

## **ABSTRACT**

MCLAUGHLIN, WHITNEY GRACE. The Effects of Customized Psychoeducation-Based Neurocounseling Interventions on the Coping Flexibility of African American Women with Multiple Sclerosis (Under the direction of Stanley B. Baker).

Although there is substantive research on the coping styles and attitudes of African American women, there is limited research on their coping efforts and the strategies they employ within the context of chronic disease and disability. Most of the stress and coping literature on African American women focuses on daily stress (e.g., role strain), work-related stress, and stress from the various forms of oppression they experience despite the disproportionate burden of chronic disease and disability among Black women. The purpose of the present study was to evaluate the effectiveness of a Brain-Based Education and Wellness (BE WELL) intervention with African American women with Multiple Sclerosis (MS). The conceptual frameworks for the BE WELL program were the Transactional Theory of Stress and Coping (TTSC), The Indivisible Self Model of Wellness (IS-Wel Model), and the Healthy Mind Platter (HMP). Additionally, the Multicultural Social Justice Counseling Competencies (MSJCC) and the Chronic Care Model (CCM) were employed as overarching frameworks for the individualized counseling interventions. The participants were four African American women with MS ages 34 to 60 who had been diagnosed with MS for several years, self-reported dissatisfaction with their coping efforts, and expressed interest in receiving brain-health information. The participants lived in various communities in a southeastern county in a southern state. The identity intersections of race, gender, and disability were part of the present study's inclusion criteria since health disparities are disproportionately experienced by socially marginalized populations. Additionally, despite the high incidence of MS among African American women, this sub-population among people with MS (PwMS) are underserved and under researched although they

experience a more aggressive disease course compared to other racial and ethnic groups. The present study was guided by four research questions pertaining to (a) the intervention's effectiveness in increasing several coping measures, that is, evaluation coping, adaptive coping, and total coping flexibility; and (b) the intervention's overall effectiveness as rated by each participant. The three effectiveness research questions were analyzed using an *N-of-1/ A-B-A* single-case research design (SCRD) over the course of 12-weeks. During the first two weeks, the baseline phase (A1), data were collected on each participant's coping process using the Coping Flexibility Scale (CFS). Next, the treatment phase (B) was implemented. In this phase, the counselor/investigator meet with four participants individually for eight weeks and facilitated customized interventions that lasted approximately an hour long per session. During the treatment phase, participants continued to complete the CFS twice a week. After those eight weeks, the treatment was removed, and participants continued to complete the assessment twice a week in the withdrawal phase (A2). The dependent variables that were captured from the CFS results were analyzed via an R software package, *SSD for R*. The data were examined using both visual and statistical analyses. This involved using descriptive statistics including measures of central tendency and variability, autocorrelations, and regression analysis to look for trends. The G index was used to calculate effect sizes and the non-parametric test Conservative Dual-Criteria (CDC) was used as a robust statistical analysis tool to compare the phases of each coping measure. Based on the findings, the customized BE WELL intervention was found most effective for increasing evaluation coping and overall coping flexibility across three participants and moderately effective for increasing adaptive coping. The remaining research question addressed social validity and the Attitudes Toward Treatment (ATT) was used to assess participant ratings. Results from the ATT validated the findings from the visual and quantitative

analysis as all participants' ratings unveiled that each participant experienced positive treatment effects from the BE WELL program. Furthermore, the treatment was replicated four times to enhance generalization of the findings further validating the intervention's effect. The findings suggest that customized psychoeducation-based neurocounseling interventions like those in the BE WELL program provide a promising approach to brain-based wellness that warrants further investigation.

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The Effects of Customized Psychoeducation-Based Neurocounseling Interventions on the  
Coping Flexibility of African American Women with Multiple Sclerosis

by  
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## **DEDICATION**

First and foremost, I must thank my Lord and Savior, Jesus Christ. Without Him, I can do nothing. I dedicate this dissertation to my village of support and anyone that has shown me genuine love throughout this journey. I would also like to dedicate this piece of work to those living with multiple sclerosis - your strength is unmatched.

## **BIOGRAPHY**

Whitney Grace McLaughlin is a native of North Carolina. She is a Board-Certified licensed clinical mental health counselor. She earned her Bachelor of Arts degree in Sociology with a minor in creative writing from the University of North Carolina at Chapel Hill. She also earned her Master of Arts degree in Clinical Mental Health Counseling from Wake Forest University. She is the 2019 recipient of the Don C. Locke Multicultural and Social Justice Award.

Whitney has over five years of counseling experience serving children and adults, as well as couples and families, in various settings including education, residential treatment, healthcare, and private practice. Whitney has worked in the higher education setting for over 10 years and has professional experiences in the areas of college access, enrollment management, and career planning. Within these areas, she has worked as a college advisor, financial aid specialist/higher education professional, and career coach serving thousands of students and families with their post-secondary goals and aspirations. As a clinical mental health counselor, she has had professional experiences in outpatient settings and residential treatment. She has worked as a residential counselor with foster care youth living with complex trauma and as a psychotherapist in private practice helping clients with a myriad of behavioral health concerns. Throughout her doctoral program, she has served as the Graduate Assistant in the Poole College of Management Career Center where she provides career counseling, resources and support to help undergraduate students with their career-related needs. She has also been a Chapter Resident Director with the Fraternity and Sorority Life office where she has supervised three sorority houses with over 150 residents.

In 2008, Whitney discovered that a family member had been diagnosed with multiple sclerosis (MS) and in 2017, a second family member was diagnosed. Her desire to learn more about this chronic disease and support her loved ones led her to become a Global MS Ambassador with the National Multiple Sclerosis Society. In this role, she has been an advocate for the MS community to raise awareness, support care partners, and work with those living with MS to overcome barriers related to their social, emotional, and career development needs. In addition to being an MS Ambassador, Whitney has been a support group facilitator for family members of people with MS. In 2018, she delivered the keynote address for the annual African American MS Conference where she highlighted mood changes in MS.

Whitney has been involved in various professional organizations which have provided her the opportunity to lead and serve alongside her colleagues. She is a member of the American Counseling Association, as well as the North Carolina Counseling Association (NCCA) where she previously served on the Law and Ethics Subcommittee and as Secretary of the North Carolina Association of Multicultural Counseling and Development, a division of NCCA. She is a member of the Nu Sigma Chi Chapter of Chi Sigma Iota (CSI) International Counseling Honor Society and past MAC Online Representative of the WFU Pi Alpha Chapter of CSI. Whitney is a published scholar and her research interests include holistic wellness, integrating neuroscience into counseling practice (neurocounseling), evaluating coping processes, integrated care, and racial disparities in mental health.

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## CHAPTER 1: INTRODUCTION

According to the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP, 2018a), over half (approximately 60%, or 177 million) of all adults in the U.S. have a chronic disease and 4 out of 10 have two or more. The NCCDPHP (2018b) defines *chronic diseases* broadly as “conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both” (para. 1). For African American (Black) women, the prevalence of chronic diseases is very common since they experience disproportionately high rates of “high profile” chronic health conditions such as hypertension, cardiovascular disease, and diabetes (Centers for Disease Control and Prevention [CDC], 2017; Thorpe et al., 2016). However, relatively recent research revealed that Black women are also disproportionately affected by chronic diseases that lead to acquired disabilities such as multiple sclerosis (MS) (Langer-Gould et al., 2013), a chronic neurological disease in which the immune system attacks the central nervous system and causes a host of symptoms such as numbness, fatigue, walking difficulties, cognitive issues, and vision problems (Kister et al., 2013; National Multiple Sclerosis Society [NMSS]; n.d.-a). MS affects individuals in unpredictable ways and profoundly disrupts multiple facets of overall health and well-being (Embrey, 2014).

Unfortunately, African American women with MS (AAWwMS) has become a silent epidemic, and research involving their coping experiences is lacking. In order to cope successfully with this progressive disease, AAWwMS must develop coping strategies to manage their daily lives and protect their psychological well-being since emotional distress and mood disturbances are often associated with MS (Budgar, 2017; NMSS, n.d.-b). The multiple dimensions of identity of AAWwMS also indicate that they must not only cope with the stress of having a chronic neurological disease but also with the various forms of oppression (e.g., sexism,

racism, gendered racism, microaggressions) they experience. Therefore, AAWwMS may benefit from coping skills training focused on helping them manage various stressors and better understand how their coping behavior affects their psychosocial functioning and their overall well-being. They may also benefit from interventions that incorporate brain-based psychoeducation into coping skills training because it can further promote brain health which is essential for individuals living with a degenerative neurological disorder like MS (Fuller, et al., 2012; Miller, 2016). These coping strategies and behaviors can be taught by skilled mental health professionals who specifically understand the various needs and challenges of individuals living with a chronic disease. Therefore, more research focused on improving the coping process and rehabilitative needs of AAWwMS is needed.

Coping is the process of adaptation to stressful situations (Lazarus & Folkman, 1984). Coping with the physical, emotional, and social stressors inherent to many chronic health conditions including MS requires the ability to accurately assess stressful situations, develop a repertoire of coping strategies, and possess the skills to moderate and modify coping efforts in real time (McCabe et al., 2004). This is vital because one must be willing to abandon a coping strategy that produces an undesirable outcome for one that produces a favorable one according to the nature of each stressful situation. This process is called *coping flexibility* and it involves perceiving that a coping strategy is ineffective and ceasing to use that method in order to produce and implement an alternative coping strategy (Kato, 2012). Essentially, coping flexibility refers to one's ability to effectively modify coping behaviors based upon situational demands and coping resources that are accessible and available.

In seminal works on the concept of coping (e.g., Lazarus, 1966; Lazarus & Folkman, 1984; Pearlin & Schooler, 1978), the notion of flexibility promotes psychological adjustment to

various stressful life changes as well as perceptions of coping self-efficacy. This process is crucial for everyone but particularly for individuals with a chronic disease because living with a compromised state of health is likely to increase stress levels, and, in the case of MS, stress has been linked to flare-ups or exacerbations of symptoms and emotional distress (Dennison et al., 2009; Karagkouni et al., 2013; Mohr et al., 2004). Thus, providing coping skills training that emphasizes flexibility in strategy selection and strategy effectiveness for AAWwMS is necessary and should be a priority to providers and organizations working with the MS population.

Appropriate assistance, education, representation, and support are essential to providing culturally competent quality care, especially for people of color (POC) with chronic health conditions (Betancourt et al., 2003). In the case of MS, the Model of Comprehensive Care is the recommended treatment approach that includes (a) modifying the disease course, (b) treating exacerbations or attacks, (c) managing symptoms, (d) promoting function through rehabilitation, and (e) providing emotional support (NMSS, n.d.-c). This approach involves the expertise of many different health care professionals and clinicians such as neurologists, physical therapists, primary care physicians, neuropsychologists, and mental health professionals. Thus, clinical mental health counselors (the term counselors will be used moving forward) can play a pivotal role in helping to improve the lives of people with MS (PwMS). Working alongside providers to help look beyond symptoms and into cultural and systemic factors that impact coping behaviors of individuals living with chronic diseases is much needed and deserves more scholarly attention.

Fortunately, counselors can help individuals with a chronic disease (e.g., AAWwMS) acquire new coping resources and learn strategies to improve their psychosocial functioning while considering cultural, environmental, and systemic factors. This is because counselors are guided by the Multicultural Social Justice Counseling Competencies (MSJCC) (Ratts et al.,

2016) a framework for inclusive practice that was endorsed by the American Counseling Association (ACA). The MSJCC incorporate a socioecological model to help provide counselors with a multilevel framework for individual counseling and social justice advocacy. These competencies were developed due to “the need to take a more contextual approach to working with clients and communities, recognizing that individuals are part of a larger ecosystem...understanding these contexts is becoming increasingly important, especially for individuals from historically marginalized backgrounds.” (Ratts et al., 2016, p. 33). Using the MSJCC, counselors can be advocates for AAWwMS at the intrapersonal, interpersonal, institutional, and international level. For instance, they can provide direct care, help health care providers utilize a more culturally sensitive approach when working with this population, advocate for policies to help make mental health treatment more accessible and affordable for the underserved, and help provide best practices for working with individuals living with MS on an international scale. Furthermore, counselors are instrumental in helping individuals with their coping process because they utilize a wellness-focused and strengths-based approach. This has become the cornerstone of the profession (Erford, 2017; Nassar & Niles, 2018) because it emphasizes holism and the contextual factors that impact one’s mental and emotional health.

In the last decade, the counseling profession has also embraced the integration of neuroscience into counseling practice. Montes (2013) coined the term neurocounseling to describe this new counseling approach and respected scholars and practitioners in the field have championed this surge of interest. Neuroscience provides the information and tools that support the goal of counseling which is to empower people, especially those from diverse backgrounds, and to address systemic barriers that prevent optimal mental health and wellness (Field et al., 2017). There is a compelling link between the intersections of identity (e.g., race, gender,

socioeconomic status, acquired disability), mental health outcomes, and health disparities because of the biological mechanisms that are affected among those who are considered to be in the margins of society (Berger & Sarnyai, 2015; Pieterse et al., 2012). By incorporating brain-based knowledge into their practice, counselors can help clients learn a unique approach to wellness and explore new methods for adapting and regulating through life's difficulties.

Counselors have the unique opportunity to help AAWwMS explore the intersections of their identity (e.g., race, gender, and acquired disability) in relation to their coping efforts in the context of the various systems (e.g., family, culture, community, and health care) in which they interact. They can draw upon the MSJCC to help guide their practice and develop interventions that address the cultural and systemic factors impacting their behaviors and concerns. Lastly, they can integrate neuroeducation into their counseling approach to help these women learn more about the brain-body connection in order to achieve optimal health despite living with MS.

The need for coping flexibility interventions is great because using ineffective coping strategies to manage chronic diseases can have detrimental effects on psychological adjustment and overall quality of life (QoL) (Brajkovic et al., 2009; Goretti et al., 2010; Livneh, 2017; Megari, 2013). Furthermore, in the case of MS, ineffective coping strategies can lead to the worsening of symptoms and acquired disabilities due to its direct influence on nonadherence to treatment and recommendations from health care providers (Costello et al., 2008; Hundt et al., 2015). PwMS who use ineffective coping mechanisms are prone to more long-term emotional and psychological impairment than those that employ adaptive coping strategies (Arnett et al., 2002; Grech et al., 2018). Maladaptive (i.e., ineffective) coping strategies such as wishful thinking can lead to social, psychological, and emotional problems that can negatively affect an individual's overall functioning and relationships (Pakenham, 1999, 2006). Maladaptive coping

strategies have also been linked to more long-term mental health issues such as depression and anxiety while adaptive coping has been linked to optimism and improved resilience to stress (Gloria & Steinhardt, 2014). For individuals living with a chronic health condition, adaptive coping has also been associated with improved disease management and symptom reduction (Smyth et al., 1999). The difficulties and losses associated with having a chronic condition like MS reveal that more needs to be done to help these individuals adjust to changes they experience throughout the course of their disease in addition to managing their everyday lives.

Counselors can use multi-modal approaches to help create empirically-based customizable programs that enhance the coping process and improve adaptational outcomes. Additionally, counselors can integrate neuroscience into interventions to help individuals better understand their experience through brain-based psychoeducation (Field et al., 2017). Even though an individual's coping must be understood in the context of their unique characteristics and circumstances, the scholarly literature supporting individualized coping flexibility interventions is lacking. Moreover, the challenges, needs, and perspectives of Black women living with MS is limited and deserves more scholarly attention. Thus, a great need exists to help this underserved and under researched population with their coping efforts.

### **Statement of the Problem**

The National Multiple Sclerosis Society, the primary fundraising organization for MS research, emphasizes the importance of coping and stress management among those living with MS stating that “learning to eliminate unnecessary stressors – and manage the ones that are here to stay is essential...” (NMSS, n.d.-d). Their concerted efforts to provide education and support to those living with MS have led to several publications, initiatives, and wellness programs (e.g., Coping with Change) tailored to meet individual coping needs and the MS community at large.

As a result, the coping strategies and beliefs among PwMS have become a major focus in MS research. Over the last two decades, researchers have examined the coping behaviors and adaptational outcomes among PwMS. However, the concept of coping flexibility among this population has not received much scholarly attention, and the coping strategies and health outcomes of AAWwMS have been under researched despite the prevalence of MS among Black women.

Interestingly, the focus on women with MS is substantial since there are significant gender differences in diagnosis and clinical manifestation (Harbo et al., 2013; National Institute of Environmental Health Sciences [NIEHS], 2012). MS is at least two to three times more common in women than men (Compston & Coles, 2002; Wallin et al., 2012) and women are more likely to have greater instances of acquired disability and need more assistance with activities of daily living than are men with MS (Foley, 1998). However, only certain groups of women, specifically European and White American women, have received considerable attention in MS research. The coping strategies and rehabilitative needs of these women have dominated the MS literature. While AAWwMS have been included in a few studies on coping (e.g., Stuifbergen et al., 2003), they have been underrepresented and never the focus. Thus, interventions that enhance the coping flexibility of AAWwMS must be further examined.

The importance of adaptive (i.e., effective) coping strategies among PwMS has been well documented in the literature. However, a gap in the body of knowledge related to Black women living with this chronic disease still exists. Historically, their coping behaviors, emotional support needs, and mental health have not been a focus in the MS literature. This dearth of information was examined in a review by Khan et al. (2015) where they found that out of nearly 60,000 published articles on MS, only 113, or about 0.002%, focused on African Americans.

This finding is disturbing since MS tends to have a more aggressive disease course among African Americans compared to other racial/ethnic groups (Cree et al., 2004; Khan et al., 2015) and it is problematic since an epidemiological study found that African Americans had a 47% increased risk of MS compared to European Americans (Langer-Gould et al., 2013). This increased risk is due to the pronounced gender differences among African Americans as MS is three times more common in Black women than men (Langer-Gould et al., 2013).

Although MS is a growing epidemic among Black women, the symptoms they experience are just as varied and unpredictable as in the larger MS community. No two people have exactly the same symptoms, and each person's symptoms can change or fluctuate over time (NMSS, n.d.-a). The disease-related factors and psychosocial stressors that are associated with MS indicate that flexibility in coping strategies and resources is needed (Benz & Reynolds, 2011; José et al., 2016). Thus, customized interventions may help AAWwMS learn to utilize coping flexibility to manage the various changes that occur as a result of their symptoms and situational demands.

From a counselor's perspective, it is imperative to recognize that coping flexibility is an important aspect of mental health and overall health and well-being. When one does not have the psychological flexibility to change from using an ineffective coping strategy to a more effective one, they are at an increased risk of psychosocial and emotional problems (Gloria & Steinhardt, 2014; Roussi et al., 2007). For PwMS, there is a need to acquire greater knowledge and skills and gain access to adequate resources for better coping and adaptation (Nowaczyk & Cierpialkowska, 2016; Sanaeinasab et al., 2017). A more targeted approach to understanding the coping needs among people living with chronic diseases like MS could improve researchers' and counselors' awareness of the multifarious factors that influence one's coping process. These

efforts can translate into effective prevention strategies and interventions that reduce the effects of stress and improve the overall wellness of those living with a chronic health condition (Deter, 2012).

In literature reviews on coping interventions with PwMS, specific guidance on which interventions work based upon symptoms, individual characteristics, and contextual factors is lacking. This is because the research on coping strategies in MS is hampered by numerous methodological weaknesses and therefore, it is difficult to draw robust conclusions that lead to practice guidelines (Finalyson, 2013). In general, the aim of coping interventions is to (a) establish a therapeutic relationship, (b) facilitate awareness of feelings and perspectives, (c) identify stressful situations and demands, (d) define coping goals, and (e) modify coping behaviors to improve adaptational outcomes (Heim, 1995; Schwartz & Rogers, 1994; Martz & Livneh, 2007). Unfortunately, the research methods employed in reviewed studies (e.g., Heesen et al., 2012) were overwhelmingly experimental designs and did not consider individual nuances within the coping process. However, intervention programs that provide individual service delivery for people living with a chronic disease are needed and desired and may be more efficacious than group-based interventions (das Nair et al., 2016).

Improving the coping process of individuals with chronic diseases begins with a multimethod assessment including questionnaires to develop a symptom profile, pre- and post-self-report measures relevant to stress management and coping objectives, and self-monitoring throughout the intervention (José et al., 2016). Studies have shown that when people with unpredictable chronic diseases learn effective coping skills and their emotional health and attitude toward problem-solving improves (Calandri et al., 2017). Therefore, it is important for counselors and other mental health practitioners working with the MS population to develop

interventions based on individual coping needs and implement strategies that promote adaptive coping and improved health outcomes.

There are benefits to supporting coping flexibility interventions for PwMS, but the literature examining such interventions is lacking since most MS coping research is cross-sectional or longitudinal in nature. Although coping flexibility is an important aspect of psychosocial adaptation to living with a chronic disease, there has been far less research into its measurement compared to other related concepts, including psychological adjustment and stress management (Agland et al., 2018; Reynard et al., 2014; Sullivan et al., 2004). This lack of research is surprising considering the adverse effects of maladaptive coping, including increased emotional distress, poor symptom management, and low self-esteem (Costello et al., 2008; Mikula et al., 2018; Warren et al., 1991). Living with a chronic neurological condition like MS places a strain on individuals affected by the disease, their families, and on the health care system (Gooch et al., 2017). These factors combined help to support the need for individualized interventions focused on coping flexibility.

For people living with a neurological condition like MS, information and education related to brain function and anatomy is needed and desired in order for them to feel more informed about their health status. According to Salinas et al. (2016), African Americans and Hispanic/Latinx Americans with MS, are especially interested in topics related to progression, stages of the disease, and overall brain health in addition to information on symptoms and treatment. Most neuroeducation the MS population receives comes from health care providers (e.g., neurologists) and/or educational programming from organizations working with the MS population. However, many POC living with complex chronic diseases and physical disabilities may have difficulty accessing and utilizing specialty care and resources. This may be due in part

to socioeconomic barriers such as lack of or limited insurance, low income, and lower education levels and cultural factors such as religious beliefs and perceived discrimination within the health care system (Khan et al., 2015; Nelson, 2002). Additionally, in the context of the patient-provider relationship, physicians may exhibit racial bias and provide less patient-centered communication and informed-decision making with racial/ethnic minority utilizing health care services (Blair et al., 2014; Cooper et al., 2012; Hagiwara et al., 2017). These factors indicate that for POC with chronic diseases may not receive adequate information related to disease management and other health-related information (e.g., brain health). Incorporating neuroeducation into coping interventions may be beneficial for AAWwMS, and, furthermore, this empirical research will add to the dearth of brain-based counseling literature (Beeson & Field, 2017).

To address the need for coping flexibility interventions with AAWwMS, this present study will employ a single-case research design to examine the effects of an individualized intervention with AAWwMS. In addition, the study will provide strategies on how to integrate neuroscience into counseling practice by incorporating neuroeducation into the customized interventions. A major goal of the study was to offer information to professional counselors working with marginalized clients living with chronic health conditions to help them learn how to evaluate and modify their coping behaviors. Specifically, counselors can utilize information gleaned from this study to identify strategies to develop individualized interventions that address the two components of coping flexibility (e.g., evaluation and adaptive coping). Also, it is hoped that counselors will find the wellness framework and integration of neuroscientific concepts into the intervention useful and applicable to counseling practice.

## **Purpose of the Study**

Research has consistently shown that individuals who have difficulty coping with a chronic disease have poor problem-solving skills, low self-management, and a decreased overall QoL (Auduly et al., 2016; Calandri et al., 2017; Montel & Bungener, 2007). These individuals may benefit from a coping flexibility intervention rather than other means such as peer support (Schwartz, 1999). Therefore, the purpose of this study is to implement and examine the effects of customized neurocounseling interventions on the coping flexibility among AAWwMS. Given the lack of attention on Black women living with this complex neurological disease, a goal of the present study is to use this research to elucidate their coping needs and encourage AAWwMS to be both proactive and self-sufficient in monitoring and modifying their coping efforts. Furthermore, an additional goal is to provide effective brain-based interventions that may be useful for people with stress-related chronic diseases like MS to enhance their knowledge of the neuroendocrine effects of stress. A third goal is to expand the body of knowledge on Black women in the MS literature and coping flexibility in counseling literature. The fourth goal is to enhance the participant's knowledge on the interconnectedness of psychological well-being and brain health using applicable conceptual frameworks as viable foundations for both service delivery and understanding the context of the customized interventions. The last goal is to enhance the self-monitoring and overall coping processes of the participants.

For this study, an *N*-of-1/ABA single-case research design (SCRD) was used to investigate the effects of the intervention (Kazdin, 2016). In SCRDS, a single-case functions as one unit of analysis in which an intervention is rigorously evaluated with one or a small number of cases (Kazdin, 2011). According to Lundervold and Belwood (2000), the SCRDS should be the primary methodology used in counseling research for two reasons. First, counselors frequently

work with individual clients who have unique challenges and concerns. Second, the primary focus of counseling practice is to develop techniques that are effective for the individual case or to build upon techniques. Moreover, SCRDS are a practical way to establish preliminary support for novel practices and assess how programs are applied with underrepresented populations (Morris & Wester, 2018). A SCRDS was used in the present study because it “offers counseling practitioners and researchers a practical and viable method for evaluating the effectiveness of interventions that target behavior, emotions, personal characteristics, and other counseling-related constructs of interest” (Kazdin, 2011, p. 394).

The SCRDS in the present study was the primary method to evaluate the effectiveness of an 8-session Brain-Based Education and Wellness (BE WELL) intervention with AAWwMS. The BE WELL intervention was used with AAWwMS who may have difficulty coping with various stressors and would like to enhance their overall health and wellness. The interventions will specifically target evaluation and adaptive components of coping while providing various strategies to improve coping efforts. The Transactional Theory of Stress and Coping (TTSC) (Lazarus & Folkman, 1984) and the Indivisible Self Model of Wellness (IS-Wel) (Myers & Sweeney, 2004) were integrated into the program, with a specific emphasis on the Coping Self, a second-order factor of the IS-Wel model. Additionally, the Healthy Mind Platter for Optimal Brain Matter (HMP) model (Rock, Siegel, Poelmans, & Payne, 2012) was used to develop the BE WELL framework. The MSJCC model (Ratts, et al., 2016) was utilized as an overarching framework for this study since it provides best practices for counselor and client interactions. The intervention framework was created and the customized interventions were facilitated by the counselor/investigator.

## **Rationale for the Study**

For individuals living with chronic diseases, there are many disease-specific and non-disease-related factors that interact and have a profound effect on their lives. Loss, variability, and uncertainty are common themes that PwMS experience. These themes are also experienced by people with other chronic diseases marked by unpredictability (e.g., rheumatoid arthritis (RA), chronic fatigue syndrome, Parkinson's disease). Livneh and Antonak (2005) provided an overview of the literature on psychosocial adaptation to chronic disease and disability as a primer for counselors and listed factors typically associated with the process of adapting to disabling conditions. These factors include: (a) the degree of functional loss and limitations due to acquired disability, (b) changes in one's ability to perform daily activities and life roles, (c) long-term medical treatment and rehabilitation, (d) uncertain prognosis, (e) the psychosocial stress associated with the disease process itself, (f) sustained financial loss (e.g., reduced or complete loss of income, increased medical bills), and (g) the impact on family and friends (Livneh & Antonak, 2005). Although there is a higher incidence of MS among Black women than any other racial/ethnic group in the U.S. (Langer-Gould et al., 2013), their coping experiences have been and continue to be underrepresented.

Given the lack of research on coping among AAWwMS, it is necessary that more attention be given to this population to identify how the intersections of identity (e.g., race, gender, disability) and contextual factors (e.g., culture, family, community) interact with and are influenced by their rehabilitative needs and flexibility in their coping efforts. Several studies from other disciplines have noted the lack of focus on AAWwMS, and the counseling literature continues to highlight the importance of effective coping skills and healthy adaptation among

individuals living with chronic health conditions (Livneh 2016; Stuntzner & Hartley, 2014, 2015). Thus, counselors can play an integral role in providing support for this group.

Utilizing intervention strategies to enhance AAWwMS' coping process is needed. Examining the effects of coping flexibility interventions on AAWwMS will give counselors in community, private practice, and integrated care settings useful knowledge. There are few studies on coping flexibility in the large body of coping literature because the construct has not received much research attention (Cheng et al., 2014). However, coping flexibility has significant implications for psychological adjustment, overall QoL, and counseling practice. Therefore, it is imperative that more attention be given to this subject from the counseling field.

Schwartz and Rogers (1994) posited that effective interventions designed to teach coping flexibility to individuals with chronic diseases have two main objectives. One objective is to help facilitate awareness of feelings and perspectives. A second goal is to help people learn and practice new skills that facilitate flexible coping strategies to improve psychosocial adaptation (Schwartz & Rogers, 1994). Coping flexibility is a problem-solving behavior that is vital for stress management and fostering resilience (Cheng, 2017; Galatzer-Levy et al., 2012) but research involving this cognitive process is limited.

Although coping is an individualized process, most interventions aimed to help people with chronic diseases improve their coping strategies and behaviors are based on group comparisons. This is no different with MS since most coping interventions involving this population are primarily experimental designs that evaluate related constructs (e.g., stress management, psychological adjustment (José et al., 2016). Previous reviewers found no significant differences in treatment outcomes when comparing individual and group-based coping interventions in MS research (Moss-Morris, 2013). However, Firth (2014) found that

individual interventions were more effective than group-based ones in the short-term, and they had comparable long-term outcomes.

Correspondingly, in a comparison study of individual and group-based interventions related to coping with MS, das Nair et al. (2016) found considerable benefit in using an individualized approach compared to a group intervention. Additionally, adherence to the individual treatment was well received by participants compared to the group intervention. Despite the variability in symptoms and experiences among those with MS, researchers have only utilized experimental designs to examine the effects of coping flexibility interventions with this population (Heesen et al., 2012; Sanaeinasab, 2017; Schwartz, 1999; Stuifbergen et al., 2003). As a result, the bulk of the literature reflects group-based outcomes and does not consider individual and cultural differences that impact the coping process, especially among those from marginalized groups such as Black women.

There are only a few single-case research designs that focus on coping skills training in the current literature. As a result, researchers are left with interventions that use experimental design methods. For individuals living with a chronic neurological disease, it is believed that an individualized program that incorporates neuroscience, wellness, and multicultural components may be more effective than interventions designed to teach coping flexibility utilizing a one-size-fits-all approach. The present study will provide the BE WELL framework for counselors and researchers to replicate and contribute to the scarce amount of SCRDS and brain-based counseling research.

### **Research Method, Variable, and Question**

For the present study, an *N*-of-1/ A-B-A single-subject experimental design was

used. This design was replicated at least eight times with each participant in order to enhance generalization of the findings and offset possible attrition from participants. Baseline (Phase A1) data were collected first. Next, participants met with the investigator individually once per week over the course of six weeks (Phase B [treatment]). After implementation of the eight-week intervention, the withdrawal phase began. This was a two-week hiatus from the treatment where outcome data were collected (Phase A2). Overall, the experiment, in its entirety, was delivered over a 12-week time frame.

For the present study, the customized neurocounseling intervention was the independent variable and coping flexibility was the dependent variable. The purpose of this study, which was to examine the effects of customized individual neurocounseling interventions on the coping flexibility of Black women with MS, is reflected in the following research questions:

1. What effect did the customized neurocounseling interventions have on the coping flexibility of participants across the treatment and withdrawal phases? Specific sub-questions to be addressed include:
  - 1a. Did participants' self-reports and self-monitoring indicate a desired change in evaluation coping?
  - 1b. Did participants' self-reports and self-monitoring indicate a change in adaptive coping?
  - 1c. Did participants' self-reports and self-monitoring indicate a change in total coping flexibility (both evaluation and adaptive coping combined)?
2. How did the participants rate the social validity of the interventions?

## **Definition of Terms**

**1. Multiple Sclerosis** – is considered to be an autoimmune disease in which the body's immune system attacks the central nervous system (CNS). While most MS experts believe it to be an autoimmune disease, this continues to be a topic of debate in the scientific community (NMSS, n.d-e). However, in the case of MS, the immune system attacks myelin, the insulation that protects the nerve fibers in the CNS. It also can attack oligodendrocytes (myelin producing cells) and the nerve fibers themselves (NMSS, n.d.-e). Once an individual's CNS is attacked, a host of neurologic symptoms can appear including vision loss, numbness, cognitive issues, paralysis, and walking difficulties (Rolak, 2016). Dr. Jean Martin-Charcot, also known as “the father of neurology,” coined the term multiple sclerosis and was the first to diagnose a living patient in 1868 (Kumar et al., 2011; Pearce, 2005).

a. **African American Women with Multiple Sclerosis (AAWwMS)** – refers to American women with total or partial black African descent who have received an official MS diagnosis. African American women and Black women was used interchangeably so AAWwMS may also be referred to as Black women with MS.

**2. Coping flexibility** – has been defined numerous ways in conventional coping research. The Transactional Theory of Stress and Coping (i.e., transactional model) has often been used as the conceptual framework for coping flexibility because it presumes that coping can change over time and in accordance with the demands of a particular stressful encounter (Lazarus, 1999). For this study, coping flexibility is a latent variable and Kato's (2012) definition was used because it includes aspects of meta-coping, such as grasping a situation, monitoring during coping efforts, and evaluating coping outcomes. Coping flexibility refers to “one's ability to effectively modify coping behavior according to the nature of each stressful situation” (Kato, 2012, p. 262).

Specifically, coping flexibility is defined as “the ability to discontinue an ineffective coping strategy and produce and implement an alternative coping strategy. This definition encompasses two reciprocal processes: evaluation coping and adaptive coping” (Kato, 2012, p. 264). Total coping flexibility was obtained by summing both evaluation coping and adaptive coping scores together. Coping flexibility was measured using the Coping Flexibility Scale (CFS; Kato, 2012).

a. **Evaluation coping:** Evaluation coping occurs when a person begins to abandon the coping strategy or strategies that produce undesirable outcomes. Examples of evaluation coping strategies include understanding one’s environment, monitoring and evaluating coping outcomes, and abandoning an ineffective coping strategy if the subsequent outcome is unfavorable (Kato, 2012).

b. **Adaptive coping:** Adaptive coping occurs once an individual has deemed that a coping strategy is ineffective. This process involves creating available alternatives coping strategies and implementing them. A person must be able to develop a repertoire of coping strategies in order to produce alternatives. If an alternative coping strategy produces unfavorable outcomes, then the individual engages in the process of evaluation-adaptive coping until a favorable outcome is achieved (Kato, 2012; Kato, 2015a).

4. **Customized neurocounseling interventions-** For this study, customized neurocounseling interventions refer to specific brain-based psychoeducational strategies and counseling practices that have the potential effect of modifying a client’s coping repertoire and enhancing their alternative coping strategies. In addition, these interventions provide neuroeducation to help clients better understand the impact of their coping behaviors on their psychological well-being *and* their brain health. These interventions are developed and/or modified to meet the specific needs of the individual. An *N*-of-1/ A-B-A single-subject experimental design was used in the

study to investigate the effect of neurocounseling interventions for each participant, on an individual basis, according to their assessed need(s) on the three factors from the CFS (i.e., evaluation coping, adaptive coping, and total coping flexibility).

### **Organization of the Study**

There are five chapters in this dissertation study. In the first chapter, an introduction of the topical area of interest, statement of the problem, rationale for and purpose of the study were outlined. Additionally, the research method, questions, variables, and term definitions were also provided. Chapter two provides a review of literature focused on MS including the stressors and mental health challenges prevalent among the MS population. The gender and racial/ethnic differences in disease characteristics will also be discussed, with a focus on Black women. In addition, a review of the stress and coping literature on Black women is provided. The chapter also provides synopses of various coping research related to the coping strategies and health outcomes of PwMS and several coping intervention studies were highlighted. This chapter also contains further details on the three conceptual frameworks that were used in this study: The Transactional Theory of Stress and Coping, The Indivisible Self, and The Healthy Mind Platter. In chapter three, the methodology that was utilized in the study will be presented detailing the research design, participants, instrumentation, data collection and analysis procedures. The penultimate chapter, four, focuses on the results of the customized neurocounseling intervention. The final chapter, five, presents a discussion of the results of the study as well as recommendations for counseling practice and research.

## CHAPTER 2: LITERATURE REVIEW

This review of the literature was designed in part to provide an overview on multiple sclerosis (MS) and aspects (e.g., psychological distress) that affect the coping experiences of PwMS. More specifically, the purpose of the literature review was to present factors that impact the coping strategies, psychological health, and psychosocial functioning of AAWwMS. In addition, this review of the literature includes reflections on the concept of coping flexibility and its application to psychosocial adaptation to chronic disease and acquired disability.

Furthermore, this literature review presents an examination of interventions deemed to be empirically efficacious in improving aspects of coping flexibility with PwMS and other chronic diseases marked by variability and uncertainty (e.g., rheumatoid arthritis). There are few single-case research designs (SCRD) in the counseling literature (Foster, 2010; Lenz, 2015) exploring the effect of coping flexibility interventions since most coping interventions are group-based. There is also a lack of brain-based counseling literature (Field et al., 2017) since the integration of neuroscience into counseling practice is a relatively new clinical approach. The goal of the present study is to examine the effects of customized neurocounseling interventions on the coping flexibility of AAWwMS.

The literature review contains reflections on practitioner models, stress and coping models, related wellness theories, cultural and systemic factors, and implications for future research to improve the challenge counselors face in helping AAWwMS and more broadly, individuals with chronic diseases, improve their coping effectiveness. The literature review is presented in the following order: (a) an overview of MS - its etiology, diagnosis, characteristics and symptoms, treatment, and epidemiology, with a focus on AAWwMS; (b) perspectives on coping flexibility; (c) an overview of coping research among PwMS and Black women in

general; (c) empirically-based coping flexibility interventions; (d) neurocounseling as a brain-based clinical approach, including the neuropsychophysiological effects of stress and coping on the brain, body, behavior, and relationships; (e) selected theoretical frameworks (The Indivisible Self, Transactional Theory of Stress and Coping, The Healthy Mind Platter); and (f) a summary of this presentation.

### **Overview of Multiple Sclerosis**

To understand how MS impacts Black women, it is imperative to examine how MS develops and affects those living with this chronic disease and examine factors related to the etiology, symptomology, and epidemiology of this neurological condition. The mental health challenges associated with MS as well as a review on treatment approaches, including psychotherapeutic and psychosocial interventions, is also provided. Lastly, the racial/ethnic differences in clinical presentation and disease progression, with a focus on African Americans are examined.

Multiple Sclerosis (MS) is a chronic, autoimmune disease of the central nervous system (CNS) that impacts over 2.3 million people worldwide (Browne et al., 2014; Multiple Sclerosis International Federation [MSIF], 2018). Although MS can occur at any age, it typically begins in early adulthood between the ages of 20 and 50 (Leary, Poerter, & Thompson, 2005; Raffel, Wakerley, Nicholas, 2016). In the U.S., 50% of MS diagnoses are made before the age of 30, and three-quarters of cases are diagnosed before the age of 40 (Koch-Henriksen & Sørensen, 2010). MS is one of the main causes of non-traumatic neurological disability in young adults and nearly one million Americans have been diagnosed with the disease (NMSS, 2017). MS is an inflammatory, progressive disease that affects the CNS, which is made up of the brain, spinal cord, and optic nerves (Centers for Disease Control and Prevention, 2010). According to the

National Institute of Neurological Disorders and Stroke (n.d.), MS is the world's second most common chronic neurological disease, and compared to other chronic diseases, neurological disorders have been found to be the largest cause of acquired disability worldwide (Collins, 2017).

In MS, the immune system malfunctions and attacks different areas of the CNS at various points in time. Specifically, the myelin sheath that insulates neurons in the brain and spinal cord is attacked by immune-system cells (Iezzoni, 2010). The myelin sheath serves to facilitate and accelerate the conduction of electrical impulses along nerve fibers back and forth from the brain to the rest of the body. The attack of immune-system cells on the myelin sheath creates inflammation along the nerves where the myelin has been damaged or completely destroyed and telltale scars, also called lesions or plaques, begin to develop (Schapiro, 2003). Thus, multiple sclerosis which means “multiple scars” refers to the hardened scar tissue that forms in the CNS as a combination of the inflammation, demyelination, and nerve fiber injury and loss (Huang et al., 2017). As a result of MS attacks, CNS functions are disrupted which make it difficult for electrical impulses to be sent and received properly between the brain and the rest of the body (Dutta & Trapp, 2006; Rahn et al., 2012). This leads to a host of symptoms and complications that may include reduced physical, sensory, cognitive, and psychosocial functioning which can decrease the QoL in individuals living with this chronic condition (Goldenberg, 2012; Inglese, 2006).

### **Etiology**

Currently, there is no known cause for MS and the precise mechanisms of the disease process are not yet fully understood (Iezzoni, 2010; Schapiro, 2003). However, current knowledge from observational research (e.g., Nexø et al., 2011) suggests that MS is triggered by

a combination of immunological, infectious, genetic and environmental factors. In the case of immunological factors, immune dysregulation influences one's susceptibility to developing the disease (McFarland & Martin, 2007). Specifically, immune-system cells break through the blood brain barrier, a "functional and anatomical barrier separating the blood from neurons in the CNS" and migrate into the CNS where they cause inflammation (Høglund & Maghazachi, 2014, p. 29). Research findings indicate that once this transpires alterations in the immune response involving various immune-system cells (e.g., T-cells and B-cells) occur and wreak havoc on the CNS (Langrish et al., 2005).

Among infectious factors, many viruses and bacteria — including measles, canine distemper, human herpes virus-6, Epstein-Barr virus (EBV) and Human Endogenous Retrovirus (HERV-Fc1), have been or are being investigated to determine if they are involved in the development of MS (NMSS, n.d.-f). EBV, the virus that causes mononucleosis, has received considerable attention since a growing number of research findings from prospective studies and meta-analyses (e.g., Ascherio et al., 2001; Ascherio & Munger, 2007a) indicate that previous infection with EBV contributes to the risk of developing MS. This research has led to the exploration of immunotherapy as a possible treatment to reduce disease activity in MS (Pender & Burrows, 2014).

Over the past decade, researchers have validated the involvement of many genetic factors that increase MS susceptibility in the general population. International collaborative efforts to conduct large-scale genome-wide association studies (e.g., Baranzini et al., 2009) have led to confirmed genetic variations that have a significant effect on the development of MS. Specifically, genes such as the human leukocyte antigen (HLA) class II have demonstrated the strongest effect on MS risk (Canto & Oksenberg, 2018; Masterman et al., 2000; Moutsianas et

al., 2015; Munoz-Culla et al., 2013). The importance of genetic factors in susceptibility to MS has also been shown in genetic epidemiological studies which suggest that the risk of developing MS in the general population is approximately 0.1% (Compston & Coles, 2008). Family study findings (e.g., Ebers et al., 2004; Sadovnick et al., 1988) have indicated that first-degree relatives (parents, sibling, twins) are generally at 10–25 times greater risk of developing MS compared to the general population. Although the genetic contribution to MS risk is significant, it exists in a complex interaction with environmental factors. Extensive research has firmly established that there are several environmental factors that contribute to MS risk such as geographic region. Epidemiological studies (e.g., Milo & Kahana, 2010) have revealed that the prevalence of MS is higher in geographic regions inhabited by people of northern European descent and in regions with more temperate climates. Countries that have particularly high MS prevalence rates include the United Kingdom, Canada, Germany, Denmark, Sweden, Finland, Norway, and the United States (Smith & Schapiro, 2004).

Interestingly, moving from one geographic region to another seems to alter the risk of developing MS which is influenced by the age of the individual at the time of relocation (NMSS, n.d.-g). Those who move in early childhood tend to adopt the risk level in the geographic area themselves. However, for those who move later in adulthood this change in risk level may not appear until the next generation (NMSS, n.d.-g). Other environmental risk factors that have received strong supporting evidence of their role in the development of MS include smoking, adolescent obesity, ultraviolet light exposure, and vitamin D deficiency (Handel et al., 2011; Wingerchuk, 2011). The etiology of MS is unknown and multifaceted, and these findings provide support for the theory that MS risk is influenced by early exposure to an environmental trigger in individuals who are genetically susceptible (NMSS, n.d.-g).

## *Multiple Sclerosis and Stress*

In several reviews, researchers have cited stress as one of the environmental triggers that cause MS to develop in a genetically susceptible person (Lovera & Reza, 2013; Mohr, 2007; Stojanovich & Marisavljevich, 2008). This is because mounting evidence supports the notion that there is an association between stress and disease activity in PwMS. The majority of extant research focuses on everyday stressors and the relationship between stress and MS relapses. In a meta-analysis of 14 empirical studies on general stress and MS, Mohr et al. (2004) found there is a consistent correlation between stressful life events and subsequent MS exacerbations. The findings indicated that different types of stressors may have different health-related effects that may or may not lead to subsequent exacerbations. However, in regard to disease onset, the research is sparse. To date, there is only one systematic review that examines the literature regarding the relationship between stress and the onset of MS. Artemiadis et al. (2011) conducted the review and found that in several studies (e.g., Grant et al., 1989; Liu et al., 2009) on PwMS individuals reported experiencing more stressful life events from one to three years before onset, especially when compared to healthy controls. These stressful life events include but were not limited to (a) loss of a child, (b) interpersonal family conflicts, (c) financial problems, and (d) change of residency or lifestyle.

Although there are study findings (e.g., Riise et al., 2011) that suggest there is no association between stress and MS, the majority of the findings have indicated a link between stress and MS, and this relationship continues to be demonstrated in more recent research. Burns et al. (2014) conducted a longitudinal study to examine the relationship between stressful life events and neuroimaging markers of MS. The results indicated that major stressful events (e.g., traumatic life-threatening situations) were associated with increased risk of subsequent new and

enlarged brain lesions. Similarly, Weygandt et al. (2016) used functional MRI (fMRI) data to assess and compare neural stress responses in PwMS and healthy controls. The research findings showed that stress-induced brain activity reflects clinical disability in MS. Although there are methodological limitations in research, there has been a consistent association between stress, the onset of MS, and subsequent disease activity which suggests that MS is a stress-related condition (Sutton, 2011).

## **Diagnosis**

MS is primarily diagnosed in a clinical setting by a neurologist. A diagnosis is dependent on the demonstration of signs and symptoms of neurological deficits related to lesions found in white matter (Huang et al., 2017; Martinez-Altarriba et al., 2014). In order to distinguish MS from other chronic diseases with similar presentations, several assessments, including the McDonald criteria, may be utilized (Milo & Miller, 2014; Polman et al., 2005). To provide a differential diagnosis, these criteria depend on the location and demonstration of lesions that have been disseminated in space and time within the CNS. Lesions are found with laboratory tests and imaging, including MRI scans of the brain and spinal cord, cerebrospinal fluid analysis using a lumbar puncture procedure, and functional examinations of the nervous system (e.g., motor functions) (Huang et al., 2017). In general, a diagnosis is usually dependent on the results of MRI scans.

Currently, there are four types of MS: (a) Clinically Isolated Syndrome (CIS), (b) Relapse-Relmitting MS (RRMS), (c) Secondary-Progressive MS (SPMS), and (d) Primary-Progressive MS (PPMS) (Loma & Heyman, 2011; NMSS, n.d.-h). These types are on a continuum from the first clinical manifestation of the disease (CIS) to the most progressive and debilitating form (PPMS). Although four disease courses have been identified in MS, researchers

have proposed a new subtype of MS called Myelocortical MS based upon findings from autopsies completed on post-mortem brains and spinal cords (Trapp et al., 2018). This subtype develops as a result of substantial degeneration of grey matter areas in the brain and spinal cord (Stys, 2018; Trapp et al., 2018). Currently, this subtype is not diagnosable since more research is needed.

Typically, the disease course of MS starts with the sudden onset of neurological deficits that may or may not be noticeable. This single clinical attack of the CNS causes inflammatory symptoms that are suggestive of multiple sclerosis (MS) refers to CIS (Efendi, 2015). For deficits to be termed as CIS, the episode should last for at least 24 hours and reach a peak quite rapidly within 2-3 weeks (Efendi, 2015). For most individuals with MS (approximately 85%), the clinical presentation of the disease is a relapsing remitting course in which there is an absence of symptoms except for the relapses. Specifically, the recurrent periods of relapse are followed by remission phases after a complete or partial recovery of symptoms (Confavreux & Vukusic, 2006).

Over time, most RRMS cases will develop into SPMS which is considered to be a second phase of the disease for many individuals. This type of MS is characterized by irreversible neurological impairment that causes a steady progression of symptoms, acquired disability, and fewer or no relapses over time (Coret et al., 2018; Davies et al., 2016). The rarest form of MS, PPMS, is progressive from the start and leads to accelerated disability (Abdelhak et al., 2017; Correale et al., 2017). Approximately 15% of PwMS experience a gradually progressive clinical course from the onset of the disease that will be diagnosed as PPMS (Lublin et al., 2014). Overall, it is a challenge to diagnosis MS because of the difficulty in interpreting the different types (Przybek et al., 2015).

## **Characteristics and Symptoms**

The disease course of MS is highly unpredictable. Although MS is associated with change in average life expectancy, it is not considered a fatal condition (Huang et al., 2017). For most PwMS, the disease is characterized initially by episodes of reversible neurological deficits, which is often followed by progressive neurological deterioration over time (Goldenberg, 2012). During the disease course, some symptoms appear to be more dominant or have a greater effect on functional ability than others (Ghasemi et al., 2017).

As a complex, unpredictable disease, MS has been associated with a wide variety of symptoms that can affect one's ability to carry out normal activities of daily living. Symptoms may be mild to severe and vary greatly among and within those living with MS over time. Although there are a myriad of symptoms, the most commonly reported include fatigue, changes in cognitive function or memory, sensory problems (e.g., numbness, pain, vibrations), vision changes, bladder or bowel dysfunction, and motor changes (e.g., loss of balance, poor coordination, muscle weakness or stiffness) (Goldenberg, 2012; O'Connor et al., 2008; Foley et al., 2013; Stuke et al., 2010; Truini et al., 2013; Ziemssen, 2011). Chronic pain (e.g., musculoskeletal pain) is another common symptom of MS that had previously been overlooked (Ekram et al., 2014; Marck et al., 2017). Ambulatory problems have always been classic symptoms of this chronic disease as 50% of PwMS will need help walking within 15 years after the onset of the disease (Navikas & Link, 1996). Less common symptoms include swallowing problems, headaches, hearing loss, itching, seizures, and breathing problems (Alali et al., 2018; Hellmann et al., 2011; NMSS, n.d.-a; Shaygannejad et al., 2013; Tabby et al., 2013).

## ***Mental Health Challenges***

Due to the focus of the present study and the prevalence of mood disturbances in MS, a review of the literature on these specific symptoms is provided. In addition to cognitive and physical disability, psychological symptoms such as depression and anxiety are a common occurrence among PwMS. The prevalence of mood disturbances among PwMS is very pronounced compared to the general population and it has been heavily overlooked in clinical settings (Feinstein, 2007; Ghaffar & Feinstein, 2007; McGuigan & Hutchinson, 2006). Clinical depression and anxiety are particularly common in MS with lifetime prevalence rates as high as 50% and 45%, respectively (McGuigan & Hutchinson, 2006; Ghaffar & Feinstein, 2007; Korostil & Feinstein, 2007; Wood et al., 2013). This is significantly greater compared to the rate of clinical depression (5-10%) and anxiety (4-25%) in the general population (National Institute of Mental Health [NIMH], 2017; Remes et al., 2016).

Since depression is prevalent among PwMS, suicidal behavior among this population has also become a focal point of research. According to Pompili et al. (2012), the rates of completed suicide are significantly higher in those with MS than in the general population and researchers have found a higher prevalence of suicidal ideation in the MS population compared to people with other chronic health conditions such as arthritis and cancer (Dickstein et al., 2015). In the MS population, suicidal ideation has been linked to depressive symptoms, social isolation, younger age, progressive disease subtype, lower income, earlier disease course, higher levels of physical disability, loss of driving ability, low self-efficacy, and ineffective coping styles (Pompili et al., 2012; Paparrigopoulos et al., 2010; Turner et al., 2006). Although more recent research suggests there is no longer an increased risk of suicide in MS (Kalson-Ray et al., 2017),

the emotional health and coping strategies of PwMS, particularly those from underrepresented groups, is still needed.

In contrast to the extensive literature on depression and anxiety in MS, less attention has been paid to other serious mental health issues such as bipolar disorder and schizophrenia even though numerous case reports have documented an association between these severe mood disturbances and MS (Arneth, 2017; Camara-Lemarrooy et al., 2017; Jun-O'Connell et al., 2016; Sidhom et al., 2014). In addition, researchers have found that under investigated psychological symptoms such as paranoia, somatization, and disordered eating attitudes were more frequent among clinical samples comparing PwMS and healthy controls (Sarisoy et al., 2013).

For decades, researchers have tried to determine the multifarious causes of mood disturbances in MS. This has led to concerted efforts to focus research on three main areas: (a) clinical manifestations (e.g., brain lesion location), (b) pharmacological treatments, and (c) psychosocial stressors. In several correlational studies, researchers (e.g., Benesova et al., 2003; Dalos et al., 1983) found an increase in lesions in specific brain areas may account for differences between depressed and non-depressed persons living with MS. However, in their review Mendis et al. (2014) found that despite the association, brain lesions cannot be the sole explanation for depression in MS. This is because researchers (e.g., Bakshi et al., 2000) indicated from data in several studies that PwMS that had a high fMRI lesion accumulation did not have depression, and conversely, some with low lesion accumulation were depressed.

Pharmacological treatments of MS have also been associated with emotional disturbances (Minden, 2000; Murphy et al., 2017). According to Ciriaco et al. (2013), disease-modifying therapies (DMTs) used to slow the progress of MS have been associated with significant adverse psychiatric side effects. Specifically, mood lability, euphoria, and depressed mood. However, in

a recent systematic review on DMTs, Gasim et al. (2018) found that of the DMTs reviewed none were associated with an increased risk of adverse psychiatric effects, and some may reduce the incidence of depressive symptoms. This is primarily due to technological advancements in medicine that have reduced this threat. Although pharmacological treatments for MS and disease progression (e.g., brain lesion location and accumulation) have been viewed as possible risk factors of various emotional disturbances in MS, the research findings in these areas is conflicting and inconclusive (Chwastiak & Ehde, 2007; Gasim, 2018). However, decades of research findings overwhelmingly indicate that the prevalence of mood disturbances, specifically depression and anxiety, are in part a direct result of the various challenges, limitations, and losses associated with MS (Liu et al., 2009; Streng, 2001).

Psychosocial stressors unequivocally have a significant impact on the mental health of PwMS. As a whole, several mood disturbances in MS may be ascribed to the many facets related to living with this chronic, unpredictable, and progressive disease. Since MS affects many areas of functioning, it is likely to cause disruptions to one's education, employment, sexual relationships, family roles and friendships, and daily living activities (Green et al., 2007). Furthermore, the individual's sense of self may be significantly affected as the disease progresses and acquired disability increases. As a result, individuals may have to constantly reconstruct their self-image to overcome the limitations caused by MS (Barker et al., 2018; Boeije et al., 2002). In a meta-synthesis on social identity in PwMS, Barker et al. (2014) found that the family plays a key role in the identity reconstruction of individuals living with MS. However, perceived lack of support, social withdrawal and isolation may become the individual's response to disease progression and further contribute to the "profound impact of MS on the [individual's] social roles and their relatives' well-being" (Hakim et al., 2000, p. 288). Other psychosocial variables

affecting mood in MS include feelings related to uncertainty about daily health, the loss of self-esteem, and spiritual factors (McNulty et al. 2004). Overall, the onset and degenerative nature of MS disrupts the daily lives of individuals and families affected by the disease, which can elicit changes in mood, cognitions, and behavior that may be even more disturbing (Sá, 2008). While the underlying mechanisms of mood disturbances in MS are not fully understood and warrant further research, the treatment approach to MS is varied and has received considerable attention.

## **Treatment**

For a chronic disease with a prognostic uncertainty like MS, comprehensive treatment which includes medications, rehabilitation strategies, and emotional support is recommended (Embrey, 2014). Sadovnick et al. (1991) suggested using an interdisciplinary approach involving a neurologist, an allied health worker (e.g., nurse, counselor, or social worker) with expertise in MS, and assistance from national and local MS organizations. Most pharmacological treatments are focused on slowing the progression of the disease course (i.e., disease-modifying therapy) or symptom management (Calabresi, 2004; Johnson, 2014; Keenan & Porter, 2003; Torkildsen et al., 2016). The aim of rehabilitation interventions is to reduce the individual's disability, symptoms, and limitations in order to achieve the highest possible independence and the best QoL within the limits of the disease (Beer et al., 2012). Lastly, psychotherapeutic and psychosocial interventions are often used as an adjunct to the medical management of MS to improve mental health, facilitate decision-making, and improve stress management and coping behaviors (José et al., 2016).

