS myself, they told me I would never be able to do this. I replied, “You don’t know the God that I serve. He has made me in his image and I am more than a conqueror”. Thank you!
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Chapter One: Introduction

Using a qualitative form of inquiry from a social constructivist worldview, this investigation was designed to appraise the real-life experiences of eight (8) African American (AA) women diagnosed with Multiple Sclerosis (MS) (Creswell, 2009). This study investigated the unique daily happenstances that challenge the ability of AA women with MS to establish a disability identity (DI) (Dunn & Barcaw, 2013; Wehmeyer, 2013; Bogart, 2014) and simultaneously maintain the strenuous demands of the superwoman schema (SWS) (Woods-Giscombè, 2010). Disability identity (DI) is the construct in which an individual gains a level of awareness and acceptance of impairments following medical diagnoses of a disabling condition (e.g., Dunn & Barcaw, 2013). Cinolu & Arikan (2012) explains “identities are meaningful” components of an individual’s self-concept and self-esteem and plays a significant role in how one understands life (p.1116). The superwoman schema (SWS) is known as a proposed set of obligations in which African American women, particularly, have responsibilities to care for the needs of the family and community. These include: 1) obligation to manifest strength, 2) obligation to suppress emotions, 3) resistance to being vulnerable or dependent, 4) determination to succeed, despite limited resources, and 5) obligation to help others (Wallace, 1978; Woods-Giscombè, 2010). The SWS is also considered a component of self-concept and self-esteem for some African American women.

Consideration of the importance of psychological rehabilitation gives rationale to support the notion that these historical roles and innate obligations to care for the needs of others (Black & Peacock, 2011; Black, Murry, Cutrona, & Chen, 2009; Beauboef-
Lafontant, 2008) may overshadow the holistic wellness of an AA woman after being diagnosed with an acquired disability. By way of a qualitative design to obtain thick rich descriptions of personal accounts that describe one’s ability to identify with having a condition such as MS, this study addressed two major assumptions with four specific goals. (Lincoln & Guba, 1985)

The first assumption addressed in this study is whether or not African American women actually associate with the SWS and its historical obligations to care for the needs of others (Woods-Giscombé, 2010). This is considered a historical obligation due to the unique past of AA women, which stems from and beyond slavery. Similar to the racial identity theory developed by Helms (1993), disability identity is a component of self-efficacy and self-concept, as well as an important factor in adjustment (e.g., Bogart, 2014; Amtmann, et al., 2012; Boehmer, 2007; Bandura, 1977). Thus, the second assumption explored through this research investigation was whether, or not disability identity development is hindered by the obligations of SWS.

Once these two assumptions were explored, the investigation considered four major goals for this research. The first goal was to understand the explicit affiliations of role obligations to care for others and care for self amid African American women with this particular disease. Second, this study looked at how the identity of an AA woman pre-diagnosis with MS differs from her identity following the MS diagnosis. Next, this investigation identified themes that emerged during each interview suggesting a connection or conflict between SWS and DI. Finally, this research obtained data about
AA women with MS so that health care professionals can better assist patients in adjusting to their disability while honoring their culture

**Multiple Sclerosis and African American Women**

According to the National Institute of Neurological Disorders and Stroke (NINDS), there are currently 250,000 to 350,000 people diagnosed with MS in the United States of America with an estimated 200 new cases reported weekly (NINDS, 2014). A fundamental influence for conducting this current investigation is to obtain knowledge about the process of disability identity development specifically for African American women since prevalence rates have indicated a shift from the previously recognized projections that found White women to have higher risks of receiving a diagnosis of MS (e.g., Noonan, et al., 2010). Specifically, the Langer-Gould, Braram, Beaber & Zhang (2013) longitudinal investigation of the Southern California Kaiser Permanente Healthcare System, which found that per MS cases in women: 79.3% were Black, 67.8% White, 68.1% Hispanic, and 69.2 % Asian.

Original notions that Caucasians were diagnosed more frequently can be traced back to a 1957 study published in the *Journal of the American Medical Association* *(JAMA)* (Kurtzke, 2008). This investigation occurred across 11 Veteran Administration (VA) hospitals in a “multi-centered, placebo-controlled, randomized, double-blind, therapeutic trial” (Kurtzke, 2008, p. 1007). In 2008, editors of the *Multiple Sclerosis* journal invited JK Kurtzke, the original author of the 1957 study, to review these findings and the impact of the contributions made by the Department of Veteran Affairs, in order to respond to arguments that the research findings regarding the prevalence of MS lacked
representativeness of the current population. In response, Kurtzke (2008) challenges new researchers to replicate his study, with confidence that the overall design was sound, and if it were to be conducted on the current population of military members with MS the data would be sound also. Kurtzke recognized that the study served as evidence to a good instrument, yet had a poor sampling procedure suggesting that there was a lack of representation of African American men and women. Thus, Wallin and his colleagues developed the 2012 research investigation across all five of the military branches, which also found evidence to suggest that African Americans’ and women, in general, had higher incidence rates of MS diagnoses. Furthermore, Wallin, et al, (2012) agreed with Kurtzke that conventional studies on prevalence and risk of MS neglected attention to AA women being that investigations were conducted on a “regionally based and were not reflective of the demographic diversity of the US population” (p. 1779); however the design of the initial investigations were solid.

With findings becoming more representative of diversity and pointing solely to high incidence of MS in AA women a need has been identified to address the gaps in psychosocial literature on disability identity development. Specific to this investigation, it is observed that these studies and the other available literature on adjustment to having MS (i.e. Langer-Gould, 2012; Wallin, et al., 2012; Kurtzke, 2008) fail to highlight and address the responsibilities that African American women face, especially in regards to the coping and the identity formation process after receiving a diagnosis. Exposure to this information seeks to help professionals understand how the coping and adjustment process through the development of a disability identity might improve if it was inclusive
of their ongoing commitments, as well as, cultural and historical ways of coping with difficulties or challenges. Thus, the purpose of completing this current study is to contribute practical standards of treatment in medical, mental health and rehabilitation counseling professions when working with AA women with MS. These considerations include a focus on disability identity and role governing for AA women. Essentially, this current study attempts to familiarize health care professionals with insight about the concept of resilience for African American women with the diagnosis of MS and how they meet the needs of their communities and themselves (Durand, 2006).

In the remaining sections of this chapter, the reader will be introduced to the unique components that contribute to African American womanhood, and explore situational factors that suggest stressful lifestyles (Woods-Giscombe & Black, 2010; Hamilton-Mason, Hall, & Everett, 2009) such as the duty to uphold the “superwoman schema” (Black & Peacock, 2011; Woods-Giscombé, 2010). The assumption that AA women have super powers is a myth, which dates back in history to the era of slavery (Wallace, 1978), yet remains a prominent cause of stress for black women (Woods-Giscombé, 2010). The tenets of the SWS are considered obligations that can not, contrary to popular belief, simply be dismissed due to personal life or health related issues that may arise. So by focusing attention on the intersection of disability identity development and SWS the experiences of AA women will be contributing to the overall understanding of being an AA woman with MS. Furthermore, this chapter provides a thorough description of the purpose of the study, background, in-depth declaration of the problem, and an overview of the significance of the existing literature. Following the description of
the above-mentioned components, there will be an introduction to the research questions that will be addressed in this inquiry. The final component of this chapter will provide the reader with brief insight of the selected methodology, identification of potential limitations and definition of terms.

**Purpose**

The purpose of this study is to examine unique occurrences of developing a disability identity (DI) for African American women with Multiple Sclerosis (MS) while simultaneously managing the strenuous demands of the Superwoman Schema (SWS). This investigation is directly influenced by the 2010 dissertation entitled *Women Confronting the Reality of Multiple Sclerosis: A Qualitative Model of Self-Healing* by Carol Romagosa from the University of Utah. Although the 2010 study provided great information about the coping process for women after being diagnosed with MS, the study has questionable relevance and representativeness to AA women since the themes that emerged were collected from a sample population that included seven White women and one Black woman.

With evidence identifying an increase in the number of AA women at risk and currently diagnosed with MS, it is important to consider how the coping process may differ for this particular racial group of women and establish literature on the best practices when working with this population. The aim of this research is to provide insight to the process of developing one’s identity to include disability (Bogart, 2014; Dunn & Burcaw, 2013; Weymeyer, 2013; Kurz, Saint-Louis, Burke, & Stineman, 2008; Pakenham, 2008) while upholding the demands of SWS (e.g., Woods-Giscombé, 2010).
Conversely, it is important to acknowledge that the existing literature on coping and adjustment process after an MS diagnosis is not completely oblivious to the needs of women, in general, instead can be considered highly misrepresentative to the needs of AA women.

The goal of this study was to discover themes related to the experiences of AA women with MS. Existing literature discussed the implications of role management for the AA “superwomen”. This literature also suggests that these obligations to care for others can have negative effects on general health outcomes (e.g., stress, depression), even if no formal medical diagnoses have been rendered (Woods-Giscombé, 2010). Unfortunately, the post-diagnoses experiences related to coping with the diagnoses for AA women continues to lack cultural specific evidence. The desire of this research is to understand how these same role obligations might affect one’s health maintenance post-diagnosis; regardless of whether the obligations encourage or conflict with healthy life maintenance. One of the implications for clinical practice and future research found in the article by Woods-Giscombé (2010) suggested that awareness of how the influences of SWS manifests, for this particular racial and gender group is an imperative component of stress management. Therefore, this current study considers concepts, such as, the disability identity development model (e.g., Bogart, 2014; Dunn & Burcaw, 2013; Pakenham, 2008) and the psychosocial stages of adjustment to disability model (Dutta & Kundu, 2007) in order to understand in what ways components of superwoman schema might affect disability identity development. These aspects combined make up the theoretical framework to guide the analysis of meaning behind this phenomenon.
Healthcare professionals, individuals who have been diagnosed with MS and their caregivers (i.e. husband, parents) are expected to benefit from this discourse on establishing healthy coping skills for women who often rely solely on resilience in order to persevere. The overarching concern addressed in this study is instituted under the notion that “superwoman” characteristics are often misconstrued as detrimental or a hindrance to the establishment of a healthy disability identity. Currently, the assumption under debate is that obligations and responsibilities may be considered distracting to AA women with MS. However, according to literature that emerged during the black feminist movement, such obligations might actually serve as supportive tenets, in order for one to feel needed and fulfilled (Wallace, 1979).

**Background of the Study**

Multiple Sclerosis (MS) is an autoimmune disease typically diagnosed in persons between the ages of 20 to 40 years old, mean age of 30 years old (Milo & Miller, 2014; NINDS, 2014). Furthermore, MS is known as a disease that affects the central nervous system (CNS) “characterized by inflammation, demyelination (Guerra, 2013; Sinclair & Scroggie, 2005; Holland, Murray, & Reingold, 2002), axonal loss, and gliosis in the brain and spinal cord” (Milo & Miller, 2014, p.518). An additional known fact about MS is that diagnoses are typically rendered clinically (e.g. observation of symptoms, Magnetic Resonance Imaging). There are five forms of MS, each characterized by the patterns of disease progression, these include: 1) relapsing-remitting (RRMS), 2) primary progressive (PPMS), 3) secondary-progressive (SPMS), 4) progressive-relapsing (PRMS), or 5) clinically-isolated syndrome (CIS) (Milo & Miller, 2014). Although these
identified forms of MS are based on patient health characteristics at the time of disease diagnosis, there is no certainty in knowing the exact prognosis of the disease; medical physicians (i.e. neurologist, physical therapist) can declare no projection of potential long-term disability. The only verifiable conclusion is the progressive pattern of symptoms which “remit spontaneously” (NINDS, 2014) due to exacerbations directly associated with stress (Lalive, Burkhard & Chofflon, 2002; Gold, et.al, 2005).

Trademarked as an unjustifiable and incurable disease, the process of producing an MS diagnosis has been the topic of debate for many years. In a recent review of the diagnostic criteria by Milo & Miller (2014), writers deliver a comprehensive consideration of indicators that inform physicians to make sound distinctions between MS and other diseases with similar characteristics (e.g. Devic’s disease, sickle-cell anemia, lupus). Beginning with the notations made by the “Father of Neurology” Jean Martin Charcot, authors Milo & Miller (2014) explained the evolution of the diagnostic criteria which still includes “loss of myelin, proliferation of glial fibers or nuclei, and axonal damage” however more specific features have been identified (p. 519).

Poser and Poser (1983) presented a criterion specific to the gestational history of MS resulting in the progression index that measured prognosis using a formula of the level of disability divided by age of onset. The progression index was beneficial an led to the development of a more comprehensive criteria. Developed in 2001 and revised in 2010, this record of diagnostic criteria, known as the McDonald criteria, now provides specific evidence to consider while making a clinical determination regarding the cause of illness (Polman, Reingold, Banwell, Clanet, Cohen, et al., 2011). The McDonald
criterion consists of gathering information on number of attacks, number of lesions and progression of lesions with respect to time and space. This system of making an indisputable MS diagnosis is often used in conjunction with special imaging technology known as magnetic resonance imaging (MRI) (Milo & Miller, 2014).

As previously mentioned demyelination, the source of lesions, and inflammation are two primary characteristics of the disease. Demyelination is visually comparable to a frayed wire or electrical cord; damage to the protective covering, i.e. myelin sheath, causes interference of the nerves' ability to relay and receive signals throughout the body. Corresponding physical consequences of demyelination vary from person to person and symptoms of this unpredictable disease often cause difficulty with thought processing, speech, vision, balance, and mobility (Tzortzis, et al. 2008; Wood, et al. 2012). Additional features of the disease include numbness, motor weakness, fatigue, depression/other emotional changes, heat intolerance, and Lhermitte’s phenomenon (O’Conner, 2002; Compston & Coles, 2008; Milo & Miller, 2014). Nevertheless, advances in the criteria for a diagnosis of MS, has been enhanced by the evolution of neuroscience resulting in earlier detection of lesions. Treatment therapy for MS should not be confused with a cure; instead, this therapy acts as an approach to reduce disease activity and progression of additional symptoms/features. Drugs such as, Aubagio, Avonex, Betaseron, Rebif, and Tysabri serve the purpose of treating the disease on a cellular level and the use of pharmaceutical intervention is known as the medical model (Krieger, 2011). However, more holistic mental health interventions have been identified
as necessary for serving this populations (Shah & Mountain, 2007; Ward, Clark, & Heidrich, 2009).

In addition to the conversation of the etiology of MS, it is important to explore the prevalence of the disease as a foundational component of understanding the background of this study and piecing together its significance. Associated with and identified across a variety of racial groups, multiple sclerosis has historically been associated to have a primary prevalence amongst Caucasians, particularly gender exclusive to males (Berlin & Kurtzke, 1957). Nonetheless, recent research has emphasized that in addition to the individualized response one has to MS symptoms, racial groups, for instance, Caucasians and people of Color, have remained subject to experience the ramifications of exacerbations differently due to their genetic compositions (Gupta, Goren, Phillips, Dangond, & Stewart, 2014). Challenges in the belief that Caucasians are more likely to be diagnosed with MS suggest that the lack of focus on coping with the symptoms of MS and adjustment to the implications of an MS diagnosis for African American women indicates a deficiency in the multicultural based treatment that physicians, counselors and other mental health professionals can potentially provide (Ožura, Erdberg, & Šega, 2010)

Apart from physical impacts, individuals diagnosed with MS face emotional and personality challenges. In a study conducted by Ožura, Erdberg, & Šega (2010), fifty-one patients (13 males and 38 females) at the University Medical Centre Ljubljana were assessed to highlight the primary personality characteristics of people with MS using the Rorschach ink blot test. According to the findings of this study, personality is labeled to have a high correlation with the way in which one can manage stressful situations (2010).
This research described that most of the patients who participated in the study found it easier to cope/manage situations if they simplified situations by steering clear of emotional and cognitive complexity (2010). Although this study took place in Slovenia, and primarily included Caucasian women, it is one of few studies that assessed the management of stress in those diagnosed with MS. Moreover, this research found that people diagnosed with MS experienced symptoms of inadequacy and conversely relied on avoidant personality coping style. Schwerdtfeger, Schmukle, & Egloff (2005) suggested people who have characteristics of avoidant personality “are more engaged during social evaluative tasks and show better performance during such stressors” (p.107). However, although individuals have a desire to be close with others the persona that they exhibit in front of others is considered a façade.

The researchers concluded the discussion on personality characteristics of multiple sclerosis patients by stating that the “sample seemed to largely rely on an avoidant style of coping with problems” (Ožura, Erdberg, & Šega, 2010, p.631). The overall interpretation of the findings suggest that MS patients who can simplify a task or have avoidant personalities might have a better time adjusting to disability. However, this simplification and avoidance might be problematic for women who associate with SWS and its corresponding obligations to care for others. Finally, findings of this study also suggest that along with the progression of MS, self-care management and lifestyle adaption skills are often obstructed, “the way these patients communicate and cope with their environment…may have significant implications for effective intervention” (2010, p.631). Potential psychological effects noticed in persons with MS include: sadness, loss
of energy, feeling of worthlessness and hopelessness, loss of interest, irritability, fatigue, appetite changes, decreased sex drive, and thoughts of suicide (Sullivan, 2014).

Johnson, Terrell, Sargent & Kaufman (2007) propose one major piece of literature on the experience of AA women with MS. With the major concern of this research pinpointing whether the current literature available on coping and adjustment measures for patients with MS is conducive to African American women and the historical and cultural ways of coping, this article serves as additional grounds for the relevance of conducting the current study. This article describes the impacts of MS on African American women compared to Caucasian women; and highlights the importance of understanding cultural needs related coping, adjustment, and access to resources. In the design of this study, the researchers were aware that one of the well-known issues that African Americans, particularly, have been inclined to experience a more aggressive course of symptoms leading to a rapid progression of disability (Johnson, Terrell, Sargent, & Kaufman, 2007).

Although evidence confirmed that stressors and resources available for African Americans and Caucasians with MS were closely related, African Americans with MS had significantly fewer years of education, fewer friends (e.g., social support), and higher levels of financial stressors (2007). Researchers reported that “overall few differences were found between the two ethnic groups in quality of life, symptom severity, social stressors and resources” (Johnson, Terrell, Sargent & Kaufman, 2007, p. 211). The original sample recruited for the study included 29 Whites and 23 African Americans with Multiple Sclerosis. There was a 15% dropout rate of African American causing the
sample to include 28 European Americans and 16 African Americans. The low response of African American participants indicated a selection bias in the study and posed a serious threat to validity, according to the authors the reliability of the findings are questionable due to this threat (Johnson, Terrell, Sargent & Kaufman, 2007).

An important concept obtained from the finding of this research is that in order to understand the experiences faced by AA women it is important to research AA women, in particular, with a closer lens. This research commitment is imperative with the estimated increase of risk, diagnosis rates, and disease progression amongst AA women (Wallin, et al. 2013; Langer- Gould, et al., 2013) Furthermore, attention to the process of disability identity development and use of coping strategies are proven necessary because African American women have a tendency to take on the obligations of the SWS. This can ultimately mean that AA women associate with being capable of serving multiple roles for other (e.g., mother, father, doctor, teacher, pastor, student) all while avoiding personal needs a related to MS diagnosis.

The conflict detected is that if avoidance of stressful situations has been associated with better coping outcomes and the development of disability identity, then it is anticipated that AA women who identity their lives as inherently drawn to stressful and avoid association with disability identity because of obligations to others may face increased challenges with health. These roles and responsibilities may interfere with the attention required for health maintenance. In reviewing the evidence presented in Ozura & Sega (2010) and Johnson, Terrell, Sargent, & Kaufman (2007) it seems important that the process of coping and adjustment be examined in order to help AA women with MS
establish a healthy disability identity and decrease levels of stress for physical and mental well-being. This current study is designed under the notion that if stress is managed there will be an increase one’s ability to develop a DI while maintaining the strenuous demands of SWS. Furthermore, this research seeks to address concerns regarding the reason why AA women with MS have higher frequency of symptom exacerbations leading to fast progression of disability than Whites (e.g., Kaufman, Johnson, Moyer, Bivens & Norton, 2003; Baker, 1998). By identifying themes related to disability identity development statuses and the influence of roles and responsibilities this study assists service providers from various fields (i.e. neurology, counseling, and social worker) in implementing plans of care for AA women with MS. Furthermore, this study helps understand the cultural perspectives of the disease, as well as, provide an understanding of how AA women develop characteristics of disability as a part of their identity following an MS diagnosis.

African American women experience stress differently. According to Black & Peacock (2011), In the article entitled, Pleasing the Masses: Messages for Daily Life Management in African American Women’s Popular Media Sources, the authors discuss the three pathways of self-reliance typically observed in African American women. These three pathways comprise of: 1) managing role responsibilities, 2) managing stressors, and 3) managing basic self-care. While these may seem like universal issues that all women face, the actuality of the matter is that African American women tend to place their personal needs on the back burner under the belief that they have no other choice (p.147). Additionally, although stressors present in the form of desire to care for others, often AA women feel disconnected from external resources and isolated (Wallace, 1978; Black,
Murry, Cutrona, & Chen, 2009). Thus, the ability to care for other creates cognitive dissonance between disability identity and SWS. In this instance, the only real support is found in associations with higher powers and faith (Black & Peacock, 2011).

Evidence found in contemporary studies supporting the prognosis of MS across multiple racial groups attest that African Americans tend to have more aggressive courses of the disease, which causes a significant reduction in physical functioning (Kaufman, Johnson, Moyer, Bivens & Norton, 2003). Conversely, in more current literature, for example the recent three-year investigation in the Kaiser Permanente Healthcare System of Southern California, not only were African American women found to have aggressive symptoms but also a higher frequency of overall diagnoses above African American men, Caucasian men and Caucasian women (Langer-Gould, et al., 2013). Moreover, the Langer-Gould, et al., study provides distinguishable evidence and a projection for the future of diagnostic trends for African Americans and other underrepresented racial groups.

One can conclude that the findings of the Langer Gould, et al., (2012) study provide valuable evidence and paint a more accurate picture of MS prevalence as the country begins to respond to the new governmental mandates for all U.S. citizens to have medical insurance. Questions have surfaced in regards to whether African American women have always had a higher risk of being diagnosed, but did not have the provisional means to seek treatment (Langer-Gould, et al, 2012). As a result, the National Multiple Sclerosis Society (NMSS) now provides resources to African Americans who have been diagnosed. These resources include evidence regarding the cultural traits of
being more likely to experience more relapses, more likelihood to experience greater
disability, greater risk of requiring ambulatory assistance, and a greater likelihood to
develop issues with optic neuritis and transverse myelitis (NMSS, 2015). Additional
resources available on the website of NMSS, include links to research articles, invitations
to participate in research/ genetic studies, links to build social supports under the prompt
of an African proverb that states “when spider webs unite, they can tie up a lion”, and
three video testimonials of actual African American MS patients. The concern lies with
whether this will be enough to assist African American’s and women particularly in
learning to adjust after a diagnosis (NMSS, 2015).

Significance

This section will review the significance for exploring the experiences of African
American women with MS. This study seeks to first address two assumptions related to
the way AA women cope. However, the overall aim is to address the research questions
and contribute useful information to the body of existing literature The first assumption
to be addressed in this study is whether African American women actually associate with
the SWS and its historical principles of caring for others (Woods-Giscombé, 2010). The
second assumption that will be explored is whether disability identity development, is
hindered by obligations of SWS. In terms of significance, this study hopes to contribute
valuable information to assist, not only, AA women with MS but also their health care
providers in developing and implementing treatment. In addition to the two assumptions
mentioned above, this research study consists of four corresponding levels of
significance. These levels include: 1) to encourage positive health promotion, 2) to
explore the ramifications connected to denying disability or rejecting the development of disability identity, and 4) to explore the needs of this group in order to determine best practices on important lifestyle modifications.

**Levels of Significance**

**Significance goal one.** The first level of significance is to encourage positive health promotion behaviors (Stuifbergen, 1995). This 1995 work centered on health promotion behaviors and suggested that concepts of health promotion behaviors were practices that helped increase the overall quality of life for someone with a disease or disorder. These concepts consisted of demographic and disease factors, barriers, resources, and perceptual factors (1995, p.33). The following paragraph looks closely at each of the four concepts of health promotion behaviors in detail. Demographic/disease factors are considered to be an “association between demographic factors (age, gender, education, employment) and disease related variables (severity of illness/disability/length of illness) (1995, p.33)”. The second concept of health promotion behaviors is resources. Resources in health promotion behaviors can include social supports or self-buffering through meditation. Third is the concept of barriers, which include: time, distance, cost or availability of services. Regardless of if these barriers are internal or external there still lies the potential to experience difficulty with coping if any inconveniences arise. Lastly are the perceptual factors, which embody “perceived health, self-efficacy, and perceived demands of illness” (1995, p.35). As this research investigation takes shape it recognizes that the incorporation of health promotion behaviors may play a significant role for disability identity development in AA women with MS. A more recent study by Tyszka
& Farber (2010), supports that notion that “significant relationships were found between health-promoting behaviors (total) and increased role participation (fewer limitations from either emotional or physical health reasons) and the mental and physical components of health related quality of life (HR-QOL) (p. 654)

Significance goal two. A second area of significance in conducting this study is to explore how the experiences of AA women with MS might impact development according to Brofenbrenner’s Ecological system. This theory of human development by Urie Bronfenbrenner, suggests that the social constructs of a person can play a major role in the way that the individual views the world around them (Bronfenbrenner, 1992). Gauvain & Cole (2004) suggested that the theory was originally introduced in the 1970s as a framework that “provided development psychologists with a new way of thinking about the many environmental influences that affect human development” (p.3). According to the theory there are various key components of the model, which include two propositions and five systems of development.

The first proposition of the theory suggests that during the early parts of life, human development occurs through a “complex reciprocal interaction” between the individual, objects, and symbols from the environment closest to them (Gauvain & Cole, 2004, p.4). The second proposition indicates that the formation, power, content and direction of the experiences of development can be separate, but naturally this components end up working together in a systematic process of character building (Gauvain & Cole, 2004). The Bronfenbrenner theory has been noted to also suggest that while these two propositions are mutual, any research designs that seeks to investigate
both at the same time is known as a the “process-person-context model” (Gauvain & Cole, 2004).

In addition to the above mentioned propositions, the Brofenbrenner ecological systems theory of development also contains factors of five environmental contexts that affect development. These include: 1) Microsystems, 2) Mesosystems, 3) Exosystems, 4) Macrosystems, and 5) Chronosystems. This section will briefly discuss each system of the Brofenbrennen model. In chapter two, there will be a more detailed discussion of how each system might impact the development of AA women with MS. The microsystem, is suggested to include a pattern of social roles that are typically experienced interpersonally. These patterns deal with the face to face interactions with others that either “invite, permit, or inhibit engagement with members of a family, social group, or workplace” (Gauvain & Cole, 2004, p.5). The mesosystem is described as the interaction of two or more different settings in the individual who is currently developing is directly involved. Similarly, the exosystem also contains the interaction of two or more settings, except in this system the individual is not directly connected.

The macrosystem is defined to be “the overarching pattern of micro-,meso- and exosystems” and the characteristics that one might exude in a given culture (Gauvain & Cole, 2004, p.6). These make up the life-style, resources that one might be available to, opportunity sturctures and hazards (Gauvain & Cole, 2004). Finally is chronosystems. This is the system in which time and chronological events attribute to the way in which the growing individual develops. The systems of this theory do not have to occur in a particular hierarchy, however it is suggested that “the heritability can be shown to vary
substantially as a direct function of the magnitude of proximal processes and the quality of the environments in which they occur” (Gauvain & Cole, 2004, p.6). According to these systems, the current study has been design to determine how the influence of having MS might alter the ability of AA women with MS to remain involved in superwoman roles (i.e. motherhood, professional leadership). These systems of development will also address the idea that the lack or rejection of disability identity can potentially foster decreased rather than heightened control over stress, and ultimately over disease exacerbation.

**Significance goal three.** The third area of significance behind this investigation is to explore the ramifications connected to denying disability or rejecting the development of disability identity. Denial in general is associated with stress and anxiety. For example, Telford, Kralik, and Koch, (2006) discussed in a literature review and meta-analysis the implications of the responses people have to living with chronic illness (p. 457). Explored by explaining the background of concepts related to acceptance and denial beginning with a look at the psychoanalytic theory by Freud, it is a belief that these concepts are accompanied by the understanding that denial can have “strong negative, pathological connotations” and thus hinders the adjustment of people to disabilities (p. 459). The negative outcomes of denying disability can be associated with connection to stress according to this literature. Taking this a step further stress being connected to a heightened frequency of symptom exacerbation in MS there is again concern that a more rapid course in dysfunction and performance of AA women can transpire (Williams, 2010). These concerns are associated and largely contributed to an
attempt of avoiding what is interpreted as a persona of weakness. Through an in-depth look into the experiences of AA women, findings will contribute to understanding implications of MS within the African American community and help provide better support for AA women as they adjust to the intersection of a disability identity and the roles of SWS.

Significance goal four. Attentive to the needs of this population, the last component of the significance in completing this study is to explore the needs of this group in order to determine best practices on important lifestyle modifications. Looking at the existing literature, as a baseline to understanding the coping process of people with MS, in general, evidence suggests a lack of multicultural emphasis on treatment and interventions available for this particular group of women (Ožura, Erdberg, & Šega, 2010). Such studies are anticipated to provide information on the psychosocial impacts that tend to affect people with MS, in general (Ozura & Sega, 2010; Parkenham, 2008; Stuifbergen, 1995), but make suggestions of healthy lifestyle changes that might be unobtainable or unrealistic for African American women. Instead these components of obligation because of SWS suggest a direct link to reasons why in general, black (African American women) have been associated with more aggressive forms of the disease (Langer-Gould, et al., 2013). As previously mentioned, these obligations do not simply go away making it harder for an AA women with MS to change their lifestyle.

Support for these claims of significance directly stem from studies on psychosocial adjustment and coping for people with MS. One study in particular, which is by Romagosa (2010), outlined very important factors based on the experiences of
women with MS, however the findings of the investigation present with the potentiality of being misrepresentative. This study consisted of the personal accounts of experience after being diagnosed by seven Euro-American women and one African American participant. Through metaphors Romagosa pulled out themes of coping and “confronting reality” as mentioned by her participants (2010). She highlighted that the process of self-healing is very important and the interpretations of data from her investigation indicated eight key areas of the coping process for women. These eight key areas include: 1) loss of control over person’s sense of unity between body, self-identity, and the world; 2) increasing awareness for transformation, which includes the process of diagnosis, denial, and the wakeup call; 3) the drive for integration in order to proactively cope each day with their illness; 4) an opportunity for learning ways to reinterpret the stressful events regarding one’s values, beliefs, and goals; 5) listening to the body; 6) the learning process; 7) learning to appreciate life; and 8) life as a spiritual journey (Romagosa, 2010, p. 89-97).

**Superwoman Schema (SWS)**

This investigation will examine whether the process of coping for women is the same for African American women especially in the areas of drive for integration, opportunities for learning, listening to the body, the learning process, learning to appreciate life, and life as a spiritual journey (Woods-Giscombé, 2010). This current study will use the themes from this 2010 study as comparative themes to the themes that emerge from the eight African American women participants. Ultimately, this study seeks to play a significant role in exposing the true experiences and determine whether
the coping process after being diagnosed with MS is contingent upon the role obligations such as SWS. This research helps spark conversations on necessity to provide intentional multicultural treatment interventions for AA women with MS. In the following subsections there will be a detailed discussion on the supportive components found in this research investigation; this includes a description of the Superwomen Schema (Wallace, 1978; Woods-Giscombé, 2010) and Disability Identity (Pakenham, 2008).

Black feminist literature includes the principles and teachings on the intersectionality of the Black woman (Smith, 2013-14). Crenshaw (1989) was the first to discuss notions of intersectionality and stressed that Black women were historically predisposed to oppression; and used the expression of a traffic intersection to discuss how concepts of life overlap like a crossroad. This genesis of teaching functioned under the beliefs that “black women are inherently valuable, that our liberation is a necessity not as an adjunct to somebody else’s but because of our need as human persons for autonomy” (Hull, Bell-Scott, & 1982). Furthermore, a few particular written works (i.e., Wallace, 1978; Hull, Bell-Scott, & Smith, 1982) emerged during this movement as catalyst in the discussion on the myth of the superwoman. This current study looks to the history of black feminism in order understand the nature of this historical set of responsibilities known as the superwoman schema.

**Superwoman schema.** Introduced by Woods-Giscombé in 2010, the construct of the superwoman schema submits ideas of role responsibility for African American women, which date back to historical disparities otherwise associated with slavery, civil
rights, inequalities, and poverty. The article *Superwoman Schema: African American Women’s View of Stress, Strength, and Health*, reveals the particulars that contribute to this construct. It is within the idea of “superwoman-hood” that pinpointed five primary characteristics of the Superwoman Schema (SWS) framework. These primary characteristics are: 1) obligation to manifest strength, 2) obligation to suppress emotions, 3) resistance to being vulnerable or dependent, 4) determination to succeed, despite limited resources, and 5) obligation to help others (Woods-Giscombé, 2010). The following discussion briefly explores the five characteristics of the superwoman schema as proposed by Woods-Giscombé (2010).

**Obligation to manifest strength.** The idea of an obligation to manifest strength suggested under this characteristic designates that women feel the need to “present an image of strength” (Woods-Giscombé, 2010, p. 672). This characteristic also encompassed the ideas that women have to be associated with an image of strength. This obligation is an individualized perception of responsibility (Woods-Giscombé, 2010).

**Obligation to suppress emotions.** The idea of an obligation to suppress emotions is described as the responsibility to keep “emotions bottled up inside” (Woods-Giscombé, 2010, p.673). For women, this obligation to suppress emotion also presents as a mechanism to keep other from seeing any levels of weakness (Woods-Giscombé, 2010).

**Resistance to being vulnerable or dependent.** For AA women the notion of dependence is not an option when you have others depending on you. In order to prevent others from misusing them or “taking their kindness for weakness, a mechanism of independence is employed as a way to remain strong” (Woods-Giscombé, 2010, p.673).
**Determination to succeed despite limited resources.** For women, resilience is a characteristic that can be very beneficial. However, the characteristic to succeed despite limited resources also presents as a barrier to accessing help in order to maintain independence (Woods-Giscombe, 2010).

**Obligation to help others.** This characteristics, better known as a mentality, is to have the power to step in when others are in need and correct the issue (Woods-Giscombe, 2010).

**Research supporting the concepts of superwoman schema.** This current study assumes that even though this schema can exist with all women regardless of the levels of responsibility can lead to, a heightened potential for unhealthy impacts in African American women if not incorporated with one’s own personal needs. For example, grief can be a debilitating process depending on the level of impact. While personal time is important it is also important to decrease opportunity for idle thoughts to emerge. In this example, the SWS would be a beneficial tool because it allows the individual the opportunity to feel needed in the mist of their loss.

