

THE FEASIBILITY OF A PATIENT INFORMED, RACIALLY  
TARGETED HOME-BASED EXERCISE PROGRAM FOR  
BLACK INDIVIDUALS WITH MULTIPLE SCLEROSIS

BY

DOMINIQUE LYNN KINNETT-HOPKINS

DISSERTATION

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Doctoral Committee:

Professor Steven Petruzzello, Chair  
Professor Robert W. Motl, Director of Research, University of Alabama Birmingham  
Assistant Professor Lara A. Pilutti  
Associate Professor Mark Aber

## **Abstract**

**Background:** There has been increasing interest in the occurrence and expression of multiple sclerosis (MS) in minority populations, particularly in black individuals. Black individuals with MS may experience a more aggressive disease course, have a poorer prognosis with disease modifying therapies and have increased odds of physical comorbidities than their white counterparts. There is substantial evidence that suggests exercise training to be a promising approach for managing the manifestations of MS. However, much of this research has been conducted in white individuals. Further, black individuals with MS report lower levels of physical activity compared to white individuals with MS. A randomized controlled trial examining the feasibility of a targeted exercise training program in black individuals with MS is warranted.

**Objective:** The aim of the present study was to assess program feasibility of a three-month, home-based, racially targeted, exercise training program in the four domains of process (e.g., recruitment and retention), recourses (e.g., communication and monetary costs), management (e.g., of data management and safety reporting), and scientific outcomes (e.g., safety, burden, compliance, experience, and treatment effect) in black individuals with MS.

**Methods:** This study recruited 32 black individuals with mild-to-moderate MS related disability to participate in an exercise program. Participants completed a battery of questionnaires assessing demographic and clinical characteristics, and physical activity levels immediately prior to and following the program. Participants received a 3-month, home-based exercise program (i.e., resistance and aerobic training) which contained exercise equipment, a manual, and a log-book. Additionally, participants received periodic newsletters which emphasized social cognitive

theory principles for behavior change, and phone calls with a behavioral coach who provided motivation and social accountability.

**Results:** Results indicated that this exercise program was feasible, safe, and well received via data analysis and formative evaluation. Moreover, 24 participants completed post-assessment (75%; two dropped out, six did not return follow up assessments). The exercise program cost a total of \$3,726.57 (personnel costs = \$2128.74 USD, \$20.87 USD per/hour; exercise program costs = \$1,597.83 USD, mean cost per person = \$46.93). Total time spent administrating the program was 102 hours. Participants complied with 70% of all exercise sessions via self-reported exercise logs. There was a significant increase ( $t=-5.1$ ,  $p <.001$ ,  $d=-1.0$ ) in self-reported exercise behavior as measured by the Godin Leisure-Time Exercise Questionnaire Health Contribution Score.

**Conclusion:** The results of this study support the feasibility, acceptability, and efficacy of this home-based exercise intervention for black individuals with mild-to-moderate MS.

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## **Chapter 1 – Introduction**

### Multiple Sclerosis

Multiple sclerosis (MS) is a chronic disabling disease of the central nervous system (CNS) with a prevalence of approximately 2.5 million people worldwide and approximately 400,000 people in the United States (NMSS, 2003). It is more common in women and typically presents between the ages of 20 and 50 years (Compston & Coles, 2002). MS compromises quality of life and results in neurological disability, dysfunction of cognition and mobility (i.e., walking and balance), and symptoms of fatigue and depression (NMSS, 2003).

#### Benefits and Rates of Physical Activity in Persons with MS

The benefits of participation in physical activity and exercise in persons with MS have been well established (Motl, 2014). Physical activity and exercise have been effective for managing the manifestations of MS (e.g., fatigue, cognition, depression, walking disability, quality of life (QOL)). Consequently, physical activity has been considered one of the best therapeutic strategies for comprehensive MS care (Motl & Pilutti, 2012a), and guidelines have been developed for physical activity participation in this population (Latimer-Cheung, Ginis, et al., 2013). Despite the wealth of knowledge regarding the benefits of physical activity and exercise participation for individuals living with MS, persons with MS do not engage in sufficient levels of physical activity when compared with the general population or compared with other clinical populations (e.g., spinal cord injury, stroke; Kinnett-Hopkins, Adamson, Rougeau, & Motl, 2017).

#### Social Cognitive Determinants of Physical Activity in persons with Multiple Sclerosis

Physical activity promotion approaches based on social SCT cognitive theory (A Bandura, 1977) is widely used to explain, predict, and change health behaviors. It is triadic (i.e.,

involves behavior, individual factors, and environmental factors), dynamic, and proposes reciprocal interactions between these three factors. The main components of SCT include self-efficacy, outcome expectations, impediments/facilitators, and goal setting. SCT is the most commonly used behavioral theory in regards to physical activity promotion (Marcus et al., 2006; McAuley & Blissmer, 2000) and has been used to explain physical activity behavior in a wide range of populations (Motl, 2014c; Suh et al., 2015).

### Pragmatic Intervention for Exercise in Persons with MS

Researchers have recently begun examining practical approaches for promoting lifelong physical activity and exercise participation in persons with MS. One such method of promoting the incorporation of exercise into one's lifestyle posits developing habitual routines in a realistic setting (e.g., home-based interventions). A recent feasibility study of a four-month RCT home-based exercise intervention for persons with MS provided promising results for increasing exercise participation (Adamson, Learmonth, Kinnett-Hopkins, Bohri, & Motl, 2016; Learmonth, Adamson, Kinnett-Hopkins, Bohri, & Motl, 2017). Briefly, 51 persons with MS were randomized into a waitlist control or exercise intervention. Data indicated that participants in the intervention group complied with 75% of aerobic sessions and 68% of the resistance sessions and that there was a significant increase in exercise as measured by the Godin Leisure Time-Exercise Questionnaire (GLTEQ). The results of this study support the feasibility and investigation of the efficacy and acceptability of a home-based exercise intervention based on the physical activity guidelines and supplemented with SCT-based behavioral strategies for adults with mild-to-moderate MS.

### Multiple Sclerosis, Race, and Physical Activity



MS has often been regarded as a disease occurring in persons of Caucasian European descent (Page, Durtzke, Murphy, & Norman, 1993; NMSS, 2003), yet there has been increasing interest in the occurrence and expression of MS in minority populations, particularly in the African-American population. Recent epidemiological evidence indicates that African-American women may have a higher risk of MS than Caucasian women (risk ratio 1.59, 95% CI 1.27-1.99;  $p = .0005$ ); African-American men have a similar risk of MS compared with Caucasian men (1.04, 95% CI =.67-1.57) (Langer-Gould, Brara, Beaver, & Zhang, 2013). As a consequence of the evidence of MS in black individuals being in its infancy, there is limited research available on the unique disease course experienced by black individuals with MS. Available research indicates that black individuals with MS experience a more aggressive disease course and might have a poorer response to disease modifying therapies (Klineova, Nicholas, & Walker, 2012). Research indicates that black individuals experience greater neurological disability than white individuals, yet this disparity resolves itself once patients develop moderate difficulty walking (Kaufman, Johnson, Moyer, Bivens, & Norton, 2003). Further, black individuals have increased odds of physical comorbidities (e.g., diabetes, hypertension, heart disease, breast cancer, colon cancer, lung cancer and rectal cancer) compared with white individuals as well (Marrie et al., 2008). The promising use of physical activity and exercise as disease management strategies in largely white populations suggests that it may be an effective strategy for black individuals with MS.

Evidence of physical activity in black individuals with MS is limited. To date, there has only been one study that has evaluated the correlates and levels of physical activity of black individuals with MS, and that research suggests that black individuals with MS engage in even lower levels of physical activity compared to their white counterparts living with MS (Kinnett-Hopkins & Motl, 2016). This study also provided evidence of similar and different social cognitive

correlates of physical activity between the black and white individuals with MS. The correlates for black individuals with MS were exercise self-efficacy, outcome expectations, functional limitations as impediments and goal setting. Behavioral interventions targeting these SCT variables for increasing physical activity levels among black individuals with MS is essential. It is important to consider any and all distinctive correlates of physical activity behavior to create the most effective program for black individuals living with MS. This involves consideration of any racial and disease related influences on physical activity participation and input from the target population.