Pharmacological interventions used to treat MS primarily include disease-modifying therapies (DMTs) such as Interferon-beta1b (INF $\beta$ , Rebif), Mitoxantrone (Novantrone) Glatiramer Acetate (GA, Copaxone) and Natalizumab (Tysabri), which are used to treat

relapsing forms of MS (Torkildsen et al., 2016; Vosoughi & Freedman, 2010). These DMTs which are a combination of oral and intravenous medications are used to minimize symptoms, reduce relapses, and improve function to decrease the rate of disability progression by modulating the immune system and reducing CNS inflammation (Feinstein et al., 2015; Klauer & Zettl, 2008; EBioMedicine, 2015). In 2017, the US Food and Drug Administration approved the license for the first DMT for progressive forms of MS, Ocrelizumab (Ocrevus) (Mulero et al., 2018). Researchers have conducted several reviews to determine the effectiveness and risk profiles of various DMTs (Filippini et al., 2003; Vargas & Tyor, 2017). For instance, Giovannoni et al. (2012) conducted a review of DMTs and found that the clinical impact of IFN $\beta$  and GA SC, is modest and may be due to moderate discontinuation rates. Unfortunately, there is limited clinical data on Mitoxantrone, Natalizumab and Ocrelizumab (Giovannoni et al., 2012; Mulero et al., 2018). However, Rae-Grant et al. (2018), conducted a recent systematic review of various DMTs and found that many DMTs for both relapse-remitting and progressive forms of MS were superior to placebo in reducing new disease activity.

Rehabilitation strategies to treat MS include a range of treatments and interventions. They are often selected based on the individual's disease phase, personal needs, functional deficits, as well as specific goals (Beer et al., 2012). In a systematic review of published systematic reviews of clinical trials of MS rehabilitation programs, Khan and Bhasker (2017) found that there is an overall lack of "high-quality evidence for many modalities" due to the lack of methodologically robust studies (p. 1). However, there was strong evidence of effectiveness among the most common treatment interventions which included: (a) physical therapeutic modalities (exercise/physical activities) aimed to improve functional outcomes (i.e., mobility, muscle strength), (b) reduced fatigue, and (c) improve QoL and (b) comprehensive fatigue

management programs. There was moderate evidence of treatment effectiveness for interventions that used: (a) multidisciplinary rehabilitation (MDR) for persons with disability to improve long-term function in activity and participation, (b) cognitive-behavioral therapy (CBT) for the treatment of depression, and (c) psychoeducational programs to increase patients' knowledge and provide support (Khan & Bhasker, 2017).

Psychotherapeutic and psychosocial interventions are defined as “educational or interactive programs intended to promote healthy behaviors” (José et al., 2016, p. 115). Specifically, these interventions are designed to facilitate more effective problem-solving and treat mental health challenges that affect PwMS. Several reviews and meta-analyses (e.g., Fiest et al., 2016; Thomas et al., 2006) have been conducted to examine the effectiveness of psychotherapeutic and psychosocial interventions on various outcomes in PwMS. For instance, José et al. (2016) conducted a review and found several treatment modalities such as cognitive-behavioral therapy, psychoeducation, and mindfulness-based interventions to be effective in improving QoL among PwMS. The most recent meta-analysis on psychosocial interventions was conducted by Sesel et al. (2018). According to their findings, psychosocial interventions are effective in reducing a myriad of mental health and physical health-related problems including depression, anxiety, and fatigue. They are also effective in improving psychosocial factors (e.g., interpersonal relationships) related to QoL (Sesel et al., 2018). However, their findings were inconsistent with previous meta-analyses (e.g., Mohr & Goodkin, 1999) that provided support for the use of CBT as the “gold standard” for treating depression in PwMS. In all, Sesel et al. (2018) found these interventions to be efficacious across a range of domains which is important since MS symptoms can vary widely among PwMS.

## **Epidemiology**

MS is one of the world's most common neurological conditions and in many countries the main cause of non-traumatic neurologic disability in young adults (WHO, 2008). However, there is a lack of information on the global epidemiology of MS and the availability of resources and services for PwMS. According to the most recent *Atlas of MS* conducted by Browne et al. (2014) in 2013, the estimated number of PwMS worldwide is 2.3 million. In their meta-regression analyses on the changing demographic patterns of MS epidemiology, Koch-Henriksen and Sørensen (2010) found that the geographical distribution of MS around the globe is varied. The highest prevalence estimates (the number of PwMS alive at a specific date per 100,000 population) were found in developed countries in western Europe and North America where there is extensive epidemiological information. The lowest estimates were found in Asia, the Middle East, and Africa according to the limited number of studies from these regions. There is little information from Central and South America.

In regard to sex and gender differences, MS is universally found to be more prevalent in women than men (Harbo et al., 2013). Until the mid-20<sup>th</sup> century, MS was considered to be a chronic condition that predominantly affected men (Brain, 1930). However, within the last few decades, the prevalence ratio of women to men has significantly increased (from 2.3:1 to 3.5:1). Researchers have concluded that this marked change is truly indicative of an increase in MS among women but not men (Compston & Coles, 2002; Wallin et al., 2012). While the cause for these stark differences has not been determined, researchers believe it is due to a combination of genetic factors, hormonal changes, and environmental factors related to lifestyle and nutrition (Harbo et al., 2013).

In the U.S., MS is not considered to be a notifiable disease by the CDC. Therefore, the incidence and prevalence of MS are not consistently reported or tracked. In 2016, as part of the 21 Century Cures Act, Congress authorized the CDC to initiate development of a National Neurological Conditions Surveillance System (NNCSS) (CDC, 2018). One of the primary goals of this initiative is to track and collect data on the epidemiology of neurological conditions such as MS which will lead to more research that focuses on MS epidemiology. However, to address the current gap in prevalence estimates, the NMSS launched the MS Prevalence Initiative. The goal of the program is to determine the most cost-effective and scientifically sound method to estimate of the number of people in the U.S. who have MS (NMSS, n.d.-i).

### **African Americans and Multiple Sclerosis**

Fifteen years ago, many researchers and scholars in the medical community viewed MS as a disease that predominately affected those of European descent (NMSS, n.d.-j). Therefore, an overwhelming majority of the MS literature has reflected this group. In the U.S., the focus on Whites living with MS caused the needs and concerns of POC living with MS to be overlooked (Khan et al., 2015). In fact, the prevalence of MS among African Americans and other POC in the U.S. is considered to be a recent phenomenon (Khan et al., 2015). However, in the last decade, more emphasis has been given to African Americans and other POC in MS research. This has uncovered considerable variability in the disease course among these underserved populations compared to Whites (Khan et al., 2015).

### **Clinical Features**

Kister et al. (2010) compared the rate of disease progression among African Americans and European Americans using the Multiple Sclerosis Severity Scale (MSSS) with a sample of registrants in the New York State Multiple Sclerosis Consortium (NYSMSC) database. The

research findings indicated that African Americans had a more rapidly disabling disease course compared to Whites. Correspondingly, in a cohort-based study, Ventura et al. (2017) found that African Americans transition to more progressive forms of MS similarly to Hispanic/Latinx Americans but faster than European Americans. Overall, the rapid disease progression in African Americans has been marked by greater inflammatory disease activity and faster disability accumulation which some researchers believe may be due to a combination of genetic, immunological, and environmental factors (Khan et al., 2015).

Historically, the incidence of MS was believed to be much less common among African Americans than European Americans. However, findings from recent studies have shown that African Americans, especially Black women, have a higher incidence of MS than previously reported. In a retrospective study on newly diagnosed PwMS, Langer-Gould et al., (2013) found that the incidence rate per 100,000 persons-years was highest among African Americans (10.2) than any other major racial/ethnic group. Likewise, in another cohort study involving Gulf War-era veterans with MS, the incidence rate per 100,000 persons was higher in African Americans (12.1) than in European Americans (9.3), Hispanic Americans (8.2), Asian Americans (3.3), or Native Americans (3.1) (Wallin et al., 2012). Both studies highlighted that the high incidence rates for African Americans stemmed from the marked gender differences where incidence rates for Black women were three times that of their male counterparts. This emerging research supports the increasing awareness of MS among African Americans, particularly for Black women.

As for the clinical manifestation of MS, African Americans are more likely to experience the disease onset at an older age compared to other POC, and the average time between symptom onset and diagnosis has been about 2.3 years (Khan et al., 2015). Additionally, disease

presentation and disease course among African Americans may be more aggressive compared to other racial/ethnic populations. African Americans are more likely to have frequent relapse episodes, more difficulty recovering post-relapse, faster transition from relapsing-remitting MS to secondary progressive MS, and a higher risk of ambulatory disability compared with European Americans (Cree et al., 2009; Kister et al., 2010). Moreover, African Americans are more likely to present with opticospinal MS, which is a distinct form of MS which is restricted to the optic nerves and spinal cord (Cree et al., 2009). MRI results indicate that African Americans with MS have higher lesion volumes and nerve activity loss (Cree et al., 2009). These observations demonstrate the need to further investigate the etiology and pathology of MS among African Americans.

The gravity of the physical, psychological, and cognitive difficulties of AAWwMS and African Americans with MS as a whole cannot be overstated. Holland et al. (2011) described African Americans with MS as a vulnerable population compared to other major U.S. racial/ethnic groups living with the chronic disease because “they experience increased risks to their physical and social health and wellbeing” (p. 36). In addition to the marked differences in disease progression and clinical manifestation, African Americans with MS must also contend with more comorbid chronic health conditions. According to Buchanan et al. (2006), African Americans with MS experience a greater proportion of comorbidities including hypertension, seizure disorders, and diabetes. They are also more likely to experience physical limitations, require ambulatory assistance, and have a long-term disability much earlier than their White counterparts (Cree et al., 2004; Ventura et al., 2017).

Moreover, research on mental health problems among African Americans with MS is very limited, but racial/ethnic differences have been found in the few extant studies. In a U.S.

epidemiological study comparing the racial/ethnic differences among PwMS, Buchanan et al. (2010) found that African Americans reported higher rates of at least mild depression (45.8%) compared to Hispanic/Latinx Americans (44.2%) and European Americans (38.7%). In order to cope successfully with MS, African Americans must develop strategies to manage living with multiple chronic health conditions and furthermore, protect their psychological and emotional well-being. In addition, researchers and providers are challenged to consider their needs and concerns in order to develop more effective interventions and treatment approaches.

In 2010, Dr. Mitzi Williams, a neurologist and one of only 10 African American MS specialists in the U.S. argued that the “face” of MS is wrongly associated with White American women and should actually reflect Black women. In the article, *Exploring Our Differences: African Americans and MS*, Williams (2010) described the need to explore the inherent differences of MS among African Americans. Williams (2010) also highlighted emerging trends in African Americans with MS which showed that a higher incidence of MS may be due to environmental factors (i.e., chronic stress, vitamin D deficiency) and “mixing of the races”, or bi-racial heredity. Williams (2010) stated that these areas require more attention in order to gain a better understanding of MS and work toward a cure. However, the low participation rates of African Americans in clinical trials and other MS research continues to be a major area of concern.

### **Attitudes and Perceptions Toward Research Participation**

Historically, AAWwMS has not been a primary focus in MS research. As a result, there is a lack of research on their coping beliefs and behaviors. In order to provide comprehensive care, practitioners are challenged to become more informed on how MS affects African Americans and other diverse populations. Despite the recent focus on African Americans living with MS, their low participation rates in MS clinical trials and research in general have continued

to be a common trend (Accelerated Cure Project [ACP], 2018). Unfortunately, this trend is not unique to MS since it mirrors the same lack of participation in clinical and biomedical research across various disciplines for various chronic diseases (Chow et al., 2012; Oh et al., 2015). In a review on MS in U.S. racial/ethnic minority populations, Khan et al. (2015) highlighted the multiple challenges in increasing participation among African Americans in MS research. First, many African Americans and other POC living with MS may have difficulty accessing and utilizing specialty care due to socioeconomic barriers such as the lack of or limited insurance. Cultural influences, such as religious beliefs and perceived discrimination in health care are also thought to be potential barriers for many POC to participate in MS research (Khan et al., 2015).

For African Americans, the reluctance to participate in clinical trials and research in general is well-documented. Harris et al. (1996) found the underrepresentation of African Americans in clinical trials to be primarily due to “the legacy of African American mistrust in the medical system” (p. 630). This distrust stems from brutal experimentation and medical practices that were inflicted upon generations of African Americans (e.g., the infamous Tuskegee Syphilis Study and the sterilization of Black women). The gross abuse and blatant violence against unknowing African Americans by the White medical establishment have caused the cultural suspicion that many African Americans have regarding medical studies. In the same vein, Corbie-Smith et al. (1999) found that African Americans associated the term “medical research” with being treated like guinea pigs, being deceived, and developing a worsened health status as a result of participating.

In the MS community, this lack of participation has led to concerted efforts by various non-profit organizations to focus on improving the representation of African Americans and other racial/ethnic minority groups in MS research. The MS Society established the

Multicultural Advisory Council to help identify the best approaches to engaging in outreach within the African American community and among African American health care professionals (NMSS, 2018). The MS Minority Research Engagement Partnership Network (MS Minority Network), a division of the Accelerated Cure Project, is another initiative that strives to “develop innovative, community-endorsed, culturally appropriate strategies and solutions to promote research participation among racial and ethnic minority groups” (ACP, n.d. para. 1).

According to their website, the MS Minority Network aims to bring together diverse stakeholders including PwMS, minority health organizations, researchers and clinicians, to identify and address the issue of racial/ethnic minority underrepresentation in MS research (ACP, n.d.). These initiatives to increase racial/ethnic minority participation can help researchers and providers better understand how the disease is manifested, which treatments work best for all PwMS, and how to help individuals cope successfully. While the low participations rates of African Americans continues to be a challenge, researchers must learn to utilize a culturally sensitive approach throughout the entire research process in order to achieve success. Barrett et al. (2017) suggest that recruiters develop strategies to address: (a) fear, distrust, confidentiality, and privacy; (b) competing priorities and needs; and (c) protocol and system barriers in order to engage African Americans in research.

### **Perspectives on Coping Flexibility**

To understand the concept of coping flexibility, it is imperative to examine the stress and coping constructs. Conceptualizing the interaction between these subjective cognitive processes is essential to understanding their impact on AAWwMS and broadly speaking, people living with chronic diseases. Reviewing the literature to grasp the breadth and depth of coping is also needed to gain a comprehensive view of this crucial aspect of wellness. Without a clear understanding

of the dependent variable (i.e., coping flexibility) for the study, it would be difficult to design an intervention that addresses the targeted outcome.

Over the past 75 years, research findings have indicated that stress can have damaging effects on all aspects of health, but these effects can be mitigated by coping strategies. However, within the last decade, stress exposure has become so frequent and so severe that it has become a global crisis (World Health Organization [WHO], 2013). Given this information, it is no surprise that coping has always been and continues to be a primary focus of counseling interventions (Stuntzer & Hartley, 2014). Data compiled from nation-wide surveys like *Stress in America* (American Psychological Association [APA], 2019) are a constant reminder that counselors have a professional obligation to develop and implement programs to assist individuals with their coping efforts because coping is a crucial determinant of psychological well-being, and these outcomes largely depend on the type of strategies employed.

As an individualized process, stress occurs when one perceives that there is a threat from the surrounding environment (Lazarus & Folkman, 1984). This threat may not be physical or immediate. Instead, it may be psychological such as ruminating on impending deadlines, looming performance evaluations, or worrying about one's health but these are all examples of situations that can stimulate the stress response (McEwen, 2012). While some stressful encounters are trivial (e.g., waiting in line) and last for a moment, others are more prolonged and have a significant impact on one's daily life (e.g., repeated exposure to neighborhood violence).

In the context of living with a chronic disease, stressful experiences have the propensity to become chronic occurrences due to the myriad of stressors associated with disease management (e.g., medication and rehabilitation costs) as well as daily life stressors. Momentary or acute stress is associated with adverse psychological and emotional responses that can last hours after the stressor has been removed (Jones et al., 2013). Repeated exposure to stressful

situations may become chronic stress which can lead to emotional dysregulation and increased mental health problems such as depression and anxiety (Gold et al., 2015; Ross et al., 2017). Furthermore, prolonged exposure to chronically stressful environments can erode a person's overall health and sense of well-being (Marin et al., 2011; Michl et al., 2013). While researchers have found that both momentary and chronic stress have negative physical, physiological, and psychological effects (Bell, 2014; Juster et al., 2010), more recent research indicates that stress has adverse neurological effects too. For instance, stress may cause swelling or inflammation in the brain which can impair executive functioning (Radley et al., 2015; Rohleder, 2014). This can lead to a host of cognitive issues such as reduced or delayed information processing and problem-solving abilities, both of which are necessary to effectively coping with stress (Fredrickson & Branigan, 2005; Maghan, 2017).

*Coping* is defined as a dynamic, process-oriented approach where intentional actions are utilized by an individual to manage or resolve a situation that is appraised as stressful (Lazarus & Folkman, 1984). Effectively coping with stress is essential for optimal health and well-being. People who cope more effectively with stress tend to have less health-related problems, greater resilience and longevity, more successful adaptation, and report an overall better QoL (Cheng et al., 2014; Kato, 2012; Lawrence et al., 2015). In the stress and coping literature, several scholars and researchers have categorized coping strategies to better understand the range of coping efforts used to manage stress within various contexts including living with a chronic disease. Coping categorizations include: (a) problem-focused (PFC) v. emotion-focused (EFC) (Lazarus & Folkman, 1984), (b) active v. passive (Brown & Nicassio, 1987), (c) cognitive v. behavioral (Astor-Dubin & Hammen, 1984), and (d) approach v. avoidant (Moos et al., 1990). Skinner et al.

(2003) identified over 100 category systems to classify coping strategies and determined that no two systems contained the same set of categories.

Coping research has largely focused on PFC and EFC, constructs that were first proposed in Lazarus and Folkman's Transactional Theory of Stress and Coping (TTSC) (Lazarus, 1993; Lazarus & Folkman, 1984, 1987), the most influential coping theory to date. These strategies focus on two major functions of coping—problem management (i.e., PFC) and emotion regulation (i.e., EFC). A PFC strategy is an active attempt to change the stressful situation. An EFC strategy is a coping response that is initiated to reduce negative emotions that are evoked by the stressor instead of directly addressing the source itself (Lazarus & Folkman, 1984). Despite the vast array of coping categories, unbounded strategies, and the lack of consensus among theorists, researchers and clinicians alike still believe that certain coping strategies are more effective than others. In general, researchers and practitioners suggest that PFC is associated with better health outcomes (Penley et al., 2002). However, some researchers have found that EFC can also be an effective means of coping and at times associated with better psychological adjustment and mental health outcomes (Stanton & Low, 2012). This is especially true for people living with chronic conditions characterized by functional loss and uncertainty such as MS (McCabe & Battista, 2004; McCabe et al., 2004; Schwartz, 1999). As a result of inconsistent findings in the coping literature, a new perspective of the coping process and a new concept, coping flexibility, emerged.

Unfortunately, coping flexibility can be a difficult construct to observe and measure, in part because it is a complex process that has been defined in numerous ways, both practically and empirically. The coping flexibility construct stems from the Transactional Theory of Stress and Coping (TTSC) (Lazarus & Folkman 1984, 1987). Several researchers have described

coping flexibility as a problem-solving skill in which individuals can demonstrate higher-order of thinking abilities. Cheng and Cheung (2005) described coping flexibility as a type of complex thinking that involves two separate cognitive dimensions: differentiation and integration.

Whereas differentiation refers to the ability to perceive multiple factors and consider multiple perspectives within a specific stressful context, integration refers to making trade-offs regarding the strengths and limitations of different coping strategies.

Schwartz (1990) defined coping flexibility as a cognitive process in which one recognizes that a coping strategy is ineffective. As a result, the individual shifts into a purposive trial and error method to test other alternative strategies until a desired outcome is reached. Schwartz's (1990) perspective emphasizes that effective coping leads to a sense of control despite the severity or duration of a stressful situation. Kato (2012) expanded this definition and classified coping flexibility as the ability to discontinue an ineffective coping strategy and produce and implement an alternative strategy. According to Kato's (2012) definition, individuals actively cope with stress regardless of the stressor and as a result engage in two reciprocal processes: evaluation coping and adaptive coping. Evaluation coping refers to monitoring and evaluating the effects of a coping strategy and abandoning the strategy if the outcome is unfavorable. Thus, coping flexibility involves being aware of coping strategies, both cognitive and behavioral, and implementing strategies that help to alleviate the negative effects of stress and produce adaptive outcomes (Kato, 2012).

Most stressors are complex and require the use of multiple coping strategies to effectively deal with a single stressful event. Although this perspective would highlight the significance of coping flexibility research, relatively little research has been conducted to evaluate this construct compared to coping in general (Bonanno & Burton, 2013). However, more recently efforts have

been made to focus on this important aspect of psychological adjustment. In a meta-analysis on coping flexibility, Cheng et al. (2014) summarized that within the coping literature five main approaches have been used to assess this construct: (a) a broad coping repertoire, (b) a well-balanced coping profile, (c) strategy-situation fit, (d) cross-situational variability in strategy deployment, and (e) the perceived ability to cope with environmental changes. The broad repertoire and balanced profile perspectives refer to the structure of one's coping methods and strategies, whereas the cross-situational variability and strategy-situation fit categories involve the interplay between environmental factors, strategy selection, and implementation. Lastly, the perceived ability approach refers to the appraisal of one's self-efficacy in utilizing coping strategies to effectively manage situational change (Cheng et al., 2014).

In the context of coping research, coping flexibility has often been assessed by testing the Coping Flexibility Hypothesis (CFH) which proposes that more flexibility in coping is related to better adaptational outcomes and overall health and wellness (Kato, 2012). Essentially, more flexibility equates to more coping effectiveness. A coping strategy is deemed effective if it reduces psychological distress or increases well-being. The CFH has been validated in several studies (e. g., Cheng, 2001; Kato, 2015b). Researchers have found that people who have a range of diverse coping strategies are at an advantage compared to those who do not (Cheng, 2003; Kato, 2012). Furthermore, individuals who report greater coping flexibility tend to also report fewer psychological, emotional, and physiological problems (Cheng et al., 2014; Kato, 2001; Sideridis, 2006) and better recovery from illness or injury (Kato, 2015c; Roussi et al., 2007). Moreover, coping flexibility also predicts mental health outcomes (Lester et al., 1994; Rodin et al., 2017), and high flexibility is associated with other trait measures of well-being, including resilience, self-efficacy, and optimism among others (Cheng et al., 2014). However, low coping

flexibility, or rigidity, has been linked to several mental health problems including depression and post-traumatic stress disorder (Rodin et al., 2017).

### **Coping Flexibility Among People with Multiple Sclerosis**

The coping experiences among PwMS are unique to each individual and vary depending on factors such as age, gender, cultural aspects, and disease characteristics. Although the clinical manifestation of MS varies from person to person in terms of symptoms and severity, there are some commonalities among the larger community of individuals living with MS. Disease-related stressors and general stress are often the focus in research among PwMS and include the following: (a) living with common symptoms (e.g., fatigue), (b) maintaining employment, (c) financial stability, and (d) managing role expectations. In addition, the uncertainty of how disease progression will affect one's identity and QoL are additional stressors that PwMS may encounter (Alschuler & Beier, 2015). PwMS must also cope with other stressors such as social stress. For example, members of historically marginalized groups living with MS (e.g., AAWwMS) must also contend with microaggressive stress which is stress caused by subtle expressions of discrimination (Sue, 2010). Thus, coping is considered to be the one of the most important factors in disease management and the overall health and well-being for PwMS.

Research on coping by PwMS has consistently shown that individuals engage in a mixture of PFC and EFC strategies at different stages throughout their disease course (Lode et al., 2007). For instance, several researchers have found that PwMS mainly engage in EFC strategies early in the disease course (e.g., Buelow, 1991). This form of coping is often used as a psychological strategy to buffer the emotional distress that is often associated with being diagnosed with a chronic disease (Calandri et al., 2017). Additionally, in the early stages of a chronic disease, individuals may experience strong emotional responses such as depression,

anxiety, anger, and grief (Turner & Kelly, 2000). EFC helps to regulate these negative emotions in efforts to prevent further emotional distress. These coping strategies are also used in connection to exacerbations or attacks from the disease (Warren et al., 1991). In contrast to the early stages of MS, PFC strategies are often used when individuals have lived with the disease for several years and experienced debilitating symptoms that have impacted their daily lives (DalMonte et al., 2004). This shift in coping throughout the disease course suggests that utilizing counseling interventions to help individuals build a coping repertoire in the early stages of MS may improve their psychological adjustment and psychosocial functioning as the MS progresses.

Coping is essential for stress reduction and preventing or decreasing the impact of stress-related relapses in MS (Mohr et al., 2004). Since controllability is a key factor in determining the impact of stress on mood and behavior (Breier et al., 1987; Henderson et al., 2012), coping research among PwMS has also focused on the differences in coping with controllable and uncontrollable stressors. Although stressors are considered controllable or uncontrollable based on individuals' perceptions, the bulk of research has focused on group differences without examining individual ones. In the context of living with a chronic disease, when a stressor is controllable PFC may be best and most effective, while EFC may yield results that are more successful when the stressor cannot be changed or controlled (e.g., experiencing a relapse) (Satterfield, 2008; Stern et al., 1982). Research data suggest this is also true among PwMS. In a cross-sectional study on coping among veterans with MS, Roubinov et al. (2015) found that PFC strategies aimed to change uncontrollable MS-related stressors (e.g., cognitive, sensory, or motor deficits) led to an increase in symptoms of depression and anxiety. However, coping strategies used to manage difficult emotions in the face of uncontrollable stressors led to improved mental health outcomes. In the Turner and Williams (2015) study, these strategies were called meaning-

focused coping because they emphasized cultivating acceptance and finding meaning when facing a challenging situation, but it has many parallels to EFC.

Several researchers have also compared the use of coping strategies between PwMS and the general population. For example, McCabe et al. (2004) found that PwMS were more likely to engage in EFC strategies compared to the general population. According to McCabe et al.'s (2004) findings, respondents with MS indicated that they were more likely to use a detached style of coping in comparison to respondents representing the general population. Gender differences were also found in the study. Men with MS were less likely to adopt problem-solving coping styles and seeking support which was associated with poorer levels of psychological adjustment. However, women (both with MS and from the general population) were more likely to indicate using coping strategies that involved seeking social support and focusing on the positive compared to men (McCabe et al., 2004) and this has remained consistent in longitudinal studies (e.g., McCabe et al., 2009).

While the focus on coping among PwMS has primarily focused on the individual, the role of health care providers (e.g., physicians, physical therapists, and mental health professionals) on the coping efforts of PwMS cannot be minimized. Counselors and other practitioners have the ability to influence the coping efforts of persons living with MS. Sufficient information, emotional support, and cultural sensitivity from providers have a significant impact on how individuals cope with chronic disease (Buelow, 1991). Larsen et al. (2007) found that quality information provided by health care providers (e.g., neurologist, clinical practitioner, MS nurse) at the early stages of the disease may help facilitate more effective coping strategies and overall chronic disease management among PwMS. In a qualitative study on successful coping among women with MS, Pinson et al. (1999) found that only 40% of participants felt they had sufficient

or ample support from their health care providers at the time of diagnosis. By the conclusion of the study, participants felt they had received adequate or abundant support from their providers and that this support aided their coping efforts (Pinson et al., 2009).

As the research indicates, the appraisal of stressful situations determines the type of coping strategies one utilizes (Cheng et al., 2014; Henderson et al., 2012; Kato, 2001). When coping strategies do not aid in stress reduction and adversely affect one's mental health and well-being, they are considered to be ineffective. Living with MS can challenge an individual's coping self-efficacy, but it does not mean one cannot gain new tools to successfully cope with this chronic disease. Instead, living with MS means integrating and recalibrating coping efforts to adjust and readjust to a new normal. In the context of living with a chronic disease, the ability to increase flexibility in coping strategies may be associated with better treatment adherence and may lead to reduced relapses (Costello et al., 2008). Therefore, the benefits of counseling geared toward improving coping flexibility could support the overall health and wellness of AAWwMS by promoting adaptive coping skills and better chronic disease management.

Coping flexibility does not fit into a one-size-fits-all category, as there are vast individual differences that impact the coping process. While considerable research has been done to examine the coping patterns of PwMS, there has not been a focus on AAWwMS. Although AAWwMS may have similar dimensions of identity (e.g., race, gender), MS is a disease of great variability and unpredictability that further impacts their coping behaviors. Additionally, systemic and cultural factors contribute to the coping resources and strategies that are accessible to AAWwMS to manage their stress while living with this chronic disease.

## **Cultural Factors Affecting African American Women with Multiple Sclerosis**

Cultural perceptions of stress and coping influence how perceived and actual threats to one's well-being are appraised and which coping strategies are initiated (Thomas et al., 2008). According to Folkman and Moskowitz (2004) "an important motivation for studying coping is the belief that within a given culture certain ways of coping are more and less effective in promoting emotional well-being and addressing problems causing distress" (p. 753).

Environmental factors partly determine the pressures and demands (i.e., ongoing stressors) that impact the individual and the social resources available to them, but the cultural context shapes these stressors and resources (Chun et al., 2006).

Cultural group membership, particularly among historically oppressed groups, influences these perceptions and belief systems associated with stress and coping processes because it has a significant effect on the nature and frequency of potentially stressful life events that one may experience. According to Slavin et al. (1991), there are four ways that members from historically marginalized groups are exposed to potentially stressful encounters in their daily lives. These stress-inducing events include: (a) simply having a minority status within the context of majority cultural settings, (b) experiencing overt and covert acts of discrimination with regularity, (c) lacking political power and financial security because of group membership that is often concentrated in lower socioeconomic status categories, and (d) facing increased hostility as a result of practicing unique customs.

Although stress appraisal and the coping response are individualized processes, research findings across disciplines indicate significant cross-cultural differences, particularly between minority-majority culture comparisons. However, these studies often focus on college students or working professionals (e.g., Hashim, 2003; Salash, 2013). Within the context of chronic disease,

culture plays an important role in: (a) one's understanding of the disease; (b) care-seeking behaviors; (c) stress management and coping strategies; (d) and treatment choices, options, and compliance (Turner, 1996). However, for individuals with stress-related chronic health conditions, cultural differences in the type, frequency, and intensity of stressors can adversely impact their symptoms. In the MS context, there is only one study (to the counselor/investigator's knowledge) that examined cross-cultural differences related to stress *and* Black women as a primary focus of the research. Johnson et al. (2007) explored whether social stressors and resources differed among African Americans and European Americans with MS. The significant findings from the study were that African Americans reported having fewer friend resources and more financial stressors compared to White participants; but among both groups, participants with fewer financial resources reported more symptom severity. Although the research on cultural differences in stress and coping among PwMS is scant, this study provides key insights and highlights the importance of how social positions influence the appraisal of stress and perceived coping needs.

Based on the literature, it appears as if individualized interventions aimed to target coping flexibility must incorporate cultural perceptions and beliefs related to stress appraisal and the coping process. Cultural traditions and customs that promote resilience are believed to be beneficial to the coping process (Holtorf, 2018). Therefore, incorporating cultural influences is necessary in order to develop a coping flexibility program that meets the unique and diverse needs of AAWwMS.

### **Common Stressors and Coping Strategies Among African American Women**

Dimensions of identity have a significant influence on the coping strategies one uses to respond to stressful situations. Due to their membership in multiple oppressed groups,

AAWwMS may be at an increased risk of stress exposure which makes them vulnerable to experiencing relapses and a worsening of their MS. Intersectionality has been a primary theoretical framework used to describe how multiple social identities such as race, gender, socioeconomic status, and disability intersect at the individual or micro level to reflect the interlocking systems of privilege and oppression (i.e., racism, sexism, classism, ableism) at the macro or institutional/systemic level (Bowleg, 2012; Crenshaw, 1991). Intersectionality is rooted in Black Feminist thought and has been integral in describing the lived experiences of Black women from their own context and vantage point (Bowleg, 2012). Although there is substantive research on the coping styles and attitudes of Black women, there is limited research on their coping experiences within the context of chronic disease and disability. Most of the coping literature on Black women focuses on daily stress (e.g., role strain), work-related stress, and stress from the various forms of oppression they experience (Gay & Tate, 1998; Pieterse et al., 2013). Within these contexts, Black women have utilized a variety of coping mechanisms and these same strategies have also been found within the context of managing a chronic disease and disability.

The coping efforts of Black women may be influenced by their unique experience and cultural beliefs based upon the intersection of their gender and racial identity. Therefore, it is important to consider the coping strategies they utilize and how these strategies either promote or impede coping flexibility. In a qualitative study on the coping efforts of Black women, Everett et al. (2010) found that participants identified common sources of stress which included: (a) balancing work and family responsibilities, (b) experiencing role strain, (c) having financial stress, and (d) being the “go-to person” to address family problems. Everett et al. (2010) found that Black women used EFC and PFC, such as spirituality, prayer, and engaging in self-care

behaviors to cope with these stressors. Similarly, Drakeford (2017) found that Black women used a mixture of approach and avoidance strategies, but overall participants reported spirituality as the most utilized coping strategy. These findings support previous research that indicates spirituality as a significant and effective coping strategy for various stressors experienced by Black women. Overall, Black women engage in a variety of coping mechanisms to manage general stress and the same is true within the work environment.

Researchers have examined Black women's coping responses to work-related stress which is often viewed as separate from general stress because it often occurs due to stress-inducing management practices and adverse working conditions (Bhui et al., 2016). Work-related stress is defined as "a response people may have when presented with work demands and pressures that are not matched to their knowledge and abilities and which challenge their ability to cope" (WHO, n.d., para. 3). Historically, Black women tend to rely on spirituality as a coping resource in the work setting (Bacchus, 2008; Bacchus & Holley, 2004). Bacchus and Holley (2004) found that, within the context of the workplace, spirituality provides both problem management and emotional regulation for Black women. This is because engaging in spiritual practices such as prayer, meditation, and inspirational readings serve many different coping functions for Black women. These functions include being a means of gaining personal strength, a resource to assist in decision-making, and a strategy to reappraise stressful situations (Bacchus & Holley, 2004). The use of spirituality to cope with work-related stress has also been supported in other studies (e.g., Bacchus, 2008; Charters et al., 2008).

Another coping resource that Black women use to manage work-related stress is social support. Linnabery et al. (2014) found that among professional Black women social support from coworkers, family, church members, and supervisors predicted their well-being, particularly for

participants who did not regularly cope by using inner resources. These findings support previous research that suggests that Black women often use spirituality and seeking social support as coping strategies (Mattis, 2002).

Researchers have also investigated how Black women cope with various forms of oppression, including racism, sexism, and gendered racism. Through analysis of oral history data, Lykes (1983) found that Black women demonstrated coping flexibility, especially when coping with institutionalized discrimination. While some women engaged in a direct instrumental strategy to confront discrimination, others either indirectly addressed the problem or took no immediate action at all. Similarly, in a qualitative study, Shorter-Gooden (2004) examined Black women's reactions to racism and sexism and their coping efforts. The strategies most utilized by participants were a combination of internal resources and external behaviors. Internal resources included engaging in spiritual practices such as looking to ancestors for strength and valuing themselves. External behaviors included seeking social support, being assertive, and modifying speech and conduct with others.

Black women also experience a unique form of discrimination called gendered racism which refers to the simultaneous experience of both racism and sexism (Essed, 1991). In a correlational study, Thomas et al. (2008) explored the relationship between the accumulative effect of gendered racism and psychological distress among Black women and found that participants engaged in a combination of coping strategies. Specifically, Thomas et al. (2008) found that the use of cognitive-emotional coping styles reduced the harmful effects of discrimination among Black women. These strategies were described as efforts to manage environmental stressors such as blotting out the incident, minimizing the negative, or engaging in healthy distraction. In another study, Lewis et al. (2013) found that Black women coped with

gendered racism through various coping strategies that were described as resistance coping (e.g., resisting Eurocentric standards), collective coping (e.g., leaning on others for support), and self-protective coping (e.g., desensitizing, escaping, and becoming a Black “Superwoman”). For participants, desensitizing and escaping were described as the use of avoidance coping strategies such as eating or sleeping (Lewis et al., 2013). Becoming a Black “Superwoman” involved absorbing gendered racism by taking on multiple roles and responsibilities as a way to shield oneself and exemplify strength and resilience. This cognitive strategy aligns with the Strong Black Woman (SBW) stereotype which is a common coping mechanism among Black women that has received a lot of criticism (Donovan & West, 2015; Nelson et al., 2016). Based on decades of coping research, Black women have utilized a combination of strategies to cope with various forms of oppression.

More recently, Black women’s coping responses within the context of chronic disease and disability have become a focal point. Most of the literature has focused on how Black women cope with chronic health conditions such as HIV/AIDS (Watkins-Hayes et al., 2012), diabetes (Newlin et al., 2010), chronic pain (Tan et al., 2005), cardiovascular disease (Warren-Findlow & Issel, 2010), cancer (Gaston-Johansson, Haisfield-Wolfe, Reddick, Goldstein, & Lawal, 2013), and kidney disease (Lissanu et al., 2019). Yet, the coping responses of Black women living with MS is scant. This research is much needed since McLaughlin (2017) found that stress management was identified as an important self-care activity in a sample of AAWwMS.

Coping with a chronic disease and/or disability involves adjusting to the notion of living with a compromised state of health (e.g. Dutta & Kundu, 2007, Holt et al., 2014), and coping with the idea of making necessary life changes, such as readjusting life roles and changing one’s

employment status (Dekker & de Groot, 2018; Livneh & Martz, 2012). To address these stressors and more, Black women engage in a combination of coping strategies. For example, Warren-Findlow and Issel (2010) found that Black women with heart disease engage in active coping strategies such as “not worrying”, a cognitive buffering strategy, to prevent the worsening of their health and to protect against psychological paralysis. Spirituality is another common coping strategy among Black women with chronic diseases (e.g., diabetes, cancer) (Gaston-Johansson et al., 2013) and so is endorsement of the SBW stereotype. In a qualitative study on the psychological adjustment process of AAWwMS, Henry (2016) found that participants endorsed the Superwoman Schema (Woods-Giscombé, 2010), a construct closely related to the SBW stereotype, as a coping mechanism post-diagnosis. In sum, Black women cope with chronic disease and disability by using cognitive and behavioral strategies to help them adjust and readjust to the various changes and stressors associated with having a chronic health condition.

In addition to examining coping responses used by Black women, researchers have also investigated the relationship between coping strategies and psychological distress. Adaptive coping strategies are considered to be effective coping responses since they decrease distress while maladaptive coping increases distress (Zeidner & Saklofske, 1996). Unfortunately, the lived experiences of Black women include various forms of oppression in addition to daily life stress, and for some they must also contend with stressors associated with chronic disease and disability. The coping strategies they employ to address these various stressors may serve to mitigate or exacerbate psychological distress. In several studies (e.g., Szymanski & Lewis, 2016; West et al., 2010) PFC strategies as a whole were found to often weaken the positive relationship between stressful events (e.g., racism) and mood disturbances such as depression. Based on this

coping research, PFC could be more adaptive for Black women when they feel that the stressor is controllable. In contrast, avoidant and PFC strategies partially mediate the positive relationship between various stressors (e.g., gendered racism, workplace stress) and psychological distress and reduced QoL (Gaston-Johansson et al., 2013; Greer, 2011; Thomas et al., 2008; Utsey et al., 2000). These studies collectively suggest that forms of EFC and avoidant coping may increase distress for Black women unless there is some level of uncontrollability.

Overall, Black women use a combination of strategies to cope with a wide range of stressors. The research findings discussed in this section indicate that Black women engage in coping responses that exhibit coping flexibility but may not fit traditional categorizations of coping (e.g., prayer as a PFC strategy). Since culture plays a significant role in the stress and coping process, Black women's cultural perceptions of coping must be included in interventions that focus on the coping efforts of this group. Furthermore, some culturally-specific coping responses of Black women such as the SBW stereotype, may actually inhibit adaptive coping and generate more stress that takes a toll on the psychological and physical health of this population (Donovan & West, 2015).

### ***Strong Black Woman Stereotype***

Although strength is often embraced as a prevalent feature of Black womanhood, Black women's endorsement of the SBW stereotype has been met with criticism because this race-gender schema has been associated with adverse health outcomes in empirical research. The SBW stereotype has been a cultural archetype of Black women "prescribing that Black women render a guise of self-reliance, selflessness, and psychological, emotional and physical strength" (Baker et al., 2015, p. 51). The narrative associated with being a Strong Black Woman was created during slavery as a survival response and since then it has been passed down

intergenerationally as part of the socialization process for Black girls (Donovan & West, 2015). Most scholars ascribe two central tenets to the SBW stereotype: strength and caregiving. Regarding strength, the SBW is perceived as having a Teflon demeanor in which she is naturally resilient and emotionally contained, able to handle any and every stress and trauma she encounters without difficulty. Her strength is also shown through her self-sufficiency, self-control, and unmatched work ethic because she works tirelessly, consistently going above and beyond what is expected without complaint (Collins, 2004; Wallace, 1990; Woods-Giscombé, 2010). When it comes to caregiving, the SBW is perceived as self-sacrificing, always giving her time, energy, and resources to help others without expecting any reciprocity. She consistently puts others needs before her own regardless of the circumstance (Beauboeuf-Lafontant, 2009; Harrington et al., 2010). Overall, the SBW stereotype is a kind of “superwoman syndrome” that Black women are expected to embody in order to successfully balance roles and responsibilities in their work, family, and the community.

Researchers have found that Black women’s beliefs tied to the SBW stereotype have a significant impact on their coping behaviors. Black women adhering to the SBW stereotype may inadvertently increase the amount of stress they experience, and internalization of this label could represent a form of internalized oppression (Bacchus, 2008). Scholars have even suggested that the SBW stereotype may be a liability for Black women because of the possible psychological distress and other negative health consequences associated with it (Corbin et al., 2018; Wang & Beydoun, 2007). Moreover, trying to be strong despite one’s circumstances or one’s mental health is problematic because it predicts maladaptive coping strategies such as overeating and emotional inhibition and it can predict help-seeking attitudes and behaviors (Harrington et al., 2010; Woods-Giscombe, 2010). Watson and Hunter (2015) examined the role

of the SBW schema on mental health and help-seeking behaviors of Black women and found that participants who endorsed the SBW stereotype experienced more anxiety and depression symptoms and resistance toward professional mental health treatment than those who did not. Drakeford (2017) also found positive relationships between adherence to the SBW stereotype, emotional suppression, and psychological distress among Black women. These findings support and extend previous research on adverse health outcomes associated with endorsement of the SBW stereotype.

In addition, anecdotal and qualitative evidence suggests that endorsing the SBW stereotype restricts Black women's ability to engage in adaptive coping which exacerbates psychological distress associated with stress. For example, Bailey (2018) explored intergenerational differences among Black women regarding their views on the SBW stereotype and found that young adults generally rejected endorsing this characteristic compared to middle-aged and older women. Participants that rejected the stereotype reasoned that it "limited the opportunity for Black women to be vulnerable, display emotion, or need the help of others" (Bailey, 2018, p. 15). In another study, Nelson et al. (2016) found that Black women have ambivalent perceptions of the SBW stereotype because of its historical and sociocultural context. However, participants sought to consciously redefine what it means to be a Strong Black Woman to make this cultural narrative more realistic. Although strength is a revered aspect of Black womanhood, endorsement of the SBW stereotype creates unhealthy and unrealistic demands upon Black women to balance multiple responsibilities and care for others all while maintaining a façade of strength and a false sense of empowerment.

For Black women, the SBW stereotype may represent a unique stressor that can further complicate their coping responses. The cultural beliefs associated with this label must be

considered when working with AAWwMS on their coping efforts. Health care providers, counselors, and other practitioners must be mindful of the significance of this stereotype when working with Black women. Furthermore, they must seek to understand how Black women make meaning of this role and its impact on their coping response and help-seeking behaviors to address their physical and mental health needs.

### **Cross-Cultural Interactions with Health Care Providers**

As the U.S. population become more diverse, health care providers are challenged to become more culturally competent to meet the changing needs of individuals seeking treatment for their chronic diseases. According to data from the U.S. Census Bureau, by 2025 America's population is projected to be 58 % White and by 2060, the population is projected to be 44 % White, indicating significant demographic and cultural changes in the nation (Vespa et al., 2018). Although the U.S. population is becoming more diversified, the physician workforce has been diversifying at a much slower pace and uneven course. In a retrospective study examining racial/ethnic diversity among physicians, Xierali and Nivet (2018) found that Whites constituted the majority of all medical specialties. Specifically, Whites comprised 75% of family physicians and general practitioners, who constitute the largest group among physicians.

When PwMS experience symptoms that cause them to seek medical attention, they often see a primary care physician or several other specialists before they are finally referred to a neurologist, who is the only medical professional that can make the official MS diagnosis. In the U.S., over 63% of neurologists identified as White and of this group 62% were men (Peckham, 2017). Fourteen percent of neurologists described themselves as having Asian Indian descent and only 5% were Hispanic/Latinx. Unfortunately, only 1% of neurologists are African American (Peckham, 2017). Therefore, at the time of diagnosis, most PwMS more than likely met with a

neurologist who was a White male. Clearly, this relatively homogenous physician population does not reflect the growing diversity among PwMS and these cross-cultural patient-provider interactions have contributed to significant racial/ethnic differences in the diagnosis process.

In an ethnographic study exploring the experiences of African Americans and European Americans with MS, Loveland (1999) found significant cross-cultural differences and interactions among providers and participants. First, none of the 100 participants, which included 23 Black women, had consulted an African-American physician leading up to an official diagnosis. Second, Black women were disproportionately told that their MS symptoms were due to an emotional or psychological issue even when they were hospitalized or tested for conditions that might explain their symptoms. Almost 30% of AAWwMS from the study had that experience, versus only 11% of White women. Lastly, once a diagnosis of MS was reached, the type and content of communication by the physician to the person with MS and their family members was noticeably different. Providers used terms such as "demyelinating" or "demyelination" to explain the MS diagnosis to Whites diagnosed with MS, but no such terms were used with African-Americans (Loveland, 1999). In a more recent qualitative study, AAWwMS reported similar experiences leading up to an official diagnosis (Henry, 2016). These instances may be a microcosm of how cross-cultural differences can impact the type and quality of care that African Americans receive that can lead to health care disparities.

For decades, researchers have developed a growing body of literature to examine the widespread and persistent racial and ethnic disparities in health care. These disparities make it difficult for Black women and African Americans as a whole to build trust with the medical establishment (George et al., 2014). Health care disparities include not only physical care but also mental health treatment and social services (Donnelly et al., 2007). In a critical review on

the racial and ethnic disparities in health care quality, Fiscella and Sanders (2016) identified several contributing factors of this complex phenomenon. While some factors are related to sociocultural dimensions (e.g., race, ethnicity, poverty, limited education), other factors are related to interpersonal dynamics (e.g., patient-provider relationship). For instance, implicit clinician racial bias has garnered much attention in public health literature (Dovidio & Fiske, 2012). This is due in part to research that indicates that physicians may exhibit racial bias in their decision making when it comes to the management of chronic health conditions such as chronic pain (Anderson et al., 2009; Hall et al., 2015). Furthermore, physician racial bias has also been associated with less patient-centered communication and informed-decision making with racial/ethnic minority patients (Blair et al., 2014; Cooper et al., 2012; Hagiwara et al., 2017). These findings are disturbing especially for POC with chronic conditions like AAWwMS who must frequently use the health care system. These findings are also significant because they ultimately contribute to the overall health outcomes of POC in the U.S.

Similarly, in mental health care, racial and ethnic disparities persist. Robust evidence shows that POC are least likely to seek mental health treatment compared to Whites (Jimenez et al., 2013; Le Cook et al., 2013). However, when they do they receive treatment that is poor quality and not the care they needed. In addition, an audit study conducted by Shin et al. (2016) revealed provider racial bias in promoting mental health services based upon stereotypical Black and White sounding names. Shin et al. (2016) linked the study to provider recommendations in actual practice but this link is speculative. Overall, the research clearly indicates that more concerted efforts must be taken by health care professionals to help reduce the racial and ethnic disparities in all realms of the health care system in order to improve health outcomes for all.

Black women have disproportionately been diagnosed with various chronic diseases and now MS is no exception. With Black women now becoming the face of MS, providers and practitioners working with this group need to become more culturally competent and the health care system needs to have more representation to meet the ever-changing needs of this population and PwMS overall. Counselors can play a critical role in helping AAWwMS cope with stressors associated with frequent interaction with the health care system and engage in social justice and advocacy efforts to help improve their lives.

### **Multicultural Competence of Clinical Mental Health Counselors**

The counseling profession calls on counselors to engage in efforts to advocate and address social inequities within various systems in society (Decker et al., 2016). According to the American Mental Health Counseling Association (AMHCA, 2015), “counselors may serve as advocates at the individual, institutional, and/or societal level in an effort to foster sociopolitical change that meets the needs of the client or the community” (p. 23). Counselors must be culturally competent and utilize a counseling approach that emphasizes the intersectionality of each client and address issues of power, privilege, and oppression within the therapeutic relationship (Ratts, et al., 2016). Fortunately, the Multicultural Social Justice Counseling Competencies (MSJCC; Ratts et al., 2016) were developed to be *the* model that counselors can utilize to help them self-reflect and work through their personal cultural development as they support clients throughout the therapeutic process. The MSJCC can serve as a tool and a guide to help counselors develop individualized coping flexibility interventions like the one that was used in the present study.

### ***MSJCC Framework***

The MSJCC offers counselors a framework to emphasize cultural and contextual factors when working with clients in clinical practice. Society has become more diverse, and as a result multicultural competence has become a primary concern of counseling scholars and practitioners. Counselors must be aware of their clients' worldview as well as their own. Intersections of identity and multicultural perspectives should be addressed in the counseling relationship and a focal point in designing individualized interventions.

Based on a socioecological framework, the MSJCC (Ratts, et al., 2016) is made up of four quadrants which are used to illustrate the intersection of identities and the dynamics of power, privilege, and oppression that influence the counseling relationship (Ratts et al., 2016). Four developmental domains are represented within each quadrant. These domains contribute to the development of multicultural and social justice competence and include the following: (a) counselor self-awareness, (b) client worldview, (c) counseling relationship, and (d) counseling and advocacy interventions. The MSJCC are further organized into four aspirational competencies of attitudes and beliefs, knowledge, skills, and action (Ratts, et al., 2016). The MSJCC reflects how the privileged and marginalized statuses of counselors and clients, their unique worldviews, and cultural biases and beliefs interact and influence the counseling relationship (Ratts, et al., 2016). Being culturally competent is vital to counseling practice and needed to “culturally anchor interventions” (Bernal & Sáez-Santiago, p. 129). Otherwise, counselors may utilize Eurocentric-based interventions that may actually be oppressive and harmful to culturally diverse clients and their communities. To demonstrate cultural competence ascribed by the MSJCC, counselors must be aware of their personal and professional influences and biases, intentionally work on all four developmental domains, and implement interventions

that are culturally relevant to client's needs and concerns (Sue et al., 2015). Thus, for counselors working with AAWwMS, it is important to recognize cultural and systemic factors that affect their coping efforts, QoL, and their disease course in order to provide culturally competent mental health treatment.

### **Systemic Factors Affecting African American Women with Multiple Sclerosis**

Over half of all adults in the U.S. have a chronic health condition, but African Americans and low-income populations are often disproportionately affected (CDC, 2013). As a result, these groups experience a significant burden of chronic conditions which in part have led to disparities in overall health outcomes. While clinician bias and other cultural factors can contribute to health care disparities, health inequities which are described as "systematic differences in the health of groups and communities occupying unequal positions in society that are avoidable and unjust" (Weinstein et al., 2017, p. 20) are also contributing factors. These inequities reflect an unfair distribution of health risks and access to quality health care and preventive services.

In 2002, the Institute of Medicine (IOM, 2002) report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* called national attention to the sobering data on racial/ethnic disparities in health care in the U.S. As a consequence, Congress authorized the Agency for Healthcare Research and Quality (AHRQ) to annually report on national and state health care disparities. Fifteen years later and the most recent minority health report (AHRQ, 2017) still indicates significant racial/ethnic, socioeconomic, and geographical differences in access to and quality of health care services and programs. These stark differences have long-term effects since they contribute to the overall health outcomes of millions of POC in the U.S.

## **Persistent Disparities in Health Care Access and Affordability**

People living with chronic diseases use health care services more often compared to those who do not have a chronic health condition in an effort to receive treatment, education, and support for their chronic disease management. This frequent interaction with the health care system has a direct impact on increasing health care costs. According to the CDC (2019), 90% of the nation's \$3.3 trillion health care expenditures are due to chronic and mental health conditions. To help reduce costs and improve health care delivery, policymakers passed the Patient Protection and Affordable Care Act (ACA) in 2010. Provisions of the ACA focused on five main areas of health care: (a) increasing health insurance coverage, (b) incentivizing performance and wellness, (c) improving value by reducing waste, (d) increasing access to preventative care and quality health care services, and (e) improving public health (Chait & Glied, 2018; French et al., 2016). While the ACA has had a significant impact on health insurance expansion and other systemic issues within the health care system (e.g., rising costs) (Obama, 2016; U.S. Department of Health and Human Services [HHS], 2015), disparities persist by geographic location, race/ethnicity, and income. This disparity gap could not be more evident among PwMS.

Health care access and utilization continue to be a challenge for certain segments of PwMS especially when it comes to specialty care. Saadi et al. (2017) analyzed nationally representative data from the 2006–2013 Medical Expenditure Panel Survey (MEPS) to evaluate differences in the use of neurologic care across a wide range of neurological conditions in the U.S. PwMS participated in the study. The research findings indicated that the profile of participants who had at least one outpatient neurologist visit were older White women with MS who were privately insured, had at least a post-secondary education, and a had a high

socioeconomic status. In contrast, African American participants were nearly 30% less likely to see an outpatient neurologist compared to their White counterparts. These findings support and extend previous research by Minden et al. (2008) who examined access to and use of neurologists among a broad, national sample of PwMS. The findings from that study showed that African Americans with MS who were disabled, had low income, were uninsured, or lived in rural areas were the least likely to receive care by a neurologist. According to Saadi et al. (2017), remedying disparities in neurologic health care access and utilization will require a systematic overhaul that includes: (a) improving health insurance coverage and access, (b) developing and implementing culturally relevant health literacy programs, (c) educating staff and providers about bias and the importance of culturally competent care, (d) and increasing the proportion of POC in the neurology workforce.

For PwMS, receiving specialty care from a neurologist is recommended because it increases the likelihood of taking DMTs and leads to more engagement with the health care system (Minden et al., 2008). This is because PwMS who are being treated by a neurologist are more likely to receive treatment through outpatient rehabilitation programs and to utilize occupational therapists, urologists, and physical therapists compared to PwMS that are not being treated by a neurologist. Interestingly, this increased utilization of health care services does not translate to mental health treatment which may be due to a lack of disseminated information to neurologists on resources and services (Minden et al., 2008). In order to receive comprehensive care to manage MS, PwMS must have access to needed services but even still, access does not equate to affordability which is another area of concern.

The high cost of quality health care continues to be a barrier for people with chronic diseases and disabilities. The way the U.S. health care system is organized and financed, the lack

of price transparency, and the type of health insurance used to pay for services have all been cited as contributing factors to the high costs (Dalen, 2010; Muir et al., 2013), and these reasons all disproportionately affect POC and low-income populations seeking health care services (Oliver, 2008). This systemic issue must be addressed since financial stress is common among PwMS and others with chronic health conditions, and these stressors impact both physical and mental health (Skinner, Zautra, & Reich, 2004). Moreover, qualitative evidence indicates that the affordability of medical treatments and care required for chronic disease management have been identified as key reasons of economic hardship (Jeon et al., 2009). De Judicibus and McCabe (2007) conducted interviews with PwMS, health care professionals and family members of PwMS to examine the impact of financial costs associated with MS on families affected by the disease. The findings from the study indicated that direct and indirect costs related to MS care and treatment such as medical testing, treatment and medication placed significant financial strain on PwMS and their families and had a major impact on their QoL.

### **Role of Clinical Mental Health Counselors**

For counselors working with PwMS, stress associated with health care accessibility and affordability must be acknowledged and discussed, and strategies to improve health care utilization and financial strain should be explored. More specifically for AAWwMS, counselors can develop strategies to help these women cope with social stressors and financial stressors they may simultaneously experience in their interactions with the health care system. At the institutional level, counselors can support health care reform policies that seek to make health care more accessible and affordable because these limitations significantly impact POC and low-income populations. Counselors can also partner with providers to advocate for better care coordination to streamline services and increase comprehensive care which many scholars and

researchers believe can help reduce overall costs and improve health outcomes (Khullar & Chokshi, 2018; Marek et al., 2014).

Counselors are in a prime position to help people with chronic health conditions like AAWwMS cope with stressors and changes associated with their disease and daily life occurrences by creating interventions to reduce stress and improve adaptive coping (Vowles & Mccracken, 2010). Thus, counselors must keep current with literature on coping and psychological adjustment and design innovative empirical-based interventions to address the needs and concerns of clients with chronic disease. Lastly, counselors are encouraged to partner with physicians and other health care professionals to consult on client care to ultimately improve health outcomes. This client-centered approach is the cornerstone of the Chronic Care Model (Wagner et al., 1996).