Moreover, with this construct being one that conveys a historical association with responsibility to nurture, it is unrealistic to believe that once an individual is diagnosed with Multiple Sclerosis their role obligations are eradicated completely or by any means voluntarily decreased (e.g., Kamenou, 2008). Kamenou (2008) studied 26 minority women, 15 ethnic men, eight White women and six White men to determine how these different groups deal with demands and role obligations. The findings suggest that ethnic women have difficulty dealing and managing cultural, community and religious demands
however the dimensions of responsibilities were “accentuated by their communities and families’ cultural and religious expectations” (Kamenou, 2008, p.107). Intersection of these obligations are often layered on top of the new and important responsibility to self-care and cope with any changes to physical and mental well-being in order to prevent further sickness. The idea of SWS alone poses a concern for African American women with MS to have healthy psychosocial adjustment to disability (Wineman, Durand, & Steiner, 1994). This study looks at SWS particular from a psychological view, meaning that the individual self-establishes these roles as important and a part of their daily life and survival.

In this study, the suggestion to incorporate superwoman schema into the process of adjustment and disability identity development are also presented as work-life balance. Work-life balance is the idea of taking on multiple roles and responsibilities between home (ex. children, husband) and work. Work-life balance suggests that there are potentially healthy techniques that can be incorporated to help AA women with MS managed roles (Roehling, Hernandez-Jarvis, & Swope, 2005). This universal issue of balance has been studied to impact a wide variety of people (Roehling, Hernandez-Jarvis, & Swope, 2005).

The lack of a work-life balance can effect people from all multicultural backgrounds. Furthermore, the lack of a work-life balance can cause increased stress and a decrease in productivity. Work-life balance is considered in this investigation to be a significant factor in the wellbeing of individuals and their ability to maintain a well-adjusted life. According to Roehling, Hernandez-Jarvis, & Swope (2005), work-family
spillover “occurs when strains and conflicts in one domain negatively affect one’s mood and behavior in the other domain” (p. 841). With this interpretation, work-life balance in this study assumes a universal role that supports the idea of SWS because of the observable similarities and the accessibility to peer-reviewed published data on the concepts. The term balance is what makes this concept a potentially beneficial tool to manage the experiences of AA women with MS. This notion assumes that neither disability identity or superwoman schema has to be ignored and can both be incorporated simultaneously with support from healthcare providers and other members of the woman’s support network.

**Disability Identity**

According to a recent study by, Kathleen R. Bogart describes in a recent study on disability identity includes not only the factors of one’s holistic self-concept but also comprises factors of disability self-efficacy and self-concept (Bogart, 2014). Based on the Social Identity Theory by Tajfel & Turner (1979) people from stigmatized groups tend to strive for positive self-concept in one of two ways: 1) through assimilation by denying their disability or 2) by affirming their relationship to having a disability in a positive way (Bogart, 2014, p.108). One of the two major assumptions in this study is to explore whether disability identity development is hindered by obligations of SWS. Exploration of the multi-faceted components of disability identity include the notions of disability self-efficacy and self-concepts. These concepts are described by Amtmann, et al., (2012) as an effect to the “types of goals a person sets, the course of action a person takes, how
long a person will persist, and thus, whether or not the person succeed in attaining goals” (Bogart, 2014, p. 108).

**Stages of Adjustment to Disability**

The process that occurs before the development of a disability identity is known as the psychological adjustment to disability. This current study identifies the stages purposed by Dutta and Kundu (2007) with consideration to Calabro (1990). This is considered the proposed cognitive behavioral model of adjustment to disability for analysis and clinical management. The Dutta and Kundu (2007) model include eight major phases which include: 1) shock, 2) realization, 3) denial, 4) depression, 5) anger, 6) hostility, 7) acknowledgment and 8) adjustment (Dutta & Kundu, 2007). Explained in the text as a fluid system, individuals may start at one level and shift in either a progressive or regressive manner. For example, first experiencing anger and then moving directly to acknowledging the disability and adjusting to any corresponding changes in ability is a possible course of the adjustment process. If for instance, some traumatic experience occurs the individual can digress from adjustment to depression and hostility. There is no limit to the amount of times that this process can occur (2007).

In addition to these eight ‘fluid’ stages of adjustment to disability for which an individual may migrate after a diagnosis, Dutta and Kundu (2007) focus their attention to the three person-specific stages proposed by Pedersen (1988). These include: 1) awareness of the common beliefs about the differences and similarities, 2) knowledge and insight of culturally learned assumptions, and 3) skills to effectively interact with people of different cultures (p.6). These common beliefs are considered play a major role
in the stages of adjustment to disability because social social and personal expectations have the potential to be reflected in their willingness to acknowledge certain limitations. Moreover, Koop (2014) argued in an online Nursing Times newsletter that individuals who acquire a disability may always grieve the loss of functioning in one manner or another making this adjustment process ongoing. Koop (2014) suggests that “the inability to live normally never allows one to forget about their disability” (p. 11). For this reason, it is important to consider what adjustment to disability looks like for African American women with MS and potentially other acquired and congenital disabilities. For example, individuals with acquired disabilities may have a different experience with adjustment than individuals with congenital disabilities and vis-à-vis. In the following section there will be an in-depth look at the process of adjustment for both congenital and acquired disabilities and how these different experiences may present during the therapeutic process.

Adjustment to disability for congenital and acquired disabilities. According to Merriam-Webster (2015), an online dictionary resource, congenital means ‘existing at or dating back to birth’ while acquired is defined as the insists of ‘gaining over time’. A relevant discussion on this topic can be found in Bogart (2014). The author discusses the role of disability self-concept in adaptation to congenital or acquired disabilities. The study identifies that the purpose of the investigation was to “examine whether people with congenital compared with acquired disabilities have better satisfaction with life (SWL) because of a stronger disability self-concept. The design of this study used 226 online participants (congenital; n=62 and acquired; n=164) to obtain results from surveys on
SWL. The investigation consisted of three main hypotheses based on how the participants associated with self-esteem, self-efficacy, disability identity, performance of activities of daily living (ADL), and income based on duration of disability and congenital onset (2014).

The outcomes of this particular study proved that “people with congenital onset had higher disability self-concept and SWL than the participants with acquired onset” (Bogart, 2014, p.112). With this notion, and by making the top two stages of adjustment parallel to high self-concept or self-efficacy there is proof in the discussion that this processes are different for people with congenital versus acquired disabilities. However, under the notion that every individual has a different experience it is important to foster the conversation of adjustment to loss (acquired) verses adjustment to social inclusion (congenital).

The process of adjustment to disability for individuals with acquired disability can be considered a dual process. On one hand is the adjustment to what is not “normal” and often the loss or potential to lose an important function, such as walking. On the other hand is the process of “fitting in” with society. The process of adjustment for individuals with congenital disabilities may, however, be targeted solely on fitting in with the larger normed society. An example of this phenomenen is, for instance is the adjustment and coping process of someone who was born deaf as opposed to someone who lost their hearing later in life. The adjustment process for the individual who had congenital deafness would be fitting in and communicating with others who can hear and do not know how to use sign language.
On the other hand is the individual who has acquired deafness. For this individual the adjustment process might be two-fold. Meaning the individual may be trying to figure out his or her own limitations and at the same time figure out a way to best communicate with others. Thus, when referring to the stages of adjustment to disability in this study, the directed focus is to look at both the conflicts of loss and the conflicts with society pressures of ‘normal’. In the next section, there will be a detailed look at the background of this study and how attention to the questions under investigation are projected to assist African American women with MS after being diagnosed.

**Statement of the Problem**

In a study by Black, Murray, Cutrona, and Chen (2009) authors’ presented evidence that African American women have a tendency to implement role accumulation on a daily basis as mothers under pressure to manage financial concerns. The principles of role accumulations are described to include the ideas that black women “historically have been characterized” as the primary support within the community with a heightened likelihood of fulfilling multiple roles (Black, Murry, Cutrona, & Chen, 2009, p.146). The notions of role accumulation theory are actually presented as an aid for black women to obtain enhancement of self-concept and overall life satisfaction (Black & Peacock, 2011; Black, Murry, Cutrona, & Chen, 2009; Nordenmark, 2004). According to Woods-Giscombe & Lobel (2008) the stressors that African American women face relate to burdens of intersectionality between race and gender identity (e.g., Smith, 2013-14; Shields, 2008), as well as, universal and global stressors. These stressors are suggested to potentially be overwhelming and support the notion of intersectionality and role overload.
Gold, et al., (2005) presented evidence in a study on the role of stress-response and progression of MS causing mental health professionals to consider treatment interventions that consist of support for minimizing stress related exacerbations. In order to minimize stress induced exacerbations in African American women with MS, healthcare professionals from medical and mental health arenas are being tasked with the duty to assist AA women with the reclassification of their identity and responsibilities to maintain the obligations outlines by the SWS. Additionally, the goal of a reimagined intervention set that is specific to the needs of AA women is to clearly encourage that the development of a disability identity are essential to the coping and adjustment process.

In identifying significance in completing such a study, evidence revealed that the prevalence of Multiple Sclerosis (MS) amongst African Americans is a phenomenon that contradicts even the earliest accounts of occurrence. These original trends of diagnoses among Caucasians and the frequency of documented cases dates back to a 1957 study published in the Journal of the American Medical Association (JAMA) (Kurtzke, 2008). This investigation occurred across 11 Veteran Administration (VA) hospitals in a “multi-centered, placebo-controlled, randomized, double-blind, therapeutic trial” (Kurtzke, 2008, p.1007). This study investigated Isoniazid, a prescription drugs, used to treat MS amongst U.S. military service members. In 2008, editors of the Multiple Sclerosis journal invited JK Kurtzke, the original author of the 1957 study, to review these findings and the impact of the contributions made by the Department of Veterans Affairs.

In the 2008 response, JF Kurtzke reinforced support to show that the experimental design of the 1957 investigation was sound. Furthermore, that even today the results and
scores on the Expanded Disability Status Scale (EDSS), a tool used during the investigation, rightfully examined the status of disability for military members with MS. The EDSS remains a scoring instrument used to determine the type and severity of Multiple Sclerosis (Kurtzke, 2008), however, some researchers argue that the EDSS only evaluates a portion of the holistic quality of life for individuals who have been diagnosed (Twork, et al., 2010). This ordinal 0-10 scale assessment has been validated, nevertheless warrants the need for additional consideration when it comes to the “the benefits or harm of various therapies” (Cho, et al., 2014, p. 1217); in this current study focus is specifically on emotional and identity development based interventions.

Going through each step of the original Kurtzke and Berlin (1957) investigation, Kurtzke (2008) reminded readers that the evidence found in the study was accurate to the population and makeup of Veteran services during that particular era. He also recognized that the study was the first, class one treatment trial and “comprised the only available nationwide morbidity distribution of MS in the United States” (Kurtzke, 2008 p.1007). It is mentioned that Davenport’s 1922 attempt which looked at the cases of those rejected from serving in the military because of a previous MS diagnoses, was in fact successful in providing a demographic view of trend, for that specific generation. What stands out from these two pieces is the notion that a trend of MS prevalence corresponds to each of the specific eras in which the sample belongs.

Moreover, this idea suggests that overtime the results of a study become less representative of the current population under investigation. Subjectively, one can infer that Kurtzke’s final statement in this review was a charge for researchers to conduct a
more up to date investigation using a similar design and database comprised of the Department of Veterans Affairs (VA) as a provisional listing of clinical and epidemiological study of MS (Kurtzke, 2008).

In a more recent investigation, Michael T. Wallin and colleagues completed a similar study to that of the one completed in 1957 with assistance from JF Kurtzke himself as a co-investigator. This examination used the database of the Veterans Administration (VA) from the Gulf War era to identify MS diagnoses and incidence rates by race, sex, and service (Wallin, et al., 2012). Methods of the analysis used in this study reviewed all five military branches including Army, Navy, Marine Corps, Air Force, and Coast Guard. A total of 2691 participants with a mean age of symptom onset of 30.0 years were identified. These results highlighted three important findings: 1) members in the Army were diagnosed more frequently than any other service branch, 2) “The relative risk ratio for Blacks versus Whites was 1.27 (CI 1.16-1.39)” (Wallin, et al, 2012, p.1782), and 3) females had a risk ratio of 3.39 (CI 3.13-3.67) versus males (Wallin, et al., 2012, p. 1782).

This analysis displayed a more up to date breakdown of incidence and risk in the US, and contrary to popular belief, African Americans are more susceptible to the disease than Caucasians and any other race. These finding further suggest a concern to whether the available literature on coping and adjustment to life demands for African American women, in particular, address the needs of the formerly identified majority group (Wallin, et al, 2012). These research findings pointed to the idea that the prevalence of MS for
African Americans warrants increased attention and best-practice evidence. This conversation in particularly leads to the exposure of gaps and further build upon the

Research continues to advocate that African Americans typically have more aggressive forms of MS serving as a leading indicator of the rapid progression of symptoms and long-term disability (Gupta, et al, 2014), however information on management and regulation of self-care for this particular group remains scarce (Black, Murry, Cutrona, & Chen, 2009). Large gaps remain in the literature addressing basic questions about how the everyday life experiences of AA women, for example an inability to manage financial responsibilities or handle stressful situations since these factors are considered to impact psychological and physical health as persons with MS (Black, Murry, Cutrona, & Chen, 2009).

The impact of Multiple Sclerosis on African American women is described in the article by (Johnson, Terrell, Sargent, & Kaufman, 2007). Authors recommended that the first step to understanding the impact of MS is by exploring the culture of the disease, and secondly is the notion of probing the influence of stressors and resources among people from different groups (Johnson, Terrell, Sargent, & Kaufman, 2007). The purpose of this research investigation is to explore these types of services for African American women with MS specifically, including: 1) assistance with establishing a disability identity and 2) the management of life roles and responsibilities after the diagnoses. These two services are anticipated to provide a proactive response to the influence of stressors for AA women.
Overview of Methodology

The methodology used in this investigation has been fashioned according to the models of collecting data from a qualitative stance of research. Patton (2002) suggests that the use of qualitative strategies are beneficial in approaching the research question from a “naturalistic view to the extent that the research takes place in real world settings and the researcher does not attempt to manipulate the phenomenon of interest” (p.39). This study utilized qualitative inquiry in order to identify a collection of themes, patterns, concepts, and insights (Patton, 2002) about the experiences of the African American women with Multiple Sclerosis. According to Creswell (2009), the collection of research data can occur using quantitative strategies or qualitative strategies and through a combination of the two strategies known as mixed methodology. However, this current study has identified that the most appropriate strategy to assist in exploring the lived world experiences of African American women is through phenomenology. Phenomenology is a widespread qualitative approach, which seeks to capture the life world the participants from their lived experience (Patton, 2002).

The research design of this investigation linked the ideas of subjectivism with phenomenology as the selected methodology. Furthermore, the methodological stance of this investigation describe the research design based on the identified research questions and three conceptual/theoretical frameworks.

With consideration to the responsibilities of AA women as identifies in black feminist literature, this study incorporates a conceptual framework consisting of the development and maintenance of disability identity and the nature of the superwoman
schema to examine how these two phenomena interact in their ability to adjust to a MS diagnosis. The expression of how these women view their lived world are ascertained from three central research questions. This following section will include a brief overview of the three research questions and three theoretical frameworks that govern this study.

**Research Questions**

In the current study the use of qualitative methodology, specifically from an interpretivist theoretical perspective seeks to answer three central research questions. These include: 1) How do African American women associate with the Superwoman Schema?, 2) What is the essence of the experience for African American women with MS?, and 3) What challenges do African American women with MS experience in regards to maintaining role obligations of SWS and the development of a disability identity? With the data obtained through one-to-one semi-structured interviews with the eight (N=8) participants, themes that emerge seek to answer the second and third research questions. Particularly, this research design uses a phenomenological approach to answer the research questions because this qualitative research method is suggested to include an examination of the lived experiences and understanding of how people live in the world (2013, p. 26), and is used to uncover “the essence of the experience” of the individual (2013, p.26).

**Sampling and participant recruitment.** Using the process of selecting research participants suggested by Cone and Foster (2006), the sampling procedure used in this current study identify, the following: 1) who will participate, 2) how many will
participate, and 3) how will they be selected (p. 129). This type of purposeful sampling will assist in participant selection based on two specific criteria: 1) diagnosis of Multiple Sclerosis and 2) identification as an African American (black) woman. There are no age limitations or years of diagnoses set to restrict participation. By leaving the participant criteria open rather than specific there will be a greater opportunity for true un-manipulated experiences of African American women to be available. This study obtained participation from eight (N=8) women. Participants were recruited through online resources, such as Facebook and Patients like Me. Recruitment also occurred through snowball sampling, also known as, networking strategies (e.g., Bowen & Moore, 2014).

**Limitations**

In a research article by Dickson-Swift, James, Kippen, & Liampttong (2007), it is suggested that there are some specific challenges that researchers delving into qualitative investigations should bear in mind before beginning their studies. The premise of this research by Dickson-Swift, James, Kippen, & Liampttong (2007) offers information and suggestions when conducting sensitive research. These suggestions were based on the grounded theory investigation that produced themes from interviews of thirty, (N=30) qualitative researchers who served as their research participants (2007).

This article by Dickson-Swift, James, Kippen & Liampttong (2007) suggests that six issues related to conducting sensitive research should be considered: 1) rapport development, 2) use of researcher self-disclosure, 3) listening to untold stories, 4) feelings of guilt and vulnerability, 5) leaving the research relationship and 6) researcher
exhaustion. As a result, the discussion on these core issues related to conducting sensitive research allude to the fact that researchers “need to be able to make an assessment of the impact of the research on both the participants and themselves” (2007, p. 328). This process of considering safety also suggests a level of protection during the analysis of data. Thus, one limitation of this current study on African American women with multiple sclerosis includes the assurance of safety for both the research participants and the researcher by considering the six above-mentioned characteristics of conducting sensitive research with awareness of potential limitations. Furthermore, in keeping that, the researcher herself identifies as an African American woman with MS, the consideration of these limitations have been identified as an important component of the research design.

Moreover, in the article on conducting sensitive research, authors Dickson-Swift, James, Kippen, & Liampttong (2007), also recommend strategies to include when facing the challenges of conducting sensitive research. First, is the suggestion that researchers conducting this type of research consider their own health when dissecting someone else’s experience, secondly, is the suggestion that researchers identify methods of debriefing and ensuring that interviews are not scheduled back to back. Some debriefing options is described as receiving supervision or consulting with members of the research team keeping in mind the responsibility to keep the information of the participants confidential. These limitations helped in assuring that the psychological well-being of the research participant and researchers are addressed proactively.
Potential limitations of this study also include the process of obtaining participants using a snowballing-networking procedure (Bowen & Moore, 2014), potentially low response rate and time constraints with collecting data from interviews, transcribing the interviews, response rates of participants for the second follow-up interview, technical difficulties with conducting electronic video distance interviews.

**Definitions of Terms**

**Adjustment to Disability**: Explained as the understanding of “self- in relation-to-others” (e.g. Dutta & Kundu, 2007), adjustment to disability is the process of gaining psychosocial awareness after being diagnosed with a disease and/or disability.

**Autoimmune Disease**: a disease in which the body's defense system malfunctions and attacks a part of the body itself rather than foreign matter (NINDS, 2014).

**Disability Identity (DI)**: According to the literature by Dunn & Burcaw (2013), disability identity is “presumed to be an important and adaptive psychosocial contrast in the lives of many people with disabilities” (p.148). This explanation of disability also includes the idea that is beneficial and encompasses a positive sense of self, feelings of connection and solidarity to the disability community (2013, p.148). DI has been connected in the literature as an extension of the intersectionality between self, expressions of individuality, and accounts of group affiliation” (p.149).

**Essence**: Coping with MS as an African American woman given the guise of Superwoman Schema as a model for health.

**Exacerbation**: The term ‘exacerbation’ has been associated in research and literature as the episode of “neurological” disturbance (e.g., Ontaneda & Rae-Grant, 2009;
Schumacker, Beebe, Kibler, Kurland, Kurtzke, & McDowell, et al., 1965). An exacerbation is identified as present symptom worsening or the development of new symptoms. Research suggests that each episode can last for up to a 24 hour period (Schumacker, et al., 1965, p. 554). As research continues to develop evidence evolves to signify the manner in which an exacerbation of MS symptoms is triggered including, stress, heat, fever, or infection. Terms that are used interchangeably with exacerbation include relapses, attacks and bouts (Ontaneda & Rae-Grant, 2009).

**Multiple Sclerosis (MS):** MS is an autoimmune disorder that affects the central nervous system (CNS) and is characterized by damage to the myelin sheath (*see* demyelination). There are four identified course of MS, which include: 1) relapsing remitting (RRMS), 2) primary-progressive (PPMS), 3) secondary-progressive (SPMS) and 4) progressive relapsing (PRMS) (Stankiewicz, Chaubal, & Buckle, 2012). Currently MS affects 250,000-350,000 people in the United States with an estimated 200 new cases reported weekly.

**Myelin:** a fatty covering insulating nerve cell fibers in the brain and spinal cord, myelin facilitates the smooth, high-speed transmission of electrochemical messages between these components of the central nervous system and the rest of the body. In MS, myelin is damaged through a process known as demyelination, which results in distorted or blocked signals (NINDS, 2014).

**Phenomenology:** Known as an interpretive philosophy, phenomenology emerged according to the views of Husserl during the last 1800s and early 1900s (Savin-Baden & Major, 2013, p. 26). This qualitative research method is suggested to include an
examination of the lived experiences and understanding of how people live in the world
(2013, p. 26), and is used to uncover “the essence of the experience” of the individual
(2013, p.26).

Relapsing-remitting MS: a form of MS in which an episode of symptoms occurs and is
followed by a recovery period before another attack occurs (NINDS, 2014).

Superwoman Schema (SWS): The perceptions of the superwoman schema entail
contextual factors, benefits and liabilities of roles and responsibilities to care for others.
In the study by Woods-Giscombé (2010) five major tenets of SWS were highlighted,
including: 1) obligation to manifest strength, 2) obligation to suppress emotions, 3)
resistance to being vulnerable or dependent, 4) determination to succeed, despite limited
resources, and 5) obligation to help others.

The McDonald Criteria: Recognized as an evaluation and diagnostic criteria for
determining if symptoms are caused by Multiple Sclerosis. The McDonald criteria has
been revised according to standards accepted in 2010 (Polman, Reingold, Banwell,
Clanet, Cohen, et al., 2011).
Chapter Two: Literature Review

African American (AA) women are, in most cases, considered the backbone of the communities in which they live and are often obligated to care for the needs of others (Wood-Giscombè, 2010). This commitment to the needs of others suggests a conflict in their ability to care for their own individual health and personal needs. For AA women diagnosed with Multiple Sclerosis (MS), a condition exacerbated by stress (Schwartz, et al., 1999), greater attention to the needs of this population is now imperative. Research has indicated in recent years that the prevalence, risk, and severity rates are highest amongst AA women (Langer-Gould, Brara, Beaber, and Zhang, 2013; Wallin, et al., 2012; Kurtzke, 2008). This is a new finding as in the past rates of risk and prevalence was highest among Caucasian males. This current investigation focusing of the needs of this particular group by tuning into the obligations of the Superwoman Schema (SWS) and related influences on the development and maintenance of a Disability Identity (DI).

This current chapter serves a literature review for this current study of AA women diagnosed with MS and their lived experiences related to DI.

This current chapter recognizes that the purpose of the literature review is to “start with the general literature in the topic area and gradually narrow the focus to the specific area of research” (Cone and Foster, 2006, p.85). The following sections of this chapter will comprehensively examine evidence specific to AA women with MS and the essence of their lived experience. This chapter provides information about the following: a) the experience of AA women with MS, b) the historical context of disability identity, c) the historical context of the superwoman schema, d) the culture of disability, e) exposing the
missing links in existing literature, and f) a discussion specific to the process of coping with MS. The major goal of this chapter is to build a case to support the significance of conducting this research.

**Investigating the Experiences of African American Women with MS**

Evidence of the prevalence of Multiple Sclerosis continues to suggest that African American (AA) women are not only at a higher risk of having a more aggressive form of the disease. However, recent studies indicate that AA women have a higher prevalence over any other racial group (Langer-Gould, et al, 2013; Wallin, et al., 2012; Kurtzke, 2008). Due to this trend, it is vital to explore the lived experiences of AA women in order to provide mental health and rehabilitation services that are consistent with their unique needs (Langer-Gould, et al., 2013). MS currently affects 250,000-350,000 Americans (NINDS, 2014). It is also suggested that the current ration of women to men with MS is 2:1. Although evidence has not yet indicated the exact number of AA women with the disease on a national level studies like, Kurtzke (2008), Langer-Gould, et al. (2013), and Wallin (2012) provide evidential support. While literature exists on the mental health challenges that people with this MS face (Romagosa, 2010), literature remains somewhat misrepresentative of the cultural based experiences of AA women.

A good example of this how literature continues to be misrepresentative of cultural specific experiences that trace back to the findings of the dissertation entitled *Women confronting the reality of Multiple Sclerosis: A qualitative model of self-healing* (Romagosa, 2010). This particular study serves as the rationale for conducting the current research investigation, primarily because the sample of women who participate in the
2010 study included eight (8) Euro-American women and only one (1) African American woman. Later in the chapter, there will be a closer look at the Romagosa (2010) investigation. However, this review of literature begins with a discussion of multiple sclerosis (MS) by looking at the etiology, prevalence/incidence, treatment and incidence specifically in African American women.

Multiple Sclerosis

Literature and research on Multiple Sclerosis (MS) define this disease, which affects the lives of 250,000-350,000 Americans as a “chronic inflammatory disease of the central nervous system (CNS)” (Gandhi & Weiner, 2012, p.3). As previously mentioned, the ratio of women to men diagnosed with MS is 2:1; however, evidence on the exact number of AA women diagnosed has yet to be documented in a nationwide study.

According to the Mayo Clinic for Medical Education and Research (2014), symptoms of Multiple Sclerosis (MS) are evident when the protective sheath (myelin) of the nerve endings are damaged and fail to send signals/messages from the brain to other parts of the body. This deterioration process of the myelin sheath called demyelination (Holland, Murray, & Reingold, 2002) is the process of bodily dysfunction.

The process of demyelination causes scars to form on the brain and spinal cord. These scars trigger symptoms including numbness, limb weakness, loss of vision, tingling, electrical shock sensation to the neck and spine, slurred speech, difficulty with gait and fatigue (e.g. Wood, van der Mei, Ponsonby, Quinn, et al., 2012; Tzortzis, et al, 2008). These symptoms or “episodes of clinical worsening”, called exacerbations, are described to include new or reoccurring symptoms (Ontaneda & Rae-Grant, 2009).
Today, in literature and research, evidence has shown a link between MS exacerbations and stress, ultimately suggesting that higher levels of stress result in an increase in the frequency of exacerbations and eventually an increase in the potential for permanent disability (Schwartz, et al., 1999).

**Etiology.** Multiple Sclerosis is a disease in which medical researchers and neurologist have yet to determine the exact etiology. However, scholars have concluded that there are a series of prospective causes of this autoimmune disorder and four specific courses of the disease. The causes that have been through scientific research, include: 1) vitamin D deficiency (e.g. Hewer, Lucas, van der Mei & Taylor, 2012), 2) HLA susceptible genetic variants (Ghandi & Weiner, 2012; Isobe, et al., 2013), or 3) infection/virus (Ikeda, 2014). Other potential causes have been linked to, ethnicity, vaccinations, climate, gender, smoking and diet (Ghandi & Weiner, 2012).

As mentioned above, the four specific types of MS that can occur progressively include: 1) relapsing remitting (RRMS), 2) primary-progressive (PPMS), 3) secondary-progressive (SPMS) and 4) progressive relapsing (PRMS) (Lublin & Reingold, 1996). This section provides a thorough look at the various types of MS in order to provide the reader with insight about the disease manifestation.

RRMS occurs when the myelin sheath is undergoes inflammatory attack, this course is observed when there are more brain lesions. SPMS, is the second phase of RRMS and occurs when people may experience nerve damage or total deterioration as opposed inflammation, which can be restored. PPMS is also identified and an inflammation attack to the myelin, however there are more lesions on the spinal cord then
observed in someone with RRMS. The final type or phase is referred to as PRMS. PRMS is least common, but has been described to occur when there is a steady worsening of neurological function. (NMSS, 2013)

**Prevalence.** A study by Ma, Chan, & Carruthers (2014), reported the incidences, prevalence, costs, and overall impacts of disability, as it relates to the needs of services, of the most common conditions in the United States to examine how each might require rehabilitation. The eight conditions highlighted in this research, included: 1) multiple sclerosis, 2) stroke, 3) spinal cord injury, 4) traumatic brain injury, 5) osteoarthritis, 6) rheumatoid arthritis, 7) limb loss and 8) back pain. These conditions were identified as the top illnesses to require rehabilitation services, such as therapy and counseling, within the U.S health care system at the time of the investigation. The methods of this research included a meta-analysis chart of incidence, prevalence, costs and impact on disability of the eight common conditions. As a result, of the meta-analysis, Multiple Sclerosis was designated at a lower rank as far as rehabilitation needs as opposed to the other seven conditions.

However, according to the National Multiple Sclerosis Society (NMSS), there are more than 2.3 million people diagnosed with the disease worldwide (2013). Noonan, et al., (2010) suggested that for every 100,000 persons in the U.S. an average of 58-95 people have MS. Based on these numbers the research also suggests that the annual direct cost of care is roughly $16 billion in 2009 and $18 billion in 2013. Per person with MS this estimated cost equates to $52,244 (2009) and $60,078 (2013), each year. Additional information provided in the meta-analysis by Ma, Chan, & Carruthers (2014) illustrated
that the average time from disease onset to difficulty walking is eight years, fifteen for cane use and thirty for wheelchair use. As for work limitations, in 2013 there was a reported 56.5% unemployment rate among people with MS (Ma, Chan, & Carruthers, 2014, p. 990).

**Incidence in African Americans (AA).** As previously mentioned, several studies discuss the newly found prevalence of MS in African Americans. In 2010, African American neurologist and medical director at the Augusta MS Center published a research article and response to the incidence of MS. Mitzi Williams, argued that the “face” is wrongly associated with Caucasian women and should reflect AA women. In her article, *Exploring Our Differences: African Americans and MS* (2010) Williams described the need for an exploration of the inherit differences that the disease manifests on the physical and mental wellness of AA. She discussed specifically that a major barrier to treatment for individuals who are AA involves a lack of trust for participation in certain therapies and clinical experiments. This mistrust can be attributed to the historical Tuskegee Syphilis Experiment (2010). Williams (2010) also discussed the trends in African Americans with MS, which include higher incidence due to environmental factors (i.e., stress, lack of vitamin D), as well as “mixing of the races”, or bi-racial heredity that require attention (2010).

This discussion concluded with her views on implications for future research. It is regarded that:

There is a dire need for more enrollment of African Americans in clinical trials to determine if there are alternate treatment approaches needed and if any other
factors causing severe progression may be ascertained. Knowledge of all the faces of MS through continued research will allow us to gain a better understanding of the disease and work toward a cure (Williams, 2010).

Dr. William presented information specific to African American women with MS at the 12th Annual Leadership Summit on Health Disparities & Congressional Black Caucus Spring Health Braintrust through the National Minority Quality Forum (NMQF) on April 20th, 2015. She highlighted in the presentation that the most common presenting symptoms for AA include optic neuritis and walking difficulties. Furthermore, the presentation provided information about patients who are less likely to obtain treatment from a neurologist, these characteristics include: lack of health insurance, lower income, African Americans, living in rural areas, illness longer than 15 years (Minden, et al. 2008).

Williams summarized the presentation with three main points. These included: 1) there is a growing body of research over the past decade that points to differences in disease activity and phenotypes in African Americans with MS, 2) the true incidence of the disease in this population is unknown, but it is not likely as low as reported from studies and surveys done in 1970s, and 3) poor recruitment in research trails make it difficult to generalize results to populations with different disease characteristics (Williams, 2015). This charge for research serves as proof to the need to include AA women in qualitative studies to understand the impact the impact of stress on exacerbations.
Treatment. The treatment of MS is according to FDA-approved medications. Currently there are several types of IFN-β-1a medications including, Betaseron, Avonex, Copaxone, Rebif, Tysabri, and Gilenya (Stankiewicz & Khoury, 2012). However, many of these medications have side effects that can cause a threat to mental health and increase in stress (2012). One particular side effect is known as Progressive multifocal leukoencephalopathy (PML) this condition is identified as a rare brain infection. The above-mentioned modifying disease agents are not considered cures and are known only to delay the course of the disease (2010). These drugs can be taking orally, subcutaneously, or intramuscular. While the treatment of MS occurs through injections, therapy has been known to cause injection anxiety and phobias that lead to increased stress (e.g., Mohr, Cox, Epstein, & Boudewyn, 2002). These therapy drugs are prescribed by a neurologist.

Symptoms that accompany MS also include bladder problems, emotional changes, fatigue, itching, pain, bowel dysfunction, sexual dysfunction, spasticity, tremors and depression (NMSS, 2015). Drugs to correct these symptoms can be prescribed by the neurologist or a general practitioner. Stress, however is not among the list of treatment since this symptom can not be treated by medication. This suggests that alternative medicine such as counseling, both clinical mental health and clinical rehabilitation can be useful strategies. In order for counseling practitioners to provide multiculturally competent services for AA women with MS the range of life experiences for this population must be explored.
Considering the overall manifestation of MS on AA women it is important to consider how these physical and emotional manifestations affect this population. The next section of this chapter seeks to provide descriptions of the two theoretical framework components that drive this investigation. First is disability identity and the association of self-concept and self-efficacy, which contributes to the experience of being diagnosed with an acquired disability, and second is the exploration of the superwoman schema deriving from black feminist theory. As this review of the literature unfolds in connection to the present study, it is desired that two assumptions be addressed: 1) that the development of a disability identity is imperative to healthy adjustment to an acquired disability and 2) the superwoman schema is prevalent in AA community and contributes to the unique experiences of African American women with MS.

**Historical Context of Disability Identity**

Disability identity (DI) is known as the self-concept one embraces after being diagnosed with a disease that may or may not cause disabling conditions (Dunn & Burcaw, 2013; Weymeyer, 2013; Stocker, 2001). When a healthy disability identity is constructed and implemented into daily perceptions of well being, the individual is reported to have higher satisfaction with life (Glass, 1999), increased belief that life goals are attainable (Bogart, 2014) and increase association with the entire minority community of people with disabilities (Kurz, Saint-Louis, Burke, & Stineman, 2008). Dunn and Burcaw (2013) explored the process of developing an identity as a “psychosocial construct” for which a key question is often posed: “does disability identity supersede other identities a person may possess (e.g., race, parent, friend, spouse,
employer, employee) (p.149)? This question however has an often-predictable answer. Similar to the conflicts that a person may experience when evolving though the stages of racial identity development (Helms, 1990), people moving to develop a DI are also capable of experiencing conflict in determining the role of disability since these characteristics are more often than not associated with undesirability and incapability. This idea is fostered under the notion that a person with a disability is less likely to desire kinship or association with the disability community due to a long history of stigmas and maltreatment (Anastasiou & Kauffman, 2013).