#### Needs for Tailoring Physical Activity in Black Individuals with Multiple Sclerosis

A limitation of previous research in promoting physical activity and exercise to persons with MS is a lack of involvement of the target group during the developmental stage. To date, there are not any patient-informed exercise interventions for black persons living with MS. Involvement of the target group is important when considering promoting physical activity in black individuals with MS for numerous reasons. Namely, intervention adjustments to the individual's or subgroup's readiness for change and cultural norms are suggested to yield greater effectiveness (Prochaska, Velicier, Rossi, Goldstein, & et al, 1994). Further, African Americans have reported unique barriers to physical activity participation (e.g., lacking safe places to walk) compared to barriers of Caucasian and Hispanic populations (e.g., too tired; Heesch, Brown, & Blanton, 2000). Additionally, research has indicated that matching cultural characteristics of minorities with public health initiatives designed to impact individuals of that target group may increase receptivity to, acceptance of, and salience of health information and programs (Thomas, & Fine, 2004). Currently, some initiatives are failing at increasing physical activity participation in persons with MS (Kinnett-Hopkins et al., 2017), yet the exact reasons are unknown. There is

extensive evidence of factors such as belief systems, religious and cultural values, life experiences and group identity that alter how information is received (Thomas & Fine, 2004) and may impact the incorporation of physical activity behavior into one's daily life. It is imperative for successful interventions to understand how an individual's perception of themselves and of the world impacts their behaviors so that initiatives can cater to behavior change successfully. The lack of involvement of the target group may have hindered researcher's ability to identify and address important information and factors that may influence physical activity participation.

### The Present Study

Prior to conducting a RCT on the effects of a home-based exercise program for black individuals living with MS, it is important to examine the feasibility of such an approach. To that end, this study examined the feasibility of a patient-informed, three-month, home-based, racially targeted, exercise program for black individuals with MS based on recently developed physical activity guidelines (i.e., two aerobic sessions for 30 minutes two times per week and two strength training sessions targeting major muscle groups two times per week) and SCT principles of behavior change for increasing physical activity behavior in black individuals with MS. The primary aim of this project was to assess program feasibility in the four domains of process (e.g., recruitment and retention), resources (e.g., communication and monetary costs), management (e.g., of data management and safety reporting), and scientific outcomes (e.g., safety, burden, compliance, experience, and treatment effect). This study significantly contributes to the literature on black individuals with MS and also fills an important gap in the literature regarding exercise in black individuals with MS.

## **Chapter 2 – Review of Literature**

### OVERVIEW

The current review of literature provides information for developing the rationale for the design of the present study of the feasibility of a patient-informed, racially targeted, exercise program in persons with MS. It consists of six categories; MS; benefits and rates of physical activity in persons with MS; social cognitive determinants of physical activity in persons with MS; pragmatic intervention for physical activity in persons with MS; MS, race, and physical activity; and tailoring physical activity interventions for black individuals with MS. Lastly, this chapter concludes with a brief summary of the rationale and experimental design of the study.

### MULTIPLE SCLEROSIS

MS is described as a non-traumatic, inflammatory demyelinating disease of the CNS (Mayr et al., 2003; Wallin, Page, & Kurtzke, 2000). MS is characterized by a person's immune system attacking and damaging the myelin surrounding the axons of neurons. Myelin enables sustained and rapid conduction of nerve impulses throughout the CNS. However, when the myelin is attacked, impulse conduction is slowed or absent which may result in neurological impairment, functional imitations, symptoms (e.g., fatigue, pain), and permanent disability (Lublin & Reingold, 1996).

MS affects 2.5 million people worldwide and approximately 1 per 1000 persons in the United States (NMSS, 2003). Onset typically occurs in the 3<sup>rd</sup> and 4<sup>th</sup> decade of life and affects women two times more than men (NMSS, 2003; Wallin et al., 2000). Evidence has largely demonstrated that MS is a disease of northern European ancestry and least common in persons of African, Asian, and Hispanic descent (Compston & Coles, 2002; NMSS, 2003). However, recent

evidence has suggested that African Americans may experience a higher risk of developing MS than previously thought.

MS is one of the most common neurological diseases and consists of four main disease courses; relapsing-remitting, secondary progressive, primary progressive, and progressive relapsing. Relapsing-remitting MS (RRMS) accounts for roughly 80% of all MS cases and it is characterized by acute exacerbations, followed by periods of partial or full recovery (NMSS, 2005). Approximately 50% of persons with MS develop secondary progressive MS (SPMS), and it is characterized by a steady progression of clinical neurological damage. Primary progressive MS (PPMS) develops in approximately 10% of persons with MS and is characterized by a gradual progression of the disease and a decline in physical abilities without definite remissions (Reipert, 2004). Progressive relapsing MS (PRMS) is the rarest type of MS and is characterized by a steady decline of neurological function from onset coupled with acute exacerbations of symptoms (Lublin & Reingold, 1996).

The manifestations of MS are unpredictable and there is wide variation in the presentation of the disease from person to person. Typically, MS presents through symptoms of fatigue, walking disability, spasticity, cognitive dysfunction, bladder and bowel problems, depression, pain, balance impairments, numbness, and decreased quality of life (Motl, 2014; NMSS, 2003). MS related symptoms can significantly impact behavior and quality of life (Miller & Dishon, 2006).

## BENEFITS & RATES OF PHYSICAL ACTIVITY IN PERSONS WITH MS

### *Benefits of Physical Activity in Persons with MS*

Physical activity and exercise are promising behavioral approaches for managing the manifestations of MS (Motl, 2014). Physical activity is defined as any body movement produced

by the skeletal muscles that results in a substantial increase over resting energy expenditure (Bouchard & Shephard, 1994). Physical activities fall into the categories of household physical activity (e.g., mowing, sweeping floors, etc.), occupational physical activity (e.g., walking, moving equipment, etc.), transportation physical activity (e.g., cycling, walking, etc.), and leisure-time physical activity (e.g., recreation, exercise, etc.). Exercise is a subset of physical activity and is defined as a planned, structured, repetitive physical activity behavior with the goal of increasing physical fitness. In 2013, physical activity guidelines for persons with MS were developed (Latimer-Cheung, Martin Ginis, et al., 2013). These guidelines recommend aerobic exercise sessions for 30 minutes two times per week and resistance training sessions targeting major muscle groups two times per week. Further, the guidelines suggest that meeting the recommended level of activity may reduce symptoms such as fatigue, improve mobility, and enhance quality of life.

There is much evidence that speaks to the benefits for participating in physical activity and exercise in persons with MS (Motl, 2014; Motl & Pilutti, 2012). The manifestations of MS present through symptoms that may affect walking ability, fatigue, and quality of life. Several meta-analyses have detailed the benefits of exercise training on fatigue (Pilutti, Greenlee, Motl, Nickrent, & Petruzzello, 2013), walking mobility (Snook & Motl, 2009), and quality of life (Motl & Gosney, 2008). Other research has suggested additional benefits on improving cardiorespiratory fitness, cognition, muscle endurance and strength, balance, gait, and decreasing fatigue and depression (Ensari, Motl, & Pilutti, 2014; Latimer-Cheung, Ginis, et al., 2013). Specifically, one study examined self-report surveys of persons with MS categorized as exercisers and non-exercisers and discovered that individuals that participated in regular exercise had more satisfactory fatigue, depression and quality of life compared with those who were

categorized as non-exercisers (Stroud & Minahan, 2009). Additionally, one study conveyed that physical activity and exercise training are associated with improvements in walking impairment in participants with MS who experience this symptom (Motl, Goldman, & Benedict, 2010). As a result of these benefits, exercise training is regarded as one of the best therapeutic strategies for all-inclusive MS care (Robert Motl et al., 2010). This has sparked a great effort to promote the benefits of physical activity and exercise by stakeholders (e.g., NMSS, neurologist, physicians).