### **Chronic Care Model**

Over the past few decades, the increased incidence of chronic disease poses major challenges for the health care system. To address these challenges, Wagner et al., 1996) developed the Chronic Care Model (CCM), a shift from the traditional medical model, that focuses on essential elements of chronic disease care instead of acute conditions. Wielawski (2006) further extended the model to include culturally relevant elements in service delivery. The evidence-based model provides guidance for effective chronic disease care to help providers collaborate and coordinate care. In addition, the model provides practitioners with a strategy to design and implement outcome-based comprehensive care programs to show accountability in service delivery and chronic disease management (Bodenheimer et al., 2002; Coleman et al., 2009; Dunn & Conard, 2018; Wagner et al., 2001). The CCM applies to a broad range of chronic diseases including neurological conditions such as MS and serves as a guide for physicians to

utilize practices that meet the complex needs of people with chronic health conditions. The model also provides a blueprint for the integrated role of counselors supporting clients with chronic disease and disability. In addition to supporting clients, counselors can support the team of health care professionals treating chronic diseases within the six components of the model: (a) health care organization, (b) delivery-system design, (c) clinical information systems, (d) decision support, (e) client self-management support, and (f) community resources. Each of the components is briefly described.

The first component, health care organization, refers to the overarching structure of the system providing health care services to clients. The second component, delivery-system design, refers to the arrangement of the team of providers and practitioners as well as structure for services and follow-up care. These coordinated efforts establish comprehensive care that includes not only medical but also counseling services and psychoeducational programs for clients. Health literacy and cultural sensitivity are two important features of the delivery system. The third component, clinical information systems, includes requirements to maintain accurate, up-to-date client records that are accessible by all health care professionals working on the treatment team. Clinical information systems are electronic file-keeping databases that counselors and other health care professional may not receive training for, but counselors are trained to take accurate clinical notes and document clients' progress. Therefore, counselors within the CCM can provide current and essential information for care coordination related to the client's mental health status, goals, and outcomes (Sheesley, 2016).

The fourth component, decision support, refers to gathering knowledge on the most up-to-date information about disease characteristics, best practices and evidence-based treatments by providers, caregivers, and clients. To gather this information, providers and practitioners

must receive continuing education regarding the most recent research related to the chronic disease being treated. The fifth component, client self-management support, refers to the support provided by caregivers and professionals to assist people with chronic conditions to be active and informed self-managers (Fraser et al., 2013). Counselors can play an integral role in providing self-management support to clients by devising collaborative counseling plans and using interventions that help clients establish valuable and achievable goals (ACA, 2014). The sixth and final component, community resources, involves linking and using community resources to support health care efforts provided by the treatment team. Church-based support groups, local community health programs, clinic-based psychoeducational groups and internet-based support groups, are examples of acceptable community interventions (Grover & Joshi, 2015). Counselors can partner with communities and organizations to advocate for strategies and solutions to improve the health outcomes of community members.

The CCM (1996) allows counselors to be part of an interdisciplinary team where clinicians can connect and collaborate to help clients achieve an optimal level of health and well-being. This individualized approach to care coordination compliments the work of mental health counselors to deliver direct services to clients through a customized counseling plan and tailored interventions. This dissertation study will highlight the role of counselors within the CCM (1996) and best practices set forth by the *ACA Code of Ethics* (ACA, 2014) to design an intervention based on empirically supported theoretical models that have been effective with people with chronic disease and more specifically PwMS. To develop a wellness-based coping flexibility intervention for AAWwMS, a review of outcome-based coping research with PwMS is provided.

## Coping Flexibility Interventions

Based on the findings of two meta-analyses, Mullen and colleagues (Mullen et al., 1985; Mullen et al., 1992) proposed five research principles that investigators should apply in order to develop a quality intervention for outcome-based research with people living with a chronic condition. These principles include:

- (a) *relevance*—tailoring the program to knowledge, beliefs, and circumstances of the learner;
- (b) *individualization*—allowing learners to have personal questions answered or pacing their instructions;
- (c) *feedback*—providing information to learners about their level of accomplishment;
- (d) *reinforcement*—rewarding the behavior in ways other than feedback (e.g., social support); and
- (e) *facilitation*—providing a way for the learner to take action and/or reduce barriers (as cited in Stuifbergen, 2003, p. 468).

Unfortunately, the primary research method used in outcome research with people with a chronic disease are group comparisons despite marked differences between individuals diagnosed with the same chronic condition. In MS research, there is also a lack of literature pertaining to individualized interventions with PwMS. Additionally, in the context of coping outcome-based research, the bulk of coping flexibility interventions are done in clinical settings as group-based programs. Few intervention studies related to this concept have used a single-case research design.

The intervention strategies utilized in the literature typically fall into the category of coping skills training programs with a focus on group comparisons. According to Stensrud and Stensrud (1983), coping skills training is a systematic approach to stress management. Coping skills training interventions create the potential for behavior change to occur by increasing

awareness, providing new knowledge and perspectives, and teaching specific strategies that can be learned and practiced by participants to cope with a myriad of stressors. Many of these programs are grounded in Lazarus and Folkman's (1984) TTSC, the most influential coping theory to date. The following is an overview of select coping flexibility interventions used with PwMS.

### **Study One**

Through a meta-analysis Sesel et al. (2018) examined the effectiveness of psychosocial interventions for PwMS to assess the efficacy of such approaches for a range of psychosocial factors including emotional distress, depression, fatigue, pain and QoL outcomes. The results indicated that cognitive behavioral therapy (CBT) was the most common intervention tested. Other interventions included progressive muscle relaxation training, self-management, mindfulness, motivational interviewing, and coping skills training. Psychosocial interventions consistently showed a moderate effect on various outcomes among PwMS regardless of symptom profile and demographic and disease-specific factors. Based upon moderator analyses, Sesel et al. (2018) concluded that CBT interventions, when considered alone, appeared to be less effective than other psychological interventions which is inconsistent with previous meta-analyses (e.g., Hind et al., 2014; Mohr & Goodkin, 1999) that provided support for the use of CBT interventions for depression in PwMS. Sesel et al. (2018) postulated that one reason for this apparent lack of efficacy may be due to the time-limited nature of CBT compared to other psychotherapeutic interventions. There were fewer therapy hours on average for CBT interventions (i.e., 9.25 hours) compared to non-CBT studies (i.e., 19.79 hours) The findings of this study support the need for longer doses of therapy (i.e., the treatment modality) to be woven into the psychosocial intervention.

## Study Two

Schwartz (1999) conducted a longitudinal study to present a controlled comparison of two psychosocial interventions for PwMS, and more broadly chronic diseases marked by functional loss and unpredictability. The interventions were conducted over an 8-week timespan. The first intervention was a coping skills group ( $n = 64$ ) in a clinical setting facilitated by a health professional. The second intervention group involved peer telephone support ( $n = 68$ ) provided by hired lay PwMS who were trained in active listening techniques based in Rogerian therapy. Schwartz (1999) compared the effects of the interventions to determine whether there were significant findings on several domains related to QoL: clinical health, role performance, adaptability, and well-being. It was speculated that both of the interventions would have little or no effect on clinical health outcomes, but they would have a significant and positive effect on the other life domains. However, because the coping skills group was a more intense intervention that required more commitment, more effort, and it taught participants new skills, it was anticipated that it would have a stronger impact on improving or maintaining QoL.

The results indicated that the coping skills group intervention yielded significant gains over time in psychosocial role performance, coping behavior, and numerous aspects of well-being despite functional deterioration. In contrast, the peer telephone support intervention did not produce significant findings, influenced few outcomes, and led to a more negative appraisal of one's condition and abilities (e.g., reduced self-efficacy, external health locus of control) (Schwartz, 1999). However, the peer telephone support intervention was most helpful among participants with mood disorders (e.g., depression) compared to the coping skills group. Overall, the coping skills group was also deemed to be a better vehicle for facilitating response shift, helping patients to change their internal scripts, their perceptions on QoL, and their priorities.

The findings of this study support the need for coping skills training that includes reframing techniques and goal setting to be incorporated into a coping flexibility intervention.

### **Study Three**

Kugler et al. (2000) conducted an intervention study in a clinical setting to examine mental health outcomes and the psychoneuroimmunological effects of coping training in PwMS. Interestingly, the study did not include an explicit theoretical framework to guide the research. One of the study's weak points was the group design. Researchers did not clearly outline and operationally define a well-organized coping training program that could easily be replicated in a clinical setting. The 10-week coping training group included information about MS, psychoeducation, and the education and implementation of active coping strategies. Thirty-four participants who had recently been diagnosed with MS and were not taking disease modifying therapies received the intervention. The results were based off of 19 participants who had provided complete questionnaire data and completed their immunological check-up at the conclusion of the intervention. The goal of the coping training group was to help participants develop coping skills to improve their QoL and physical mobility and lessen MS progression by assessing immune parameters associated with the disease course.

Participants completed questionnaires to assess QoL, depression, and physical mobility and supplied blood samples throughout the course of the study to assess immune system functioning. A major finding of the study was the statistically significant reduction in depression among participants. In regard to immune parameters, researchers found an overall increase in cytotoxic T-cells and inconsistent findings in the activity of TH-1 cells and TH-2 cells. Cytotoxic T-cells are beneficial because they play a key role in adaptive cellular response and they prevent many bacterial infections and viruses (Anderson et al., 2006; Janeway et al., 2001). However,

TH-1 and TH-2 cells provide pro-inflammatory and anti-inflammatory responses, respectively, and therefore, a balance between these immune system functions is needed to maintain equilibrium (Berger, 2000). According to the findings of Kugler et al.'s (2000) study, psychosocial interventions can have a positive effect on specific immune system functions and incorporating brain-based psychoeducation into coping interventions can help PwMS better understand the brain-body connection.

#### **Study Four**

Drawing from the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984, 1987), Sanaeinasab et al. (2017) completed a randomized clinical trial to explore the coping effectiveness of a transactional model education program with Iranian women with MS. Researchers compared within and between treatment conditions for two intervention protocols with 80 Iranian women with MS in a clinical setting. The researchers tied TTSC's concept of coping into the education program. Participants completed two pre-post psychometric instruments at baseline and at 1-month and 3-month follow-ups to assess perceived stress and the effectiveness of specific coping behaviors.

Study participants were randomly separated into two distinct treatment protocols. The first protocol, the transactional model education program, focused on coping skills training to teach coping flexibility and the second protocol, the psychosocial care group, focused on standard psychosocial care provided by the MS Society which included emotional support and disease-related education. Participants who took part in the education program experienced a considerable reduction in perceived stress over time that was significantly more than participants in the control group. Another major finding of the study was the difference in coping behaviors and perceived coping effectiveness between groups. The use and effectiveness of PFC styles

increased in the intervention group and the effectiveness of EFC styles increased as well, despite the decrease in use over time. A key strength of the study was the group design. Researchers had an adequately powered sample size and clearly outlined and described the education program intervention that could easily be replicated in a clinical or real-world setting. The findings of this study support the need for PwMS to be able to fully engage in educational programs that incorporate various coping styles to reap the full benefits of a TTSC-based intervention.

### **Study Five**

Stuifbergen et al. (2003) employed an experimental research design to evaluate the effectiveness of a wellness-based intervention that focused on health-promoting behaviors (e.g., effective coping skills) aimed to improve the health and well-being of women with MS. The intervention was called The Wellness Program for Women with MS. It was a two-phase intervention program that included lifestyle-change classes over 8 weeks and post-intervention telephone follow-ups for three months. One hundred and thirteen women (ages 21–70 years) of varying racial and ethnic backgrounds, education levels, and socioeconomic status participated in the study. In the study, Black women comprised 12% of the sample. Participants completed a battery of pre- and post-measures on the constructs of severity of impairment, self-efficacy, health-promoting behavior barriers, health-promoting behavior resources, health-promoting behaviors, and QoL. Participants showed statistically significant improvements in self-efficacy, health behaviors, and selected aspects of QoL (pain and mental health). However, there were several other aspects of QoL (social functioning, physical function and vitality) where no statistically significant difference was found between groups. The study supported the use of wellness-based interventions to improve health-promoting behaviors and the effect they have on the overall wellness of women with varied backgrounds and circumstances living with MS.

## Summary of Studies

The aforementioned studies provided a variety of interventions that were utilized to increase various aspects of coping among PwMS. However, no studies identified interventions that utilized a brain-based framework solely with AAWwMS. Furthermore, the researchers used a heterogenous mix of methodological approaches to obtain and analyze data which further complicate how to measure a latent variable like coping flexibility. Nonetheless, important findings emerged and elucidated how the quality of the intervention was a key determinant in treatment effectiveness.

More specifically, theory-driven psychosocial interventions have been deemed beneficial in delivering coping skills training to PwMS to improve coping flexibility (Sanaeinasab et al., 2017; Schwartz & Rogers, 1994; Schwartz, 1999). This approach emphasizes the cognitive and behavioral strategies involved in the coping process to mitigate stress-inducing events linked to disease-related problems and general stressors. Wellness-based interventions have been influential in providing a holistic approach to coping and helping PwMS develop a coping repertoire. Coping skills training is centered on the development of problem-solving skills and self-regulation strategies for minimizing the health-damaging effects of stress and improving QoL.

Although several of the reviewed studies provided support for models based on coping-theory (e.g., TTSC), none of them utilized a single-case research design. Since there is much variability in the clinical presentation of MS, this brings into question whether group comparisons are sufficient and furthermore, if individualized interventions exploring cognitive and behavioral components of coping flexibility would produce similar results. To expound upon creating a brain-based framework to support single-case research designs, an overview of

neurocounseling, an emerging counseling approach (McHenry et al., 2014), is provided along with a brief overview of neuroeducation and its relevance to AAWwMS.

### **Neurocounseling**

In recent years, neurocounseling has become an emerging psychotherapeutic practice in the counseling field. In the last five years, there has been a tremendous outpouring of neuroscience-related interest within the counseling profession. This has led to the publication of counselor-oriented neuroscience textbooks (Chapin & Russell-Chapin, 2013; Luke, 2015; McHenry et al., 2014) and neuroscience-related articles in professional counseling journals to introduce counselors to this new approach (Russell-Chapin 2016; Field et al., 2015; Ivey, Ivey & Zalaquett, 2011; Makinson & Young, 2012; Miller & Barrio Minton, 2016). It has also led to the formation of neuroscience interest networks across several counseling associations and divisions like the American Mental Health Counselors Association (AMHCA). This interest continues to grow and has led to more concerted efforts to develop practical and developmentally appropriate strategies to implement neurocounseling with clients.

*Neurocounseling* is defined as “the integration of neuroscience into the practice of counseling, by teaching and illustrating the physiological underpinnings of many of our mental health concerns” (Russell-Chaplin, 2016, p. 93). In 2017, the American Counseling Association published its first text on this new counseling approach (ACA, 2017). The primary goal of the text is to help counselors learn more about neuroscience and provide guidance on how to integrate this new brain-based approach into their work with clients (Field et al., 2017). There are a variety of uses for neurocounseling. First, neurocounseling can be used by counseling practitioners to understand how and why psychotherapy changes the brain (Russell-Chapin, 2016). Next, neurocounseling can be used to help clinicians better understand clients’ presenting

concerns and enhance case conceptualization and treatment planning by using a brain-based perspective. Lastly, neurocounseling provides counselors with a more holistic approach to working with clients by emphasizing wellness and mind-body integration (Field et al., 2017).

Neurocounseling also includes technical approaches such as biofeedback and neurofeedback which are useful in assessment and intervention strategies to help clients reduce distress, modify their physiology, and enhance their self-regulation (Field et al., 2017).

Neurocounseling can help clients better understand their experience and circumstances through brain-based psychoeducation commonly referred to as neuroeducation. An overview of this psychoeducational approach and its relevance to AAWwMS is provided next.

### **Neuroeducation**

Counselors can translate new knowledge about the brain-mind-body relationship from the neuroscience field into counseling practice. One primary method of providing this information is through neuroeducation. Fishbane (2013) coined the term neuroeducation which has also been referred to as internal education and brain talk. Miller (2016) defined neuroeducation as “a didactic or experiential-based intervention that aims to reduce client distress and improve client outcome by helping clients understand the neurological processes underlying mental functioning” (p. 105).

Within the context of counseling, clients have been eager to gain knowledge related to how the mind is shaped, regulated, and changed over time in response to external experiences (Badenoch, 2008). Currently, there is a lack of brain-based counseling literature, but practitioners have reported that integrating neuroeducation into their work with clients provides many benefits (Cozolino, 2010; Fishbane, 2013; Miller & Barrio Minton, 2016). The most frequently reported outcomes of neuroeducation from clients are: (a) increased compassion and empathy for self and

others, (b) greater empowerment, and (c) a way to normalize the ups and downs of the change process (Miller, 2016). By combining neuroeducation with established therapeutic approaches, counselors can help clients develop more positive self-narratives, modify ineffective ingrained coping behaviors, and gain a neuro-informed understanding of how to improve their health and wellness (Field et al., 2017; Miller, 2016). For clients living with chronic neurological conditions like AAWwMS, neuroeducation is essential. Integrating neuroeducation into counseling work with AAWwMS is necessary because learning neuroscientific concepts can help AAWwMS engage in activities that improve their psychological well-being and preserve their brain functioning.

### **Relevance to African American Women with MS**

Black women living with MS must cope not only with the stress of having a chronic neurological disease but also with the various forms of oppression they experience (e.g., sexism, racism, gendered racism, ableism, microaggressions). Multiple dimensions of neurobiology have provided information and understanding of the biological processes and physiological responses that occur when one experiences oppression. Research findings have shown that being subjected to discrimination and social injustice activate the stress response or the fight-or-flight sympathetic system in the body (Goosby et al., 2018; Harrell et al., 2003). Repeated or prolonged exposure to discrimination can quickly translate into chronic stress and cause dysregulation of the stress response resulting in adverse neuropsychophysiological (neurological, psychological, and physiological) effects on the brain and body (Mariotti, 2015). MS is considered to be a stress-related disease since repeated activation of the stress response has consistently been associated with exacerbations (Mohr et al. (2004). Therefore, helping AAWwMS enhance their coping flexibility by acquiring new coping strategies and resources and

modifying others can help buffer the effects of stress to improve their mental health and hopefully reduce the occurrence of MS relapses.

Research findings indicate that POC with MS desire to learn more about brain structure and function to feel better informed about managing their MS (Salinas et al., 2016). Data from several meta-analyses have shown that interventions that include brain-based education and disease information for specific symptoms (e.g., fatigue) are more effective with PwMS than other treatment modalities (e.g., medication) (Asano & Finalyson, 2014; Wendebourg et al., 2017). This research highlights the importance of integrating brain-based psychoeducation into counseling interventions. Incorporating a brain-based perspective (e.g., neurocounseling) into counseling practice is a relatively new approach. Thus, the ethical implications of integrating neuroscience into clinical practice is provided.

### **Ethical Implications**

Several experts (e.g., Luke, Field, Beeson, & Jones, 2019) have discussed the ethical implications of implementing neurocounseling with clients. First, there are insufficient standards for guiding the training and practice of neuroscience integration into counseling practice. Second, the integration of neuroscience into counseling may lead to counselors giving preference to non-humanistic aspects of the client and/or the treatment process (e.g., basic science). Third, neuroscience research is often very complex and continuously evolving which may make it difficult for counselors to integrate principles into counseling practice. Fourth, the integration of neuroscience into counseling may have unintended negative consequences on clients and/or counselors. Lastly, neuroscience information may be intentionally misused in a way that harms clients.

To help counselors ethically integrate neuroscience principles into counseling practice, Luke et al. (2019) recommend that counselors stay up to date with current literature from basic and translational science and critically evaluate findings. They also suggest that counselors avoid harm to clients by using neuroeducation as a supplement that does not underemphasize client self-determination. Moving forward, standards of practice must be developed to create a benchmark for ethical practice and standards for entry level and advanced practitioners must be identified.

In the present study, several neuroscientific concepts were incorporated into the intervention to further emphasize and explicate the significance of coping flexibility and improve brain health literacy. These topics include neuroeducation related to (a) neuroplasticity, (b) neurogenesis, (c) memory consolidation, (d) activation of the sympathetic and parasympathetic response, and (e) executive functioning. Lastly, to support and guide this psychosocial intervention, the coping theory, wellness model, and brain-based framework that were used in the present study will be reviewed. They are as follows: the Indivisible Self Model of Wellness (Myers & Sweeney, 2004), the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), and the Healthy Mind Platter (Rock et al., 2012).

### **Conceptual Frameworks**

Three conceptual frameworks, the Indivisible Self (IS-Wel), the Transactional Theory of Stress and Coping (TTSC), and The Healthy Mind Platter (HMP) were all identified as relevant and appropriate frameworks for this dissertation study based on tenets that are applicable to factors associated with stress and coping responses. Although these conceptual frameworks are not specific to AAWwMS, they describe the intrapersonal, interpersonal, and environmental factors that impact an individual's cognitive, physiological, and behavioral stress response, their

perceived coping flexibility, and their efforts to engage in coping behaviors for optimal wellness. Due to the nature of the clinical population that was the focus of this study, an emphasis was placed on theory application to diverse populations. The three conceptual frameworks for this study will help to generate an understanding of the coping efforts of AAWwMS, a group that has historically been underserved and overlooked among PwMS. In addition, these frameworks will provide a rationale for the appropriateness of counseling strategies and resources used in service delivery.

### ***The Indivisible Self Model (IS-Wel Model)***

In the counseling profession, wellness is a foundational principle (ACA, 2014; Myers & Sweeney, 2008; Roscoe, 2009) that differentiates counselors from other helping professionals (Mellin et al., 2011). While the social work and psychology fields utilize the medical model, counselors are trained to incorporate wellness into clinical practice because of its emphasis on holism and optimal health beyond the absence of mental or physical disease or disability (Adams et al., 1997; McDonald, 2011; Roscoe, 2009). Wellness is not the absence of a compromised state of health nor is it a destination. Rather, it is the apex of a continuum in which illness and disease lie at the bottom, health lies in the middle, and a more holistic, positive view of optimal health and functioning are at the top. Wellness is touted as *the* paradigm for counseling and development (Myers, 1992; Roscoe, 2009). Therefore, counselors are encouraged to explore the full range of health with clients through “developmental, preventive, and wellness-enhancing interventions” (Myers & Sweeney, 2008, p. 482).

**Key constructs and definitions.** The Indivisible Self Wellness Model (IS-Wel, Myers & Sweeney, 2004; 2008) is an evidence-based wellness model that is based on key principles from Alfred Adler’s (Adler, 1954; Ansbacher & Ansbacher, 1956) theory of Individual Psychology

which emphasizes finding a balance within the individual. The essence of Adler's theory was the emphasis on the phenomenological worldview and the strengths-based perspective that people are unique, creative, capable, and responsible (Adler, 1954, 1963). The IS-Wel framework stems from the Wheel of Wellness model (Myers et al., 2000) which laid the foundation for evidence-based practice in wellness for counseling practitioners. After testing the factor structure of the IS-Wel model (Hattie et al., 2004), the results of the factor analyses indicated that wellness was the higher-order factor and there were five second-order factors and 17 sub-factors. Each sub-factor represents an aspect of wellness that could be enhanced based on individual needs and lifestyle goals (Myers & Sweeney, 2004, 2008). The five major factors are:  *coping self, creative self, social self, essential self, and physical self*. Since the present study focuses on coping flexibility, the coping self was discussed first and, in much detail, while a brief overview is provided for the other second-order factors.

*Coping self.* In the IS-Wel model, the  *coping self* is defined as “the combination of elements that regulate one's responses to life events and provide a means to transcend the negative effects of these events” (Myers & Sweeney, 2004, p. 237). The coping self helps the individual cope with various challenges associated with daily living and promotes resilience (Myers & Sweeney, 2005). Robust research evidence has supported the idea that effective coping responses throughout the lifespan contribute to reduced psychological distress and greater levels of overall life satisfaction (Buser & Kearney, 2017; Dwivedi & Rastogi, 2017; Pretorius et al., 2010). In addition, researchers have found that stress management, made possible by the coping self, contributes to overall wellness (Carver & Conner-Smith, 2010; Conley et al., 2012; Sharma & Rush, 2014).

This major factor is comprised of four key elements: *stress management*, *leisure*, *self-worth*, and *realistic beliefs*. *Stress management* includes the use of coping strategies, the ability to accept change, and the maturity to identify stressful encounters as growth opportunities (Myers & Sweeney, 2008). *Leisure* is described as engaging in enjoyable activities that bring satisfaction to one's life. When one is fully immersed in a leisure activity, a sense of "flow" or the feeling of being totally absorbed in something that brings pleasure and enjoyment occurs (Csikszentmihalyi, 2000). Leisure opens pathways for individuals to experience growth in various areas including creativity, spirituality, and interpersonal relationships (Myers & Sweeney, 2004).

In the previous version of the IS-Wel model referred to as the Wheel of Wellness, leisure and work were conceptualized as related constructs (Myers et al., 2000). However, in this model of wellness, leisure and work are separated into two distinct constructs based upon research evidence that showed leisure to be a separate phenomenon of Adler's notion of a work life task (Myers & Sweeney, 2004). In the IS-Wel model, leisure is included in the coping self while work is a sub-factor of the creative self (Myers & Sweeney, 2004, 2008). *Self-worth* is another key aspect of the coping self. Self-worth refers to the significance of having self-efficacy and self-acceptance in managing difficulties in life. According to Myers and Sweeney (2004), self-efficacy and self-worth are positively associated and lead to a more accepting view of oneself. This construct is related to the fourth construct of *realistic beliefs*, which refers to cognitive efforts to reduce perfectionism and irrational thinking in order to prevent distress and further emotional dysregulation (Myers & Sweeney, 2008). Overall, the coping self, is the culmination of these four constructs which interconnect and affect each other.

***Creative self.*** The *creative self* is defined as “the combination of attributes that each of us forms to make a unique place among others in our social interactions and to positively interpret our world” (Myers & Sweeney, 2008, p. 485). There are five components to this factor: *thinking, emotions, control, work, and positive humor*. The *thinking* sub-factor involves problem-solving, critical thinking, knowledge acquisition, curiosity, open-mindedness, and experimenting with new ideas (Myers & Sweeney, 2008). This construct relates to the concept of intellectual wellness from earlier theoretical perspectives on wellness (Roscoe, 2009).

The *emotions* sub-factor includes self-awareness of one’s emotions, the interconnectedness of thoughts and emotions, and the ability to express and process them (Myers & Sweeney, 2008). The next component, *control*, is closely related to the self-efficacy concept, and it involves the perceived ability to influence the trajectory of one’s life. When an individual has control, she understands her needs and goals and self-advocates for them. (Myers & Sweeney, 2008). *Positive humor* is another construct included in the creative self, and it is described as a coping strategy to help manage stress by being playful and finding ways not to take oneself too seriously. Myers and Sweeney (2004) included research on humor’s positive health effects (Bennett, 1998) to further highlight its importance to the creative self and overall wellness. *Work*, the final construct in the creative self, is defined as “an essential element of human experience” (Myers & Sweeney, 2004, p. 237). Myers and Sweeney (2004) propose that work is essential to the creative self because it allows for creative self-expression which brings satisfaction.

***Social self.*** The *social self* is characterized by two constructs: friendship and love (Myers, & Sweeney, 2004). In the IS-Wel model, friendships and intimate relationships enhance the quality and length of life, thus contributing positively to overall QoL. Conversely, Myers and

Sweeney (2005) assert that isolation and alienation from others can lead to a lack of social support which is generally associated with a reduced QoL. The support of family, either biological or family of choice, is essential to mental health over the lifespan (Kawachi & Berkman, 2001; Wang et al., 2018). While the friendship construct includes support and connection that does not come from family or romantic relationships, the love concept is more complex. Love is described as both the ability to be intimate and vulnerable and having a family or family-like support system based on shared values, mutual understanding, and healthy communication (Myers & Sweeney, 2008).

***Essential self.*** The essential self has existential components since it involves how individuals make meaning from life experiences and develop their sense of purpose (Myers & Sweeney, 2004). The four components of the essential self are *spirituality, gender identity, cultural identity, and self-care*. Previous wellness models (e.g., Hettler, 1980) characterize spirituality as a necessary aspect of wellness, and the IS-Wel model is no exception. Spirituality is distinct from religiosity as it “incorporates one's existential sense of meaning, purpose, and hopefulness toward life” (Myers & Sweeney, 2005, p. 238).

Identity development is an important process within the context of the essential self. *Gender identity* and *cultural identity* are conceptualized as “the filters through which life experiences are seen and as influences upon how others are experienced in response to ourselves” (Myers & Sweeney, 2004, p. 238). Thus, these two aspects of identity heavily influence our perceptions of the world around us and ourselves. *Self-care* includes proactive efforts to be healthy and well and to live a long life, whereas the lack of self-care reflects the loss of a sense of meaning and purpose in life (Myers & Sweeney, 2004).

**Physical self.** Wellness is described as the integration of the “mind, body, and spirit” (Hattie et al., 2004, p. 363). In the IS-Wel model, the physical self refers to the body and includes *exercise* and *nutrition* which both play an integral role to healthy living. Exercise involves physical activity to maintain good physical condition or stretching to maintain flexibility. Nutrition is defined as having a balanced diet, maintaining a healthy weight, and having healthy eating habits (Myers & Sweeney, 2008). While these components of the physical self are important, Myers and Sweeney (2005) assert that these aspects of wellness should not be overemphasized in determining one’s level of wellness and overall life satisfaction.

**Context.** The IS-Wel model also highlights the role of various contexts on development and how these contexts influence one’s overall wellness and QoL (Myers & Sweeney, 2005). The contexts within the IS-Wel that impact daily functioning are *local*, *institutional*, *global* and *chronometrical* (Myers & Sweeney, 2005). *Local contexts* include families, neighborhoods, and communities while *institutional* contexts include education, government, religion, business and industry, and the media. *Global* contexts are described as the political arena, culture, global events, and the environment. These specific contexts become more salient through media and mass distribution. Lastly, the *chronometrical* context reflects the recognition that attitudes, beliefs, and behaviors change over time.

Overall, the IS-Wel model provides a foundation for evidence-based practice for counseling professionals (Myers & Sweeney, 2004). As a strengths-based approach, the model can be used by practitioners to tailor interventions to help clients improve specific aspects of wellness based on individual goals and needs. Each component of the IS-Wel model is independent, yet they influence and are influenced by all the other elements and together they contribute to holistic wellness. Overall, efforts to achieve wellness are comprised of the five

factors and the various life contexts that are considered to be essential to overall health and well-being (Myers & Sweeney, 2004).

**Usefulness and testability.** While the IS-Wel model has been the most utilized wellness theory in the counseling literature (Roscoe, 2009), its generalizability to a wide variety of diverse populations is lacking. The model has primarily been used with student populations and working adults (e.g., Lewis & Myers, 2010; Tatar & Myers, 2010; Watson et al., 2014; Watson et al., 2010; Spurgeon, 2009). The 5F-Wel, an evidence-based tool that stems from the IS-Wel model, was found to be a reliable test of wellness with a sample of help-seeking adolescents (Watson & Lemon, 2011), and Appalachian youth (Mynatt et al., 2014). Researchers have also used the IS-Wel model in numerous studies with graduate counseling studies to examine aspects of wellness (Ohrt et al., 2015; Roach & Young, 2007; Smith et al., 2007).

The IS-Wel model has been tested with other populations including refugees (Blount & Acquaye, 2018), low-income rural women across the lifespan (Gill et al., 2015), and a sample of caregivers of persons with dementia (Clarke et al., 2016). However, little is known about its use with people living with chronic disease (e.g., MS, diabetes, cardiovascular disease) or disability (e.g., mobility impairment) (Fullen, 2019; Snook & Oliver, 2014). Application of the IS-Wel model with these populations is much needed since over half of U.S. adults have a chronic disease and nearly 40 million Americans have a disability which is defined as serious difficulty with hearing, vision, cognition, walking or climbing stairs, as well as difficulty with self-care and independent living (U.S. Census Bureau [USCB], 2015). More specifically, no published data have been collected specifically using the IS-Wel with PwMS. Similarly, findings from a review of published literature did not identify any research using the IS-Wel with predominantly Black women, who are disproportionately diagnosed with chronic diseases (CDC, 2017, Thorpe et al.,

2016). Although the IS-Wel is an evidence-based model of wellness, the generalizability of the model can be strengthened through more research with diverse groups within various life contexts.

**Theoretical issues.** In addition to a lack of generalizable data, there are theoretical issues within the IS-Wel that should be addressed. By definition, wellness theory is multidimensional, holistic, synergistic, context-dependent, and salutogenic (McMahon & Fleury, 2012; Roscoe, 2009) but it is not multiculturally inclusive. The IS-Wel model is a westernized interpretation of wellness that is primarily based on an individualistic, Eurocentric-based worldview. Therefore, the model does not fully integrate diverse cultural notions of health and well-being. For instance, within the essential self, the sub-factors of gender and cultural identity are described in part as the individual being able to transcend these intersections of identity (Myers & Sweeney, 2008). This description ignores the various forms of oppression (e.g., white supremacy, ethnocentrism, racism, sexism) that marginalized groups have experienced and continue to experience in society. For many groups, cultural pride and racial identity formation are indicators of adaptive coping and resilience (Cunningham et al., 2018; Womack & Sloan, 2017). Gender identity is a form of self-expression that promotes well-being, particularly among marginalized and underserved populations such as transgender youth and sexual minorities (Zeeman et al., 2016). The stress-buffering effects of these sub-factors promote mental health and do not need to be transcended.

Similarly, the IS-Wel model does not give considerable attention to social justice issues that create and perpetuate disparities in social institutions (e.g., health care access and affordability). The model mentions the influence of institutional contexts that include social and political structures, including education, government, and media that empower or oppress

individuals and groups. However, Myers and Sweeney (2004) give no further consideration to systemic racism, sexism, gendered racism, ethnocentrism, xenophobia, lack of access to social services and health care, and how the adverse effects of trauma impact wellness in the model. The IS-Wel model emphasizes individual intentions and efforts to be well. This implies that individuals are solely responsible for their level of wellness and conversely, if they are not well, it is their fault (Cohen & Timini, 2008; Prilleltensky, 2008; Tankwanchi, 2018). Integrating social justice concepts of liberation and empowerment that connect wellness to personal, relational, and collective needs could strengthen the IS-Wel model.

**Implications for counselors.** Using a holistic wellness paradigm when counseling individuals provides a blueprint for assessing the multiple dimensions of wellness in the IS-Wel model (e.g., self-care, self-worth, spirituality, stress management) and customizing interventions to both improve and further strengthen dimensions of wellness to improve overall QoL. This is much needed for individuals living with chronic conditions marked by variability and unpredictability like MS because they may experience significant changes to health and functioning as the MS progresses. In contrast to the physician's role, counselors can assess the whole person and conceptualize client concerns rather than simply target client distress and presenting concerns (Barden et al., 2015). According to Fetter and Koch (2009), when counselors use a holistic approach to therapy and focus on the whole person, they become "skilled and efficacious at helping clients take inventory of the many aspects of their life" (p. 13) that influence their overall health and well-being.

A well-structured, comprehensive wellness program can complement the specialty care and chronic disease management that people with chronic disabling conditions receive from health care professionals. In the IS-Wel model, health, disease, and disability can coexist.

However, there may be some difficulty in distinguishing wellness from disease management because both may focus on enhancing similar behavior (e.g., exercise, nutrition, self-care activities). Stuifbergen et al. (2010) recommend that when counselors do wellness work with people living with chronic disease and disability, they use interventions that “clearly have health or wellness in the foreground and illness or disability as context” (p. 134).

Using a wellness model such as the IS-Wel requires counseling practitioners to be holistic in their clinical practice and use of counseling techniques. However, this may spark ethical concerns since counselors should only practice within the bounds of their competence when engaged in wellness work with clients (ACA, 2014). For example, counselors should use caution when advising clients on exercise regimens or diets and nutritional plans. Collaboration with other professionals and making appropriate referrals to specialists such as certified dietitians, fitness trainers, and physicians are essential for counselors working with clients using a wellness paradigm (Granello, 2000). Promoting optimal wellness with clients involves the implementation of various counseling skills and techniques to elicit change throughout the counseling process.

The IS-Wel model is a valuable tool that counselors can use to determine the most appropriate and effective interventions to achieve greater client success. Using the IS-Wel model allows clients to assess, prioritize, and target one or two dimensions of wellness that they perceive to be deficient. Counselors can use clients’ wellness goals to choose the most effective therapeutic interventions related to the dimensions of wellness clients wish to change and adjust their counseling approach as needed (Fetter & Koch, 2009). According to Granello (2000), clinical tools that counselors often incorporate in wellness work with clients include a combination of education, behavioral change techniques, cognitive behavioral interventions, and

various skills training for clients which may include relaxation, stress reduction and problem-solving skills.

Coping flexibility is an aspect of wellness that counselors can target to help clients improve their life satisfaction and overall QoL. Counselors can use the IS-Wel model to assess internal and contextual factors that may either enhance or impede the client's coping efforts. They can also customize interventions to target specific areas of coping (e.g., self-worth, stress management) to strengthen the client's coping effectiveness and overall wellness.

### ***Transactional Theory of Stress and Coping (TTSC)***

TTSC was initially developed by Lazarus (1966) and later revised by Lazarus and Folkman (1984). Several names such as the transactional model, cognitive appraisal theory, and the psychological stress and coping theory have been used to refer to TTSC. In TTSC, stress is viewed as a relationship, a bidirectional transaction between the individual and the environment. Everyday stressful encounters which are referred to as "daily hassles of living" are emphasized instead of the traditional focus on major life events (Lazarus & Folkman, 1984). Individuals are constantly appraising stimuli (i.e., events and encounters) within their environment and appraising is an evaluative process that generates emotions. As individuals appraise stimuli, they determine whether those cues are harmful, threatening, or challenging (i.e., stressors). When an individual appraises an event or an encounter as stressful, the stress response is activated which can lead to a distressing experience. This calls for the mobilization of coping strategies to either manage emotions or attempt to directly address the stressor itself. When an individual engages in the coping process, a change to the person-environment relationship occurs and the individual reappraises the relationship as either favorable, unfavorable, or unresolved. Unfavorable or unresolved resolutions of stressful transactions cause more distress. As a result, the individual

will consider further coping options in order to attempt to resolve the stressor. In contrast, positive emotions are evoked when a favorable resolution of stressors occurs (Lazarus & Folkman, 1984).

**Key constructs and definitions.** One of the key constructs of TTSC is *psychological stress*. Lazarus and Folkman (1984) define *psychological stress* as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p. 19). To determine whether a particular person-environment relationship is stressful or not depends upon cognitive appraisal.

**Cognitive appraisal.** In TTSC, the individual’s subjective interpretation of an individual-environmental transaction is a phenomenological process called *cognitive appraisal*. Cognitive appraisal is defined as an evaluative process in which one attributes meaning or significance to a stimulus from the environment with respect to one’s well-being (Lazarus & Folkman, 1984). Furthermore, it determines “why and to what extent a particular transaction or series of transactions between the person and the environment is stressful” (Lazarus & Folkman, 1984, p. 19). The appraisal process of an individual-environmental transaction converges between and is influenced by two distinct forces: (a) an individual’s worldview, which is heavily influenced by experience and includes their beliefs, values and goals; and (b) environmental factors, such as demands and resources (Lazarus, 1991; Lazarus & Folkman, 1984).

According to Lazarus and Folkman (1984), individuals differ in their sensitivity and vulnerability to certain types of events as well as their interpretations and reactions. Therefore, the variation in worldviews and the complex and unpredictable nature of environmental contexts explicate the “great variation in the appraisals people make in the same environmental context”

(Lazarus, 1991, p. 6). Therefore, although PwMS may share some diseases-related stressors, their appraisal of those stressors is inherently unique to the individuals.

Appraisal is essential in TTSC because it emphasizes that it is the individual's perception of an event as stressful, rather than the event itself, that ultimately determines whether coping strategies are activated and whether the stressor is eventually resolved (Lazarus, 1991, 1999). Ultimately, the complex process of cognitive appraisal plays a mediating role in the stress response because it determines whether an event is relevant to an individual's personal well-being, and, if so, in what ways (Folkman, 1984).

Lazarus and Folkman (1984) described two types of appraisal: *primary appraisal and secondary appraisal*. In the primary appraisal process, an individual ascribes meaning to a specific individual-environmental transaction and determines the importance of that transaction to their overall well-being (Lazarus & Folkman, 1984). The transaction is deemed to be one of the following: (a) benign-positive (has a positive effect on one's well-being), irrelevant (of no significance or value to one's well-being), or stressful (event could signify harm/loss, threat, or challenge). In TTSC, the first two categories do not evoke negative emotions or the need for one to initiate coping strategies. It is only the third category (i.e., stressful transactions) that is of primary interest. Stressful transactions may further be appraised as producing significant harm/loss, threatened harm/loss, or pose a challenge (Lazarus & Folkman, 1984). Threat and harm appraisals refer to transactions that provoke negative emotions such as fear, anxiety, and anger. Challenge appraisals differ from harm/threat appraisals because they focus on the potential for one's gain and/or growth when sufficient coping resources are available and are characterized by positive emotions such as excitement and exhilaration (Lazarus, 1991; Lazarus & Folkman, 1984).

*Secondary appraisal* is initiated when one encounters a stressful event, whether it be a threat or a challenge, to determine what must be done to manage the situation. Lazarus and Folkman (1984) define secondary appraisal as “a complex evaluative process that takes into account which coping options are available, the likelihood that a given coping option will accomplish what it is supposed to, and the likelihood that one can apply a particular strategy or set of strategies effectively” (p. 35). When a specific transaction is deemed to be stressful, secondary appraisal is initiated to help individuals identify and evaluate: (a) their coping resources (e.g., self-efficacy), (b) situational variables (e.g., level of support), and (c) coping style (i.e., the manner in which the individual has coped with similar events in the past) (Dewe & Cooper, 2007; Folkman, 1984). The interaction between these factors determines the coping actions that are executed to “shape, manage, or resolve the event” (Dewe & Cooper, 2007, p. 144). Appraisal is essential in TTSC because it emphasizes that the perception of stress, rather than the event itself, is what ultimately determines whether coping strategies are activated and whether the stressor is eventually resolved (Lazarus & Folkman, 1984). Furthermore, because cognitive appraisal determines whether an event is relevant to an individual’s personal well-being it plays a mediating role in stress responsiveness and adaptational outcomes.

According to Lazarus and Folkman (1984), *reappraisal* refers to “a changed appraisal on the basis of new information from the environment, which may resist or nourish pressures from the person, and/or information from the person’s own reactions” (p. 38). It is described as a subsequent process that occurs after the initial appraisal has been completed. Reappraisal occurs during the same encounter; it simply modifies the earlier appraisal. Reappraisals may also be self-generated, and, in that case, they are described as coping strategies because they may be

used to reinterpret a specific transaction from the past more positively, or to deal with present transactions by viewing them as less threatening (Lazarus & Folkman, 1984).

**Coping.** When an individual has appraised an event as stressful (primary appraisal) and efforts to resolve or manage the event are required (secondary appraisal), coping actions are initiated (Lazarus & Folkman, 1984). In TTSC, *coping* which is defined as a process-oriented, dynamic approach involves “constantly changing cognitive and behavioral efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of a person” (Lazarus & Folkman, 1984, p. 141). According to TTSC, coping involves conscious, intentional actions that are utilized by an individual to manage or resolve a situation that is appraised as stressful (Lazarus & Folkman, 1984).

Coping strategies are categorized as either *problem-focused* or *emotion-focused*. Problem-focused strategies directly manage the stressful events. Emotion-focused coping strategies regulate emotions that arise as a consequence of the stressful encounter (Lazarus & Folkman, 1984). In this model, coping efforts do not need to be effective (e.g., binge drinking could be considered coping). Adaptational outcomes refer to the short-term and long-term consequences of stress. A favorable emotional response may occur because of successful adaptation. Unsuccessful adaptation to a stressful event may result in distress and physiological disturbances that initiate further coping strategies to be utilized until emotional stability has been achieved (Lazarus & Folkman, 1984).

Overall, TTSC emphasizes that stress is made up of the “shifting patterns of cognitive appraisal and reappraisal, coping and emotional processes” (Lazarus & Folkman, 1984, p. 156), a continuous cycle of transactions between the individual and environment. These transactions are used to evaluate and reevaluate stressful events that are viewed as disruptive to an individual’s

state of equilibrium. Once an event is identified as stressful, coping strategies are initiated to help the individual adapt and ultimately resolve this imbalance.

**Usefulness and testability.** Research evidence generally supports TTSC. Specifically, research findings have supported the mediating role of cognitive appraisals occurring between environmental and individual resources and demands. The literature has also provided evidence of the moderating and mediating role of coping strategies on subsequent mental, emotional, and physical health outcomes. For example, Meade et al. (2010) found support for the mediating role of stress appraisals between both situational factors (e.g., financial difficulties, lack of healthcare access) and personal resources (e.g., adaptability) and the positive impact of coping behaviors on psychological health. More recently, Kar et al. (2019) demonstrated support of the coping process as an interpretive, individualized approach to stress management in their systematic review on coping among PwMS. In another recent study, Ukueberuwa and Arnett (2019) provided evidence of the protective effects of adaptive coping against adverse psychological outcomes (e.g., depressive symptoms).

TTSC has also been used as a theoretical framework for psychological assessments used to measure stress and coping styles. One such assessment is the Coping Flexibility Scale (CFS; Kato, 2012) that was used in the present study. Since the 1960s, scholars and researchers have described TTSC as the most influential coping theory because it has been the most widely used in coping interventions (Cheng et al., 2014). In MS literature, TTSC has been the primary theoretical framework for the vast majority of coping research on PwMS (Montel & Bungener, 2007; Pakenham, 1999, 2006; Sanaeinasab et al., 2017; van den Akker et al., 2016).

Overall, scholars and researchers concluded that TTSC can be tested empirically. Specifically, the researchers largely concur that an individual's appraisal of a stressful situation

tremendously influences the resultant physiological response and emotional state, initiated coping strategies, and subsequent outcomes (e.g., Sakakibara & Endo, 2015). Emerging neuroscience research findings also suggest that perceived stress may have more deleterious effects on the brain and body than researchers previously thought (Crum et al., 2013). This aligns with the stress process outlined in TTSC. Based upon this examination, TTSC has been and continues to be a useful theory in conceptualizing psychological stress and the coping process. The inclusion of psychophysiological effects of stress and coping within TTSC make it appealing for research assessing the effects of neurocounseling interventions on coping flexibility.

**Theoretical issues.** Many scholars consider TTSC to be a standard model of the stress process and coping response, but it is not centered on the stress of various forms of oppression and the influence of culture on coping strategies. While Lazarus and Folkman (1984) acknowledge that cultural values and beliefs are contributing factors to an individual's coping efforts, they do not integrate specific cultural elements into the model. Many scholars have suggested that one's cultural identity may influence the coping process (Chun et al., 2006), yet, much of the coping literature overlooks culture-relevant dimensions in coping and the use of culture-specific coping strategies. According to Pendersen (2006), this is problematic because "all behaviors are learned and displayed in a cultural context [therefore], we can expect cultural context to influence the experiences of stress and coping" (p. 579). The Multicultural Model of the Stress Process (Slavin et al., 1991) was created to expand TTSC and includes several cultural elements to fill a gap in the coping literature. Unfortunately, the model may be too complex to test empirically (Slavin et al., 1991).

Lastly, Lazarus and Folkman's categorization of coping strategies as either problem-focused or emotion-focused has been critiqued by scholars and researchers due to its lack of cultural congruence. For instance, prayer, a common coping strategy used by Black women, has been described as an emotion-focused strategy. However, Bacchus and Holley (2004) found that, when asked to describe spirituality and prayer as either emotion-focused or PFC, most Black women viewed prayer as a problem-solving strategy. While TTSC addresses the influence of culture and social positions on stress and coping, a more detailed and comprehensive conceptualization would be more helpful.

**Implications for counselors.** Although cultural influences on stress and coping are briefly addressed in the theory, TTSC appears to be a relevant framework for exploring a client's coping process. TTSC has often been used as a theoretical framework for coping interventions in experimental studies even though Lazarus and Folkman (1984) seem to suggest that customized interventions for single-subject design studies would be more appropriate. Lazarus and Folkman (1984) view coping as an individualized process and group interventions make it difficult to account for variations at the individual level. Das Nair et al. (2016) support using an individualized approach to coping research compared to using group-based interventions because there is much variability among PwMS.

In TTSC, the bi-directional relationship between the person and the environment is the impetus that causes psychological stress and the subsequent coping process to occur. Therefore, contextual factors are just as significant as intrapersonal ones, and they should also be a primary focus in coping interventions. Over 40 years of research findings have supported this viewpoint. For example, Parkes (1986) found that environmental and situational factors were significant predictors of coping, and Navrady et al. (2018) concluded that both genetics and environmental

effects are major contributing factors to coping style. These findings indicate that counselors should highlight the significance of environmental factors in coping flexibility interventions. Counselors can implement interventions in the community where clients live and work to help them assess their coping resources.

Counselors should also use a culturally sensitive, individualized approach when trying to improve clients' coping and adaptation competencies. For the present study, this is important because Henry (2016) suggested that AAWwMS need interventions that integrate cultural perspectives since MS has historically been viewed as "a White woman's disease."

Although TTSC has been criticized for its lack of culture-relevant dimensions of stress and coping, the theory has been instrumental in shaping coping research and practice over the past 50 years (Biggs et al., 2017). It is widely used in empirically-based research examining aspects of coping among African Americans living with chronic disease and disability (Assari, 2014a, 2014b; Fritz, 2015; Gaston-Johansson et al., 2013; Graham, 2015). Counselors can use TTSC principles to help clients explore situations that trigger the stress response and identify effective coping strategies to prevent further emotional distress.

Lazarus and Folkman (1984) also incorporated psychophysiological research and psychosomatic medicine into TTSC to promote a brain-body connection in their conceptualization of the stress process. Using TTSC as a theoretical framework emphasizes that, although stress and coping are conceptualized as psychological processes, they have very real physical effects on the brain and body. Counselors must help clients strengthen and expand their coping efforts by linking their coping strategies to their brain health in addition to their psychosocial functioning (Field et al., 2017). This may include helping AAWwMS explore meditation or mindfulness-based coping since it is related to aspects of spirituality. Thus,

counselors may use TTSC as a framework to design and explore stress and coping interventions that will assist people with chronic disease and disability in meeting their QoL standards.

### ***The Healthy Mind Platter (HMP)***

Extensive neuroscience research has shown the negative effects of chronic stress and the lack of adaptive coping on specific brain functions and anatomical regions (Arnsten, 2009; Arnsten et al., 2015; Finsterwald & Alberini, 2014; Radley et al., 2015). For example, a large body of neurobiology research findings have indicated that chronic stress can cause inflammation or swelling in the brain (Liu et al., 2017; Rohleder, 2014). Researchers have also found that repeated or prolonged exposure to stress can alter brain structures that result in impaired brain functioning (Radley et al., 2015). Therefore, effective coping strategies are essential to not only physical and mental health but also neurologic health and functioning. The Healthy Mind Platter (HMP) is a brain-based wellness framework that utilizes a holistic approach to explain how optimal neurocognitive functioning and well-being can be maintained through daily mental habits (Rock et al., 2012).

The HMP was developed by Rock and colleagues (2012) as an integrative brain-based approach to wellness assessment and psychoeducation. As a healthy lifestyle framework, HMP emphasizes daily cerebral habits to promote optimal brain functioning and mental productivity. The HMP was inspired by the U.S. government's relaunch of the food pyramid as a 'healthy eating plate' in 2011 (United States Department of Agriculture [USDA], 2011) to describe important aspects of brain health. According to Rock et al. (2012), the objective of the HMP is:

To propose a framework for creating and maintaining mental well-being, summarizing and integrating distinct strands of neuroscience and psychology research, so it can be used

to inform communities such as schools, organizations, governments, and communities, as well as families and individuals, about best practices for promoting mental health (p. 1).

The HMP was developed as a framework of everyday activities that collectively optimize brain health *and* promote wellness.

**Key constructs and definitions.** One of the key constructs of HMP is *mental activities*. Rock et al. (2012) conceptualize mental activities as seven specific areas of wellness that nurture the mind and promote optimal brain functioning. These seven mental activities include: (1) *time in*, (2) *focus time* (3) *playtime* (4) *connecting time*, (5) *physical time*, (6) *sleep time*, and (7) *down time* and each will be described below.

***Time in.*** The first mental activity, *time in*, involves quiet internal reflection, meditation, and relaxation strategies that aid in stress reduction (Rock et al., 2012). Time in activities involve a quiet environment, a comfortable posture, focused attention, openness, and a reflective attitude. Engaging in spiritual practices like prayer and practicing acceptance of experience are comparable to the HMP's mental activity of time in. Several meta-analyses and reviews have shown the mental health benefits of spirituality and meditation (AbdAleti et al., 2016; Goncalves et al., 2015; Goyal et al., 2014; Hofmann et al., 2010). However, in the last decade, research has also emerged showing the benefits of time in activities like meditation and mindfulness exercises on brain structures and functions. For example, research evidence indicates that meditation and mindfulness practices have been linked to improved information processing (Luders et al., 2009), slowing age-related neurologic decline (Laneri et al, 2015), and increasing the size of the hippocampus, the area of the brain involved in the formation and organization of memories (Holzel et al., 2011). As coping strategies, the time in activities proposed by Rock and colleagues

(2012) are reflective practices that aid in mindful awareness, perspective taking, stress reduction and emotion regulation.

***Focus time.*** The second mental activity, *focus time*, pertains to goal-oriented tasks that require focused attention and lead to optimal performance (Rock et al. 2012). These activities primarily involve executive functions in the brain that help with problem solving, self-monitoring, concentration, and working memory. According to Rock et al. (2012) focus time “involves the application of a singular attentional focus on a task that permits a sense of mastery and completion...focus time enables an individual to avoid the sense of being overwhelmed and incomplete that so often accompanies multitasking” (p. 16). Focus time activities may include work or leisure activities but they involve a sense of “flow” or complete absorption in what one does (Nakamura & Csikszentmihalyi, 2009). Thus, focus activities can occur across a wide spectrum of areas including education, music, sports, gaming, artmaking, and spiritual and religious practice. Research findings have shown that focused attention coupled with physical exercise may help to prevent neurological degeneration associated with Alzheimer’s disease (Baumgart et al., 2015). As a coping strategy, focus time can help to enhance neurocognitive performance and improve executive functioning.

***Playtime.*** The third mental activity, *playtime*, refers to engagement in creative or spontaneous activity that results in decreasing emotionally dysregulated behavior and increasing new neural connections in the brain (Rock et al., 2012). Examples of play time activities include artmaking (e.g., coloring mandalas, painting, music making), dancing, and playing games (Rock et al., 2012). According to Spinka et al. (2005) play enables an individual to develop psychological flexibility that is needed for managing one’s emotional response to unexpected events in which there is a sudden loss of control. Decades of neuroscience research have shown

the importance of the play-joy system in child development, but more recent research indicates this essential phenomenon in adult creativity and learning (Panksepp & Biven, 2012). In addition to enhancing areas of the brain involved in creativity such as the prefrontal cortex, the concept of play facilitates neuroplasticity, the establishment and consolidation of new neuronal pathways in the brain (Shaffer, 2016; Stewart et al., 2016).

**Connecting time.** *Connecting time* is the fourth mental activity in the HMP. This activity refers to face-to-face interactions and engagement with the natural world to activate relational circuitry in the brain (Rock et al., 2012). Strong interpersonal relationships provide social support, a resource for coping, that is critical to mental health and overall well-being. Research findings have shown the benefits of social support on endocrine, cardiovascular, and immune system functioning (Uchino, 2006). Additionally, interpersonal neurobiology research findings suggest that social support plays a significant role in the emotional regulation circuitry in the brain, especially on the amygdala, the brain structure that is responsible for detecting fear (Sherman et al., 2015).

**Physical time.** The fifth mental activity, *physical time*, is defined as physical activity, preferably aerobic, that strengthens the brain and body (Rock et al. 2012). Rock et al. (2012) do not provide recommendations on specific regimens, instead, the benefits of regular cardio and exercise are highlighted in the HMP. Aerobic activity is included in the HMP because of the vast literature that indicates the numerous positive effects of exercise on physical, physiological, psychological, and neurocognitive health. For example, exercise activates neural mechanisms that protect the brain from damage. Specifically, it increases levels of brain-derived neurotrophic factor (BDNF), a molecule that enhances the growth and survival of neurons, improves learning and mental performance, and protects against cognitive decline (Cotman & Engesser-Cesar,

2002; Cotman & Berchtold, 2002; Erickson et al., 2011; Phillips et al., 2014; Spalding et al., 2013). Compared to other HMP activities, physical time has the most robust research evidence because of its far-reaching benefits on various health domains.