Gill (1997) provided insight into the categories of DI through an explanation of the four types of integration. The four types of integration in DI development include: 1) coming to feel we belong’ (integrating into society), 2) coming home’ (integrating with the disability community), 3) coming together’ (internally integrating our sameness and differentness) and 4) coming out (integrating how we feel with how we present ourselves). “Coming home (integrating with the disability community)”, for instance, includes an understanding that “people with disabilities feel comfortable associating with disabled peers, others (i.e., people without disabilities) vigorously avoid such contact, especially in activities or gatherings primarily for ‘the disabled” (Gill, 1997, p. 42).

Although people with MS can have hidden disabilities in earlier stages, individuals may It is suggested that due to the stigma on having a disability, which is set forth by the majority group, people with acquired disabilities experience anxiety towards accepting affiliation with this group ultimately hindering the quest for integration and identity development (Gill, 1997). Furthermore, this literature suggests that people with
disabilities often feel like “objects of charity and targets of professional remediation…and excluded from ‘normal’ life” (Gill, 1997, p. 42); however, it is imperative that healthcare professionals consider the process of personal empowerment to improve activism in this particular arena.

Pakenham (2008) describes the benefits of establishing an identity that encompasses a disability. This study described 16 sensemaking themes that are observed to encourage higher satisfaction with life and low reports of depression/anxiety specifically for people with MS (Pakenham, 2008). These 16 factors include: casual explanations, acceptance, experienced growth, spiritual/religious explanations, MS a ‘wake-up call’ for lifestyle change, MS catalyst for relationship growth and change, MS the illuminator, new life goals, life appreciation, other worse off than me, MS opens new doors, luck/chance, everything has a purpose, and making sense of the symptom puzzle. These 16 factors serve as a foundation for this study and will be explained later in this chapter in greater detail. However, the significance in understanding if there is any uniqueness when specifically working with female African American women is consistent with the attempt to understand whether the roles and responsibilities of the superwoman schema are unique and if yes, in what way. An interesting idea to note about the Pakenham study is that it was conducted using a mixed methods approach and no indication was given to the race of the individual participants. This current study is interested in determining to what degree do these 16 factors of sense making affect AA women.
Other key components of disability identity suggested by Gill (1997) merit attention in areas such as, integrating into society, internally integrating our sameness and differentness, and integrating how we feel with how we present ourselves. Thus the consideration of identity also includes what theorists today deem to be the social comparison model. Social comparison is the idea that one must meet the expectations defined and eluded by the larger group (e.g., Anastasiou & Kauffman, 2013). In this case, people without disabilities. Considering that people are representatives of the group to which they are most closely related, whether through genetic or physical features, comes the ideas that because of these similarities one must obliged to identifiers and denote that particular cluster (Festinger, 1954). An example of this is suggestive of the stereotypes of accessible parking. If one parks in an accessible spot, he/she is expected to exit the vehicle with some type of visible physical impairment rather than the need to park because of an invisible disability. Another highlight of the social comparison model is the idea that people should live up to these social roles (e.g., Festinger, 1954; Anastasiou & Kauffman, 2013). This type of responsibility to society has been found to be anxiety provoking and a reason why the process of disability identity is constricted (Gill, 1997). Under the realm of this model, one may experience a feeling of heightened levels of expectation to function at a certain capacity at all times in order to maintain these roles, i.e. the superwoman schema (Woods-Giscombé, 2010).

**Culture of Disability**

Another major component of this research is to understand the culture of disability for AA women with MS. In 2010, authors Balcazar, Suarez-Balcazar, Taylor-
Ritzler, & Keys published the book entitled *Race, Culture and Disability: Rehabilitation Science and Practice*. This particular text identifies the foundational premises of healthcare and rehabilitation for people from minority and racial backgrounds. In the first few chapters the authors describe the likings of this tedious process of conducting race-based research and developing a more beautiful research question (Berger, 2014) that address the needs of various minority communities. Furthermore this book explained that there are particular influences that should be considered when researching treatment for members of various cultures and racial backgrounds. The topic of the book is most relevant to the culture of disability and focuses on concepts of this particular study can be found in chapter three “Disability Identity and Racial—Cultural Identity Development: Points of Congruence, Divergence and Interplay. This information embodies the concept of disability identity and a basis for interpreting how developing an identity can be challenging when expectations of roles are predestined by cultural roles and racial identity. Yet the presence of disability identity is described as favorable in confronting the issues surrounding the wellbeing of the individual after a diagnosis.

Authors’ designate that disability identity entails more than just how one evaluates him or herself in relation to disability, but also includes the ability to grasp the sentiment of blackness, which consist of the principles of the nigrescence theory (Balcazar, Suarez-Balcazar, Taylor-Ritzler, & Keys, 2010, p.35). The nigrescence theory developed by Cross in 1971, is slated to have derived from impressions that black people evolved over time during the conversion from negro-to-black. Similarly, authors explain that for people with acquired disabilities tend to advance towards accepting disability and
establishing a healthy identity gradually. Discussed in this chapter, authors describe that
disability identity is connected by racial, cultural and even the likeness of existentialism
(Balcazar, Suarez-Balcazar, Taylor-Ritzler, & Keys, 2010), which suggests that during
this time of evolution individuals may emphasize their existence as a person free and
responsible for determining their own development through acts of personal will (Corey,
2008). Exploring the realm of racial and cultural identity development is the notion of
five racialized levels that describe this concept in depth, these include: (1) individual-
biological, (2) individual-psychological, (3) group, (4) community, and (5) culture
(Balcazar, & Suarez-Balcazar, 2010, p.34). It is proposed that although the idea of
identity in regards to race and disability appear as a simple task, this process involves not
only a willingness to explore areas of growth, but also to evolve past the disruptions of a
normal experience as outlined by a more medically normed prototype (2010). As a result
of this text it has become increasingly important that an understanding of how minorities,
particularly AA women, interpret disability. From there determine how to provide
assistance with health and disability management.

In a brief examination of the traditional medical model (Anderson, 1995), there is
a clear explanation of why the framework of care lacks a level of consideration to the
needs of blacks and other minorities with disabilities. In this text the author attempts to
portray the medical model in a positive light…

The classic example of the traditional medical model in action is the treatment of
the hospitalized, acutely ill patient. A physician diagnoses the disease, decides if
the patient should be admitted to the hospital, and then guides the subsequent
care. Patients make an initial crucial decision in the process—to put themselves in the hands of the physician, i.e., to accept the care that the physician prescribes. The physician is then in charge of, and responsible for, treatment of the illness. (Anderson, 1995, p.412-413).

However, the impression “treatment of illness” suggests that care requires only a singularly positioned façade instead of addressing one’s more holistic needs, like mental health counseling for example. Similarly, Smart (2009) explained the topic of the biomedical model and the issues related to negligence to care for patients diagnosed with a variety of diseases. The literature helps support the notion that more is required in understanding the nature of disability. The author reports that the “biomedical model ignores the social aspects of disablement and essentially treats all individuals with the same diagnosis by applying identical treatment regimens, regardless of differences in the individuals’ needs, resources, or assets. This tendency to see the individual patient as a diagnosis has led disability scholars to term the Biomedical Model diagnosis-diven rather than ‘individual-focused’” (Smart, 2009, p.4).

**Self-concept.** Kathleen R. Bogart (2014) conducted a study to examine the relationships between the development of disability self-concept and the particular type of disability, for instance, acquired or congenital. This literature extends an understanding of self-concept in a manner that included the multidimensional facets of various corresponding segments, such as, self-efficacy (e.g., Bandura, 1977), self-esteem (e.g., Crocker & Major, 1989), satisfaction with life (e.g., Diener, Emmons, Larson, & Griffin, 1985), and group identity (e.g., Crocker & Major, 1989). When connecting the ideas of
self-concept to people with disabilities, the literature suggests that findings tend to minimize and combine the notions of self-esteem under the umbrella of self-concept. Self-esteem for example is “characterized as the positive and negative evaluations one has for personal identity (Rosenberg, 1965 as cited in Bogart 2014, p. 108). Yet, the self-esteem aspect of self-concept differs even by broad definition. Self-concept includes the ideas that an individual with a disability has for strengths based on their mental outlook. Found to be a predictor of satisfaction with life because of its indicatory principles that they have the ability to do whatever they put their mind to.

However, it is equally important to consider the fundamental factors that contribute to the development of self-concept and those specific experiences that accompany this process. This particular literature does a wholesome job of explaining the adaptation process when the disability is either acquired or congenital in a discussion of the potential differences that may be evident. Although the article disregards the matter of race and adaption to disability through attention to self-concept, it does provide a fascinating prospective to accepting that based on other dynamics, such as rather the individual is diagnosed with an acquired or congenital disability, honing in on unique needs of the patient is imperative to treatment. Here also we see that the various sectors of the adjustment process require individualized thoughtfulness rather than normalized to all with disabilities. Conversely, this study informs health care providers and general readers that when planning treatment for people with disabilities it is above all important to assist in fostering self-concept (Bogart, 2014 p. 107)
Historical Context of Superwoman Schema (SWS)

The quest to understand what the Superwoman Schema is and determine if it exists today for African American women requires examination of the history of both the womanist and black feminist theory. Two major works published in this movement include: “Black Macho and the myth of the superwoman” by Michelle Wallace (1978, 79) and “All the Women are White, All the Blacks are men, But some of us are brave” edited by Gloria Hull, Patricia Bell Scott and Barbara Smith (1982). In this next section and as a component in discovering the experiences of African American women with MS, there recognition that there is significance in considering history as an initial tool in building pride.

Black feminist literature. A key player in literature from the black feminist movement is Michelle Wallace. In her famous book entitled Black Macho and the Myth of the Superwoman, she describes the intersectionality of race, gender, and class. The interpretation of this conversation is that black women have been characterized as ‘too much’ in every arena including, “too domineering, too strong, too aggressive, too outspoken, too castrating, and too masculine” (Wallace, 1978, p.91) and most of all the black woman is the reason why the black man has been unsuccessful. Wallace goes on to talk about how the women in her life had no other choice but to be all of those things because they typically had to do it alone. Like her mother who was twenty-two, divorced with two children and her aunt who was focused to quit her PhD program after constantly being accused of illiteracy. Yet, the meaning of this message was more than characteristic
of what she had witnessed from the women closest to her, but an innate responsibility to care for others passed down from slavery to all Black women.

Wallace (1978) stated that the black woman embodies the fundamental image of “inordinate strength, with an ability for tolerating an unusual amount of misery and heavy, distasteful work. This woman does not have the same fears, weaknesses, and insecurities as other women but believes herself to be and is, in fact stronger emotionally than most men…she is the embodiment of Mother Earth, the quintessential mother with infinite sexual, life-giving, and nurturing reserves. In other words, she is a superwoman” (Wallace, 1978, p. 107). Wallace further writes to describe the nature of the strong black women, using these illustrious words:

Sapphire. Mammy. Tragic mulatto wench. Workhorse, can swing an ax, lift a load, pick cotton with any man. A wonderful housekeeper. Excellent with children. Very clean. Very religious. A terrific mother. A great little singer and dancer and a devoted teacher and social worker. She’s always had more opportunities than the black man because she was no threat to the white man so he made it easy for her. But curiously enough, she frequently ends up on welfare. Nevertheless, she is more educated and makes more money than the black man. She is more likely to be employed and more likely to be a professional than the black man. And subsequently she provides the main support for the family. Not beautiful, rather hard looking unless she has white blood, but then very beautiful. The black ones are exotic though, great in bed, tigers. And very fertile. If she is middle class she tends to be uptight about sex, prudish. She is hard on and
unsupportive of black men, domineering, castrating. She tends to wear the pants around her house. Very strong. Sorrow rolls right off her brow like so much rain. Tough, unfeminine. Opposed to women’s rights movements, considers herself already liberated. Nevertheless, unworldly. Definitely not a dreamer, rigid, inflexible, uncompassionate, lacking in goals any more imaginative than a basket of fried chicken and a good fuck (Wallace, 1978, p.107)

Similarly, in the book entitled *All the women are white, all the blacks are men, but some of us are brave: Black Women’s Studies* by Gloria Hull, Patricia Bell Scott, and Barbara Smith authors describe the nature of intersectionality in which black women have been programmed to abide by. This includes the struggle to “separate race from class for sex oppression. In the current study an added level is the idea of disability identity. With this interpretation of the superwoman characteristic it is important to look at what role the superwoman schema/myth has on the development of disability identity. In the next section of this discussion of the superwoman schema, we look at the literature by Woods-Giscombé (2010).

**The myth of the superwoman schema.** This discussion on the phenomenon of superwoman schema explores how this particular embodiment of characteristics is the structuring lifestyle of many African American women. The idea that women exhibit abilities comparable to a fictional character with super powers and an ability to be omnipresent is an idea that seemed from therapy. These women have learned to raise children, work for companies and help them flourish, and manage the responsibilities at the church or other places of worship without batting an eye. However, the expectation to
have an “S on your chest” is a possible reason why there are higher rates of illness and disease among AA women. The schema is yet a characteristic that does not just go away with time or diagnoses for that matter.

Woods-Giscombé (2010) provided an in-depth discussion of the superwoman schema and its effect on stress, strength, and health of African American women. Thanks to this assessment the authors explained several ideas related to survivorship and healthcare. The purpose and design of the 2010 study was to identify themes of the superwomen schema in order to develop an instrument that would allow practitioners the opportunity to measure the phenomenon and exam its impact on health.

The sample of the study was derived from members of a community in a discrete metropolitan area of the southeastern region of the US. Using a total of eight focus groups as the primary setting of the study, 48 women were selected based on predetermined criteria (2010). For a total of 2-2½ hours the groups met to exchange dialogue and respond to the ten questions related to stress, coping, and ideas about the superwoman schema. Table 1 lists the questions presented in the study by Woods-Giscombé (2010).
Table 1

*Questions presented in Wood-Giscombe (2010) study on Superwomen Schema*

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) When I say the word stress what does it mean for you?</td>
</tr>
<tr>
<td>2) What causes stress in your life?</td>
</tr>
<tr>
<td>3) How do you cope with stress?</td>
</tr>
<tr>
<td>4) How did you see the women (mothers, grandmothers) in your life cope with stress?</td>
</tr>
<tr>
<td>5) Have you ever heard the term Strong Black Woman/Black Superwoman?</td>
</tr>
<tr>
<td>6) What is a Strong Black Woman/Black Superwoman?</td>
</tr>
<tr>
<td>7) What are her characteristics?</td>
</tr>
<tr>
<td>8) How did they develop?</td>
</tr>
<tr>
<td>9) Is being a Strong Black Woman/Black Superwoman a good thing?</td>
</tr>
<tr>
<td>10) Is there anything bad about being a Strong Black Woman/Black Superwoman?</td>
</tr>
</tbody>
</table>

(2010, p. 670-671)

Based on the qualitative data analysis several important concepts yielded the development of the preliminary superwoman schema conceptual framework. This framework serves a very specific purpose in this study. In this framework, authors present the specific characteristics of African American women under five major topic areas: 1) obligation to manifest strength, 2) obligation to suppress emotions, 3) resistance to being vulnerable or dependent, 4) determination to succeed despite limited resources and 5) obligation to help others. The next section explores each of these more in depth.

**Obligation to manifest strength.** When looking at the face value of people it is often easy to assume or associate the major stereotypes with that individual. Take for example the idea of a newborn baby. For most people reading this the first things that may have come into your mind was the image of pacifiers, diapers and little fingers and toes. Some may have imaged a particular baby and remembered even the scent of Johnson and Johnson’s lotion. These characteristics carry from one to the next. If we are
talking about a railroad engineer the image of a top hat and matching lined overalls might be the original image, now picture an African American woman. The image of a strong women might look different for the older generation of Black women than the image of the younger black women. However, the reality is if we discuss all the things that an African American woman can do we might answer in unison, everything. African American women are considered the beacon of strength and have been for centuries (e.g., Wallace, 1978). With this notion came the expectation or obligation be manifest strength.

An obligation differs slightly from a decision in this way. Obligations simply mean the duty, responsibility or requirement to be strong. Like in boxing, these women are challenged to never get caught with their backs up against the rope, to keep their feet moving and even if they get knocked down to get back up swinging”. The challenges discussed with this is that this obligation can easily be a persona or image that is not genuine. The falseness of this can ultimately lead to burnout and depression.

**Obligation to suppress emotions.** Finding a balance to care for others and care for self can be challenging. In many situations it might be safe to say that suppressing emotions is typically not within the realm of questioning, but rather the only option that an individual may have. This notion to suppress emotions is a characteristic that women of the Woods-Giscombé (2010) investigation considered to a technique helpful in returning to “business as usual” (p.7). Furthermore, these women found the idea of publicly expressing emotion to be a “sign of weakness” and ultimately unacceptable. A concern; however, with suppressing emotions related specifically for African American women with multiple sclerosis is the connectivity of linking suppression of emotions to
1) anxiety, 2) depression, and 3) stress. All three of the above mentioned disturbances have been found to cause heightened frequency in disease related exacerbations (2010). With this notion it is therefore important to consider how suppressing emotions can actually be detrimental if not appropriately incorporated into treatment.

**Resistance to being vulnerable or dependent.** The term vulnerable is often closely associated with negative connotations. In this particular section of the superwoman schema author Woods-Giscombé report evidence that women with a tendency to resist vulnerability and do not depend on other do so because they want to avoid “getting hurt. Considering this, an AA woman with MS may be hesitant to display vulnerability in order to protect her own emotions. Areas of life and work might ultimately be affected. An example of how these women might be affected might be that one’s intimate relationships may suffer.

**Determination to succeed despite limited resources.** Turning “lemons into lemonade” is a metaphor used to describe the resourcefulness of women serving in various roles. Possibly interpreted as an interesting challenge the determination to make “it” work is a quality of the superwoman schema. This concept is slated to include success regardless of limited resources (Woods-Giscombé, 2010). Consisting of heightened ambition, the overall outcomes for African American women are to complete what they have started with intense determination. Just as this can have positive effects there are also potential for negative experiences when forcing success despite limitations. Explained simply in this article, the author reports the statements of participants as
neglect for taking breaks when needed and sacrificing the amount of sleep (Woods-Giscombé, 2010, p. 674).

**Obligation to help others.** Evidence on obligation to help others is the final concept explained in the characteristics of the superwoman schema. This is the ultimate embodiment of caretakership. Participants of the study explained that the obligation to help others is often due to an inability to say ‘no’ when people would request favors or pass on responsibilities to them. Conversely, the obligation is connected to a sense of guilt and shame if they were to decline a request for help. The action of accepting several responsibilities has the potential to develop into an extensive list of tasks and duties which cannot be declined due to the other aspects of the superwoman schema such as, obligation to manifest strength and determination to succeed despite limited resources.

In the proceeding exploration of the superwoman schema characteristics it is clear to notice that being an African American women with multiple sclerosis may be a significant experience that prompts a need for a closer investigation into what mental health services should include in order for successful adjustment to occur following a diagnoses. The assumption presented in this study suggests that the roles of SWS adopt major contributing factors surrounding the experiences AA women have when attempting to develop a disability identity. Furthermore, factors of this experience include adjustment to disability, social comparison, and satisfaction with life. The next section of this literature analysis looks closely at these constructs.

**Social comparison theory.** Similar to the superwoman schema, the theory of social comparison has been identified as a instrumental influence for performance
obligations outlined by society. First proposed by Festinger, (1954) the theory suggests that people have an initiate outlook of themselves based on the definitions of normal expressed by society. The research completed by Festinger (1954) suggests the nine hypotheses for appraisal and evaluation of abilities. These hypotheses include: 1) the existence of a drive to evaluate opinions and abilities, 2) evaluation of opinion and abilities by comparison with the opinions and abilities of others, 3) the tendency to compare oneself to a specific person, 4) the unidirectional drive upward to demonstrate abilities rather than opinions, 5) non-social restraints to change one’s ability, large absence of opinion, 6) comparison with others is accompanied by hostility, continues comparison with others implies unpleasant consequences, 7) as factors increase in importance of some group as the comparison group, pressure toward uniformity will increase, 8) if someone has stronger opinions and abilities they are considered divergent, and 9) when there is a range of opinion and ability in a group the relative strength of three manifestations of pressures toward uniformity will be different for those who are close to the mode of the group than for those who are distant from the mode (Festinger, 1954 p.117-134). Considering the principles outlined in the social comparison theory it is identified for all people that social pressures may heighten the desire to meet the expectations and conform (Festinger, 1954). When the ability to meet these standards is compromised one may experience an overall sense of worthlessness.

Much of the foundational literature that emerged from the rehabilitation counseling profession begins with a description of the stigmas that were placed on people with disabilities. These insights of the past suggest that people with disabilities were
mistreated and often isolated from society. Thus earning an association with vulnerability. The concentration on the history of mental and physical health helps isolate the reason why a variety of laws were established to protect the rights of this population, for example, Smith–Hugh’s act of 1917 and the Americans with Disabilities Act of 1990s. However, the ideas that were shunned by legal standards still present with some unconscious lingering attitudes. The term vulnerability alone suggests a continuum of neediness and dependency (Mechanic & Tanner, 2007). This social stigma may present as an additional barrier for this population. This notion further alludes to the idea that people with disabilities attempt to keep their disabilities hidden to prevent associations with vulnerability or witness. In the models of the Johari window, this would be considered the “hidden from others” quadrant (Chang, Chen, Huang & Yuan, 2012).

Conversely, this idea connects to African American women with MS because, not only is the social standard now consistent of the strengths of SWS but also inclusive of standards of the norm. This type of stress can weigh heavily on performance, self-esteem, and overall satisfaction with life.

**Work-life balance.** As discussed in chapter one, work-life balance (WLB) is the idea of accurately maintaining roles in the work settings and life based environments (i.e., family, health, dating, & intimacy) in a simultaneous fashion (e.g., Roehling, Hernandez-Jarvis, & Swope, 2005; Kamenou, 2008). Work-life balance is considered here as a challenging concept during the adjustment period post diagnoses of multiple sclerosis for African American women. Looking closely at the literature conducted by Kamenou
(2008), it is noticeable that several key statements are made to describe in detail this experience.

Research regarding work-life balance remains under scrutiny because information only associated WLB with gender and racial concerns. However, the discussion of balancing these two important itineraries for with disabilities and caregivers is of equal importance (Kamenou, 2008, p.100). An additional focus of attention is given to the idea that women, in general are expected to meet expectations of social comparison even while at work. Described as following the mold of being “assertive, confident and wholly committed to the organization, with higher chances of fitting in and being accepted only if they are westernized, in terms of appearance, behavior and language” (Kamenou, 2008, p. 100).

Disability self-efficacy. Not with intention of forcing, a distinction between self-efficacy and self-concept, but it is important to note that the prime characteristics of each play a part in the larger picture of disability adjustment and identity. These components of adjustment are often overlooked. In this instance, self-efficacy or disability self-efficacy is described as the type of goals one sets or what actions must occur for successful coping to transpire (Boehmer, 2007). In this 2007 publication, Boehmer determined that “individuals with younger age identities reported lower levels of perceived disability and avoidance oriented coping and higher levels of satisfaction with recovery, self-efficacy and meaning-focused coping than individuals with older age identities” (p. 895).
In laymen’s term, this study presents evidence that the younger the patient the better likelihood the individual has to becoming aware of perceived disability. Highlighted also in this literature is a detailed definition of coping by Lazarus & Folkman (1987), which states “coping means activity aimed at overcoming adversity to return the person to an active life” (as cited in Boehmer, 2007, p. 897). Thus, self-efficacy is considered to be the more long-term view of the disability and how life can continue in spite of the accompanying required adjustments that might be different from the majority group. The conversation on coping explores the concept of meaning-focused coping, which basically serves as strategies of reinterpretation and acceptance based on determining the meaning of a given situation (Folkman & Moskowitz, 2004), like disability for example.

**Satisfaction with life (SWL).** The unspoken purpose of this coping gander is to improve the satisfaction with life after being diagnosed with a potentially debilitating disease such as multiple sclerosis. The topic of disability identity for all people whether acquired and congenital, individuals also face the challenge of evaluating their overall satisfaction with life. Bogart (2014) strategically evaluated participants using the Satisfaction with Life Scale by Diener, Emmons, Larsen & Griffen (1985). First and foremost the author explained the connection as the perspective and individual accepts (e.g. Glass, 1999). These considerations determined that satisfaction with life is the foundation of how people learn to function as well as approach life goals with belief that it is possible. Furthermore, SWL is known to represent how one gauges or evaluates the ‘hand of cards that have been dealt to them’.
For people with acquired disabilities this is considered to be a difficult task as opposed to people with congenital disabilities due to the understanding of what a “normal” life is like for people in society. The level of satisfaction can foster of determine the direction one is welling to move along a metaphor sliding scale or spectrum towards success. Satisfaction of life, although not typically evaluated through a paper form based assessment illustrates levels based on what is considered daily life performance and initiative.

**Stages of adjustment to disability.** In scrutinizing a larger scale of satisfaction with life and the process for which an individual with an acquired disability arrives at a place where he/she can evolve in spite of various life challenges, it is essential to consider and comprehend the stages of adjustment to disability. Several authors provide interpretations of this process (i.e. Shontz, 1965; Calabro, 1990), however in this study focus is given to the eight stage model proposed in the chapter on psychosocial adjustment to disability by Dutta and Kundu (2007). This particular model provides a more detailed and comprehensive take on the necessary components the make up the disability adjustment experiences. Dutta and Kundu (2007) suggest that the process of adjustment involves levels of 1) shock, 2) realization, 3) denial, 4) depression, 5) anger, 6) hostility, 7) acknowledgment and finally 8) adjustment. The author did a great job of tying the loss ends of this often-ambiguous process through consideration of minute details, which connect adjustment to disability to the hierarchy of needs suggested by Abraham Maslow. These needs incorporate self-actualization, esteem, love/belonging, safety, and physiological wellness (e.g., Mathes, 1981).
Another influential aspect of this chapter as it provides an interpretation of adjustment to disability are noticed as discreet suggestion that this process may be after all difficult for African American women with MS. The discussion includes the acknowledgment that “physical and financial limitations, delayed treatment, the associated stereotypes of having a disability and even the ambiguities for future functional abilities weigh heavily on the physical, emotional, vocational, social and economic long-term effects one has” (e.g., Elsenberg, Gleuckauf, & Zaretsky, 1993; Shapiro, 1994, as cited in Dutta and Kundu, 2007, p.3). The particular influence that the authors begin with is the concepts of disability under the umbrella of two infamous models: 1) the medical model and 2) the social model.

The medical model has been in more recent decades the preferred form of treatment as opposed to the social model because of its tendency to be another solution for the fast pace world that we live in. The medical model basically looks at the worldview of healing through “the elimination and prevention of disease and disability” (2007, p.4), or what researchers consider “the new eugenics” (O'Brien, 2011). For example, the 1985 literature by Daniel Kevles, he explained that “eugenicists argued that if a nation developed methods to ensure that those with desired characteristics bred in greater numbers while at the same time diminishing the breeding of those with undesirable characteristics, the species would be improved” (as cited in O’Brien, 2011,p. 347 -348). As with this idea, which is not particularly realistic, the social model categorizes disability as a problem based on the conditions within the social environment (2007, p.4).
One example that seeks to describe this notion of a social based concept is that of accessible parking spaces, sometimes referred to as “handicapped”. Resulting from this language that lacked person-first flare, rather than the parking spaces the people who may utilize the space are often described to be handicapped. Thinking about the person with a disability has abruptly turned into suggestive jargon that the person is ultimately incapable of functioning. Unfortunately, this age-old social construct has resulted in the understanding that people with disabilities are undesirable and needy. The fact that this is the reality of many people with acquired disabilities. Underlying implications suggest that it is harder to adjust to having a disease because of the associated stigma. A key concept of the social model described in the chapter by Dutta and Kundu (2007) is another the notion that in order for the issues of disability to be addressed there needs to be a more accepting definition of wellness within the larger society. Hence the development of research that describes the benefits of person first language and adjustment to disability as an increase of dignity and respect (Jensen, et al., 2013).

Dutta and Kundu (2007) used the phrase “dispel ignorance” when they discussed adjustment to disability and as a description of the large influence for which adjustment can be difficult; at the hands of society. Pedersen (1988) is referenced in an effort to illustrate of impact of the disability adjustment process from a multicultural perspective. The three central stages of gaining awareness, competency, and sensitivity actually support the need for a study such as this one to present evidence of best-practice when working with African American women during the first three years post diagnosis. Three stages of gain include: 1) awareness of the common beliefs about the differences and
similarities, 2) knowledge and insight of culturally learned assumptions, and 3) skills to effectively interact with people of different cultures (Pedersen, 1988, as cited in, Dutta and Kundu, 2007). Furthermore, the authors suggest that these concepts help with increasing personal power, energy, and decision-making (Dutta and Kundu, 2007). The outcome of such practice would ultimately increase adjustment by providing awareness of the stereotypical interpretations about differences and similarities of “functioning after being diagnosed, providing knowledge and insight of culturally learned assumptions of living with a disability, and extracting skills to effectively interact with people” (as cited in Dutta and Kundu, p. 6).

In a very sophisticated manner the authors discuss briefly the consequences of denying or neglecting the presence of a disability identity. With the acceptance that adjustment to disability is the foundation of this idea, it is written in this particular chapter that more detrimental experiences are caused the evaluation of “body image, functional capabilities, social role and autonomy… often triggering a sense of tremendous loss and self-pity” (Dutta & Kundu, 2007, p. 10). With recognition that this is a potential downfall for mental health and overall wellness, a deeper exploration of the adjustment process is delivered. Self- in-relation to others, as well as, culture considerations are at the center of moving to more advance stages.

Synthesizing the literature on adjustment to disability means also looking a other proposed models of adjustment. As with the model presented by Franklin Shontz, this version also includes three major phases: 1) pre-encounter, 2) post-encounter, and 3) rationale re-encounter (Calabro, 1990). The pre-encounter phase refers to the adjustment
associated with symptoms that cause unusual changes before or pre-diagnoses with a disease. For people with MS this phase may be occurring as the onset of disease related symptoms begin to become apparent. Such symptoms may include; numbness, vertigo, of difficulty with speech and vision, for example. The post-encounter phase is described as the time when the individual begins to accept the necessary life changes in order to live a healthy life style. The rational re-encounter phase is labeled to consist of a more temporary level of adjustment if there is another encounter with trauma or exacerbation is experience. For people with multiple sclerosis this phase can potentially include the fears of exacerbation, which have no known cause.

Amongst each of these phases lie the eight stages of adjustment mentioned earlier in this section. These defense mechanisms are presented in list form and are considered to be the key features of one’s experience; however, this list is not sequential and individuals on the journey to adjustment can revert at any time to a higher or lower stage (Dutta & Kundu, 2007, p. 12). As this process cannot guarantee a set level of adjustment it is considered desirable and healthy for individuals to exhibit symptoms or characteristic associated with the various stages to signify that change is occurring in some form of fashion. The stages of adjustment each comprise of various elements that help explain what area of coping for the newly diagnosed individual. In learning about the stages it is helpful to consider the various aspects of life for which adjustment may be more or less overall advanced. For example, physically adjusting to a disability may be slightly easier than adjusting to the disability and disease on a more tangible level such as in the work environment, intimate dating life, or religious affiliations. What can be said is the early
identification of the various roles one has played prior to the onset and diagnoses gives
range for the mental health and rehabilitation provider to incorporate adjustment practices
form a more holistic standpoint.

Association with the disability community in spite of expectations from your
own community. Only a small body of literature has been published with a focus on the
relationship one establishes with the disability/disabled community after a personal
diagnosis with an acquired disability (e.g. Gill, 1997). Evidence from studies on the
association with a historically unfavorable group, such as this, it is suggested that higher
level of satisfaction with life (SWL) must be identified first. This means that the
individual is able to set aside the concept of not being able to function in the same
capacity but instead foster the necessary adjustment in order to make the best of their life
situations. The old saying is to be able to turn “lemons into to lemonade”. The key
influences in association with the disability community is to advocate and help foster an
understanding that life with less does not mean life in despair (Gill, 1997). Furthermore,
being associated with is particular community can be a difficult process for African
Americans, in particular due to the deeper connections with church, religion, and faith yet
this does not negate the connections with others who may not have a faith based
connection. A women diagnosed with Multiple Sclerosis might be expected to denounce
or shy away from claiming association with the disability community due to expectations
of healing and deliverance. Yet, this is described to be a difficult task especially if the
symptoms of MS are still present. African Americans heavily associated with the church
can expect complete healing of disease but are more reliant on medication to treat the
more common illnesses such as influenza or high blood pressure (e.g. Balcazar, Suarez-Balcazar, Taylor-Ritzler, & Keys, 2010). Thus associating with a community like the one of people with disabilities is not really an accepted method of adjustment however it can play an impactful role in support and encouragement to keep pushing towards their desired outcomes and life goals.

**Involvement in health promotion activities.** Another aspect of the being diagnosed with Multiple Sclerosis for African American women is the concept of involvement in health promotion. There has been an uprising of health related efforts to get African Americans in general on a path of health and wellness. Particularly for women and children of this race. For example, First Lady Michelle Obama has developed a platform of becoming more active and taking extreme interest in discussing the patterns of buying healthier foods for the household and even becoming more conscious of preparing the food (Let’s Move, 2015). For African American women with MS again this stands out as a challenge since a large majority takes on the superwoman schema with multiple life roles taking away their ability to properly take the time to participate in these health promotion activities. To them it may seem easier to grab a burger in between transitions from job number one to job number two.

Other than food and the standpoint of adjustment with physical wellness, health promotion activities help an individual with this particular disease though involvement in treatment for mental health concerns and support. The National Multiple Sclerosis Society (NMSS) is an outlet that connects information and research findings to patients and caregivers. There is also a space for connecting with others with the disease to share
experiences. In recent years, NMSS developed a webpage specific to African American women with the diagnoses. In searching the outlet one will find links to reach and prevalence for people that identify as African American/Black, three videos of reference from a patient, caregiver, and researcher, and a few nice pictures of Black models with slogans of encouragement. However, this potentially useful page lacks a few vary key ideas that could help Black women in particular. This idea is again the premise of this study. To understand the impact of the superwoman schema roles on the process of adjustment to disability, discussion of how to redefine the process of caring for self and others without losing a sense of purpose, and figuring a plan to connect African American women to accessing support within the first three years of diagnoses.

Exposing the Missing Link of Current Research

The concepts reviewed thus far in this literature analysis contribute to what is needed in order to understand how African American women with multiple sclerosis view their lived world. This case is built on the interpreting specifically the placement of disability identity development and the roles of the superwomen women schema. The following is a detail exploration of the study by Carol Romagosa (2010) and her interpretation of the experiences that women with MS face. The study has sparked the need to look specifically at the experience of AA women in order to help them after being diagnosed with MS.