#### *Rates of Physical Activity in Persons with MS*

Despite the vast and well established benefits of physical activity and exercise participation, and promotional efforts of increasing physical activity participation by stakeholders, persons with MS engage in less physical activity than their non-diseased counterparts (Kinnett-Hopkins et al., 2017) and have been for the past decade (Motl, McAuley, & Snook, 2005). A meta-analysis conducted just over a decade ago reported that between the period of 1997 and 2004 persons with MS engaged in significantly less physical activity when compared with non-diseased, healthy controls and persons with other disease conditions (e.g., chronic fatigue syndrome, chronic obstructive pulmonary disease, and cerebral palsy). The meta-analysis included 13 studies of 2,360 persons with MS participants and reported an overall, moderate-to-large weighted mean effect size (ES) of  $-0.60$  (95% CI =  $-0.77, -0.44$ ) indicating that individuals with MS engaged in significantly less physical activity than diseased and non-diseased populations (Motl, McAuley, & Snook, 2005).

That observation served as a clarion call for the systematic evaluation of physical activity measures in MS (Motl & Sandroff, 2010) and subsequent research has largely included validated self-report surveys or motion sensors, such as pedometers and accelerometers. Further, the development of physical activity guidelines has resulted in increased interest in promotion of

physical activity. Additionally, we have entered into a new treatment era for MS that may have changed the degree of impact of MS and its influence on physical activity levels (e.g., improved treatment for mobility may have increased rates of physical activities that require ambulation). The presumed result of these efforts would be an increased awareness of, and participation in, physical activity among individuals living with MS.

However, a recent meta-analysis conducted by Kinnett-Hopkins et al., (2017) concluded that although the past decade has been a period of dramatic expansion of research on physical activity in MS, there are similar rates of physical activity in persons with MS compared with healthy controls as were found in the 2005 meta-analysis. This updated review included 21 studies involving 5,303 persons with MS and yielded a mean ES of  $-0.57$  (95% CI=  $-0.76$ ,  $-0.37$ ). The weighted mean ES was heterogeneous ( $Q=443.811$ ,  $df=31$ ,  $p<0.001$ ). The magnitude of the mean ES increased when comparing the MS population with non-diseased populations, but decreased when comparing MS with clinical populations.

One important moderator of physical activity level examined in the updated meta-analysis is the comparison group (i.e., clinical vs. non-diseased). The previous meta-analysis reported that the magnitude of difference in physical activity among those with MS compared with non-diseased populations was large and approached 1 SD. The updated meta-analysis replicated that observation such that the magnitude of difference compared with non-diseased populations was 1 SD. The combined ES of clinical and non-diseased populations was significantly smaller than the ES of only non-diseased persons. The ES of the MS population in comparison to other chronic disease populations (e.g., muscular dystrophy, joint and connective tissue disease, etc.) was non-significant; however, the ES was larger when comparing the MS population with non-chronic disease clinical populations (e.g., stroke, traumatic brain injury,



etc.). The previous meta-analysis reported that clinical populations engaged in slightly more physical activity than those with MS. However, the updated meta-analysis indicated that physical activity levels of other chronic diseases align more with the physical activity levels of those living with MS than other disabled populations. This finding suggests that degree of disability may not be the primary factor influencing physical activity participation; rather, the presence of a chronic disease presents a unique barrier to physical activity beyond a need for adaptations.

This result is alarming considering the low levels of physical activity among adults in the United States (MMWR, 2004) and the efforts of stakeholders in the promotion of physical activity over the past decade (Latimer-Cheung, Ginis, et al., 2013). This concern may be magnified when considering the association of physical inactivity and increased risk of comorbid conditions among those living with MS that can result in hypertension, heart disease, and diabetes (Marrie et al., 2008). Collectively, this reinforces the importance of increasing physical activity and exercise levels and the investigation of more successful promotional efforts for individuals living with MS.

## SOCIAL COGNITIVE DETERMINANTS OF PHYSICAL ACTIVITY IN PERSONS WITH MS

The SCT established by Albert Bandura in 1986 has been widely applied and supported in the literature and was originally known as the social learning theory (Bandura, 1971). This theory integrates social and cognitive psychology with behaviorism and established the idea of reciprocal determinism which suggests that personal factors (beliefs, attitudes) and the environment (physical, social) are interacting determinants of one another. This theory evolved from previous models that believed human behavior was solely determined by the environment. The introduction of intrapersonal factors and behaviors to the environment's influence provided

a more complete picture of human behavior. SCT operates under the assumption that each person's unique beliefs and attitudes as well as their physical and social environments can explain their behaviors. This is highlighted in the definition of the most notable construct of SCT, self-efficacy. Self-efficacy is an individual's belief in their ability to produce a specific outcome despite barriers and that belief is determined by personal and environmental factors (A Bandura, 1977). There are four sources of self-efficacy; mastery experiences, social modeling, social persuasion, and interpretation of physiological and affective responses.

SCT is comprised of additional agents that help explain behavior. Bandura provided a structural model detailing the psychosocial agents which include outcome expectations (i.e., physical, social and self-evaluative outcome expectations), sociocultural factors (i.e., impediments and facilitators), and self-regulation (i.e., goal setting and planning). Outcome expectations are a belief that completing a certain behavior or task will result in specific consequences. Sociostructural factors aid in explaining social support. Self-regulation provides motivation for participating in the behavior and is influenced by self-efficacy, outcome expectations, and sociostructural factors (Bandura, 1977).

SCT is the most commonly used behavioral theory in regards to physical activity promotion (Marcus et al., 2006; McAuley & Blissmer, 2000). Much research has investigated the effects of studies grounded in SCT (Dzewaltowski, 1994; Rovniak, Anderson, Winett, & Stephens, 2002). There has been much success in predicting correlates of physical activity in persons living with MS (Kinnett-Hopkins & Motl, 2016; Motl, McAuley, & Sandroff, 2013). A previous research study examined self-efficacy, enjoyment, social support, and disability as correlates of physical activity through a SCT lens (Motl, Snook, McAuley, & Gliottoni, 2006). This study included 196 participants with MS who completed a battery of questionnaires.

Further, participants wore an accelerometer for seven days as an objective measure of physical activity. This study reported that individuals with higher levels of self-efficacy ( $\beta = .29, p < .001$ ) and enjoyment ( $\gamma = .28, p < .001$ ) engaged in a greater amount of physical activity. Further, they examined the associations among symptoms, self-efficacy, and physical activity in persons with MS in the context of SCT and the results indicated that symptoms had direct negative relationships with self-efficacy ( $\gamma = -.32$ ) and physical activity ( $\gamma = -.24$ ), and self-efficacy had a direct positive relationship with physical activity ( $\beta = .57$ ). This study provided evidence of the importance of self-efficacy regarding symptoms and physical activity in persons with MS.

Other studies have reported that self-efficacy and outcome expectations directly influenced physical activity in persons with MS. Additionally, self-efficacy was indirectly associated with physical activity by way of goal-setting, self-evaluative outcome expectations, and impediments among persons with RRMS (Suh et al., 2011). In particular, a recent study examined correlates of physical activity over a period of two and a half years in persons with MS (Motl et al., 2013). They observed significant linear changes in self-reported and objectively measured physical activity, self-efficacy, walking impairment, and disability over the two-and-a-half-year time period. Fatigue, depression, and pain remained unchanged. Changes in both self-reported and objective physical activity were associated with changes in self-efficacy, after controlling for confounders (i.e., age, sex, and disease duration). Further, another recent study examined the difference in SCT correlates of physical activity in 151 black and 185 white individuals with MS (Kinnett-Hopkins & Motl, 2016). Participants were recruited through the North American Research Committee on Multiple Sclerosis Registry (NARCOMS) and completed a battery of questionnaires. Physical activity levels were significantly correlated with self-efficacy, outcome expectations, functional limitations as impediments, and goal setting in

black participants with MS and the magnitude of correlations were comparable with those observed in the white participants with MS.

#### PRAGMATIC INTERVENTION FOR PHYSICAL ACTIVITY IN PERSONS WITH MS

Promoting lifelong physical activity participation in persons with MS is of high priority. For nearly 10 years, researchers have investigated approaches for increasing physical activity participation in persons with MS (McAuley et al., 2007). Yet, the success of such efforts are lackluster given the unwavering participation rates over this 10-year time period (Kinnett-Hopkins et al., 2017).