***Sleep time.*** The sixth mental activity, *sleep time*, is defined as the brain's resting state that helps individuals recover from daily activities and improve memory and learning (Rock et al., 2012). Sleep time includes both night time sleep and napping. Rock et al. (2012) describe adequate sleep as an average of eight hours per day but they also mention that there is wide individual variation. Stress can negatively impact sleeping patterns. Thus, sleep time can help to prevent further distress and aid in stress reduction (Rock et al., 2012). While some individuals may be able to function with as little as four hours or need as much as 12 hours. Rock et al. (2012) recognize sleep as a process essential to maintaining homeostasis and healthy functioning, but it is described as even more vital to brain health. Research evidence indicates that sleep plays a vital role in critical brain functions, such as memory function, creative processing, and emotion regulation. Specifically, recent findings suggest that adequate sleep is critical for solidifying or consolidating memory into long-term knowledge (Potkin & Bunney, 2012; Rasch & Born, 2013).

***Downtime.*** The last mental activity, *downtime*, refers to relaxing without a specific goal or focus. Downtime is not equivalent to leisure time which is described as active activities like playing sports or reading. According to Rock et al. (2012), downtime is being un-goal-focused, living in the moment, and being open to spontaneity. Research findings suggest this inactive wake state or daydreaming activates the default mode network that may permit integration across the brain's hemispheres and improve problem-solving (Gerlach et al., 2011). This resting wake

state may also be characterized as activity in the right hemisphere of the brain that leads to the development of new insights (Segal, 2004).

Overall, the HMP highlights seven lifestyle activities that promote neurologic functioning and other dimensions of health and wellness. Rock et al. (2012) describe the elements of the HMP while incorporating scientific knowledge into the model. Although it is described as a lifestyle framework to balance work and leisure, the HMP highlights several activities that can be essential to coping with the context of disease and disability.

**Usefulness and testability.** Research evidence generally supports the mental activities proposed in HMP as essential to brain health and mental, emotional, and physical wellness. Rock et al. (2012) describe the elements of the HMP as antecedents and moderators for three variables: creativity, mental health and cognitive performance. However, other variables such as stress reduction and coping effectiveness may also be applicable. Rock et al. (2012) claim that the model can be used to generate hypotheses for future research and that it can serve as a framework for brain health practice. The HMP is a relatively new framework in the neuroscience literature. Unfortunately, several database searches for research studies including the HMP framework produced no results, but there are numerous outcome-based studies focusing on one or more activities from the framework (e.g., Lin et al., 2015).

Scholars and researchers concluded that the mental activities described in the HMP are empirically-based. While research findings continue to emerge, robust evidence from various disciplines demonstrate the benefits of these lifestyle activities on several critical health domains. Furthermore, researchers have been challenged to utilize more sophisticated and complex research designs to better understand the mechanisms involved in activities that improve neurocognitive health to further demonstrate the usefulness of the model (Stillman et al., 2016).

Based upon this examination, the HMP is a useful framework for developing interventions that target coping flexibility. Despite the lack of research literature on the HMP framework, the focus on activities that promote wellness, brain health and neurocognitive functioning in the model make it appealing for research examining the effects of brain-based coping interventions with AAWwMS.

**Theoretical issues.** First, the mental activities described in the HMP are not reflective of all possible lifestyle activities that can be identified as coping strategies. There is no exhaustive list of coping responses, yet, Rock and colleagues (2012) present the HMP framework as if the seven activities highlighted in the model are all inclusive. In addition, the categories used to describe the mental activities are broad and many activities may fit into multiple categories which may further complicate research efforts. For example, playing sports may be labeled as either a physical time, focus time, or playtime activity depending on the context and this could become problematic when trying to operationalize variables.

Second, the HMP (Rock et al., 2012) is based on a westernized view of a healthy lifestyle. Therefore, the framework may lack culturally congruent conceptualizations of the seven mental activities. Several categories in the HMP are associated with “leisure activities” which may not be relevant in certain cultural contexts because leisure varies across countries and cultures. Additionally, sociocultural factors influence one’s ability and frequency to engage in HMP activities. Rock et al. (2012) state that ideally all seven mental activities would be completed on a daily basis to maximize their neurocognitive benefits. However, for certain groups (e.g., low-income populations) the lack of resources and competing demands impact the level of engagement in leisure activities. While the HMP provides a useful framework on brain-based wellness, a culturally relevant and more comprehensive model may be more useful.

**Implications for counselors.** Although there is a lack of outcome-based research using the HMP, it appears to be a relevant framework for exploring coping activities for diverse populations. More specifically, it appears to be a valuable model for counseling practitioners who desire to assist individuals living with chronic disease and disability like AAWwMS with their coping efforts. When individuals are allowed to take more of an active role in their coping responses, they can develop skills and gain tools that will help them evaluate their coping efforts and improve coping effectiveness. While the HMP has not been used in coping research, it does seem to be a feasible framework for customized interventions to improve clients' coping repertoire. Using the HMP would allow counselors to educate clients, especially those affected by chronic neurological conditions like MS, on brain health and the importance of engaging in activities that preserve and improve neurocognitive functioning.

Moreover, the counseling profession has embraced the integration of neuroscience into counseling practice (Field et al., 2017). Using HMP as a framework for brain-based psychoeducation can help counselors communicate the connection between the brain and behavior and support clients making more informed decisions regarding their health and wellness. Counselors can use brain-based counseling approaches to empower clients and help normalize the ups and downs involved in the change process. Thus, counselors may use a framework like the HMP to include objective neuroscience-related research into the counseling process to help improve client outcomes.

### **Summary**

In this review of the literature, coping flexibility among PwMS was examined from several perspectives. More specifically, systemic and cultural factors that impact AAWwMS were reviewed in order to develop an evidence-based coping flexibility intervention for this

population. Research findings have indicated that Black women have common stressors related to the workplace, daily life, and the various forms of oppression they experience, and they often utilize a variety of coping strategies including spirituality, social support, and problem-solving to address stressful situations. In addition, research has also shown that ingrained cultural perceptions of coping (e.g., Strong Black Woman) and persistent health care disparities may impede Black women's coping effectiveness and promote further stress. In the U.S., AAWwMS have been overlooked in the MS literature although recent research indicates that they are becoming the face of this chronic disease (Langer-Gould et al., 2013). Therefore, there is a need for evidence-based SCRDS with this population that focuses on their coping efforts.

The Multicultural Social Justice Counseling Competencies (MSJCC; Ratts et al., 2016), were explored as a framework to understand how cultural dynamics between the counselor and client interact and influence the counseling dyad. The framework provides counselors with guidance on how to take client's knowledge, skills, attitudes, and beliefs into account when developing interventions to target specific attitudes and behaviors. The MSJCC also challenges and supports counselors' efforts to increase their own awareness of privileged and marginalized identities within and outside of the counseling relationship to better understand the client's worldview (Ratts et al., 2016).

The Chronic Care Model (Wagner et al., 1996) was utilized to support the role of counselors in developing a coping flexibility intervention that integrates cultural elements into service delivery. This model outlines essential components of comprehensive care that support the delivery of interventions for people with chronic disease and disability. Both models provide a structure for delivering direct services to AAWwMS in the community utilizing a wellness-

based intervention that includes brain-based psychoeducation, individualized health planning, and responsive services that support the personalized health care approach (Snyderman, 2012).

The professional literature regarding AAWwMS indicates that they often face cultural and systemic health care disparities such as clinician racial bias, poor patient-centered communication, and the lack of access and affordability for specialty care. Although there are studies supporting the use of coping flexibility interventions with PwMS, most of this research has been conducted with groups in clinical settings. Little is known about the effectiveness of individualized wellness-based interventions that are specifically designed to meet the individual's coping needs while living with MS. The Transactional Theory of Stress and Coping (TTSC), the Indivisible Self Wellness (IS-Wel) model and components of the Healthy Mind Platter (HMP) were presented as the theoretical frameworks for this dissertation study. These theories were the foundation for the development of a brain-based wellness intervention to target coping flexibility among participants.

## CHAPTER 3: METHOD

### Research Design

The effects of a brain-based coping flexibility intervention for AAWwMS were examined using an *N*-of-1/ABA single-case research design (SCRD) (Kazdin, 2016; Lenz, 2015). Since African Americans have been described as a vulnerable population among PwMS (Holland et al., 2011), a focus on Black women is needed. This is because they have an increased risk of developing MS that is three times greater than their male counterparts. Due to the silent epidemic of MS among Black women and the concerted efforts to increase African American participation in MS research, it is no surprise the needs and experiences of this group have come to the forefront in the MS community (Williams, 2010).

Individualized interventions have been shown to be effective among PwMS which is worth highlighting because the symptom profile and disease course vary from person to person. One of the key findings from das Nair et al.'s (2016) comparative study between group-based and individual-based coping interventions with PwMS was that adherence to treatment was greater for participants who received the individual treatment than those who received the group-based one. While SCRDS have been shown to be effective with individuals living with chronic health conditions such as chronic pain (Vlaeyen et al., 2001), the research is lacking.

The rationale for using SCRDS in the present study was to help AAWwMS self-monitor their coping efforts and learn effective coping skills to enhance their mental/emotional health and overall QoL. Using this cost-effective, individualized approach allowed participants to explore aspects of the coping process that are specific to their needs and experiences and enhance their brain health literacy. Furthermore, this method provides counselors with a one-on-one framework that is needed to provide a client-centered approach with clients living with a chronic

disease as outlined in the *ACA Code of Ethics* (ACA, 2014) and the Chronic Care Model (Wagner et al., 1996).

**N-of-1/Single Case Research Design.** In the behavioral sciences, single-case research design (SCRD) is viewed as a rigorous method for evaluating treatment effects (Cohen et al., 2014; Lenz, 2015). SCRД was first introduced in Sidman’s (1960) seminal work entitled, *Tactics of Scientific Research: Evaluating Experimental Data in Psychology*. In the text, Sidman (1960) demonstrated how to apply this research approach within the context of behavior change in experimental psychology. SCRДs are also known N-of-1, single-subject, small n designs, single-case experimental designs, time-series designs, and intrasubject replication designs (Cohen et al., 2014; Ray, 2015). In SCRДs, data are collected from cases and analyzed for changes throughout the course of the study (Kazdin, 2016). A case, also known as an individual unit of interest, is the subject that receives the intervention and is assessed over time (Kratowill et al., 2013). A case can either be an individual person, like in this study, or a group of participants such as a family or a cohort of people (Morgan & Morgan, 2009). A key feature of SCRДs is that study participants serve as their own control, a principle known as baseline logic (Sidman, 1960). This is needed for comparison purposes so that researchers can assess change over time and overall treatment effectiveness (Gallo et al., 2013; Ray, 2015). SCRДs consist of a baseline period (phase A) and a treatment stage (phase B). Another phase in SCRДs that may be implemented is called the withdrawal phase (Heppner et al., 2015). The SCRД is a feasible approach to counseling research since it “offers counseling practitioners and researchers a practical and viable method for evaluating the effectiveness of interventions that target behavior, emotions, personal characteristics, and other counseling-related constructs of interest” (Ray, 2015, p. 394). Thus, SCRДs are described as “an ideal tool for establishing the viability of treatments in real-

life settings” (Byiers et al., 2012, p. 2). Practitioners are able to determine whether an intervention is effective based on the systematic components of the SCRD. These include: (a) the identification of target behavior, (b) establishing treatment goals, (b) utilizing treatment phases, (c) having participants as their own control at baseline assessment, (d) the application of continuous assessment of the dependent variable, and (e) the stability of performance within phases (Heppner et al., 2015; Kazdin, 2011; Ray, 2015). The SCRD has gained traction in the counseling field because it aligns well with evidence-based practice (Lenz, 2015).

Over the past few decades, evidence-based practice (EBP) has become the gold standard for the behavioral sciences and related fields (Gast & Ledford, 2018a). Many scholars (e.g., Smith et al., 2014) assert that the obligation to use EBP is heavily influenced by health care providers and government agencies to increase treatment quality and accountability. Evidence-based practice refers to “intervention procedures that have been scientifically verified as being effective for changing a specific behavior of interest, under given conditions, and for particular participants” (Gast & Ledford, 2018a, p. 5). Guidelines set forth by the *ACA Code of Ethics* (2014) require that “counselors have a responsibility to the public to engage in counseling practices that are based on rigorous research methodologies” (para. 11). This responsibility falls primarily on counseling practitioners who must be willing and able to locate and use empirically-based research. Although counselors are required to use evidence-based interventions with clients, there is a dearth of literature pertaining to SCRDs. This is unfortunate since SCRDs “are likely the most applicable to counselors in their daily clinical practices as each client presents a single-subject study” (Heppner, et al., 2015, p. 331).

In the last decade, there has been increased interest in SCRDs within the counseling field (Baker, 2012; Foster, 2010; Lundervold & Belwood, 2000; Sharpley, 2007). In more recent

years, the counseling profession has given more attention to this type of research. In 2015, the American Counseling Association devoted a special issue of its flagship journal, the *Journal of Counseling & Development*, to SCRDS (Lenz, 2015). In the article, Lenz (2015) described the benefits and rationale for the use of SCRDS and argued that employing this type of research design is a “scientifically rigorous, yet flexible approach for estimating the benefit of interventions that can be evaluated across counseling settings” (p. 389). However, the reluctance for counselors to engage in SCRDS and report their findings continues to be a challenge. As a result, SCRDS has not been heavily utilized in counseling research (Barlow et al., 2009; Gallo et al., 2013; Sharpley, 2007; Smith et al., 2014). Lundervold & Belwood (2000) asserted that counselors may not engage in SCRDS due to several factors including the lack of adequate training in appropriate research methodology and confusion about which data analysis methods to employ. Additionally, Ray (2015) suggested that counselors may lack an understanding of how to interpret data gathered from SCRDS which also creates a barrier to improving use of this research approach. When single-subject designs are used appropriately, information gleaned from the study will help answer research questions pertaining to the efficacy of an intervention (Sharpley, 2007). Smith et al. (2014) outlined several criteria for evidence-based practices using SCRDS in counseling. The criteria include: (a) a complete description of the participants and setting, (b) a comprehensive definition of dependent variables, (c) a complete description of the independent variable, (d) a baseline phase is utilized, (e) internal validity is experimentally controlled, (f) external validity, and (g) social validity. SCRDS is a good fit for EBP because it examines what treatment works best for whom and under what conditions (Gast & Ledford, 2018a; Ray, 2015).

There are several types of SCRDS that an investigator may choose from depending upon the targeted behavior and goals of the study. Common SCRDS methods researchers use are the simple time series (or AB) design, the withdrawal or reversal (ABA or ABAB) design, the multiple-baseline/multiple-probe design, the changing-criterion design, the multiple-treatment design, the time lagged design, the rapid iterative alternation design and the adapted alternating treatments designs (Byiers et al., 2012; Gast & Ledford, 2018b). Other SCRDS designs include more variations of reversal (e.g., ABA'B and BAB) designs (Gast & Ledford, 2018b).

The ABA withdrawal design was used in the present study. According to Morgan and Morgan (2009), the ABA design is “a simple yet powerful means of assessing the effects of the independent variable on behavior, and it has played a significant role in both basic and applied behavioral research” (p. 100). Correspondingly, Shadish et al. (2002) assert that the ABA design is one of “the most effective and powerful” research designs that counselors can employ in their clinical practice (p. 171). From an experimental perspective, the ABA design is more useful than the basic AB design because it “includes an additional demonstration of effect, strengthening the argument that the independent variable was responsible for observed changes in the dependent variable if behavior changes in the expected direction for each condition change” (Gaston & Ledford, 2018b, p. 216). The ABA withdrawal design is a user-friendly research methodology which makes it appealing to practitioners who want to assess the individual and contextual factors that impact the therapeutic progress (Morgan & Morgan, 2009). The primary benefits of a well-designed ABA single-subject experiment include the ease of implementation and strong experimental control conditions (Babel et al., 2018; Byiers et al., 2012). A key disadvantage of an ABA withdrawal design is the ethical issue associated with withdrawing or reversing an

effective intervention based on the assumption that all targeted behaviors are reversible (Byiers, et al., 2012).

Although there has been a renewed focus on SCRDS in the counseling literature and among other disciplines, a consensus on effective, empirically verifiable methods to quantitatively interpret the data is lacking (Brossart et al., 2011; Busk & Marascuilo, 1992; Ray, 2015). Over the past few decades, the statistical techniques available to analyze SCRDS have become more robust and quite complex. To date, there is still inconsistency within the scholarly community on which data analysis methods to use for SCRDS regardless of the design type. For example, the use of indices to determine effect sizes has been highly debated among scholars (e.g., Kratochwill et al., 2010; Parker et al., 2011; Wolery et al., 2010). More information and guidance are needed regarding how to perform analyses for SCRDS that accurately and comprehensively represent the data and determine treatment effectiveness.

In an ABA withdrawal design, the experiment begins with the baseline phase (A1) in which observations of the dependent variables are gathered. Historically, the dependent variable is an observable behavior that is problematic; however, the dependent variable (i.e., outcome variable) can be symptoms, covert behaviors, or emotional states of the participants (Ray, 2015). In the next phase of the study, the treatment phase (B), the intervention (i.e., independent variable) is introduced and implemented for a specific period of time. The experiment concludes with gathering data on the dependent variables in the withdrawal phase (A2) where the intervention is no longer administered (Lenz, 2015). In the withdrawal phase, the treatment is withheld to demonstrate the effects of the manipulated variable (i.e., intervention) (Gast et al., 2018).

Using SCRDS can also help counselors establish a protocol to indicate intervention accountability that can further lead to action-oriented research which focuses on producing local rather than generalized knowledge (Baker, 2012). According to Baker (2012), “Counseling practitioners who evaluate their local interventions can use the findings to improve their practice and to be accountable to their stakeholders” (p., 42). For example, counselors working on chronic care teams can document treatment efficacy and inform stakeholders such as primary care physicians, specialists, and physical therapists, of client progress and justify recommendations for chronic disease management.

SCRDS can easily be employed by clinical mental health counselors to help clients improve aspects of their mental health and wellness. In addition, SCRDS can provide substantive results that take individual differences into account when assessing the efficacy of an intervention. Although SCRDS have been championed as a practical, comprehensive approach to outcome-based research, they do have several limitations. The small sample in SCRDS is a key limitation since it affects both internal and external validity. Specifically, small sample sizes in SCRDS pose threats to internal validity because of history (the unplanned or unrelated events that occur during the study that impact the outcome), maturation (the changes in behavior that occur with the passage of time), testing effects (the impact of responding to the same test repeatedly), attrition (the loss of participants during the course of a study), adaptation (the recorded behavior of participants may differ from their natural behavior due to the novel conditions in which data are collected), and the Hawthorne Effect (the alteration of participants’ behavior due to their awareness of being observed) (Heppner et al., 2015; Gast & Ledford, 2018a). Using a sample of  $N = 1$  also poses threats to external validity especially if there is no replication (Gast & Ledford, 2018b).

Other limitations include systematic issues such as procedural infidelity (the lack of adherence to treatment protocols by investigators) and data instability (the indication that there is a large amount of variability in the data over time) (Gast & Ledford, 2018a). However, despite these limitations, scholars and practitioners view SCRDS as an evidence-based approach to clinical practice because they “represent a practical strategy for making inferences about the efficacy of an intervention, establishing evidentiary support for counseling practices, and giving voice to counseling activities with small or understudied populations” (Lenz, 2015, p. 387).

To implement a single-case research design, the minimum sample size needed is  $N = 1$ . However, to protect against attrition, most researchers use at least a minimum of three participants (Lenz, 2015). For the present study, the goal was to recruit at least five participants to safeguard against attrition and to better assess the efficacy of the intervention. Having a larger sample size will also help to increase the external validity of the study.

For the present study, participants served as their own comparison or control condition throughout the course of the ABA single-case design. Throughout the intervention, multiple observations or measurements were gathered in a time-series format and through participant self-monitoring. This allowed the counselor/investigator to examine changes over time and determine whether any changes that occurred were due to the intervention (i.e., independent variable). In addition to adhering to the methodical procedures of the SCRDS, the counselor collected data in session (e.g., field notes) and through participant self-monitoring. Once the withdrawal phase has concluded, the data points were graphed for visual analysis. In SCRDS, visual analysis is the primary method of data evaluation (Spriggs et al., 2018). Graphic representations of the data allowed the counselor/investigator to make inferences about intervention effectiveness (Heppner,

et al., 2015, Lenz, 2015). A more detailed description of the treatment protocol is provided in the procedure section.

**Research questions.** The *N*-of-1/ABA single subject experimental design described above was used in the present study to examine the following research questions:

1. What effect do the customized neurocounseling interventions have on the coping flexibility of participants across the treatment and withdrawal phases? Specific sub-questions to be addressed include:
  - 1a. Did participants' self-reports and self-monitoring indicate a desired change in evaluation coping?
  - 1b. Did participants' self-reports and self-monitoring indicate a change in adaptive coping?
  - 1c. Did participants' self-reports and self-monitoring indicate a change in total coping flexibility (both evaluation and adaptive coping combined)?
2. How did the participants rate the social validity of the interventions?

## **Participants**

**Population.** The participants that were recruited for this study were AAWwMS who had been diagnosed with MS for at least one month prior to the study. They were recruited from the population residing in surrounding metropolitan cities in a southeastern state. According to the U.S. Census Bureau (2018), the state that the participants reside in has a population of 10,383,620. Fifty-one percent of the total population is female, 10% live with a disability, and 22% are African American. Unfortunately, specific data on the population of AAWwMS in the state is unknown since MS is not considered to be a notifiable disease by the CDC. The state where participants reside has a very active chapter of the National Multiple Sclerosis Society.

The NMSS chapter in this state has been integral in developing programs geared toward the African American community (e.g., the African American Conference for Families Affected by MS). It serves over 18,000 individuals living with MS and their families in two states. In the state where prospective participants reside, the chapter has three locations and serves 97 counties. There are also several pharmaceutical companies in the region that provide free educational programs related to DMTs and MS research updates such as Biogen's Above MS program (Biogen, 2019) and Genetech's Patient Education events (Genetech, 2019).

According to the state department of public health (2018), data from the state in which prospective participants live indicated that for several social and economic well-being factors (e.g., poverty, unemployment, and disability status) African Americans fared worse than other racial/ethnic groups. Approximately 25% of African Americans in the state live in poverty, over 6% are unemployed, and 15% have a disability (2018). In regard to health care access, approximately 11% of African Americans ages 18-64 had no health insurance. In addition, 18% of African Americans in the state could not see a doctor in the past year because of cost compared to 12.8% of their White counterparts. These data reveal several key points regarding African Americans who reside in the southeastern state where the study was conducted. First, the data show significant and disproportionate stratification in health status and economic security for African Americans in comparison to Whites, Hispanics/Latinx, and American Indians in the state. Furthermore, these data also reveal another key point regarding the population of interest. These data show that African Americans are especially at risk of not getting the quality health care they need to manage chronic health conditions or disabilities they have given the state's health equity report.

Drawing from the population of interest, the BE WELL intervention focused on increasing the coping flexibility of AAWwMS. Research findings indicate that coping flexibility may positively impact medical treatment adherence for PwMS and lead to reduced relapses (Costello et al., 2008). Therefore, engaging participants in wellness-based coping flexibility interventions can potentially improve chronic disease management, particularly for participants who face systemic and/or cultural barriers to receiving quality care (e.g., having limited or lack health insurance). Furthermore, coping interventions may indirectly help reduce health care costs associated with unnecessary hospital stays and emergency room visits (Wielawski, 2006). AAWwMS who have difficulty coping or who want to improve their coping efforts for various stressors that may or may not be related to their MS were recruited for this study. The inclusion criteria included the following: (a) must identify as an African American female, (b) must have received an official MS diagnosis at least one month prior to the study, (c) must be between the age of 18 and 70 years, (d) must have difficulty with coping and/or seek opportunities to improve coping strategies, and (e) must have a desire to learn about wellness from a brain-based perspective. There were no participants that demonstrated that they were cognitively impaired throughout the recruitment process.

**Sample.** A total of four AAWwMS participated in the study. While recruiting a random sample would be ideal, it was not possible due to the population of interest, financial restrictions, and time constraints. Therefore, a non-random sampling strategy (e.g., convenience sample) was used for the present study. Three of the participants were recruited from a half-day community program for PwMS and their care partners. The other participant was recruited from her connection with Genentech and the local NMSS chapter. Participant background and demographic data were captured using the Background and Demographic Questionnaire (BDQ).

Their demographics and background information are reported in Table 1. To protect the identity of participants, each was assigned a pseudonym.

**Table 1***Participant Background and Demographic Data*

<b>Participant</b>	<b>Age</b>	<b>Highest Education Level</b>	<b>Occupation</b>	<b>Marital Status</b>	<b>Religious Affiliation</b>	<b>Diagnosis</b>	<b>DMT</b>
Aggie	34	Bachelor's	FT	Married	Christianity	RRMS	Yes
Yvonne	60	HS Diploma	Unemployed	Married	Christianity	RRMS	Yes
Chelsea	45	Master's	Unemployed	Married	Christianity	RRMS	Yes
Tonya	38	Master's	FT	Married	Christianity	RRMS	Yes

*Note.* FT = full-time employment; RRMS = relapse-remitting multiple sclerosis; DMT = disease modifying therapy

## **Instrumentation**

The following measures were utilized in the present study: The Coping Flexibility Scale (dependent measures) and the Attitudes Toward Treatment scale (social validity measure).

**Coping flexibility variable.** The Coping Flexibility Scale (CFS; Kato, 2012) was used to measure the dependent variables of the study. They are: (a) evaluation coping, (b) adaptive coping, and (c) total coping flexibility. Participants completed the 10-items from the CFS on a weekly basis, and the scores were used to assess the effects of the intervention across the three phases. Exploratory and confirmatory factor analyses identified two subscales (i.e., evaluation coping and adaptive coping) across 10 items in the CFS (Kato, 2012). The sum of both factors will then be used to assess the total coping flexibility. The CFS has solid psychometric properties that support its use in evaluating the coping process. Due to the clinical population, the need to reduce response burden and excessive testing, the CFS was selected for the present study.

The CFS (Kato, 2012) is a 10-item self-report questionnaire specifically designed to measure coping flexibility. The CFS stems from Lazarus and Folkman's (1984) stress and coping theory, TTSC, but later revisions of the theory, particularly the revised model proposed by Folkman (1997, 2008), were identified as very influential to the scale development. According to Kato (2012), the CFS "focuses on coping processes that lead to a favorable outcome" which is included in Folkman's revised model where the concept of meaning-focused coping is introduced. This form of coping refers to a coping strategy that works when a situation is not favorably resolved. Two scales make up the instrument: the evaluation coping component, to assess coping strategies (e.g., I only use certain ways to cope with stress) and the adaptive coping component, to assess coping effectiveness (e.g., If a stressful situation has not improved, I use other ways to cope with that situation.). Both scales are used to measure the participants' ability

to monitor and discontinue ineffective coping. Two of the evaluation coping items are reverse-scored (e.g., I only use certain ways to cope with stress and I fail to notice when I have been unable to cope with stress). Participants respond on a 4-point scale (from 1= not applicable to 4= very applicable). For each of the CFS's scales (e.g., evaluation coping and adaptive coping) there are five questions. Scores range from 10-40 and are calculated by summing the items in each scale. Higher scores from the CFS indicate more coping flexibility and effective coping.

Although coping flexibility is not a relatively new construct to be measured with self-report assessments, the CFS is the only measure that focuses on improving coping effectiveness *and* monitoring the use of alternative coping strategies. Other measures such as the Coping Flexibility Questionnaire (CFQ; Cheng, 2001). focus on situation-appropriate coping and have not been used extensively with various and diverse populations. Additionally, self-report measures of coping flexibility: the Flex (Schwartz & Daltroy, 1991), the Coping Inventory (Zeitlin, 1985), and an open-ended questionnaire by Westman and Shirom (1995) only measure the variability in one's coping pattern across situations (e.g., coping repertoire). The CFS has evidence of some structural validity across samples that includes college students, workers, and individuals with chronic conditions (Kato, 2012, 2015a, 2015c) and it has been used to assess the effects of a coping intervention in a real-world setting (Jones, 2015). The instrument has primarily been used with Japanese samples (Kato, 2012, 2015a, 2015c), but it has demonstrated good reliability (ranging from  $\alpha = .83$  to  $\alpha = .87$ ) with a sample of adults in the United States (Jones, 2015). Both internal consistency of the subscales and construct validity have been documented, with internal consistency on evaluation coping ranging from .45 – .68 and adaptive coping ranging from .67 – .88 (Kato, 2012). The internal consistency of the subscales has been challenged especially in Western samples. Reed (2016) found that while the adaptive coping

subscale had good reliability ( $\alpha = 0.85$ ), the evaluation coping subscale had low reliability ( $\alpha = 0.48$ ). This finding supports previous analysis of the CFS which also revealed that the reliability of the evaluation coping subscale was low, and there was a lack of support for the two-factor structure of the CFS (Jones, 2015) despite Kato's (2012) CFA analysis. Researchers speculate this may likely be due to two items on the evaluation coping subscale, which also happen to be the only two reverse-scored items in the CFS. It is possible that either the wording of those items, the English-language translation of the items, or the evaluation coping subscale itself may be the issue.

Psychometric properties of the CFS have been established primarily using 11 samples from Japan to support the instrument's structural validity (Kato, 2012). Convergent and discriminant validity with other coping constructs has been documented. Kato (2012) found moderately high criterion-related validity that ranged between .70 to .86 between the CFS and other theoretically related concepts like accommodative coping (e.g., The Tenacious Goal Pursuit and Flexible Goal Adjustment Scale) (Tenflex, 30 items; Brandtstadter & Renner, 1990) and cognitive flexibility (e.g., The Cognitive Flexibility Scale) (CFS, 12 items; Martin & Rubin, 1995). The CFS can be administered individually or in groups with an estimated duration of 10 minutes (Kato, 2012). It is important to note that the CFS has not been widely utilized with diverse samples. To the counselor/investigator's knowledge, the CFS has only been used with two Western samples (one in the United States and one in the United Kingdom). Kato (2012), the author of the CFS, and other researchers have suggested that more research with cross-cultural samples and diverse populations is needed to resolve the structural validity issue with the CFS.

The CFS has several advantages that make it a viable tool to measure coping flexibility with AAWwMS. First, it is the only coping flexibility scale specifically designed to help

participants monitor alternative coping strategies *and* discontinue ineffective coping strategies. Second, it has been used with individuals living with chronic health conditions (e.g., chronic headaches) and takes individual differences (e.g., the subjective appraisals of stressful situations) into account since individual and cultural factors play an influential role in the coping process within the context of a chronic disease. Third, it is user-friendly since it has only 10 items and does not take long to administer and score. Fourth, it is a free resource that can easily be accessed from the original article's supplement (Kato, 2012) and permission from the author to use the scale can easily be obtained by contacting the author for consent. Unfortunately, the primary disadvantages of the CFS includes its structural validity issues and the lack of extensive use with diverse samples. While more research needs to be conducted to develop robust evidence for the CFS's external validity, it has acceptable psychometric properties. For the purposes of this study, the advantages of utilizing the instrument outweigh its limitations. There is no required sequential order for the items in the CFS so the questions were randomized for the present study. A copy of the CFS can be found in Appendix C and an outline of the two subscales can be found in Appendix D.

**Social validity measure.** Social validity refers to the social significance, or the value that is placed on an intervention (Wolf, 1978). Wolf (1978) and Kazdin (1977) have produced seminal works that have been influential to the conceptualization of social validity. *Social validity* can be defined as “changes in behavior that are clinically significant or actually make a difference in the client's life” (Kazdin, 1977, p. 427). According to Wolf (1978) social validity is an outcome-based measure that focuses on three distinct areas: the social significance of treatment goals, the social appropriateness of intervention delivery, and the social importance of the efficaciousness or outcomes of the intervention in applied research. The social validity

construct stems from behavior analysis and it emphasizes the client's perspective in treatment delivery and efficacy rather than clinical judgments (Carr et al., 1999; Foster & Mash, 1999; Kennedy, 1992; Snodgrass et al., 2018). Thus, counselors are challenged to suspend their views about implementation of the intervention and respect the client's perception of how well it worked. In the present study, the measure of social validity that was used was based on participant feedback.

For the present study, the primary goal of using the Attitude Toward Treatment (ATT; Baker, n.d.) measure was to acquire participant social validity feedback. Participants completed the ATT as a post-intervention assessment to assess their attitudes about the value of the intervention at the end of the treatment program. The ATT is a self-report measure designed to assess how confident participants were about the intervention after receiving it. Researchers have used the ATT as a measure of social validity in various studies (Dowden, 2010; Kiselica et al., 1994) including SCRDs (Lohmann, 2018, Williams et al., 2018). The ATT has fourteen 7-point Likert-type items worded in past tense to reflect the post-intervention attitudes and perceptions of the participants. Scores can range from 14 to 98 with higher scores indicating an increased level of confidence in viewing an intervention as efficacious. The ATT is considered to be a common measure of social validity mainly because it provides a measure of the clients' subjective experiences (Hott et al., 2015). A copy of the ATT can be found in Appendix E.

### **Brain-based Education and Wellness (BE WELL) Intervention Program**

For the present study, the customized individual psychoeducation-based neurocounseling interventions were designed to help participants improve their coping flexibility (i.e., evaluation coping and adaptive coping efforts). As a psychosocial treatment approach, these customized wellness-focused interventions served as the independent variable in the study. The entire study

spanned the course of 12 weeks and the neurocounseling interventions were delivered during an eight-week timeframe. The counselor/investigator developed and named this intervention as the Brain-based Education and Wellness (BE WELL) Program.

The BE WELL program is based on an empirical theoretical framework that is wellness-focused. This framework was used by the counselor/investigator to create the individualized treatment plan based on participants' evaluation and adaptive coping scores obtained on the Coping Flexibility Scale (CFS; Kato, 2012). The information presented in this section provides a description and detailed explanation of the development and creation of the BE WELL program. Information pertaining to the counselor/investigator's experience in the field of counseling and clinical work with the multiple sclerosis (MS) population is also provided. This section is comprised of four subsections: (a) integration of theory into the interventions, (b) integration of neuroscience (e.g., neuroeducation) into the interventions (c) customized BE WELL intervention program, and (d) counselor/investigator experience.

**Integrating theory into the interventions.** From an applied perspective, theories are essential to planning, implementing, and evaluating interventions aimed to motivate individuals toward positive change (e.g., health promotion) (Bartholomew et al., 2006). Theory-based interventions help to identify which variables should be targeted for the intervention and which should produce an effect of an intervention. From a theoretical perspective, conducting research using theory-based interventions can lead to theory refinement and new theoretical approaches (Lippke & Ziegelmann, 2008). This is essential for the continual development of wellness and health promotion programs (Rothman, 2004). Coping is a key concept in research with people living with chronic diseases. Therefore, scholars have developed models on how to design theory-driven psychosocial inventions to teach coping flexibility to people living with chronic

conditions (e.g., Schwartz & Rogers, 1994). For the BE WELL intervention, the Indivisible Self (IS-Wel) (Myers & Sweeney, 2004) and the Transactional Theory of Stress and Coping (TTSC) (Lazarus & Folkman, 1984) were utilized as the framework for the intervention.

In the MS literature, TTSC has been the primary theoretical framework used in coping interventions and research (Montel & Bungener, 2007; Pakenham, 1999, 2006; Sanaeinasab et al., 2017; van den Akker et al., 2016), and previous studies have also shown that utilizing wellness models (e.g., The Health Promotion Model, Health Belief Model) in coping interventions, similar to the one that was applied in this study, have helped PwMS improve their coping behaviors (Stuifbergen et al., 2003). The BE WELL intervention consists of applying the specific IS-Wel concept of the Coping Self to help participants examine the dynamics of coping based upon this evidence-based model. In the IS-Wel model, the Coping Self is composed of elements that help individuals to self-regulate their psychological, emotional, and behavioral responses to life events and promote resilience. These elements include leisure, stress management, realistic beliefs, and self-worth (Myers & Sweeney, 2004).

The IS-Wel model stems from Adler's (1954) Individual Psychology Theory that presents a holistic approach to wellness. Thus, each element of the Coping Self includes skills strategies and techniques is derived from various evidence-based counseling theories, including cognitive-behavioral therapy and mindfulness-based stress reduction. Leisure is comprised of recreational activities that produce a state that Csikszentmihalyi (1990) describes as "flow". These activities yield growth in both creative and spiritual dimensions that provide value and meaning to one's life (Myers & Sweeney, 2006). Stress management includes the on-going assessment of coping resources and acquiring strategies to prevent and reduce the negative effects of stress. Realistic beliefs refer to one's ability to perceive reality accurately and

eliminate unrealistic beliefs and irrational thinking. Self-worth relates to self-esteem and the unconditional acceptance of oneself, including positive attributes and imperfections. Exploration of the various components of the Coping Self were used to help participants develop a range of coping strategies that not only aid in self-efficacy and stress reduction but also promote brain health.

To help participants identify their stress cues and coping deficits, the BE WELL intervention incorporated concepts from Lazarus and Folkman's (1984) TTSC. According to Lazarus and Folkman (1984), stress is defined as the product of a bidirectional transaction between the individual and the environment in which the individual engages in primary appraisal and interprets the encounter as either harmful or threatening to their well-being. The stress that results from this transaction impacts the individual internally through multiple systems: (a) cognitive, (b) physiological, (c) affective, (d) psychological, (e) neurologically, and (f) externally (e.g., their relationship to their environment). Helping participants pinpoint their internal and external stressors informed the goal setting process and helped to identify individual needs for the BE WELL personal wellness plans.

According to TTSC Theory, once individuals have determined that they are experiencing a stressful event, they engage in another evaluative process (i.e., secondary appraisal) to determine how to respond to the stressor. This initiates coping, which is a conscious response to a stressful encounter. Coping strategies are used to regulate emotions or manage or resolve the stressor (Lazarus & Folkman, 1984). In TTSC Theory, coping behaviors are described as either emotion-focused or problem focused. When initial efforts to cope fail, the individual may engage in reappraisal in order to modify cognitions and/or behaviors to mitigate the harmful effects of stress. This evaluative process was woven into the BE WELL intervention to help participants

use perspective taking and problem-solving strategies to gain insight into stress-inducing situations, encourage self-monitoring, and improve stress management and positive coping skills. Applying TTSC Theory to the BE WELL intervention helped participants examine their cognitive appraisal and reappraisal processes that precede their subsequent coping response.

Most psychoeducation programs and interventions used with PwMS focus on providing information and application (e.g., Sanaeinasab et al., 2017). The present intervention is no different, but it also focused on exploring coping behaviors through a neuroscientific lens. Specifically, participants were exposed to skills and activities (e.g., role playing, meditation exercises, deep breathing techniques) that were designed to help them problem solve, regulate their emotions, and reduce the neuropsychophysiological impact of stress on their brain and body. The overarching goal of using this theory-driven intervention was to help participants become more aware of their traditional coping responses, identify ineffective coping strategies, and adopt new and more efficacious coping behaviors that promote brain health in addition to psychosocial functioning. Whereas the IS-Wel model helps individuals develop cognitive and behavioral responses that promote health and wellness within a social context, TTSC Theory addresses the activation of stress and the subsequent coping response using a sociopsychological and psychosomatic approach. The integration of theory in the BE WELL intervention is illustrated in Figure 1.

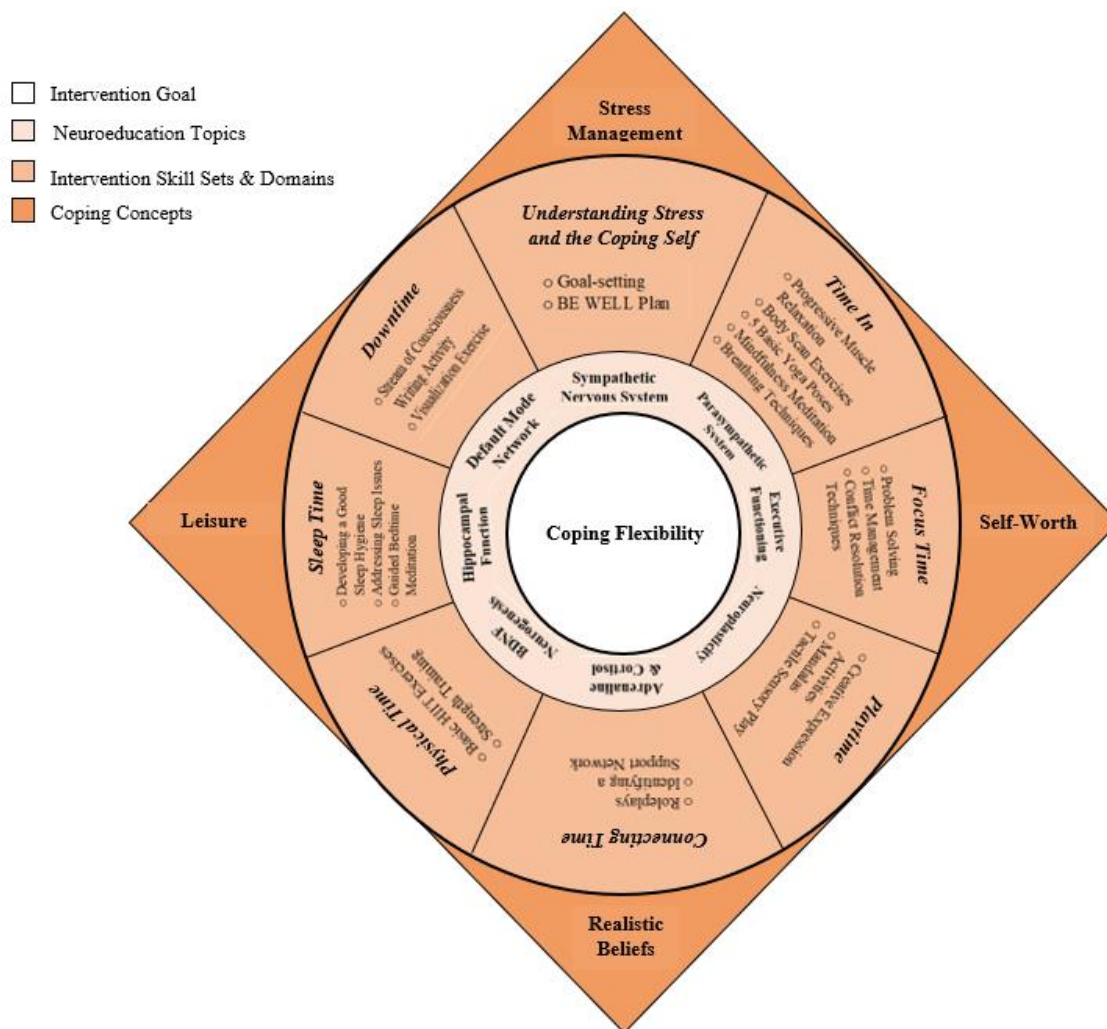
**Integrating neuroscience into the interventions.** The Healthy Mind Platter (HMP) (Rock et al., 2012) was used as a framework to help structure the individual sessions and integrate neuroeducation into the BE WELL intervention. HMP complements the IS-Wel model in that it provides a holistic framework on how to engage in wellness activities that promote mental, relational, and brain health. This is particularly important for people living with

neurological disorders that have a degenerative trajectory such as MS. The model also complements TTSC Theory because the aim is to help individuals develop an adaptive coping repertoire for both manageable and uncontrollable stressors. Furthermore, research findings have shown that coping skills training that includes psychoeducation and psychotherapeutic components can significantly improve neuroimmunological functions (e.g., increase cytotoxic T-cells) that are adversely impacted by MS and/or the activation of the stress response (Kugler et al., 2000; Mohr et al., 2012).

A neuroeducation topic was explored in each BE WELL intervention session and used to help the participant process how each specific coping strategies can improve components of brain health (e.g., function, volume) in addition to their mental health. For example, the HMP “time-in” neuro-cognitive activity has been described as “a very particular type of conscious, focused attention on the inner life of the self in the here and now” (Rock et al., p. 12) It consists of activities in which one engages in mindfulness-based strategies that promote deep relaxation and produce a metacognitive state. The neuroeducation topic for this HMP activity focused on engaging the parasympathetic system (i.e., the relaxation response). The counselor explored the key factors in this dynamic neurophysiological system using developmentally appropriate language with participants. Specifically, the counselor/investigator focused on the autonomic body functions involved in the parasympathetic system and the effects of attunement and mindful awareness on the prefrontal cortex.

By integrating neuroscience into the coping interventions, participants can become more informed about the brain-body connection. Living with a complex neurological disease with an unknown prognosis can easily make one feel overwhelmed. Providing neuroeducation while exploring new coping strategies to improve brain health can help participants regain some sense

of control and knowledge about their bodies despite living with an unpredictable chronic health condition. Integrating neuroscience into this psychosocial intervention can help clients better understand their experience. Integrating neuroeducation into the BE WELL intervention also provides the counselor with a more holistic, wellness-based, mind-body approach to working with this clinical population. Lastly, the inclusion of neuroscientific concepts related to the central nervous system and physiological processes underlying human functioning into this intervention program align with the counseling profession's stance that neuroscience can support and advance the profession (Beeson & Field, 2017; Field et al., 2017).



**Figure 1**

*Brain-based Education and Wellness (BE WELL) Theory to Intervention Paradigm*

**Customized individual BE WELL intervention.** The present study was an examination of the effects of a customized individual neurocounseling intervention designed to enhance the coping flexibility of four Black women living with MS. According to Schwartz and Rogers (1994), there are several essential components of an intervention program that are effective in enhancing the coping flexibility of people living with a chronic disease. These components include (a) rapport-building, (b) goal-setting, (c) facilitating awareness, (d) practicing new skills to enhance coping resources, and (e) building and maintaining support. Participants in the study

had an opportunity to gain knowledge and strategies to improve their coping flexibility through customized individual neurocounseling interventions administered by a counselor who is knowledgeable about working with individuals living with a chronic health condition. The essential components of Schwartz and Roger's (1994) psychosocial intervention were also utilized when creating and administering these customized neurocounseling interventions.

The activities for the BE WELL intervention program were based on the HMP framework. Thus, all participants received interventions based on the BE WELL framework described herein. However, modifications were customized for each participant based on their individual characteristics and specific needs. The independent variable of the study was the BE WELL intervention, which was delivered over the course of 8 weeks. Baseline data were collected during weeks one and two, and during weeks 11 and 12, withdrawal data were collected. The BE WELL intervention integrated brain-based psychoeducational components (i.e., neuroeducation) throughout the eight sessions. The sessions were customized based on participants' direct and indirect needs. Each intervention was individualized to address participants' needs based on their assessment scores on the CFS (Kato, 2012).

For example, an intervention developed for a participant who scored low on adaptive coping would be different from an intervention for a participant who scored low on evaluative coping. While participants have diverse needs, each intervention covered all seven HMP activities (i.e., physical time, sleep time, focus time, time-in, connect time, play time, and down time). During the initial individual meeting, participants identified social/emotional goals related to coping, health promotion, and chronic disease management. Additionally, each participant developed a personal wellness action plan to address identified needs with assistance from the counselor/investigator.

The BE WELL intervention framework can be found in Appendix F along with a list of supplemental coping activities. Several activities were inspired by *The Five Factor Wellness and Habit Change Workbook* (Myers & Sweeney, 2006) while others stem from evidence-based counseling strategies and techniques (e.g., reframing and mindfulness-based stress reduction meditation). The goals listed on the BE WELL action plans adhered to the IS-Wel Coping Self. Participants created goals that address the domains of leisure, stress management, realistic beliefs, and self-worth (Myers & Sweeney, 2004). Using the IS-Wel definitions of the Coping Self elements (Myers & Sweeney, 2004), the counselor/investigator helped participants monitor their behavior by establishing goals specific to their individual needs. The activities listed on the BE WELL plan reflected participants' coping flexibility needs based on their CFS (Kato, 2012) assessment. The counselor/investigator and participants collaboratively worked together to identify goals and desired outcomes, and the counselor/investigator reviewed the BE WELL plan with participants on a weekly basis. At the conclusion of each session, participants were encouraged to practice their newly acquired knowledge and skills and engage in journaling as homework. To ensure consistency with each intervention, the same structure for the treatment protocol was followed with each participant throughout the duration of the study. Participant progress was monitored, and any possible barriers that may hinder goal attainment were discussed. Each participants' BE WELL plan is provided in the appendices.

**Counselor/investigator experience.** The counselor/investigator is a 32-year-old African American woman enrolled in a counseling and counselor education doctoral program at a southeastern university. She is the principal counselor/ investigator who developed the BE WELL intervention program and will collect and analyze the data. The counselor/investigator holds a Bachelor of Arts degree in Sociology and a Master of Arts degree in Clinical Mental

Health Counseling. She is a Licensed Professional Counselor Associate, a Board-Certified Counselor, and a Global Multiple Sclerosis Ambassador with the National Multiple Sclerosis Society. She has professional experiences in the areas of education, career, mental health, and substance abuse counseling and has over 10 years of experience working in the education, residential, hospital, and private practice settings with diverse clients and communities.

She has conducted research and published articles on self-care and stress management. She also developed a neuroeducation activity that was included in a recent publication on integrating neuroscience into counseling practice (Miller & Beeson, in press). The counselor/investigator became interested in neurocounseling during her clinical training when she interned at a behavioral health facility while leading the daily substance abuse outpatient program and co-facilitating the weekly multifamily psychoeducational groups. Council for Accreditation of Counseling Related Education Programs (CACREP) counseling programs do not require students to take neurobiology courses nor is this knowledge required for counseling licensure. Thus, the counselor/investigator has sought out continuing education and professional development opportunities to enhance her knowledge of neuroscientific concepts and how to integrate neuroeducation into counseling practice.

The counselor/investigator has become dedicated to integrating neuroscience into counseling practice to help clients explore the brain-body connection and be empowered to improve their neurological, psychological, and emotional health. She has worked with PwMS on overcoming barriers related to their social, emotional, and career development needs. She has been involved with the MS Society, specifically, the chapter in the state in which she resides for two years. In addition to being an MS Ambassador and support group facilitator for family members of PwMS, she delivered the keynote address for the 2018 annual African American MS

Conference where she highlighted mood changes in MS. To continue her interest in integrating neuroscience into counseling practice and promoting wellness within the MS population, the counselor/investigator consulted with key stakeholders (e.g., physical therapists, health care providers) affiliated with the MS Society for this study.

In conclusion, ensuring treatment fidelity is vital to developing and administering a customized intervention (Hott et al., 2015). A description and explanation of the BE WELL intervention program has been provided. The information presented above provides specifics about the structure of the customized intervention, the integration of theory and neuroscience into the content of the intervention, and the counselor/investigator's experience, to clearly identify the independent variable for the study.

## **Procedure**

**Recruiting participants.** After Institutional Review Board (IRB) approval, participants were recruited through various means including posting flyers in the community in locations frequented by PwMS (e.g., neurology clinics, physical therapy practices), attending educational programs, and utilizing a personal network of associates acquired through working with the MS Society. Interested participants were invited to meet individually with the counselor/investigator in-person to discuss the study in more detail. Prospective participants were informed of the nature of the study, the benefits participants may gain from the study, topical areas of focus that will be covered during individual counseling sessions, expectations of participants, the duration of the intervention program, and the intended use of the results. In addition, prospective participants were informed that a small incentive would be given to participants that completed the entire 12-week study.

Throughout the recruitment process, the counselor/investigator referred to a script (see Appendix H) to maintain consistency in the information that was shared. Upon agreement from participants, hard copies of the consent form were disseminated (see Appendix A). The counselor/investigator worked with each participant individually to obtain the signed consent form. At the conclusion of the BE WELL intervention program, all four participants received a \$30.00 gift card as a token of appreciation for completing the entire experiment.

**Data collection.** An *N*-of-1/ABA single-case research design was used for this study. During the first phase of the study, phase A1, also known as the baseline phase, the counselor/investigator met with each participant to show them how and where to locate the CFS and answer any questions the participants have about the process. To ensure participant confidentiality, assessments were completed via *Qualtrics*, a web-based survey data analysis service that uses Transport Layer Security (TLS) encryption for transmitted data. Participants received reminders with links to the assessment via the *BZ Reminder App* to take the assessment. To ensure participants were able to use the App and access the assessments, the counselor/investigator helped participants with their initial login, addressed any technical issues, and answer any questions related to the intervention program.

To further protect the identities of participants, a code was used in lieu of their names to help participants log into *Qualtrics*. Items on the CFS were randomized each time participants took the assessment since there was no sequential order. By randomizing the items, the participant's familiarity with the order of the questions were reduced. The completed assessments helped the counselor/investigator create an initial plan that focused on the participant's coping needs prior to treatment. The counselor/investigator also developed a time schedule for each participant that consisted of a *Qualtrics* link via a university portal to complete

the instruments electronically. Participants were instructed to complete the instrument on the assigned dates during the two weeks before the first counseling intervention session.

Assessments were administered twice on a weekly basis and participants developed a schedule via the *BZ Reminder App* noting when to complete the assessments.

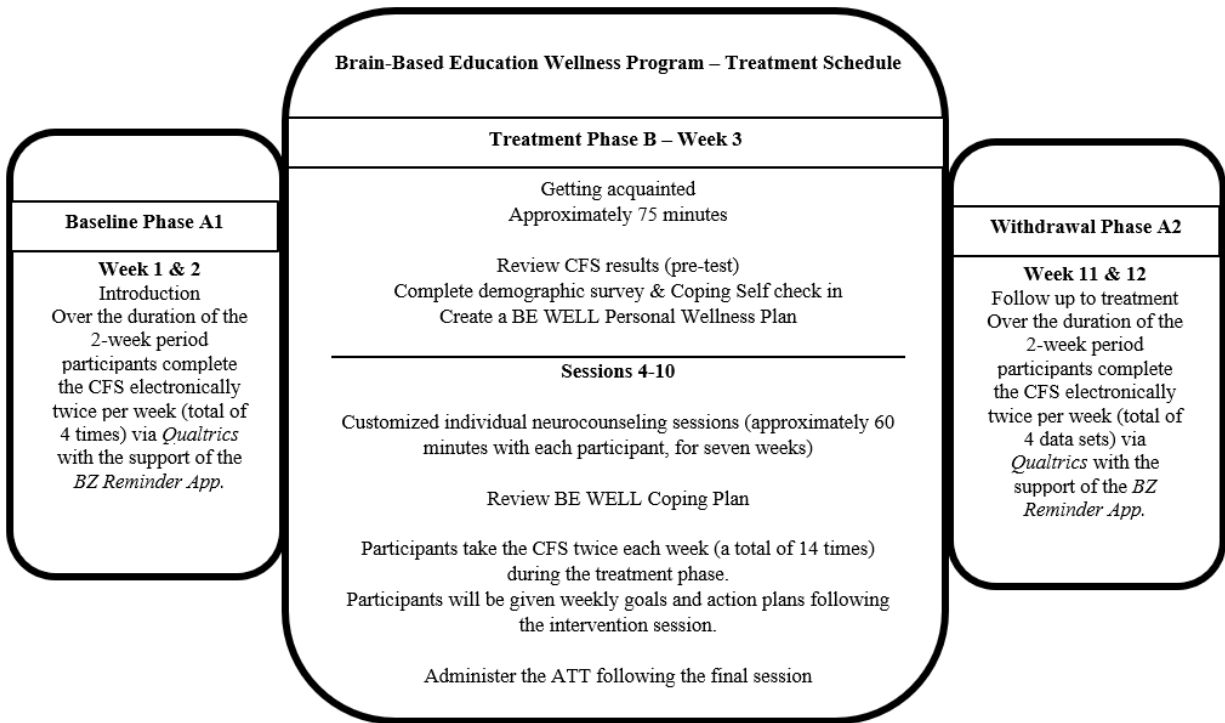
For phase B of the study (intervention phase), the counselor/investigator met with each participant individually at an agreed upon time and location for a full session (60 minutes) during the treatment phase (weeks three through ten). The first session focused on rapport building, identification of the stress process, and establishing coping and personal goals. Subsequent sessions focused on delivering the customized individual neurocounseling interventions to enhance the coping flexibility of participants, using the treatment goals as a guide. Each intervention was designed to facilitate the individual needs of the participants while also incorporating the two factors of the CFS within the HMP framework. At the end of each session during the treatment phase, the participant took the CFS. During the first session, assessment results were reviewed with each participant. Then the Brain-Based Education and Wellness (BEWELL) plan was introduced to the participants and the counselor/investigator worked with them in a collaborative effort to complete the plan (see Appendix G).

Each treatment session began with a review of the previous session. The participants' goals and progress toward meeting the treatment goals were discussed. Goals focused on increasing coping flexibility as determined by the CFS scores. At the beginning and end of each session during the intervention phase, participants completed the CFS. Each participant's assessment scores were monitored to assess individual change through the duration of the study. To do this, each participant's assessment scores were visually plotted on a line graph on a weekly basis. The dependent variables (i.e., evaluation coping, adaptive coping, and total

coping) were plotted on the ordinate or *y*-axis, and the temporal variables were plotted on the abscissa or *x*-axis of the graphs.

Once phase B (intervention phase) ended, participants completed the Attitudes Toward Treatment (ATT) measure, a self-report assessment designed to assess participants' attitudes and perceptions about the value of an intervention. The ATT was administered electronically through *Qualtrics*. During the post-intervention phase (phase A2), a two-week follow-up to treatment occurred (weeks 11-12). During this time, participants completed the CFS four times. This was used as a means to assess for any changes in scores that may have occurred after the withdrawal of the intervention. Once the last assessment scores were captured in *Qualtrics*, each participant received a \$30 gift card as a token of gratitude for their participation.