The study by Romagosa (2010) derives from a similar exploratory nature as this current research investigation and included the primary question of “how do women with the chronic illness multiple sclerosis (MS) cope with the distress of MS and move
through and beyond suffering into a proactive process of self-healing?” (p.4). By way of qualitative strategies the researcher took a constructivist approach in understanding the process of prioritizing the role of coping as a self-healing mechanism after being diagnosed. Romagosa (2010) used grounded theory as an interpreter of the phenomenon and personally transcribed interviews as the primary source of data collection. Romagosa explained that she chose this method of data management in order to “explain how the women played an active role in their own healing process by identifying their strengths and competencies and their common coping strategies that promoted positive psychological perspective” (p. 15). Although there was a sound design, which combined experience of having a chronic illness, self-healing and coping, the research by Romagosa (2010) lacked a key aspect in defining how women describe the role in their self-healing. This gap is noteworthy when looking at the sample of women for which she studied in this research. Romagosa talks about exploring the experiences of a “variety of women” however had a sample of eight women, seven of whom she described as Euro American and only ONE African American (2010). The current study seeks to address the misrepresentation in the Romagosa study by specifically examining the experience of developing a disability identity for African American women.

A concern, which has captured the curiosity of researchers and practitioners in a range of mental health and related fields, consists of the process of conceptualizing how individuals from various racial, gender, and even disability groups maneuver to make sense of disability (e.g., Pakenham, 2008; Baker, 1998) and obtain life goals “normally” after being diagnosed with an acquired disability (e.g., Holt, Clark, Debnam, & Roth,
The term “normal” here is not used as a comparison to the non-disabled community. Rather, normal is indicative of a life in which disability is a part of how an individual identifies and functions instead of viewing themselves in relation to society as ‘damaged goods’ (e.g., O’Brien, 2011).

Two particular challenges are noted as recurring themes in existing mental health and rehabilitation literature regarding MS: 1) adjusting to the notion of having a disease and/or disability (e.g. Dutta & Kundu, 2007, Holt, Clark, Debnam, Roth., 2014), and 2) coping with the idea of making necessary life changes, such as, reconsidering roles that induce stress (e.g., Senders, Bourdette, Hanes, Yadav, & Shinto, 2014; Johnson, Terrell, Sargent & Kaufman, 2007). Both of these contribute to the philosophies outlines in models of health promotion behaviors (Stuifbergen, 1995). Without consideration to the stages of adjustment and development of a disability identity for someone with an acquired aliment it is assumed that their feelings towards life and success will come to a traumatic standstill. Thus, it is imperative that direction of available literature with the anticipated rise in diagnosis of African American women be inclusive of their unique experiences.

Life for people with acquired disabilities has proven to consist of higher levels of stress and depression (Bogart, 2014). These considerations pinpoint an ultimatum of identifying the specific experiences of African American women with Multiple Sclerosis (e.g. Durand, 2006; Kaufman, Johnson, Bivens, & Norton, 2003; Woods-Giscombé, 2010). Furthermore, evidence is now being targeted to discuss how making the necessary
life changes and establishing a disability identity can decrease depression, anxiety, and ultimately effect the correlating severity of disability; exacerbations of MS have been directly linked to stress (e.g. Ackerman, et al., 2003; Buljevac, et al., 2003). This chapter includes a thorough description of MS and the disease course in African Americans, women in general, as well as, a comprehensive review of the current literature on adjustment to disability, the superwoman schema and disability identity development.

**Coping with Multiple Sclerosis**

The conversation of coping is a necessity when exploring how people with Multiple Sclerosis manage life roles and social interactions. When delving into the literature for guidance and best practice directives for serving this particular group, however it becomes evident that the samples used in these published studies lack a certain level of representativeness to the experiences of African American women. Defined as the “constantly changing cognitive and behavioral effort [used] to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folman 1984, p.141), coping requires attention to the a variety of life arenas so that the new form of evaluation is accurate to ability and opinion. As determined in the previous section by looking closely at the effect of social comparison, this presents as an important contributor in the wellbeing of the entire population.

Carol Romagosa for example, conducted research as a requirement of her higher education degree on the topic, *Confronting the Reality of Multiple Sclerosis: A Qualitative Model of Self-Healing* (2010). This study looked at the coping style of
women with Multiple Sclerosis with a specific focus on stories, metaphors, and meaning. The study consisted of seven Euro-American women and one African American woman, ages 30 to 66. Conducted using qualitative specific forms of inquiry, participant interviews sought to explore the theoretical principles as well as using observations. An evident notion of this study pulled together the major theme of the research in order to obtain information across one core category “Confronting Reality” and five main subcategories: 1) waking up, 2) balancing act, 3) ongoing struggle with acceptance, 4) acceptance as self-health and 5) transcendence as self-healing. While these outlines criteria can be universal in the experiences of African American women it is questionable rather the research did more to harm the other women with Multiple Sclerosis instead of foster positive evolution. Take for example the principles of the social comparison model and ideas of social anxiety once more. These two mentalities suggests that the ideas of wanting to be accepted can weigh heavily on performance and furthermore as we look at the concepts of the superwoman schema this can lead to the overall suppression of emotions. Missing links in literature such as this, signify the need of providing specific exploration on the experiences of African American women with MS and how these women, in particular, develop a disability identity while maintaining the strenuous roles of the superwomen schema.

**Conclusion**

In conclusion, this current research study addresses the gaps found in the 2010 study by Carol Romagosa, which focused on coping for women with MS, but lacked accurate representation of African American women and the implications for future
research suggested by Woods- Giscombé (2010). This 2010 study suggested that future research should “explore the differences between women who do and do not endorse the superwoman role” (p.680). In this current study, specific attention will be given to the difference between African American women who may or may not endorse the superwoman schema and their experiences with developing a disability identity.
Chapter Three: Methodology

This chapter will provide detailed reflection of the conceptual framework and methodological approach used in the development of this research design. Savin-Baden & Major (2013) designate that the manner of constructing a conceptual framework in research includes a “collection of general but related concepts from the literature that serve as partial background for the study to support the need for investigating the research question” (p. 138). In this current study the collection of general concepts included the ideas of the superwomen schema (SWS) Wallace, 1978; Wood-Giscombé, (2010) and the concept of disability identity development (DI) (Bogart, 2014). The significance of conducting this investigation is to identify to what extent do AA women associate with the “superwomen schema” and to identify if the process of developing a DI after being diagnosed with an acquired disability is influenced by the roles and responsibilities of SWS (Woods-Giscombé, 2010; Wallace, 1978).

Through providing a detailed look at the specific method of inquiry, this chapter will present a rationale for selecting the methodology, insight about the research design, the setting in which the data will be collected, and the procedure for sampling and recruiting participants. Also, this chapter will feature the projected procedures for data collection and data analysis which are centered on ensuring ethical integrity to accurately represent the study participants, the researcher and the data in accordance with the standards of conducting research (e.g., Glesne, 2011, 162-183). The overall goal of this chapter is to explain how the use of qualitative methodology is the most appropriate methodological choice in answering three central research question, 1) How do African
American women associate with the Superwoman Schema?, 2) What is the essence of the experience for African American women with MS?, and 3) How do African American women with MS make sense of disability identity while maintaining the roles and responsibilities of the superwoman schema?

**Rationale for Methodology**

The qualitative strategy to research is defined by Creswell (2009) as a procedure that draws on “text and image data with unique steps in information analysis and diverse strategies of inquiry” (p.173). According to Glesne (2011), conducting qualitative research is like “learning to paint” (p.3), for in order to grasp the concepts of this method one must observe the works of previous researchers, learn the specifics behind the techniques and methods used, practice on a regular basis and become comfortable with adapting the strategies to describe their own work. Patton (2002) adds that qualitative research is a collection of findings such as themes, patterns, concepts, insights, and understandings. All of which are utilized in providing “thick, rich, descriptions” (e.g. Guba & Lincoln, 1981; Denzin, 1978) for rendering an accurate depiction of an individuals’ experience.

According to Creswell (2009), there are two main strategies of research including: 1) quantitative strategies and 2) qualitative strategies. There is also a third strategy that is a combination of the two known as mixed methodology (2009). Quantitative strategies to research, although widely recognized for its ability to gain information from larger samples, would not be a good approach for this current study since the focus under investigation is to gain awareness and insight about the specific experiences that African
American women have after being diagnosed with MS. The premise of quantitative research is expressed as the process of studying a sample of the population through “numeric description” rather than through tenets of narrative (2009, p. 12-13). Creswell (2009) describes in a discussion of the criteria for selecting a research design that qualitative approach according to Morse (1991) is most useful when “a topic is new, or has never been addressed with a certain sample or group of people, and existing theories do not apply with the particular sample or group under study (as cited in Creswell, 2009, p. 18). Considering how qualitative research impacts the interpretations of experience, this investigation has been developed based on the definition that “qualitative designs are naturalistic to the extent that the research takes place in real world settings and the researcher does not attempt to manipulate the phenomenon of interest” (Patton, 2002, p.39).

This current study investigates the lived experiences of African American women diagnosed with Multiple Sclerosis (MS) using a phenomenological approach to research. Ploeg (1999) provided suggestions for identifying the research design that best fits the research questions. In this article the author used Van Manen (1990) to explain the aim of phenomenology. It is described here that the aim is to investigate the lived experiences of a people. Furthermore, phenomenology is slated to be the tool used to collect data specifically through exposure to the lived world of the individual being studied (Van Manen, 1990; Ploeg, 1999). This current study uses phenomenology as the best methodology to answer the three research questions because this will allow the “researcher [to] reduce data gathered as lengthy interviews describing the shared
experience of several informants to a central meaning, or “essence” of the experience” (McCaslin & Wilson-Scott, 2003, p. 447).

**Research Design**

The research design of the current study connects subjectivism as the epistemology or the process of determining “what kinds of knowledge is legitimate and adequate” (Gray, 2013, p. 19), with an interpretivist theoretical framework as the hypothetical perspective, and phenomenology as the methodology. As mentioned in the literature review (see Chapter Two), the design of this investigation has a primary concentration to uncover the experiences of developing a disability identity (DI) while upholding in the role of caretakership for others (i.e., family, community), specifically in AA women. With new evidence suggesting that AA women are at a higher risk of diagnosis and for having more aggressive forms of the disease (Johnson, Terrell, Sargent, & Kaufman, 2007; Langer-Gould, et al., 2013), the use of a qualitative design will tell the story of how the intersectionality of roles (e.g. Wallace, 1978) can cause increase levels of stress for this population. In attention, this type of research opened up the dialogue on incorporating mental health best practices that take into consideration the perceived obligations to nurture the community. The battle between caring for self and caring for others functions as an impression of conflict, which has the potential to increase stress and affect one’s ability to adjustment to disability. The outcome of this investigation provide details about the experience and be interpreted through the conceptual frameworks of SWS and DI.
Conceptual and Interpretative Frameworks

Subjectivity, or subjectivism in research is explained as the element of intrapersonal understanding, perceptions and interpretations of life and the world around you (Demirdirek, 2010). Savin-Baden & Major (2013) further this explanation through an outline of the various types of research perspectives (p.56). Three forms of the nature of research are listed under the examples of perspectives from different philosophical traditions, which include, objectivity, subjectivity and intersubjectivity. Subjectivism specifically is known to fully describe where the individuals’ placement may be in relation to others with the understanding that their worldview may be similar when there are major life conditions that are parallel (Demirdirek, 2010). In the current study subjectivism was used to help describe the realities constructed by each participant while keeping the subject and researcher actively involved (2013, p. 59).

The next major component of this research design is known as the interpretivist theoretical framework. It was suggested by Higgs & McAllister (2007) suggested that, “novice researchers often gets lost in the literature on interpretive research” (p. 34 as cited in Patton, 2002). However, the vulnerability of becoming consumed in this type of literature has been primarily associated with the tendency to be heavily compacted with language that can ultimately be misinterpreted. Conversely, in this current research the use of interpretivism, seeks to provide a structure of concepts that lead to the illustration and support of theoretical assumptions. Once again these assumptions regard the roles of SWS and the important of developing a DI. The interpretivist stance is intended to “assert that natural reality (and the laws of science) and social realities are different and
therefore require different kinds of method” (Gray, 2013, p. 23). This current research design identifies the existing research on coping for women, in general with MS, which has been completed more often using Caucasian participants (Romagosa, 2010). This current study argues that since AA women have different social realities their process of developing DI requires individualized attention. In this next section we will look again at what disability identity is and why it is considered an important component of adjustment to disability. The experiences gathered in this research will be done through an interpretive lens.

**Superwoman schema.** Introduced by Woods-Giscombé in 2010, the construct of the superwoman schema submits ideas of role responsibility for African American women, which dates back to historical disparities otherwise associated with slavery, civil rights inequalities and poverty. The article *Superwoman Schema: African American Women’s View of Stress, Strength, and Health*, reveals the particulars that contribute to this construct. It is within the idea of “superwoman-hood” that pinpointed five primary characteristics of the Superwoman Schema (SWS) framework. These primary characteristics include: 1) obligation to manifest strength, 2) obligation to suppress emotions, 3) resistance to being vulnerable or dependent, 4) determination to succeed, despite limited resources, and 5) obligation to help others (2010). Below is a brief description of each of the five characteristics of the superwoman schema as proposed by Woods-Giscombé (2010)

**Obligation to manifest strength.** The idea of an obligation to manifest strength suggested under this characteristic designates that women feel the need to “present and
image of strength. This characteristic also encompassed the ideas that women have to be associated with an image of strength. This obligation is interpreted as an individualized perceived responsibility.

**Obligation to suppress emotions.** The idea of an obligation to suppress emotions is described as the responsibility to keep “emotions bottled up inside” (Woods-Giscombé, 2010). For women, this obligation to suppress emotion also presents as a mechanism to keep other from seeing any levels of weakness.

**Resistance to being vulnerable or dependent.** For women the notion of dependence is not an option when you have others depending on you. In order to prevent others from misusing them or “taking their kindness for weakness, a mechanism of independence is employed as a way to “remain strong”.

**Determination to succeed despite limited resources.** For women, resilience is a characteristic that can be very beneficial. However, the characteristic to succeed despite limited resources also presents as a ploy to refuse help in order to maintain independence.

**Obligation to help others.** This characteristics or better known as a mentality is to have the power to step in when others are in need and correct the issue.

This study uses the obligations of the superwoman schema (SWS) as outlined by Wood-Giscombe (2010) as the observable characteristics that determined if the eight participants associated with the obligations of SWS. These outlined obligations were used to explore who the eight participants understand their lived world in relation to the ability to develop a disability identity.
Disability Identity

As discussed in the previous chapter (see chapter 2), the literature on disability identity development has identified components of self-concept and disability self-efficacy as the theoretical framework of beliefs concerning the ever so important coping and adjustment process for people with acquired disabilities (Bogart, 2014). In 2005, Jennifer Gibson proposed that the process of disability identity development occurs over three fundamental stages: 1) the passive awareness stage, 2) the realization stage, and 3) the acceptance stage. The development of this particular model has been associated around the ideas that historically medical professionals and mental health practitioners have played a role in the depersonalization of individuals with disabilities by attributing to the “less than” perceptions. This idea suggests that in the way that practitioners’ used people with disabilities as subject of science experiments, societal and personal views would only contribute to an increase of victimization (Gibson, 2006).

According to the disability identity development model and in comparison to a range of other multicultural identity models (Gibson, 2006, p. 7), this process suggest that understanding the perceptions and struggles of individuals with disabilities is imperative to treatment and adjustment. Furthermore, Gibson (2006) suggests, “identity development of persons with disabilities can be fluid” (p. 7) and clients will not always fit into one particular stage at the start of adjustment and in the third stage overtime. In the current study, the use of the disability identity development model (Gibson, 2006) will serve as a guide for interpreting who the participant views having Multiple Sclerosis. Based on the current stage in which the participant is in, questions related to superwoman schema were
asked to interpret “how African American women with multiple sclerosis make sense of disability identity while maintaining the roles and responsibilities of the superwoman schema.

Adjustment to disability. Additionally, the previous chapter focuses on the procedure known as adjustment to disability. The process consists of eight specific components of mental health wellness and coping. These components of adjustment include: 1) shock, 2) realization, 3) denial, 4) depression, 5) anger, 6) hostility, 7) acknowledgment and finally 8) adjustment (Dutta and Kundu, 2007). As an individual with a disability comes to a realization of their life challenges and advance onward with life aspirations in spite of those extreme barriers, it is suggested that the individual ultimately has a higher level of adjustment. In addition to the discussion on adjustment to disability by Dutta and Kundu (2007), Pedersen (1988) offered input by illustrating that the impacts of disability adjustment also include three central stages of gaining awareness, competency, and sensitivity.

These central stages consist of 1) awareness of the common beliefs about the differences and similarities, 2) knowledge and insight of culturally learned assumptions, and 3) skills to effectively interact with people of different cultures (Pedersen, 1988, as cited in, Dutta and Kundu, 2007). Based on the conversation by Dutta and Kundu, as well as other scholars who have discussed adjustment to disability, this current research seeks to “provide knowledge and insight of culturally learned assumptions of living with a disability, and extracting skills to effectively interact with people” (as cited in Dutta and Kundu, p. 6). While it is important to consider both DI and the stages of adjustment to
disability, this next section will explore why phenomenology is the best fit for this current investigation.

**Phenomenology**

Due to the dynamics that make this particular population unique, for example, prevalence of having more aggressive forms of the disease (Kaufman, Johnson, Moyer, Bivens, & Norton, 2003) and higher risk of being diagnosed over any other race and gender (Langer-Gould, et.al., 2013), this research investigation was conducted by way of a phenomenological structure (Glesne, 2011; Merriam, 1998). The research practice known as phenomenology has been described as widely used by many investigators, however is most fitting in this particular study in order to “gain a deeper understanding of the nature or meaning of everyday experiences (Patton, 2002, p. 104). In regards to the nature of meaning this current study seeks to understand: 1) the meaning of superwomen schema and the related characteristics, 2) the meaning of disability identity and 3) the meaning of how these women understand the affect that the SWS has on their DI development, if any. Furthermore, phenomenology was used in this study as a means to respond to the assumption suggested by Husserl (1972). This assumption or basic notion elucidates that we often know only what we have experienced and with this awareness there is ultimately extended levels of attention to the meanings that make up our consciousness and awareness to life meaning (Patton, 2002). In this case, the assumption is that AA women only know how to be superwoman and care for the needs of others while putting their own needs (i.e. health and wellness) on hold. The use of the phenomenology approach in this study helped in honing in on the “unique set of
experiences which are treated as truth and which determine that individual’s behavior” (Eichelberger, 1989, p.6 as cited in Patton, 2002, p. 107). Wolff, 1981, stated that “one may merely know that no one is alone and hope that a singular story, as every true story is singular, will in the magic way of some things apply, connect, resonate, touch a major chord” (Wolff, 1981, p.72).

The idea of “individual’s behavior” does set the stage for understanding that even though African American women are highlighted in this study, each participant has an experience worth hearing and the identification of their specific experiences can potentially explain this phenomenon. The foundation question mentioned by Patton (2002) in the discussion of phenomenology as a conceptual framework of qualitative inquiry is “what is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?” (p.104). A quote by Charles Addams helps support the idea that these stories matter. It rejects the idea that because the stories of non-black women have already been told (e.g., Romagosa, 2010) regarding coping that those accounts truly depict the experiences of AA women, “normal is an illusion, what is normal for a spider is chaos to a fly”. Thus, this investigation and research design attests that there is no normal coping style for all women with MS. With specific attention to AA women in this current study, phenomenology seems most fitting to the purpose of answering the question of what specific experience do African American women diagnosed with Multiple Sclerosis have in developing a disability identity while attempting to maintain the responsibilities and roles of the superwoman schema (Woods-Giscombé, 2010).
Additionally, this study looked closely at the within-participants experiences (Cone & Foster, 2006) to determine whether management of healing and wholeness opportunities are found to be consistent amongst African American women by comparing the emerging themes (Patton, 2002) as well as identifying consistency with any related challenges that make this process difficult. It has been hypothesized that the variation of experiences of participants will show similarities. Yet, when compared to the information found in the existing literature on SWS for women without MS, and DI for all people with acquired and congenital disabilities will have noticeably significant experiences for AA women with the disease. The information gained during this investigation seeks to help develop a new forum of discussions on best-practices to consider when serving this population.

**Sampling Strategy**

Cone and Foster (2006) offer direction in explaining the process of selecting participants for a research study. They suggest that three major questions be clarified. These focal questions include: 1) who will participate, 2) how many will participate, and 3) how will they be selected (2006, p. 129). For this research investigation all three of the questions can and will be addressed in this particular discussion on participants.

**Participant selection.** Beginning with the first question, who will participate?, this study seeks to obtain thick rich description of the specific experiences of African American women after being diagnosed with multiple sclerosis (MS). This study has two set criteria for which outline participant eligibility, including: 1) must have a diagnosis of MS) and 2) must self-identify as an African American female. The second question posed
by Cone and Foster (2006) is how many will participate? In effort to explore a range of experiences and analyze whether this understandings of SWS and DI overlap in any way this research investigation comprised eight (N=8) participants that meet the selection criteria. Each of the selected participants were asked to complete basic demographic questions about their age, location, marital status, employment and duration of diagnosis (see Appendix A). Qualitative researchers often have small sample sizes because the purpose is to explore phenomena in depth and to gain a deeper understanding of it.

**Participant recruitment.** This third question by Cone and Foster (2006) asks how the participants were selected. According to Elde (2008), recruitment of participants in qualitative research refers to the process of inviting individuals who match the criteria to join the study. Specially, in the process of recruitment, researchers are encouraged to purposely seek out individuals whom are best suited for assisting in answering the identified research question (s) (2008). Inclusive criteria represents the factors for which the individuals’ have parallels.

Patton (2002) provides an explanation of sampling specific to the process of conducting qualitative research. In Patton (2002), the author describes purposeful sampling for qualitative investigations as a small sample. For example, (N=1) as opposed to larger randomly selected samples found in quantitative research. It is likewise suggested in the literature on sampling of participants in qualitative research that what is considered as bias in quantitative inquiry is actually seen as focused sampling with “logic and power” (2002, p. 231) in qualitative research.
For this study, description of participant selection are summarized by the use of three strategies of qualitative sampling (Patton, 2002). These include: 1) theory-based sampling, 2) snowball or networking (Bowen & Moore, 2014), and 3) criterion sampling. The following discussion of the sampling techniques there includes a detailed overview the Patient like Me setting for participant recruitment.

The first of the three is theory-based sampling, As discussed by Patton (2002) this type of sampling “the researcher samples incidents, slices of life, time periods, or people on the basis of their potential manifestations or representation of important theoretical constructs” (p.238). Breaking down each of these outlined components of theory based sampling, this research looks at African American women who have only been diagnosed with multiple sclerosis based on SWS construction.

The second strategy is snowball or networking (Bowen & Moore, 2014). This strategy is consistent with this study under the idea that African American women with MS know someone else with the diagnoses. Patton explains that snowballing is when “cases of interest from sampling people who know people who know people who know cases are information rich” (2002, p. 242). This ultimately means that the pool of participants are open and most likely in this case closely tied to the criterion of individuals as outlined for the study. This idea leads us to the third and final strategy of sampling that was used for this investigation. The strategy known as criterion sampling will be used under the notion that eight (N=8) participants for this study were selected based on their relationship to the outlined criterion, which includes AA women with MS.
Site Selection

**Patients like me.** In this current study the site selection procedure is slightly different. Instead of entering into an actual community setting, this study recruited participates using an online community. Known as an online support community for people with disabilities, Patients like me, was co-founded in 2004 by Benjamin Heywood, James Heywood, and Jeff Cole engineers from MIT. This health data sharing platform serves as an opportunity for people with disabilities to mingle with others who share similar diagnoses. The for-profit company, which has free registration to persons with disabilities, values four core principles: 1) putting patients’ first, 2) promoting transparency, fostering openness, and creating “wow” (Patients Like Me, 2015).

Currently, the website offers 18 umbrella communities consisting of 60+ conditions. The MS community has 41,508 members. The members of this MS community can be filtered by age, gender, interest, conditions, MS type, years since first symptom, years since diagnosis, condition status, ethnicity and race to name a few. Using this tool, I sent the flyer of recruitment to prospective participants by filtering the gender and race only to female and AA. The website allows for communication between members. This means that permission was not needed to recruit the participation of women with MS.

**Open community snowballing.** In addition to the use of the patients like me website and resource this study also open recruitment to the community of people who are not currently using the patients like me resource. Thus, participants were not be selected based on a certain demographic area such as only in the state of Ohio. Instead the invitation to participate will be opened to individuals in other states throughout the
continental US. The main focus of recruitment is obtaining participants who are African American women with Multiple Sclerosis.

**Data Collection Methods**

**Interviewing.** In the literature the data collection method of interviewing is explored as the process in which an interviewer sparks conversation with the interviewee on the topic under investigation (Savin-Baden & Major, 2013). In a conversation on the origin of interviews (2013), the authors explain that researcher “originally used interviews to question meanings of experiences and to provide access to the context of participant’ behaviors” (Seidman, 1998, p. 4). Although there are a variety of interview types, four specific types are known as structured, semi-structured, unstructured, and informal. For the purpose of the current study the interviews were conducted in a semi-structured manner. This type of interview allowed the participants to answer some questions and also include key components of their lived experience.

Semi-structured interviews allow the interviewer to use a predetermined set of questions during the conversation however also includes the responses of the participants in the comments and reactions (Savin-Baden & Major, 2013). Using the semi-structured strategy of interviewing, the current study followed the questions but from time to time divert from the questions to respond to responses for clarity and/or justification of meaning (2013). The questions asked during the interviews of the current study have been designed as open-ended questions. In the current study, the researcher recognized that there are several roles and responsibilities that accompany this system of data
collection. These roles and responsibilities include and listening and observing the participants during an interview.

Finally, the process of conducting interviews in the current study was conducted using internet media outlets. Since the participants were from various locations within the continental U.S. interviews were made available to take place either via telephone interviews, computer conferencing (i.e. Skype, FaceTime, Google Hangouts), or face to face interviews. The last component of the interviews included with structure of the questions that were asked to each of the participants.

In Savin-Baden & Major (2013) authors offer a discussion of the process of developing strong interview questions. These suggestions outline five key areas to which the questions can focus on in order to extract the most appropriate information about the individuals’ experiences. The key areas of initial questions include behaviors, opinions/attitudes/values, feelings, knowledge, and senses. In combination, the questions included direct/descriptive, narrative, and structural questions (Savin-Baden & Major, 2013, p. 365). Additionally, in order to obtain in-depth data the questions to be asked during the participant interviews also included contrast, evaluative, circular, and comparative questions (2013). The final types of questions asked during the participant interviews are follow-up questions. This manner of question allowed for verification, prompts and probes, follow-up, and closure questions (2013). The next section will thoroughly describe the interview questions as well as provide a detailed interview protocol according to Savin-Baden & Major (2013, p. 368). Appendix A illustrates the questions that was used during the interviewing process.
The Structure and Development of the Research Interview Questions

The eleven questions used for the purpose of the data collection process are consistent with the principles of open-ended and semi-structured interviews as outlined by Patton (2002). The interview questions used to guide the interview process are located in Table 2. While the first nine questions of the interviews were directly related to obtaining information about personal experiences, the final two questions are considered expert recommendations for healthcare professionals working with this population of women and other AA women with MS. These responses and themes are discussed below.

Table 2
Research Interview Questions

| Q1 | How would you describe your current roles and responsibilities? |
| Q2 | Thinking about these roles and responsibilities, how would you describe your current level of stress, if any, related to managing these roles? |
| Q3 | How would you describe your ability to cope with stress prior to being diagnosed with MS? |
| Q4 | How do you describe your ability to cope with stress today? |
| Q5 | How would you describe your identity? |
| Q6 | What role, if any, does identity play in coping with stress? |
| Q7 | How did you learn about managing multiple roles? |
| Q7a | What are the most important things in your life today? |
| Q8 | How would you describe your overall experience after being diagnosed with MS? |
| Q9 | How would you describe your experience particularly with role management after being diagnosed with MS? |
| Q10 | What advice would you give to someone who has just discovered that she has MS? |
| Q11 | What advice would you give to health educators and other health professionals who work with people who have MS? |
The interview questions listed in Table 2 were developed with a strategic purpose of gaining insight into the lived experiences of AA women with Multiple Sclerosis (MS). These interview questions considered the three alternate approaches to preparation, conceptualization, and instrumentation of research proposed by Patton (2002). The three variations in the design of qualitative research instrumentation, include: 1) informal conversational, 2) general interview approach, and 3) standardized open-ended (2000, p. 342). The eleven interview questions listed in Table 2 address two of these three variations: 1) informal conversational and 2) standardized open-ended. Patton (2002) supports the combination approach to interviewing and suggests that, this combined strategy, which uses two or all three of these variations, offers the interviewer flexibility in probing and in determining when it is appropriate to explore certain subjects in greater depth, or even to pose questions about new areas of inquiry that were not originally anticipated in the interview instrument’s development (2002, p. 347).

This notion of “probing” was very important in the development of the eleven interview questions used in the investigation. It was anticipated that some of the participants might not feel comfortable talking about experiences and that metaphors might be used to express feelings (e.g., Romagosa, 2010). These probing questions provided the opportunity to ask participants to comprehensively describe their feelings to garner the embedded lived experiences and the meaning attached to those experiences. Questions used in the investigation also vary between six forms of question, including: 1) experience and behavior questions, 2) opinion and values questions, 3) feeling questions,
4) knowledge questions, 5) sensory questions, and 6) background demographic questions (Patton, 2002).

**Additional Components of the Interview Process**

In addition to the interviews, this process of the research investigation took into account the non-verbal cues through participant observations. Patton (2002) states that it is important to consider that “observing activities, interactions, what people say, what they do, and the nature of the physical setting is important in a comprehensive approach to fieldwork” (Patton, 2002, p. 295). Field notes were collected in order to help the researcher keep track of the behavioral reactions, body language cues, and verbal responses varying from participant to participant. Information documented using observations assists in understanding the meaning of participant responses on a deeper level specifically through monitoring body language.

For example, during Meredith’s interview it was noted that the participant sat with a closed posture. According to the research by Allan and Barbara Pease (2004), body postures, such as crossed-arms-on chest, represent a universal language of defensiveness. Meredith defensiveness was indicative of uncertainty and avoidance. This uncertainty is also suggestive of adjustment to disability characteristics realization and denial. The realization phase suggests that Meredith may experience “anxiety, confusion in thinking, fear of death and uncertainty about the future” (Dutta & Kundu, 2007, p. 12). Meredith also exemplified symptoms of the denial and defensive retreat, which are considered a coping strategy against painful realization of the long-term effects of
disability or a disease” (Dutta & Kundu, 2007, p.12). This evidence that was initially observed by body language is supported by the verbal responses that Meredith provided.

Sometimes it sucks to have MS like, like affecting me but other than that I am still in school…Well, sometimes I think about like the future cause I am like…im spending my 20s in medical school and everyone else is having fun and then I am going to be in debt for most of my thirty’s and forty’s and finally when I get out of debt and should be enjoying life…. That’s when like MS really gets bad so… that’s some of the bad days that I really think about but other than that I don’t know it. It doesn’t affect me emotionally…Umm… sometimes I cry but not that much anymore. I’m too busy, to do anything else…Umm, it’s kinda hard now because I am doing rotations so I’m on my feet like 12 hours a day and it really starts to like burn and I don’t want the people that I am working with to know so I don’t want to be like, oh can I sit down so I just have to push through it but I be so tired but… Umm, it’s kinda hard now because I am doing rotations so I’m on my feet like 12 hours a day and it really starts to like burn and I don’t want the people that I am working with to know so I don’t want to be like, oh can I sit down so I just have to push through it but I be so tired but (Meredith. personal communication. August 30, 2015).

Another example of information collected through body language and participant observation was noted in the interview with Akeelah. Allan & Barbara Pease (2004) discuss the concept of “faking it till you make it”. It is suggested that people cast themselves “into a believable role in an interview and mentally practice in advance how
they will behave if they want others to take them seriously” (Pease & Pease, 2004, p. 353). For Akeelah, her behaviors were suggestive of a form of avoidance regarding her true feelings. Specially, it was noted that Akeelah was more inauthentic about her experiences because her mother was in the room and she felt the need to hide her actual feelings in order to protect her mother. She explained that her mother is not comfortable discussing the diagnoses so she has to fake or down play her experience while she is present.

**Data Interpretation and Analysis**

The definition of data interpretation is “the act of explication, explanation and elucidation”. The literature by Peshkin (1993), describes that data interpretation allows outcomes to be explained in order to create meaning. In addition, it is the notion of elaborating on the ideas of existing theory in order to develop new concepts. Savin-Baden & Major (2013) suggest that there are various components or data interpretation and four good practices of data interpretation. These include the acknowledgement of subjectivity, demonstration of the tentative nature of interpretation, openness to negotiation and renegotiation of meaning, recognition of the role of shared ‘truth’ (2013,p. 463). This study will used the SWS and to analyze the data.

The approach to documenting these interpretations used in this study include the idea of “acknowledging one’s view of how the process happens, supported with a theoretical perspective” (2013, p.464). In this study, the process under investigation is the development of disability identity and the theoretical perspective is the theory of disability identity and the superwomen schema. Two additional aspects of conducting
sufficient data interpretation was used here in order to understand the meaning of the responses provided by this investigation include demonstrating the move from analysis to interpretation and mapping the interpretive process.

Savin-Baden & Major (2013), provide criteria for evaluation data interpretation. The criteria asks a series of five question, each of which are explored below. First, what is being argued for the ways these data are presented? In this study, the argument is that African American women are likely to identify with characteristics of the superwoman schema and therefore they have a difficult time developing a disability identity. Because of the difficulty, the adjustment process is more challenging. Furthermore, it is argued here that if African American women were to learn of the manage roles of the SWS the process would not be as difficult after being diagnosed with an acquired disability.

Second, how are people’s biographies included? In this study the biographies of the participants play a major part in understanding how or if the development or SWS has been contributed by their experiences. Third, what are the values being portrayed. The values her being portrayed included, the values of the AA women experience, value of SWS and value of DI. Fourth, what are the interpretations saying about those who are part of the study? These interpretations seek to argue that African American have a different experience after being diagnosed and the coping process cannot neglect the responsibilities of SWS. Finally, how is the context being represented? The context of this data that came for the participant narratives represents AA women with MS in a manner of strength however mindful that their historical/innate role to care does not go away after being diagnosed. By finding ways to incorporate self-wellness with
community wellness, these women had an opportunity to decrease the frequency of exacerbations and ultimately the association of more aggressive forms of the disease.