Most physical activity promotion research in persons with MS has been developed utilizing in-person activity under supervision (Rodgers et al., 1999; Solari et al., 1999). In-person supervised interventions require a vast amount of resources (e.g., trained exercise specialist, equipment, time, money) and may not be generalizable outside of a research setting. Additionally, the lack of long-term follow-up of successful physical activity and exercise interventions fails to provide understanding of the true impact of these studies (McAuley et al., 2007) and their ability to provide the tools necessary for sustained physical activity participation once the study has ended. This has led to the exploration and development of pragmatic interventions for physical activity in persons with MS under the belief that integrating physical activity patterns through home-based studies may provide sustained engagement in physical activity.

One study explored a 12-week, randomized controlled trial (RCT) of a SCT based, internet delivered physical activity intervention (Motl, Dlugonski, Wojcicki, McAuley, & Mohr, 2011). 54 persons with MS were randomized into either the internet intervention or a waitlist control condition. The participants completed a battery of measures examining physical activity

levels, self-efficacy, outcome expectations, functional limitations as impediments, and goals setting pre and post intervention. Individuals in the intervention reported a statistically significant increase in physical activity over the 12-week period in comparison to the waitlist control condition and goal setting was a significant mediator.

Learmonth et al., conducted a recent feasibility study of a four-month, RCT, home-based, exercise intervention based on the guidelines for physical activity for persons with MS supplemented with behavioral strategies to encourage compliance (2017). This study included 51 persons with mild-to-moderate MS who were randomized into either the exercise intervention condition or a waitlist control condition. Feasibility was based on the four domains of process (e.g., recruitment), resource (e.g., monetary costs), management (e.g., personnel time requirements) and scientific outcomes (e.g., treatment effect). Participants in both conditions completed home-based assessments before and after the 4-month period. The results indicated that there was a statistically significant time by group interaction on GLTEQ ( $F=6.94$ ,  $P < 0.01$ ,  $\eta_p^2 = 0.12$ ); this indicating a moderate increase ( $d \geq .50$ ) in self-reported exercise behavior for the intervention. The results support the feasibility and acceptability of a home-based exercise intervention based on the physical activity guidelines and supplemented with behavioral strategies for adults with mild-to-moderate disability due to MS.

#### MS, RACE, AND PHYSICAL ACTIVITY

There is limited research available on the unique disease course experienced by black individuals with MS. This is largely due to the long held belief that MS did not often occur in minority populations. However, recent evidence suggests that African Americans experience a higher risk of developing MS than previously reported (African American women = risk ratio 1.59, 95% CI 1.27-1.99;  $p = .0005$ ; African American men = 1.04, 95% CI = .67-1.57) in

comparison with Caucasian women and men, respectively (Langer-Gould, Brara, Beaver, & Zhang, 2013). Further, black individuals with MS experience a more aggressive disease course and might have a poorer response to disease modifying therapies (Klineova, Nicholas, & Walker, 2012). Research indicates that black individuals experience greater neurological disability than white individuals, yet this disparity resolves itself once patients develop moderate difficulty walking (Kaufman, Johnson, Moyer, Bivens, & Norton, 2003). Black individuals have increased odds of physical comorbidities (e.g., diabetes, hypertension, heart disease, breast cancer, colon cancer, lung cancer and rectal cancer) compared with white individuals as well (Marrie et al., 2008).

Relatively little investigation of health behavior disparities, such as physical activity behavior, has been conducted in black individuals with MS. Such inquiry is imperative considering the evidence of considerable benefit of physical activity in those with MS (Latimer-Cheung et al., 2013). There is some evidence of physical activity differences between white individuals and non-white individuals with MS (Klaren et al., 2015), yet the samples are limited in that they are mostly of white persons and current research has not focused on black individuals. There is only evidence from one study which examined physical activity levels of black individuals in comparison to white individuals (Kinnett-Hopkins & Motl, 2016). This study reported that black individuals are significantly less physically active than their white counterparts. These results echoed evidence reported in the general population of higher odds of physical *inactivity* in black individuals (OR=1.40; 95%CI 1.30-1.51) compared to white individuals (Wilson-Frederick et al., 2014). Collectively, this suggests that there may be a greater need for increased physical activity and exercise participation and promotion in black individuals with MS.

## TAILORING PHYSICAL ACTIVITY INTERVENTIONS IN BLACK INDIVIDUALS WITH MS

The efforts for promoting physical activity participation in persons with MS are failing at successfully increasing physical activity levels, especially for black individuals with MS. Over the past 10 years we have witnessed a lack of change in physical activity levels in the general MS population despite the vast amount of small, lab-based, supervised trials which provide evidence of the benefits of physical activity and exercise participation. Further, black individuals with MS engage in even lower levels of physical activity in comparison to their white counterparts (Kinnett-Hopkins & Motl, 2016). There has been a call for researchers to explore the reasons why individuals with MS are not engaging in physical activity and to design targeted and tailored interventions that can produce sustained participation in physical activity.

In regards to black individuals with MS, there has been no investigation into the effectiveness of physical activity promotion or interventions in comparison to the largely studied white population. Such interventions should be adjusted to the individual's or subgroup's readiness for change and cultural norms in order to yield greater effectiveness (Prochaska et al., 1994). Additionally, a study conducted by Heesch, Brown & Blanton (2000) discovered that African American women described dissimilar reasons for not participating in physical activity in comparison to Caucasian and Hispanic populations. That is, African American women noted "lacking safe places to walk" as a significant barrier to physical activity whereas Caucasians noted being "too tired" and "self-conscious" and Hispanics noted "lacked time" and "too tired" as reasons why they did not engage in physical activity. Other studies have conveyed unique attitudes of African Americans regarding neighborhood safety concerns, body image, burden of redoing hair, and lack of time due to extensive family and church obligations (Resnicow, 2002).

In order to effectively promote physical activity and exercise, the interventions have to be consistent with the norms, beliefs, values, expectations, and practices of the target population.

There is no one-size-fits-all for increasing physical activity levels equally among groups.

Unfortunately, in the available literature, few studies that target black individuals describe why the authors decided to tailor the physical activity program (Pekmezi et al., 2009), or how the racial or cultural modifications impacted the outcome of the study (Banks-Wallace & Conn, 2002). These are important to understand to determine the efficacy of targeting and tailoring a physical activity intervention. The primary goal of modifying a physical activity intervention is to develop a program that may yield the most success for the target group. Specifically, when considering the established benefits of physical activity participation on lowering the risk of hypertension, diabetes, and other diseases that are common in the MS population, with the knowledge of low physical activity participation in black individuals, it suggests that they may have more to gain by increasing their physical activity levels.

To properly execute such interventions, one may consider the potential benefits of a systematic approach to the development of the program that includes members of the target group which should begin with a feasibility study. For instance, to target African Americans with MS, it would be ideal to understand: (a) the correlates of physical activity; (b) their ideal physical activity program; (c) the importance of racially or culturally targeting and tailoring an intervention; (d) their specific facilitators, barriers, motivations, and meaning of physical activity and; (e) their feedback on the interventions appropriateness. Often researchers determine what would be best for the target population to do in an intervention. However, if researchers include walking in an intervention, but this specific group has high concerns of neighborhood safety, it is not in the best interest of the participant to engage in that behavior outside their home nor is it



best for adherence to the protocol. The approach outlined would involve participants at every step of the development process, allowing for the greatest success of tailoring a program that should not experience high levels of attrition and may yield the greater benefit.

### THE PRESENT STUDY

To that end, I conducted a systematic development approach for a racially targeted, home-based exercise program for black individuals living with MS.

The first study of this approach examined the correlates of physical activity for black individuals with MS and indicated some degree of generality in SCT variables as correlates of physical activity between black and white individuals with MS. Self-efficacy, outcome expectations, functional limitations as impediments, and goal setting and planning were identified as correlates of physical activity in black individuals with MS. Further, this study suggested that the same interventions utilized in largely white populations could be applied for increasing physical activity among black individuals with MS with the consideration of sociodemographic and cultural differences (Kinnett-Hopkins & Motl, 2016).