In summary, data were collected over 12 weeks. The baseline for participants was made up of four assessment scores from specific points in time in weeks one and two. The intervention stage lasted 8 weeks and included eight sessions with assessments prior to and after each counseling session and four follow-up measures were obtained in weeks 11 and 12. A schedule of the data collection process is displayed in Figure 2.



**Figure 2**

*Schedule of Data Collection*

**Data analysis.** Two main research questions and three sub-questions pertaining to coping flexibility were addressed in the present study. The first question is directly related to coping flexibility measure; the latter question focused on social validity. To strengthen the results of the present study, several methods of data analysis were utilized including (a) visual analysis, (b) descriptive statistics, (c) effect sizes, (d) data exploration through autocorrelation and regression analysis, (e) non-parametric analysis, and (f) social validity measures from participants were provided. An explanation of each type of data analysis that were used in the present study is provided below.

**Visual analysis.** In SCRDS, visual analysis is the most widely used method of data analysis. Thus, visual analysis of graphic displays of data is the gold standard for single-subject experimental research (Lane & Gast, 2014). Visual analysis involves “systematic procedures

used to evaluate specific characteristics of data patterns and evaluate the presence of a functional relation. It facilitates formative evaluation of intervention effectiveness allowing for close examination of the data over time and across conditions” (Barton et al., 2018, p. 180).

Therefore, visual representations of the data were the foundation for interpreting the intervention’s effect on the targeted outcome (Hott et al., 2015; Vannest & Ninci, 2015). In the present study, the time series data captured from participant responses were plotted graphically on the  $y$  (dependent variable) and  $x$  (temporal variable) axes for each participant. The baseline, treatment, and withdrawal phase of the CFS factor scores for each participant were presented visually. These visual graphs were used to examine the data for trends, changes, and the stability of the intervention’s effects across participants.

***Descriptive statistics.*** Descriptive statistics were used to describe the coping flexibility (dependent variable) patterns of the participants. A trend line was calculated to help determine the appropriate type of analysis for data exploration (Auerbach & Zeitlin, 2014). Measures of central tendency and variability (dispersion of the data) were used to examine the data for common trends and outliers. Reviewing the dispersion of the data, also provided an opportunity to find autocorrelation and examine trends within the observations.

***Data exploration.*** In  $N$ -of-1/ABA single-subject experimental designs it is important to look for autocorrelation and trends between phases. Autocorrelation refers to “the lack of independence in SCRD data, such that data points that are closer together in time are more similar than those that are farther apart in time” (Moeyaert et al., 2018, p. 402). Autocorrelation analysis helped to detect the serial dependency of time series data which determined whether each observation in each phase and factor of the study was independent or unrelated. This is a key assumption for parametric analysis methods (Bloom et al., 2009). In the present study,

autocorrelations were revealed through regression analysis. Once autocorrelations were completed, regression analyses were used to determine if there were significant trends in any phase of the study for the dependent variables and if there were significant trends, parametric analysis would not provide reliable information.

In the present study, parametric methods were not applied due to the low observation numbers, autocorrelation in the treatment phase and significant trend throughout the study. Due to these conditions, the Conservative Dual-Criteria (CDC) (Fisher et al., 2003; Swoboda et al., 2010) was used as a robust statistical analysis tool to compare the phases of each factor. Using CDC as a statistical analysis method allows the mean and regression lines of the phase to be compared. For the present study, the goal was to determine if there was a significant increase in attitude (i.e., coping flexibility). With CDC, the mean and regression lines of the comparison phase as well as the number of observations in the comparison phase are used to determine a significance threshold. A significant result occurred when the actual account was equal to or greater than the threshold.

*Effect sizes.* To delve further into the impact of the BE WELL interventions, effect sizes evaluating treatment efficacy were calculated. Vannest and Ninci (2015) define effect size (ES) as a “quantitative index that estimates the meaningfulness of change associated with the intervention” (p. 403). Effect sizes in addition to visual analysis provided an added layer of credibility, reliability, and defensibility of the findings (Vannest & Ninci, 2015). Non-parametric techniques are often employed with the type of data found in SCRDS (Vannest & Ninci, 2015) and this study was no exception. Parker et al. (2011) identified nine non-parametric methods or nonoverlap indices for estimating effect sizes. For the present study, the G-index was used to determine effect size (Cohen, 1988). The G-index is considered to be a more robust measure for

outliers, trends, and autocorrelation compared to other indices (Auerbach & Zeitlin, 2014) and it is the preferred method for smaller samples (Cohen, 1988).

To calculate the G-index, only the proportion of scores in the desired zone above the regression line were used. This is because the desired outcome is an increase in CFS scores. Therefore, the desired zone was above the regression line due to an expected increase in scores from the baseline to the treatment phase. Then the baseline average was subtracted from the intervention average. A positive G-index indicates an improvement in the score while a negative value indicates no improvement. For data points that were not autocorrelated and did not have a significant trend, the G-index was calculated using the mean for those variables. For data points with autocorrelation or a significant trend, the G-index was calculated using the median. Suggested criteria for interpreting effect sizes are provided in the counseling literature. G-indices may be categorized as small (0.1–.30), medium (0.31–0.50), and large (>0.51) (Vannest & Ninci, 2015).

***Statistical analysis.*** Multiple methods of data analysis were used to further examine the effects of the study by looking at whether a statistical significance was detected between the phases. Regression analysis were measured for each participant, factor, and phase to determine if there is a trend in each phase of the study. Robust autocorrelation in the treatment phase across factors and trend for most phases and factors were found using the CDC statistical analyses. This was needed to make comparisons between treatment phases. This data added another rich layer to support the graphic representations, regressions, and effect sizes.

***Treatment fidelity.*** To reduce confounding exposure from occurring in the study, the counselor/investigator documented any unforeseen circumstances, such as changes in symptoms, behavior, or the participant's social environment that may have influenced treatment outcomes

throughout the intervention program by taking field notes. By documenting these events, the counselor/investigator was able to better control threats to the internal validity and increase external validity (Hott et al., 2015). In addition, the post-intervention social validity measure provided an added layer of credibility to the findings.

*Summary of the data analysis.* In the present study, examining the data began with visual analysis. The data were further examined by using detailed analyses to examine the effects of each intervention with participants. Various statistical analysis tools and methods were used to strengthen the findings and support the overall results. The final data analysis method involved the counselor/investigator seeking feedback from participants on their attitude and perceptions toward the value of the intervention. This social validity measure complemented each layer of the data analysis.

## **Summary**

Chapter three addressed the methodology for the present study. In the chapter, the background and use of the study's research design (*N*-of-1/ABA single case research design) were explained and a description of the targeted population for the study was provided. Additionally, the research questions, instrumentation, a description of the customized intervention program, and the data collection and analysis procedures were also provided. Detailed information regarding each participant's BE WELL intervention during the treatment phase are presented in Appendix G.

## CHAPTER 4: RESULTS

The purpose of this study was to examine the effects of customized psychoeducation-based neurocounseling interventions on the coping flexibility among AAWwMS. The intervention was called the Brain-based Wellness (BE WELL) program and it was based on a theoretical framework that included components of the IS-Wel model, TTSC, and HMP. The intervention specifically targeted evaluation coping and adaptive coping components of coping flexibility while providing various strategies to improve coping efforts. The eight-week intervention was customized for each participant based on their individual needs related to their coping flexibility scores from the Coping Flexibility Scale (Kato, 2012). An *N*-of-1/ABA single-case research design (SCRD) was used to investigate the effects of the intervention (Kazdin, 2016) with AAWwMS. To analyze the data collected from each phase (baseline, treatment, withdrawal) of the study, the R software package, *SSD for R*, was used (Auerbach & Zeitlin, 2014).

This chapter is organized based on the two research questions that guided the present study. For the first research question, the data that were collected and analyzed for each of the dependent variables, evaluation coping, adaptive coping, and total coping flexibility for each participant. The results are presented individually for each participant. A profile of each participant's biography is provided first. Then the goals that were established for each participant at the onset of the study are provided and they are followed by the results for each component of coping flexibility. Following the results is a summary that includes a visual analysis for each dependent variable across participants.

The second research question pertained to measuring social validity. Participants' perceptions of the effectiveness of the intervention were examined in this question. The Attitudes

Toward Treatment (ATT; Baker, n.d.) measure was given to each participant following the final intervention session to gather the information on their experience in the BE WELL program. Results of participants' ATT scores were provided along with an explanation of the perceived effectiveness. The results from this social validity measure were used as an additional layer of data to support the visual and quantitative analyses.

### **Coping Flexibility Results Across All BE WELL Participants**

The present study was an SCRCD that included four participants: Aggie, Yvonne, Chelsea, and Tonya; to address the coping flexibility of PwMS, specifically African American women with MS, in response to a customized psychoeducation-based neurocounseling intervention. Evaluation coping, adaptive coping, and total coping flexibility were evaluated across three phases: baseline, treatment (intervention), and withdrawal. Each participant was evaluated independently utilizing single case design analysis methods. Visual and quantitative analyses were completed for each participant, coping measure, and phase of the study.

To answer the first research question, the assessment was used to assess all three coping measures: (a) evaluation coping was defined as abandoning a coping strategy or strategies that produce undesirable outcomes, (b) adaptive coping occurred once an individual deemed that a coping strategy was ineffective and implemented a more effective one, and (c) total coping flexibility was the summation of both evaluation and adaptive coping scores on the CFS (Kato, 2012). The CFS was completed by all participants throughout the duration of the intervention program as a method for data collection. For each participant, visual and statistical analyses were completed for each factor and phase via the R software package, *SSD for R* (Auerbach & Zeitlin, 2014). The G-index statistic in the present study was used to calculate effect size (Cohen, 1988). The individual data results for all participants are presented in the following order: (a) visual

analysis, (b) descriptive statistics, (c) data exploration, (d) effect sizes (e) statistical analysis, and (f) summary for each participant.

### **Aggie**

Aggie was a 34-year old African American woman living with relapse-remitting multiple sclerosis (RRMS). She had been living with MS for at least five years and her primary symptoms included fatigue, muscle spasms, pain, and spasticity. She had a cane but hardly ever used it because she generally did not have any difficulty walking on her own. In addition to her MS, Aggie had been diagnosed with one other chronic health condition. She received her bachelor's degree and was employed full-time. She lived in a rural town with her husband and they earned a middle-class income. She did not have any children. In the past six months, she identified her primary sources of stress as financial and work-related stress.

Aggie aspired to become a mother and wanted her husband to become more involved in helping her manage their financial obligations. She also wanted to advance in her career and began searching for other job opportunities during the study. She was also motivated to seek new employment because of the possibility of future layoffs from her current employer. Aggie was going to counseling and her support network consisted of her husband, mother, sister, and a friend who lived in another state.

Although Aggie had private insurance, she shared on several occasions that her interactions with various healthcare providers had been an ongoing source of stress. She had a treatment team that included her primary care physician and neurologist and she usually had to visit her doctor for an MS-related visit at least once every three months. Overall, she described her relationship with these providers as helpful. However, she felt that her needs and concerns were dismissed by other providers she had been referred to for procedures or consultations. She

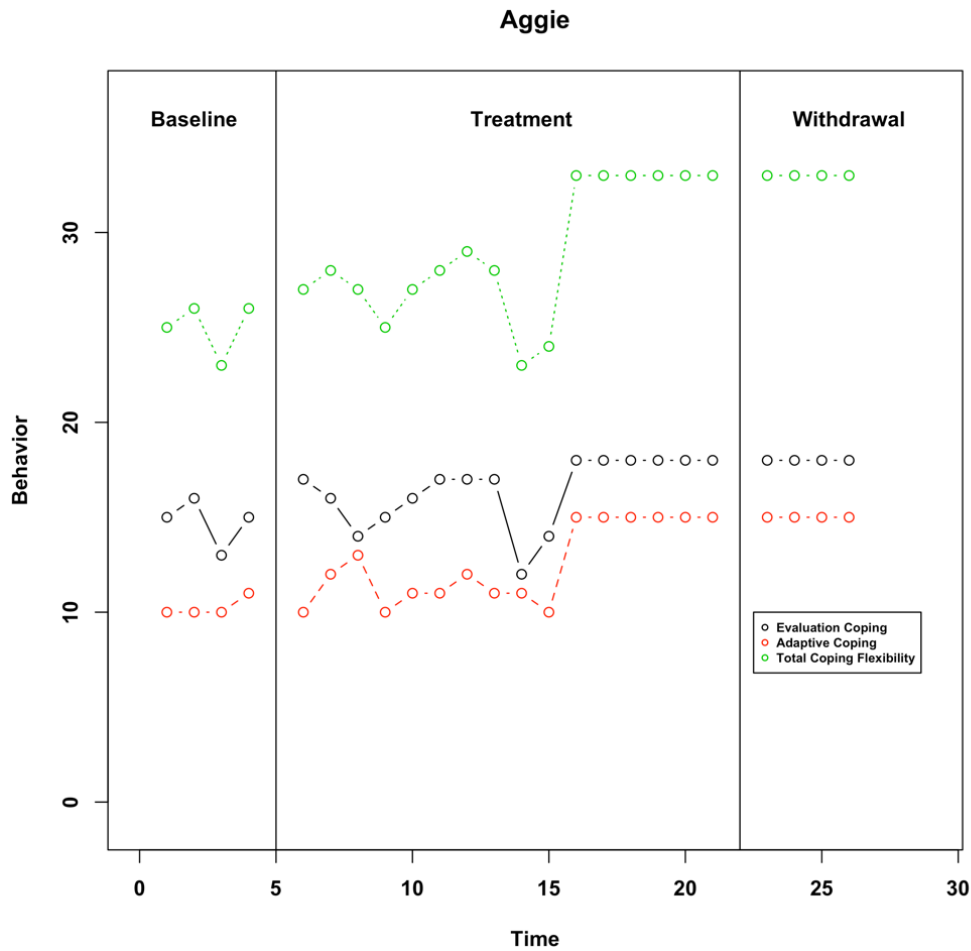
also mentioned that she felt like a “guinea pig” because of all the various disease modifying therapies she had been prescribed to manage her MS. In addition, she was worried about the out-of-pocket costs for an upcoming MRI that she needed to have done.

At the outset of the BE WELL program, Aggie indicated that she was moderately dissatisfied with her efforts to cope with stress. She described herself as being a “perfectionist” at times and that she often felt the need to be in control. She also experienced sleep problems and mentioned that she could not remember the last time she had quality sleep. Although she worked full-time, her job provided her with the flexibility to work both on-site and from home. She described her job as “demanding” and as a result, she had experienced what she identified as panic attacks because of the stress from work. Aggie really wanted to work on improving her coping efforts and learning new strategies to deal with stressful situation, particularly when it comes to her job. As such, Aggie established three coping flexibility intervention goals (see Appendix G). Goal one: To reduce the occurrence of panic attacks. Goal two: Create healthy boundaries, particularly in the work setting. Goal three: Develop more adaptive coping strategies to regulate emotions in stressful situations, particularly in the work environment. For her BE WELL wellness plan, Aggie identified one coping strategy that she wanted to work on. Her SMART coping goal was to develop a list of affirmations, quotes, and scriptures to help reframe her negative self-talk regarding work-related stress and to counteract her irrational thinking patterns (i.e., filtering and using ‘should’ statements) that increase her stress burden.

### **Visual Analysis**

Aggie’s responses displayed a semi-stable baseline pattern for each of the coping flexibility measures (see Figure 3). Adaptive coping was more stable than evaluation coping and total coping flexibility. While a more stable baseline is desired, the concurrent baseline phases

did not display wide fluctuations or obvious repetitive cycles. The treatment phase of all coping measures followed a similar pattern. There was a semi-stable increase for the first eight observations of the treatment phase. There was then a steep increase in coping flexibility that was maintained throughout the withdrawal phase. After treatment, the withdrawal phase indicated stability on all factors, showing that Aggie’s coping responses remained at treatment levels. This indicated that the BE WELL intervention did have a positive effect on her coping process. Overall, the BE WELL intervention appeared to successfully increase Aggie’s coping flexibility.



**Figure 3**

*Visual Analysis of Coping Flexibility for Aggie*

## **Descriptive Statistics**

To further evaluate Aggie's results, descriptive statistics were used to analyze the data including the number of observations in phase, mean, 10% trim mean (for use in the case of outliers), median, standard deviation, coefficient of variation, range, and interquartile range (IQR). Descriptive statistics for both central tendency and variability were computed for each of the factors and phases of Aggie's coping flexibility. As shown in Table 2 and Table 3, the data were roughly normally distributed for each of the coping flexibility measures. The *n* (Baseline = 4, Treatment = 16, and Withdrawal = 4) indicates no missing values. A comparison of central tendency measures, mean, 10% trimmed mean, and median, indicated no significant outliers (see Table 2). A comparison of variability measures, standard deviation and coefficient of variation, indicated moderate variability across the baseline and treatment phase of each coping measure (see Table 3). The withdrawal phase had no variability as it was stable. The mean and median showed an increase from baseline-to-treatment phases and treatment to withdrawal phases. The range and IQR indicated that adaptive coping was less than evaluation coping. The IQR was congruent with the difference in magnitude of the coping measures with total coping flexibility having the greatest IQR and evaluation coping having the least. All observations fell within two standard deviations of the mean suggesting no extreme variability.

**Table 2***Descriptive Statistics of Central Tendency for Aggie*

	<i>n</i>			<i>Mean</i>			<b>10% Trim Mean</b>			<b>Median</b>		
	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>
<b>Evaluation</b>	4	16	4	14.75	16.438	18.00	14.75	16.643	18.00	15.00	17.00	18.00
<b>Adaptive</b>	4	16	4	10.25	12.562	15.00	10.25	12.571	15.00	10.00	12.00	15.00
<b>Total</b>	4	16	4	25.00	29.00	33.00	25.00	29.143	33.00	25.50	28.00	33.00

*Note.* Descriptive statistics include *n* = number of observations in the phase; 10% Trim Mean (for use in case of outliers); Total = total coping flexibility; Phases include A1 = baseline; B = treatment; A2 = withdrawal.

**Table 3***Descriptive Statistics of Variability for Aggie*

	<i>SD</i>			<i>CV</i>			<b>Range (min, max)</b>			<b>IQR</b>		
	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>
<b>Evaluation</b>	1.258	1.825	0	0.085	0.111	0	(13,16)	(12,18)	(18,18)	0.75	2.25	0
<b>Adaptive</b>	0.50	2.097	0	0.049	0.167	0	(10,11)	(10,15)	(15,15)	0.25	4.00	0
<b>Total</b>	1.414	3.54	0	0.057	0.12	0	(23,26)	(23,33)	(33,33)	1.50	6.00	0

*Note.* Descriptive statistics include *SD* = standard of deviation; *CV* = coefficient of variation; Total = total coping flexibility. There are no missing values. Phases include A1 = baseline; B = treatment; A2 = withdrawal

## Data Exploration

Both autocorrelation and regression analyses were completed to determine if traditional parametric analyses could be used to determine the effect of the intervention. Autocorrelation was calculated for each phase of each coping measure for Aggie. Autocorrelation is calculated to determine if each observation within each phase of each coping measure is independent, a key assumption of parametric analysis methods (see Table 4).

**Table 4**

*Autocorrelation Across Each Phase of Each Coping Measure for Aggie*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?
<b>Evaluation</b>	-1.263	0.26	NO	0.626	0.04	<b>YES</b>	NA	NA	NA
<b>Adaptive</b>	0.889	0.45	NO	0.899	0.001	<b>YES</b>	NA	NA	NA
<b>Total</b>	-1.556	0.143	<b>YES</b>	0.908	0.001	<b>YES</b>	NA	NA	NA

*Note.* Rf2 = multiple correlation coefficient; Sig. = significance value; Auto corr.? = whether autocorrelation was detected; Total = total coping flexibility. Significance level:  $\alpha = .05$ .

Significance values less than 0.05 in the treatment phase were considered significant due to the small number of observations. There were no significance values less than 0.05 in other phases.

NA occurs where there is no variability to compute autocorrelation.

Significant autocorrelation was seen where the Rf2 significance was less than 0.05.

There was significant autocorrelation in the treatment phase but there was no significant autocorrelation in the baseline and withdrawal phases. Regression analysis was also used to

determine if there was a significant trend in any phase of each coping measure for Aggie. If there is a significant trend in any phase, measures of central tendency lack the ability to accurately assess the typical response. Regression is measured to determine if there is a trend in each phase of the study for each coping measure. As shown in Table 5, significant autocorrelation is seen where the p-value is less than .05. There was a significant trend in the treatment phase of each of the coping measures.

**Table 5**

*Regression Across Each Phase of Each Coping Measure for Aggie*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Slope	p-value	Trend?	Slope	p-value	Trend?	Slope	p-value	Trend?
<b>Evaluation</b>	-0.30	.692	NO	0.172	.008	<b>YES</b>	0	NA	NA
<b>Adaptive</b>	0.30	.225	NO	0.328	> .001	<b>YES</b>	0	NA	NA
<b>Total</b>	0	1	NO	0.50	.004	<b>YES</b>	0	NA	NA

*Note.* Trend? = significant trend in the phase; Total = total coping flexibility. Significance level:  $\alpha = .05$ . Significance values less than .05 in the treatment phase were considered significant due to the small number of observations. NA occurs where there is no variability to compute trend.

While visual analysis is the gold standard for SCRDs, the effect size and statistical analysis methods can be used to support quantitative single case design studies. The decision of whether to use traditional parametric methods was based on the data presented above. Due to the presence of treatment phase autocorrelation (see Table 4) and significant trend (see Table 5) non-parametric methods were used to further analyze the data.

## Effect Sizes

To further support the visual analysis of Aggie’s results, the non-parametric effect size method, G-index, was used to calculate effect size. (Cohen, 1988). The G-index method is robust to outliers, trend and autocorrelation. The G-index compares regression lines across the two phases of interest. Where there is significant trend, the regression line G-index is used. Otherwise the median G-index is used. For the interpretation of effect size the following criteria are used: small effect size (0.1–0.3), medium effect size (0.31–0.50), and large effect size (>0.51). As expected, based on the visual analysis, there was a large to medium effect size from the baseline phase to withdrawal phase (see Table 6). There was also a medium effect size for the between the baseline-to-treatment phase. The negative effect sizes were expected in phases where there was little to no change in the desired direction (increase in the three coping measures).

**Table 6**

*G-index Effect Sizes for Each Coping Measure During Each Phase for Aggie*

	<b>Baseline/Treatment</b>		<b>Baseline/Withdrawal</b>		<b>Treatment/Withdrawal</b>	
	<b>G-index</b>	<b>Effect size</b>	<b>G-index</b>	<b>Effect size</b>	<b>G-index</b>	<b>Effect size</b>
<b>Evaluation</b>	0.50	<b>Medium</b>	0.75	<b>Large</b>	-0.50	Medium (Negative)
<b>Adaptive</b>	-0.125	Small (Negative)	0.75	<b>Large</b>	-0.438	Small (Negative)
<b>Total</b>	0.312	<b>Medium</b>	0.50	<b>Medium</b>	-0.688	Large (Negative)

*Note.* Total = total coping flexibility. Bolded values indicate a medium to large effect size in the desired direction. Effect size determination: size small effect size (0.1–0.30), medium effect size (0.31–0.50), and large effect size (>0.51). Regression line G-index used instead of the mean.

## **Statistical Analysis**

Due to the significant trend and autocorrelation found in several phases, the Conservative Dual-Criteria (CDC) was used as a robust statistical analysis tool to compare the phases of each coping measure. The CDC utilizes both the mean and regression lines of the phase to be compared (Auerbach & Zeitlin, 2014). The goal was to determine if there was a significant increase in coping flexibility. CDC determines a significance threshold compared to the number of observations above or below the regression and mean lines. A significant result occurs when the actual amount is equal to or greater than the threshold. The desired outcome was an increase in coping flexibility, therefore the CDC<sub>above</sub> function was computed. Using the CDC helped to determine where the differences occurred in the coping measures when comparing treatment to baseline, withdrawal to baseline, and withdrawal to treatment (see Table 7).

As noted in the data, there were significant differences for evaluation coping and total coping flexibility from baseline-to-treatment in accordance with the effect size results. There was also a significant difference between the baseline and withdrawal phase for each of the coping measures. As expected, no significant difference in the coping measures was seen between the treatment and withdrawal phase.

**Table 7***Conservative Dual-Criteria (CDC) for Each Coping Measure Across Phases for Aggie*

	<b>Baseline/Treatment</b>		<b>Baseline/Withdrawal</b>		<b>Treatment/Withdrawal</b>	
	<b>Significant Threshold</b>	<b>Actual Count</b>	<b>Significant Threshold</b>	<b>Actual Count</b>	<b>Significant Threshold</b>	<b>Actual Count</b>
<b>Evaluation</b>	12	12*	0	4*	0	0
<b>Adaptive</b>	12	5	0	4*	0	0
<b>Total</b>	12	13*	0	4*	0	0

*Note.* Total = total coping flexibility; \* = significance threshold met. When the threshold is 0, the maximum number of data points are above the regression and mean line. When this occurs, the result is considered significant. There was a significant increase in all coping measures between the baseline-to-withdrawal phase.

### **Summary of Aggie’s Findings**

Overall, the BE WELL intervention program positively impacted Aggie’s coping process and subsequent behaviors. Both the visual analysis and quantitative analysis demonstrated the success of the intervention for Aggie for all coping measures (evaluation coping, adaptive coping, and total coping flexibility). It is also important to note that Aggie maintained the increased coping flexibility after the treatment was withdrawn. Aggie’s goals consisted of reducing the occurrence of panic attacks, creating healthy boundaries, particularly in the work setting, and developing more adaptive coping strategies to regulate emotions in the work environment. Based on the data analysis, Aggie was successful in achieving her coping goals. More specifically, the intervention appeared to improve Aggie’s ability to abandon ineffective coping behaviors such as negative self-talk and increase cognitive adaptive coping strategies.

Regarding Aggie's SMART coping goal, she developed a list of positive affirmations and inspirational messages that helped her reframe irrational thinking patterns.

### **Yvonne**

Yvonne was a 60-year old African American woman living with relapse-remitting multiple sclerosis (RRMS). She had been living with MS for 10 years and her symptoms included fatigue, walking difficulties, numbness/tingling, spasticity, pain, and bladder/bowel problems. The highest level of education that she completed was her high school diploma. She was unemployed and she had a low-income for her household due to her acquired disability from having MS. She lived in an urban area in an apartment with her husband. She had three adult daughters. Although she had a support network, she wanted to deepen those ties, particularly with her daughters and sisters. In the past six months, she identified her primary source of stress as MS-related stress.

Although Yvonne had assistive devices such as a rolling walker and a portable mobilized wheelchair, she did not regularly use them at home. She primarily used these devices when she would go into the community and when she would travel. She was glad to have those devices, but she did not want to become dependent on them. In addition to her MS, Yvonne had been diagnosed with two other chronic health conditions. Yvonne had insurance and she had a treatment team that included her primary care physician and neurologist. She usually had to visit her doctor for an MS-related visit at least once every six months. She was currently taking a DMT to manage her MS. She had experienced what she described as depression since being diagnosed with MS. However, she had never sought mental health treatment.

Yvonne described herself as an "inventor" and aspired to become an author. She lived near family and would often provide childcare for family members. Her support network

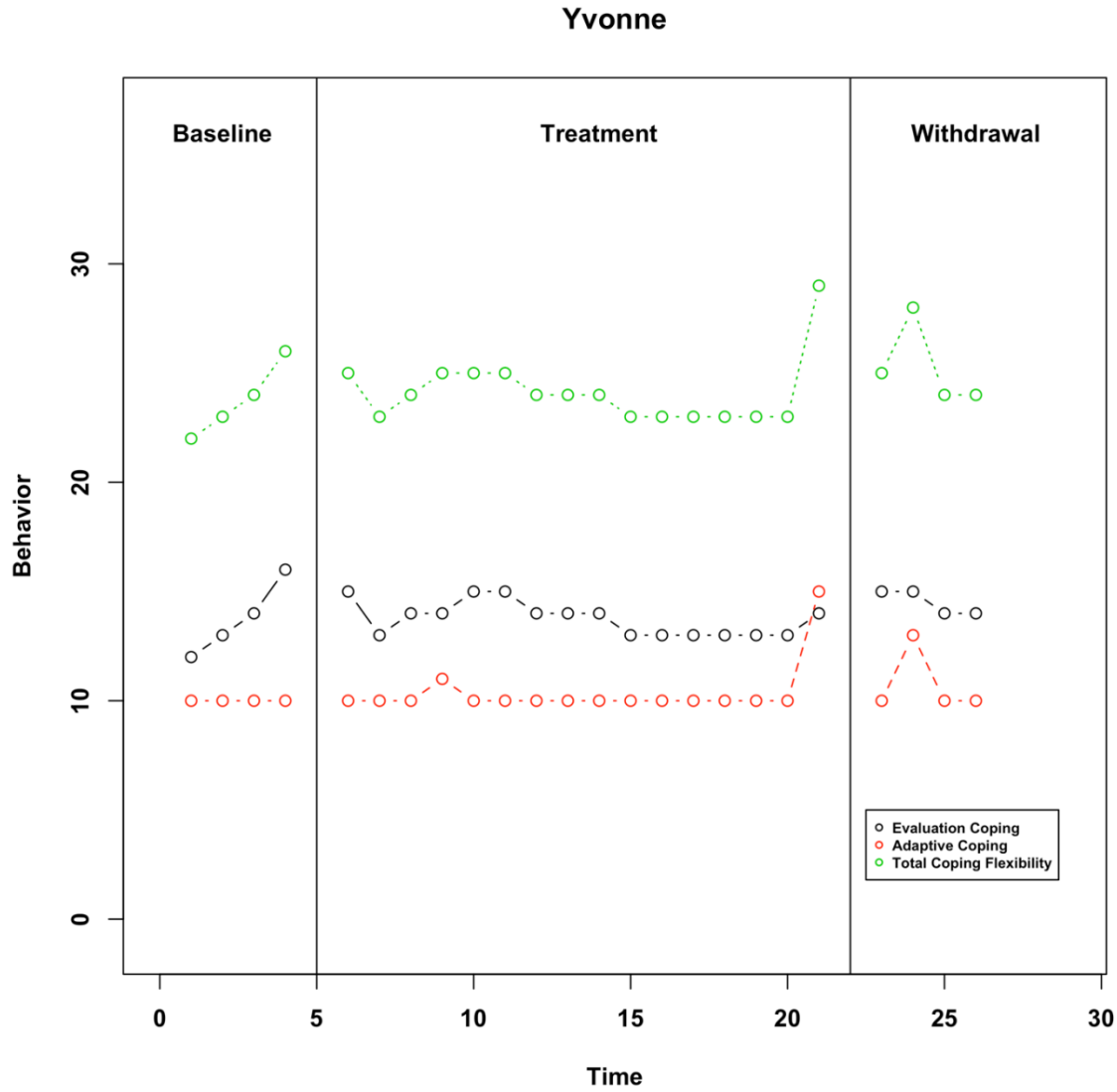
consisted of her mother, daughters, and husband. However, she felt most comfortable confiding in her mother and one of her daughters.

At the outset of the BE WELL program, Yvonne indicated that she was slightly dissatisfied with her efforts to cope with stress. Yvonne described herself as being a “collector” and that at times she had difficulty letting go of things that she had acquired throughout her life. However, she stated that she was highly motivated to get rid of things because she wanted to declutter her home. Yvonne really wanted to work on identifying stressors that were controllable vs. uncontrollable to improve her evaluation coping. She also wanted to work on improving her coping efforts and learn more adaptive coping strategies, particularly when it came to managing her MS symptoms. As such, Yvonne established two coping flexibility intervention goals (see Appendix G). Goal one: To assess stressful situations that were controllable vs. uncontrollable. Goal two: Develop more adaptive coping strategies to regulate emotions and better manage stressful situations related to her MS symptoms. For her BE WELL wellness plan, Yvonne identified two SMART coping strategies that she wanted to improve throughout the program. Her SMART coping goals were to: (a) go to weekly exercise sessions at the gym on Tuesdays and Thursdays to lose 10 pounds in 8 weeks and: (b) remove at least half of the items in closets and storage containers to declutter the home (the equivalent of nine large storage bins).

### **Visual Analysis**

Yvonne’s responses displayed a stable baseline pattern for each of the total coping flexibility measures (see Figure 4). An increasing trend baseline was seen for adaptive coping and evaluation coping. While a more stable (non-increasing) baseline was desired, the concurrent baseline phases did not display wide fluctuations or obvious repetitive cycles. The treatment phase of all coping measures follows a similar pattern. There was a semi-stable pattern

across the treatment without the desired significant increase from baseline-to-treatment or a stable withdrawal period when treatment was withdrawn. The intervention appeared to have not been successful in leading to the desired increase in Yvonne’s coping flexibility. However, it is of note that Yvonne’s coping flexibility did increase slightly.



**Figure 4**

*Visual Analysis of Coping Flexibility for Yvonne*

## **Descriptive Statistics**

To further evaluate Yvonne's results, descriptive statistics were used to analyze the data which included the number of observations in phase, mean, 10% trim mean (used in the case of outliers), median, standard deviation, coefficient of variation, range, and interquartile range (IQR). Descriptive statistics for both central tendency and variability were computed for each of the factors and phases of Yvonne's coping flexibility. As shown in Table 8 and 9, the data were roughly normally distributed for each the coping flexibility measures. The n (Baseline = 4, Treatment = 16, and Withdrawal = 4) indicates no missing values. A comparison of central tendency measures, mean, 10% trimmed mean, and median, indicated no significant outliers. A comparison of variability measures, standard deviation and coefficient of variation, indicated minimum variability across the baseline and treatment phase of each coping measure. The mean and median showed a slight increase from baseline-to-treatment phases and treatment to withdrawal phases. The range and IQR indicated that changes in adaptive coping were less than evaluative coping. The IQR was correlative to the difference in magnitude of the coping measures with total coping flexibility having the greatest IQR and adaptive coping having the least. The withdrawal phase had small variability as it was semi-stable. All observations fell within two standard deviations of the mean suggesting no extreme variability.

**Table 8***Descriptive Statistics of Central Tendency for Yvonne*

	<i>n</i>			<i>Mean</i>			<b>10% Trim Mean</b>			<b>Median</b>		
	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>
<b>Evaluation</b>	4	16	4	13.75	13.75	14.50	13.75	13.714	14.50	13.50	14.00	14.50
<b>Adaptive</b>	4	16	4	10.00	10.375	10.75	10.00	10.071	10.75	10.00	10.00	10.00
<b>Total</b>	4	16	4	23.75	14.125	25.25	23.75	23.857	25.25	23.50	24.00	24.50

*Note.* Descriptive statistics include *n* = number of observations in the phase; 10% Trim Mean (for use in case of outliers); Total = total coping flexibility; Phases include A1 = baseline; B = treatment; A2 = withdrawal.

**Table 9***Descriptive Statistics of Variability for Yvonne*

	<i>SD</i>			<i>CV</i>			<b>Range (min, max)</b>			<b>IQR</b>		
	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>
<b>Evaluation</b>	1.708	0.775	0.577	0.124	0.056	0.04	(12,16)	(13,15)	(14,15)	1.75	1	1
<b>Adaptive</b>	0	1.258	1.50	0	0.121	0.14	(10,10)	(10,15)	(10,13)	0	0	0.75
<b>Total</b>	1.708	1.544	1.893	0.072	0.064	0.075	(22,26)	(23,29)	(24,28)	1.75	2	1.75

*Note.* Descriptive statistics include *SD* = standard of deviation; *CV* = coefficient of variation; Total = total coping flexibility. There are no missing values. Phases include A1 = baseline; B = treatment; A2 = withdrawal.

## Data Exploration

Both autocorrelation and regression analyses were completed to determine if traditional parametric analyses could be used to determine the effect of the intervention. Autocorrelation was calculated for each phase of each coping measure for Yvonne. Autocorrelation was calculated to determine if each observation within each phase of each coping measure was independent, a key assumption of parametric analysis methods. Based on Yvonne's results, significant autocorrelation was seen where the Rf2 Significance is less than 0.05. There was significant autocorrelation in the treatment phase for evaluation and adaptive coping. There was no significant autocorrelation in the withdrawal phase. The baseline phase had significant autocorrelation in evaluation coping and total coping flexibility. Significant autocorrelation was seen where the p-value was less than .05 (see Table 10).

**Table 10**

*Autocorrelation Across Each Phase of Each Coping Measure for Yvonne*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?
<b>Evaluation</b>	1.752	0.083	<b>YES</b>	0.667	0.027	<b>YES</b>	1.367	0.229	NO
<b>Adaptive</b>	NA	NA	NO	0.575	0.062	<b>YES</b>	0.887	0.45	NO
<b>Total</b>	1.752	0.083	<b>YES</b>	0.513	0.101	<b>NO</b>	0.434	0.721	NO

*Note.* Rf2 = multiple correlation coefficient; Sig. = significance value; Auto corr.? = whether autocorrelation was detected; Total = total coping flexibility. Significance level:  $\alpha=0.05$ . NA occurs where there is no variability to compute autocorrelation.

Regression analysis was also used to determine if there was a significant trend in any phase of each coping measure for Yvonne. If there was a significant trend in any phase, measures of central tendency lack the ability to accurately assess the typical response. Regression is measured to determine if there is a trend in each phase of the study for each coping measure. As shown in Table 11, there was a significant trend in the treatment phase for evaluation coping.

**Table 11**

*Regression Across Each Phase of Each Coping Measure for Yvonne*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Slope	p-value	Trend?	Slope	p-value	Trend?	Slope	p-value	Trend?
<b>Evaluation</b>	1.30	.017	<b>YES</b>	-0.091	0.024	<b>YES</b>	-0.40	.106	NO
<b>Adaptive</b>	0	NA	NA	0.097	0.162	NO	-0.30	.742	NO
<b>Total</b>	1.30	.017	<b>YES</b>	0.006	0.947	NO	-0.70	.523	NO

*Note.* Trend? = significant trend in the phase; Total = total coping flexibility. Significance level:  $\alpha=0.05$ . Significance values less than 0.05 in the treatment phase were considered significant due to the small number of observations. NA occurs where there is no variability to compute trend.

While visual analysis is the gold standard for SCRDS, the use of effect size and statistical analysis methods can be used to provide further validity and reliability of quantitative data in single case design studies. The decision of whether to use traditional parametric methods was based on the data presented above. Due to the presence of treatment phase autocorrelation (see Table 10) and significant trend (see Table 11), non-parametric methods were used.

## Effect Sizes

To further support the visual analysis of Yvonne’s results, the non-parametric effect size method, G-index, was used to calculate effect size. (Cohen, 1988). The G-index method is robust to outliers, trend and autocorrelation. As expected, based on the visual analysis, there was only a medium effect size for evaluation coping from treatment to withdrawal phase (see Table 12). The negative effect sizes are expected in phases where there is little to no change in the desired direction (increased values for each of the coping measures).

**Table 12**

*G-index Effect Sizes for Each Coping Measure During Each Phase for Yvonne*

	<b>Baseline/Treatment</b>		<b>Baseline/Withdrawal</b>		<b>Treatment/Withdrawal</b>	
	<b>G-index</b>	<b>Effect size</b>	<b>G-index</b>	<b>Effect size</b>	<b>G-index</b>	<b>Effect size</b>
<b>Evaluation</b>	-0.50	Medium (Negative)	0.50	Medium (Negative)	0.562	<b>Medium</b>
<b>Adaptive</b>	0.125	Small	0.25	Small	-0.062	None
<b>Total</b>	-0.50	Medium (Negative)	0.50	Medium (Negative)	0.188	Small (Negative)

*Note.* Total = total coping flexibility. Bolded values indicate a medium to large effect size in the desired direction. Effect size determination: size small effect size (0.1–0.30), medium effect size (0.31–0.50), and large effect size (>0.51). Regression line G-index used instead of the mean.

## Statistical Analysis

To expound upon the effect sizes, the Conservative Dual-Criteria (CDC) was used as a robust statistical analysis tool to compare the phases of each coping measure. The CDC utilizes both the mean and regression lines of the phase to be compared (Auerbach & Zeitlin, 2014). The goal was to determine if there was a significant increase in coping flexibility. The CDC determines a significance threshold compared to the number of observations above or below the

regression and mean lines. A significant result occurs when the actual amount is equal to or greater than the threshold. The desired outcome was an increase in coping flexibility, therefore, the CDC above function was used to do the analysis. As shown in Table 13, significant differences were seen for evaluation coping in the treatment to withdrawal phase in accordance with the effect size results. As expected, no significant difference was seen in adaptive coping or total coping flexibility between the treatment and withdrawal phase.

**Table 13**

*Conservative Dual-Criteria (CDC) for Each Coping Measure Across Phases for Yvonne*

	Baseline/Treatment		Baseline/Withdrawal		Treatment/Withdrawal	
	Significant Threshold	Actual Count	Significant Threshold	Actual Count	Significant Threshold	Actual Count
<b>Evaluation</b>	12	0	0	0	0	4*
<b>Adaptive</b>	12	2	0	1	0	1
<b>Total</b>	12	0	0	0	0	2

*Note.* Total = total coping flexibility; \* = significance threshold met. When the threshold is 0, the maximum number of data points are above the regression and mean line. When this occurs, the result is considered significant. There was a significant increase in evaluation coping between the treatment to withdrawal phase.

### **Summary of Yvonne's Findings**

Overall, both the visual and statistical analysis demonstrated the very limited success of the intervention for Yvonne for all coping measures. Though a medium effect size was found between the treatment and withdrawal phases, the effect was not statistically significant. It is also important to note that Yvonne did not see a decrease in coping flexibility beyond that of the

baseline phase. Therefore, while the intervention did not cause significant increases on all coping measures, it did not appear to decrease Yvonne's coping flexibility. Yvonne's goals consisted of enhancing her ability to assess stressors as controllable or uncontrollable and develop more adaptive coping strategies to regulate emotions and manage stressful situations related to her MS symptoms. Based on the data analysis, it is uncertain whether Yvonne achieved her goals.

One observable explanation for the intervention's ineffectiveness may in part be due to distractions that occurred during intervention sessions. For example, there were several instances when a family member was present while Yvonne was completing intervention activities and/or the coping assessment and she became distracted. It was also observed that Yvonne seemed confused by the reverse-coded questions due to her facial expressions and questions she asked while taking the assessment. While it is uncertain, it is possible that Yvonne may have had some difficulty comprehending certain assessment questions. Regarding her SMART goals, at the conclusion of the study, Yvonne only completed her second SMART goal. She did not attempt to complete her first SMART goal while in the BE WELL program.

### **Chelsea**

Chelsea was a 45-year old African American woman living with relapse-remitting multiple sclerosis (RRMS). She had been living with MS for eight years, and symptoms included fatigue, numbness/tingling, spasticity, pain, vision problems, bladder/bowel problems, and insomnia. The highest level of education that she completed was her master's degree. She was unemployed due to her acquired disability from MS.

Chelsea lived in a suburban residential area with her husband and youngest son and they earned a middle-class income. Chelsea's father also lived with her and her family since she had

become his primary caregiver. She had another son that lived out of state. Chelsea had a support network that included her family and several friends. She identified her adult son and a good girlfriend that lived out of state as the primary persons in her support network that she would turn to for support. In the past six months, she identified financial stress, MS-related stress, and interpersonal relationship problems as her primary stressors.

In addition to her MS, Chelsea had been diagnosed with several other chronic health conditions. Chelsea had insurance and she had a treatment team that included her primary care physician, neurologist, and therapist. Overall, she described her relationship with these providers as helpful. She frequently visited her doctor for an MS-related visit at least once every week. She was currently taking a DMT to manage her MS. Although Chelsea had been diagnosed with several mood disorders, she rarely met with a therapist.

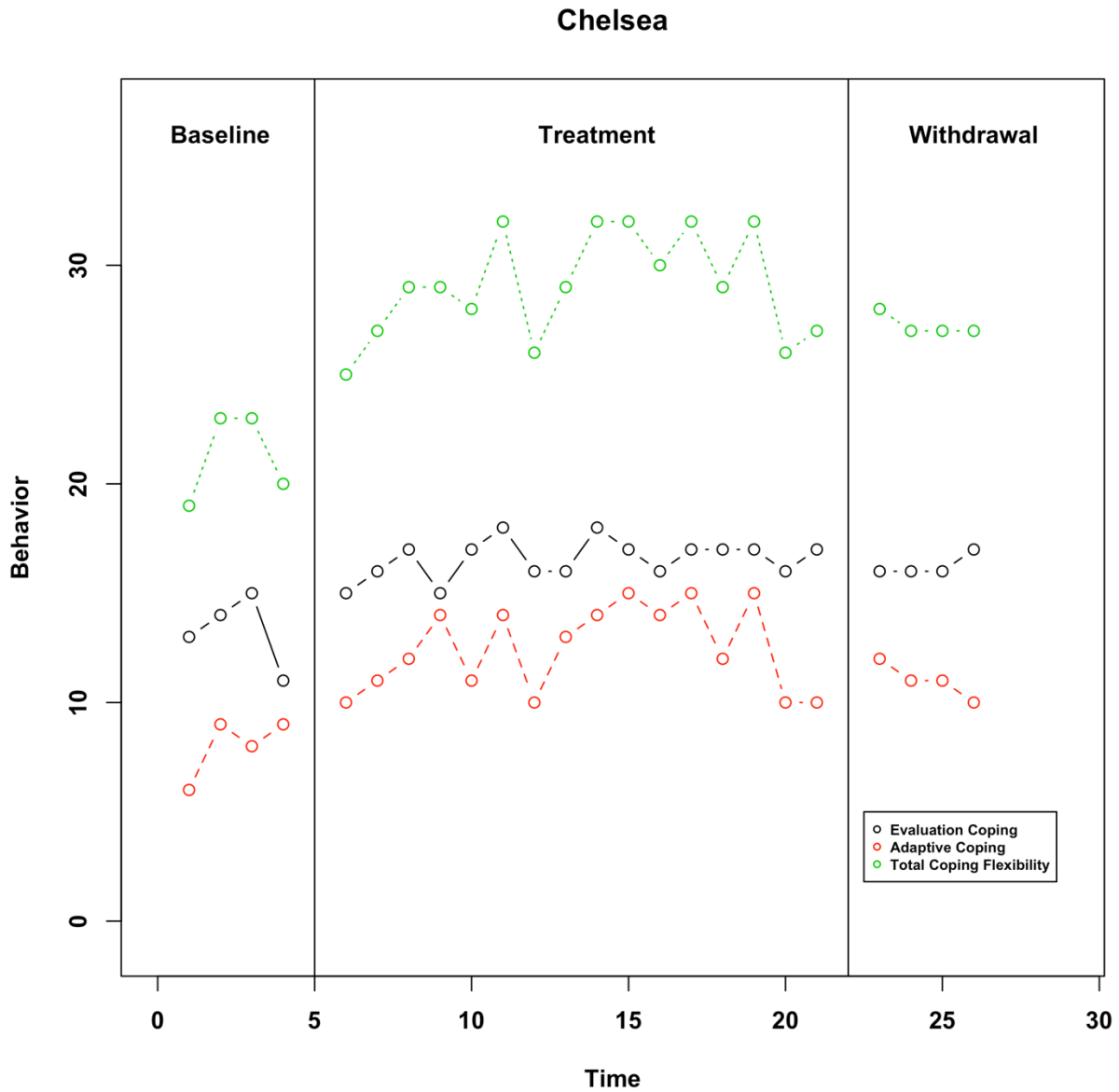
Chelsea described herself as the “fixer” because she felt that she had always been the problem solver for her family. She was very involved in the community and often volunteered at school events. She was also a patient speaker representative for a large pharmaceutical company in the area. In this role, she often presented to others living with MS and their care partners about her experience with MS and the DMT that she used to treat her MS. This opportunity also allowed her to travel and speak to other audiences including health care providers, researchers, and corporate sponsors.

At the outset of the BE WELL program, Chelsea indicated that she was slightly dissatisfied with her efforts to cope with stress. She described that it had been difficult to be the primary caregiver for her father in addition to her other obligations. She had been struggling with constantly worrying about him because he needed to constantly be supervised. As a result, Chelsea had not made herself a priority. She had sleeping problems and she shared that she had

been drinking more alcohol recently as a way to cope. Chelsea was highly motivated to make changes because she shared that she had experienced some suicidal ideation. Chelsea really wanted to work on identifying stressors that were controllable vs. uncontrollable. She also wanted to work on improving her coping efforts and learn more adaptive coping strategies, particularly when it came to managing her household and regulating her emotions. As such, Chelsea established three coping flexibility intervention goals (see Appendix G). Goal one: To recognize when coping efforts produced unfavorable results. Goal two: To reduce alcohol consumption. Goal three: Develop more adaptive coping strategies to regulate emotions and manage stressful situations. For her BE WELL wellness plan, Chelsea identified one specific coping strategy that she wanted to improve throughout the program. Her SMART coping goal was to get seven hours of sleep three to four times each week by developing a sleep hygiene.

### **Visual Analysis**

Chelsea did not develop a stable baseline pattern for each of the total coping flexibility measures (see Figure 4). Instead, an increasing baseline trend was primarily seen for all coping measures. While a more stable (non-increasing) baseline is desired, the concurrent baseline phases did not display wide fluctuations or obvious repetitive cycles. The treatment phase of all coping measures followed a similar pattern. There was a fluctuating pattern across the treatment phase with the desired significant increase from baseline-to-treatment. Increased coping flexibility was not maintained during the withdrawal period when treatment was withdrawn. The intervention appeared to have been successful, leading to the desired increase in Chelsea's coping flexibility. However, it is important to note that Chelsea's total coping flexibility did not maintain the complete magnitude in gains, but, instead, showed an overall gain in coping flexibility.



**Figure 5**

*Visual Analysis of Coping Flexibility for Chelsea*

### Descriptive Statistics

To further evaluate Chelsea’s results, descriptive statistics were used to analyze the data which included the number of observations in phase, mean, 10% trim mean (used in the case of outliers), median, standard deviation, coefficient of variation, range, and Interquartile range

(IQR). Descriptive statistics for both central tendency and variability were computed for each of the factors and phases of Chelsea’s coping flexibility. As shown in Table 14 and 15, the data are roughly normally distributed for each the coping flexibility measures. The n (Baseline = 4, Treatment = 16, and Withdrawal = 4) indicated no missing values. A comparison of central tendency measures, mean, 10% trimmed mean, and median, indicated no significant outliers. A comparison of variability measures, standard deviation and coefficient of variation, indicated minimum variability across the baseline and treatment phase of each coping measure. The withdrawal phase had minimal variability as it was semi-stable. The mean and median showed a slight increase from baseline-to-treatment phases and slight decreases from treatment to withdrawal phases. The range indicated that adaptive coping results were less than evaluation coping results. All observations fell within two standard deviations of the mean suggesting no extreme variability.

**Table 14**

*Descriptive Statistics of Central Tendency for Chelsea*

	<i>n</i>			<i>Mean</i>			<i>10% Trim Mean</i>			<i>Median</i>		
	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>
<b>Evaluation</b>	4	16	4	13.25	16.562	16.25	13.25	16.571	16.25	13.50	17.00	16.00
<b>Adaptive</b>	4	16	4	8.00	12.50	11.00	8.00	12.50	11.00	8.50	12.50	11.00
<b>Total</b>	4	16	4	21.25	29.062	27.25	21.25	29.143	27.25	21.50	29.00	27.00

*Note.* Descriptive statistics include *n* = number of observations in the phase; 10% Trim Mean (for use in case of outliers); Total = total coping flexibility; Phases include A1 = baseline; B = treatment; A2 = withdrawal.

**Table 15***Descriptive Statistics of Variability for Chelsea*

	<i>SD</i>			<i>CV</i>			<b>Range (min, max)</b>			<b>IQR</b>		
	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>
<b>Evaluation</b>	1.708	0.892	0.50	0.129	0.054	0.031	(11,15)	(15,18)	(16,17)	1.75	1	0.25
<b>Adaptive</b>	1.414	1.966	0.816	0.177	0.157	0.074	(6,9)	(10,15)	(10,12)	1.50	3.25	0.50
<b>Total</b>	2.062	2.435	0.50	0.097	0.084	0.018	(19,23)	(25,32)	(27,28)	3.25	5.00	0.25

*Note.* Descriptive statistics include *SD* = standard of deviation; *CV* = coefficient of variation;

Total = total coping flexibility. There are no missing values. Phases include A1 = baseline; B = treatment; A2 = withdrawal.

**Data Exploration**

Both autocorrelation and regression analyses were completed to determine if traditional parametric analyses could be used to determine the effect of the intervention. Autocorrelation was calculated for each phase of each coping measure for Chelsea to determine if each observation within each phase of each coping measure is independent, a key assumption of parametric analysis methods. Based on Chelsea's results, there was no significant autocorrelation in any phase for any of the coping measures (see Table 16).

**Table 16***Autocorrelation Across Each Phase of Each Coping Measure for Chelsea*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?
<b>Evaluation</b>	-0.076	0.95	NO	0.007	0.983	NO	0.889	0.45	NO
<b>Adaptive</b>	0.222	0.856	NO	0.23	0.478	NO	1.333	0.229	NO
<b>Total</b>	0.052	0.966	NO	0.269	0.405	NO	0.889	0.45	NO

*Note.* Rf2 = multiple correlation coefficient; Sig. = significance value; Auto corr.? = whether autocorrelation was detected; Total = total coping flexibility. Significance level:  $\alpha = 0.05$ .

Regression analysis was used to determine if there was a significant trend in any phase of each coping measure for Chelsea. If there is a significant trend in any phase measures of central tendency lack the ability to accurately assess the typical response. Regression is measured to determine if there is a trend in each phase of the study for each coping measure. As shown in Table 17, there was no significant trend in any phase for any coping measure.

**Table 17***Regression Across Each Phase of Each Coping Measure for Chelsea*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Slope	p-value	Trend?	Slope	p-value	Trend?	Slope	p-value	Trend?
<b>Evaluation</b>	-0.50	.622	NO	0.063	.201	NO	0.30	.225	NO
<b>Adaptive</b>	0.80	.270	NO	0.068	.544	NO	-0.60	.051	NO
<b>Total</b>	0.30	.081	NO	0.131	.339	NO	-0.30	.225	NO

*Note.* Trend? = significant trend in the phase; Total = total coping flexibility. NA occurs where there is no variability to compute trend. Significance level:  $\alpha = 0.05$ .

While visual analysis is the gold standard for SCRDs, the use of effect size and statistical analysis methods can be used to support quantitative single case design studies. The decision of whether to use traditional parametric methods was based on the data presented above.

Assumptions for parametric analysis were met. However, for comparison purposes, the non-parametric CDC method was the statistical analysis tool that was used.

### **Effect Sizes**

To further support the visual analysis of Chelsea's results, the non-parametric effect size method, G-index, was used to calculate effect size. (Cohen, 1988). More specifically, a mean-based G-index was used. The G-index method is robust to outliers, trend and autocorrelation. As expected, when examining Chelsea's data, there was a medium effect size from between baseline and treatment phase as well as baseline and withdrawal phase for all coping measures (see Table 18). Additionally, the negative effect sizes were shown in phases where there was little to no change in the desired direction (increase in coping flexibility).

**Table 18***G-index Effect Sizes for Each Coping Measure During Each Phase for Chelsea*

	<b>Baseline/Treatment</b>		<b>Baseline/Withdrawal</b>		<b>Treatment/Withdrawal</b>	
	<b>G-index</b>	<b>Effect size</b>	<b>G-index</b>	<b>Effect size</b>	<b>G-index</b>	<b>Effect size</b>
<b>Evaluation</b>	0.50	<b>Medium</b>	0.50	<b>Medium</b>	-0.312	Medium (Negative)
<b>Adaptive</b>	0.50	<b>Medium</b>	0.50	<b>Medium</b>	-0.50	Medium (Negative)
<b>Total</b>	0.50	<b>Medium</b>	0.50	<b>Medium</b>	-0.375	Medium (Negative)

*Note.* Total = total coping flexibility. Bolded values indicate a medium to large effect size in the desired direction. Effect size determination: size small effect size (0.1–0.3), medium effect size (0.31–0.50), and large effect size (>0.51). A mean-based G-index was used.

### **Statistical Analysis**

To expound upon the effect sizes, the Conservative Dual-Criteria (CDC) was used as a robust statistical analysis tool to compare the phases of each coping measure. The CDC utilizes both the mean and regression lines of the phase to be compared (Auerbach & Zeitlin, 2014). The goal was to determine if there was a significant increase in coping flexibility. As shown in Table 19, significant differences were detected for evaluation coping and total coping flexibility in the baseline-to-treatment and treatment to withdrawal phases in accordance with the effect size results. As expected, no significant difference was seen in adaptive coping between the phases.