While all these are important factors of this process, Savin-Baden & Major (2013) suggest that there are two issues to be aware of during data interpretation. These include oversimplification, which is the idea of only looking at the surface of meaning and negotiation and renegotiation of meaning, which is the idea of double-checking for clarity however in that process the true meaning can be misinterpreted.

Transcribing. The above section elucidates the process of interpreting the information obtained during interviews with the participants. This process occurred using transcription of data. Transcription of data was completed by the researcher rather than through an outside source or professional transcriber. This allowed the researcher to increase familiarity with the responses of the participants. This also allowed the researcher to ensure that the meaning and context of data is representative (Patton, 2002).

Trustworthiness and Credibility

According to Patton (2002, p.66), one way of ensuring reflectivity of voice and perspective on strategic themes in qualitative inquiry is through triangulation. Broken down into three key areas which include: 1) those studied (participants), 2) those receiving the study (audience), and 3) self (as the qualitative inquirer). As suggested in each of these three realms there are several questions that require attention and exploration. For example in the first part of triangulation participants are asked specifically how they know what they know?, what shapes or has shaped their worldview and ultimately how do they know? (Patton, 2002, p. 66). Next, is the questioning of those
receiving the study also known as the audience? Some examples of the questions asked to these individuals while ensuring that the interpretations are reflexive include how do they make sense of what is given to them, and what perspective do they bring to the findings. Finally, there are a set of specific questions that must be asked to one’s self. These include what do I know?, What shapes and has shaped my perspective?, with what voice do I share my perspective? (Patton, 2002, p.66).

**Researcher as Instrument**

Patton (2002) suggests that in qualitative research, “the researcher is the instrument” (p. 14). With this conceptualization of instruments used in qualitative research it is equally important to define the elements of this tool in the design of the research. Patton (2002) also describes that it is the researcher who takes on the sole responsibility for the way in which the data is managed and conversely how the findings are reported. It is suggested that “because the researcher is the instrument in qualitative inquiry, a qualitative report should be completed” (2002, p.566). The qualitative report is the element of the study that explains the training of the research and level of expertise that makes them capable of assuming a responsibility of such nature. The report also takes into account that consideration of the various concepts are pivotal to the investigation. As previously mentioned the research design of this investigation linked the ideas of subjectivism as the epistemology or the process of determining “what kinds of knowledge is legitimate and adequate” (Gray, 2013, p. 19), with an interpretivist theoretical framework as the hypothetical perspective, and phenomenology as the selected methodology. The idea of interpretivism suggests that the researcher was
responsible for interpreting the meaning of the lived experience and social world, particularly in this study on the experience of AA women with MS.

Furthermore, consideration was given to the potential investigator effects, which includes, a) reaction to those in the setting, b) changes in the fieldworker during the course of the data collection, c) the predisposition, selective perceptions, and or bias, and researcher incompetence. Although the role of the researcher is critical it is also imperative to understand that, the position of viewing the lived experiences of other can be challenging. Conversely, while the information about these experiences were collected using interviews the researcher analyzed the themes related to the specific experiences of AA women with MS as they emerged. In the next section, there will be a discussion of the researcher and the components of personal experiences that will contribute to the research outcomes.

**Qualitative report.** The research of this study self-identifies as an African American woman, single, and currently working to fulfill the requirements of her doctoral degree. The researcher grew up in inner city Cleveland and moved to Alabama to pursue her undergraduate and graduate studies in 2004. After the completion of her graduate degree, the researcher moved to Pittsburgh, Pennsylvania to work at the Office of Vocational Rehabilitation (OVR). In February 2012, the researcher was diagnosed with relapsing-remitting multiple sclerosis at UPMC hospital in Pittsburgh, PA. Raised by both her mother and father in a Christian environment the researcher was taught to value faith and healing first. Furthermore, although the researcher was raised in a family dynamic that included both parents she was typically reared by her mother. The
researcher attributes the strength of her mother was her first experience and exposure to
the superwomen schema. The researcher has two older siblings (both female). The
researcher recalls past experiences of seeing her mother tend to the children while her
father worked was when she began to interpret the roles and responsibilities that women
have to nurture the family and the community.

As mentioned in the limitations and delimitations section (see Chapter 1), this
study on the experiences of African American women with MS is considered sensitive
research. The researcher identifies as an African American woman with MS herself and
recognizes that there is value as well as considerations of conducting researcher on a
topic that is also a lived experience. However, the researcher is interested in hearing the
stories of other women how are currently living with the disease. Furthermore, the
researcher is interested in interpreting the meaning of experiences for other AA women
with MS in order to add to the body of literature available. Looking closely at the process
of using the researcher as the instrument in the next section there will be a response to the

The experience that the researcher brings to this research is associated with a
background in counseling. The researcher considers this early experience and exposure to
active listening and the empathy of others as a practice a beneficial tool. With a master’s
in Rehabilitation Counseling from Alabama State University and experience of working
in the field from the Office of Vocational Rehabilitation in Pittsburgh, PA, the researcher
is an expert in understanding that Maslow’s hierarchy of needs plays an important role in
the adjustment and rehabilitation process. The researcher has not only personally
experienced the process of disability identity development and conflict of the superwoman schema roles and responsibilities but she has witnessed them first hand through interaction with friends, family members and clients. The most important goal of the researcher is to identity how this experience of maintaining the strenuous roles of SWS and process of developing a DI shape the worldview of African American women with MS. Furthermore, with the estimate rise of diagnoses amongst AA women with MS, the researcher seeks to contribute to the existing literature evidence to support the idea that these women have different lived experiences after being diagnosed.

**Ethical consideration.** In this particular study, ethical consideration of conducting researcher is divided across three is specific areas: 1) the governing body of the counseling professional, the American Counseling Association, 2) the governing body of the rehabilitation counseling profession, and 3) the Institutional Review Board at Ohio University. Creswell (2009) mentions that there are ethical considerations to consider and anticipate when conducting research. The key areas include ethical issues in the: 1) research problem, 2) purpose and questions, 3) data collection, 4) data analysis and interpretation, and 5) writing and dissemination the research. The discussion of ethical consideration in this study helps to identifying the prospective concerns. In this current study in addition to reading and understanding the potentials for ethical concern in these areas, the use of informed consent helped in the protection of the researcher and the research participants. In the informed consent there will be identification of the researcher, sponsoring institutions, purpose of the research, benefits for participating, level and type of participant involvement, indication of how the participants were
selected, notation of risks to the participants, guarantee of confidentiality, assurance that
the participant can withdraw at any time and provision of names of persons to contact if
questions arise (Creswell, 2009, p. 89). This investigation recognizes that there are a lot
more ethical concerns that can arise during a research investigation and that they cannot
all be planned for. Still the goal of this study is to follow the design as approved and
refrain from ethical violations. The following will include a discussion of the ethical
considerations outlined by the American Counseling Association (ACA), Commission on
Rehabilitation Counselor Certification (CRCC) Association and the Institutional Review
Board (IRB) at Ohio University.

In section G of the 2014 ACA code of professional ethics there are five major
components that fall under research and publication. These five areas include: 1) research
responsibility, 2) rights of the research participants, 3) managing and maintaining
boundaries, 4) reporting results, and 5) publications and presentations. All of these five
major areas are conceded by subsections that specific the ethical codes of the profession
in regards to research. The objective as mentioned in the introduction of sections G is to
outline how “counselors who conduct research are encourage to contribute to the
knowledge based of the profession and promote clearer understanding of the conditions
that lead to a healthy and more just society” (ACA, 2014, p. 15). With these outlines set
of ethics this research acknowledges not only that governing exists but also where to
locate answers about whether something is considered to be a violation. Similarly, there
are professional ethics for rehabilitation counselors. Found under Section I: Research and
Publication with five subsections: 1) research responsibilities, 2) informed consent and disclosure, 3) reporting results, 4) publications and presentations, and 5) confidentiality.

In addition to these professional governing bodies in counseling, this research followed the ethical codes outlined by the professional review board at Ohio University. The Office of Research Compliance at Ohio University is committed to the fair treatment of humans that commit to clinical trials, interviews, and observations. This study complete the necessary forms as well as comply with the policy of conducting research.

Conclusion

This chapter provided a detailed outline of the procedures and anticipated outcomes of this current study. The chapter explained the rationale and purpose of the methodology research design, the criteria for participant selection and sampling strategies. Furthermore, this chapter concluded with an overview of characteristics of the researcher as the instrument and the process of data collection and analysis. Overall the rationale of this chapter was to reiterate the purpose and significance of conducting the study. The following two chapters will begin to explore the actually themes collected which that will assist in answering the research questions under investigation.
Chapter Four: We Are Not Monolithic: Portraits of African American Women with Multiple Sclerosis (MS)

The purpose of this phenomenological study is to explore the lived experiences related to SWS and DI for African American (AA) women diagnosed with Multiple Sclerosis (MS). In addition, the overall aim of this research is to address the research questions in order to contribute culturally specific evidence to existing literature. Particularly, the literature that addresses the psychological based needs of individuals who have MS. Ideas presented in existing literature on adjustment to MS seem to fall short in the area of addressing those distinct needs of AA women and the level of psychological care required in order to assist AA women through the adjustment to disability process.

As mentioned in previous chapters, this research has looked at the trends of MS and prevalence rates in the United States. These trends suggest that AA women are more likely to have more aggressive forms of the disease (Kaufman, Johnson, Moyer, Bivens, & Norton, 2003); but also indicate that AA women are more likely to be diagnosed more than males and any other race (e.g., Kurtzke, 2008; Wallin, et al, 2012, Langer-Gould, 2013). With this evidence, gaps in the psychosocial and counseling literature, in particular, show that research conducted to understand the unequivocal lived experiences of AA women with MS is essential.

This current chapter provides a thorough description of the eight research participants and an in-depth look at the unique stories related to their experiences of living with MS. Furthermore, this chapter delves into how their experiences with
disability identity (DI) and the superwoman schema (SWS) relate to being African American women. The goal of this chapter is to first paint a picture of the eight participants and begin the exploration of the research finding.

Stories of Diagnosis: Capturing the Participants Lived Experiences with MS

This research study recruited eight participants each of whom self-identified according to three criteria: 1) identification as African American (black), 2) identification as a female, and 3) a diagnoses of Multiple Sclerosis (MS). This section introduces each of the eight (8) participants and paints a picture of them through the exploration of related facts about their lives as an African American women living with Multiple Sclerosis.

**Fancy.** The first participant, Fancy, is a 30-year-old, self-identified African American woman who was diagnosed with Relapsing-Remitting Multiple Sclerosis (RRMS) at the age of 26. She has short dark-brown hair with a few streaks of honey blond coloring for fashion. During the interview, it appeared she had just left the hair salon because her slightly longer at the top and faded on each side hair cut was neatly curled. Fancy has brown eyes and occasionally wears glasses to improve her vision and focus. She has a medium body weight and is about 5 feet 4 inches tall. During the first interview, she wore causal clothes typical for a Saturday morning. Fancy exemplifies a pleasurable and outgoing spirit. Her demeanor at the start of the interview exuded a readiness and willingness to talk about her daily-life experiences as an African American woman currently living with MS.

After the recruitment flyer was posted to Facebook, Fancy responded almost immediately via social media. She also was the first of eight participants to select a time
slot for both the first and second follow up interviews. She demonstrated a commitment to participating in the research study. Her enthusiasm was also illustrated through her positive attitude and flexibility throughout the duration of the interviewing and follow-up process.

Fancy was born, raised, and currently resides in a southeastern US city. The pseudonym Fancy was given to this participant in honor of the jewelry business that she started after she was diagnosed with MS. She explained that she initially started making jewelry as a form of recreation and a way to manage symptoms of stress. Additionally, Fancy mentioned that the cost of her treatment without insurance and frequent visits to the doctor were beginning to add up. The financial strains where adding up for her and for her family. Fancy explained that at one point her grandmother was paying for her injections out of pocket. An almost $4000 cost, monthly. Fancy eventually started selling her jewelry creations in order to make additional money to help out as best as she cold. In addition to the financial benefits of making jewelry, Fancy received her bachelor’s degree in recreational therapy and explained that she believes that art and recreation therapy serve as a useful tool in the coping process.

As mentioned above, it was observed that Fancy had a smile on her face, which indicated an openness to the interview and the topic of discussion. Using Skype, the research interview location took place in what appeared to be the family or living room space of her mother’s home. Fancy, explained that she was 26-years-old at the time of her official diagnosis. She was been diagnosed with Relapsing-Remitting Multiple Sclerosis (RRMS). Prior to the official diagnosis, Fancy explained that she experienced terrible MS
related symptoms, such as, fatigue, numbness, and vision loss. However, when the symptoms worsened she was incapable of receiving treatment because she was pregnant with her daughter. Fancy stated that, “…no neurologist wanted to touch me because I was pregnant.” (Fancy. personal communication. August 29, 2015).

Furthermore, she explained on several occasions that doctors told her there was nothing they could do to provide accurate assessment or treatment until after she gave birth. Ultimately, Fancy described in what appeared to be a frustrated tone, that every time she would go to the doctors for treatment, she would be sent home with no clues about the cause of the symptoms and no medication other than Tylenol to take some of the pain away. In the end, after experiencing a number of falls and visits to the ER, the doctors were finally forced to give her an MRI, which was completed without contrast, even though she was pregnant to ascertain the source of her experiences. She recalled,

They gave me one [MRI] without contrast. Because you could see what was going on, or what have you, and when the doctor called me back in, he was like well, we do see some lesions on your brain and it looks like you have MS. But, we can’t do anything while you’re pregnant…because you can’t take any medications for MS while you’re pregnant. They told me you can’t do anything while you’re pregnant so after you have the baby come back and then we’ll do a lumbar puncture to verify that you have MS and then we’ll go for treatment from there. It was like 3 or 4 months that I was in pain and distress, fatigue, and kept falling (Fancy. personal communication. August 29, 2015).
During the interview, as she talked about her lived experiences following the diagnoses with MS, Fancy seemed to be positive and enthusiastic about the opportunity to contribute to the research and her responses indicated higher levels of disability self-efficacy according to its definition. As mentioned in previous chapters, disability self-efficacy refers to control over behaviors and motivation to with confidence (Bandura, 1977). Additionally, based on the responses provided by Fancy she seemed to be at a higher phase in the system known as psychosocial adjustment to disability. Her statements were clear and concise, and representative of acknowledgement and adjustment (Dutta and Kundu, 2007). However, some of the statements she made suggest some hostility, which is suggest to be represented by “obstruction of treatment, verbal aggressiveness and criticism, and feelings of antagonism” (Dutta and Kundu, 2007, p.13).

In regards to the SWS, Fancy described her experiences with managing external roles, such as, placing the needs of her family before her own health needs. These life experiences that she discussed eluded to potential threats to her overall well-being. For example, she mentioned a desire to work but, unable to sustain employment, responsibilities of mothering, and the active role of being a wife and caretaker for her husband who was diagnosed with Sickle Cell Anemia. Fancy’s interview proved that her experiences with being diagnosed with MS directly correspond to the theoretical perspective of DI and SWS. The next section explores the second participant in the same way to determine how her experience as an AA woman with MS relates to DI and SWS.

**Sybil.** Sybil, the second woman to participate in the research interviews, is currently 37 years old. She was diagnosed with RRMS at the age of 31 after what she
described to be a traumatic spout of illness. Sybil is currently married to her second husband and is a mother to two children; a daughter who is age 13 and a son who is 10. Sybil explained that her first husband and biological father of her two children had “died from a massive heart attack.” (Sybil. personal communication, August 29, 2015). Sybil explained that she was remarried in 2008 and had only been diagnosed for one year when the symptoms of the illness intensified. A key factor in the explanation of her lived experiences was the support she has continues to receive from her family. One way in particular is through the love and devotion that her husband has shown in helping her raise her two children.

In regards to her physical features, Sybil has a fair-skinned complexion and appears to be overweight. She wears her brown hair in a short curly style. During the interview, Sybil wore what appeared to be a comfortable lounge attire. It was observed during the Skype interview, that Sybil was wearing a oxygen-tube y-connector. This breathing tube was situated on her face throughout the duration of the interview. This device is used to help her breathe better. Additional components observed during the interview is that Sybil sat on what appeared to be a sofa chair during the interview.

Sybil was placed on disability restrictions from working because of the severity of her illness, which has lead to a rapid decline in her health. For this reason, Sybil is the recipient of governmental assistance for healthcare and income. Her husband also receives bid work for additional income in order to support the family needs. Sybil, explained that though she tries to remain active since she is no longer working. However,
to assist her with tending to the chores around the house she currently has a home health aid who comes weekly. In regards to SWS, this suggests that Sybil may

Sybil was, open and concise about the opportunity to discuss her experience as an AA women diagnosed with MS. Just as explained in the exploration of Fancy, Sybil’s willingness to be frank about her experiences living with MS represent identification with DI. Sybil has been living with the disease for six years, the amount of time that she has been living with the disease suggests that she has accepted the diagnoses and adjusted to the disease.

Sybil was born, raised, and continues to reside in a rural town located in the southeastern region of the United States. Sybil completed high school and worked for several years in the medical field as a certified nursing assistance (CNA). At the time of her diagnoses, Sybil worked as a manager of local fast-food restaurant. During the interview Sybil talked about her experience of being diagnosed as disturbing and stressful. She stated that for a while she had been feeling sick but she could not figure out what was wrong. Sybil explained her initial assumption was the sickness was correlated to the diagnosis of diabetes mellitus she received around the age of 12. Her story of being diagnosed with MS, however, originates back to the day in particular when she was scheduled to open the restaurant she managed.

She described that one morning in particular, she woke up as usual with intentions to complete a routine and head to work in order to open the store. She noticed that “something wasn’t right” because she felt dizzy and nauseous (Sybil, personal communication, August 29, 2015). Furthermore, she remembered thinking to herself she
would not tell her husband because she “didn’t want him to worry” (Sybil, personal communication, August 29, 2015). Ignoring the signs and unusual symptoms she experienced that morning, Sybil went to work hoping and praying that things would improve. Sybil explained the series of events that led her diagnosis of Multiple Sclerosis.

I didn’t say anything to my husband cause I had to go open the store, but I got up, I was just so tired, but I felt like everything, like I was spinning, my head, I have never had a headache. I had a headache; stuff was spinning, like I had vertigo. I got vertigo. I was spinning that morning, I was like oh, I like I couldn't shake it, but I went on to work like I normally do. But when I got work, I was sitting there counting money. I thought twenty, oh my! You know, but then I start feeling numb in my face and my left side got numb. Like I had a stroke. I couldn’t feel nothing. Like from my face all the way down my arm, my left leg, I was like, oh my goodness. You know, it hit my left side, you know. The only thing I remember is getting up, going to try and throw water or something on my face because I was sweating. And that's all I remember. And I woke up at the hospital. (Sybil, personal communication. August 29, 2015).

Sybil’s description of her diagnosis story led to what seemed to be an emotional memory about that particular day. Sybil described when she woke up in the hospital that she assumed she had a stroke.

Mhmm hmm. and I woke up at the hospital. And when I woke up at the hospital my medical doctor at the time, he was like, no, I want to keep her and I want to do a MRI, I want to see if she had a stroke because she had been complaining about
her legs you know, on that left side you know, say she can’t feel it and she has hypertension. And I just remember going through the MRI and it scared me because I have never had a MRI (Sybil, personal communication, August 29, 2015).

Sybil further explained that even after the doctor told her it was MS, she was confused as to why her left side had gone numb. She still believed that it was a mild stroke, but the doctors assured her brain lesions were rather consistent with MS. She explained the only symptom she had prior to passing out at work that morning was fatigue yet that morning in particular, symptoms worsened.

And he was like, how long have you been walking around like this? And I said, well, for months I just felt very tired. The only symptom I had was I was very fatigued. Very fatigued and then I got the headache, when I got that. That one morning I got up. Headache and I just felt like I was spinning, you know. And when I got to work, then I felt the numbness and it was all one symptom hit me, just that one symptom hit me and after that I stayed like two weeks in the hospital. I had to do a spinal tap you know, to rule out Gurds and all this other stuff. He told me I couldn't go back to work right then and I was like, oh...I am going back. So I went back and the same thing happened again. But, I had to grab my left side and I thought wont going to be able to walk, but I did, I did it you know. I don't feel this left side really, but I have been disabled since Two-thousand and nine. I wasn't able to go back to work anymore (Sybil, personal communication. August 29, 2015).
As observed during the interview, Sybil is a mother and aspires to provide the best for her family. This obligation to care for others suggests that she does associate with the principles of SWS (Woods-Giscombe, 2010); however, her health status and disabilities obstruct her from preforming as well as she would like. This conflict in roles is believed to be a source of depression and levels of anxiety. Furthermore, the way that she describes her experience seems congruent to the SWS principle of obligations to suppress emotions (Woods-Giscombe, 2010). Similar to Fancy, Sybil has been diagnosed with MS for years and she seems comfortable disclosing that she has MS; however, her association with disability self-efficacy is observed to be low. Sybil’s lower level of self-efficacy can be attributed to many factors; such as, social economic status (SES) or lack of education education. Sybil, like Fancy also discussed the concepts of negative talk from her healthcare providers. Her doctor told her that she would not be able to go back to work and thus she has not returned to work. This presents as a psychosomatic response to negative talk. These experiences prove that Sybil’s understanding of DI and SWS connects to her racialized life as an African American woman with MS. The next participant is Meredith. The narrative of her lived experiences will also explore the concepts of DI and SWS.

Meredith. The third participant, Meredith is a 25-year-old African American female. Meredith is soft-spoken and speaks with a low monotone. Although Meredith speaks with a soft voice, she has a southern accent, which is evident through the pronunciation of certain words. She is a slender build and wears a natural hair style. Meredith is originally from a major southern city, however, she left the area following
Meredith presents as a very intelligent woman as evidenced by the completion of all the requirement of the medical program where she is currently enrolled. Furthermore, during the interview she used medical terminology to describe the disease, symptoms she has experienced, and the medication she has been prescribed.

Meredith was recruited through the networking method of research sampling proposed by Bowen & Moore (2014). She was informed of the study through a close relative who shared the research recruitment flyer. During the interview, which occurred via FaceTime, Meredith sat on what appeared to be a living room sofa with her electronic device (computer) situated on what appeared to be a coffee table. She was dressed in a t-shirt and jogging pants; attire appropriate for a Sunday afternoon. Her demeanor was pleasant, however, she seemed censored or reserved at the start of the interview. It was observed that it took a while for her to warm-up to the conversation. This hesitancy was evident by the way she framed responses to the interview questions; her responses were short and to the point. Meredith was encouraged to elaborate on responses in order to make sure the meaning was interrupted correctly. In addition to Meredith’s resistance in
replying to interview questions the researcher considers if she could have been the reason why the participant was reluctant to respond. This unenthusiastic behavior was not exhibited in the first two participants. However, it should be noted that Meredith, unlike the previous two participants has a newer diagnosis in comparison to the length of time that Fancy and Sybil have been diagnosed. In regards to the psychosocial stages of adjustment to disability (Dutta & Kundu, 2007), it is evident that Meredith conveys a level of denial and she is unable to be candid about a disease that she has not accepted.

At the beginning of the interview, Meredith explained she was diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in November 2014. When asked about the medication she was currently taking, she used the actual medical terminology to describe the prescription. She indicated “I am on Copaxone or the real-name is Glatiramer Acetate injections, 3 times a week and I am on gabapentin capsules three times a day, everyday” (Meredith, personal communication. August 30, 2015). Meredith described the experiences that prerequisite to the official diagnose of MS in a calm manner. She expressed that her family was more concerned about what she was experiencing and she was convinced the symptoms could have simply been related to the stresses of being in medical school.

Um, maybe about three years ago, I, well maybe since college, I was always tired, but I don’t know if that was college or what. Always having to take naps, but three years ago I started noticing tingling in my legs and the tingling would progress to burning. Um, so that’s when I first noticed symptoms, I guess (Meredith, personal communication. August 30, 2015).
Additionally, Meredith described that even though she knew something was not right in her body, she was encouraged by her sister to see a doctor. She recalled, “I told them at first like… oh my physician is like going crazy and so my sister was like you should go and get that checked out” (Meredith, personal communication, August 30, 2015). The major symptoms Meredith experienced, although undermined as stress from school included double vision and dizziness. She explained her initial concern was whether she had popped a blood vessel in her eyes. With this cause of symptoms in mind, Meredith originally sought examination and treatment from an Ophthalmologist.

I was having like crazy double vision, like crazy double vision. Like my eyes where going like this (Moves fingers back and forth in a wind shield wiper motion) and dizziness and I was um falling down stairs and stuff like that so I actually went to the eye doctor because I thought it was an eye problem. And I had just taking a big test at school. So we both were like all…maybe it’s just stress. But the eye doctor, he was like I want you to go see a real doctor just in case. And so I went to the real doctor and he was like ohh, it might be stress, but I want you to get an MRI, just in case and I was like, okay, maybe I like popped a blood vessel or something, you know and then I got the MRI and the doctor called me and was like yea, I got the MRI and it looks like MS, so… I was like what? So then he referred me to a neurologist and that’s just it (Meredith, personal communication, August 30, 2015).

Meredith presents as an individual who is determined to complete the things she puts her mind to. Presently, Meredith’s is focused on completing medical school. During
the interview, she revealed her greatest concern related to the future. As it relates to SWS this suggests that Meredith feels obligated to manifest strength and oppress emotions. She was honest about this fear, which apart from the rest of the interview was concise. Meredith explained that she is worried about what her quality of life will be like if she is unable to do the things that she one day hopes to do after she finishes medical school. Her realistic concern pinpoints a few facts.

First, Meredith is one of two participants who have been diagnosed for a year or less. This suggests that individuals who have not been diagnosed for long are still moving through the stages of psychosocial adjustment to disability. The second circumstance is that because Meredith does not associate with MS there is evidence to suggest she does not have a disability identity. This lack of association to the diagnoses was noted to be related to her faith and religious beliefs. Meredith mentioned in her interviews that her relationship with God forces her to be mindful about what she claims over her life and the words that she allows to come out of her mouth. She believes that if she speaks something it can become reality. The next participant Autumn also explored these concerns and they will be explored more closely in the next section.

Autumn. The fourth participant, Autumn was referred to the study through the networking approach. She received the research flyer through a family friend. Autumn is a 31-year-old African American female from a Midwestern city in the United States. She is a college graduate with a Bachelor’s degree in Specialized Studies and Political Science and a Master’s in Business Administration. Autumn is single with no children and currently resides with her mother in her hometown. She describes herself as an
entrepreneur and is the CEO & Editor-in-Chief of a magazine she started in 2012. She is highly motivated and passionate about the success of the magazine and the fitness program for which she is part owner. Autumn is a problem solver, energetic and focused on making a difference in the lives of people in her local community.

Autumn also wears her hair in a short natural hair style and has a reddish rinse for fashion. She has a very vibrant smile that attracts others to her. During the interview, Autumn sat in her car and was wearing workout attire. She informed the researcher that following the interview she would be heading to her evening exercise class. This exercise class was hosted by the company of which she is a part owner. She demonstrated flexibility throughout the interview and was mindful of time for the interview and the start of the fitness class. During the interview there were unexpected technical difficulties with reception. The which led to the use of Google Hangouts, a video conferencing server offered through Google.

Once the interview was capable of commencing, Autumn started off the conversation by explaining how her diagnosis of Relapsing-Remitting Multiple Sclerosis came about. In 2012, at the age of 27 with only two weeks until her 28th birthday, she began to notice symptoms that were abnormal. Autumn explained her original idea was she had a scratch or severe eye irritation which caused the issues with her vision.

Um, it was kind of crazy my onset symptoms was um, optic neuritis and I didn’t know until I got to the ER. I thought it was something simple like, you know a scratch…I don’t know some type of scratch or irritation in my eye. And I have a
history of migraine and I have a history of, um, or not a history of but, I wear
glasses (Autumn. personal communication. August 31, 2015).

Autumn also expressed that her life prior to being diagnosed was highly stressful because
she was in the process of getting her magazine off the ground.

…so I had been having for weeks, I had been having these like really bad
migraines and I would kind of have like blurred vision and it was a stressful time.
I hated my job, I was working two jobs, and well I hated one of them. I was
working two jobs and, uh on top of that, I was starting my magazine (Autumn.
personal communication. August 31, 2015).

In addition to working the two jobs and in the attempt to start her own magazine, Autumn
clarified she had been attempting to self-medicate the symptoms related to MS mostly by
taking frequent naps to help beat the fatigue rather than taking the symptoms seriously
and seeking professional assessment. Furthermore, she indicated the symptoms worsened
to the point where on one occasion while at work she sat with both of her eyes closed;
this position was what she described to be the only one that felt comfortable and
temporarily relieved of pain. She proceeded to describe that the pain had become so
severe that on this particular day she had to call her mother for help. The most interesting
piece about her discussion of the experience was the way she described her decision to
stay at work rather than going to the hospital for treatment.

…so I called the like the regular you know optho... uh ophthalmologist and tried
to get a uh eye appointment at like a lens crafters or something and then like I
went to lunch and it was like the vision part was getting worse to the point that it
was like a shooting pain in my eye so when I got um, I called my mother and told her I needed her to meet me and drive me to the hospital. So I stayed at work like a crazy person I stayed at work for the rest of that day. Um drove home went to the ER and when I got to the ER I was still cool like I’m all right man you know the doctor, you know how they do, they're like you know so what's going on and I’m like well you know I’ve got some eye problems I’m like I don't know it's probably a scratch on you know my cornea retina you know I don't I don't know these terms really but you know I listened to what somebody else told me. (Laughter) So she's like okay and she you know she did the most basic eye test in the world you know cover this eye look and tell me what you see so I do that I cover up my left eye look out my right eye everything is fine. I covered my right eye and could look out my left eye and I can't even see the doorknob on the door (Autumn. personal communication. August 31, 2015).

Autumn recognized in her reflection of the day when her symptoms were most severe, she explained that she felt like a “crazy person” because she ignored the symptoms and stayed at work. When she finally decided to go to the ER she recognized that something was wrong; yet, doctors released her without a diagnose or information of what the cause of these symptoms. She explained that although she was released without a formal diagnosis she recognized that everything was not okay. However, Autumn went on to try and function as ‘normal’ as possible because of her roles and responsibilities.

Autumn explained that after she was diagnosed her interest and determination to become an entrepreneur rather than working in the corporate arena increased after she
was diagnosed with MS. This illustration of resilience suggests that Autumn demonstrates a determination to succeed despite limited resources associates and an obligation to manifest strength, two characteristics of SWS. She expressed that in addition to her desire to focus on the type of work she loves her business helps her work at her own pace. She described that this is an important aspect of living with MS. Autumn’s overall determination suggests that she has a high self-efficacy and is able to associate with DI.

Akeelah. The fifth participant, Akeelah is 26-years old. She currently lives in a Midwestern city with her mother. Following graduation from her Masters program she moved back home to help with bills and other responsibilities. She had only been diagnosed for about a month when the recruitment flyer for the research study was posted on social media. Akeelah reached out with interest in contributing to literature related to coping with MS, which she observed to be misrepresentative of the lived experiences that African American women face.

Akeelah has a slender build and mostly wears her hair in natural styles. During the interview, she was causally dressed in a tank top and jeans and stated she had recently come home from a day of running errands. Akeelah speaks in a soft and calm tone to strategically formulate her thoughts. She has an introverted personality, however; during the second follow-up interview, she directly described herself as an ambivert. Gentle and empathetic can be used to describe her demeanor. Akeelah is currently in a dating relationship, however, she is not married and does not have children. Akeelah holds a Bachelor’s degree in magazine journalism and a Master’s degree in clinical mental health
counseling. Although she is employed as a mental health therapist, Akeelah enjoys blogging in her spare time which ties into her Bachelor training and experience.

The primary source of video conferencing used during the interview with Akeelah was FaceTime. This Apple product-specific application, however presented with some reception issues due to the area in which she lived. There was not a strong signal available making the connection weak and the loss of connection more frequent. Several times during the interview, the call was dropped or delayed. The suggestion was made to switch the video conferencing application to Skype or Google Hangouts, however, once Akeelah found a good spot in her house the interview was able to continue with minimum interruptions.

As mentioned previously, Akeelah had only been diagnosed little over a month before the recruitment information had been disseminated. However, she was interested in providing her story about the diagnostic process led up to an official diagnosis and her current lived experiences. Akeelah described that more recently she has begun a regimen of administering a MS specialty medication known as Copaxone. This subcutaneous injection is self-administered three times per week.

Akeelah talked about her initial experiences with symptoms consistent with MS, which led to a formal diagnosis. She explained that in September of 2014 she began to notice symptoms of vertigo, migraines, dizziness, and inability to maintain her balance. She talked about the noticeable decline and issues related to her vision.

But, I really had trouble with the vision and the double vision. That double vision happened in March of this year. That lasted about 10 days. I wasn’t able to
drive…um and I was able to care for myself obviously in the house but, like I said I wasn’t able to drive, and do things of that nature on my own. Debilitating in a way. Disabling, I guess is a better word for that (Akeelah. personal communication, September 4, 2015).

Akeelah continued by describing how she woke up one morning and was unable to get her vision to focus. An additional piece of information to note about the conversation was Akeelah seemed disconnected during the first part of the interview. It was evident that she was trying to keep the conversation and her raw thoughts censored because her mother was in the room. She answered most of the questions with simple answers, but did not really go into depth about her experience or emotional responses related to being diagnosed. During the interview, it was noted that her mother was preparing to leave for work and Akeelah asked the researcher to hold for a second. The side bar conversation seemed to be Akeelah’s attempt to explain to her mother what the purpose of the interview was about. She said later in the interview that she had not explained to her mother prior to the call what we would be speaking about. She also later explained why she was so censored while her mother was in the room.

She is…(long pause), you know she is mom and I’m still looking out for her, we don’t, we talk about my diagnoses but she (deep breaths in and out). I mean, she’s a nurse and she deals with people’s stuff everyday but this you know, I’m her daughter, I think it is so different. Um, so you know I, Well, first of all I didn’t let her know before you had called what we were going to be doing (laughs) um, so she didn’t really have a heads up for real for real, and then secondly I still am kind
of weary about the way that I talk about the diagnoses and this around her. Um, don’t want to over worry her too, too much (Akeelah. personal communication. September 4, 2015).

Even during the simple demographic data collection portion of the interview, it was evident she had an innate desire to protect others around her, especially her mother. Specifically, Akeelah is uncomfortable with talking about her experience in front of her mother because it is still a sensitive subject. This expression of protection is consistent with the characteristic of SWS known as an obligation to manifest strength. Akeelah’s association with SWS was also observed in the matter that she answered the interview questions. At the start of the interview she answered the questions with hesitation. Her responses also specified an obligation to suppress emotions. Although her answers started off with what seemed like a covert filter, once her mother left for work, Akeelah provided more in-depth details about her experiences since being diagnosed. Akeelah’s behaviors also indicated that she is in the lower stages of adjustment to disability (Dutta & Kundu, 2007). This is a shared trait also noticed amongst the sixth participant, Zoe.