The next study explored the next three steps of the systematic approach (i.e., ideal physical activity program, the importance of racially or culturally tailoring an exercise program, and the specific facilitators, barriers, motivations of exercise). Namely, this study investigated 40 black individuals with MS' ideal exercise program, how important is it for a program to be racially or culturally tailored, and how important social cognitive correlates are in relation to participating in an exercise program through an online survey. The evidence from this study suggests that black individuals with MS would like to engage in 5 ( $\pm 1.6$ ) exercise sessions per week at a moderate intensity with the support of a behavioral coach (57.5% of the sample). The exercise sessions would consist of resistance/weight training (52.5%) and easy or fast walking

(35% and 20%, respectively). The behavioral coach would interact with the participant on a tapering basis (i.e., more contact at the beginning of the program and fewer interactions as the program progresses). The expectations of their ideal program would increase muscle strength (65%), improve overall body functioning (60%), increase ability to perform daily activities (57.5%), manage stress (57.5%), lose weight (47.5%), decrease fatigue (47.5%), increase sense of personal accomplishment (45%), increase flexibility (45%), increase endurance (45%). Common barriers that black individuals with MS reported needing assistance with were fatigue (40%), time management (32.5%), and cost (22.5%). Facilitators that black individuals with MS reported may help keep them engaged in an exercise program were a personal trainer (57.5%), more exercise information (32.5%), exercise equipment (32.5%), and clear instructions (30%). Lastly, participants noted that cultural and racial tailoring was very important (32.5%), or had some importance (25%). Specifically, feeling represented in the media of the program (40% very important; 25% some importance), including motivational content from people who share their race (27.5% very important; 37.5% some importance), being based in faith (17.5% very important; 32.5% some importance), and having the same race as the behavioral coach (12.5% very important; 42.5% some importance) were all important factors to be considered in the design of an exercise program (Kinnett-Hopkins & Motl, in preparation.)

Lastly, the qualitative investigation of the meaning, motivation, barriers, and facilitators of exercise (N=10) and feedback on a previous iteration of a home-based exercise intervention was examined (N=8; Adamson et al., 2016; Kinnett-Hopkins, Adamson, & Motl, in preparation). Participants in this cohort indicated that they perceived exercise and physical activity as isomorphic terms rather than independent behaviors. However, most participants explained that their personal experience with exercise was an important part of their life. Participant 1

explained that exercise provides her with “a sense of, um, belonging. A sense of, uh, being productive. So just because [she has] MS [she doesn’t] feel like [her] life is over...” Further, participants expressed a desire to engage in more exercise as they were not currently sufficiently active. Their motivation for exercising included feelings of obligation, knowledge of health benefits, enjoyment, social support, defiance of MS, and their faith. Barriers to exercise participation included MS symptoms (e.g., fatigue, walking impairment), not having the necessary resources, fear, and time. Lastly, regarding facilitators to physical activity participants expressed that resources, requirements of daily living made engaging in physical activity easier. Feedback related to the previous iteration of a home-based exercise program provided suggestions for “cater[ing] to [our] audience” (i.e., black individuals with MS) in the exercise instruction photographs, consistency of font size throughout the program manual, and providing race specific resources and research on the benefits of exercise in MS.

The primary aim of the current study was to examine the feasibility of a patient-informed three-month, home-based, racially targeted, exercise training program in the four domains of process (e.g., recruitment and retention), resources (e.g., communication and monetary costs), management (e.g., of data management and safety reporting), and scientific outcomes (e.g., safety, burden, compliance, experience, and treatment effect) in black individuals with MS largely based on the previously described studies.

### **Chapter 3 – Methods**

The present study was a racially targeted extension of a developed exercise program for persons with MS (Adamson et al., 2016; Learmonth et al., 2017). It examined the feasibility of a patient informed, three-month, home-based, racially targeted, exercise training program in the four domains of process (e.g., recruitment and retention), resources (e.g., communication and monetary costs), management (e.g., of data management and safety reporting), and scientific outcomes (e.g., safety, burden, compliance, experience, and treatment effect) in black individuals with MS largely based on exploratory studies that have examined the desires, motivations, facilitators, and barriers to exercise in black persons with MS. The results of this study may inform the development of RCTs which may determine the actual efficacy and effectiveness of this exercise intervention for increasing exercise behavior and improving outcomes in black individuals with MS.

#### *Participants Recruitment and Eligibility*

The procedure was approved by the University of Illinois at Urbana-Champaign Institutional Review Board and all participants provided written informed consent. The CONSORT diagram details participant recruitment and enrollment (Figure 1). Prospective participants were identified from the Exercise Neuroscience Research Laboratory (ENRL) database. A three-armed recruitment effort was utilized in this study to recruit identified participants. Specifically, potential participants were emailed a flyer of the study and directed to express interest via email or phone. One week after the initial email, potential participants were mailed a flyer and encouraged to email or phone the ENRL for more information. One week after the anticipated arrival of the mailed letters (i.e., four days later) potential participants who had not contacted the ENRL were called and recruited into the study. After expressing initial

interest, persons were contacted by phone and were provided a full description of the program. Interested individuals were screened for inclusion/exclusion criteria. The inclusion criteria were as follows: (a) age 18-64 years; (b) self-reported diagnosis of MS; (c) Patient Determined Disability Steps (PDDS) scale score  $\leq 4.0$  (i.e., mild or moderate disability consistent with the recommendations in the guidelines for exercise in MS); (d) self-reported relapse free in past 30 days; (e) willing and able to participate in a three-month home-based exercise program; (f) self-reported non-exercisers (as measured by a health contribution score (HCS) of 23 or less on the GLTEQ); (g) asymptomatic (i.e., one or fewer affirmatives on the Physical Activity Readiness Questionnaire (PAR-Q)) or physician approval for undertaking exercise training for those with 2 or more affirmatives on the PAR-Q; (h) identify as black or African-American; and (i) have internet access. More than 1 affirmative on the PAR-Q indicates that the participant is at more than a minimal risk for exercise-related complications and therefore physician approval was required prior to enrolling such participants in this study. Participants who did not meet those criteria were excluded from this study. A power analysis with G\*Power 3.0.10 was used to determine sample size. A sample of 32 was estimated as the basis of an assumed attrition rate of 20% (Pilutti et al., 2014), a significance level of .05, and power of .80. Due to the disproportionate prevalence of MS in women as opposed to men it was expected to enroll more women than men.

### *Feasibility Metrics*

This study collected outcomes based on process, resource, management, and scientific metrics of feasibility. A summary of these metrics are provided in Table 1.

*Process Feasibility.* This metric documents recruitment and retention. Data on (a) recruitment rates and refusal rates were collected by recording all contact with potential

participants and any refusal reasons. Evidence of (b) retention and attrition rates were collected by recording all participants' flow throughout the study; and adherence, via participant log books, chats, and exercise participation as measured during follow-up assessment.

*Resource Feasibility.* This metric established communication and monetary requirements of the program. Evidence of: (c) all communication with participants were collected by recording details of contact with all potential and enrolled participants; (d) monetary costs of the research was collected by reporting all monetary costs for the study incurred by the researchers.

*Management Feasibility.* This metric determined data management and safety reporting of the study. Evidence of: (e) procedures and time required to obtain ethical approval from IRB, examined via communication between staff and the University IRB; (f) staff preparation and report time for participant communication, examined via documenting preparation, call time, attempted call time and report-taking time per participant during the program; (g) time and accuracy in data collection/entry, monitored through checking for data completeness, and recording time to collect, enter and check data, and lastly; (h) documentation of the reporting and handling constraints of adverse events (AE), serious adverse events (SAE), and clinical emergencies was collected.

*Scientific Feasibility.* This metric determined program safety, burden, compliance, experience, and treatment effect of the program. Evidence of: (i) all AEs, SAEs, and clinical emergencies; (j) participant burden, compliance, and experience during the assessment experience and the program; assessment burden was documented through participant self-report of time to complete the assessment questionnaire online. Program experience was documented by having participants self-report parameters of sessions in log-books and during phone chats

(e.g., frequency, duration, intensity, and type), and (k) the scientific treatment effect, measured by a change in exercise behavior via GLTEQ.