**Table 19***Conservative Dual-Criteria (CDC) for Each Coping Measure Across Phases for Chelsea*

	<b>Baseline/Treatment</b>		<b>Baseline/Withdrawal</b>		<b>Treatment/Withdrawal</b>	
	<b>Significant Threshold</b>	<b>Actual Count</b>	<b>Significant Threshold</b>	<b>Actual Count</b>	<b>Significant Threshold</b>	<b>Actual Count</b>
<b>Evaluation</b>	12	16*	0	4*	0	0
<b>Adaptive</b>	12	2	0	1	0	0
<b>Total</b>	12	14*	0	4*	0	0

*Note.* Total = total coping flexibility; \* = significance threshold met. When the threshold is 0, the maximum number of data points are above the regression and mean line. When this occurs, the result is considered significant. There was a significant increase in evaluation coping and total coping flexibility between the basement to withdrawal phase.

### **Summary of Chelsea’s Findings**

Overall, the intervention seemed to be effective for Chelsea, particularly in evaluation coping and total coping flexibility. Both the visual analysis and quantitative analysis demonstrated the success of the intervention for Chelsea on all coping measures (evaluation coping, adaptive coping, and total coping flexibility). While Chelsea did see a decrease in coping flexibility once the treatment was withdrawn, it was not beyond that of the baseline phase.

Chelsea’s goals consisted of recognizing when her coping efforts produced unfavorable results, reducing her alcohol consumption, and improving her emotional self-regulation. Her SMART coping goal involved developing a better sleep hygiene to get at least seven hours of sleep three to four times a week. Based on the data analysis, it appears that Chelsea was

successful in achieving some of her goals, particularly the ones that pertained to evaluation coping. Regarding her SMART coping goal, Chelsea reported that she had developed a sleep hygiene that helped her increase the quantity and quality of her sleep by the end of the intervention.

### **Tonya**

Tonya was a 38-year old African American woman living with relapse-remitting multiple sclerosis (RRMS). She had been living with MS for at least five years and her primary symptoms included fatigue, numbness/tingling, and cognitive issues. She had not been diagnosed with any other medical conditions. Tonya received her bachelor's degree and was employed full-time. She lived in an urban residential area with her husband and their two children. They earned a middle-class income. In the past six months, Tonya identified her primary sources of stress as financial and work-related stress.

Tonya aspired to advance in her career and work in a more fulfilling position. She also wanted to seek out new opportunities that allowed her to express herself more creatively. Tonya had experienced mental health challenges since being diagnosed with MS and she had been diagnosed with depression and anxiety. She saw a counselor every week. Yvonne's support network consisted of her husband, parents, and a friend who lived in another state.

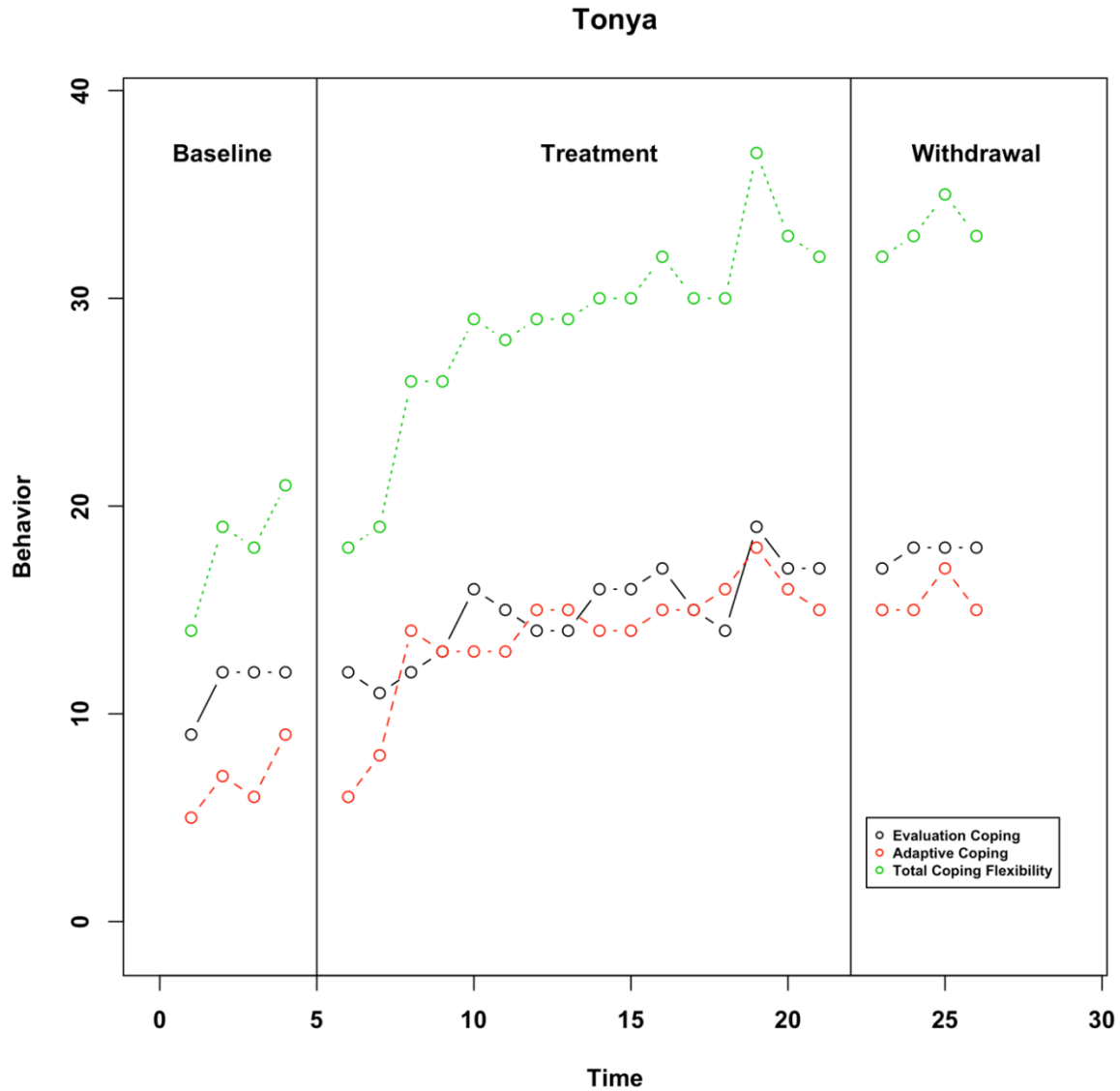
Tonya had a treatment team that included her primary care physician, neurologist, and counselor. She usually had to visit her doctor for an MS-related visit at least once every three months. She had recently started a new DMT to manage her MS and she liked it because she felt more energized after taking it.

At the outset of the BE WELL program, Tonya indicated that she was slightly dissatisfied with her efforts to cope with stress. She described herself as being a "black and white thinker"

(i.e., polarized thinking) and felt the need to seek out validation because of her internalized fear of rejection. Currently, she was experiencing sleep problems. Although she worked full-time, her job provided her with the flexibility to work both on-site and from home. Tonya was motivated to work on her coping strategies because she wanted to learn new tools and skills and she also wanted to model healthy coping behaviors for her children. As such, Tonya established three goals (see Appendix G). Goal one: To reduce cognitive distortions, specifically “all-or-nothing” thinking patterns. Goal two: To recognize when coping efforts produced unfavorable results. Goal three: Develop more adaptive coping strategies to regulate emotions and better manage stressful situations. For her BE WELL wellness plan, Tonya identified one coping strategy that she wanted to work on. Her SMART coping goal was to walk for 20 minutes one day a week (preferably on Saturdays).

### **Visual Analysis**

Tonya displayed a semi-stable baseline pattern for adaptive and total coping flexibility. However, evaluation coping reached stability in the baseline phase. While a more stable baseline is desired for adaptive and total coping flexibility, the concurrent baseline phases did not display wide fluctuations or obvious repetitive cycles. The treatment phase of all coping measures followed an increasing semi-stable pattern. There was a steep increase in coping flexibility throughout the treatment phase that was maintained throughout the withdrawal phase. The withdrawal phase was semi-stable and showed a slight decrease after treatment withdrawal. Overall, the intervention appeared to be successful in increasing Tonya’s coping flexibility.



**Figure 6**

*Visual Analysis of Coping Flexibility for Tonya*

**Descriptive Statistics**

To further evaluate Tonya’s results, descriptive statistics were used to analyze the data which included the number of observations in phase, mean, 10% trim mean (for use in the case of outliers), median, standard deviation, coefficient of variation, range, and Interquartile range (IQR). Descriptive statistics for both central tendency and variability were computed for each of

the factors and phases of Tonya’s coping flexibility. As shown in Tables 20 and 21, the data were roughly normally distributed for each the coping flexibility measures. A comparison of central tendency measures, mean, 10% trimmed mean, and median, indicated no significant outliers. A comparison of variability measures, standard deviation and coefficient of variation, indicated moderate variability across the baseline and treatment phase of each coping measure. The withdrawal phase had no variability as it was stable. The mean and median showed an increase from baseline-to-treatment phases and treatment to withdrawal phases. The range and IQR indicated that adaptive coping was less than evaluative coping. The IQR was correlated to the difference in magnitude of the coping measures with total coping flexibility having the greatest IQR and evaluation coping having the least. All observations fell within two standard deviations of the mean suggesting no extreme variability.

**Table 20**

*Descriptive Statistics of Central Tendency for Tonya*

	<i>n</i>			<i>Mean</i>			<b>10% Trim Mean</b>			<b>Median</b>		
	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>	<b>A1</b>	<b>B</b>	<b>A2</b>
<b>Evaluation</b>	4	16	4	11.25	14.875	17.75	11.25	14.857	17.75	12.00	15.00	18.00
<b>Adaptive</b>	4	16	4	6.75	13.75	15.50	6.75	14	15.50	6.50	14.50	15.00
<b>Total</b>	4	16	4	18	28.625	33.25	18	28.786	33.25	18.25	29.50	33.00

*Note.* Descriptive statistics include *n* = number of observations in the phase; 10% Trim Mean (for use in case of outliers); Total = total coping flexibility; Phases include A1 = baseline; B = treatment; A2 = withdrawal.

**Table 21***Descriptive Statistics of Variability for Tonya*

	<i>SD</i>			<i>CV</i>			Range (min, max)			<i>IQR</i>		
	A1	B	A2	A1	B	A2	A1	B	A2	A1	B	A2
<b>Evaluation</b>	1.50	2.187	0.50	0.133	0.147	0.028	(9,12)	(11,19)	(17,18)	0.75	2.50	0.25
<b>Adaptive</b>	1.08	2.955	1.00	0.253	0.215	0.065	(5,9)	(6,18)	(15,17)	1.75	2.00	0.50
<b>Total</b>	2.944	4.759	1.258	0.164	0.166	0.038	(14,21)	(18,37)	(32,35)	2.50	3.00	0.75

*Note.* Descriptive statistics include *SD* = standard of deviation; *CV* = coefficient of variation;

Total = total coping flexibility. There are no missing values. Phases include A1 = baseline; B = treatment; A2 = withdrawal.

### **Data Exploration**

Both autocorrelation and regression analyses were completed to determine if traditional parametric analyses could be used to determine the effect of the intervention. Autocorrelation was calculated for each phase of each coping measure for Tonya to determine if each observation within each phase of each coping measure is independent, a key assumption of parametric analysis methods. Significant autocorrelation was seen where the  $R^2$  significance is less than 0.05. Based on Tonya's results, there was significant autocorrelation in the treatment phase (see Table 22). However, there was no significant autocorrelation in the baseline and withdrawal phases.

**Table 22***Autocorrelation Across Each Phase of Each Coping Measure for Tonya*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?	Rf2	Sig.	Auto corr.?
<b>Evaluation</b>	0.889	0.45	NO	0.841	0.003	<b>YES</b>	0.889	0.45	NO
<b>Adaptive</b>	0.553	0.659	NO	1.043	0	<b>YES</b>	-0.889	0.45	NO
<b>Total</b>	0.872	0.459	NO	1.066	0	<b>YES</b>	0.14	0.909	NO

*Note.* Rf2 = multiple correlation coefficient; Sig. = significance value; Auto corr.? = whether autocorrelation was detected; Total = total coping flexibility. Significance level:  $\alpha = 0.05$ .

Significance values less than 0.05 in the treatment phase were considered significant due to the small number of observations. There were no significance values less than 0.05 in other phases.

Regression analysis was used to determine if there was a significant trend in any phase of each coping measure for Chelsea. If there is a significant trend in any phase measures of central tendency lack the ability to accurately assess the typical response. Regression is measured to determine if there is a trend in each phase of the study for each coping measure. Significant autocorrelation is seen where the p-value is less than .05. As shown in Table 23, there was a significant trend in the treatment phase for each of the coping measures.

**Table 23***Regression Across Each Phase of Each Coping Measure for Tonya*

	Baseline (A1)			Treatment (B)			Withdrawal (A2)		
	Slope	p-value	Trend?	Slope	p-value	Trend?	Slope	p-value	Trend?
<b>Evaluation</b>	0.90	.225	NO	0.368	< .001	<b>YES</b>	0.30	.225	NO
<b>Adaptive</b>	1.10	.168	NO	0.485	< .001	<b>YES</b>	0.20	.742	NO
<b>Total</b>	2.00	.123	NO	0.853	< .001	<b>YES</b>	0.50	.487	NO

*Note.* Trend? = significant trend in the phase; Total = total coping flexibility. Significance level:  $\alpha = 0.05$ . Significance values less than 0.05 in the treatment phase were considered significant due to the small number of observations.

While visual analysis is the gold standard for SCRDs, the use of effect size and statistical analysis methods can be used to support quantitative single case design studies. The decision of whether to use traditional parametric methods was based on the data presented above. Due to the presence of treatment phase autocorrelation (see Table 22) and significant trend (see Table 23) non-parametric methods were used to further analyze the data.

### **Effect Sizes**

To further support the visual analysis of Tonya's results, the non-parametric effect size method, G-index, was used to calculate effect size. (Cohen, 1988). The G-index method is robust to outliers, trend and autocorrelation. As expected, based on the visual analysis, there was a large to medium effect size for the baseline-to-withdrawal phase for all coping measures (see Table 24). The negative effect sizes were expected in phases where there was little to no change in the desired direction (increase in coping flexibility).

**Table 24***G-index Effect Sizes for Each Coping Measure During Each Phase for Tonya*

	Baseline/Treatment		Baseline/Withdrawal		Treatment/Withdrawal	
	G-index	Effect size	G-index	Effect size	G-index	Effect size
<b>Evaluation</b>	-0.50	Medium (Negative)	1.00	<b>Large</b>	-0.375	Small (Negative)
<b>Adaptive</b>	-0.375	Medium (Negative)	0.50	<b>Medium</b>	-0.625	Large (Negative)
<b>Total</b>	-0.25	Small (Negative)	0.50	<b>Medium</b>	-0.625	Large (Negative)

*Note.* Total = total coping flexibility. Bolded values indicate a medium to large effect size in the desired direction. Effect size determination: size small effect size (0.1–0.3), medium effect size (0.31–0.50), and large effect size (>0.51). Regression line G-index used instead of the mean.

### **Statistical Analysis**

Due to the significant trend and autocorrelation found in the treatment phase, the Conservative Dual-Criteria (CDC) was used as a robust statistical analysis tool to compare the phases of each coping measure. The CDC utilizes both the mean and regression lines of the phase to be compared (Auerbach & Zeitlin, 2014). The goal was to determine if there was a significant increase in coping flexibility. CDC determines a significance threshold compared to the number of observations above or below the regression and mean lines. A significant result occurs when the actual amount is equal to or greater than the threshold. The desired outcome was an increase in coping flexibility, therefore the CDC above function was computed. Using the CDC helped to determine where the differences occurred in the coping measures when comparing treatment to baseline, withdrawal to baseline, and withdrawal to treatment (see Table 25).

As noted in the data, there was a significant difference in score improvements between the baseline and withdrawal phases for each of the coping measures. As expected, there were no significant differences observed between the treatment and withdrawal phase for any of the coping measures. The significant increases in evaluation coping, adaptive coping, and total coping flexibility were supported by the calculated effect sizes and the visual analysis indicating that overall, the BE WELL intervention had the desired effect for increasing Tonya’s coping process.

**Table 25**

*Conservative Dual-Criteria (CDC) for Each Coping Measure Across Phases for Tonya*

	Baseline/Treatment		Baseline/Withdrawal		Treatment/Withdrawal	
	Significant Threshold	Actual Count	Significant Threshold	Actual Count	Significant Threshold	Actual Count
<b>Evaluation</b>	12	0	0	4*	0	0
<b>Adaptive</b>	12	1	0	4*	0	0
<b>Total</b>	12	0	0	4*	0	0

*Note.* Total = total coping flexibility; \* = significance threshold met. When the threshold is 0, the maximum number of data points are above the regression and mean line. When this occurs, the result is considered significant. There was a significant increase in all coping measures between the baseline-to-withdrawal phase.

**Summary of Tonya’s Findings**

In summary, the data supported the BE WELL intervention’s effectiveness in helping Tonya improve her ability to assess her coping efforts and increase her use of more adaptive strategies. The most significant result of Tonya’s intervention can be seen in the increase in her

evaluation coping. It is important to note that Tonya maintained the increased coping flexibility after the treatment was withdrawn.

Tonya's goals consisted of reducing cognitive distortions, recognizing when coping efforts produced unfavorable results, and developing more adaptive strategies to regulate her emotions and manage stressful situations. Based on the data analysis, Tonya was successful in achieving her coping goals. More specifically, the intervention appeared to improve Tonya's ability to abandon her "all-or-nothing" thinking and increase the use of adaptive cognitive coping strategies such as cognitive restructuring. Regarding Tonya's SMART coping goal, she consistently engaged in physical activity by walking for at least 20 minutes once a week during her participation in the program.

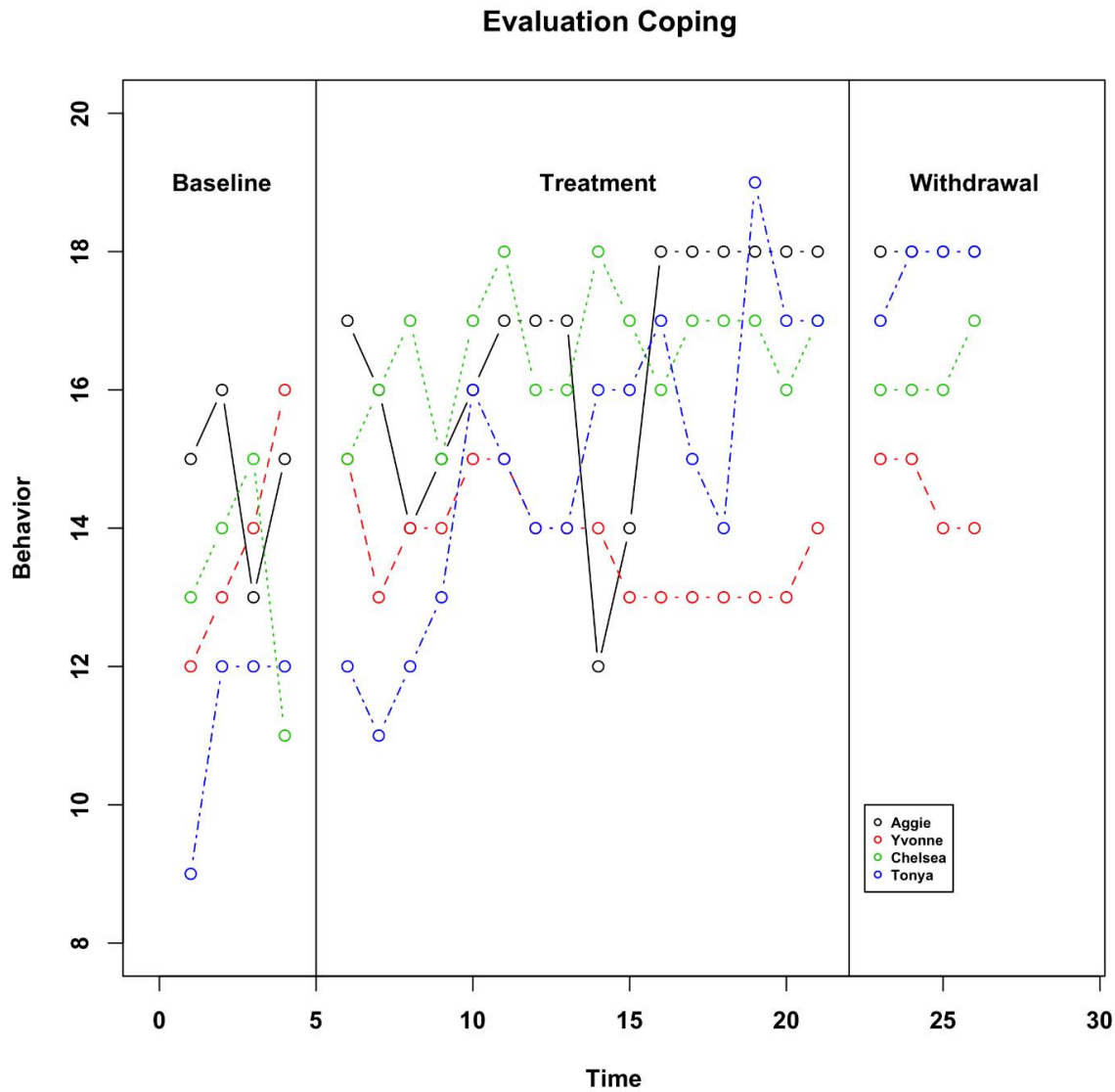
### **Summary of Dependent Variables Across All BE WELL Participants**

This section provides a collective summary of the data across all participants. To compare the intervention's effect on each participant's coping process, data from the baseline (A1), treatment (B), and withdrawal (A2) phases were visually plotted on each coping measure across all participants. The graphical data are presented in the following order: (a) evaluation coping (b) adaptive coping, (c) total coping flexibility, and concludes with an (d) collective summary of the BE WELL intervention findings.

### **Evaluation Coping**

Overall, the visual analysis indicated that the BE WELL intervention had a positive and significant effect for three participants, Aggie, Chelsea, and Tonya (see Figure 7). Due to the minimum variability across the baseline and treatment phase of each coping measure in Yvonne's observations, there were no noticeable changes during the intervention. As shown in Tables 6 and 24, Aggie and Tonya both had large effect sizes,  $ES = 0.75$  and  $ES = 1.00$ ,

respectively, and results from their CDC statistical analyses indicated a significant increase in evaluation coping (see Table 7 and 25). This indicated that both Aggie and Tonya benefited from the intervention in regard to their evaluation coping. Chelsea also experienced favorable gains in evaluation coping between baseline-to-treatment and treatment to withdrawal with a medium effect size of  $ES = .50$  for both phases (see Table 24).



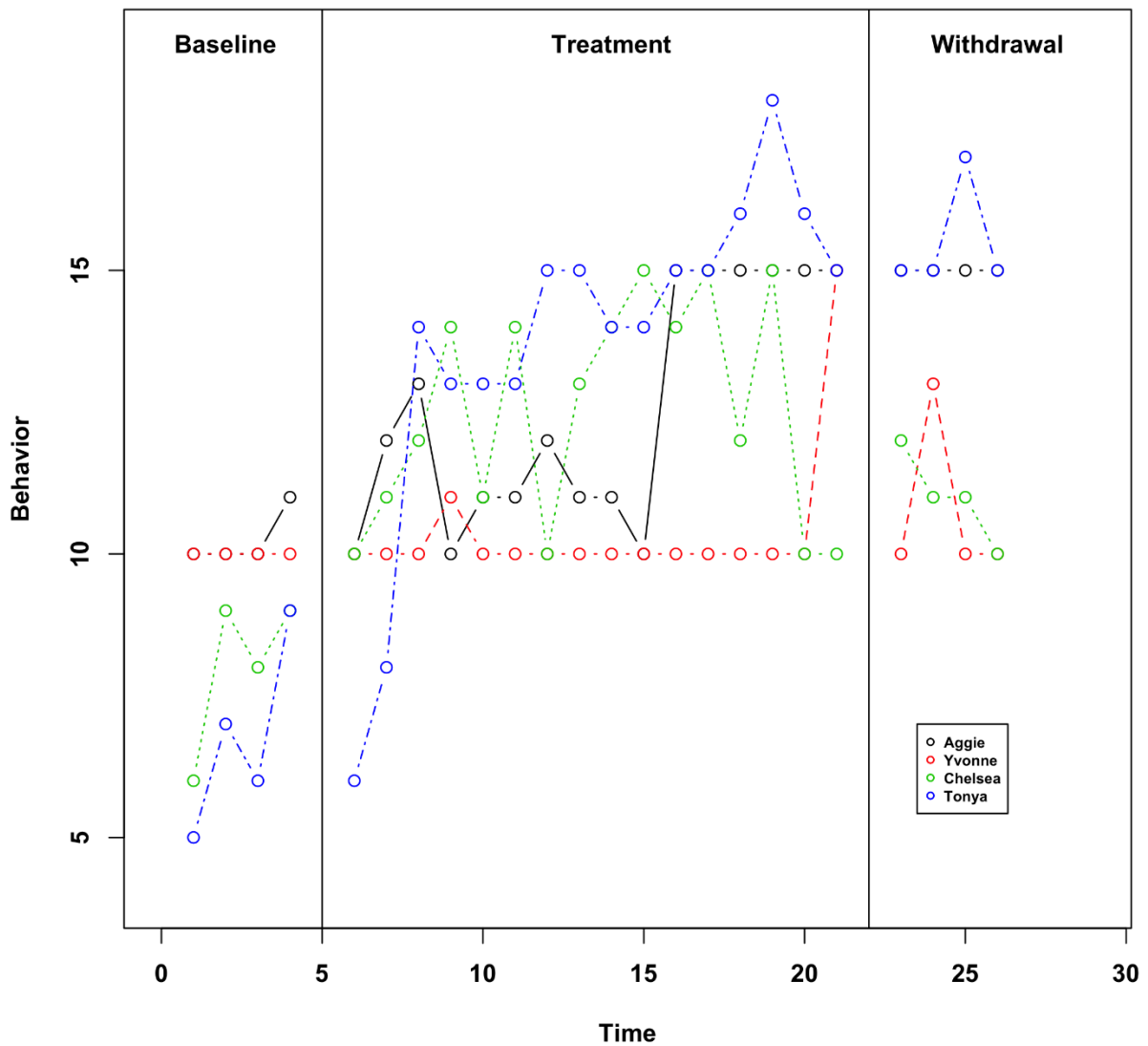
**Figure 7**

*Evaluation Coping Changes Between Phases*

## **Adaptive Coping**

Regarding adaptive coping, the intervention had a positive effect on two of the participants, Aggie and Tonya (see Figure 8). As shown in Tables 6, Aggie's intervention yielded a large effect ( $ES = .75$ ) during baseline-to-treatment and the effect was significant as the CDC results indicated (see Table 7). Tonya had a medium effect in adaptive coping during the treatment to withdrawal phase ( $ES = .50$ ), and a significant difference was also detected as shown in Table 25. As for Chelsea and Yvonne, their adaptive coping results indicated small to medium effect sizes,  $ES = .25$  and  $ES = .50$ , in the baseline-to-withdrawal phases, respectively (Table 18 and Table 12) with no significant differences detected (see Tables 13 and 19).

## Adaptive Coping



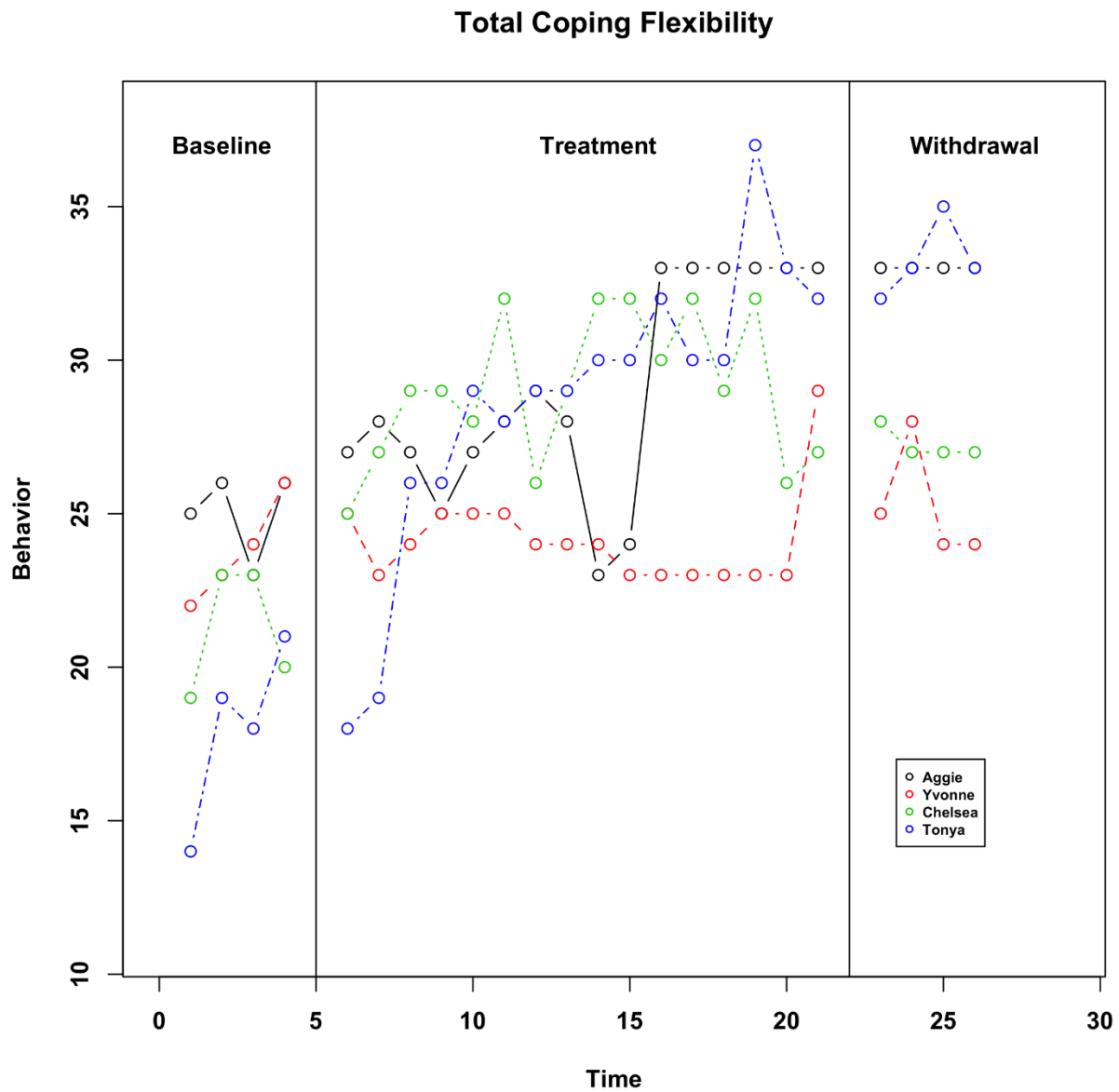
**Figure 8**

*Adaptive Coping Changes Between Phases*

### Total Coping Flexibility

Overall, the intervention successfully increased total coping flexibility in the three participants, Aggie, Chelsea, and Tonya (see Figure 9). Yvonne's results had limited variability and indicated that while the intervention did not significantly increase her coping flexibility, that

is, it did not decrease her coping flexibility beyond the lowest threshold at baseline (see Figure 3 and Table 12). For Tonya, the effect size for total coping flexibility was in the medium range for baseline-to-withdrawal  $ES = .50$  (see Table 24) and significant differences were detected (see Table 25). Aggie and Chelsea's effect sizes were also in the medium range but these results were seen for both baseline-to-treatment  $ES = .50$  and baseline-to-withdrawal  $ES = .50$ , respectively, (see Tables 6 and Table 18) and significant differences were detected (see Table 7 and Table 19). Of the three participants for whom there was an increase in their total coping flexibility, Aggie reaped the most benefits because she achieved the largest effect size,  $ES = .75$ , for two of three coping measures (see Table 6), and significant differences were detected between the baseline and withdrawal phase for each of the coping measures (see Table 7). Additionally, she maintained increased coping flexibility post-intervention during the treatment to withdrawal phase (see Figure 3 and Figure 9).



**Figure 9**

*Total Coping Flexibility Between Phases*

### Summary of Coping Flexibility Findings Across All BE WELL Participants

In conclusion, the BE WELL interventions seemed to have positive effects for each of the participants' coping flexibility. Yvonne was the exception as only slight effects were observed.

For three participants, the most profound effects occurred in increasing evaluation coping.

Across all participants, the BE WELL interventions slightly affected adaptive coping since only moderate effects were observed. The current section provided a collective summary of the data across participants for all coping measures between phases. Data from the baseline, treatment, and withdrawal phases were visually plotted for each dependent variable across all participants. The graphical data were presented in the following order: (a) evaluation coping, (b) adaptive coping, (c) total coping flexibility, and the section concluded with a (d) collective summary of the BE WELL intervention findings.

### **Unforeseen Participant and Environmental Changes**

All unforeseen changes in each participant's circumstances and behaviors that may have influenced the findings were documented by the counselor/investigator. Additionally, all changes in the setting where the interventions were given that may have also influenced the findings were documented. This action was taken to control for threats to the internal validity of the study (Hott et al., 2015). For participants, Yvonne and Tonya, the treatment phase of the intervention (phase B) was conducted in their homes by the counselor/investigator. For Aggie, the treatment occurred in the community and for Chelsea treatment sessions were conducted in the home and in the community over the course of the 8-week intervention. Based on the various environmental settings in which each treatment was given, participants' behaviors may have been impacted during the BE WELL sessions.

All of Aggie's BE WELL intervention sessions were conducted in the community in a private setting in a public location. Thus, the mere presence of other individuals in the building could have impacted her behavior but this was not observed. Aggie appeared to have thoroughly enjoyed meeting in the community and was able to receive the individualized attention desired. During the third session, the counselor/investigator observed that Aggie was more tense than the

previous session as observed through her nonverbal language. She shared that she was worried about the out-of-pocket expenses that she had for an upcoming MRI. She appeared to be worried that this cost would cause her to cancel vacations plans she had made with her family. By the next session, Aggie appeared to be less worried about the MRI expenses since she sought support her family and resources from the MS Society.

In the fifth session, Aggie also appeared to experience some discomfort while discussing her hesitancy to express her feelings with others. This change in behavior occurred when discussing the cognitive dissonance she experienced regarding money management. She expressed that she wanted her partner to be more involved in managing their finances, but she maintained an independent mindset despite being married. She cited that this was due to her upbringing and previous financial problems. Aggie was supported during the session by the counselor/investigator and she was challenged to reframe her thoughts about money management. At the next session, Aggie seemed more relaxed and expressed that she found the previous session to be beneficial to her.

Yvonne's BE WELL sessions were all conducted in her home. She appeared to have support for her goals within her home environment. She lived in an apartment complex with multiple units. Other family members lived in the same complex. Yvonne's spouse was present (i.e., in the same room) for the fourth and sixth sessions. Although he verbally gave his support for her involvement with the program, he did not actively engage with the counselor/investigator before or after sessions. His presence could have impacted Yvonne's behavior, but the counselor/investigator observed that she seemed to be comfortable with him being in the room. Yvonne's assistive devices (rolling walker, mobilized wheelchair) were clearly visible in her home. However, she rarely used them because she stayed seated throughout the duration of each

BE WELL session. The only time the counselor/investigator observed her using an assistive device was when she used the rolling walker to lock the front door after a BE WELL session ended.

Yvonne appeared to have thoroughly enjoyed meeting in her home despite the environmental changes that occurred. However, during the third BE WELL session, she became noticeably upset as she discussed the strained relationship she had with one of her daughters. She shared that there were several incidents that occurred between the two of them that were never discussed and resolved. This disclosure prompted the counselor/investigator to spend additional time talking with the participant about the situation to help her get back to a place where she felt affirmed and supported. By the next session, Yvonne shared that she spoke with her daughter about their relationship and used some of the suggestions (e.g., “I-Messages”) that the counselor/investigator recommended to communicate her feelings. She shared that the conversation went well, and she was glad to have been vulnerable with her daughter.

During the seventh BE WELL session, Yvonne shared that she had a leak in her apartment that had spread, and maintenance was trying to prevent more water damage from occurring. However, the issues were taking much longer to fix because of the limited maintenance staff and management issues. During the session, Yvonne also shared that a family member and her children had temporarily moved in because they had recently been evicted. As a result, Yvonne had become a temporary babysitter. At the beginning of the session, she was holding her family member’s baby and at one point the counselor/investigator held the baby while Yvonne completed her assessments. Yvonne shared that there had been some tension with her spouse because of their new house guests but she said that her family member was actively trying to find another place to stay. At the end of the BE WELL program, Yvonne’s family

member had not found housing. Overall, Yvonne's home environment appeared to be safe but not as supportive as she would have liked it to be.

Chelsea had the most noticeable unforeseen changes in behaviors. As the primary caregiver for her father, Chelsea shared that she often felt like no one else understood the psychological and physical toll it took on her to care for him. Although she expressed frustrations with family members, she felt that nothing fruitful came from those discussions. In the first BE WELL session, she confided in the counselor/investigator that she had recently experienced suicidal ideation and she was engaging in excessive drinking to help her cope with stress. This disclosure prompted the counselor/investigator to spend additional time contracting for safety, discussing resources, and assessing whether she would still be a good candidate for the program. By the end of the session, it was evident that Chelsea needed the additional support and she was committed to being in the BE WELL program.

In the second BE WELL session, Chelsea had a more relaxed mood. She shared that she was able to fly her father down to another state to stay with other family members temporarily. This was an unforeseen change to the participant's home environment that lasted for two weeks. During the fourth BE WELL session, Chelsea shared that she felt better about her ability to manage taking care of her father and stop micromanaging. She also shared that she had improved her coping behaviors since she was sleeping better, and she had temporarily stopped drinking alcohol altogether. The counselor/investigator also noticed that the participant had more self-efficacy than previous sessions and her affect was more euthymic.

In the seventh BE WELL session, the counselor/investigator noticed a shift in Chelsea's demeanor as she presented with an irritable mood. Chelsea shared that she was having communication issues with her husband and son. As a result, she stated that she felt "unheard

and disrespected". She expressed that she was frustrated by the lack of initiative to help manage the household. She also mentioned that she had recently had her DMT infusion and she physically had to take a step back from some of her responsibilities in the community because she had an infection. This carried over into the final BE WELL session since Chelsea was noticeably tired and she continued to express frustrations about others not helping with scheduling and managing the household. She also shared that she had returned from flying across the country to check in on her eldest child who recently had a physical injury. The culmination of these circumstances led to her feeling overburdened. The counselor/investigator spent some additional time talking with her about these recent events to help her get back to a place where she felt valued and supported. Chelsea completed the program by actively participating in the visualization exercise for the session and expressing gratitude for the changes and progress she made while in the BE WELL program.

Tonya completed all BE WELL sessions in her home, and she appeared to have thoroughly enjoyed meeting there. Similar to other participants she often expressed appreciation to the counselor/investigator for being able to conduct the sessions at her convenience and furthermore, that she received the individualized attention she desired. From the counselor/investigator's perspective, Tonya appeared to have support from her family members throughout her participation in the BE WELL program.

### **Social Validity Measure**

At the conclusion of the BE WELL intervention program, all participants completed the Attitude Toward Treatment (ATT). This self-report measure was designed to assess participants' attitudes about the value of the intervention (see Appendix E). The ATT consists of fourteen 7-point Likert-type items worded in past tense to reflect the post-intervention attitudes and

perceptions of the participants. Scores can range from 14 to 98 with higher scores indicating an increased level of confidence in viewing an intervention as efficacious. The ATT is considered to be a common measure of social validity mainly because it provides a measure of the clients' subjective experiences (Hott et al., 2015).

As shown in Table 26, all participants, including Yvonne, rated the interventions as a valuable neuro-informed wellness program with total scores ranging from 89 to 98. Participants' ATT scores demonstrated that participants found the BE WELL intervention to be beneficial and impactful and they complemented and supported the visual analyses and non-parametric analyses of participants' coping flexibility.

**Table 26**

*Attitude Toward Treatment Scores: Mean Values, Standard Deviations, and Total Scores*

<b>Aggie</b>	<b>Yvonne</b>	<b>Chelsea</b>	<b>Tonya</b>
<i>M</i> = 6.43	<i>M</i> = 7.00	<i>M</i> = 6.35	<i>M</i> = 6.21
<i>SD</i> = 1.60	<i>SD</i> = 0.00	<i>SD</i> = 1.34	<i>SD</i> = 1.58
Total score = 90	Total score = 98	Total score = 89	Total score = 87

*Note.* Total intervention sample *M* = 6.50; *SD* = 1.31 (*M* = mean; *SD* = standard deviation).

Lowest score = 14, Highest score = 98

## **CHAPTER 5: DISCUSSION**

For this final chapter, an overview of the study is provided along with a discussion of the individual findings and the recommendations based on the data analysis results detailed in Chapter Four. The contents of this chapter include the following: (a) overview of the study, (b) discussion of the findings including similarities and differences across all participants, (c) contributions to the scholarly literature, (d) research to practice, (e) strengths, (f) limitations, (g) recommendations (h) future implications, and (i) concluding remarks.

### **Overview of the Study**

The purpose of the present study was to evaluate the effectiveness of a coping flexibility intervention with African American women living with multiple sclerosis. There is a need for more individualized interventions for individuals living with chronic disease and disability, including people with MS. As such, a framework entitled the Brain-Based Education and Wellness (BE WELL) program was designed to address the stress appraisal and coping needs of Black women with MS in a southeastern county in various residential settings. Four AAWwMS participated in the present study and each exhibited some dissatisfaction with her efforts to cope with stress.

Sufficient information, emotional support, and cultural sensitivity from providers influence the coping efforts of people living with a chronic disease (Buelow, 1991; Freeman-Hildreth et al., 2019). Since counselors and other practitioners can have a significant impact on how individuals cope with chronic disease, the BE WELL intervention focused on using psychoeducation and therapeutic activities to address the coping efforts and emotional well-being of participants in their natural setting. Given the lack of attention on Black women living with MS, a goal of the present study was to use this research to elucidate their coping efforts and

experiences. Furthermore, an additional goal was to provide effective brain-based interventions that may be useful for people with stress-related chronic diseases like MS to enhance their knowledge of neurophysiological impact of stress. Another goal was to enhance the self-monitoring and overall coping processes of the participants.

The BE WELL intervention was a practical, evidenced-based program that integrated concepts from the Transactional Theory of Stress and Coping (TTSC; Lazarus & Folkman, 1984) and the Indivisible Self Model of Wellness (IS-Wel; Myers & Sweeney, 2004). Additionally, the Healthy Mind Platter for Optimal Brain Matter model (HMP; Rock et al., 2012) was used to develop the BE WELL framework. The Multicultural Social Justice Counseling Competencies model (MSJCC; Ratts, et al., 2016) and the Chronic Care Model (CCM; Wagner et al., 1996) were utilized as overarching frameworks for the program since they were integral in the development of this client-centered intervention. A diagram of the BE WELL framework is shown in Figure 1. This conceptualization of the intervention guided the customization process and the development of each individual BE WELL plan (see Appendix G). Based on the coping flexibility literature, the present study was designed to examine effective ways to improve self-monitoring of coping strategies as well as individual coping efforts which include better emotional regulation and problem-solving. The research questions were as follows:

1. What effect do the customized neurocounseling interventions have on the coping flexibility of participants across the treatment and withdrawal phases? Specific sub-questions to be addressed include:
  - 1a. Did participants' self-reports and self-monitoring indicate a desired change in evaluation coping?

1b. Did participants' self-reports and self-monitoring indicate a change in adaptive coping?

1c. Did participants' self-reports and self-monitoring indicate a change in total coping flexibility (both evaluation and adaptive coping combined)?

2. How did the participants rate the social validity of the interventions?

An *N*-of-1/ A-B-A single-case research design (SCRD) was used for the present study.

To increase the generalization of the findings, the SCRД was replicated four times, one time for each participant. The intervention program began with the baseline phase (phase A1) where participants completed the CFS twice for two weeks. Next, participants met with the counselor/investigator individually once a week for one-hour sessions over the course of eight-weeks. This was the treatment phase (phase B) of the study where the BE WELL program was introduced. Once the program ended, participants underwent a withdrawal of treatment phase (phase A2) for an additional two weeks.

Throughout the 12-week study, participants took the Coping Flexibility Scale (CFS; Kato, 2012) to assess all coping flexibility factors. All of the dependent variables (i.e., evaluation coping, adaptive coping, total coping flexibility) were derived from this measure. Throughout the duration of the study, the measures were taken by each participant a total of 24 times: four during the baseline phase, 16 during the treatment phase and four during the withdrawal phase.

Several methods were used to analyze and examine the data across the baseline-to-treatment and treatment-to-withdrawal phases to see if observed changes throughout the intervention were stable across all four participants. The types of data analyses that were used to examine the data include descriptive statistics, effect sizes, and non-parametric analyses. These analyses were used to determine the effectiveness of the intervention and the strength of the

effect. Baseline-to-withdrawal phases were also evaluated for significant differences between phases and effect sizes were calculated using the G-index.

Overall, the findings indicated that the customized BE WELL intervention program was most effective for increasing evaluation coping and total coping flexibility across three of the four participants. The intervention was also effective in increasing adaptive coping for three of the four participants, but overall the changes noted for adaptive coping were moderate in comparison to evaluation coping. A more detailed description of the findings across each participant is provided in the next section.

### **Discussion of the Findings**

Four customized interventions were developed from the BE WELL framework. Each intervention was tailored to meet participant's needs and personal goals. The findings are presented below.

#### **Aggie**

Overall, Aggie benefited from the BE WELL intervention on all three coping measures (i.e., evaluation coping, adaptive coping, and coping flexibility) and she maintained increased coping flexibility after the treatment was withdrawn. Aggie's ATT score also reflected the favorable gains she made in her coping process and use of adaptive strategies since she provided the second highest score when rating the value of the intervention. It is no surprise that the intervention had a significant effect on Aggie's coping efforts because she expressed that she experienced no episodes of overwhelming stress which she described as panic attacks while she participated in the program. Furthermore, as she progressed in the BE WELL program, Aggie more readily engaged in reframing her irrational thoughts without being prompted.

Most of Aggie's intervention focused on recognizing her stress response, utilizing cognitive restructuring, engaging in leisure activities, and improving communication skills (see Appendix G). Aggie's goals involved stress appraisal, meta-coping skills and monitoring the outcome of coping efforts. Her goals also reflected the cognitive and affective component of coping flexibility (i.e. evaluation coping). In the future, for clients with similar irrational thinking patterns like Aggie that increase stress burden it would be beneficial to explore more cognitive coping strategies such as positive reappraisal and disengagement into the intervention. By doing so, clients can increase their coping repertoire and learn how to identify which cognitive coping strategies produce desired results for various stressors. Recognizing irrational beliefs and thoughts early on can help individuals engage in meta-cognitive skills more and prevent further emotional distress.

### **Yvonne**

Unfortunately, the BE WELL intervention did not have the desired effect on Yvonne's coping efforts. As mentioned in the previous chapter, there were a few instances during intervention sessions where Yvonne became distracted by family members and she had unforeseen environmental changes occur during the intervention. It was also observed that she may have had some difficulty answering the reverse coded CFS questions. The distractions coupled with possible comprehension issues may have contributed to her lack of progress.

Although the data analysis demonstrated that the intervention produced slight effects in Yvonne's coping flexibility, she expressed that she enjoyed the weekly BE WELL sessions and rated the intervention favorably. In fact, Yvonne gave the highest rating of all the participants which was the highest score that could be given on the social validity measure. Yvonne's intervention rating does not support the moderate effects observed from the quantitative and

visual data. Therefore, the high intervention rating contradicts Yvonne's observed results on all coping measures across all phases.

In the future, for clients like Yvonne, the environment in which the intervention is given should be considered. For example, Yvonne may have benefited from being in a neutral location that provided a private place to do the intervention activities rather than meeting in a familiar place with the opportunity for more distractions. In addition, more prescreening measures may be needed to ensure participants are appropriate for a wellness intervention designed to enhance coping flexibility. Based on observational data, one can only speculate that Yvonne may not have met all of the criteria for the study. More specifically, one can only wonder if Yvonne had possible cognitive impairment which is a common symptom in MS since it occurs in approximately 65% of PwMS (Rahn et al., 2012). Perhaps for future intervention studies, it may be helpful to include additional screening methods including cognitive assessments and consultation with healthcare providers to help screen prospective participants for possible cognitive impairment.

### **Chelsea**

Chelsea also benefited from the BE WELL intervention program on all coping measures albeit not to the same degree as Aggie and Tonya. Interestingly, Chelsea's visual analysis indicated a fluctuating pattern for each coping measure although there was a significant increase in the desired direction. One possible explanation for this was that Chelsea also experienced several unforeseen changes to her environment while participating in the BE WELL program. She traveled to two states over the course of the 12-week study and she experienced changes in her home environment when her father returned to stay in her home. As noted earlier, Chelsea

was experiencing intense emotional distress at the beginning of the BE WELL program and desired to develop more adaptive strategies to help her deal with chronic stressors.

Chelsea's goals consisted of recognizing when her coping behaviors produced unfavorable results. Since Chelsea's goals were more behavior-based, the intervention did not examine cognitive coping strategies and irrational thought patterns in detail. Reflecting on Chelsea's needs, she could have benefited from learning some additional skills such as cognitive restructuring to help her develop more effective coping strategies for the reoccurring stressors in her life. In working with clients like Chelsea, a longer intervention program that allows for a stable baseline to be developed and longer treatment phase may be warranted. Nevertheless, Chelsea made marked progress in her coping behaviors and based on her high ATT results, she found the intervention to be valuable.

### **Tonya**

Tonya also demonstrated an increase in all three coping measures from her participation in the BE WELL program. Tonya's goals consisted of reducing cognitive distortions and identifying when her coping response produced undesired outcomes (see Appendix G). Given that Aggie and Tonya had similar goals, several components of their individualized interventions mirrored one another regarding evaluation and adaptive coping. Although Tonya did not maintain the same level of increased coping flexibility once the treatment was withdrawn, she did achieve significant results in the desired direction that enhanced her coping efforts. More specifically, the large effect size for evaluation coping from baseline to withdrawal indicated that Tonya acquired healthy strategies to assess her coping response and develop more effective coping methods.

Similar to Aggie, Tonya's intervention focused primarily on improving cognitive coping strategies to reduce her stress burden and enhance her psychosocial functioning. Like Aggie, behavioral coping strategies were not addressed as frequently as cognitive and affective aspects of the coping process. Overall, Tonya made significant gains in her coping flexibility and she rated the intervention favorably.

### **Summary of the BE WELL Intervention Findings**

Each participant had a customized intervention based on their CFS scores and personal goals (see Appendix G). In addition to visual analyses, effect sizes and non-parametric analyses were conducted to provide support for the findings and further strengthen the intervention's effect. In addition to the visual and quantitative data, the ATT was used as a social validity measure to assess each participant's perception of the program. All of the data sources were complimentary to one another and demonstrated that the customized BE WELL interventions seemed to be beneficial as a brain-based wellness program to enhance coping flexibility.

### **Contributions to the Scholarly Literature**

The present study demonstrated an innovative approach to counseling practice using customized psychoeducation-based neurocounseling interventions. Furthermore, it centered on African American women with MS, an underserved and under researched population. Lastly, this study supported the use of SCRD to develop repeated measurements to assess individual variability within a coping intervention. Consequently, this study makes several contributions to the scholarly literature in various disciplines.

### **Counseling Literature**

First, this study adds to the growing brain-based counseling literature. Ivey et al. (2011) presented a call to action for counselors to integrate neuroscience into their work with clients and

communities in order to “be ready for the next decade” (p. 114) of counseling in the 21<sup>st</sup> century. To do this, Ivey et al. (2011) instructed counselors to: (a) engage in continuing education that focuses on neuroscience in counseling, (b) increase the application of knowledge with self and others, (c) educate colleagues and students, (d) emphasize the neurological impacts of social injustice, (e) emphasize implications of positive societal change from a biopsychosocial and neuroscientific perspective, and (f) integrate more neuroscience education for clients into counseling practice, encourage stress reduction, and encourage exercise and wellness. As a result, scholars have stressed the importance of developing innovative counseling practices that integrate neuroeducation and other neuroscience research (Beeson & Field, 2017; Miller, 2016). The integration of neuroscience knowledge and research into counseling practice, referred to as neurocounseling, was clearly demonstrated throughout the BE WELL program. Using an SCRD to integrate neuroscience research into a wellness program proved to be beneficial since each intervention topic and activity were tailored to participants’ needs making the content more culturally relevant for participants. Moreover, the customized interventions provided a practical application and developmentally appropriate strategy on how to implement neurocounseling with clients.

Researchers have cited SCRDs as a pragmatic way to establish preliminary support for novel counseling interventions and practices (Morris & Wester, 2018). Using an SCRD made the psychoeducation-based neurocounseling interventions easy to plan and implement. Additionally, the HMP framework provided structure for each of the customized interventions sessions. The desire to gain more knowledge and information related to brain health and functioning is well documented (Badenoch, 2008; Field et al., 2017). The BE WELL program provides an example

of how counselors can explore complex neuroscientific concepts with clients using a wellness framework.

### **Multiple Sclerosis Literature**

This research also makes a significant contribution to the MS literature. It is the first intervention study to center Black women with MS and their coping efforts. Several qualitative studies have been conducted to elucidate the experiences of AAWwMS (e.g., Henry, 2016) but this study involved using quantitative research to examine the effects of a psychosocial tertiary intervention with AAWwMS. While Black women with MS share some commonalities, they also experience significant differences in MS symptoms, treatment, environmental influences, and life experiences. This study highlights the variability among AAWwMs and counters historical perspectives that once excluded African Americans from clinical research such as the belief that racial and ethnic minority populations are essentially analogous, without significant differences (Taylor, 2003). While much progress has been made to include African Americans and other racial and ethnic minorities in clinical research, their underrepresentation due to low participation rates continues to be a challenge for researchers.

Within the MS community, this is no different since participation among African Americans in research continues to be low. However, this study demonstrated that concerted efforts to utilize a culturally sensitive approach throughout the entire research process (Barrett et al., 2017; Otado et al., 2015) can help researchers achieve success in engaging more African Americans in clinical research. For the present study, the counselor/investigator used a community outreach/field-based approach to recruit participants. More specifically, the counselor/investigator participated in a community event and engaged potential participants by educating and explaining the study in person. According to Otado et al.'s (2015) research on

culturally competent strategies for recruitment and retention of African Americans in clinical studies, this community-centered approach is “the single most effective recruitment strategy when working with African American populations” (p. 463). The counselor/investigator was also able to implement effective retention strategies as outlined by Otado et al. (2015) to ensure active participation from study participants. These strategies included cultivating rapport with participants, providing follow up communication to inquire about participants’ well-being, and being flexible in accommodating participants’ schedules, including nights and weekends, to reduce the likelihood of participant attrition.

### **Stress and Coping Literature**

Another key contribution to the scholarly literature that set this study apart was the use of SCRD methods for stress and coping research within the context of chronic disease and disability. In the stress and coping literature, most research to date that includes coping interventions relied on traditional between-group experimental and quasi-experimental designs to examine coping interventions (e.g., Nolte & Osborne, 2012; Yusufov et al., 2019; Zhang, 2018). This is also true in the coping research with PwMS (Heesen et al., 2012; José et al., 2016; Mohr et al., 2012; O’Hara et al., 2002; Sanaeinasab, 2017; Schwartz, 1999; Stuifbergen et al., 2003) despite recent research that found considerable benefit in using individualized interventions (das Nair et al., 2016; Firth, 2014). For individuals living with chronic disease and disability, the use of adaptive coping strategies has been linked to adherence to medical treatment and more specifically for PwMS, reduced relapses (Costello et al., 2008). Yet, there is a paucity of literature pertaining to customized coping interventions within the context of chronic disease and disability.

In 2002, the World Health Organization produced an extensive report called *Innovative Care for Chronic Conditions: Building Blocks for Action*. The report provided a review of evidence-based research of creative and innovative programs around the world for coping with and managing chronic conditions. In the review, the WHO (2002) found that using innovative approaches to help individuals better manage and cope with chronic health conditions had positive effects on outcome variables. Several of these benefits included: (a) positive lifestyle changes; (b) increased knowledge and better self-care practices; (c) improved functioning, productivity, and quality of life; (d) reductions in pain and fatigue; (e) improvement in activity levels; (f) diminished levels of disability; and (g) improved self-reported health status. Although the data outlined in the review provided support for innovative and alternative methods for managing chronic conditions, the WHO has not published any subsequent comprehensive reports on this topic. So, it seems that more data to support alternative approaches to enhancing coping efforts and chronic disease management are warranted.