Zoe. Zoe, participant number six, is a 23-year-old African American woman from a southeastern city located in the United States. She was diagnosed with RRMS at the age of 20. Zoe seems to be a reserved individual; however, she was eager to participate in the study after someone shared with her the flyer via social media. She immediately responded to the recruitment flyer and contacted the researcher via the instant message application on Facebook.
During the Skype interview, Zoe laid on a bed with the lights off and the curtains closed. The pink window curtains and the incoming sunlight made the room appear to have pink walls. Zoe wore glasses and a pink bonnet on her head. During the interview only she placed the camera close to her body so only the top half of her body was seen. She was wearing a plain t-shirt. In the background while the interview was occurring, Zoe had the television on and the noticeable sound of what appeared to be the news. When her son entered the room he asked Zoe to turn the channel to Mickey Mouse Club. The background sound went from a vague news reporter to the sounds of the children’s show theme song. At one point during the interview, Zoe’s young son sat on her lap in order to see what was going on and who she was talking to on the screen.

Zoe is a mother of a 3 year-old little boy. In addition to being a full-time mom, she is currently pursuing a college degree in criminal law at a small institution in her town. She hopes to one day attend a four-year college to pursue a Bachelor’s degree. Zoe explained that she one day hopes to attend law school. Due to her roles as a mother and a full-time student, Zoe is currently unemployed.

When asked to describe her experience after being diagnosed, she stated the MS symptoms had actually been evident since she was 14 years old. Zoe described that she remembered being in middle school when she noticed something was different.

I was tingling, head hurting, all that type stuff. Like blurry vision and I go to the emergency room and they talking about, that’s just sinus and that cleared up. It was like a few weeks. I had to quit cheering and everything. They was like what is this. It disappeared and then it cam back on a few months after I graduated high
school. And then the symptoms started coming back. And then I just started getting use to it and then I noticed like My vision, cause I wear glasses anyway, I been wearing glass, since what, since whatever. I was like, whats going on with my vision? I lost my vision in my right eye for a few weeks. Then that cleared up and then some months later it happen in my left eye. And that cleared up…weeks later. Im like what is going on? And then, yea, like a few month after I graduated high school, I noticed I was tingling. Everyone said it look like I had a seizure... I was like I aint notice that. I aint see it (Zoe. Personal communication. September 6, 2015).

While the symptoms were noticeable earlier in her life, Zoe described that when she became pregnant with her son the symptoms disappeared.

Everythang cleared up. Cause it first started when I was fourteen then okay I had my son when I was a senior in high school and then okay graduated, few months later then the summer (garbled, sounds like musta been) after we graduated high school, that’s when the symptoms started back so fourteen, fifteen, sixteen, seventeen, eighteen, like five years later is when the symptoms started back but different (Zoe. Personal communication. September 6, 2015).

Following the pregnancy, however, Zoe explained the symptoms came back and were possibly more intense than before.

Vision loss, tingling… like the world is moving and don’t no body else see it.

Then like I couldn’t see my hand move, my legs move, I be asking people is that
moving stuff be moving, I be like seeing stuff moving… but its just me seeing trimmers (Zoe. Personal communication. September 6, 2015)

Based on the interview with Zoe and the above mentioned conversation regarding her experiences with MS, it is evident that she associates with the SWS. Zoe’s experience indicates that she has obligation to manifest strength, obligation to suppress emotions, resistance to being vulnerable or dependent, determination to succeed despite limited resources and an obligation to care for her son.

**Lena.** The seventh participant, Lena, is 61 years old. She has been living with MS longer than the other participants. Lena was diagnosed with MS at the age of 55 and compared to the other seven participants she had a late life diagnoses. The other participates had all been diagnosed between the ages of 20 to 30. Lena has both a kind and gentle personality. She speaks in a low tone and is very articulate. She appeared to be mindful of the fact that she sometimes has difficulty with word finding and as a results takes a proactive approach to this MS related symptom by speaking in a calm and steady manner. Lena has brown hair and wears a short curly natural afro. She is a medium build body type standing about 5’5. She reported that recently she has intentionally lost a significant amount of weight for health reasons. An important feature to note about Lena is that she has a genuine smile, which makes her more approachable.

During the interview, which was conducted via Skype, Lena sat in what appeared to be her home office. There were pictures, elephant statues, and other artifacts that covered the wall. Immediately behind her there stood a rosewood stained bookself covered with what appeared to be academic textbooks. Lena was wearing a plain t-shirt
and slacks and her hair was in a natural style. Prior to the start of the interview, Lena made sure that on her end the computer camera was clear by readjusting the chair position. She had a cup of water sitting on the desk and during the interview she would occasionally take a sip of water.

Lena is a licensed clinical speech pathologist and has worked at a public university located in the midwest for several years. She recently retired and is currently teaching one class this semester with two official days devoted for office hours per week. She enjoys spending time with her husband and talked a lot about their relationship and how he consistently demonstrates his love and support towards her. Lena has one daughter and no grandchildren. She stated the relationship with her now husband did not begin until after she had been diagnosed with Multiple Sclerosis and in the beginning of their relationship she would blow him off because of how her medication and health-related symptoms made her feel at the time.

Lena described the experiences that led up to her diagnoses. She stated she would have to rewind the clock back 14 years in order to start from the very beginning. Now at the age of 61, Lena was diagnosed with RRMS in 2001 at the age of 47. She recalled that at the time her daughter was in the area also attending the local university, but not living with her. She described her history of symptoms had one particular instance of blindness. She had not noticed anything abnormal until the morning when she woke up blind in her right eye.

I hadn't had any. Um, what happened was in, uh, the first part of August I woke up one morning and I was blind in my right eye. Um, and, I was here actually,
um, and kind of sort of thought huh, because I wear glasses. I have had vision problems since; I think I got glasses when I was 10. So I didn't think anything about it until I really realized that I could not see anything out of that eye. So, I went to the hospital and they did some tests and they diagnosed me with some disease that only 76-year-old White males get (Lena. personal communication. September 6, 2015).

Similar to other research participants, Lena’s immediate reaction was to make an appointment with an ophthalmologist to assess the reasoning for the vision change. She describes, “so I went to my ophthalmologist, which is the one that is the medical doctor, uh you know, that one… Um, and his he, um, did an exam of the optic nerve, he did the, uh, visual fields test and said, I think you have MS and you need to see a neurologist. So that was you know, I always thought MS was a White woman’s disease” (Lena. personal communication. September 6, 2015).

While the symptoms were evident in November and consistent with MS, Lena did not receive an official diagnosis until May. Although Lena was very thorough in her responses during the interview, she did not talk a lot about the initial diagnose and what symptoms she experienced. Lena’s focus when answering interview questions were centered around her post-diagnosis experience. She talked about the challenges that she has faced in the area of being a mother, being a wife and maintaining a professional career. The final participant, Jasmine also discusses her experience as a mother and a caretaker to members of her family and friends.
Jasmine. Twenty-nine-year-old Jasmine is the eighth and final research participant. She currently resides in a Midwestern City with her four children and her mother. Jasmine was diagnosed with RRMS at the age of 25. During the interview, Jasmine presented as enthusiastic with characteristics of resilience such as the determination to take care of her four children, her mother who has been diagnosed with cancer, and lastly herself. She has a kind heart and spirit that exudes empathy.

Jasmine is currently unemployed and identifies as a stay at home mom. She has a high school diploma and briefly attended college at a historically Black college located on the East coast to play college softball. She completed one year of school however explained that she was home sick so she returned to her home town in order to be with her family. Jasmine presents as very family oriented. This transition occurred before she was diagnosed with MS, however, after returning home Jasmine became pregnant with her first child. It was after the birth of her son that she began noticing symptoms of MS. She recalled the confusion she had about what was happening to her. Furthermore, during the interview, Jasmine talked about the onset of symptoms and first indication that she needed to seek medical treatment.

Ok, I say in 2008... the beginning of 2008, I was going to school and I was taking public transportation and I had my son so, in the beginning like January, February I was dizzy and I could not walk straight and everybody thought I was drunk and my feet were numb and I could not see good. And when everything started happening to me and I was going to the neurologist so I was trying to make the appointment but, then they cancelled the appointment so it actually took me all
the way until May to get diagnosed. And that’s when my hands and my body was just going numb from my toes all the way up, and that was crazy. …I felt like I couldn’t walk straight I was walking into stuff and falling off the bus and all kind of crazy stuff. And that is when and got my MRI and they noticed all the lesions on my brain and they told me pretty much, you have MS (Jasmine. personal communication. September 7, 2015).

Following the diagnoses, Jasmine explained that she decided against returning to school and work for the wellbeing of her children. As mentioned above, she has four children (two boys and two girls). Three of her children are biological and one of her children was adopted. Jasmine stressed that although she adopted her sisters daughter, it is important to emphasize the idea that her adopted daughter is just as much hers as the three that she actually carried. She further stated it is very important that her children are aware she loves them unconditionally.

Um, my current roles and responsibilities? Um, I feel like my roles is very important, I feel like I am a mom first, I have to be a provider, I have to take care of home. You know I feel like on one hand I could be in business mode because I have a child special needs and I feel like constantly I’m up there working with my children and so my life is really busy for real (Jasmine. personal communication. September 7, 2015).

Jasmine’s act of devotion to family signifies an association with the characteristics of SWS. Her story of commitment to family indicates an obligation to manifest strength as well as an obligation to help others. Additionally, due to her lack of
employment, Jasmines devotion suggests a determination to succeed at being a mother despite limited resources. On top of the commitment to her family, Jasmine has recently been in an abusive relationship with the father of her children. This is relevant information to the study because of the association between stress and increased exacerbations. Jasmine has had to take on the role of motherhood while being in a relationship that was unhealthy and unsafe. These dual roles suggest an obligation to suppress emotions for the good of her family.

In regards to disability identity, Jasmine seems very comfortable disclosing that she has MS. She described in words a level of release received when she is able to talk to random people about her problems, mostly because she feels that they are unable to judge her.

I vent. I talk about all my business. I tell everybody everything so can’t nobody talk about me. I’m so serious. Like I just tell strangers and like I been through a lot of situations and I found especially and I find that talking about the stuff that bothers me to people who don’t even care…it helps me and I don’t care because…what is you gone say about me? You do…hey you don’t know the half of it. But at least I get it off of my shoulders and I get to talk about it. It helps sometimes even talking to my mom and talking to people that care too. I get certain of feedback and I realize that everybody’s perception is different. So I like to talk to different people. I realized that I am cool for real and even though I can’t do everything that I want to do physically, mentally I know how I can do it and
that is better off than most people who are supposed to be normal and okay. And that’s it (Jasmine. personal communication. September 7, 2015).

Furthermore, when considering Jasmine’s association with disability it was discussed that she feels confident in her ability to complete goals and tasks regardless of MS. She explained that it is the reminders and concerns of her family members, which make her slow down.

You know, and just like playing with my kids. I want to get a bike and I want to ride bike with them right but, like my brother said, you too fragile so you be done feel off and broke every bone in your body. And I be like “oh be quiet” but guess what the reality is he is probably right I don’t have the balance to do that. Even though my mind tells me I can do anything. My body tells me, oh no girl you can’t (laughs). You don’t understand. I physically want to do everything but I am not able to. To me sometimes that hurts my feelings. You know what I mean. Like why I got to be limited (Jasmine. personal communication. September 7, 2015)?

**Summary**

In the introduction of the eight participants, information was provided to paint pictures of the women how comprised of the sample. Introductions in the previous section also serve the purpose of exploring whether or not the participants associate with the characteristics of SWS and DI. Findings of this specific examination suggest that each of the participants do in fact associate with at least one or more of the SWS characteristic and also levels of self-efficacy outlined as a component of disability identity.
In the next section, Table 3 proceeds a discussion to compare and contrast the significance of the sample and how they inform the understanding of AA living with MS. This chart provides a snapshot of the participants current age, age at time of diagnosis, MS type, current medication, educational status, employment, relationship, whether the participant has children and the geographical region where the participant currently resides. The participants each self-identified in accordance with the outlined investigation criteria, thus all eight were African-American women diagnosed with Multiple Sclerosis (MS). This information has been identified as a necessary part of this introduction of the participants because the analysis of meaning for each of the participants as it relates to SWS and DI considers how their differences make their overall lived experiences unique.

**Demographic Trends**

The participants of the study were selected to provide personal accounts of their lived experiences as AA women with Multiple Sclerosis. In addition to these personal statements about their lived experiences, this study compares and contrasts the demographic information of the participants in order to determine how these factors contribute or impact life. This analysis considers nine specific components of the lived experiences of AA women with MS. These components include: 1) current age, 2) age at time of diagnoses, 3) type of MS, 4) current medication, 5) relationship status, 6) educational status, 7) employment status, 8) children, and 9) geographical region. The following discussion begins with Table 3, which provides a critical exploration of how these factors shape the significance of the lived experiences for AA women with MS.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Current Age</th>
<th>Age at time of Diagnosis</th>
<th>Type of MS</th>
<th>Current Medication</th>
<th>Relationship Status</th>
<th>Educational Status</th>
<th>Employment Status</th>
<th>Children Y/N, if yes # of Children</th>
<th>Region</th>
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<td>30</td>
<td>26</td>
<td>RRMS</td>
<td>Tysabri</td>
<td>Separate/Married</td>
<td>BD</td>
<td>Unemployed/Entrepreneur</td>
<td>Yes (2)</td>
<td>SE</td>
</tr>
<tr>
<td>Sybil</td>
<td>37</td>
<td>31</td>
<td>RRMS</td>
<td>Copaxone/Married</td>
<td>Married</td>
<td>HSD</td>
<td>Unemployed/Disability</td>
<td>Yes (2)</td>
<td>SE</td>
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<tr>
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<td>24</td>
<td>RRMS</td>
<td>Copaxone</td>
<td>Single</td>
<td>MD</td>
<td>Medical Student</td>
<td>No</td>
<td>MW</td>
</tr>
<tr>
<td>Autumn</td>
<td>31</td>
<td>27</td>
<td>RRMS</td>
<td>Tecfidera</td>
<td>Single</td>
<td>MD</td>
<td>Entrepreneur</td>
<td>No</td>
<td>MW</td>
</tr>
<tr>
<td>Akeelah</td>
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<td>26</td>
<td>RRMS</td>
<td>Copaxone</td>
<td>Single</td>
<td>MD</td>
<td>Employed/MH Counselor</td>
<td>No</td>
<td>MW</td>
</tr>
<tr>
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<td>20</td>
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<td>SE</td>
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<td>55</td>
<td>RRMS</td>
<td>Plegritty</td>
<td>Married</td>
<td>MD</td>
<td>Retired</td>
<td>Yes (1)</td>
<td>MW</td>
</tr>
<tr>
<td>Jasmine</td>
<td>29</td>
<td>25</td>
<td>RRMS</td>
<td>Gilenya</td>
<td>Single</td>
<td>HSD</td>
<td>Unemployed</td>
<td>Yes (4)</td>
<td>MW</td>
</tr>
</tbody>
</table>
Current Age

During analysis of the demographic information attention was given to the current age of each participant. This information suggests that most of the participants are between the ages of 21 and 41. This is considered to be a time when most people are actively involved in activities, such as love, marriage, procreation, and job advancements. Furthermore, according to Erik Erickson’s Psychosexual Stages Theory people representing early adulthood have a role conflict of intimacy vs. isolation and people in adulthood have a role conflict of generativity vs. stagnation. Literature suggests that these ages consist of the virtues of love and care. Also, that these represent the peak of relationships and caring for others through empathy and concern. Observing this factor in particular shows that this particular group of women may have been challenged to fulfill roles that are concerned normal parts of human growth and development (Thayer-Bacon, Stone, & Sprecher, 2013).

Age at Onset

Seven of eight participants (87.5%) reported an initial diagnoses with MS to occur in their mid 20’s and early 30’s. The remaining participant, Lena reported a late stage onset and received an official diagnoses at the age of 55-years-old. The age of the participants again represents an association of the psychosexual stages. By the time Lena was diagnosed with MS she had been married to her first husband, raised a daughter, and established a career as a speech pathologist. Although this suggests that Lena, for example, is able to manage and cope with MS she explained that her initial experience also required adjustment. The participants who had been diagnosed in their 20’s and 30’s...
each described a sense of fear and worry about what the future would hold. They described concern as to whether or not they would be able to get married and start families and more importantly whether they would be able to be successful in their careers. It was noted however, that even though Lena was diagnosed at the age of 55, she still had these same concerned. In her narrative she mentioned that after the death of her husband, she too had concerns about dating and disclosing the diagnoses to her now husband. However, this indicated that these experiences about the future can occur in people who are diagnosed earlier or later in life.

**Type of Multiple Sclerosis**

Each of the eight participants reported receiving a diagnoses of Relapsing Remitting Multiple Sclerosis (RRMS). As mentioned in previous chapters, RRMS is considered the least aggressive form of the disease. Symptoms relapse and remit with affects that worsen over time. Statistics show that approximately 85% of individuals diagnosed with MS were diagnosed with RRMS (NMSS, 2015). There are four different types of MS, including: 1) relapsing-remitting (RRMS), 2) secondary-progressive (SPMS), 3) primary-progressive (PPMS) and 4) progressive-relapsing (PRMS) (Milo & Miller, 2014).

**Medication**

Although MS has an unknown etiology, prognosis and cure, medical advances suggest the progression of the disease can be reduced through therapeutic specialty drugs (MS Disease Modifying Medication, 2015). These drugs are typically prescribed by the acting neurologist and through pharmacology that takes into account the biological traits
and lab results of each individual patient (MS Disease Modifying Medication, 2015). For this reason, of the eight participants, there was a variety of five different medications reported, including: 1) Tysabri, 2) Copaxone, 3) Tecfidera, 4) Plegrity, and 5) Gilenya. The following paragraph will provide a brief description of these five MS specialty medications and include information about the type of medication,

**Tysabri.** Brand name natalizumab, this drug is a prescription medication that is used as a therapy for adults diagnosed with Multiple Sclerosis. The drug is described to slow the symptoms related to an MS diagnoses and ultimately decrease the frequency of exacerbations. An important safety consideration of this drug is multifocal leukoencephalopathy (PML). PML is a rare infection of the brain, which can lead to severe disability. Tysabri is administered through an infusion process required every 28 days for two hours. The therapy must be administered at a location that is registered to complete the treatment, such as, an infusion or cancer center, physician’s office, or a local hospital. For more information about Tysabri visit:

**Copaxone.** Brand name, glatiramer acetate injection, this drug is self-administered three times a week subcutaneously. Subcutaneous is a medical term representing the location directly underneath the skin, a fatty patch of meat. The experiments conducted in a clinical trial rendered evidence to support that the therapy reduced the frequency of exacerbations by 34% compared to the placebo For more information about Copaxone visit www.copaxone.com/about-copaxone.
Tecfidera. Brand name dimethyl fumarate, is an oral medication self-administered twice daily. This medication is considered revolutionary as it is among the first oral medication to be approved by the Food and Drug Administration (FDA). It was official made available to patients in September 2013. The pill is offered through the drug manufacturer Biogen and presents with warning such as, the potentials of having an allergic reaction, (e.g., hives, swelling and difficulty breathing), in addition to PML For more information about Tecfidera visit: http://www.tecfidera.com/about

Plegridy. Brand name, peginterferon beta-1a, is a self-administered injection. This injection is administered once every two weeks. This drug also has been found to decrease relapses, delay the progression of debilitating symptoms and decrease the frequency and intensity of lesions found on the brain. Plegridy has side effects that range from liver problems, to nausea and possibly death. This drugs also highlights potential psychosocial side effects including, depression, suicidal ideations nervousness and anxiety. For more information about Plegridy visit https://www.plegridy.com/about/

Gilenya. Brand name flingolimod, this drug is a capsule taken once daily. This drug is known to have side effects such as, slowed heart rate, dizziness and PML (citation needed). Addition side effects include neck stiffness, sensitivity to light and meningitis. An interesting fact about the Gilenya website is that the advertisements for the drug contain pictures of African American women and women of color compared to other medication websites that only have a few culture specific pictures. For more information about Gilenya visit http://www.gilenya.com/index.jsp
Information about the specific drug that each participant is currently taking plays a major role in their experience as an AA woman with MS. The above narratives explains basic information about various MS prescriptions, including: how the drugs are administered, how often the drugs are administered, and the corresponding side effects. Specifically, information about the type of drug that the participants take are important to this study because it communicates further their lived experiences. As mentioned in previous chapters, medications developed for people with MS do not cure the disease, but rather are suggested to slow down the progression of the disease. Thus the idea of following a medication regimen is a very important component of disease management.

During the interviews, each participant talked about the experiences that they have had identifying an MS medication therapy that was a good fit for them. Fancy, for example, talked about tribulations in identifying a working medication. She explained that on several occasions she switched from medication to medication because the drugs she was prescribe were not working and actually caused many adverse side effect. Fancy stated, “So, when I say they started treating me like a ginnie pig because the copazone wasn’t working or what have you, then they were talking about putting me on Tysabri at that time but research and reading behind it I was like noooo” (Fancy, personal communication, August 29, 2015).

On the other hand, Akeelah described her personal experience of becoming acclimated to following an injection regimen, and how this part of disease management has changed her life. Akeelah is a young professional who enjoys spending time with friends, dating and traveling. However, she has been prescribed Copaxone, a drug that is
administered three times per week, subcutaneously. She explained that she has to plan specific accommodations for storing medication if she plans to travel or even when she plans to have a social drink with her friends during the week. Another component of Akeelah’s lived experience as it relates to medication is her hesitancy to perform the injection with people around. She described that she has not told people what type of medication she takes and does the injections in private.

So, I am now on injection medication that I do three times a week. Um, now for when I am here or when I am at home, nothing really changes you know, its been a little difficult when I have to do my injection in the morning and then go to work simply because when I do my injection sometimes I get a little light headed and nauseous. And it is not right after I do the injection, usually it happens a little while after. I wasn’t going to throw up or anything I just had a little bit of a nauseous feeling. Um, yesterday when I did the injection, um, I was a light headed. I had to drive to work um, so I sat in the car for a little bit until that feeling passes. I’ve been out of town um, once. When I had to do the injection for myself, I was in the bathroom… At the time neither of my friend knew (Fancy, personal communication, August 29, 2015).

Additional Demographic Trends

Relationship status. Two participants identified that they were currently married and living with their spouses. One participant mentioned that she was separated, however, still legally married. The remaining five participants were single and/or dating. The relationship statuses of each participants’ were explored in order to understand how
their social supports contributed to their lived experiences as AA women with MS. Examining relationship statuses also provide an understanding the magnitude for which multiple roles of SWS contributed to the overall experience with DI.

**Educational status.** All of the participants report the completion of a high school diploma. Five of the eight participants received a Bachelor’s degree. Four of those five participants completed a Master’s degree and one participant is currently working towards becoming a medical physician. The exploration of the education status of each participant suggest that their understanding of the disease is increased with more education. For example, Meredith, the participant studying to become a medical doctor, used the medical term for the name brand of medication that she takes. In her interview she also focused heavily on what could assist other AA women with MS through a medical versus a psychological perspective on experience. When asked what advice she would give to another AA woman who just found out she had MS, Meredith replied, “I guess…make sure you talk to your doctor about any problems you have, have somebody you can talk to about it, look it up. I mean I’m in medical school so I kinda understand but I would still tell them to look it up so you understand everything about it. I guess that’s it” (Meredith. personal communication. August 30, 2015).

**Employment status.** Two participants have been placed on disability upon recommendation of their doctors and thus currently unemployed due to health related limitations. Two separate participants self-identify as entrepreneurs and the next two participants are full-time students. One of the participants recently retired and works as a part-time instructor and the last participant works a full-time job as a mental health
therapist. Information about the employment statuses of the participants indicates how these women provide for their families and take care of their responsibilities. The employment statuses also play a major role in understanding the lived experiences of AA women with MS for the purpose of exploring challenges that women may face in regards to going to work and managing pain. As you may recall from the previous sections, Sybil was on the way to work when her symptoms intensified. She ignored the signs that something was wrong in order to fulfill her obligations as a manager who needed to open the store. Autumn also explained that she was at work when symptoms of optic neuritis worsened, yet she felt as though she had to keep going, even if that meant staying for her whole shift and working with only one eye open.

**Children.** Of the eight participants all but three have children. Two participants, Zoe and Lena each have one child. Zoe’s son is a toddler while Lena’s daughter is in her late 20’s and lives on her own in a neighboring city. Two participants, Fancy and Sybil, have two children a boy and a girl. Fancy’s children are under the age of ten and Sybil’s children are considered preteen. Jasmine has four children in total, one of which is adopted. This information is important to understanding their lived experiences as AA women with MS because it also provides a visual of their responsibilities to care.

**Geographical region.** Using the networking and snowballing approach to research recruitment participants were selecting from two geographical regions: 1) Southeast and Midwest. There were three participants from the Southeast region of the United States and five participants residing in the Midwest region of the United States.
Conclusion

In this chapter there was an in-depth look at each of the eight participants. This chapter provided a closer look at the participants and explored how their lived experiences as women with MS are not monolithic, but instead unique contributors to literature on coping with MS for AA women. In the following chapter, each of the eleven semi-structured interview questions and the responses from each participant are explored. The overall purpose of chapter six is to examine the themes that emerged.
Chapter Five: From the Vantage Point of African American Women with MS

This current chapter explores and interprets the responses recorded through interviews and observations of eight participants. This analysis of data is used to elucidate, “the essence of shared experiences” of African American (AA) women with MS (Patton, 2002, p. 107). This chapter describes the emergent themes and meanings embedded in the lived experiences of these eight African American women with MS. This current chapter provides a thorough comparison of common themes through the analysis of data and for the overarching purpose of determining whether the lived experiences of AA women diagnosed with MS are unique. Marshall and Rossman (1999) organized this exploration of themes according to the seven-steps of analyzing qualitative data. These six phases include: 1) organizing the data, 2) generating categories and themes, 3) coding the data, 4) testing emergent understanding of the data, 5) searching for alternate explanations of the data, and 6) writing the data analysis.

Evidence yielded from interaction with the participants highlight major themes related to the specific lived experiences of AA women diagnosed with MS. The use of the characteristics of Superwoman Schema (SWS) and Disability Identity Theory (DI) are used to help analyze the data obtained from interviews and observations. In the next section, these findings are explored.

MS and the Black Experience: Oh My!

There are three categories, which include themes related to the experiences of AA women with MS. These three categories include: 1) shock, 2) transition, and 3) adjustment. Figure 1 provides an illustration of the theme matrix. This matrix highlights
the three categories and the corresponding themes. The category identified as shock, includes themes that emerged from the participant interviews as they discussed experiences during prediagnosis. The second category, identified as transition, consists of themes that emerged when participants explained their lived experiences of managing life with MS and the third category is known as adjustment. Themes that fell under this category included ideas of hope or despair about the future.

Figure 1. The theme matrix highlights the themes that emerged during the investigation across three different categories which include: Shock, Transition, and Adjustment.

Table 4 (see below) illustrates a summary of the emerging themes. This table describes the themes, relevant quotations from participant accounts, and an explanation of nature of the theme.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Relevant Quotations</th>
<th>Nature of the Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial of Symptoms</td>
<td>I thought it was something simple like you know a scratch of some type or irritation in my eye.</td>
<td>Participants explained a time when they denied or downplayed symptoms in order to complete other duties.</td>
</tr>
<tr>
<td>Self-Diagnosis and Treatment</td>
<td>I was watching a basketball game and I cannot think of the basketball players name but he was having symptoms of MS and I was like that’s what I got cause we got the same symptoms.</td>
<td>Participants explained that instead of seeking treatment they initially attempted to diagnose symptoms and treat themselves independently.</td>
</tr>
<tr>
<td>Responsibility to Others</td>
<td>I have two kids and having kids and having MS has been (laughs) a ha, crazy</td>
<td>All of the participants described responsibilities to someone or something (i.e. themselves whether a child, husband, or career.</td>
</tr>
<tr>
<td>Fear About the Future</td>
<td>Well, sometimes I think about like the future cause I am like...I’m spending my 20s in medical school and everyone else is having fun and then I am going to be in debt for most of my thirty’s and forty’s and finally when I get out of debt and should be enjoying life.... That’s when like MS really gets bad so...</td>
<td>Many of the participants described their concern about the disease prognosis and how disability might make them incapable to reach personal and professional goals.</td>
</tr>
<tr>
<td>Faking Fine/Avoidance</td>
<td>I am doing rotations so I’m on my feet like 12 hours a day and it really starts to like burn and I don’t want the people that I am working with to know so I don’t want to be like, oh can I sit down so I just have to push through it</td>
<td>The idea of faking fine and avoidance was mentioned by all of the participants. Participants explained the notion of faking fine in order to uphold the persona of strength.</td>
</tr>
</tbody>
</table>
It’s crazy because at the same time you still have to be a mother, you still have tasks that you have to complete. The participants explained that they each had to maintain roles and persevere through fatigue.

I was crying because I had MS and I was crying even harder because I’m mad that I was crying. I’m not emotional. The participants shared thoughts about being emotional vulnerable. Underlying meaning and actual accounts suggest emotional displacement.

It is difficult but everything in life is hard. Participants described reactions to the future both personally and professionally.

God said I’m healed All of the participants described strong reactions to the role of God and faith about their destiny.

I will talk it out if I’m feeling stressful, ah, my husband is a great ear Participants explained that openness with others helps in the healing process. It should be noted that openness about the disability comes over time.

I laugh it off. I joke all day long Participants described that humor as related to adjustment and a component to understanding the importance of life.

Category One: Shock

Each of the eight participants discussed their lived experiences by responding to the interview questions. The shock phase embodies a time when the participants first started to experiencing symptoms, events that led up to the diagnosis, and following the
initial diagnosis. Four themes emerged regarding the lived experiences of AA women with MS in correspondence to the shock phase. These include: 1) denial of symptoms, 2) self-diagnosed and treatment, 3) responsibility to children, education and/or career, and 4) traumatic experience/fear about the future.

**Denial of symptoms.** Many of the participants discussed denial and avoidance of symptoms such as fatigue or vision issues prior to receiving their diagnosis of MS. This theme represents the notion that AA women often deny being sick because of other responsibilities, such as, mothering, being a provider, or commitment to education goals. This theme also suggests that when the symptoms were present some of the participants’ immediate responses were to keep pushing and avoid the signs of illness. These behaviors indicate that AA women with MS associate with SWS in several ways including the obligation to manifest strength, to suppress emotions, and a resistance to being vulnerable (Woods-Giscombe, 2010). For example, Fancy explained, “when I was pregnant with my three, my four-year-old, in 2010-2011 when I first started experiencing symptoms, but now that I have it [MS] I can look back and see that I had symptoms before (Fancy, personal communication. August 29, 2015).” On the other hand, another participant provided a more detailed understanding of how the superwoman schema prevented AA women from seeking medical because of the historical and cultural notion of strength.

Sybil specifically remembered ignoring the symptoms the day she received a formal diagnosis of MS.
…it was one day I was at home. I got up that morning, I didn’t say anything to my husband cause I had to open the store, but I got up. I was just so tired, but I felt like everything, like I was spinning, my head. I have never had a headache. But, I had a headache, stuff was spinning, like I had Vertigo. I was spinning that morning, I was like oh, I like I couldn't shake it, so I went on to work like I normally do. But when I got to work, I was sitting there counting money. I thought twenty, oh my, you know, but then I start feeling numb in my face and my left side got numb. Like I had a stroke. I couldn’t feel nothing. Like from my face all the way down my arm, my left leg, I was like, oh my goodness. You know, it hit my left side, you know. The only thing I remember is getting up, going to try and throw water or something on my face because I was sweating. And that's all I remember. And I woke up at the hospital (Sybil, personal communication, August 29, 2015).

Meredith’s experience of denial of MS symptoms included the idea that she could not pinpoint exactly when her symptoms started. She explained that for her the fatigue was normal and that need for naps was a part of her routine. Furthermore, Meredith mentioned that even though she remembered the tingling progressing into a burning sensation the onset of the tingling was a blur. She denied any association between her symptoms and a possible illness, like MS, but instead contributed her symptoms to her every day hectic schedule where she dealt with the symptoms by taking an appreciated daily nap to reboot her energy.
um, maybe about three years ago, I… well maybe since college. I was always
tired, but I don’t know if that was college or what. Always having to take naps but
three years ago I started noticing tingling in my legs and the tingling would
progress to burning. Um, so that’s when I first noticed symptoms. I guess
(Meredith, personal communication. August 30, 2015).

Autumn shared the day the symptoms worsened that she ignored them because
she was at work. She stated that the issue of blurry vision had worsened on that particular
day; however, she felt obligated to stay on her post instead of leaving work to go to the
emergency room. It is important to note Autumn was a bank teller at the time; so, leaving
work was not an easy thing because she was responsible for money. She explained that
her only option was to stay and sit with her eyes closed unless there was a customer that
she was assisting.

…it was like the vision part was getting worse to the point that it was like a
shooting pain in my eyes… I stayed at work like a crazy person, I stayed at work
for the rest of that day. Um, and drove home (Autumn. personal communication. August 31, 2015).

Similarly, Akeelah also ignored her symptoms like vertigo, migraines, and
dizziness because she figured her health related symptoms were somatic responses to
stress. As a mental health counselor, Akeelah described her responsibility as a drug and
alcohol recovery counselor was very demanding. Akeelah indicated that although her
symptoms started around September 2014, debilitating issues with her vision did not
worsen until March 2015 and because the symptoms were intense, she could no longer ignore the warning signs.

Umm, last September, last year [2014]. Almost a year ago. Like almost exactly to the date… um, vertigo, migraines, dizziness, off balance, I guess those were my major symptoms… My vision, That didn’t happen until March of this year. But, I really had trouble with the vision and the double vision… I woke up and umm I couldn’t get my vision to focus (Akeelah. personal communication, September 4, 2015).

Zoe stated that because her symptoms were on and off she avoided going to the doctor because the symptoms seemed temporary and not that big of a concern.

I was tingling, head hurting, all that type stuff. Like blurry vision and I went to the emergency room and they were talking about, that’s just sinus and that it would clear up. It was like a few weeks. I had to quit cheering and everything. They was like what is this. It disappeared and then it cam back on a few months after I graduated high school. And then the symptoms started coming back. And then I just started getting use to it. But I noticed my vision was worse, cause I wear glasses anyway, I been wearing glasses. I was like, whats going on with my vision? I lost my vision in my right eye for a few weeks. Then that cleared up and then some months later it happen in my left eye. And that cleared up…weeks later. Im like what is going on (Zoe. Personal communication. September 6, 2015)?
Lena stated her symptoms also became evident and were somewhat expected because she had worn glasses all of her life. She also avoided treatment in denial that the presenting symptoms were anything of a concern and she could go on with her daily life without seeking immediate attention.