### *Measures*

*Demographic Characteristics.* Participant characteristics were measured using a demographic questionnaire that was developed specifically for this study. This questionnaire included questions designed to obtain information about age, weight, height, employment, education, marital status, sex, and income.

*Health History.* Participant's health and history were measured using a questionnaire that asks participants to indicate (yes or no) whether or not they have been diagnosed with a list of 18 different comorbidities (e.g., diabetes, obesity, hypertension). Responses were summed to obtain a total number of comorbidities, and further, to self-report information regarding their MS diagnosis (i.e., stage of disease, time since diagnosis in months, treatment regimen), and other history.

*Exercise Behavior.* Participant's exercise behavior was measured using a self-report survey before and immediately following the intervention. The GLTEQ (Godin, 2011) consists of three open-ended questions that measure the frequency of strenuous (e.g., jogging), moderate (e.g., fast walking), and mild (e.g., easy walking) exercise for sessions more than 15 minutes during one's free time in the preceding week. The weekly frequencies of strenuous, moderate, and mild activities were multiplied by 9, 5, and 3 metabolic equivalents (METs) respectively, and the sum was calculated to form a measure of total leisure activity. Additionally, the health contribution score (HCS; i.e., equivalent of time spent in moderate-to-vigorous activity) was calculated from the frequency of only strenuous and moderate activities. The frequencies for strenuous and moderate activities were multiplied by 9 and 5 METs, respectively, and then

summed into a HCS (0-98) that reflects MET/minutes per week. The scores are then classified into three categories: active (substantial benefits;  $\geq 24$  MET/minutes per week), moderately active (some benefits; 14-23 MET/minutes per week), and insufficiently active (less substantial or low benefits;  $\leq 13$  MET/minutes per week; Godin, 2011).

### *Procedures*

*Exercise Program.* All participants received a pedometer, elastic resistance bands, a manual, a log book, exercise video demos on USBs, and access to a secret Facebook group.

*Pedometer and Elastic Resistance Bands.* A pedometer and a set of elastic resistance bands were provided to each participant to aid in their aerobic and strength training exercise sessions. The specific utilization of these materials are described in detail below.

*Manual.* The manual served as a training guide which encompassed a detailed description of the exercises to be performed in a progressive manner over a three-month time period. All program materials were written at a 7<sup>th</sup> grade reading level. The exercise prescription was based on the physical activity guidelines for persons with MS (Latimer-Cheung et al., 2013). A more detailed description of the exercise program is available in Table 2. The aerobic training sessions involved 10-30 minutes of moderate-intensity walking two days a week. The pedometer provided facilitated the participants in monitoring and tracking the intensity of walking based on steps per minute. Participants were coached to use the pedometers exclusively during bouts of walking at a step rate of 100 steps per minute. This is a unique application of the pedometer and this stepping rate corresponds to moderate-intensity exercise in persons with MS (Agiouvasitis & Motl, 2014). The strength training involved one to two sets of 10-15 repetitions of up to 10 exercises targeting lower body, upper body, and core muscle groups performed two days per week. For the strength training sessions, participants were provided with a pool of 10 different



resistance training exercises (e.g., chair raise, abdominal curl, shoulder raise). Participants were encouraged to choose from a variety of target groups (e.g., lower body, upper body, core) for each session as to not overwork or underwork a specific area of the body. Participants were provided with elastic resistance bands to complete the exercises (Black Mountain Products, McHenry, IL). To aid participants in proper form techniques of the prescribed exercises, exercise video demonstrations were provided on a USB.

*Log book.* The log books (i.e., paper copy and online copy) provided a self-monitoring tool which enabled participants to record each aerobic and resistance training session. It further served as a measure of compliance by comparing data provided with the recommended exercise prescription.

*Progression.* The exercise program included three separate speeds of progression to reaching the physical activity guidelines. During the second week of the program participants discussed which program progression best suited their capability and goals with their behavioral coach. Each program progression reached the recommended levels of activity after 10 weeks of participation in the program (see Table 2).

*Behavioral Component.* This exercise program was supplemented with a SCT-based behavioral educational component to enhance exercise adherence. The exercise program focused on correlates of physical activity that have been associated with physical activity levels in black individuals with MS (Kinnett-Hopkins & Motl, 2016b). The concentration of the SCT educational component included: outcome expectations, self-monitoring, self-efficacy, overcoming barriers, and identifying facilitators. The educational component was primarily delivered through two mediums; newsletters and coaching calls.

*Newsletters.* Participants received newsletters via the USPS periodically throughout the program (i.e., weeks 1,2,3,4,6,9). The newsletters provided information on the aforementioned topics, resource section (e.g., NMSS websites for additional information), testimonials of black individuals with MS who have benefitted from engaging in exercise, and tips regarding exercise for participants to try at home.

*Coaching Calls.* Participants engaged in six one-on-one, semi-structured, phone chats with a behavioral coach (i.e., weeks 1,2,3,4,6,9). The behavioral coach was a trained doctoral-level graduate student who has 5 years of experience on the application of SCT in MS. Coaching calls coincided with the arrival of the newsletters and complemented their content. Consistency between participants was insured by using a standardized script for each call which contained: (a) an update on the progress of the program; (b) understanding of the newsletter and its content; and (c) an opportunity for participants to ask any questions they may have had. Additionally, they served as a method of accountability to encourage exercise adherence.

*Tailoring.* A detailed explanation of racial tailoring modifications is provided in Table 3. This exercise program was racially tailored based on the following: correlates of physical activity in black individuals with MS (Kinnett-Hopkins & Motl, 2016); ideal physical activity program for black individuals with MS (Kinnett-Hopkins, & Motl, in preparation); the importance of racially or culturally tailoring an intervention (Kinnett-Hopkins, Adamson, & Motl, in preparation); and the specific facilitators, barriers, and motivations of exercise (Kinnett-Hopkins, & Motl, in preparation; Kinnett-Hopkins, Adamson, & Motl, in preparation).

The correlates of physical activity for black individuals with MS are self-efficacy, outcome expectations, functional limitations as impediments, and goal setting and planning. The behavioral components of this program (e.g., newsletters, coaching) focused on the correlates

specific to black individuals with MS. For example, outcome expectations such as increasing muscle strength, and improving overall body functioning were highly discussed as they have been reported to be the most important exercise outcome expectations for this population (Kinnett-Hopkins, & Motl, in preparation).

Black individuals with MS expressed a preference to engage in 5 ( $\pm 1.6$ ) exercise sessions per week, the present program prescribed four exercise sessions per week based on the physical activity recommendations for individuals with mild-to-moderate MS. However, participants were encouraged to engage in additional aerobic and resistance training sessions if they desired. The preferred exercise modalities of this population were walking and strength training; consequently, those were the modalities prescribed in this program. Participants requested speaking with the behavioral coach on a tapering basis (i.e., more contact at the beginning of the program and fewer interactions as the program progressed) and consequently had coaching calls on weeks 1,2,3,4,6, and 9 (Kinnett-Hopkins & Motl, in preparation).

The most important outcome expectations, common barriers, and facilitators to engaging in exercise in black individuals with MS were addressed through the educational behavioral components. The most important outcome expectations were increased muscle strength (65% of the sample), improved overall body functioning (60%), increased ability to perform daily activities (57.5%), manage stress (57.5%), lose weight (47.5%), decreased fatigue (47.5%), increase sense of personal accomplishment (45%), increased flexibility (45%), and increased endurance (45%). The newsletters and coaching calls provided information regarding these outcome expectations in the outcome expectations newsletter and the corresponding coaching call catered to these outcome expectations on an individualized basis. The most common barriers for this population that were conveyed were fatigue (40%), time management (32.5%), and cost

(22.5%). Evidence regarding exercises benefits on fatigue were highlighted in the overcoming barriers newsletter. Time management strategies were addressed in the tips section of the newsletter and the program provided all materials free of cost, which eliminated the cost barrier. Facilitators that were reported as necessary for engaging in an exercise program were a personal trainer (57.5%), more exercise information (32.5%), exercise equipment (32.5%), and clear instructions (30%). The behavioral coach served as a remote personal trainer. The manual and exercise materials offered clear instructions and were provided with the program.