Many of the studies contained in the WHO (2002) report were between-group experimental and quasi-experimental designs that focused on group-based interventions with “innovative formats to deliver new programs, [including] group visits, telephone follow-up, and home-based strategies” (p. 98). Cost-effectiveness and time constraints are often cited as primary reasons for utilizing group-based interventions with people living with a chronic disease and disability (Hoddinott et al., 2010). However, researchers have noted that this is problematic because everyone’s needs are seldom met with a one-size-fits-all approach (Hoddinott et al., 2010). Furthermore, researchers have argued that some group-based interventions may actually increase health inequalities because the recruitment process attracts more educated and higher income participants (Hoddinott et al., 2010; Rogers et al., 2009). Fortunately, customized

counseling interventions are a viable option to help people learn alternative ways to cope with stress while living with a chronic condition. SCRD studies like the one used in the present study can be used to assess and monitor individual's specific needs.

Customized interventions using SCRD methods provide better ways to assist PwMS with their coping efforts and more broadly, people with chronic disease and disability. Using SCRD as a psychological intervention in naturalistic settings has several advantages. To begin with, SCRDs are a practical way to demonstrate research evidence to support novel practices (Morris & Wester, 2018). Additionally, in SCRDs there are strong experimental conditions because each case serves as its own control (Babel et al., 2018; Byiers et al., 2012), eliminating the need to have a control group, a key component of between-group experimental and quasi-experimental designs (Byiers, et al., 2012). Finally, the replication rate in published SCRD research is higher than between-group experimental research (Lemons et al., 2016).

The focus on the individual level as opposed to the group level is another key benefit of SCRD. Group-based interventions do not take individual differences into account. Thus, group designs may make causal inferences and generalized conclusions that the intervention was effective for the majority of participants, which may not be a true assumption as group dynamics may impact treatment results and some individuals may not actually respond to the intervention (Byiers, et al., 2012). SCRD allows for treatment effects to be evaluated at the individual level (Byiers, et al., 2012; Foster, 2010; Lenz, 2015). From a social justice perspective, this is significant because SCRDs highlight how counseling interventions and programs can be culturally anchored to better serve individuals from marginalized groups. Thus, CMHCs can develop strategies on how to advocate for individuals from underserved groups at the micro- and macro-level (Morris & Wester, 2018).

Due to the varied symptom profile and contextual factors that impact PwMS, SCRDS would be an alternative approach for counselors to use to help individuals living with MS who self-report dissatisfaction with their coping strategies and experience emotional distress to enhance their coping efforts. Coping is an individualized, phenomenological process that is influenced by culture, intersections of identity, the sociopolitical context, and environmental factors. Thus, SCRDS would provide a viable method to evaluate the effectiveness of an intervention on individual outcomes as opposed to group-based outcomes.

### **Research to Practice**

Information was gleaned from several studies to ascertain how to develop a customized coping flexibility intervention. More specifically, research from various disciplines was reviewed and applied to the development of the BE WELL framework (see Appendix F). First, Cheng et al. (2012) found that using a coping flexibility intervention for stress reduction and improved mental health outcomes was more effective than only using a cognitive-behavioral intervention. These findings supported the emphasis on enhancing coping flexibility within a coping skills training intervention rather than simply teaching individuals about coping strategies. Additionally, Cheng et al.'s (2014) meta-analysis on coping flexibility and Kato's research on the coping flexibility hypothesis (2012, 2015b) (i.e., more coping flexibility leads to improved health outcomes) helped identify the conceptual framework for this intervention study. The findings of Cheng et al.'s (2014) and Kato's (2015b) research supported the dual-process theory of coping flexibility. This theoretical framework extends the body of stress and coping research by emphasizing the underlying cognitive and psychological processes in adaptive coping rather than solely examining coping styles which has historically dominated the stress and coping literature. Lazarus and Folkman's (1984) Transactional Theory of Stress and Coping (TTSC) is

foundational to this dual-process theory and it has been integral to coping and psychosocial adaptation research of which this study is no exception. In addition to the current body of stress and coping literature, the present study's findings demonstrated that integrating TTSC concepts into brain-based wellness interventions was not only effective but also highly valuable.

The focus on wellness within the context of chronic disease and disability was also central to the BE WELL intervention. Coping is an essential element of the evidence-based Indivisible Self Model of Wellness (IS-Wel model) (Myers & Sweeney, 2004), and each of the four components of the IS-Wel model's Coping Self: (a) realistic beliefs, (b) leisure, (c) stress management, and (d) self-worth were integrated into the intervention framework and used to establish participant goals. The findings from the present study supported previous research that indicated individuals who learn stress management techniques, cognitive restructuring skills, and emotional self-regulation strategies exercise more psychological flexibility and have an increased ability to adapt to stressful situations (Myers & Sweeney, 2008). In the present study, three of the four participants were able to apply these coping skills (i.e., stress management techniques, cognitive restructuring skills, and emotional self-regulation strategies) while enhancing their psychosocial functioning and adapting to environmental demands.

In addition to becoming more evaluative of their coping response, participants also gained knowledge on the interconnectedness of psychological well-being and optimal brain health and functioning since the BE WELL intervention drew heavily upon Rock et al.'s (2012) Healthy Mind Platter. According to Rock et al. (2012), an effective wellness intervention should utilize a holistic approach and incorporate the seven HMP mental activities which include: (a) time in, (b) focus time, (c) playtime, (d) connecting time, (e) physical time, (f) sleep time, and (g) down time. Rock et al. (2012) further explained that effective coping strategies are essential

to not only physical and mental health but also neurologic health and functioning. An observation in the present study was that all four participants had problems with the quantity and quality of their sleep at the beginning of the BE WELL program. When participants were given information and resources on the neurophysiological and psychological impact of sleep deprivation, they were better able to problem solve and brainstorm alternative strategies to improve their sleep hygiene. This observation supports the importance of providing neuroeducation with coping skills training to help individuals understand the brain-body connection, particularly the neuropsychophysiological impacts of stress, and encourage the use of more effective coping strategies.

To summarize, the present study was based on theory (i.e., the MSJCC framework and the CCM model) and the integration of neuroscience research to aid in the development of an evidence-based customized wellness intervention. The population of interest for these individualized counseling interventions were African American women with MS. To examine the intervention's effect, SCR D methodology was utilized since most coping interventions with PwMS and more broadly, individuals with chronic disease and disability, are group-based research designs. Researchers generally do not consider customization in coping intervention studies since they usually opt for between-group experimental and quasi-experimental designs. Coping is an individualized process that is influenced by several factors including identity intersections and the environment. For this reason, researchers and counselors must utilize more applicable and practical interventions to individualize treatment for clients with specific needs and varied goals. Using customized interventions in SCR D provide a relevant and viable means to address the complex needs of individuals with chronic disease and disability. According to the counseling literature, counseling practitioners often underestimate the potential quality of life for

individuals with disabilities (Sue et al., 2019). SCRD interventions can be used to not only address challenges to coping with stress but also to empower clients, enhance their strengths, and achieve an optimal level of wellness. Additionally, SCRDs simulate real-life counseling environments and provide flexibility in treatment planning. This is needed when working with clients who experience numerous health challenges due to a chronic health condition. Based on the study's findings, developing customized brain-based wellness interventions appears to be successful for individuals within the context of chronic disease and disability

### **Strengths**

There are several strengths of the BE WELL intervention that should be noted. First, the present study included replication of the BE WELL intervention with four participants. To make an SCRD more generalizable, it is recommended that an *N*-of-1 study be replicated for a minimum of three times (Lenz, 2015). A key strength of single-case research designs is to show change as a result of utilizing an intervention (Byiers et al., 2012; Gast & Ledford, 2018b; Kazdin, 2011; Lenz, 2015; Ray, 2015) while controlling for threats to validity (Byiers, et al., 2012; Kazdin, 2011). For the SCRD used in this present study, each participant served as her own control which increased internal validity. Thus, the individual differences that evolved throughout the phases of the study indicated that the results supported generalizability of this *N*-of-1 study.

Another strength of this study involved using psychoeducation-based neurocounseling interventions to enhance coping efforts. The BE WELL framework for the present study involved integrating neuroscience research that focused on optimal brain health with coping skills training based on evidence-based research. All participants rated the intervention as a

valuable wellness program. This demonstrated that using neuro-informed mental health counseling to supplement wellness activities in the intervention program was beneficial.

Another key strength of the present study was the one-on-one BE WELL sessions that were facilitated by the counselor/investigator for eight sessions with each participant. These sessions were executed according to participants' identified needs and desired coping and stress management goals from their treatment plans. Unlike most coping skills training programs with PwMS, the sessions were not an all-inclusive, group-based approach to helping participants engage in health behavior change and increase the use of effective coping strategies. The interventions were individualized and directed toward increasing coping flexibility. The customized approach was tailored to suit each participant's needs. Also, participant ratings of their customized BE WELL intervention indicated that they each perceived the treatment to be beneficial and valuable. This feedback further highlights the success of this brain-based wellness program.

Finally, to enhance the credibility of the study's findings, the counselor/investigator utilized the ATT as a social validity measure to supplement the dependent variable assessment. In addition, the counselor/investigator documented any unforeseen circumstances and changes in behavior that may have affected data. This data collection method added to the study's fidelity since it controlled for confounding exposure and highlighted what was occurring during the weekly BE WELL sessions. Correspondingly, a layered data analysis approach was used to further validate and expound upon the findings. The first layer of data analysis involved using visual analyses to provide graphical representations of the data. The second layer of analysis included descriptive statistics of central tendency and variability. The third layer involved trying to detect autocorrelation and trend to determine the appropriate statistical analysis methods.

Lastly, effect sizes were calculated, and the CDC non-parametric analysis tool provided confirmatory support for the visual analysis. Overall, these data analysis methods provided a rich, in-depth examination of the intervention's effect on participants' coping flexibility.

### **Limitations**

Although there were several strengths in the present study, there were also several limitations that warrant discussion. For example, a convenience sample was used for this study. All but one of the participants were recruited from a community event for people living with MS and their care partners. Therefore, the participants were comprised of a convenience sample rather than a randomized group of participants. Furthermore, although the study spanned 12 weeks, there was limited opportunity to collect more data across all phases of the study. Ideally, the study would have spanned a longer time frame, particularly during baseline to ensure stabilization. If not, the lack of time to collect data to observe participants' baseline coping flexibility prior to the treatment poses a threat to internal validity (Heppner et al., 2015).

Furthermore, using additional dependent measures could have enhanced the range and distribution of the outcome data. Although the study spanned 12-weeks, the use of one dependent measure may not have allowed the intervention to be as effective for some participants and consequently, the treatment resulted in smaller effect sizes. However, other factors such as the population of interest and setting must be considered in relationship to effect sizes. Since PwMS may be considered high risk due to various reasons, self-monitoring throughout the duration of the study was challenging. Furthermore, two participants had significant changes to their environment throughout the course of BE WELL interventions so a small effect size for coping measures may be considered sufficient.

Testing could have also threatened the internal validity of the study. Although the CFS was a 10-question survey that took less than 10 minutes to complete and the questions were randomized, participants took the survey 24 times over the course of the 12-week intervention. Therefore, participants could have remembered their responses from previous assessments. They could have also become uninterested with using the assessment to evaluate their coping efforts. Additionally, the environments in which the interventions occurred (i.e., in the home or in the community) could have been distracting to participants and interfered with participants' responses. Since participants took the survey regularly, fatigue and testing bias were a concern. The repetitive process of answering the same questions creates testing familiarity which can lead to testing bias which is a well-documented phenomenon that can impact research outcomes (Lavrakas, 2008).

Furthermore, in retrospect, using the CFS as the only dependent variable assessment was not ideal for the present study. Although it was a 10-question survey that assessed evaluation *and* adaptive coping, the wording of some survey questions (e.g., the reverse-scored questions) may have caused confusion for one or more of the participants based on observations and their responses. This was a limitation that was noted in another study (Jones, 2015). Reflecting on the study, it may also have been beneficial to use another assessment that measured related constructs such as resilience, well-being or quality of life factors to further assess the effects of the BE WELL program. Examples include the psychological well-being subscale from the Self-Rated Abilities for Health Practices (SRAHP) assessment (Becker et al., 1993) and subscales from Ryff's Psychological Well-being Scale (Ryff, 1989).

In terms of taking the assessments on a schedule, for the most part, the participants took the assessments when promoted. However, the failure to have a consistent schedule for data

collection throughout the phases of the study proved to be a limitation. During all three phases, there were a few occasions where the counselor/investigator had to remind participants to take the survey to ensure that two responses were recorded for each participant each week. While participants used the *BZ Reminder App* the first two weeks of the study, they were given the option to use the *BZ Reminder App* or their own method during the withdrawal phase to ensure they completed the assessment in a timely manner.

Another limitation that posed a threat to the internal validity of the study was that two out of four participants were receiving mental health counseling while participating in the intervention. One of the participants started counseling at the outset of the program and met with her counselor irregularly while the other participant had already been in counseling and met with her counselor on a weekly basis. Because of this, the treatment alone may not account for all the changes observed in the participants' responses. Active participation in their mental health treatment may have contributed to high pre-treatment scores on some CFS factors and also enhanced responses during the course of the treatment intervention. However, all participants reported that they felt dissatisfied with their coping efforts at the start of the program and found value in the intervention. To eliminate this threat, the selection strategy for the study could have been to only include participants who had not or were not currently receiving mental health treatment.

Lastly, the fact that the author of this dissertation was also the counselor/investigator that conducted and designed the customized BE WELL interventions is another limitation. While this provided consistency throughout the BE WELL program, it can also be problematic. The counselor/investigator had a direct interest in the outcome of the study and participants were also aware that the goal was to enhance their coping flexibility. Additionally, the

counselor/investigator was present on multiple occasions while participants completed the assessment during the treatment phase. Thus, the Hawthorne effect could have come into play. Participants could have purposefully answered questions on the coping flexibility measure to what they thought the counselor/investigator desired which would have been a threat to internal validity (McCambridge et al., 2014). However, the use of repeated measures and self-monitoring data may have helped decrease this internal threat as it helped to monitor trends and changes at each data point and phase of the study.

### **Recommendations**

In the present study, several lessons were learned that could be used to adjust future replications of the BE WELL program. First, it is essential to identify eligible candidates for intervention studies because failure to meet recruitment goals can negatively impact clinical outcomes. Although the present study involved utilizing a psychoeducation-based intervention, it was classified as a clinical trial by the IRB. According to Patterson et al. (2010), problems identifying eligible participants for clinical trials through clinical services and programs are a major concern, especially for vulnerable populations. Identifying cost-effective prescreening and screening activities to determine participant eligibility is needed to ensure all participants meet the study's inclusion criteria.

In the present study, it was observed that one of the participants had some difficulty answering assessment questions on more than one occasion. While this observation could have been due to basic comprehension issues such as reading too fast, it could have also involved factors related to the participant's eligibility (e.g., mild cognitive impairment). Since cognitive impairment is common among PwMS (Rahn et al., 2012), utilizing screening assessments to detect possible cognitive issues may be warranted. Intervention studies often have time

constraints so brief surveys may be more feasible than a full-diagnostic assessment. Brief survey tools such as the Mini-Cog (Borson et al., 2000) and Montreal Cognitive Assessment (MoCA; Hobson, 2015) may be useful and both require minimal training to interpret results. Additionally, mental status exams that assess executive function, memory, and attention such as the Saint Louis University Mental Status Examination (SLUMS; Tariq et al., 2006) may be included in the recruitment process to ensure eligible candidates are selected.

Next, the setting of the intervention varied for participants. While some participants completed the BE WELL program in their homes, others completed the intervention in the community. For two participants in particular, significant unforeseen environmental changes in their homes could have impacted their participation in the program and their treatment results. Ideally, the customized interventions would have occurred in distraction-free environments. Although it is appropriate for CMHCs to deliver these customized interventions, the BE WELL program could also be delivered by rehabilitation counselors. Rehabilitation counselors provide client-centered approaches to enhance the self-determination and inclusion of individuals with psychiatric, developmental, cognitive, emotional, or physical disabilities into mainstream life (Kirk & LaForge, 1995; Wright, 1960). While there are similarities and differences between CMHCs and rehabilitation counselors, both can be influential in helping individuals with chronic disease and disability achieve an optimal level of functioning and mental wellness.

However, if an individual's adjustment to disability is their sole source of stress then it may be recommended that the BE WELL intervention be delivered by a rehabilitation counselor, ideally, one that has built rapport with the individual and may have access to pertinent information about the individual's disability. The rehabilitation counselor would likely be aware of possible modifications that may need to be implemented to ensure the intervention is delivered

appropriately to meet the individual's needs. In the present study, the interventions were tailored to address participants' dissatisfaction with their coping strategies for a myriad of stressors that were both disease-specific and non-disease related factors. Therefore, depending on the individual's goals and presenting concerns, the BE WELL interventions may either be delivered by a CMHC or a rehabilitation counselor. However, it is important that the BE WELL intervention be delivered in a distraction-free atmosphere, preferably, the individual's natural environment rather than a clinical setting unless this is not feasible.

In the present study, African American women with MS were the population of interest. However, the BE WELL intervention is not gender, race, disability, or culture-specific and could easily be applied with males, individuals from other racial and ethnic backgrounds, and people living with other chronic health conditions. The goal of the intervention is to increase coping flexibility to help individuals self-monitor their coping efforts and develop more adaptive strategies. This client-centered approach is especially needed for individuals from historically marginalized and underserved groups who are vulnerable to chronic stress due to the various forms of oppression they experience. As a culturally responsive counseling approach, the BE WELL intervention was designed to address not only daily stressors (e.g., role strain) but also cultural and systemic factors that impacted their coping behaviors and created a climate of repeated exposure to stressful encounters. In the present study, several participants shared their frustrations and the perceived discrimination they experienced from individuals and institutions they encountered. For example, Aggie shared that her requests as well as her primary physician's request to have a preventative procedure completed were repeatedly dismissed by the specialist she was referred to. Bearing witness to her experience, promoting self-advocacy, and identifying principles from the Patient's Bill of Rights and Responsibilities (HHS, 2017) that applied to her

situation allowed the participant to feel affirmed, supported, and empowered to contest the lack of care she received from the referral. Unfortunately, this is a microcosm of the cultural (e.g., perceived discrimination in cross-cultural interactions) and systemic factors (e.g., lack of quality care) that have contributed to poor health outcomes for some sub-populations (e.g., people of color, individuals in rural communities) living with chronic disease and disability.

Over the last few decades, researchers have unequivocally linked health disparities, including mental health, to social, economic, and physical determinants of health (e.g., Bleich et al., 2012; Braveman et al., 2011; Raghupathi, 2018; Singh et al., 2017; Vega & Sribney, 2017). As a result, several scholars have indicated that advancing health equity begins with framing the disproportionate burden of chronic disease and disability among marginalized and medically underserved communities as a social injustice (Benfer, 2015; Braveman et al., 2011; Chapman, 2010). Despite the goals and objectives of national initiatives such as Healthy People 2020 and the National Partnership for Action to End Health Disparities, health equity in the U.S. continues to be unrealized as pervasive health disparities continue to persist (American Public Health Association [APHA], 2018).

To eliminate health disparities, scholars advocate that counselors and other health providers should design interventions based on cultural and linguistic sensitivity and equity (Sanchez et al., 2016) integrated models (Wrenn et al., 2017), policy (McGuire & Miranda, 2008), and research (Alegria et al., 2016). Both the Chronic Care Model (Wagner et al., 1996) and MSJCC (Ratts, et al., 2016) require counselors to provide culturally responsive interventions that address individual, interpersonal, and systemic factors. In the present study, the BE WELL program was used as a psychosocial tertiary intervention, but it could also be implemented as a primary or secondary intervention. However, for vulnerable populations such as people of color,

LGTBQIA+ individuals, low-income groups, and people with disabilities, it would be ideal for the customized BE WELL interventions to be implemented alongside more structural interventions such as housing, employment, and legal support. Structural interventions are designed to shift “the social, physical, economic, or political environments that may shape or constrain health behaviors and outcomes, altering the larger social context by which health disparities emerge and persist” (Brown et al., 2019, p. 72). Most interventions aimed to improve health outcomes and reduce health disparities have focused primarily on individual and interpersonal factors and this has limited their ability to generate more sustained improvements especially for POC. Regarding replication of the present study, it would be of interest to implement the BE WELL intervention with other historically marginalized and medically underserved groups using a culturally homogenous sample (e.g., Latinx women with diabetes, Native American men with substance use disorders) before using a heterogenous one to see if the findings would show similar results as it did in this study. Additionally, further replication of the BE WELL program should be conducted in conjunction with or integrated into a structural intervention to sustain more long-term effects individually and systemically.

Along with using customized interventions to address pervasive health disparities, future replications of the BE WELL program as an *N*-of-1/ABA withdrawal design should be altered. First, all intervention sessions should be extended to 60-75-minute sessions depending on the individual’s needs. Additional time may be necessary for some participants to fully participate in the intervention sessions and short breaks may be needed so each session may vary in duration. The seven essential mental activities from the Healthy Mind Platter (HMP) were used to structure the 8-session BE WELL program. In the present study, the last session included introducing an essential mental activity and facilitating termination. For future replications of

the BE-WELL program, a 9-week intervention framework is recommended. The first session would include rapport building, psychoeducation, goal setting, and action planning. Sessions two through eight would involve highlighting an essential mental activity from the HMP and providing relevant psychoeducation and neuroscience research. The last session would focus solely on closing/termination.

In addition to increasing the duration of intervention sessions, the length of the baseline and withdrawal phases should be increased from two to four weeks. In the present study, none of the participants were able to develop a stable baseline across all of the coping measures. Additionally, only one of the participants maintained an increase in all coping measures once the treatment was withdrawn. Increasing the length of the baseline and withdrawal phases would allow more data to be gathered and more meaningful observations of pre-and post-intervention changes. Extending the baseline and withdrawal phases would make observed differences among participants more pronounced and individual effects from the customized interventions even more palpable.

### **Future Implications**

For individuals living with chronic disease and disability, adaptive coping has been associated with improved disease management and symptom reduction (Smyth et al., 1999). Conversely, maladaptive coping strategies have been linked to long-term interpersonal and emotional distress (Gloria & Steinhardt, 2014). For people living with a chronic disease like MS, ineffective coping strategies can also lead to the worsening of symptoms and acquired disabilities due to the link between maladaptive coping and nonadherence to treatment and recommendations from health care providers (Costello et al., 2008; Hundt et al., 2015). The difficulties and losses associated with having a chronic condition like MS reveal that more needs

to be done to help these individuals adjust to changes they experience throughout the course of their disease in addition to managing their everyday lives. The need for coping flexibility interventions is great because using ineffective coping strategies to manage chronic disease and disability can have detrimental effects on psychological adjustment and overall quality of life (QoL) (Brajkovic et al., 2009; Goretti et al., 2010; Livneh, 2017; Megari, 2013). Therefore, it is imperative that counselors take an active role to help individuals living with chronic health conditions self-monitor their coping patterns and acquire more adaptive strategies to address individual, interpersonal, and systemic factors that contribute to their stress burden.

The results of the present study have significant implications for CMHCs working in integrated care, private practice, and community settings who of work PwMS, and more broadly, individuals living with chronic disease and disability from marginalized and underserved groups. First, interventions must be culturally responsive and affirming. To do this, counselors must understand how the identity intersections such as gender, race, socioeconomic status, and disability impact coping behaviors because for African American women coping mechanisms such as the Strong Black Woman have been and continue to be used to manage stress (Corbin et al., 2018; Drakeford, 2017; Wang & Beydoun, 2007; Watson & Hunter, 2015). Additionally, counselors must be flexible and accommodating to individuals who have invisible and physical disabilities and seek to develop creative and innovative approaches to address individual specific needs. This is especially needed for people with disabilities since many of these individuals, regardless of disability type, face significant challenges including attitudinal, architectural, environmental, medical, employment, access, and personal barriers that impede their psychosocial functioning and quality of life (QoL) (Stuntzer & Hartley, 2014; Sue et al., 2019).

Recently, a growing body of literature anchored in health disparity research focuses on the coping responses of Black women within the context of chronic disease and disability (Miles, 2018; Warren-Findlow & Issel, 2010) since they disproportionately experience adverse QoL factors compared to other racial/ethnic groups (Cheatam, 2015; Fuller-Thomson et al., 2009; Oberoi et al., 2015). Understanding the various social, economic, geographic, and systemic factors that impact the health outcomes of specific sub-populations is a crucial aspect of multicultural competence (Lee, 2008; Saha et al., 2008). However, researchers and practitioners must not use sweeping generalizations when designing interventions. Instead, they must be intentional with developing personalized treatment plans. Thus, it is important that researchers and practitioners continue to explore interventions that target meta-coping skills and abilities (e.g., coping flexibility) using SCRDS and provide additional resources and strategies on how to develop and implement such interventions.

In addition to utilizing more customized interventions, policy-level changes regarding the healthcare and rehabilitative needs of vulnerable populations such as African American women with MS must also be considered when discussing stressors that significantly impact individuals with chronic disease and disability. Despite targeted efforts to improve health equity in the U.S., only modest reductions in health disparities have been observed (APHA, 2018; Purnell et al., 2016). Counselors can be actively involved in informing policy makers about the attitudinal and structural barriers that individuals with chronic disease and disability face and offer strategies to develop systemic and structural interventions to help individuals overcome these barriers. In this regard, counselors can engage and coordinate policy efforts alongside healthcare providers, non-profit organizations and disability rights activists such as the American Disabled for Attendant

Programs Today (ADAPT) (National ADAPT, 2019) to organize events such as an advocacy day or seek legislative action through regional, national, and international professional organizations.

In the present study, an attempt was made to integrate neuroscience research into a coping skills training program to help participants enhance their coping flexibility. As the burgeoning literature on neurocounseling continues to grow, clear training and practice standards for the profession are lacking while the inclusion of neuroscience into counselor training (CACREP, 2016), practice standards (AMHCA, 2018), and professional discourse continues to increase (e.g., Beeson et al., 2019; Beeson & Field, 2017). In addition, some counseling programs have even developed post-master's neurocounseling certificate programs (Bradley University, 2019). The use of neuroscience research in the broader mental health field continues to expand, and it is important for the counseling profession to evaluate emerging trends in research, scholarship, and practice, including those related to neuroscience (Beeson et al., 2019). Collectively, counselors can determine what findings, if any, should influence the profession.

While this interest in neuroscience has been met with optimism, it has also been met with staunch criticism due to growing concerns regarding its impact on the humanistic foundations of the counseling profession (Wilkinson, 2018, 2019). There are many unknowns regarding the effectiveness of neurocounseling interventions on clinical outcomes and client welfare. Consequently, this justifies the need for researchers and practitioners to continually develop and evaluate innovative practices which is at the core of the ACA's Code of Ethics (2014).

Fortunately, SCRDS provide a practical research method for introducing and implementing innovative counseling practices. The SCRDS offers counselors and researchers a feasible method to use multimodal approaches such as neurocounseling to help create empirically-based customizable programs that improve clinical outcomes. When rigorously

designed, SCRDS can provide a viable alternative to large group experimental studies such as randomized clinical trials (RCTs) since they involve repeated measures and the manipulation of an independent variable (Lobo et al., 2017). Most of the research on coping and wellness interventions are based on either community-based programs or those offered via small groups in clinical and educational settings (Rigby, 2003; Sanaeinasab, 2017; Stuifbergen et al., 2003; Victorson et al., 2014; Williams et al., 2001). While these interventions provide relevant information, they are based on a one-size-fits-all model and not tailored to the specific and diverse needs of clients. Additionally, customized interventions such as SCRDS provide more flexibility and client-centeredness than RCTs and this is especially needed when working with individuals with chronic disease and disability since researchers have found individualized interventions to be as effective as group-based interventions (Zelinsky & Shadish, 2018) and in some cases more effective (das Nair et al., 2016; Firth, 2014). Thus, more research using SCRDS in the counseling literature is warranted.

It is hoped that information can be gleaned from the findings of this present study on how counselors can help individuals enhance their coping process and overall wellness. More specifically, it is hoped that CMHCs can be viewed as instrumental in helping individuals from marginalized and underserved groups who are living with chronic disease and disability better manage their stress, regulate emotions, self-monitor their coping efforts, and reduce maladaptive coping behaviors. Rather than relying on traditional group-based coping interventions, people with chronic disease and/or disability, such as African American women with MS, should be offered customized interventions to address their specific needs and lifestyle. To work with the MS population and more broadly with individuals living with chronic health conditions, CMHCs must develop knowledge about the client's culture, symptom profile, support network, and work

with providers to provide more individualized care. Additionally, it is essential that health providers (e.g. primary care physicians, neurologists) and counselors examine better ways to consult with each other and support individuals living with chronic disease and disability. Instead of working in silos, clinicians can work more collaboratively in integrated care, other outpatient settings, and in the community to provide comprehensive holistic care.

### **Conclusion**

In conclusion, the present study was an investigation of the effects of a psychoeducation-based wellness intervention that integrated neuroscientific concepts and research into a coping skills training program. The program was developed to fill a need for individualized counseling interventions with individuals from underserved populations living with chronic disease and disability. For this study, the population of interest was African American women living with multiple sclerosis. The findings revealed that customized interventions can indeed enhance the coping process of individuals living with a complex chronic disease.

As a brain-based wellness intervention, the BE WELL program is a unique approach to empirical-based research. While the Transactional Theory of Stress and Coping and the IS-Wel model have been used in the stress and coping literature, the Healthy Mind Platter (HMP) has not. However, based on the findings from the study, HMP does seem to be a feasible framework for customized interventions that aim to enhance an individual's coping process. Future research that further investigates the use of the BE WELL program with various populations are warranted. The strengths and limitations of the present study highlight that future studies may be designed to replicate or modify the procedures used in this study to expound upon these findings. Conversely, they may also be designed to minimize limitations found in this study.

Overall, the greatest strength of the BE WELL program was that all four participants valued the customized interventions. This is evidenced by their high social validity ratings which indicated that participants found the program to be meaningful and helpful. These observations coupled with the intervention's effectiveness demonstrate that this study was successful in applying a culturally responsive approach to psychoeducation-based neurocounseling in real-world settings. As health disparities persist, counselors must be in the forefront advocating for marginalized and medically underserved populations by working with clients and communities to address the various personal and systemic factors that adversely impact health outcomes.

In conclusion, the present study offers important contributions to counseling, MS, and stress and coping research and adds to understanding how SCRDS can be used to evaluate the efficacy of individualized brain-based wellness interventions within the context of chronic disease and disability. Furthermore, the present study demonstrates that personalized counseling interventions are an effective approach to holistic wellness and more specifically, helping individuals improve their coping efforts. To meet the unique and varied needs of diverse clients, counselors must become more creative and innovative in the modalities and treatment methods they employ. Developing customized interventions demonstrates how counselors can provide culturally responsive counseling and treatment planning and avoid a stereotypical, "one-size-fits-all" approach in a society with rich diversity.

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## APPENDICES

## **Appendix A: Consent Form**

### **Consent Form**

#### **North Carolina State University INFORMED CONSENT FORM for RESEARCH**

**Title of Study:** The Effects of Customized Psychoeducation-Based Neurocounseling Interventions on the Coping Flexibility of African American Women with Multiple Sclerosis (eIRB# 16895)

**Principal Investigator:** Whitney McLaughlin, MA, LPCA, NCC, wgmclaug@ncsu.edu, 910-528-7480

**Faculty Point of Contact:** Dr. Stanley Baker, LPC, sbaker@ncsu.edu, 919-515-6360

#### **What are some general things you should know about research studies?**

**You are being asked to take part in a research study.** Your participation in this study is voluntary. You have the right to be a part of this study, to choose not to participate and to stop participating at any time without penalty. The purpose of this research study is to gain a better understanding of how wellness interventions impact one's ability to increase flexibility in coping strategies to manage stress and regulate emotions in healthy ways. We will do this through asking you to participate in weekly wellness sessions and completing weekly surveys on a computer.

You are not guaranteed any personal benefits from being in this study. Research studies also may pose risks to those who participate. You may want to participate in this research because you will gain a better understanding of how stress impacts mental and emotional health as well as information on brain health and positive coping strategies. You may not want to participate in this research because of the timeframe. It is an intervention study that involves a time span of 12 weeks to complete.

In this consent form you will find specific details about the research in which you are being asked to participate. If you do not understand something in this form it is your right to ask the researcher for clarification or more information. A copy of this consent form will be provided to you. If at any time you have questions about your participation, do not hesitate to contact the researcher(s) named above or the NC State IRB office (contact information is noted below).

#### **What is the purpose of this study?**

The purpose of the study is to help African American women with multiple sclerosis improve flexibility in their coping and learn about effective ways to cope with stress through a personalized counseling intervention designed specifically for their individual needs. This intervention may help you learn new coping strategies as well as how to monitor your coping efforts. Furthermore, you may learn new coping strategies that may increase your overall mental and emotional well-being.

Given that MS is a neurological condition and a brain-based counseling approach will be used for the study, the interventions are not designed to reverse MS or change the disease course. Rather, the interventions are to help individuals learn and apply coping skills that may help them reduce their stress load and improve their well-being.

### **Am I eligible to be a participant in this study?**

There will be approximately 3-5 participants in this study.

In order to be a participant in this study you must:

- (a) identify as an African American female
- (b) have received an official MS diagnosis at least one month prior to the study
- (c) be between the age of 18 and 70 years
- (d) have difficulty with coping and/or seek opportunities to improve coping strategies, and
- (e) have a desire to learn about wellness from a brain-based perspective.

You cannot participate in this study if you have significant cognitive impairment due to MS or demonstrate that you are cognitively impaired from self-reports (by your own admission). This study is not appropriate for individuals with significant cognitive issues (e.g., difficulty with reading comprehension, consistent short-term memory problems) or developmental disabilities. Individuals with significant vision loss or impairment (such as being legally blind) due to MS or individuals who demonstrate that they are visually impaired and do not or cannot use corrective lenses will not be able to participate in this study. This study is not appropriate for individuals with significant or severe vision loss or impairment due to several of the intervention activities in the BE WELL program.

### **What do some of these terms below mean?**

Throughout this consent form there are some repeated words or phrases being used that you might not be familiar with and you may ask the researcher for any additional clarification.

**De-identified information:** This was once identifiable information that has been recorded by the researcher in a way that your identity is no longer directly on the information. This means that the researcher either has a master list with your code and real name that they can use to link to the information or they do not have a list like this and though they used to be able to link your identity to the information, there is no longer a way to link your real identity to the information.

### **What will happen if you take part in the study?**

If you agree to participate in this study, you will be asked to do all of the following: engage in an eight-session intervention with the investigator on a date, time, and location that is best for you and your availability. The total time that you will need to dedicate to the study is 12 weeks (with the hours required each week listed below). The investigator will serve as the wellness researcher in the intervention program and will provide the customized BE WELL interventions. The time frame and commitment of the study are as follows:

- If you participate, you will take an assessment twice a week for the first two weeks of the study. These assessments will measure your level of coping flexibility (your ability to monitor your coping efforts). You will be given a link to take the survey on

an electronic device. If you do not have a device, a paper form will be provided in a sealed envelope. The survey will take less than five minutes to complete.

- You will be completing a survey that is confidential– you will need to take the survey using a browser in incognito/private mode and your information will not be saved unless you submit the survey. Instructions will be provided and the wellness researcher will walk through the steps to completing the survey with you.
- After the two weeks, you will begin to meet with the wellness researcher for eight sessions. We will meet at an agreed upon date and time and location that is most convenient for you (such as your home or a neutral, private location). Each session will last up to 60 minutes except for the first session which will be about 75 minutes.
- In our first meeting, we will set goals and review the results of the coping survey. Together, we will come up with a plan to address the areas that need additional attention.
- After the initial meeting, you will continue to take the measures twice a week during the treatment period. This will help us monitor any changes.
- During each meeting, we will work on activities designed just for you based on your needs. The wellness researcher will take some notes during the session which will be used to track the changes and effectiveness in the interventions in order to adapt further sessions for you and/or the research process. These notes will then be transferred to the investigator’s password-protected computer and stored in a password-protected file.
- You will be encouraged to engage in healthy coping strategies (e.g., deep breathing, daydreaming) in between meetings that will also be used as ways to help you achieve your wellness goals.
- After you complete the eight sessions, you will receive a survey to gather your feedback on how you felt about the intervention program. You will be given a link to take the survey on an electronic device.
- For the final two weeks of the program, you will go back to doing what you did before the intervention sessions and take the coping flexibility survey on your device twice a week for two more weeks and once that is completed then the study is over.
- If you agree to be in the study, I will give you a calendar noting the times you will need to take the measure and we will set up times to meet. You will also receive reminders via the free BZ Reminder app (which I will install on your phone with your permission).

The total amount of time that you will be participating in this study is 12 weeks (2 weeks completing the coping flexibility survey followed by the 8-week intervention and then ending with 2 weeks completing the coping flexibility survey again).

The following procedures are experimental: the 8-week wellness intervention sessions; however, the wellness interventions themselves are established evidence-based best practices.

### **Risks and benefits**

There is a risk that you may not improve the ability to monitor your coping behaviors and effectively cope with stress as stressful situations are brought to the forefront. Note: Over a short

amount of time, this hypersensitivity to stress should subside. There may also be other possible side effects of participating in this wellness program that are not yet known. As a wellness researcher, these are the measures I am taking to mitigate those risks I am only focusing on coping from a wellness-based perspective and not focusing on chronic disease management. Wellness counseling emphasizes mental health as well as healthy social and emotional development. As a result, the likelihood of the risk occurring is low and the magnitude of harm that could come to you is minimal.

Sharing information about your medical diagnosis/treatment could pose a risk regarding employment and insurability (your ability to receive insurance coverage) as this information could cause you to be “outed” to your employer and impact eligibility and access to insurance due to having one or more preexisting conditions. For this study, risks of unintentional disclosure of participants’ medical condition to employers and insurance carriers is minimal. Participants will only be asked to disclose their current occupation (if this applies) in general terms. You will not be asked to provide the name of your employer or any third-party information related to your employment status. Any and all third-party information provided by you regarding your employment will not be collected. Participants are instructed to discuss information related to their employment in general terms.

Sharing information about coping with a chronic disease like MS and other stressors may stimulate some emotional distress or discomfort. In order to minimize any potential discomfort, support will be given in the following ways: (a) you may elect to withdraw from the study at any point in time; (b) at the start of each session, I will do a check-in and assess your level of comfort in participating; (c) you will have the option to postpone and reschedule sessions for any reason; and (e) following the intervention, I will allow you to have some time for reflection.

There is a risk the intervention program will not work, and flexibility in your coping will not improve. If this is the case, then I will meet with you to provide resources for additional assistance. I will take all the necessary precautions to make sure that you feel comfortable during the intervention. As this intervention will be personalized, you and I will work closely to meet your desired goals and make sure that they are attainable. In the event more clinical-based counseling is needed, I will meet with you and share the Community Resources List and help with the referral process to contact a mental health provider for services.

Potential direct benefits to be gained by your participation is that you will gain a better understanding of the stressors you experience, how stress impacts your mental and emotional health, and how your coping efforts can support your brain health and functioning. It is anticipated that you will gain a better understanding of how to engage in effective coping strategies to better manage stress and regulate emotions that may generate from stressful situations. It is also anticipated that you will gain more knowledge related to your brain health and functioning. You may also learn skills to improve communication in your relationships. The coping skills and brain-based education will provide information that you can choose to take with you (as handouts will be provided for some sessions) and continue to use.

### **Other options**

Instead of participating in this research, there are alternative programs available to you. These include receiving support and educational materials focused on wellness and coping with stress

from the National Multiple Sclerosis Society (NMSS) at [www.nationalmssociety.org/](http://www.nationalmssociety.org/). Additionally, the MS Navigator program through the NMSS provides an individualized approach to care and support for various needs and concerns including wellness education. Please call 1-800-344-4867 or visit <https://www.nationalmssociety.org/Resources-Support/Find-Support/Ask-an-MS-Navigator> for more information.

Several pharmaceutical companies (e.g., Biogen and Genetech/Ocrevus) host live events and webinars that are focused on health and wellness throughout the country. For more information on Biogen's Above MS program, please call 1-800-456-2255 or visit [www.abovems.com/en\\_us/home/abovems/program.html](http://www.abovems.com/en_us/home/abovems/program.html). For more information on Genetech/Ocrevus Patient Educational Events, please call 1-844-OCREVUS (1-844-627-3887) or visit [www.ocrevus.com/patient/support/ms-events.html](http://www.ocrevus.com/patient/support/ms-events.html)

### **Right to withdraw your participation**

You can stop participating in this study at any time for any reason. In order to stop your participation, please notify me via phone or in-person. If you choose to withdraw your consent and stop participating, you can expect the investigator will destroy the data that you have provided from the surveys up until the point you withdraw and your information will not be included in any data analysis or in the final written report.

### **Confidentiality**

The information in the study records will be kept confidential to the full extent allowed by law. Data will be stored securely on an NC State managed system. To help maximize the benefits of your participation in this project, by further contributing to science and our community, your de-identified information will be stored for future research and may be shared with other people without additional consent from you.

Unless you give explicit permission to the contrary, no reference will be made in oral or written reports which could link you to the study. Individual data with identifiable details removed may be made available to the public as required by a professional association, journal, or funding agency. De-identified data may be used or shared by the principal investigator or others for presentation, publication, or future research purposes.

The information in the study including assessments and notes will be kept confidential to the full extent allowed by law and North Carolina State University's Institutional Review Board. Data will be kept in an encrypted password-protected file in a cloud storage provider used by NC State University that only the principal investigator will have access to. No reference will be made in oral or written reports which could link you to the study. Your name will not be shared on any final written reports.

For this study, please note there are some limits to confidentiality. If at any point during the study, I become concerned that a participant is hurting or about to hurt herself or someone else, I am required to report this information to the proper authorities.

### **Compensation**

For participating in this study, you will receive a \$30 gift card at the end of the study. If you miss your weekly session, there will be a makeup session provided within 7 days of the missed session. Due to the time frame of the research study, if the make-up session does not occur within one week, then you will no longer be eligible to participate. If you do not complete the entire study the gift card will be pro-rated based on the time that you participated in the study.

If you withdraw from the study prior to its completion, the gift card amount will be pro-rated at a rate of \$2.50/week. For example if you withdraw from the study in week 5, then the pro-rated amount will be \$12.50. If you withdraw in week 10, the pro-rated amount will be \$25.

### **Emergency medical treatment**

If you are hurt or injured during the study session(s), the researcher will call 911 for necessary care. There is no provision for compensation or free medical care for you if you are injured as a result of this study. Please note, there will be no physical activity requirement for this study. This study is meant to be educational and provide you with information related to brain health, coping skills, and wellness.

### **What if you are a college student?**

Participation in this study is not a course requirement and your participation or lack thereof, will not affect your class standing or grades at your institution.

### **What if you have questions about this study?**

If you have questions at any time about the study itself or the procedures implemented in this study, you may contact the researcher, Whitney McLaughlin by calling 910-528-7480 or via email at wgmclaug@ncsu.edu, or at her NC State physical address 2310 Stinson Drive, Raleigh, NC, 27695.

### **What if you have questions about your rights as a research participant?**

If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact the NC State IRB (institutional Review Board) Office via email at irb-director@ncsu.edu or via phone at 1.919.515.8754. An IRB office helps participants if they have any issues regarding research activities.

You can also find out more information about research, why you would or would not want to be a research participant, questions to ask as a research participant, and more information about your rights by going to this website: <http://go.ncsu.edu/research-participant>

### **Consent to Participate**

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study with the understanding that I may choose not to participate or to stop participating at any time without penalty or loss of benefits to which I am otherwise entitled.

**Participant's printed name** \_\_\_\_\_

**Participant's signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**Investigator's signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**A copy of this form will be provided to you to take with you.**

### Community Resources List

Name	Address	Telephone	Services Provided	Website
<b>UNC Healthcare Crisis and Assessment Service at WakeBrook</b>	107 Sunnybrook Road, Raleigh	984-974-4800	Mobile Crisis Team, mental health assessment and referral services	<a href="http://www.wakegov.com/humanservices/">http://www.wakegov.com/humanservices/</a>
<b>HopeLine</b>	P.O. Box 10490 Raleigh, NC 27605		Free and confidential crisis prevention helpline and instant messaging	<a href="http://www.hopeline-nc.org">http://www.hopeline-nc.org</a>
<b>MS Local Support Groups</b>	Greater Carolinas 3101 Industrial Drive, Suite 210 Raleigh, NC 27609	(919) 834-0678  (Toll free) 1-800-344-4867	Support/Self-help groups	<a href="http://www.nationalmssociety.org/Resources-Support/Find-Support/Join-a-Local-Support-Group">http://www.nationalmssociety.org/Resources-Support/Find-Support/Join-a-Local-Support-Group</a>  *Although the researcher is an MS Ambassador with the Greater Carolinas Chapter. She does not provide direct support or facilitate any of the local support groups.
<b>MS Connections Volunteer-led Support Groups</b>	N/A	(919) 834-0678  (Toll free) 1-800-344-4867	Online peer support and advocacy	<a href="http://www.msconnection.org/Support">http://www.msconnection.org/Support</a>
<b>MS Connections</b>	N/A	(919) 834-0678  (Toll free)	Social networking website and community for	<a href="http://www.msconnection.org/Home">http://www.msconnection.org/Home</a>

		1-800-344-4867	people living with MS, their loved ones and experts to connect in a safe and secure environment	
<b>Freedom House Recovery Center</b>	104 New Stateside Drive, Chapel Hill, NC 27516	919-967-8844	Mobile Crisis Team, mental health assessment and referral services	<a href="http://freedomhouserecovery.org">http://freedomhouserecovery.org</a>
<b>Durham Recovery Response Center (formerly Durham Center Access)</b>	309 Crutchfield St, Durham, NC 27704	905-666-0483 or 1-800-742-1890	Mobile Crisis Team, mental health assessment and referral services	<a href="http://dmhs.ca/">http://dmhs.ca/</a>

**\*\* Please note that any cost in seeking mental health or medical assistance is at your own expense.\*\***

## Appendix B: Background and Demographic Questionnaire

### Background and Demographic Questionnaire (BDQ)

**Directions:** Please provide the following demographic and background information. Please answer all questions completely by circling the letter choice(s) that represents your best response to the question being asked. There will be no attempt to identify individuals. In order to help protect your identity, I would like to you utilize a pseudonym (also known as a fictitious name), please list your fictitious name: \_\_\_\_\_

1. **What is your age?** \_\_\_\_\_
2. **What is your MS diagnosis?**
  - a. **Clinically Isolated Syndrome (CIS)** – An individual may receive a diagnosis of CIS after the first sign or symptom of the disease.
  - b. **Relapse-remitting MS (RRMS)** - This is the most common form of multiple sclerosis. About 85% of people with MS are initially diagnosed with RRMS. People with RRMS have temporary periods called relapses, flare-ups or exacerbations, when new symptoms appear.
  - c. **Secondary-progressive MS (SPMS)** - In SPMS, symptoms worsen more steadily over time, with or without the occurrence of relapses and remissions. Most people who are diagnosed with RRMS will transition to SPMS at some point
  - d. **Primary-progressive MS (PPMS)** - A rare form of MS (found in 5% of persons diagnosed with MS), PPMS is characterized by a steadily worsening disease state from the beginning, with minor relapses but no remissions, with or without recovery
3. **How long have you been diagnosed with MS?**
  - a. less than a year
  - b. 1 to 3 years
  - c. 3 to 5 years
  - d. 5 to 10 years
  - e. 10 or more years
4. **What MS symptoms do you have? Select all that apply.**
  - a. Fatigue
  - b. Walking difficulties
  - c. Numbness and tingling

- d. Spasticity (stiffness/tightness/muscle spasms)
  - e. Vision problems
  - f. Cognitive issues
  - g. Bladder or bowel problems
  - h. Pain
  - i. Other \_\_\_\_\_
- 5. Have you had any mental health challenges since being diagnosed with MS?**
- a. Yes
  - b. No
- 6. If so, have you been diagnosed with any of the following mood disorders?**
- a. Depression
  - b. Anxiety
  - c. Pseudobulbar affect
  - d. Bipolar disorder
  - e. Other \_\_\_\_\_
  - f. I have not been diagnosed with a mood disorder.
- 7. Do you currently have any other chronic physical health conditions? Select all that apply.**
- a. Hypertension (high blood pressure)
  - b. Arthritis
  - c. Irritable bowel syndrome
  - d. Chronic lung disease
  - e. Diabetes
  - f. Hyperlipidemia
  - g. Sleep disorder
  - h. Other \_\_\_\_\_
  - i. I do not have any other chronic physical health conditions.
- 8. Do you currently see a neurologist to manage your MS?**
- a. Yes
  - b. No

**9. Are you current taking a disease-modifying therapy (DMT) medication to treat your MS?**

- a. Yes
- b. No

**10. Since being diagnosed with MS, how often do you go to the doctor for an MS-related visit?**

- a. Often (I go to the doctor every other week.)
- b. Sometimes (I go to the doctor at least once a month.)
- c. Rarely (I go to the doctor once every 6 months)
- d. Hardly Ever (I go to the doctor once a year.)
- e. Never (I don't go to the doctor since being diagnosed).

**11. Since being diagnosed with MS, how often do you see a mental health professional such as a counselor or psychologist?**

- a. Very Often (I see a counselor once a week.)
- b. Often (I see a counselor every other week.)
- c. Sometimes (I see a counselor once a month)
- d. Rarely (I see a counselor once every six months.)
- e. Hardly Ever (I've see a counselor once a year)
- f. Never (I've never seen a counselor since being diagnosed.)

**12. What is the highest level of education have you completed?**

- a. Less than high school diploma
- b. High school diploma or GED
- c. Associate's Degree
- d. Bachelor's Degree
- e. Master's Degree
- f. Doctoral Degree
- g. Professional Degree (MD, JD)

**13. What is your current employment status?**

- a. Full-time      b. Part-time      c. Unemployed      d. Student

**14. What is your occupation?** \_\_\_\_\_

**15. What is your approximate average household income?**

- a. \$0-\$24,999  
b. \$25,000-\$49,000  
c. \$50,000-\$74,999  
d. \$75,000 and over

**16. Which of the following best describes the area you live in?**

- a. Urban  
b. Suburban  
c. Rural  
d. Other \_\_\_\_\_

**17. What is your religious affiliation?**

- a. Christianity  
b. Islam  
c. Hinduism  
d. Buddhism  
e. Judaism  
f. Sikhism  
g. Other \_\_\_\_\_  
h. None

**18. What is your marital status?**

- a. Single  
b. Married  
c. Separated/Divorced  
d. Widowed

**19. Do you have children?**

- a. Yes

b. No

**20. If you have children, how many under 18 years old live in your household?**

a. 1

b. 2

c. 3

d. 4 or more

e. I do not have children under 18 years old.

**21. If you have adult children, how many?**

a. 1

b. 2

c. 3

d. 4 or more

e. I do not have adult children.

**22. What types of stress have you experienced in the past 6 months? Select all that apply.**

a. financial stress

b. stress from personal relationships

c. job stress

d. academic stress

e. MS-related stress

f. Other \_\_\_\_\_

**23. How do you feel about your current efforts to cope with stress?**

a. Very dissatisfied

b. Moderately dissatisfied

c. Slightly dissatisfied

d. Neutral

e. Slightly satisfied

f. Moderately satisfied

g. Very satisfied

**24. What activities do you enjoying doing for pleasure or to reduce stress? Select all that apply.**

- a. Artmaking
- b. Engaging in physical activity
- c. Being outside/exploring nature
- d. Reading for pleasure
- e. Meditating
- f. Daydreaming
- g. Journaling
- h. Listening to music
- i. Creating a To Do list
- j. Breathing Exercises
- k. Sleeping
- l. Praying
- m. Playing a game
- n. Using aromatherapy (essential oils)
- o. Venting to trusted loved ones
- p. Other \_\_\_\_\_

**25. From the list above, how often would you say you *intentionally* engage in one or more of these activities to reduce your stress?**

- a. Daily
- b. Several times a week
- c. Several times a month
- d. Several times a year
- e. Never

**26. How aware are you of how you feel from moment to moment?**

- a. Very Often (I am almost always aware.)
- b. Often (I am generally aware.)
- c. Sometimes (I am somewhat aware.)
- d. Rarely (I am barely aware.)
- e. Hardly Ever (I am almost never aware.)

**27. How comfortable are you with expressing your feelings to others?**

- a. Extremely comfortable

- b. Moderately comfortable
- c. Slightly comfortable
- d. Neither comfortable nor uncomfortable
- e. Slightly uncomfortable
- f. Moderately uncomfortable
- g. Extremely uncomfortable

**28. What type of artmaking do you enjoy (or would you enjoy) doing for pleasure?**

**Select all that apply.**

- a. Painting
- b. Drawing
- c. Making pottery
- d. Poetry writing
- e. Writing stories
- f. Making music
- g. Coloring in coloring books
- h. Other \_\_\_\_\_
- i. I do not like to make art.

## Appendix C: Coping Flexibility Scale

### Coping Flexibility Scale

When we feel stress, we try to cope using various actions and thoughts. The following items describe stress- coping situations. Please indicate how these situations apply to you by choosing one of the following for each situation. Please answer every question using the following scale and place the number you have chosen in the blank to the left of the item

**Very applicable = 4    Applicable = 3    Somewhat applicable = 2    Not applicable = 1**

- \_\_\_1.    When a stressful situation has not improved, I try to think of other ways to cope with it.
- \_\_\_2.    I only use certain ways to cope with stress.
- \_\_\_3.    When stressed, I use several ways to cope and make the situation better.
- \_\_\_4.    When I haven't coped with a stressful situation well, I use other ways to cope with that situation.
- \_\_\_5.    If a stressful situation has not improved, I use other ways to cope with that situation.
- \_\_\_6.    I am aware of how successful or unsuccessful my attempts to cope with stress have been.
- \_\_\_7.    I fail to notice when I have been unable to cope with stress.
- \_\_\_8.    If I feel that I have failed to cope with stress, I change the way in which I deal with stress.
- \_\_\_9.    After coping with stress, I think about how well my ways of coping with stress worked or did not work.
- \_\_\_10.    If I have failed to cope with stress, I think of other ways to cope.

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Dear Dr. Tsukasa Kato,

My name is Whitney McLaughlin, MA, LPCA, NCC. I am a licensed, Board-certified counselor and a doctoral candidate from North Carolina State University. Currently, I am writing my dissertation proposal tentatively titled *The Effects of Customized Neurocounseling Interventions on the Coping Flexibility Among African American Women with Multiple Sclerosis*, under the direction of my dissertation committee chaired by Dr. Stanley Baker, who can be reached at sbaker@ncsu.edu. The IRB process has not commenced but the NC State University IRB Committee Chair, Dr. Thomas Birkland, can be contacted at 919-513-1837 or by email (tabirkla@ncsu.edu) should you have any questions or concerns. You may also direct questions to the IRB Director, Jennie Ofstein, at 919-515-8754 or email at irb-director@ncsu.edu.

I would like your permission to use the Coping Flexibility Scale in my research study. I would like to use and develop an electronic version of the survey in *Qualtrics*, a web-based survey data analysis service and also utilize printed versions of the survey under the following conditions:


- I will use the surveys only for my research study and will not sell or use it with any compensated or curriculum development activities.
- I will ensure participant confidentiality by having respondents who choose to complete an electronic version of the survey to do so only using *Qualtrics* because it utilizes Transport Layer Security (TLS) encryption for transmitted data. The survey will also be password-protected and an HTTP referrer checking feature may be utilized as an added layer of protection.
- I will ensure participant confidentiality for respondents who complete print versions of the assessment by keeping all documentation in a locked file cabinet in my home office. Participants will use pseudonyms to complete the survey. Thus, no reference will be made in oral or written reports which could link participants to the study.
- I will send a copy of my completed research study to your attention upon completion of the study.

If these are acceptable terms and conditions, please indicate so by replying to me through e-mail at [wgmclaug@ncsu.edu](mailto:wgmclaug@ncsu.edu). On the follow page you will find an example of an electronic response for this request.

Sincerely,

*Whitney McLaughlin*  
Whitney McLaughlin, MA, LPCA, NCC

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 Request for Permission to Use Coping Flexibility Scale.docx.dotx  
28K

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**KATO Tsukasa** <mtsukasa@hotmail.com>  
To: Whitney McLaughlin <wgmcclaug@ncsu.edu>

Wed, Mar 20, 2019 at 6:34 PM

Dear, Dr. **Whitney McLaughlin**

Thank you for your appreciation of my article.  
Of course, you may use the Coping Flexibility Scale.

Best

Tsukasa Kato, Prof.

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**Whitney McLaughlin** <wgmcclaug@ncsu.edu>  
To: KATO Tsukasa <mtsukasa@hotmail.com>

Wed, Mar 20, 2019 at 7:39 PM

Thank you so much! I really do appreciate it.

**Whitney McLaughlin, MA, LPCA, NCC**

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Graduate Assistant, Undergraduate Programs  
Poole College of Management Career Center  
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**NC STATE**

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## Appendix D: 10 Items of the CFS

### 10 Items of the CFS

#### **Factor 1: *Evaluation coping***

2. I only use certain ways to cope with stress (R).
6. I am aware of how successful or unsuccessful my attempts to cope with stress have been.
7. I fail to notice when I have been unable to cope with stress (R).
8. If I feel that I have failed to cope with stress, I change the way in which I deal with stress.
9. After coping with stress, I think about how well my ways of coping with stress worked or did not work.