…um, what happened was in, uh, the first part of August I woke up one morning and I was blind in my right eye… um, and kind of sort of thought huh, because I wear glasses. I have had vision problems since; I think I got glasses when I was 10. So I didn't think anything about it (Lena. personal communication. September 6, 2015).

Jasmine unlike the other seven participants did not talk much about the symptom avoidance. Jasmine was a full time student taking classes at the Community College in her town. She was also a full time mom to her first-born son, which she described to be a very important responsibility. When she noticed the symptoms, she explained that she wanted to know what was going on. Although she started to experience symptoms in February of 2008, she did not get a formal diagnosis until May.

Ok, I say in 2008 the beginning of 2008 I was going to school and I was taking public transportation and I had my son so, in the beginning like January, February I was dizzy and I could walk straight and everybody thought I was drunk and my feet were numb and I could see good and start happening to me (Jasmine. personal communication. September 7, 2015).

Seen as a collective, all of these AA women even though they were from different backgrounds and were at different education levels, had different career demands and
family responsibilities, ALL exhibited behaviors, regardless of the symptoms, of denial and/or avoidance of their MS symptoms. Consequently, denial/avoidance resonates as an emergent theme. Ninety percent of the participants either ignored or denied the signs of illness to maintain their roles and responsibilities because they believed their symptoms were not severe enough to address. According to Woods-Giscombe (2010), “stress and coping strategies have been found to be significant factors explaining health disparities in African American women” (p. 669) Denial presents as a coping strategy for these women and serves as indication that women avoid symptoms as an innate historical response. Denial and avoidance also serve as a significant indicator of how the superwoman schema influences the health behaviors of AA women with MS. They deny their own health to maintain their obligations; consequently, these women view themselves as pillars of strength rather than disabled women. Consequently, the SWS manifests as strength rather than illness in their everyday lives.

The symptoms of the illness are just another obligation to address rather than a disability because of the superwoman schema that demands they manifest strength. According to Wallace (1978), AA women demonstrate “inordinate strength, with an ability for tolerating an unusual amount of misery and heavy, distasteful work. This woman does not have the same fears, weaknesses, and insecurities as other women but believes herself to be and is, in fact stronger emotionally than most men…she is the embodiment of Mother Earth, the quintessential mother with infinite sexual, life-giving, and nurturing reserves. In other words, she is a superwoman” (Wallace, 1978, p. 107). On the other hand, these women because of the manifestations of the SWS, do not readily
develop an acceptance type disability identity. This notion of SWS shows that women ignore, avoid, and deny their symptoms. However, according to Woods-Giscombe (2010) these are normal reactions of individuals who have inadequate resources and experience oppression. This theory also highlights the John Henryism Hypothesis which was developed in 1983, suggests an additional component of SWS known at the postponement of self-care. This means that other responsibilities such as, work, education and family typically trump the necessity to seek help for themselves (James, 1994).

**Self-diagnosis and treatment.** The theme self-diagnosis and treatment suggest that these AA women with MS would try to self-diagnose the symptoms and find a treatment themselves before making an appointment with a medical doctor or neurologist. Again, the SWS allows us to understand their life choices because of their need to be independent, hardworking and strong. Fancy explained that she thought the symptoms of numbness in her legs were due to the long commute she had to make daily by car.

…um, extreme fatigue, falling and numbness. Like one day my legs went to sleep and they never woke up. I was at work and I just thought it was because of the driving back and forth, cause I was driving 30 mins. to my job, 30 mins. home and my legs went to sleep and never woke up so fatigue, numbness, pain, off balance (Fancy. personal communication. August 29, 2015).

According to Romagosa (2010), Fancy’s experience is different from the women in her study. Whereas the women in her study may have readily sought medical advice when the symptoms appeared, these women did not. Their experiences not only mention
the inability to seek care but also issues related to timing, resources, and psychological interpretation of symptoms that they felt they were able to handle on their own.

On the other hand, Sybil felt as if her symptoms were related to Arthritis or high blood pressure, conditions that runs in her family. So instead of seeking expert attention, she tried some home remedies, but was not concerned.

Well, actually I didn’t go. I was complaining a lot about uh, lifting my legs. Like I had arthritis uh, and I went and took something for arthritis and I would take a blood pressure pill. It was mainly my blood pressure. I've been taking a blood pressure pill since I was seventeen. That runs in my family (Sybil. personal communication. August 29, 2015).

Clearly, Sybil drew upon the SWS by seeking family remedies to maintain her strength, complete her tasks and meet her obligations. Furthermore, she turned to familial health knowledge to address her symptoms as did Meredith.

Meredith explained she was most concerned because her uncle has strabismus (lazy eye) and although she was concerned, she figured lazy eye was the cause of her visual discomfort. She stated, “I know one of my uncles has a lazy eye so I was like am I getting his lazy eye” (Meredith, personal communication. August 30, 2015). To address the discomfort, she did not seek medical help though. Meredith found that by taking frequent naps she would be able to temporarily fight of symptoms of fatigue and avoid tingling and burning sensations.

…um, maybe about three years ago, I… well for maybe since college. I was always tired, but I don’t know if that was college or what. Always having to take
naps but three years ago I started noticing tingling in my legs and the tingling would progress to burning. Um, so that’s when I first noticed symptoms. I guess (Meredith, personal communication. August 30, 2015).

Thus, Meredith and Sybil both exhibited characteristics of SWS when addressing their health concerns. Autumn not only denied symptoms, but she attempted to self-diagnose and treat the symptoms. Her major symptoms included vision issues. She explained that when her vision worsened while at work the only thing she felt like she could do was sit with one eye closed. Eventually, when her self-treatment no longer worked, Autumn reaching out to the ophthalmologist.

…so I wrote my magazine a week before I went to the hospital. So, I was really coupling all those things together and self-medicating. Like oh, I’m just tired I need to go to bed. I’m doing too much you know whatever. So finally one day, I was actually working overtime (laughter) and I get to work and I mean my eye was just really irritating me to the point that it really was only comfortable when my eye was closed (Autumn. personal communication. August 31, 2015).

Unlike the other women, Akeelah had a very interesting experience because during the time her symptoms presented themselves she was coping with the loss of a dear friend who passed away in a tragic car crash. Akeelah, having a mental health counseling degree believed the symptoms were caused by stress. According to Brown, Parker-Dominguez & Sorey (2000), the conceptualization and operationalization of stress is imperative. When she noticed her symptoms worsening she tried to take a step back and evaluate the things in her life that were causing stress, like the lack of supervision at
her job. Akeelah conducted self-medicating behaviors by attending yoga and attempting to process with other professionals outside of her job about these work-related stressors since the opportunity to debrief and process was not offered as a form of supervision.

It was clinical issues plus the administrative stuff that needed to be done. So there wasn’t a lot of processing time. Um, which was needed for me, umm, so I didn’t get that there. I didn’t get that elsewhere. So a lot of stress was taking on internally and I’ve learned now to process that with others, with coworkers or with other people who are in the field who may not work with me (Akeelah. personal communication, September 4, 2015).

Because of the self-reliance embedded in the SWS, when Zoe described her experience she explained straight forward that she knew her diagnosis even before the doctors knew. She had done a significant amount of independent research and compared her symptoms to the criteria for diagnosing MS. Even though her findings were consistent with MS, the practice of wanting to be informed speaks to characteristics of SWS known as resistance to being vulnerable or dependent (Woods-Giscombe, 2010). It is determined that the pre-investigation was Zoe’s way of setting an expectation so that she would not be surprised by the diagnoses when it would be rendered. For example, literature by Alice Walker describes the concept of the womanist. This concept is not, contrary to popular belief, “about being nice, or being a lady or not opening people. Instead, it represents a full-bodied view of womanhood encompassing outrageous, audacious, courageous, and inquisitive behavior. Its about wanting to know, being responsible, and in change” (Thayer-Bacon, Stone, & Sprecher, 2013, p. 276). This
practice is also considered to be Zoe’s way of being able to manifest strength, which is also a characteristic of SWS and Black feminism.

…see I’m always reading stuff so I was doing research and I was like what is this? I actually told them it was one night and I was watching a basketball game and I can not think of the basketball players name he was having symptoms of MS and he got tested and they was like he got Multiple Sclerosis. I was like that’s what I got cause we got the same symptoms and then a week or two later I told the doctor I said… you know I got MS right. He look at me and was like (skewed face) and then the test results came back. They was like you have MS. And I was like told you (Zoe. personal communication. September 6, 2015).

Hence, Zoe’s determination to explore her symptoms and get evidence through a personal investigation help her to maintain strength and in order to be in control.

Lena explained she attempted to self-diagnose and treat her symptoms. She believed she knew the real issues happening with her eyes and by simply making an appointment to have her already low-vision checked things might improve. On the other hand, Jasmine described a time when she self-mediated. She, however, talked about the fact that her performance in class was very off and it made her interested in finding out faster what was happening rather than trying to figure it out on her own. In essence, all of these AA women tried to solve the problem themselves even to the point of self-diagnosis to continue doing their normal everyday activities and meeting their responsibilities. They had the strength to figure it out on their own before seeking
professional diagnosis. The next theme is linked to this behavior because of their need as AA women to be responsible for others and plan for the future of others and themselves.

Responsibility to others/ fear for the future. The theme identified as faking fine/avoidance relates to both the characteristics of superwoman schema and disability identity. It is suggested by Woods-Giscombe (2010) that AA women have an obligation to manifest strength and an obligation to suppress emotions. This further supports the notion that AA women have to keep “emotions bottled up inside” (2010, p.673). However, in regards to disability identity and SWS it seems that it is not a matter of one superseding the other, considering the fact that Tajfel & Turner, (1979) define the theory to include a determination to obtain positive self-concept in one of two ways: 1) by denying their disability in order to be assimilated or 2) through acceptance.

The final theme to fall within the shock category of the lived experiences of AA women with MS, is identified as the responsibility to others and their fear about the future and their ability to maintain their strength to complete their responsibilities and dreams. This fits with disability identity because of its relationship to disability self-efficacy. Self-efficacy related to the belief that one can execute certain behaviors (Bandura, 1977) and also suggests is someone has motivation and confidence to succeed at a certain task. Each of the participants talked about their roles to care for others, in addition to, the role to be successful because others were watching. This theme presents as a fear for the future, which overshadowed each of them when they learned they had a disease typically diagnosed more frequently amongst older White men (Langer-Gould, Braram, Beaber, & Zhang, 2013).
Lena particularly talked about how she was confused when they told her she had lesions on her brain that were consistent with MS. She recalled, “So, I went to the hospital and they did some tests and they diagnosed me with some disease that only 76 year-old White males get” (Lena. personal communication. September 6, 2015). The meaning that is embedded in this quote by Lena suggests that she was unsure how she could have been diagnosed with a disease that was more prevalent among White males. Furthermore, how this disease would manifest itself and how she would be able to manage symptoms when most literature on care and adjustment lacked representation to her as a black woman. Furthermore, in regards to the theme of responsibility to others/fear about the future, it was evident from the participants’ interviews that the five mothers of the sample feared the disease would compromise their relationship and time with their children. For example, Fancy provided insight into this theme.

Fancy, who was pregnant at the time of her diagnosis, described the negative physical manifestations of the disease, and how they altered her relationship with her newborn child.

When I was first, when I first had my baby my sister in law actually had to move in to help me take care of my baby. Like when my baby was first born I never had her, I’d see her, oh hey, but I could barely hold her, after I had my baby, like the symptoms just came full force, or whatever, so it can be extremely rough being a parent and having MS, and depressing (Fancy. personal communication. August 29, 2015).
Fancy had just given birth to her daughter and could not even hold her. Her physical symptom of very bad numbness altered her bonding with her child and forecasted impending doom because she could not take care of her child and needed the support of others. Similarly, Jasmine also voiced similar concerns related to the fear that having MS would hinder her ability to spend time or even be active with her children.

You know, and just like playing with my kids. I want to get a bike and I want to ride bike with them right but, like my brother said, you too fragile so you be done feel off and broke every bone in your body. And I be like “oh be quiet” but guess what the reality is he is probably right I don’t have the balance to do that. Even though my mind tells me I can do anything. My body tells me, oh no girl you can’t (Jasmine, personal communication. September 7, 2015).

Whereas the mothers had legitimate concerns because mothering was one of their primary responsibilities that the disease could obstruct, the three women who had no children such as Meredith, Autumn, and Akeelah feared the future for reasons related to professional and personal goals.

Meredith was very clear about her fear for the future. Because she is in medical school, she was most fearful about the future. She discussed how the progression of the disease might alter her ability to finish school, pay off her student loans and reap the benefits of her hard work because she feared she would be too ill or even disabled to enjoy life the way she had once envisioned.

Well, sometimes I think about like the future cause I am like…I’m spending my 20s in medical school and everyone else is having fun and then I am going to be
in debt for most of my thirty’s and forty’s and finally when I get out of debt and should be enjoying life (Meredith, personal communication. August 30, 2015).

Besides the mothering and professional concerns that the women described in relation to fear about the future, Autumn, Akeelah and Sybil all had a similar experience when it came to fear about the future because death was a topic of discussion when they found out about MS. Sybil, for example, had an old classmate who was attempting to reach out and support her after he found out about her illness, but the questions he asked was insensitive.

…he asked my sister. He says, you know I heard your sister was dying. She has two weeks to live and it worried him. And my sister said, No! No! She sick, but she is fine. She said I am going to give you her number so you can call her. I am going to let her talk to you. And he did (Sybil. personal communication. August 29, 2015).

Akeelah was having a family meeting to tell her siblings about the diagnosis when her niece asked if she was going to die.

…my niece was there and she is asking me questions about MS, what it is and um, you know she asked me if I was the one in the family that started this disease and you know and is it something I am going to die of and these different things and I knew basic things, like I knew I was not going to die (Akeelah. personal communication, September 4, 2015).

Autumn’s experience was a bit more traumatizing because on the day she found out she had MS, the only person she knew with the disease passed away the same day.
…and it just so happened I have a or had a cousin who um had a very severe case of MS. I don't actually know what um she was diagnosed with because the day that I got my MRI results she died at like 11:00 the night before (Autumn. personal communication. August 31, 2015).

The meaning embedded in the experience reported by Autumn suggests that her anxiety about being diagnosed with MS exacerbated levels of stress and fear about the future. In addition to being diagnosed with a cause and cureless condition, she felt that the only person who could have given her experiential advice about how things and the future would be okay actually lost the battle and had died. Literature and theory that supports the fear of the future theme recognizes that for the AA woman who associate with SWS may have an obligation to manifest strength and an obligation to succeed with limited resources (Woods-Giscombe, 2010). Although Autumn mentioned this experience she also explained that losing the person closest to her with MS played a major role in how she had to learn how to adapt and maintain resilience.

In conclusion, all of the participants feared that MS would interfere and even had experienced how MS could alter their ability to tackle their responsibilities, relationships with loved ones and professional goals and aspirations. According to the literature, the MS is not considered a fatal disease and cases of death are rare (Harvey, 2012). Additionally, literature talks about the idea that severe conditions are most often found in people who are diagnosed at or above the age of 40, onset symptoms of motor control and mental functioning, short span between exacerbations in the first year, and rapid
progression (Harvey, 2012). From the time of diagnosis, these women explain the lived experiences that have or are anticipated to alter life choices.

Category Two: Transition

The second category identified in the exploration of the lived experiences of African American women with MS is categorized as the adjustment phase. This category represents the period of time when many of the participants started to recognize that life for them would have to be altered for them to be healthy. The category consists of three corresponding themes: 1) faking fine/repression, 2) role expectations vs. fatigue, and 3) vulnerability/emotional displacement. The following section will provide a detailed exploration of the how their lived experiences illuminated these themes within this particular category.

Faking fine/repression. This particular theme encompasses a set of behaviors and characteristics consistent with the superwomen schema as proposed by Woods-Giscombe (2010). This is when participants felt the need to pretend they were fine in order for them to refrain from appearing weak. According to Woods-Giscombe (2010), these behaviors “might explain delays in health seeking behaviors limited adherence to recommendations made by health care professionals, and lower rated of screening procedures for conditions that are treatable if caught at early stages” (p.680). In relationship to the connection of this theme to disability identity and the superwoman schema participant feedback shows that like the literature of Beauboeuf-Lafontant (2007) “cultural mandate of strength, self-silencing, excessive attunement to the needs of
others and denial of one’s own needs” is highlighted as positive reinforcement for showing strength (Woods-Giscombe, 2010, p.679).

Fancy reported that the best way she knew how to to deal with the impact of the disease in front of others was through repression and isolation.

I was depressed for like two years, I didn’t go out, I didn’t do nothing. I isolated myself from everybody, cause I felt like that was unfair, I had just graduated from college, just got married, just had a baby and now I got this disease that I can’t do anything (Fancy. personal communication. August 29, 2015).

Whereas Fancy choose to isolate herself, Meredith has no choice but to engage in social events because she is pursuing her dream.

Currently, Meredith has to fake fine because she is a medical student. She is in a stressful position as she is in her rotations and must perform well o keep up with her peers. Meredith indicated her days are long, but she chooses to keep going when she is tired rather than paying attention to her body and taking rest breaks when she needs them. She does not want to let herself look weak. Meredith has to fake fine so her fellow colleagues do not confuse her diagnoses as a weakness. For example, according to Brown (1984), “identity politics is bound in a resentment that encourages its advocates to demand recognition and protection because of their weaknesses (p.247). One may question how much this theme has to do with being an AA woman. Research by Brown (1984) finds that “identity groups that seek their freedom on the basis of an identity that has been normalized by power tie their struggle closely back into the very institution that constrain their activity in the first place” (as cited in Thayer-Bacon, Stone, and Sprecher,
2013, p.247). Although this concept lacks definitive ratios of how often this happens
evidence of the root of the matter helps to support that notion that these strength
manifestations are significant.

Umm, it’s kinda hard now because I am doing rotations. So, I’m on my feet like
12 hours a day and it really starts to like burn and I don’t want the people that I
am working with to know so I don’t want to be like, oh can I sit down so I just
have to push through it but I be so tired but I still have to study. But other than
that. That is the only way it is affecting me (Meredith, personal communication.
August 30, 2015).

Similarly, Akeelah’s interview showed she has had to fake fine for the people that
she loves. During the start of the interview, Akeelah was very short with her responses
and was not able to be candid about how she is currently doing because her mother was
in the room. She stated later in the conversation, after her mother went to work, that the
conversation about MS is still a hard pill for her mother to swallow.

She is…(long pause), you know she is mom and I’m still looking out for her, We
don’t, we talk about my diagnoses but she (deep breaths in and out). I mean, she’s
a nurse and she deals with peoples’ stuff everyday but this you know. I’m her
daughter, I think it is so different. Um, so you know I, Well, first of all, I didn’t let
her know before you had called what we were going to be doing (laughs. Um, so
she didn’t really have a heads up for real for real and then secondly I still am
kinda weary about the way that I talk about the diagnoses and this things around
her. Um, don’t want to over worry her too too much (Akeelah. personal
communication, September 4, 2015).

Autumn informed the research that as a business owner, she has had to fake fine
so others do not see her as weak. She explained on occasions when her lower body is
weak, instead of making an announcement to her friends and family, she prefers to just
insist that the day at the gym be exercising of her upper body. She explained that this
helps her remain knowledgeable and aware of her current ability, but does not make her
weakness public information for everyone else.

I’m not going to release my weakness. So, one day I might tell somebody, but no
thank you. I will just find a way to change the workout. Like, I might be like, you
know what, I want to do a cardio, can we do cardio today? Like, yeah I need a
cardio day, I’m feeling spent. Like I need a cardio day… Like or you know, I will
do something like, man we haven’t done leg day, can we do leg day. I find ways
to manipulate the situation. But, I don’t try to do something I can’t really do. And
now my trainer, I will be honest with her a lot of times and I will tell her like,
listen I can’t do x, y or z today or I’m having trouble with this, so I can’t. You
know whatever. I will be honest with her but I won’t tell anyone else (Autumn.
personal communication. August 31, 2015).

Thus, Autumn as well as others fake fine because they do not want to be perceived as
powerless or weak. These behaviors exemplify SWS. On the other hand, they do not
embrace their disability identity in these situations. Instead, they present as AA women
as still superwomen even when they are not fine. Primarily, this is because historically as
well as today, AA women fulfill many roles within their families and in society where they present as strong or possessing strength regardless of their actual physical state of being as further detailed by the next theme.

**Role expectation and fatigue.** This theme emerged as the participants talked about the transition of roles such as, mothering and employment. Fatigue is included in the theme because most of the participants talked about how much of an impact this particular symptom has had on their ability to complete certain tasks. Woods-Giscombe (2010) suggests that there are both benefits and liabilities of the schema. Described as benefits of association with SWS are preservation of self and survival, preservation of the family, and preservation of the African American community (2010). These component of the SWS theory provide evidence that the theme of role expectation and fatigue is significant. Based on the feedback from the participants it is also suggested that role expectations and fatigue make the task of caring for others a challenge. Thus, this theme seems to be more closely related to the liabilities of SWS, which includes strain in interpersonal relationships, stress related health behaviors and the embodiment of stress (2010).

Fancy, Autumn, and Jasmine all shared how their inability to maintain employment, which was a hard pill to swallow since they each have responsibilities to someone or something else, was primarily due to fatigue. Fancy was employed at what she considered her dream job. After she was fired, she was unable to keep steady employment. Fancy poignantly shared that as a college graduate her inability to keep a job was depressing.
I really don’t have any responsibilities beside looking after them on a daily basis, um, I have been taken off of work by my doctor since June the 25th 2014 because I haven’t been able to hold a job for three months without being hospitalized. My last job that I did have, I had that job almost a year and I loved the job (Fancy. personal communication. August 29, 2015).

Autumn is an entrepreneur today, however; she described her experience prior to being an entrepreneur as challenging. She explained that she was used to working two jobs and even called it her new normal. However, during the transition phase, Autumn struggled with the stress of the job. She ultimately quit both of her corporate jobs and started her own business. She stated she would never go back to the corporate office because the benefits of working for herself and being able to take care of herself are irreplaceable. The concepts of fatigue explained by Autumn are relevant under this theme because she explained that she was aware that the symptoms of fatigue might increase suddenly and decrease her performance. Instead of remaining in corporate America where she might be inclined to let others down or be reliant on others she decided that her best option was to become her own boss. Both the notion of manifesting strength and resistance to be dependent are characteristics of SWS (Woods-Giscombe, 2010).

…But like, I used to have this string desire to be in the corporate world and I wanted to do all these things and do this. And it's like, it lost so much for me because I felt like, and the things that I previously wanted to do would take away from me actually being able to be an example… Especially, so good it would cause me so much more stress than I deal with now and that's just not something I
want to put on my body… So you know, working for somebody else that scares me because I feel like I could have an episode and it can take me out and I’m now without a job and that would really. Because the consistency is that, the inconsistency slash inconsistency of that is scared me about it (Autumn. personal communication. August 31, 2015).

Whereas Autumn had found a solution to meeting her own responsibilities and address the chronic symptom of fatigue, Jasmine had a different experience.

Jasmine described her experience as a mother of four, caretaker to her mother, and the responsibilities she has to take care of herself to be overwhelming at times. Her lived experience consists of managing these roles not because she is forced to complete them, but because she is committed to the well-being of her children, her mother and herself. She discussed how one of her children has a disability and she is okay with making sure her children receive the love they deserve.

…Um, I feel like my roles is very important, I feel like I am a mom first, I have to be a provider, I have to take care of home. You know I feel like on one hand I could be in business mode because I have a child [with] special needs and I feel like constantly I’m up there working with my children and so my life is really busy for real.

Each of the women have different responsibilities. Moreover, each one has found a way to address those roles and address the fatigue ever present in their life. Truly, they live the SWS. Because this is an unconscious way of responding to the many
responsibilities they have to tackle, AA women with MS do so because they seek to maintain an appearance of strength rather than vulnerability.

**Vulnerability and emotional displacement.** The idea of emotional displacement connects to the idea of defense mechanisms and stems from Freudian literature. Displacement of emotions is considered to be one of the top nine most common mechanisms. Not only are emotions replaced with anger but it is also a potential reaction for emotions such as anger to be taken out on other people. After receiving a diagnosis of MS, many of the participants were unable to appropriately express emotions or appear vulnerable to others. Each of the women had different responses to their diagnosis. Autumn described how she felt as though she wanted to put herself in “time out” for being emotional about the diagnosis.

> I like wanted to put myself in a corner. You know at first, I tell you the truth, I was off work, and I was at home. So, I am able, like when I felt that coming on I would just go in my room and take a nap. You know (Autumn. personal communication. August 31, 2015).

Lena indicated she was an emotional eater and could eat a whole cake as a response to her diagnosis:

> So, I really think my stress was eating. My stress release was eating at the time. I joke about that now and say you know, I could eat a coconut cake but it was, it was stress (Lena. personal communication. September 6, 2015).

Akeelah was only able to express herself in front of people but stated that she finds release in the ability to scream at the top of her lungs about her fear and frustration.
in her own private space. She described, “and I remember I came home that night from work and I sat in my car and I cried and I was screaming and I was crying”.

**Category Three: Adjustment**

This category is the last and final category that was identified as a key component in understanding the lived experiences of AA women with MS. This category has been labeled adjustment because the eight participants were identified to respond according to one or the other. This category includes: 1) hope/despair, 2) role of faith, religion, and social support, 3) openness with others about the MS diagnosis, 4) and the use of humor.

**Hope/despair.** Hope represents the participants’ belief that they could actually live a healthy life and be successful. Despair represents a sense of contentment with the reports that their doctors, internet based information, and the words of others that they would not be able to succeed or maintain stability. Based on the three participants who are all unemployed or placed on disability it was noticed that these three women in particular have lower education and socioeconomic status (SES) when compared to the other five participants. In the following section there will be an examination of the themes that emerged and fall within the hope/despair theme.

Sybil does not work and has a home health aide that comes to her house weekly to help with the cooking and cleaning. One aspect to note about Sybil’s condition is that she has co-morbid conditions including hypertension and obesity.

Meredith seemed in between hope and despair about the future since she was more recently diagnosed. She seems hopeful that she might be able to continue with school, but demonstrated despair when she discussed her ability to enjoy life after
finishing school. One interesting thing to not about the interview with Meredith was that she is a medical professional and understands the importance of healthcare but does not seem to practice good healthcare herself. Meredith understands also the effects of stress on her health, but does not seem focused on managing stressful situations. She explained that when she was taking finals she was experiencing symptoms related to Multiple Sclerosis.

During exams I mean I don’t, I don’t find a way to deal with stress I just study. So… probably not the healthiest…Well, when I first had the double vision, the way my school is set up, we’re taking modules, so I had just finished like the first modules and we had our finals second year and so that’s like what triggered my relapse that time. And so usually whenever, and then I just took my board exams this summer there’s like another relapse. So whenever I have like really hard exams, it gets tough but there’s really nothing I can do about it so, whatever.

Autumn described her future as hopeful because she feels as if since learning how to manage stressful situations she can do what she desires with modifications and attentiveness to her body. Autumn is the owner and CEO of her own magazine and is currently writing a book. She explained that this type of narrative therapy helps. In addition, she is hopeful because she makes the rules. She has figured out that to be ahead of her schedules helps in managing stress and concern for missing a day or two “if” she has an exacerbation. Autumn has also realized that when she has an exacerbation or begins to notice symptoms of MS she recognizes that as an opportunity to reevaluate her
schedule so that the next time she does not do the same thing and can avoid becoming sick.

Akeelah is also hopeful, even though she has just been diagnosed. Her transition as assessed during the interview process will probably be more positive because she understands how critical emotional awareness and mindfulness can be on the brain and health. Akeelah explained that she continues to work with people with disabilities and even though the job itself can be stressful she recognizes how important it is for her to debrief and depress after sessions so that she does not overwhelm herself.

I think it plays a huge part, um, I think for myself um, I am a big internalizer. I internally process things naturally and I always have been that type of person. Um, so its for me opening up to um others, um, which is not a process that umm, its one that I wish that I could take on, on my own but I can not. Um, you know I need supports from other people. So as I identify its kinda like a um, um, not necessarily an introvert…100% um but, um there is another word for someone who likes to be alone sometimes but also like to be around people and some type of ambivert, maybe? Is that what its called, um, but anyway, um, fighting against that piece to get the support from others that’s needed.

Zoe is hopeful for the future, as she is a college student and mother. She is a researcher by nature and she is truly optimistic that there is a cure for MS and soon she will not have to deal with any of the treatment and other issues that accompany the diagnosis. Zoe was the youngest participant however, she seems determined that she can do more with her life. She is resilient and confident. Although Zoe has a lower SES she
seems like the negative things people tell her actually motivate her to do her best and be more than what people expect her to be. Zoe stated, “some people like, oh, you can’t do this, you can’t do that….yes I can. Watch and see me do it”. 

Throughout the interview process Lena provided very informative information about her 14-year experience as an AA woman with MS. She described her hope phase and explained that she has learned how to deal with herself and other people. She stated that, “…failure to plan on your part does not constitute and emergency on mine”. 

Furthermore, based on the feedback from Lena that over the years she understands how imperative it is to listen to your body, even when it comes to the small things like, eating the wrong food, being in places where you are overheated, and the unspoken issues with urinary incontinence. Lena, recently retired and although she has developed a strategy of managing stress when working with others, it is also important for her to manage the stress of and adjustment to life as a retired professional. Robert Atchley (2000) proposed that there are five stages of retirement, including: 1) the honeymoon phase, 2) the disenchantment phase, 3) the reorientation phase, 4) the stability phase, and 5) the termination phase. 

Jasmine, illustrates signs that she might be in between the hope and despair. Now that she is no longer involved in an abusive relationship she seems as if she is willing to take a step forward. She is unemployed however it seems as if she aspires to be a stay at home mom so that she can care for and raise her family. She stated that she is very involved in the development of her children and that is what keeps her going. The despair
piece comes into play when she describes the ability or inability to play with her children because her family calls her “fragile”.

It is difficult but everything in life is hard. It’s hard and it’s sad because sometimes I feel limited in the things that I can do like, for instance, I have children and I athlete and always have been and I want to do things but with the MS and my nerves and stuff I can feel as well as I use to feel or I don’t feel the same as other people do. Like recently I was in there trying to make some spaghetti and like every time I’m cooking I burn myself. Like in July, the end of July I poured hot water all over myself and had to get rushed to the hospital. You know, and just like playing with my kids. I want to get a bike and I want to ride bike with them right but, like my brother said, you too fragile so you be done feel off and broke every bone in your body. And I be like “oh be quiet” but guess what the reality is he is probably right I don’t have the balance to do that. Even though my mind tells me I can do anything. My body tells me, oh no girl you can’t (laughs) I want…I’m seriously. You don’t understand. I physically want to do everything but I am not able to. To me sometimes that hurts my feelings. You know what I mean. Every time I try to go to school, every time we try to do something my health declines rapidly.

Role of faith, religion and social support. This concept relates not only to the characteristics of superwoman schema but also the historical roles of black women. Considering the work of Wallace (1978) and Hull, Bell-Scott & Smith (1982), faith is a major indicator of the intersectionality of SWS and DI. Each of the eight participants
described their experience of living with MS to include faith, religion and the connection to a positive social support. Fancy for example stated that:

I cried like every night for two years. Every night, because I felt like it was unfair that this happen to me at this age in the prime of my life. I’m supposed to be doing everything, but I’m sick dealing with this and dealing with a husband that’s sick and I have two kids and I ain’t even 30. Cause um during that time, um or whatever, I got taken off, I stop taking rebif. I didn’t take anything because um like you said either at church my pastor told me that I was healed so being like I was I didn’t know what to do like okay he said I was healed so I know I am healed. I’m waling in faith, I’m healed but at the same time I have to go along with what the doctor says and produce the results. I wasn’t thinking and I like he said I’m healed I aint finna take nothing I’m just I’m just gonna gone off, God said I’m healed. So for two years I didn’t take anything. Probably like a year, year and a half somewhere around there I didn’t take anything (Fancy. personal communication. August 29, 2015).

Meredith is not as open as the other participants about having MS. The way she described her current responsibilities indicates that her priority right now is not her health but instead on the completion of medical school. We she talked about social support she did mention her faith and stated that they only people she trusts are her church members. She has doesn’t talk about having MS because of her faith. Although she is not open to talking about her health or illness she does consider it important that she reply on faith for
her healing. She described, “The only people I’ve told is like my bible study group, because I know that there is power in prayer.”

**Openness with others about the MS diagnosis.** This theme describes how identification with having MS (disability identity) can help with the adjustment process. A lot of women explained that MS was not about of their identity but some of them talked about the gratification they have when they are able to talk about the fact that they have the disease. This could theme can also be called the identification of a social support. All of the women explained that support system of someone who understands your experience is imperative.

Sybil described that even though she was attending an MS support group she never felt that the group would be helpful because the people there were a lot different. When she decided to stop attending the groups she described that she found another option for support through a black women network of women on Facebook who had also been diagnosed with MS. She states that she remains in contact with the people from the local group, however does not feel comfortable attending the meetings.

…my Doctor he made sure he wanted me to go to this MS group. I was like, we don’t even have a MS group here in Dothan, you know, I am the only black girl here diagnosed with this. And I was like, who going to come? So he's like, we have one, if it helps out here in locally. So, I started going there and I went. And I met a lot of nice people, like I they was like, stayed in the surrounding areas and it was like, and when I counted, it was four black people including me… these three other people stayed in the surrounding area, I was the only one from Dothan. And
I was like, yo, I am the only black person that was diagnosed. You know, but now since I have been diagnosed, several other black girls besides my sister, several others I know got diagnosed with it. And I went for a lot of years to that meeting and they would have classes on managing you know, your kids. Some of them still work, you know?... with one of them that has MS like me that stays in another county. Her and I met some over uh...one of them gave this about the information with you that I met on Facebook. I guess she was scrolling through one of my friends and seen my Facebook thing and I always put some inspiration you know, try to put some inspiration, for everybody that add me. You know... And she's my friend, she became my friend, you know what I’m saying. Because she was like, Shawn how can you, uh...she said you always happy, you don’t complain, you don’t, you know. I got over two hundred friends that's living with it now, that has it, that you know, that sending out good morning or have something godly. Saying they determined or you know, I never met, but you know, they have MS. I still check with them you know, if they having a bad day or you know (Sybil, personal communication. August 29, 2015).

Zoe, Lena and Jasmine all seemed very open with saying that they have MS and telling people about their stories. Zoe for example is a member of a MS group and considers herself an active member. Lena is very open and finds it important to encourage others with MS. Jasmine is the most open and she believes that being open about having MS is the best way to manage her stress.
I vent. I talk about all my business. I tell everybody everything so can’t nobody talk about me. I’m so serious. Like I just tell strangers and like I been through a lot of situations and I found especially and I find that talking about the stuff that bothers me to people who don’t even care…it helps me and I don’t care because….what is you gone say about me? You do…hey you don’t know the half of it. But at least I…I get it off of my shoulders and I get to talk about it. Its sometimes even talking to my mom and talking to people that care too. I get certain of feedback and I realize that everybody’s perception is different. So I like to talk to different people. I realized that I am cool for real and even though I cant do everything that I want to do physically, mentally I know how I can do it and that is better off than most people who are supposed to be normal and okay. And that’s it (Jasmine. personal communication. September 7, 2015).