The importance of racially or culturally tailoring a program was exemplified in the reported desire of knowing that the program was racially tailored just for them (32.5 very important; some importance 25%). This was addressed through images of middle aged black women as the models for all pictures in the manual, as feeling represented in the media of the program is important to this population (40% very important; 25% some importance). Additionally, including motivational content from people who share their disease and race were important (27.5% very important; 37.5% some importance), and was addressed by providing motivational quotes throughout the logbook and in each newsletter. Further, testimonials encouraging exercise by black individuals with MS were provided in each newsletter. Additionally, participants were given the opportunity to join a secret Facebook group to interact with other participants and for a source of social support. Some black individuals with MS reported that a program based in faith was important (17.5% very important; 32.5% some importance); this was addressed by having selected bible verses used as motivational tools throughout the logbook. Lastly, having the same race as the behavioral coach (12.5% very important; 42.5% some importance) carried some importance for this population and consequently, the behavioral coach/exercise specialist identified as black.

*Feedback.* Once the study was completed participants were asked to provide feedback on the program. Additionally, any participant who dropped out of the study was also asked to provide feedback on the program and reasons for quitting. Feedback assessment was conducted via an online survey regarding participant satisfaction of the program, its materials, coaching calls, and overall experience.

#### *Data Analysis*

All data were analyzed using SPSS Statistics 24.0 (Chicago, IL) and Microsoft Excel. The primary feasibility outcomes (i.e., process, resource, management, and scientific feasibility metrics) were examined by percentage and frequency analysis and descriptive statistics. The effect of the program on exercise behavior (i.e., GLTEQ) was examined using a paired samples *t*-test. The effect size for change over time was expressed as Cohen's *d* and was interpreted as small, moderate, and large based on criteria of 0.2, 0.5, and 0.8, respectively (Cohen, 1988).

## **Chapter 4 – Results**

### *Participant Characteristics*

Demographic and clinical characteristics are displayed in Table 4. Briefly, all participants identified as black/African-American, and most were female (94%) with a mean age of 51.6 ( $\pm$  9.4) years. Participants self-reported some contra-indications (i.e., diabetes, hypertension, and high cholesterol) and the majority reported a household income of less than \$40,000 USD. Participants self-reported a PDDS score of 1.5 (4 IQR; range 0-4) indicating a mild-to-moderate disability. The most common type of MS was RRMS (81%), and mean duration of MS was 15.7 ( $\pm$  7.5) years. Further, participants had an average of 2 ( $\pm$  1.7) comorbid conditions.

### *Process feasibility: Recruitment, Retention, & Adherence*

The consort diagram details participant flow and is provided in Figure 1. A total of 129 people were contacted to participate in the exercise program; all 129 via email, 126 of the 129 also via USPS, and 97 of the 129 also via telephone. There were 32 spots available in the exercise program. Slots in the program were given on a first come, first serve basis. This resulted in seven people who initiated contact after the program reached capacity. There were 68 total interested participants (53%). Thirty-two potential participants were screened and were included in the study, 25 potential participants were screened but did not meet inclusion criteria, and 11 potential participants expressed interest but were unable to be screened. Sixteen disqualified persons had a PDDS score  $>$  4, four were too active as measured by the GLTEQ, two had a relapse within 30 days, two did not meet the age requirement (i.e.,  $>$ 64 years), and one did not have Internet access. None of the 57 persons who were screened for eligibility refused to participate in the exercise program after receiving details about the program. Of the 32 who were successfully enrolled into the program, 14 initiated contact in response to the email flyer (44%),

8 initiated contact in response to mailed flyer (25%), 6 were called directly (19%), and 4 were recruited via word of mouth (12%). All persons who qualified for the study were sent an informed consent document and returned that document via USPS or electronic medium. Thirty-two participants were sent a link to the baseline testing assessment and exercise program materials. This resulted in a final sample of 32 persons with MS.

*Retention.* Thirty-one persons returned the informed consent document and the baseline testing materials and were placed into the exercise program. Concerning attrition, two participants dropped out of the program, one at week 0 (i.e., due to relapse) and one at week 4 (i.e., due to lack of time). Five participants did not complete the follow-up testing materials. The data from these five participants are not considered in the analysis of the efficacy of the program, but were included in the analysis of missing data. This resulted in a total of 24 participants who completed the study and returned post-assessment materials (retention rate 75%).

*Resource Feasibility: Communication and monetary requirements of the program*

*Communication.* All initial recruitment screening calls took between 10-20 minutes to complete. The average turn-around-time for assessments to be completed via Google Forms was 3.4 ( $\pm$  5.7 days, range 0-20 days). Participants were contacted six times throughout the program for coaching calls and 10 preferred calls in the morning (8:00am-12 noon), 18 preferred calls in the afternoon (12 noon-5:00pm), and 3 preferred calls in the evening (5:00pm-8:00pm). There were no technical issues that occurred on any of the phone communications.

*Monetary Requirements.* The total cost of the study was \$3,726.57 (personnel costs = \$2128.74 USD, \$20.87 USD per/hour; exercise program costs = \$1,597.83 USD, mean cost per person = \$46.93). The materials included in this total are as follows: \$35.44 USD for paper, \$75

USD for stamps, \$1,117.76 USD for equipment (i.e., pedometers and resistance bands), \$95.98 USD for USBs, and \$273.65 USD for shipping materials.

*Management Feasibility: Data management and safety reporting during the study*

*Ethical approval.* A total of 15 days were required to obtain ethical approval by the University of Illinois Institutional Review Board. One additional amendment was submitted for a voluntary feedback questionnaire and it was approved in less than 24 hours.

*Personnel time requirement.* Total personnel time to complete the study totaled 102 hours. This time involved: discussions and meeting between the primary investigator and researcher (4 hours each; e.g., development); racial tailoring considerations and redesign (42 hours; i.e., redesigning Project GEMS: Guidelines for Exercise in Multiple Sclerosis exercise program materials by applying the findings from the racial tailoring informative studies); recruitment preparation (3 hours); recruitment calls (12 hours); material ordering and mail preparation (9 hours), behavioral coaching calls (17 hours), external auditor calls (3 hours), and data entry, checking, and calls for missing data (8 hours).

*Missing data.* There were missing data at both time points. There was one participant who did not complete the baseline testing assessment. Of the 31 participants who completed the baseline assessment, 6 individual questions were left unanswered (i.e., SR-EDSS (3 questions); HHQ (2 questions); type of MS (1 question)). There were six participants who did not complete the post-assessment. All of the participants (N=24) who completed the post-assessment answered all questions. These results suggest an improvement in compliance of data collection during the post-assessment for those who completed the program as the post-assessment was the same as the pre-assessment. Concerning the online log books, 18 participants recorded sessions on the online log book throughout the exercise program. Six participants did not log their exercise



behavior and have consequently been excluded from the data analysis. These logs were utilized to assess participant compliance with the program by comparing the data provided with the exercise prescription given. Eight participants elected to complete the orange program (i.e., exercise prescription met the guidelines at week 6), four participants completed the blue program (i.e., exercise prescription met the guidelines at week 8), and six participants completed the white program (i.e., exercise prescription met the guidelines at week 10).

*Scientific: Safety, burden, compliance, experience, and treatment effect*

*Safety.* There were four mild adverse events reported over the three months of the program. One participant reported two falls unrelated to the study during the three-month program and three participants reported an increase in MS symptoms during the three-month program (i.e., two persons reported an increase in multiple symptoms (e.g., fatigue and walking impairment) and one person reported an increase in fatigue). All four participants continued with the prescribed program. An external auditor contacted the participants once a month inquiring about any adverse events experienced throughout the program. If the participant missed the external auditor's call, they were sent a survey via Google Forms which asked "have you experienced any adverse events (i.e., any physical, psychological, or social harm to subjects during the course of research)?" There were no adverse events reported to the external auditor or via the online survey.

*Burden, compliance, & experience.* The average time for all participants to complete the baseline and post-assessments were 19 minutes ( $\pm 7$  minutes) and 15 minutes ( $\pm 12$  minutes), respectively. Participants who completed their log book (N=18) complied fully with 70% of the total exercise sessions, and complied partially with 23% of the prescribed exercise sessions. The remaining 7% of sessions were not completed or not reported in the participant's log books.