#### **Factor 2: *Adaptive coping***

1. When a stressful situation has not improved, I try to think of other ways to cope with it.
3. When stressed, I use several ways to cope and make the situation better.
4. When I haven't coped with a stressful situation well, I use other ways to cope with that situation.
5. If a stressful situation has not improved, I use other ways to cope with that situation.
10. If I have failed to cope with stress, I think of other ways to cope.

Reverse coded items are denoted with (R).

## Appendix E: Attitude Toward Treatment

### Attitudes Toward Treatment Measure (ATT)

Now that you have completed the psychoeducation-based neurocounseling intervention program, please complete the following questions by circling the number on the scale which is closest to your feelings.

1. How confident are you that this program will be successful in helping you?

- 1 not at all confident
- 2
- 3
- 4 somewhat confident
- 5
- 6
- 7 very confident

2. How logical does this type of program seem to you?

- 1 not at all logical
- 2
- 3
- 4 somewhat logical
- 5
- 6
- 7 very logical

3. Are you willing to undertake a similar program sometime in the future?

- 1 not at all willing
- 2
- 3
- 4 somewhat willing
- 5
- 6
- 7 very willing

4. How beneficial do you think this program was for you?

- 1 not at all beneficial
- 2
- 3
- 4 somewhat beneficial
- 5

- 6
- 7 very beneficial

5. How does this program compare in effectiveness with just doing nothing?

- 1 much worse than nothing
- 2
- 3
- 4 the same as nothing
- 5
- 6
- 7 much better than nothing

6. How does this program compare in effectiveness with teaching yourself?

- 1 much better than own attempts
- 2
- 3
- 4 same as own attempts
- 5
- 6
- 7 much worse than own attempts

7. How useful were the described program techniques?

- 1 not useful at all
- 2
- 3
- 4 moderately useful
- 5
- 6
- 7 very useful

8. How well was the program explained?

- 1 not at all well
- 2
- 3
- 4 moderately well
- 5
- 6
- 7 very well

9. How believable was the program?

- 1 not at all believable

- 2
- 3
- 4 moderately believable
- 5
- 6
- 7 very believable

10. How valuable is the program in treating self-defeating behaviors?

- 1 not at all valuable
- 2
- 3
- 4 moderately valuable
- 5
- 6
- 7 very valuable

11. To what degree has the program changed your idea of problems related to self-defeating behaviors?

- 1 no change at all
- 2
- 3
- 4 moderate change
- 5
- 6
- 7 very much change

12. How understandable was the explanation of the program?

- 1 not at all understandable
- 2
- 3
- 4 moderately understandable
- 5
- 6
- 7 very understandable

13. To what degree did this program help in understanding yourself?

- 1 not at all helpful
- 2
- 3
- 4 moderately helpful
- 5
- 6

7 very helpful

14. To what extent does the program allow for insight into yourself?

1 no insight at all

2

3

4 moderate insight

5

6

7 very much insight

## Appendix F: Neurocounseling Intervention Program Framework

### Neurocounseling Intervention Program Framework

*The activities within each session will be chosen based on the participant's individual needs.*

#### **Session 1 [75 minutes]: Understanding Stress and Identifying the Coping Self:**

Neuroeducation Topic: Understanding the Activation of the Sympathetic (Fight or Flight)

##### Response

- Agenda Setting
  - Introduction
  - Description of the BE WELL Program
  - Overview of Session Framework: Time, Frequency, and Duration of Sessions
- Goal Setting & Action Planning
- Discuss the Psychological Stress Process & Autonomic Response
- The Impacts of Stress on MS and Mental, Physical, and Emotional Health
- Coping Flexibility Profile – Evaluate Coping and Adaptive Coping Attitudes
- Characteristics of Coping from a Wellness Perspective (IS-Wel Model: The Coping Self)
  - Stress Management, Leisure, Self-Worth, Realistic Beliefs
- Summary

**Session 2 [60 minutes]: Time In** - *When we quietly reflect internally, focusing on sensations, images, feelings and thoughts, we help to better integrate the brain.*

Neuroeducation Topic: Engaging the Parasympathetic (Relaxation Response) System

- Internal Factors that Trigger Stress
- Using Metaphor to Describe and Explore the Autonomic Body Functions Involved in the Parasympathetic System (The Brakes for the Sympathetic System)
- Mindfulness Techniques
- Emotion Regulation Strategies
- Summary

**Session 3 [60 minutes]: Focus Time** - *When we closely focus on tasks in a goal-oriented way, we take on challenges that make deep connections in the brain.*

Neuroeducation Topic: Improving Brain Circuits Involved in Goal-Directed Behavior

- Using Metaphor to Describe and Explore the Role of the Frontal Lobe/Executive Function (The Conductor to the Brain's Orchestra)
- External Factors that Trigger Stress
- Proactive & Reactive Responses to Stress
- Summary

**Session 4 [60 minutes]: Play Time** - *When we allow ourselves to be spontaneous or creative, playfully enjoying novel experiences, we help make new connections in the brain.*

Neuroeducation Topic: The Role of Creativity and Play in Generating Neuroplasticity

- Using Metaphor to Describe and Explore Neuroplasticity (The Brain as a Power Grid)
- Engaging in Healthy Distraction

- Self-soothing Strategies
- Summary

**Session 5** [60 minutes]: **Connecting Time** - *When we connect with other people, ideally in person, and when we take time to appreciate our connection to the natural world around us, we activate and reinforce the brain's relational circuitry.*

Neuroeducation Topic: Buffering the Secretion of Stress Hormones: The Role of Social Support

- Using Metaphor to Describe and Explore the Role of Adrenaline and Cortisol (Lighter Fluid & Charcoal) in Chronic Stress
- The Benefits of Having Social Support
- Role Plays and Case Scenarios
- Summary

**Session 6** [60 minutes]: **Physical Time** - *When we move our bodies, aerobically if medically possible, we strengthen the brain in many ways.*

Neuroeducation Topic: Promoting Brain Derived Neurotrophic Factor (BDNF) Through Physical Activity

- Using Metaphor to Describe and Explore BDNF and Its Impact on Mental, Emotional, and Physical Health (BDNF as Miracle Gro)
- Basic Information on Strength Training
- Basic Information on High Intensity Interval Training Exercises
- Resources on Physical Activity from the MS Society
- Summary
- Discuss upcoming closure session

**Session 7** [60 minutes]: **Sleep Time** - *When we give the brain the rest it needs, we consolidate learning and recover from the experiences of the day.*

Neuroeducation Topic: The Impact of a Good Night's Sleep on Hippocampal Function

- Using Metaphor to Describe and Explore the Role of the Hippocampus in Memory Consolidation During Sleep (Hippocampus as the Brain's Save Button)
- Sleep Education & Hygiene
- Summary

**Session 8** [60 minutes]: **Down Time** - *When we are non-focused, without any specific goal, and let our mind wander or simply relax, we help the brain recharge.*

Neuroeducation Topic: Activating the Default Mode Network

- Using Metaphor to Describe and Explore the Default Mode Network (The Brain's Screensaver)
- Mind Wandering With and Without Intention
- Facilitating the Wakeful Rest/Task-unrelated Thought State
- Summary
- Closure

<b>BE WELL SUPPLEMENTAL ACTIVITIES</b>			
<b>Session</b>	<b>Activity</b>	<b>Coping Strategy (PFC or EFC)</b>	<b>IS - Wel Coping Self Element (L, SM, RB, SW)</b>
<b>(UNDERSTANDING STRESS &amp; IDENTIFYING THE COPING SELF)</b>			
A1	Overview of the BE WELL Program	PFC	RB, SW, SM
A2	The Activation of The Sympathetic Nervous System (Fight or Flight Response, Freeze as an Alternative Response)		
A3	Review Coping Self and Coping Flexibility Scale Results		
A4	Setting Goals and Creating Action Plans: BE WELL Personal Wellness Plan		
<b>(TIME IN)</b>			
B1	Progressive Muscle Relaxation	EFC	L, SM
B2	Body Scan Exercise		
B3	Five Basic Yoga Poses		
B4	Mindfulness Meditation/Loving-Kindness Meditation		
B5	Diaphragmatic Breathing Techniques		
<b>(FOCUS TIME)</b>			
C1	Taking a Problem-Solving Approach to Common Stressors	PFC	L, RB, SM, SW
C2	Developing Time Management Skills		
C3	Using Conflict Resolution Strategies to Manage Difficult Situations		
<b>(PLAYTIME)</b>			

D1	Creative & Artistic Expression (Painting with Watercolors)	EFC	L, SM
D2	Creative & Artistic Expression (Poetry Writing – Formulaic I Am Poem)		
D3	Coloring Mandalas		
D4	Tactile Sensory Play with Aromatherapy Dough		

**(CONNECTING TIME)**

E1	Role Play – Initiating Social Support	EFC	SM, RB, SW
E2	Role Play – Expressing Feelings		
E3	Role Play – Sharing MS Diagnosis		
E4	Identifying Your Support Network		

**(PHYSICAL TIME)**

F1	Basic High Intensity Interval Training Information	EFC & PFC	L, SM, RB, SW
F2	Basic Strength Training Information		

**(SLEEP TIME)**

G1	Developing a Good Sleep Hygiene	EFC	SM
G2	Falling Asleep		
G3	Staying Asleep		
G4	Guided Bedtime Meditation		

**(DOWNTIME)**

H1	Stream of Consciousness Writing Activity	EFC	L, SM, SW
H2	Taking a Mental Vacation – Visualization Exercise		

**(CLOSURE)**

H3	Reflections on Participating in the BE WELL Program		
H4	Certificate of Completion Presentation		

**Appendix G: BE WELL Personal Wellness Plan**

**Individual BE WELL Personal Wellness Plan**

**Aggie**

**Social/Emotional Goals and Action Plan**

**GOAL 1:** To reduce the occurrence of panic attacks.

**ACTION STEPS TO ATTAIN GOAL:**

- Identify and recognize triggers that lead to stressful situations in the work setting
- Recognize when physiological responses to stress occur (e.g., increase in heart rate)
- Counter cognitive distortions and irrational thoughts with cognitive reframing

**GOAL 2:** Create healthier boundaries, particularly in the work setting.

**ACTION STEPS TO ATTAIN GOAL:**

- Identify triggers (e.g., when she feels overworked and recognize when she feels obligated to take on other projects, assignments, concerns from other colleagues when it is not necessary)
- Establish boundaries and implement them when needed.
- Communicate when boundaries have been violated

**GOAL 3:** Develop more adaptive coping strategies to regulate emotions and better manage stressful situations.

**ACTION STEPS TO ATTAIN GOAL:**

- Practice skills (e.g., mindfulness strategies, diaphragmatic (belly) breathing) from BE WELL sessions
- Identify at least one new adaptive coping strategy to implement throughout the program (see coping goal)
- Identify and express how she feels during and after engaging in an effective coping strategy

**SMART COPING GOAL:** I will develop a list of affirmations, quotes, and scriptures to help manage my work stress and counteract my irrational thinking pattern.

**Action Steps: How will I reach this goal?**

1. Surf the web for quotes, affirmations that speak to me
2. Find scriptures that resonate with me.
3. Use cardstock and/or other art materials to develop the list.
4. Place the list in a spot that is visible in my work area.

5. Recite the list each morning when I come to work and as often as needed.

What resources do I have?	What resources do I still need?
Internet, Bible	Stress ball
Cricket (machine used for arts and crafts)	
Cardstock	

**How will I know when I have achieved this goal?** I will have one less unrealistic or self-defeating thought at work. I will notice a reduction in panic attacks.

### Aggie's Customized Intervention

Session	Domains/Content	Tasks and Activities	Purpose and Rationale	Duration	Goals
1	<p><b>Understanding Stress and Identifying the Coping Self:</b>  <u>Neuroeducation Topic: Understanding the Activation of the Sympathetic (Fight or Flight) Response</u></p> <ul style="list-style-type: none"> <li>&gt; Rapport Building</li> <li>&gt; Structure of the BE WELL program</li> <li>&gt; Goal Setting</li> <li>&gt; Defining Stress and Coping Flexibility</li> <li>&gt; Differentiating Between Evaluation and Adaptive Coping</li> <li>&gt; Wellness Education</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Reviewing BE WELL assessment results</li> <li>&gt; Establishing Goals</li> <li>&gt; Defining Stress and Identifying Physiological Responses to Stress (Fight/Flight/Freeze)</li> <li>&gt; Reviewing the Sympathetic Nervous System Handout</li> <li>&gt; Discussing Components of the Coping Self</li> <li>&gt; Discussing Impact of Stress on MS and Mental/Emotional Health</li> </ul>	<p>To develop customized intervention framework for subsequent sessions</p> <p>To understand the four components of the Coping Self</p> <p>To examine the coping profile and identify triggers that lead to stress response</p> <p>To learn the neurophysiological effects of stress</p>	75 mins	1 SEG 2 SEG, CG

<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
		> Review Coping Flexibility Profile			
<b>2</b>	<p><b>Time In</b> <u>Neuroeducation Topic: Engaging the Parasympathetic (Relaxation Response) System</u></p> <p>&gt; Increase Awareness of Mind-Body Connection</p> <p>&gt;Internal Factors that Trigger Stress</p> <p>&gt; Using Metaphor to Describe and Explore the Autonomic Body Functions</p> <p>&gt; Explore Mindfulness Techniques and Emotion Regulation Strategies</p>	<p>&gt; Identifying Internal Triggers – Thoughts that Fuel the Stress Response</p> <p>&gt; Defining and Discussing Benefits of Mindfulness</p> <p>&gt; Reviewing the Parasympathetic Nervous System Handout</p> <p>&gt; Practicing Diaphragmatic Breathing Exercises</p>	<p>To learn about the parasympathetic nervous system</p> <p>To identify and understand how internal factors lead to stress</p> <p>To define mindfulness and examine impact of engaging in a mindfulness activity</p>	60 mins	2 SEG 3 SEG, CG
<b>3</b>	<p><b>Focus Time</b> <u>Neuroeducation Topic: Improving Brain Circuits Involved in Goal-Directed Behavior</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of the Frontal Lobe/Executive Function</p> <p>&gt; External Factors that Trigger Stress</p>	<p>&gt; Identifying External Triggers – Situations that Fuel the Stress Response</p> <p>&gt; Exploring Executive Functioning</p> <p>&gt; Developing Time Management Skills</p> <p>&gt; Identifying Ways to Improve Time</p>	<p>To understand the role of executive functioning in managing stress</p> <p>To identify and understand how external factors lead to stress</p>	60 mins	1 SEG, 2 SEG, 3 SEG, CG

	> Proactive & Reactive Responses to Stress	Management Strategies	To explore best practices for time management		
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>4</b>	<p><b>Play Time</b>  <u>Neuroeducation Topic: The Role of Creativity and Play in Generating Neuroplasticity</u></p> <p>&gt; Using Metaphor to Describe and Explore Neuroplasticity</p> <p>&gt; Engaging in Healthy Distraction</p> <p>&gt; Develop Self-soothing Strategies/Engaging in Self-care</p>	<p>&gt; Defining and Exploring Neuroplasticity</p> <p>&gt; Exploring Creative and Artistic Expression as a Coping Strategy</p> <p>&gt; Discussing Relaxation Techniques</p> <p>&gt; Coloring Mandalas Activity</p>	<p>To learn about neuroplasticity and the brain's adaptability</p> <p>To identify relaxation techniques</p> <p>To engage in a creative activity as a self-soothing coping strategy</p>	60 mins	1 SEG, 3 SEG, CG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>5</b>	<p><b>Connecting Time</b>  <u>Neuroeducation Topic: Buffering the Secretion of Stress Hormones: The Role of Social Support</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of Adrenaline and Cortisol in Chronic Stress</p> <p>&gt; Benefits of Having Social Support</p> <p>&gt; Role Plays and Case Scenarios</p>	<p>&gt; Discuss the Role of Adrenaline and Cortisol in the Stress Response</p> <p>&gt; Using "I Messages" to Strengthen Effective Communication</p> <p>&gt; Identifying and Expressing Emotions Using Feelings Wheel</p> <p>&gt; Role Playing How to Use "I Messages"</p>	<p>To explore how stress hormones impact bodily functions</p> <p>To discuss how a strong support network can buff negative effects of stress</p> <p>To identify support network and strategies to deepen those relationships</p>	60 mins	3 SEG, CG

<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>6</b>	<p><b>Physical Time</b> <u>Neuroeducation Topic:</u> <u>Promoting Brain</u> <u>Derived Neurotrophic</u> <u>Factor (BDNF)</u> <u>Through Physical</u> <u>Activity</u></p> <p>&gt; Using Metaphor to Describe and Explore BDNF and Its Impact on Mental, Emotional, and Physical Health</p> <p>&gt; Benefits of Strength Training</p> <p>&gt; Best Practices for Strength Training</p>	<p>&gt; Defining and Exploring BDNF</p> <p>&gt; Reviewing Best Practices for Strength Training</p> <p>&gt; Discussing Benefits of Exercising for MS</p> <p>&gt; Addressing Barriers to Engaging in Physical Activity</p>	<p>To learn about BDNF and its impact on brain functioning</p> <p>To discuss strategies to increase physical activity</p> <p>To identify and address barriers to engaging in physical activity</p>	60 mins	1 SEG, 3 SEG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>7</b>	<p><b>Sleep Time</b> <u>Neuroeducation Topic:</u> <u>The Impact of a Good</u> <u>Night's Sleep on</u> <u>Hippocampal Function</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of the Hippocampus in Memory Consolidation During Sleep</p> <p>&gt; Sleep Education &amp; Hygiene</p>	<p>&gt; Discussing the Role of Sleep in Hippocampal Functions</p> <p>&gt; Identifying the Benefits of Quality Sleep</p> <p>&gt; Reviewing 20 Simple Tips That May Help You Fall Asleep Quickly Handout</p>	<p>To learn about the role of sleep in memory consolidation and retrieval</p> <p>To discuss strategies to falling asleep quicker</p>	60 mins	1 SEG, 3 SEG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>8</b>	<p><b>Down Time</b> <u>Neuroeducation Topic:</u> <u>Activating the Default</u> <u>Mode Network</u></p>	<p>&gt; Learning about the Default Mode Network/Restful Wake State</p>	<p>To learn about the Default Mode Network</p>		

	<p>&gt; Using Metaphor to Describe and Explore the Default Mode Network</p> <p>&gt; Mind Wandering With and Without Intention</p> <p>&gt; Facilitating the Wakeful Rest/Task-unrelated Thought State</p> <p>&gt; Synthesizing Material from the BE WELL program</p>	<p>&gt; Engaging in a Stream of Consciousness Writing Activity</p> <p>&gt; Discussing Participation in the BE WELL program</p> <p>&gt; Completion Certificate Presentation</p>	<p>To practice a mind wandering activity</p> <p>To summarize the material covered in the BE WELL program</p> <p>To facilitate a discussion on participant's experience in the program</p>	<p>60 mins</p>	<p>1 SEG, 2 SEG, 3 SEG, CG</p>
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## Individual BE WELL Personal Wellness Plan

Yvonne

<b>Social/Emotional Goals and Action Plan</b>	
<p><b>GOAL 1:</b> To improve the ability to assess which stressful situations were controllable vs. uncontrollable.</p> <p><b>ACTION STEPS TO ATTAIN GOAL:</b></p> <ul style="list-style-type: none"> <li>• Identify and recognize triggers that lead to related to both MS-related and non-MS-related stress</li> <li>• Improve awareness of physiological and emotional responses to stress</li> <li>• Identify which stressors require her to problem-solve, which stressors require her to self-soothe, and which stressors may require a combination of the two</li> </ul> <p><b>GOAL 3:</b> Develop more adaptive coping strategies to regulate emotions and better manage stressful situations.</p> <p><b>ACTION STEPS TO ATTAIN GOAL:</b></p> <ul style="list-style-type: none"> <li>• Practice skills (e.g., problem-solving skills, using “I messages”) from BE WELL sessions</li> <li>• Identify at least one new adaptive coping strategy to implement throughout the program (see coping goal)</li> <li>• Identify which coping strategies produce favorable outcomes</li> </ul>	
<p><b>SMART COPING GOAL 1:</b> I will go to weekly exercise sessions at the gym on Tuesdays and Thursdays to lose 10 pounds in 8 weeks.</p>	
<p><b>Action Steps: How will I reach this goal?</b></p> <ol style="list-style-type: none"> <li>1. Contact transportation organization at least a week beforehand to schedule pick-up and drop-off times.</li> <li>2. Set up a visual reminder using my calendar to indicate that transportation has been scheduled</li> <li>3. Pack my workout bag the night before and place it in the chair next to the door.</li> </ol>	
What resources do I have?	What resources do I still need?
Calendar, stars (on the calendar) will be used to indicate when I have scheduled transportation for my outings to the gym.	Accountability partner
Transportation hotline	

Gym					
Equipment					
<b>How will I know when I have achieved this goal?</b> I will drop down a dress size from XL to L (14 to 12). I will be able to lift my leg up at least an 1-2 inches higher than I can right now.					
<b>SMART COPING GOAL 2:</b> I will feel less stressed when I have more floor space and storage space in my home. I will achieve this by removing at least half of my items from my closets and storage containers.					
<b>Action Steps: How will I reach this goal?</b>					
1. Develop donate/sell/ and keep piles as I organize					
2. Carefully evaluate each item					
3. Find others to help with the decluttering process					
<b>What resources do I have?</b>			<b>What resources do I still need?</b>		
Bins/boxes/bags			Participant could not think of anything at the time.		
Thrift stores (Let Go, Offer Up)					
Family members					
<b>How will I know when I have achieved this goal?</b> I will go from 19 storage bins to seven at the most and half of my total closet space will be free and clear of items. I will feel productive, happier, and more organized.					
<b>Yvonne's Customized Intervention</b>					
<b>Sess ion</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Durati on</b>	<b>Goals</b>
<b>1</b>	<b>Understanding Stress and Identifying the Coping Self:</b> <u>Neuroeducation Topic: Understanding the Activation of the Sympathetic (Fight or Flight) Response</u>  > Rapport Building	> Reviewing BE WELL assessment results  > Establishing Goals  > Defining Stress and Identifying Physiological	To develop customized intervention framework for subsequent sessions  To understand the four components		1 SEG

	<ul style="list-style-type: none"> <li>&gt; Structure of the BE WELL program</li> <li>&gt; Goal Setting</li> <li>&gt; Defining Stress and Coping Flexibility</li> <li>&gt; Differentiating Between Evaluation and Adaptive Coping</li> <li>&gt; Wellness Education</li> </ul>	<p>Responses to Stress (Fight/Flight/Freeze)</p> <ul style="list-style-type: none"> <li>&gt; Reviewing the Sympathetic Nervous System Handout</li> <li>&gt; Discussing Components of the Coping Self</li> <li>&gt; Discussing Impact of Stress on MS and Mental/Emotional Health</li> <li>&gt; Review Coping Flexibility Profile</li> </ul>	<p>of the Coping Self</p> <p>To examine the coping profile and identify triggers that lead to stress response</p> <p>To learn the neurophysiological effects of stress</p>	75 mins	2 SEG, 1 CG 2 CG
<b>Session</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duration</b>	<b>Goals</b>
2	<p><b>Time In Neuroeducation Topic:</b> <u>Engaging the Parasympathetic (Relaxation Response) System</u></p> <ul style="list-style-type: none"> <li>&gt; Increase Awareness of Mind-Body Connection</li> <li>&gt; Internal Factors that Trigger Stress</li> <li>&gt; Using Metaphor to Describe and Explore the Autonomic Body Functions</li> <li>&gt; Explore Mindfulness Techniques and Emotion Regulation Strategies</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Identifying Internal Triggers – Thoughts that Fuel the Stress Response</li> <li>&gt; Defining and Discussing Benefits of Mindfulness</li> <li>&gt; Reviewing the Parasympathetic Nervous System Handout</li> <li>&gt; Engaging in a Progressive Muscle Relaxation Exercise</li> </ul>	<p>To learn about the parasympathetic nervous system</p> <p>To identify and understand how internal factors lead to stress</p> <p>To define mindfulness and examine impact of engaging in a mindfulness activity</p>	60 mins	1 SEG, 2CG

<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>3</b>	<p><b>Focus Time</b>  <u>Neuroeducation Topic:</u>  <u>Improving Brain</u>  <u>Circuits Involved in</u>  <u>Goal-Directed</u>  <u>Behavior</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of the Frontal Lobe/Executive Function</p> <p>&gt; External Factors that Trigger Stress</p> <p>&gt; Proactive &amp; Reactive Responses to Stress</p>	<p>&gt; Identifying External Triggers – Situations that Fuel the Stress Response</p> <p>&gt; Exploring Executive Functioning</p> <p>&gt; Reviewing Problem-Solving Techniques for Stress Management Handout</p>	<p>To understand the role of executive functioning in managing stress</p> <p>To identify and understand how external factors lead to stress</p> <p>To explore how to use a problem solving approach to manage controllable stressors</p>	60 mins	1 SEG, 2 SEG, 1 CG, 2 CG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>4</b>	<p><b>Play Time</b>  <u>Neuroeducation Topic:</u>  <u>The Role of Creativity</u>  <u>and Play in Generating</u>  <u>Neuroplasticity</u></p> <p>&gt; Using Metaphor to Describe and Explore Neuroplasticity</p> <p>&gt; Engaging in Healthy Distraction</p> <p>&gt; Develop Self-soothing Strategies/Engaging in Self-care</p>	<p>&gt; Defining and Exploring Neuroplasticity</p> <p>&gt; Exploring Creative and Artistic Expression as a Coping Strategy</p> <p>&gt; Discussing Relaxation Techniques</p> <p>&gt; Engaging in Tactile Sensory Play with Aromatherapy Dough</p>	<p>To learn about neuroplasticity and the brain's adaptability</p> <p>To identify relaxation techniques</p> <p>To engage in a creative activity as a self-soothing coping strategy</p>	60 mins	1 SEG, 2 SEG,
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>

5	<p><b>Connecting Time</b>  <u>Neuroeducation Topic:</u>  <u>Buffering the Secretion of Stress Hormones:</u>  <u>The Role of Social Support</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of Adrenaline and Cortisol in Chronic Stress</p> <p>&gt; Benefits of Having Social Support</p> <p>&gt; Role Plays and Case Scenarios</p>	<p>&gt; Discuss the Role of Adrenaline and Cortisol in the Stress Response</p> <p>&gt; Identifying Social Support Network</p> <p>&gt; Identifying and Expressing Emotions Using Feelings Wheel</p> <p>&gt; Role Playing Scenarios Where Expressing Emotions is Needed</p>	<p>To explore how stress hormones impact bodily functions</p> <p>To discuss how a strong support network can buff negative effects of stress</p> <p>To identify support network and strategies to deepen those relationships</p>	60 mins	1 SEG, 2 SEG, 2 CG
Session	Domains/Content	Tasks and Activities	Purpose and Rationale	Duration	Goals
6	<p><b>Physical Time</b>  <u>Neuroeducation Topic:</u>  <u>Promoting Brain Derived Neurotrophic Factor (BDNF) Through Physical Activity</u></p> <p>&gt; Using Metaphor to Describe and Explore BDNF and Its Impact on Mental, Emotional, and Physical Health</p> <p>&gt; Benefits of Strength Training</p> <p>&gt; Best Practices for Strength Training</p>	<p>&gt; Defining and Exploring BDNF</p> <p>&gt; Reviewing Best Practices for Strength Training</p> <p>&gt; Discussing Benefits of Exercising for MS</p> <p>&gt; Addressing Barriers to Engaging in Physical Activity</p>	<p>To learn about BDNF and its impact on brain functioning</p> <p>To discuss strategies to increase physical activity</p> <p>To identify and address barriers to engaging in physical activity</p>	60 mins	1 SEG, 1 CG
Session	Domains/Content	Tasks and Activities	Purpose and Rationale	Duration	Goals
7	<p><b>Sleep Time</b>  <u>Neuroeducation Topic:</u>  <u>The Impact of a Good</u></p>	<p>&gt; Discussing the Role of Sleep in</p>	<p>To learn about the role of sleep in</p>		

	<u>Night's Sleep on Hippocampal Function</u> > Using Metaphor to Describe and Explore the Role of the Hippocampus in Memory Consolidation During Sleep > Sleep Education & Hygiene	Hippocampal Functions > Identifying the Benefits of Quality Sleep > Reviewing Developing a Good Sleep Hygiene Handout	memory consolidation and retrieval To discuss strategies to develop a good sleep hygiene and routine	60 mins	1 SEG
<b>Session</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duration</b>	<b>Goals</b>
<b>8</b>	<b>Down Time</b> <u>Neuroeducation Topic: Activating the Default Mode Network</u> > Using Metaphor to Describe and Explore the Default Mode Network > Mind Wandering With and Without Intention > Facilitating the Wakeful Rest/Task-unrelated Thought State > Synthesizing Material from the BE WELL program	> Learning about the Default Mode Network/Restful Wake State > Engaging in a Mental Vacation – Visualization Exercise > Discussing Participation in the BE WELL program > Completion Certificate Presentation	To learn about the Default Mode Network To practice a mind wandering activity To summarize the material covered in the BE WELL program To facilitate a discussion on participant's experience in the program	60 mins	1 SEG, 2 SEG, 2 CG

# Individual BE WELL Personal Wellness Plan

Chelsea

## Social/Emotional Goals and Action Plan

**GOAL 1:** To recognize when coping strategies produce unfavorable results.

**ACTION STEPS TO ATTAIN GOAL:**

- Identify emotional and physiological responses to stress
- Identify which stressors require her to problem-solve, which stressors require her to self-soothe, and which stressors may require a combination of the two
- Become more awareness of her thoughts and emotions after engaging in a coping activity

**GOAL 2:** To reduce alcohol consumption.

**ACTION STEPS TO ATTAIN GOAL:**

- Identify internal and external triggers (e.g., when she feels overwhelmed) that lead her drink alcohol excessively.
- Prioritize herself more by establishing more boundaries with others
- Seek out opportunities to get more support with caregiving.
- Monitor drinking habits.

**GOAL 3:** Develop more adaptive coping strategies to regulate emotions and better manage stressful situations.

**ACTION STEPS TO ATTAIN GOAL:**

- Practice skills (e.g., conflict resolution, mindfulness-based stress reduction techniques) from BE WELL sessions
- Identify at least one new adaptive coping strategy to implement throughout the program (see coping goal)
- Identify which coping strategies produce favorable outcomes

**SMART COPING GOAL:** I will get seven hours of sleep 3-4 times each week by developing a sleep hygiene.

**Action Steps: How will I reach this goal?**

1. Exercise/walk outside for at least 30 mins every day.
2. Drink hot tea before bedtime.
3. Develop and stick to a nighttime routine.
4. Try a guided bedtime meditation.
5. Try diagrammatic breathing exercises.

What resources do I have?	What resources do I still need?
Tea	Participant could not think of anything at the time.
Balloon (to use for breathing exercises)	
Phone/electronics (for guided meditation)	
<b>How will I know when I have achieved this goal?</b> I will feel more rested and be able to focus more and complete a task from start to finish. I will have slept at least 3-4 nights out of the week.	

### Chelsea's Customized Intervention

Sess ion	Domains/Content	Tasks and Activities	Purpose and Rationale	Durati on	Goals
<b>1</b>	<p><b>Understanding Stress and Identifying the Coping Self:</b>  <u>Neuroeducation Topic: Understanding the Activation of the Sympathetic (Fight or Flight) Response</u></p> <ul style="list-style-type: none"> <li>&gt; Rapport Building</li> <li>&gt; Structure of the BE WELL program</li> <li>&gt; Goal Setting</li> <li>&gt; Defining Stress and Coping Flexibility</li> <li>&gt; Differentiating Between Evaluation and Adaptive Coping</li> <li>&gt; Wellness Education</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Reviewing BE WELL assessment results</li> <li>&gt; Establishing Goals</li> <li>&gt; Defining Stress and Identifying Physiological Responses to Stress (Fight/Flight/Freeze)</li> <li>&gt; Reviewing the Sympathetic Nervous System Handout</li> <li>&gt; Discussing Components of the Coping Self</li> <li>&gt; Discussing Impact of Stress on MS and Mental/Emotional Health</li> <li>&gt; Review Coping Flexibility Profile</li> </ul>	<p>To develop customized intervention framework for subsequent sessions</p> <p>To understand the four components of the Coping Self</p> <p>To examine the coping profile and identify triggers that lead to stress response</p> <p>To learn the neurophysiological effects of stress</p>	75 mins	1 SEG, 2 SEG, 3 SEG, CG

<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>2</b>	<p><b>Time In</b> <u>Neuroeducation Topic:</u> <u>Engaging the</u> <u>Parasympathetic</u> <u>(Relaxation Response)</u> <u>System</u></p> <p>&gt; Increase Awareness of Mind-Body Connection</p> <p>&gt;Internal Factors that Trigger Stress</p> <p>&gt; Using Metaphor to Describe and Explore the Autonomic Body Functions</p> <p>&gt; Explore Mindfulness Techniques and Emotion Regulation Strategies</p>	<p>&gt; Identifying Internal Triggers – Thoughts that Fuel the Stress Response</p> <p>&gt; Defining and Discussing Benefits of Mindfulness</p> <p>&gt; Reviewing the Parasympathetic Nervous System Handout</p> <p>&gt; Engaging in a Body Scan Exercise</p>	<p>To learn about the parasympathetic nervous system</p> <p>To identify and understand how internal factors lead to stress</p> <p>To define mindfulness and examine impact of engaging in a mindfulness activity</p>	60 mins	1 SEG, 2 SEG, 3 SEG, CG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>3</b>	<p><b>Focus Time</b> <u>Neuroeducation Topic:</u> <u>Improving Brain</u> <u>Circuits Involved in</u> <u>Goal-Directed</u> <u>Behavior</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of the Frontal Lobe/Executive Function</p> <p>&gt; External Factors that Trigger Stress</p> <p>&gt; Proactive &amp; Reactive Responses to Stress</p>	<p>&gt; Identifying External Triggers – Situations that Fuel the Stress Response</p> <p>&gt; Exploring Executive Functioning</p> <p>&gt; Reviewing Conflict Resolution Strategies Handout</p>	<p>To understand the role of executive functioning in managing stress</p> <p>To identify and understand how external factors lead to stress</p> <p>To explore how to improve conflict</p>	60 mins	1 SEG, 2 SEG, CG

<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
			resolution to manage controllable stressors		
<b>4</b>	<p><b>Play Time</b> <u>Neuroeducation Topic: The Role of Creativity and Play in Generating Neuroplasticity</u></p> <p>&gt; Using Metaphor to Describe and Explore Neuroplasticity</p> <p>&gt; Engaging in Healthy Distraction</p> <p>&gt; Develop Self-soothing Strategies/Engaging in Self-care</p>	<p>&gt; Defining and Exploring Neuroplasticity</p> <p>&gt; Exploring Creative and Artistic Expression as a Coping Strategy</p> <p>&gt; Discussing Relaxation Techniques</p> <p>&gt; Engaging a Creative Expression Exercise – Writing Poetry</p>	<p>To learn about neuroplasticity and the brain’s adaptability</p> <p>To identify relaxation techniques</p> <p>To engage in a creative activity as a self-soothing coping strategy</p>	60 mins	1 SEG, 3 SEG, CG
<b>5</b>	<p><b>Connecting Time</b> <u>Neuroeducation Topic: Buffering the Secretion of Stress Hormones: The Role of Social Support</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of Adrenaline and Cortisol in Chronic Stress</p> <p>&gt; Benefits of Having Social Support</p> <p>&gt;Role Plays and Case Scenarios</p>	<p>&gt; Discuss the Role of Adrenaline and Cortisol in the Stress Response</p> <p>&gt; Identifying Social Support Network</p> <p>&gt; Identifying and Expressing Emotions Using Feelings Wheel</p> <p>&gt; Role Playing Scenarios where Support is Needed</p>	<p>To explore how stress hormones impact bodily functions</p> <p>To discuss how a strong support network can buff negative effects of stress</p> <p>To identify support network and strategies to deepen those relationships</p>	60 mins	1 SEG, 2 SEG, 3 SEG, CG

<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>6</b>	<p><b>Physical Time</b> <u>Neuroeducation Topic:</u> <u>Promoting Brain</u> <u>Derived Neurotrophic</u> <u>Factor (BDNF)</u> <u>Through Physical</u> <u>Activity</u></p> <p>&gt; Using Metaphor to Describe and Explore BDNF and Its Impact on Mental, Emotional, and Physical Health</p> <p>&gt; Benefits of Strength Training</p> <p>&gt; Best Practices for Strength Training</p>	<p>&gt; Defining and Exploring BDNF</p> <p>&gt; Reviewing Best Practices for Strength Training</p> <p>&gt; Discussing Benefits of Exercising for MS</p> <p>&gt; Addressing Barriers to Engaging in Physical Activity</p>	<p>To learn about BDNF and its impact on brain functioning</p> <p>To discuss strategies to increase physical activity</p> <p>To identify and address barriers to engaging in physical activity</p>	60 mins	1 SEG, 3 SEG CG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>7</b>	<p><b>Sleep Time</b> <u>Neuroeducation Topic:</u> <u>The Impact of a Good</u> <u>Night's Sleep on</u> <u>Hippocampal Function</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of the Hippocampus in Memory Consolidation During Sleep</p> <p>&gt; Sleep Education &amp; Hygiene</p>	<p>&gt; Discussing the Role of Sleep in Hippocampal Functions</p> <p>&gt; Identifying the Benefits of Quality Sleep</p> <p>&gt; Reviewing Developing a Good Sleep Hygiene Handout</p>	<p>To learn about the role of sleep in memory consolidation and retrieval</p> <p>To discuss strategies to develop a good sleep hygiene and routine</p>	60 mins	1 SEG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>8</b>	<p><b>Down Time</b> <u>Neuroeducation Topic:</u> <u>Activating the Default</u> <u>Mode Network</u></p>	<p>&gt; Learning about the Default Mode Network/Restful Wake State</p>	<p>To learn about the Default Mode Network</p>		

	<p>&gt; Using Metaphor to Describe and Explore the Default Mode Network</p> <p>&gt; Mind Wandering With and Without Intention</p> <p>&gt; Facilitating the Wakeful Rest/Task-unrelated Thought State</p> <p>&gt; Synthesizing Material from the BE WELL program</p>	<p>&gt; Engaging in a Mental Vacation – Visualization Exercise</p> <p>&gt; Discussing Participation in the BE WELL program</p> <p>&gt; Completion Certificate Presentation</p>	<p>To practice a mind wandering activity</p> <p>To summarize the material covered in the BE WELL program</p> <p>To facilitate a discussion on participant’s experience in the program</p>	<p>60 mins</p>	<p>1 SEG, 2 SEG, 3 SEG, CG</p>
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# Individual BE WELL Wellness Plan

Tonya

<b>Social/Emotional Goals and Action Plan</b>
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**GOAL 1:** To reduce cognitive distortions, specifically “all-or-nothing” thinking patterns.

**ACTION STEPS TO ATTAIN GOAL:**

- Examine evidence related to thoughts more objectively
- Engage in cost-benefit analysis to determine the advantages and disadvantages of feelings, thoughts, and behaviors attached to the cognitive distortions
- Utilize cognitive restructure to reframe negative self-talk

**GOAL 2:** To recognize when coping efforts produce unfavorable results

**ACTION STEPS TO ATTAIN GOAL:**

- Identify emotional and physiological responses to stress
- Identify which stressors require her to problem-solve, which stressors require her to self-soothe, and which stressors may require a combination of the two
- Become more awareness of her thoughts and emotions after engaging in a coping activity

**GOAL 3:** Develop more adaptive coping strategies to regulate emotions and better manage stressful situations.

**ACTION STEPS TO ATTAIN GOAL:**

- Practice skills (e.g., problem-solving, coloring mandalas) from BE WELL sessions
- Identify at least one new adaptive coping strategy to implement throughout the program (see coping goal)
- Identify which coping strategies produce favorable outcomes

**SMART COPING GOAL:** I will walk for 20 minutes one day a week (on Saturdays).

**Action Steps: How will I reach this goal?**

1. Keep sneakers by the door.
2. Set a timer/alarm on my phone.
3. Make sure to have workout gear available.

What resources do I have?	What resources do I still need?
Sneakers	Participant could not think of anything at the time.
Phone	
Workout clothes	
Area to walk in (the neighborhood).	

**How will I know when I have achieved this goal?** I will feel more rested and be able to focus more and complete a task from start to finish. I will have slept at least 3-4 nights out of the week.

**Tonya’s Customized Intervention**

<b>Sess ion</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Durati on</b>	<b>Goals</b>
<b>1</b>	<p><b>Understanding Stress and Identifying the Coping Self:</b>  <u>Neuroeducation Topic:</u>  <u>Understanding the Activation of the Sympathetic (Fight or Flight) Response</u></p> <ul style="list-style-type: none"> <li>&gt; Rapport Building</li> <li>&gt; Structure of the BE WELL program</li> <li>&gt; Goal Setting</li> <li>&gt; Defining Stress and Coping Flexibility</li> <li>&gt; Differentiating Between Evaluation and Adaptive Coping</li> <li>&gt; Wellness Education</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Reviewing BE WELL assessment results</li> <li>&gt; Establishing Goals</li> <li>&gt; Defining Stress and Identifying Physiological Responses to Stress (Fight/Flight/Freeze)</li> <li>&gt; Reviewing the Sympathetic Nervous System Handout</li> <li>&gt; Discussing Components of the Coping Self</li> <li>&gt; Discussing Impact of Stress on MS and Mental/Emotional Health</li> <li>&gt; Review Coping Flexibility Profile</li> </ul>	<p>To develop customized intervention framework for subsequent sessions</p> <p>To understand the four components of the Coping Self</p> <p>To examine the coping profile and identify triggers that lead to stress response</p> <p>To learn the neurophysiological effects of stress</p>	75 mins	1 SEG, 2 SEG, 3 SEG, CG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>2</b>	<p><b>Time In</b>  <u>Neuroeducation Topic:</u>  <u>Engaging the Parasympathetic</u></p>	<ul style="list-style-type: none"> <li>&gt; Identifying Internal Triggers – Thoughts that Fuel the Stress Response</li> </ul>	To learn about the parasympathetic nervous system		

	<p><u>(Relaxation Response) System</u></p> <p>&gt; Increase Awareness of Mind-Body Connection</p> <p>&gt; Internal Factors that Trigger Stress</p> <p>&gt; Using Metaphor to Describe and Explore the Autonomic Body Functions</p> <p>&gt; Explore Mindfulness Techniques and Emotion Regulation Strategies</p>	<p>&gt; Defining and Discussing Benefits of Mindfulness</p> <p>&gt; Reviewing the Parasympathetic Nervous System Handout</p> <p>&gt; Engaging in a Mindfulness Meditation Exercise</p>	<p>To identify and understand how internal factors lead to stress</p> <p>To define mindfulness and examine impact of engaging in a mindfulness activity</p>	60 mins	1 SEG, 2 SEG, 3 SEG, CG
<b>Session</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duration</b>	<b>Goals</b>
<b>3</b>	<p><b>Focus Time</b></p> <p><u>Neuroeducation Topic: Improving Brain Circuits Involved in Goal-Directed Behavior</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of the Frontal Lobe/Executive Function</p> <p>&gt; External Factors that Trigger Stress</p> <p>&gt; Proactive &amp; Reactive Responses to Stress</p>	<p>&gt; Identifying External Triggers – Situations that Fuel the Stress Response</p> <p>&gt; Exploring Executive Functioning</p> <p>&gt; Reviewing Problem-Solving Techniques for Stress Management Handout</p>	<p>To understand the role of executive functioning in managing stress</p> <p>To identify and understand how external factors lead to stress</p> <p>To explore how to use a problem - solving approach to manage controllable stressors</p>	60 mins	1 SEG, 2 SEG, 3 SEG CG

<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>4</b>	<p><b>Play Time</b> <u>Neuroeducation Topic:</u> <u>The Role of Creativity and Play in Generating Neuroplasticity</u></p> <p>&gt; Using Metaphor to Describe and Explore Neuroplasticity</p> <p>&gt; Engaging in Healthy Distraction</p> <p>&gt; Develop Self-soothing Strategies/Engaging in Self-care</p>	<p>&gt; Defining and Exploring Neuroplasticity</p> <p>&gt; Exploring Creative and Artistic Expression as a Coping Strategy</p> <p>&gt; Discussing Relaxation Techniques</p> <p>&gt; Coloring Mandalas Activity</p>	<p>To learn about neuroplasticity and the brain's adaptability</p> <p>To identify relaxation techniques</p> <p>To engage in a creative activity as a self-soothing coping strategy</p>	60 mins	2 SEG, 3 SEG, CG
<b>5</b>	<p><b>Connecting Time</b> <u>Neuroeducation Topic:</u> <u>Buffering the Secretion of Stress Hormones: The Role of Social Support</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of Adrenaline and Cortisol in Chronic Stress</p> <p>&gt; Benefits of Having Social Support</p> <p>&gt;Role Plays and Case Scenarios</p>	<p>&gt; Discuss the Role of Adrenaline and Cortisol in the Stress Response</p> <p>&gt; Identifying Social Support Network</p> <p>&gt; Using "I Messages" to Strengthen Effective Communication</p> <p>&gt; Identifying and Expressing Emotions Using Feelings Wheel</p> <p>&gt; Role Playing How to Use "I Messages"</p>	<p>To explore how stress hormones impact bodily functions</p> <p>To discuss how a strong support network can buff negative effects of stress</p> <p>To identify support network and strategies to deepen those relationships</p>	60 mins	1 SEG, 2 SEG, 3 SEG, CG
<b>Sessi on</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duratio n</b>	<b>Goals</b>
<b>6</b>	<b>Physical Time</b>	> Defining and Exploring BDNF	To learn about BDNF and its		

	<p><u>Neuroeducation Topic: Promoting Brain Derived Neurotrophic Factor (BDNF) Through Physical Activity</u></p> <p>&gt; Using Metaphor to Describe and Explore BDNF and Its Impact on Mental, Emotional, and Physical Health</p> <p>&gt; Benefits of Strength Training</p> <p>&gt; Best Practices for Strength Training</p>	<p>&gt; Reviewing Best Practices for Strength Training</p> <p>&gt; Discussing Benefits of Exercising for MS</p> <p>&gt; Addressing Barriers to Engaging in Physical Activity</p>	<p>impact on brain functioning</p> <p>To discuss strategies to increase physical activity</p> <p>To identify and address barriers to engaging in physical activity</p>	60 mins	2 SEG, 3 SEG CG
<b>Session</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duration</b>	<b>Goals</b>
<b>7</b>	<p><b>Sleep Time</b></p> <p><u>Neuroeducation Topic: The Impact of a Good Night's Sleep on Hippocampal Function</u></p> <p>&gt; Using Metaphor to Describe and Explore the Role of the Hippocampus in Memory Consolidation During Sleep</p> <p>&gt; Sleep Education &amp; Hygiene</p>	<p>&gt; Discussing the Role of Sleep in Hippocampal Functions</p> <p>&gt; Identifying the Benefits of Quality Sleep</p> <p>&gt; Reviewing 20 Simple Tips That May Help You Fall Asleep Quickly Handout</p>	<p>To learn about the role of sleep in memory consolidation and retrieval</p> <p>To discuss strategies that may help one fall asleep quicker</p>	60 mins	1 SEG, 2 SEG, CG
<b>Session</b>	<b>Domains/Content</b>	<b>Tasks and Activities</b>	<b>Purpose and Rationale</b>	<b>Duration</b>	<b>Goals</b>
<b>8</b>	<p><b>Down Time</b></p> <p><u>Neuroeducation Topic: Activating the Default Mode Network</u></p> <p>&gt; Using Metaphor to Describe and Explore</p>	<p>&gt; Learning about the Default Mode Network/Restful Wake State</p> <p>&gt; Engaging in a Mental Vacation –</p>	<p>To learn about the Default Mode Network</p> <p>To practice a mind</p>		1 SEG,

	<p>the Default Mode Network</p> <p>&gt; Mind Wandering With and Without Intention</p> <p>&gt; Facilitating the Wakeful Rest/Task-unrelated Thought State</p> <p>&gt; Synthesizing Material from the BE WELL program</p>	<p>Visualization Exercise</p> <p>&gt; Discussing Participation in the BE WELL program</p> <p>&gt; Completion Certificate Presentation</p>	<p>wandering activity</p> <p>To summarize the material covered in the BE WELL program</p> <p>To facilitate a discussion on participant's experience in the program</p>	<p>60 mins</p>	<p>2 SEG, 3 SEG, CG</p>
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## Appendix H: Recruitment Materials

### Recruitment Materials

# **BE WELL: A Brain-based Education and Wellness Program for African American Women Living with Multiple Sclerosis**

*Be part of an important study exploring wellness for African American women with MS!*

- Are you an African American woman?
- Are you 18 years of age or older?
- Have you been diagnosed with multiple sclerosis (MS) at least one month ago?
- Are you interested in learning more about wellness and coping with MS?
- Are you interested in learning more about brain health?

If you answered YES to these questions, you may be eligible to participate in a research study.

The purpose of this research study is to assess the effect of a wellness program on coping strategies of African American women with MS. The program focuses on coping skills and providing brain health information. Participants will receive a \$30 gift card for participating.



This study is being conducted through North Carolina State University.

**The primary contact for this study is Whitney McLaughlin. Please contact her at (910) 528-7480 or [wgmclaug@ncsu.edu](mailto:wgmclaug@ncsu.edu) for more information.**

**Research Title:** The Effects of Customized Psychoeducation-based Neurocounseling Interventions on the Coping Flexibility of African American Women with Multiple Sclerosis

**Principal Investigator:** Whitney McLaughlin, MA, LPCA, NCC

**Faculty Sponsor (if applicable):** Dr. Stanley Baker, LPC

## **Oral Recruitment Script for Counselor/Investigator**

### **Meeting with Participant**

#### **Talking Points**

##### **Introduction:**

Hello, my name is Whitney McLaughlin and I am a counselor and doctoral candidate at North Carolina State University.

Thank you for your willingness to learn more about my research. You are being asked to take part in a study pertaining to wellness, more specifically coping skills and understanding more about brain health. You were invited to participate based off your interest in learning more about the study. I truly appreciate your willingness to learn more about my research on the importance of coping among African American women living with MS.

I would like to begin by sharing with you a little about my background and interest, information about the study itself, and then end by answering any questions that you may have. Feel free to stop me at any time if you have a question or need clarification on something.

##### **About Me**

- **My educational background**

The counselor/investigator is currently enrolled in a counseling and counselor education doctoral program at NC State University. This study is a part of my requirement toward completing my doctoral degree at North Carolina State University. She is the principal investigator who developed the BE WELL intervention program and will collect and analyze the data. She holds a Bachelor of Arts degree in Sociology and a Master of Arts degree in Clinical Mental Health Counseling. She is a Licensed Professional Counselor Associate, a Board-Certified Counselor.

- **My interest in wellness as it relates to healthy coping**

She has conducted research and published articles on self-care and stress management. She also developed a neuroeducation activity that was included in a recent publication on integrating neuroscience into counseling practice (Miller & Beeson, in press).

- **My counseling experience \***

The principal investigator has professional experiences in the areas of education, career, mental health, and substance abuse counseling and has over 10 years of

experience working in the education, residential, hospital, and private practice settings with diverse clients and communities.

\* Although the principal investigator is a clinical therapist by training, in this context she is a researcher that is providing wellness guidance rather than therapy. Therefore, throughout the course of the study she will present herself as a wellness researcher rather than a clinical mental health counselor. In this role, she is not bound to the same level of confidentiality regarding HIPAA data.

- **My community involvement and counseling experience with people living with MS**

The counselor/investigator has become dedicated to integrating neuroscience into counseling practice to help clients explore the brain-body connection and be empowered to improve their neurological, psychological, and emotional health. She has worked with people with MS on overcoming barriers related to their social, emotional, and career development needs. She has been involved with the MS Society, specifically, Greater Carolinas chapter for two years. In addition to being an MS Ambassador and support group facilitator for family members of people with MS, she delivered the keynote address for the 2018 annual African American MS Conference where she highlighted mood changes in MS.

- Questions?

### **About the Study**

- The purpose of the study - is to help participants learn how to increase flexibility in coping strategies to manage stress and regulate emotions in healthy ways.
- The layout of the study – review the timeline and bullet points on the consent forms for first two-weeks, eight-weeks of sessions (intervention), and last two-weeks
- Share information about the Coping Flexibility Scale and how they will be taken electronically via a provided link or by using a hard copy (if needed).
- Explain confidentiality and the assignment of pseudonyms that will only be known to the participant and the investigator.
- Explain how the ATT will be administered following the intervention. Tell them they will have not put any identifying information on the form except for their assigned pseudonym.
- Review the time commitment of the study – for the first two weeks it will be about 15 minutes in total.
- Skills addressed will be designed specifically for the participant based on identified needs.

- Questions

### **Voluntary Consent**

- Participation in this study is completely voluntary. You have the right to be a part of this study, to choose not to participate or to stop participating at any time without penalty. You will not be required to answer any questions you believe are risky and/or makes you feel uncomfortable. You do not have to participate in any session and are free to withdraw from the study at any point in time without penalty.
- Questions?

### **Risks**

- There is a risk that you may not improve the ability to monitor your coping behaviors and effectively cope with stress as stressful situations are brought to the forefront. Note: Over a short amount of time, this hypersensitivity to stress should subside. There may also be other possible side effects of participating in this wellness program that is not yet known. As a Licensed Professional Counselor Associate, these are the measures I am taking to mitigate those risks I am only focusing on coping from a wellness-based perspective and not focusing on chronic disease management. Wellness counseling emphasizes mental health as well as healthy social and emotional development. As a result, the likelihood of the risk occurring is low and the magnitude of harm that could come to you is minimal.
- There is a risk the intervention will not work, and flexibility in your coping will not improve. If this is the case, then I will meet with you to provide resources for additional assistance. I will take all the necessary precautions to make sure that you feel comfortable during the intervention. As this intervention will be personalized, you and I will work closely to meet your desired goals and make sure that they are attainable. In the event more clinical-based counseling is needed, I will meet with you and share the Community Resources List and help with the referral process to contact a mental health provider for services.
- Sharing information about coping with a chronic disease like MS and other stressors may stimulate some emotional distress. In order to minimize any potential discomfort, support will be given in the following ways: (a) you may elect to withdraw from the study at any point in time; (b) at the start of each session, I will do a check-in and assess your level of comfort in participating; (c) you will have the option to postpone and reschedule sessions for any reason; and (e) following the intervention, I will allow you to have some time for reflection.
- Some of the activities you may be asked to complete involve normal exercise, strength training and yoga. Other activities you will be asked to complete involve normal reflection and tips used for wellness.
- You may be asked to participate in an activity where aromatherapy-infused dough will be used. The dough has notes of lavender in it and it contains wheat. The company that makes the dough encourages individuals who may have sensitivity to wheat to use the

dough with caution. However, to prevent a possible allergic reaction from occurring I will select another activity for that session if you have a sensitivity or are allergic to wheat or lavender.

- Questions?

### **Benefits**

- Potential direct benefits to be gained by your participation is that you will gain a better understanding of the stressors you experience, how stress impacts your mental and emotional health, and how your coping efforts can support your brain health and functioning. It is anticipated that you will gain a better understanding of how to increase flexibility in coping and engage in effective coping strategies to better manage stress and regulate emotions that may generate from stressful situations. It is also anticipated that you will gain more knowledge related to your brain health and functioning. You may also learn skills to improve communication in your relationships. The coping skills and brain-based education will provide information that you can choose to take with you and continue to use.
- Questions?

### **Confidentiality**

- The information in the study including assessments and notes will be kept confidential to the full extent allowed by law and in accordance with ethical guidelines for counselors provided by the American Counseling Association. Data will be kept in a password-protected, encrypted file on a VPN (virtual private network) on the researcher's password-protected computer in a locked location when not in use. No reference will be made in oral or written reports which could link you to the study. Your name will not be shared on any final written reports.
- For this study, please note there are some limits to confidentiality. If at any point during the study, I become concerned that a participant is hurting or about to hurt herself or someone else, I am required to report this information to proper authorities.
- Questions?

### **Compensation**

- For participating in this study, you will receive a \$30 gift card at the end of the interview. If you miss your weekly session, there will be a makeup session provided within 7 days of the missed session. Due to the time frame of the research study, if the make-up session does not occur within one week, then you will no longer be eligible to participate. If you do not complete the entire study the gift card will be pro-rated based on the time that you participated in the study.
- Questions?

### **Your Rights**

- If you have questions at any time about the study or the procedures, you may contact the counselor/investigator, Whitney McLaughlin.
- If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact the NC State IRB office via email at [irb-director@ncsu.edu](mailto:irb-director@ncsu.edu).
- Questions?

*If you are interested in participating, I have the consent form available. If you would like to think it over and get back with me, here is my card. I will need to know by (Insert date) if you are interested. Thank you for your time and I hope to work with you soon.*