This was also evident by Akeelah’s comments from the first initial interview to the second interview which occurred approximately three weeks after the first interview. In the second interview Akeelah stated that she had begun to open up more about her diagnosis to other people.

I think it plays a huge part, um, I think for myself um, I am a big internalizer. I internally process things naturally and I always have been that type of person. Um, so its for me opening up to um others, um, which is not a process that umm, its one that I wish that I could take on, on my own but I can not. Um, you know I need supports from other people. So as I identify it’s kinda like a um, um, not necessarily an introvert…100% um but, um there is another word for someone
who likes to be alone sometimes but also like to be around people and some type of ambivert, maybe? Is that what its called, um, but anyway, um, fighting against that piece to get the support from others that’s needed, of course um (Akeelah. personal communication, September 4, 2015).

**The use of humor.** The last and final theme that emerged during the hope/despair stage was the role and use of humor to help remain positive and optimistic. All the participants mentioned the importance of spending time with others. The response provided by Fancy helped in illustrating how and why humor is a nice practice for AA women with MS. Fancy stated,

Humor, prayer…humor and prayer and my kids. Knowing that they need me…prayer and having a good support system. Like my mother, my church family and some of my friends like having a good support system, family, humor, family and my kids because (laughs) I am all they got. So I have no other choice but to get up and go (Fancy. personal communication. August 29, 2015).

**Answering the Research Questions**

In the previous section we looked at the themes that emerged during the research investigation across three phases and in relation to the lived experiences of the eight research participants. The next section of this chapter describes how the themes that emerged answer the central research questions. These three questions are: 1) How do African American women associate with the Superwoman Schema?, 2) What is the essence of the lived experience for African American women with MS?, and 3) What
challenges do African American women with MS experience in regards to maintaining role obligations of SWS and the development of a disability identity?

**Association with Superwoman Schema**

The first of the three research questions was developed in order to understand how African American women associate with the characteristics of the Superwoman Schema. These characteristics as outlined by Woods-Giscombe (2010) include: 1) obligation to manifest strength, 2) obligation to suppress emotions, 3) resistance to being vulnerable or dependent, 4) determination to succeed despite limited resources and 5) obligation to help others. Based on the evidence collected in the findings of this research it is suggested that AA women associate with the obligations of the superwoman schema in a variety of ways; however, it was determined through interviews that each of the eight participants describe these obligations as a part of their normal routine. Some participants would describe long list of daily routines and finish explaining their roles and responsibilities with statements, such as, “nothing really outside of that” or “that is pretty much it”. These statements suggest that African American women down play their roles and responsibilities, however the obligations of the superwoman schema (2010) are present amongst this particular group of women.

**The Essence of the Lived Experience**

The second research question that guided this research investigation asked, what is the essence of the lived experiences of African American women with MS? This question can be simply answered by calling it a process of psycho-education or a learning process of trial and error. These women explained that over three specific phases,
include: 1) shock, 2) transition and 3) adjustment that experiences such as denial of symptoms, self-diagnosis and treatment, responsibility to others, fear, faking fine, fatigue, and vulnerability. The third and final research question helped in expanding upon these findings. The final question that directed this research investigation will be explored in the next section and include a comparison of the finding from Romagosa (2010) to the themes that emerged in this study regarding the specific challenges that AA women with MS.

**Challenges that African American Women with MS Experience**

The last question that directed this research was, what challenges do African American women with MS experience in regards to maintaining role obligations of SWS and the development of a disability identity? Carol Romagosa highlighted eight themes in her research study on women with MS, in general. These eight key themes include: 1) loss of control over person’s sense of unity between body, self-identity, and the world, 2) increasing awareness for transformation, which includes the process of diagnosis, denial, and the wake up call, 3) the drive for integration in order to proactively cope each day with their illness, 4) an opportunity for learning ways to reinterpret the stressful events regarding one’s values, beliefs, and goals, 5) listening to the body, 6) the learning process, 7) learning to appreciate life, and 8) life as a spiritual journey (Romagosa, 2010, p. 89-97).

As discussed earlier in the chapter, and listed in figure 1, the themes that emerged in this particular study include: 1) denial/avoidance of symptoms, 2) self-diagnosis and treatment, 3) responsibility to others/fear about the future, 4) faking fine/avoidance, 5)
role expectations/fatigue, 6) vulnerability/feelings emotional displacement, 7) hope/despair, 8) role of faith/religion, 9) openness with others about the MS diagnosis, 10) use of humor/sublimation. When looking at the two different studies and particularly the sample of women from the seven Euro-American women and eight African American women the themes that emerged do provide indication that there is significant differences that African American women face in the development of a disability identity while maintaining the strenuous demands of the superwoman schema. In the following paragraphs there will be a detailed look at these challenges that were uncovered in the research investigation.

Being preoccupied with other roles. A reason why women of this study showed to have a hard time associating or accepting a disability identity is because other roles required too much of their time like mothering and working towards an education. Based on the feedback of the participants many of them were more concerned with family and success to take the time and revamp their already established identities that were developed prior to the diagnosis. This suggests that these women attempt to get back to ‘business as usual’ following the diagnosis. This also can pose as a threat because the once stressful life activities are not altered with attention to ways of minimizing stress in order to maintain active involvement. This lack of attention and incorporation of a disability identity thus can lead to more frequent exacerbations.

Religion and faith encourages women to rebuke MS related illness. Another reason why AA women with MS find it difficult to associate with disability identity is because their religions and faith encourages them to denounce and rebuke illness.
According to Woods-Giscombe (2010), AA believe that “relying on God offered encouragement in the context of inadequate tangible resources” (p. 676). Almost all of the participant mentioned faith and healing through the power of prayer. One participant even mentioned an instance when someone with MS was attempting to warn her about possible symptoms and she stated that she would not claim that over her life.

…my brothers friend has the more progressive form of MS and…he kinda deteriorated very quickly, you know he, his doctors told him I think last week his doctors told him that he would never be able to draw again and you know he, one of his messages that got back to me… was that ‘when you start having trouble writing or when you start having trouble speaking, you know, um, we can talk more about, you know about you …how you handle this or something like that. I am not claiming that over my life. I am not claiming that I am going to have trouble, speaking or writing, or walking. That I am going to be using a cane or wheelchair or anything like that over my life. That is not something that I am going to claim or something I am going to get into with my MS. With my disease, um, like I think that you said, um, I know that you said. I’m… I have a disability but I am not disabled. These are not things that I um, claim over my life, there is power in the tongue and I am not going to, this is not going to beat me, you know um, it may slow me down a bit and um, it may and it may not, you know (Akeelah. personal communication, September 4, 2015).

Another participant stated that there was power in words and claiming or associating with MS goes against everything that she believes as a Christian. This is an
interesting concept because these ideas and principles seem to stem from a long list of association with the moral model of disability, which suggests that if someone has a disability then it is a punishment from God as a result of something that they must have done or something that their parents did wrong.

A very interesting piece of evidence that AA women have a hard time associating with MS because of their religion and faith was obtained from Fancy. Fancy stated that because her pastor prayed for her that she stopped taking MS medication for months. She was ultimately testing her faith. At the same time, her husband was in a coma and her stress caused her to have exacerbated symptoms but she still did not take medicine, nor did she leave her husband’s side to get treatment and care for herself.

I didn’t take anything because um like you said either at church my pastor told me that I was healed so being like I was I didn’t know what to do like okay he said I was healed so I know I am healed. I’m walking in faith, I’m healed but at the same time I have to go along with what the doctor says and produce the results. I wasn’t thinking and I like he said I’m healed I aint finna take nothing im just I’m just gonna gone off, God said I’m healed. So for two years I didn’t take anything. Probably like a year, year and a half somewhere around there I didn’t take anything, no drugs (Fancy. personal communication. August 29, 2015).

Lack of awareness about how identity is constructed. The third piece of evidence during this research investigation to support the determination that AA women with MS do have a difficult time association with disability identity is because some may similar have a lack of awareness about how identity is constructed/form. Erik Erikson
proposed the stages of identity formation, which occur overtime. There are eight stages of identity formation that occur of the course of one’s development and include: 1) trust vs. mistrust, 2) autonomy vs. shame, 3) initiative vs. guilt, 4) industry vs. inferiority, 5) identity vs. confusion, 6) intimacy vs. isolation, 7) generativity vs. stagnation, and 8) ego integrity vs. despair (Erikson, 1974). The interesting piece about this developmental model is that people change over time and appropriately/correspondingly so will the things that are included in their being. For example at the sixth stage, known as intimacy vs. isolation the basic virtue is considered to be love and the age range of people at this stage of identity is 18 to 40 (Erikson, 1979). Like with this stage and there being a basic virtue proceeding stage of identity is generativity vs. stagnation whereas care is the basic virtue. For AA women with MS, the sudden change in identity can also cause a crisis. Just as suggested by Erik Erikson.


This current research investigation considered the findings of the Romagosa (2010) study, which investigated the lived experiences of women diagnosed with MS. However, although the 2010 study contains many components that are useful when providing services the sample of the study was found not to be representative of AA women. Romagosa (2010) highlighted eight themes which included: 1) loss of control over person’s sense of unity between body, self-identity and the world, 2) increasing awareness for transformation, which includes the process of diagnosis, denial, and the wake up call, 3) the drive for integration in order to proactively cope each day with their illness, 4) An opportunity for learning ways to reinterpret the stressful events regarding
one’s values, beliefs, and goals, 5) listening to the body, 6) the learning process, 7) learning to appreciate life, and 8) life as a spiritual journey (Romagosa, 2010, p.89-97). The purpose of identifying the themes from this study is to highlight the similarities noticed and also to specify how the unique differences that AA women have can impact their ability to develop a disability identity significantly.

Of the eight themes listed above, evidence from the participants of this study show that there are many similarities. For instance, this current study highlighted denial/avoidance of symptoms, self-diagnosis and treatment, vulnerability/feelings-emotional displacement, role of faith/religion, and use of humor. These specific themes are found to correspond with the findings of the 2010 study especially when considering the loss of control and denial that women face. Additionally, there where some areas of overlap in regards to hope/despair and role expectations. However, while these themes overlapped the specific experiences where noted to be influenced by unique challenges of intersectionality that AA women have faced for centuries (Wallace, 1978; Woods-Giscombe, 2010). These components of intersectionality are also directly related to the roles and responsibilities of SWS and make the consideration of differences that AA women pertinent when providing treatment.

Conclusion

For the African American women with Multiple Sclerosis, the superwoman, her kryptonite is stress. Unlike the fictional character, superman, the AA superwoman cannot pinpoint what causes stress This chapter has painted a vivid picture of what the life of an
African American woman with MS looks like. The last and final chapter will discuss the limitations and recommendations about the findings presented in the study.
Chapter Six: Discussion and Recommendations

Using a qualitative form of inquiry from a social constructivist worldview (Creswell, 2009), this investigation was designed to appraise the real-life experiences of African American (AA) women diagnosed with Multiple Sclerosis (MS) and the unique daily happenstances that challenge their acuity to establish a disability identity (DI) (Dunn & Barcaw, 2013; Wehmeyer, 2013 & Bogart, 2014) while simultaneously maintaining the strenuous demands of the superwoman schema (SWS) (Woods-Giscombe, 2010). The current study collected thick rich descriptions related to the experiences of the eight research participants through interviews and observations. The major goal of the study was to understand if AA women with MS have a unique experience and contribute multicultural specific evidence to literature on coping and adjustment.

This research investigation addressed two major assumptions. The first assumption addressed in this study was whether African American women actually associate with the SWS and its historical principles of caring for others (Woods-Giscombe, 2010). Evidence through participant contacts prove that AA women do associate with the characteristic of SWS as proposed by Woods-Giscombé (2010), which include: 1) obligation to manifest strength, 2) obligation to suppress emotions, 3) resistance to being vulnerable or dependent, 4) determination to succeed, despite limited resources, and 5) obligation to help others. The second assumption explored focused on whether disability identity development is hindered by obligations of SWS. This second assumption of whether the roles and responsibilities of SWS that AA women with MS
face hinders their ability to develop a disability identity was also confirmed. Through personal accounts of the participants it was observed that some of the women felt that accepting the diagnoses of MS was a weakness or a sign of disbelief in faith and God.

This research investigation also answered three central research questions, including: 1) How do African American women associate with the superwoman schema?, 2) What is the essence of the lived experience for African American women with MS?, and 3) What challenges do African American women with MS experience in regards to maintaining role obligations of SWS and the development of a disability identity? The final chapter of this phenomenological study will describe what lessons were learned through the investigation and include: 1) implications for policy and practices on healthcare educators, 2) implications for healthcare providers, 3) recommendations for positive health care promotion of African American women with MS, and 4) limitations and recommendations for future research.

**Implications for Policy and Practices of Health Care Providers**

New trends of prevalence suggest that African American women are more likely to have more aggressive forms of the disease (Kaufman, Johnson, Moyer, Bivens, & Norton, 2003) and a higher risk of being diagnosed over any other race and gender (Langer-Gould, et.al., 2013). Bases on the proposed increase in diagnoses prevalence among African American women with Multiple Sclerosis (MS), this research was completed to contribute to the body of knowledge information that will assist African American women with the process of psychological adjustment and disability identity development. In accordance with the information obtained from the research interviews,
this section describes implications for policy and practices of health care providers. The implications proposed in this chapter can be relevant for Medical Physicians, Nurses, Neurologist, Physical Therapists, Occupational Therapist, Speech Pathologists, and most importantly Mental Health practitioners and Rehabilitation Counselors. This discussion of implications is divided into two sections: 1) exploration of multicultural considerations and 2) an examination of the specific recommendations provided by the eight research participants who serve as expert eye-witnesses.

**Multicultural considerations.** Based on the feedback from the eight participants many of them described that no additional information was provided in regards to what an MS diagnosis means after they were diagnosed. For most of the participants they were left in the dark to research what MS is and looks like independently. Based on the feedback of the participants that is a very scary expectation. One participant in particular stated that she was given a piece of paper at the time of diagnosis as a method to educate her on what the disease involves. This research suggests that this method is not best-practice for African American women, for several reasons, including lower educational abilities making the information found in the MS educational pamphlet potentially foreign and ambiguous. A more useful best-practice would be to explain what MS is and begin immediate plans to provide support through medical and social networks. The development of social supports should also consider diversity and the dynamics of group development. The women of the study suggested that they find it easier to relate to other black women with MS, as opposed to other people who they may not be comfortable
with. Sybil’s explanation of her group experience with other racial and gender groups from outside of her community who made the experience less effective.

Furthermore, healthcare providers and healthcare educators are encouraged to consider establishing the discussion of the adjustment process during the initial diagnosis period for African American women. This conversation about the adjustment to disability process is suggested to help women recognize that the process of adjustment, regardless of whether disability identity development is accepted or not, is an imperative component of positive health behaviors (Stuifberger, 1995). As mentioned above this type of awareness of self-care is suggested to ultimately benefit the care and performance of this particular group of women.

Another implication for healthcare providers and health care educators is to refrain from the use of “negative talk” when describing the disease to AA women (Sood, 2015). Being abrupt and direct with a medical prognosis can be beneficial; however, it can also be detrimental to the health and well-being of an African American woman who has just been diagnosed with a debilitating condition. Additionally, the abruptness of such a diagnosis alone can cause crisis for African American women and the use of words and phrases from a medical professional like ‘you will not be able to’ or ‘your limitations will not allow’ her to do something. This can have the potential to only make matters worse for African American women. Based on the information collected in this study, this type of negative talk seems to have a specific influence on AA women with lower educational backgrounds and socioeconomic statuses (SES). Practitioners should also consider SES were rendering a diagnoses.
Participant Recommendations for Healthcare Provider and Educators

Each of the eight research participants were asked, what advice they would give to a healthcare educator or provider when working with an AA woman with MS. Each of the participants provided valuable suggestions that could potentially be beneficial to the service provision and ultimately the health transition for this particular group of women.

Fancy suggested that healthcare professionals such as doctors be straightforward, yet supportive.

I really don’t know because um my doctor I love her to death. She is straight forward she is not going to let you get down she like yea, she was like yeah you have lesions and it looks like a Christmas tree but you gonna get through this. We gotta rearrange somethings but you are going to get through. Just continue to encourage them don’t be so said like oh… well you have all these lesions, you probably won’t be able to do this don’t, you know…just keep them encouraged and let them know what can happen but enforce positive and that you can do it. With the right attitude with the right help, will and drive you can do it (Fancy, personal communication via Skype. August 29, 2015).

Sybil suggested that more research be conducted to find a cure for the disease. She also talked about the importance of multiculturalism and diversity being infused into the medical treatment process. She believed that her experience was that the services did not really address her needs as a patient and were more catered to white women and men with MS.
No, I didn’t, I didn’t think none of that related to black people. Because I was thinking like… really? Cause like I said, there was one guy there, he had it since nineteen eighty-eight or something like that, he was diagnosed (Sybil. personal communication via Skype. August 29, 2015).

Meredith suggested that medical professionals be honest and open about all diseases, conditions, and disorders that AA women are at risk for. She describes that these conversations are needed in general.

Tell them, um just maybe think about like health overall like at risk for diabetes, family history about that so, umm take it as an opportunity to talk about health and how I was able to catch it early, I think so, I just …and just make sure health a priority now because black women try not., I mean not try not to but just be too busy and don’t really put their health first and so that would be my umm suggestion…Like I work-out more, I eat healthy, it’s just the emotional part , I don’t really have time for that (Meredith, personal communication via FaceTime. August 30, 2015).

Autumn’s suggestion for health care educators and health care providers was to speak in lay terms or lay language. She also suggested that connections to a social support system of other AA women with MS should be considered a component of first response.

Um, don’t think clinical. You know, sometimes you got to break things, and that's the thing I appreciated the most about my doctor. He gave me the clinical and he said okay, here's these two. And he gave me all and then he said; okay, now let’s
sit here and talk. And we had a conversation about what was really going on, what I can expect and all of that. He sat next to me. He didn’t stand in front of me and you know, kind of almost preach to me. We had a conversation and I think that that's important (Autumn. personal communication via Google Hangouts. August 31, 2015).

Akeelah suggested that health care providers and educators listen to the patients’ needs and speak to women in a manner of respect and not just cite a textbook like they are reporting scientific findings.

My physician assistant I just felt like he didn’t listen to me, he was very kinda textbook, he, your telling me you have this symptoms so I am going to give you this because this is what is supposed to happen. So my doctor, and this is what I would suggest for doctors that are treating African American women with MS is to really listen to what they are saying and take into account the research (Akeelah. personal communication via FaceTime, September 4, 2015).

Zoe is hopeful that there is a cure out there. Her major suggestion was for medical professionals and educator to hurry up and find the cure. Even if it means that they go into a jungle and find the perfect plant.

There is a cure out there. Yall need to go to a rain forest or something….no I am not laughing, im dead serious go to the rain forest and get one of these plants. Yea… mix it up there go your cure right there. All these aint no cure then came up. No… something aint adding up (Zoe. Personal communication via Skype. September 6, 2015).
Lena was very thorough in discussing her suggestions for health care professionals and healthcare educators.

I think the health care system has to change all together, but that is a whole another conversation. I think that encouraging the person to write things down, so that when they come to the appointment, they can be specific about it. I think that if they um, if they figure out a way to listen to what is actually being said, rather than already having an answer ready before the person can finish their statement. So, I laugh...I laugh about, and I know you've done it too, you know the peg test (Lena. personal communication via Skype. September 6, 2015).

Lena also explained that cultural competence is mandatory.

To recognize that you don’t have it all, you won’t have it all, you can’t have it all. You can have as much as you can tolerate, but that's really important to use that for the health professional to recognize that there is a whole cultural issue here that's being dealt with (Lena. personal communication via Skype. September 6, 2015).

**Recommendation for the Positive Health Promotion of AA Women with MS**

This section provides suggestions and recommendations for positive health promotion behaviors of African American women with MS. The first recommendation that the participant experts made for women newly diagnosed, is to get the facts about the disease even if the medical professional fails to fully explain the condition. Information can be obtained from the organizations such as the National Multiple Sclerosis Society (http://www.nationalmssociety.org/Resources-Support/Resources-for-Specific-
Populations/African-American-Resources), Multiple Sclerosis Association of American (http://www.mymsaa.org), or the Multiple Sclerosis Foundation (http://www.msfocus.org). In addition to these organizations, AA women with MS are encouraged to join local support or even develop supports locally that might cater to the needs of AA women with MS.

The eight participants were asked to respond to the following question during the research interviews, “What advice would you give to an AA women who has just found out that she has been diagnosed with MS? The following section goes into detail about the participants’ recommendations.

It’s not the end… is not the end of the world. It’s gone be hard but you can do it. Every day is a struggle, but you just have to push through it. Don’t give up. You have to have a positive attitude. Positive support system and you can’t, if you cry you can’t stay there. If you have a pity party you can’t stay there. While it’s not, it’s you can’t have a pity party. Because it can take you out literally. Fin you somebody who has MS and talk to them often. Any time you need too because it makes you feel better it makes you feel like oh I’m not crazy. There is somebody else going through this too, or what have you, but you gotta have a positive support system. Anything that is …it gotta go and learn how to say no and mean it and don’t feel bad about it…learn how to say no and mean it and don’t feel bad about it (Fancy. personal communication via Skype. August 29, 2015).

Sybil suggested:
My advice when that first find out, I mean, to let them know first off, it’s not the end of the world and it’s not dead. You know, you're not I mean; you're not going to die. I mean when they say there's no years, you know, that don’t mean you going to die. You know what I’m saying? You can live with anything, you know uh...and you know, it depends on how you handle it and how you...how you can uh...how you put it, how you handle it and how...how would i say it uh...how you would handle it because mmm...how would you handle it because some people think when someone tells them something, oh my god, I’m going to die, oh my god, you know, they can take it, don’t take it. Get all the information and knowledge you can about it you know, and just be determine, just be determine, don’t give up, fight. Be the best warrior you can. I tell them, be the best warrior you can. Get everything you can. You know, if they push on you, you got to make sure you take your medicine. You know what I’m saying. Make sure if you can exercise, exercise…You can eat right; you know what I’m saying. Do everything you can. If you are able still walk, you able still move your muscles, if you still able to walk, use them. USE THEM! Just be the best warrior you can. Don’t give up (Sybil. personal communication via Skype. August 29, 2015).

Meredith suggests was simply to understand MS.

I guess cliché make sure you talk to your doctor about any problems you have, have somebody you can talk to about it, look it up. I mean I’m in medical school so I kinda understand the disease more than maybe a non-medical person would know about, but I would still tell them to look it up so you understand everything
about it. I guess that’s it (Meredith, personal communication via FaceTime. August 30, 2015).

Autumn suggested that AA women stay strong and resilient.

You will be okay, you will. Once you decide that you are going to be okay, you will be okay. But, it is instantly a decision you have to make. And do not let me speak, you know the word I hated the most was "awww". Um, the biggest things is you will be your version of okay. And you need to accept that. Because at the end of the day, all the jobs and careers and all that kind of stuff its, you’re not happy and you’re not living the best life you can today, none of that stuff matters at all (Autumn. personal communication via Google Hangouts. August 31, 2015).

Akeelah recommends that AA women with MS be emotionally aware of their feelings and try to respond appropriately. She stated, “Um, I guess that um, you have…so um, the whole letting the feelings run its course” (Akeelah. personal communication via FaceTime, September 4, 2015).

Zoe was an encourager and suggested that other women try to stay strong and don’t let go of their passions and goals.

Girl stay stronf and don’t let nobody tell you… they always be like that’s a white person disease which they are starting to think a lot of blacks starting to come up with it now and don’t listen to what anyone tells you. Stay focused and go for the goals that you are trying yo accomplish, or have accomplished and keep going (Zoe. Personal communication via Skype. September 6, 2015).
Lena suggested that AA women do several things including self-advocating for the right neurologist.

…first, to find a Neurologist who will listen to you… the second one is, figure out what works for you. Um, listen to your body. Keep and journal or a diary or you know, on the days that you don’t feel well, write it down. What is it about you that don’t feel well? You know, is it just overall fatigue, is it that…um…And when you think about that okay, look at the scene, behavior and the consequences. So, what happen before you didn’t feel well and what was the consequence of you not feeling well… Um the third thing is, I believe in Talk Therapy. I think you need to find a group, um if you are group person. Some people are not group people. Um, online, if you can handle the stuff that is online. I can’t, so I, even though I am on a couple of listservs, I don’t look at them anymore because they were becoming just really different (Lena. personal communication via Skype. September 6, 2015).

Finally, Jasmine suggests and recommends that AA women with MS pray about it.

…first thing is just pray about it you. Pray for your strengthen you know. And don’t feel like life is over cause it’s not. I feel like…Another set of advice I would give is to just make sure you have a good support system because it is all about the support. And love from your family or whoever your support system is and have somebody to talk to. And everybody is not going to be able to understand what you are going through. And that’s okay. You know as long as you can understand it and you can deal with it cause it is all about managing yourself. And
understanding when you are too tired to move forward because it’s a lot of time when you are out with your friends and they can continue but you can’t you have to know your own limitations. And do only what you can do. And the main thing is to pray. Prayer is powerful and I truly believe that (Jasmine. personal communication via Skype. September 7, 2015).

**Limitations and Recommendations for Future Research**

This final section will explore the limitations and recommendations for future research in the area of African American women with MS. Beginning with the limitations of the study and recommendations on how to strengthen the research.

**Limitations**

This study like all other studies has limitations that if improved and replicated in the future can help to build upon the necessity to consider such research. There are three limitations that will be discussed in this section, these include: 1) the length of time from the first to the second interview, 2) use of video conferencing rather than face-to-face interview, and 3) failures to hear from two of the participants to participate in the second follow-up interview.

The first limitation covers the fact that the length of time between the first and second interview was not predetermined. After the participants complete the first interview, the researcher informed them that they would be contacted to set up a time to hold the second round of interviews. The suggestions for future research is to have the participants select their times for the first and second interview at the beginning of the interview process. The initial reason for telling the participants that they would be
contacted to select a second interview was so that the transitions could be completed. However, by waiting many of the participants were difficult to get in contact with.

The second limitation was the use of video conferencing rather than face-to-face interviews to conduct the research. The original reason for choosing this format was to open up the selection of participant to more than just northern states. However, for participants in more rural areas the internet connection was poor causing delays and a frequency in the number of times the calls were disconnected. This is considered a limitation because the participants might have been frustrated or lost their train of thought when they were disrupted by the poor Internet connection.

The third limitation was a failure to hear from two of the eight participants to complete the second round of follow-up questions. During the second interview there were three important questions that the participants were asked to answer. These two participants, Fancy and Meredith did not have a chance to explain and respond. In the next section there will be a discussion of the two major areas of recommendations for future research.

**Recommendations**

There two major areas that can be reviewed in future investigations in order to add to the conversation of what this particular group needs in order to have better psychological adjustment to disability. The first recommendation for future research is to focus specifically on the socioeconomic status, education and resilience of AA women with MS to determine whether their ability to manage multiple roles is connected to these variables. The second recommendation for future research is to replicate this
investigation with a specific focus on the lived experiences of AA women who have been
diagnosed with the more progressive types of MS, including, secondary-progressive
(SPMS), primary-progressive (PPMS) and progressive-relapsing (PRMS). This current
study focused on the lived experiences of AA women with MS, however all of the
participants has been diagnosed with relapsing-remitting (RRMS).

Conclusion

Using a qualitative form of inquiry from a social constructivist worldview
(Creswell, 2009), this investigation was designed to appraise the real-life experiences of
eight (8) African American (AA) women diagnosed with Multiple Sclerosis (MS) and the
unique daily happenstances that challenge their acuity to establish a disability identity
(DI) (Dunn & Barcaw, 2013; Wehmeyer, 2013 & Bogart, 2014) while simultaneously
maintaining the strenuous demands of the superwoman schema (SWS) (Woods-
Giscombe, 2010). This study consisted of three central research questions, which
included: 1) How do African American women associate with the Superwoman Schema?,
2) What is the essence of the lived experience for African American women with MS?,
and 3) What challenges do African American women with MS experience in regards to
maintaining role obligations of SWS and the development of a disability identity?

Based on the investigation it has been proven that AA women with MS do find it
difficult to associate with disability identity after being diagnosed. Furthermore, this
research proved that the essence of the lived experiences for African American women
with MS is unique and consistent with the principle of the superwoman schema (SWS).
Finally, this research explained that the challenges that AA women with MS face
regarding the ability to maintain role obligations of SWS and the development of disability identity are unique and require special attention from healthcare providers and educators.
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doi:10.1212/WNL.0b013e31829bfe2f


Lena. personal communication via Skype. September 6, 2015.


Meredith, personal communication via FaceTime. August 30, 2015.


Appendix A: IRB Approval

The following research study has been reviewed and approved by the Institutional Review Board at Ohio University for the period listed below. This review was conducted through an expedited review procedure as defined in the federal regulations as Category(-ies):

7

Project Title: A Phenomenological Study of African American Women with Multiple Sclerosis: Disability Identity and the Superwoman Schema

Primary Investigator: Jessica Henry
Co-Investigator(s):

Faculty Advisor: Mona Robinson
Department: Counselor Education and Supervision

Approval Date: 8-11-15
Expiration Date: 8-10-16

This approval is valid until the expiration date listed above. If you wish to continue beyond the expiration date, you must submit a periodic review application and obtain approval prior to continuation.

The approval remains in effect provided the study is conducted exactly as described in your approved application. Any additions or modifications to the project must be reviewed and approved by the IRB (as an amendment) prior to implementation.

IRB approval does not supersede other regulatory requirements, such as HIPAA, FERPA, PPRA, etc.
Adverse events/unanticipated problems must be reported to the IRB promptly.
Appendix B: Approved Informed Consent

Ohio University Adult Consent Form with Signature

Title of Research: A Phenomenology Study of African American Women with Multiple Sclerosis: Disability Identity and the Superwoman Schema

Researcher(s): Jessica S. Henry, Ohio University

You are being asked to participate in this research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

Explanation of Study

If you agree to participate, you will be asked to complete a total of two interviews. The first interview will contain questions specific to your personal experience as an African American woman who has been diagnosed with Multiple Sclerosis. A second interview will allow for follow-up regarding responses from the first interview. The second interview will occur a month after the first interview. Each interview will be audio recorded. The participants’ time in the study will not exceed 3 hours in two interviews spread across, at most, two months.

Below please select the box that indicates whether you agree or disagree to be audio recorded during each of the two interviews.

☐ Yes, I agree to be audio recorded during the interviews.
☐ No, I do not agree to be audio recorded during the interviews.

Risks and Discomforts
You will be asked to describe your experiences regarding your diagnoses of MS. This might be distressing for you. If this happens or you wish to discontinue your participation for any reason, you may do so at anytime.

Benefits
The participants will not gain any specific individual benefits by participating in the study. However, this study will serve as an opportunity to have African American women voice the specific experiences of disease adjustment and coping as well as aid in the development of new interventions that will assist AA women with MS.
Confidentiality and Records
Audio recordings will be transcribed by Jessica Henry and any names mentioned will be changed (i.e., pseudo names will be used) Note: The recordings of each interview along with the master list will be destroyed no later than September 2016.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:
* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU;

Compensation
At the end of your participation you will receive a $20 Visa Gift Card compensation for your participation.

Contact Information
If you have any questions regarding this study, please contact the investigator Jessica Henry, jh112603@ohio.edu, 216-773-0356 or the advisor Dr. Mona Robinson, robinsoh@ohio.edu.

If you have any questions regarding your rights as a research participant, please contact Dr. Chris Hayhow, Director of Research Compliance, Ohio University, (740)593-0664 or hayhow@ohio.edu.

By signing below, you are agreeing that:
• you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered;
• you have been informed of potential risks and they have been explained to your satisfaction;
• you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study;
• you are 18 years of age or older;
• your participation in this research is completely voluntary;
• you may leave the study at any time; if you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

PRINT NAME: ______________________ DATE: ____________
SIGN NAME HERE: ______________________

Version Date: 07/29/15
Appendix C: Interview Questions

Time of Interview: 
Place of Interview: 
Date: 
Interviewee: 
Interviewer: 

Interview Procedure:
You are being asked to participate in a study investigation African American women with Multiple Sclerosis. The purpose of the study is to investigate how African American women develop a disability identity while maintaining the strenuous demands of the superwoman schema. During this interview you will be asked to respond to several open-ended questions. You may choose not to answer any or all of the questions. The procedure will involve taping the interview, and the tape of the interview will be transcribed verbatim. Your results will be confidential and your name will not be used to identify the interview.

1. Basic Demographic Information
   a. What is your first name? 
   b. How old are you now? 
      i. How old were you at the time of your diagnoses with MS? 
   c. Where are you from? 
      i. Where were you born? 
      ii. Where did you grow up? 
   d. What type of Multiple Sclerosis do you have? 
   e. When did you notice symptoms related to MS? 

2. Interview Questions
   a. How would you describe your current roles and responsibilities? 
   b. Thinking about these roles and responsibilities, how would you describe your current level of stress, if any, related to managing these roles? 
   c. How would you describe your ability to cope with stress prior to being diagnosed with MS? 
   d. How do you describe your ability to cope with stress today? 
   e. How would you describe your identity? 
   f. What role, if any, does identity play in coping with stress? 
   g. How did you learn about managing multiple roles? 
      i. What are the most important things in your life today? 
   h. How would you describe your overall experience after being diagnosed with MS? 
   i. How would you describe your experience particularly with role management after being diagnosed with MS? 
   j. What advice would you give to someone who has just discovered that she has MS?
k. What advice would you give to health educators and other health professionals who work with people who have MS?

**Informed Consent:**
Please sign the informed consent form signaling your willingness to participate.

**Closing:**
Thank you for participating in this interview. I appreciate you taking the time to participate in this research investigation. I may contact you in the future for the purpose of follow up questions. All the information collected will be kept confidential for your safety. If you have any questions, please feel free to contact me by telephone at 216-773-0356.
Appendix D: Recruitment Flyer

Are you an African American Woman with Multiple Sclerosis (MS)?

If so, I would like to talk with you!

Commitment to participate in this research investigation will include two interviews. Each interview will last no more than one hour. Each interview will take place either face-to-face or via electronic video resources (e.g. FaceTime, Skype).

Participants will receive ONE $20 Visa Gift Card.

You can participate in this research study if you:
✓ Identify as African American
✓ Identify as a female
✓ Have a medical diagnosis of Multiple Sclerosis

For questions or more info please contact
Jessica S. Henry:
(216) 773-0356
jh112603@ohio.edu

Ohio University