Specifically, participants fully complied with 63% of the aerobic sessions, partially completed 24%, and did not complete 13% of the aerobic sessions. Further, participants fully complied with 77% of the resistance sessions, partially completed 14%, and did not complete 9% of the resistance sessions. The mean duration of the aerobic exercise sessions increased from 15 minutes ( $\pm 10$  minutes) to 26 minutes ( $\pm 11$  minutes) for a percent increase of 76% over the three-month program. The mean steps taken per aerobic exercise session increased from 1519 steps ( $\pm 1310$  steps) to 2655 steps ( $\pm 1358$  steps) for a percent increase of 75% over the three-month program (see Figure 2). The mean exercise intensity of each week's aerobic exercise sessions corresponded with a moderate intensity ( $5 \pm 3$  rate of perceived exertion (RPE)) on the Modified Borg 0 to 10 scale throughout the three-month program (see Figure 3). The mean number of resistance exercises completed per week increased from approximately 5 exercises ( $\pm 0.78$  exercises) to 9 exercises ( $\pm 2.6$  exercises) for a percent increase of about 83% over the three-month program (see Figure 4). The mean exercise intensity of each week's resistance exercise sessions ( $6 \pm 3$  RPE) corresponded with a moderate intensity on the Modified Borg 0 to 10 scale throughout the three-month program (see Figure 5). There was a total of six behavioral coaching calls throughout the three-month program. The mean behavioral coaching call compliance was 4 ( $\pm 1.8$  calls), and the mean call duration was 7 minutes ( $\pm 2$  minutes). Eight participants (25.8%) complied with all six calls, eight participants (25.8%) complied with five of the six calls, five participants (16%) complied with four of the six calls, five participants (12.9%) complied with three of the six calls, two participants (6.5%) complied with two of the six calls, two participants (6.5%) complied with one of the six calls and, two participants (6.5%) complied with zero of the six calls

Fourteen participants elected to complete the feedback questionnaire. Table 5 provides data on the evaluation of the exercise program and its components. Participants were satisfied with all aspects of the exercise program (all mean scores  $>4.3$  out of 5). Participants indicated that they would recommend the exercise program to others, participate in the program again, and continue to use the program materials to keep exercising (all mean scores 4.9 out of 5). Importantly, all participants indicated that they strongly agreed with the statement “considering how MS affects me, the GEMS-T program was appropriate.” For those who engaged in the Facebook group and completed the survey ( $n=8$ ), it was reported that participants were satisfied with the group (mean score=4.25). However, participants reported only utilizing the Facebook group “several times” throughout the study. Further, participants indicated that the exercise program was suitable for their fitness level, the time commitment was reasonable, and that the exercise program was appropriate (all mean scores  $> 4.6$  out of 5). Finally, participants conveyed that they agreed that the program represented them well (mean score 4.3 out of 5), but that they were neutral to noticing the racial tailoring of the program (mean score 3 out of 5).

*Treatment effect.* A paired samples *t*-test was utilized to compare mean scores of pre and post HCS GLTEQ scores. The mean at baseline was 1.6 ( $\pm 3.4$ ) and the mean at the end of the program was 26.0 ( $\pm 22.9$ ) as measured by the GLTEQ. The results of the paired samples *t*-test revealed a statistically significant effect over time ( $df=23, t=-5.1, p < .001, d=-1.5$ ) indicating a large increase in exercise participation. All participants were insufficiently active according to the GLTEQ health contribution score at the beginning of the program. At the close of the exercise program, 11 participants qualified as active (46%), 7 participants qualified as moderately active (29%), and 6 participants remained insufficiently active (25%).

## **Chapter 5 – Discussion**

Evidence suggests that black individuals may have an increased risk for developing MS (Langer-Gould, Brara, Beaber, & Zhang, 2013), experience a more aggressive disease course, may have a poorer response to disease modifying therapies (Klineova, Nicholas, & Walker, 2012), and have increased odds of physical comorbidities in comparison to white individuals living with MS (Marrie et al., 2008). Collectively, this evidence highlights a need for disease management strategies for black individuals living with MS. Physical activity is regarded as one of the best comprehensive MS care strategies, yet much of the research to support such claims has been conducted in white individuals living with MS (Motl, 2014). Therefore, a feasibility trial was conducted to properly inform the design and viability of subsequent research on physical activity and exercise in black individuals living with MS.

The present study assessed the feasibility of a patient informed, racially tailored, home-based exercise program in the domains of process, resource, management, and scientific feasibility. This exercise program was a racially targeted iteration of Project: GEMS (Adamson et al., 2016) for inactive, black individuals living with MS and informed by three exploratory studies (Kinnett-Hopkins & Motl, 2016; Kinnett-Hopkins et al., in preparation; Kinnett-Hopkins & Motl, in preparation). The results suggest that this three-month exercise program is a feasible approach to increasing exercise behavior in an inactive sample of black individuals living with MS.

The outcome of process feasibility concerned recruitment. The results are favorable in comparison to other home-based physical activity and exercise studies conducted in persons living with MS, as recruitment rates typically range from 11% to 52% (Learmonth et al., 2017; Pilutti, Dlugonski, Sandroff, Klaren, & Motl, 2014; Sosnoff, Finlayson, McAuley, Morrison, &

Motl, 2014; Suh et al., 2011). The three-armed approach (i.e., email followed by mail, followed by telephone call) yielded an overall recruitment rate of 53%, which suggests this approach may be a promising recruitment strategy for future studies. Further, this program may be of strong interest to this demographic as none of the 57 persons who were screened for eligibility refused to participate in the exercise program after receiving more details about the program. The retention rate of this exercise program was 75% which is less than, but is still comparable to, other studies in persons living with MS (Pilutti, Dlugonski, Sandroff, Klaren, & Motl, 2014; Saxton et al., 2013; Suh et al., 2015). Regarding attrition, two participants dropped out of the exercise program and six were lost to follow up (25%) which is more than, but still comparable to what is typically seen in exercise studies (i.e., 15%; Pilutti, Platta, Motl, & Latimer-Cheung, 2014).

The outcome of resource feasibility concerned participant communication and monetary cost. The findings from this study provide valuable insight into the requirements necessary when considering a larger RCT. The average turn-around-time for baseline assessments for the current study was about 3 days. Further, there were no technological issues throughout the duration of the exercise program which suggests that behavioral coaching calls via telephone may result in fewer technological connectivity problems in comparison to Skype or FaceTime. However it is important to note that only 25.8% of participants complied with all coaching calls and 67.7% complied with the majority of coaching calls via telephone. When considering the original exercise program wherein nearly 60% of their sample completed all coaching calls via Skype, Facetime and/or telephone call, it is possible that video chats may lead to better adherence to behavioral coaching despite the connectivity issues.

Careful deliberation of the costs of this exercise program are necessary when considering a larger trial as personnel cost and equipment costs may vary. Participants suggested that newsletters be sent via email which may cut down on the paper and postage costs. Additionally, the method of material delivery to participants was changed from the method used in the previous version. Previously, participants were mailed all materials via USPS in corrugated boxes whereas in this study all materials were sent using USPS priority mail flat rate envelopes which resulted in about a \$30 USD savings per person.

Certainly costs were involved in the original development and the cost of the modifications are what have been reported in this paper. Additionally, with regards to the broader scope of who would bear the costs of implementing such a program and the costs of maintenance (e.g., coaching calls, online materials) when assessing the feasibility of this study, it may vary based on the resources of the stakeholder and of the patients. Institutions such as rehabilitation centers who have equipment available may not require the burden of additional exercise equipment but may have to hire personnel to manage the behavioral coaching component. Other potential venues for this program to take place may include health care providers who find value capitalizing on physical activity and exercise's ability to manage the manifestations of MS. Providers may see the benefit of potential cost savings in the long run by promoting and providing materials on how to appropriately achieve the guidelines for physical activity in persons with MS. Lastly, many exercise equipment companies offer discounts for program such as this where providers may receive product at a wholesale cost.

The outcome of management feasibility concerned data management and safety reporting during the study. Communication with the University of Illinois Institutional Review Board took 15 days for ethical approval, and less than one day for amendment approval. The time to receive

approval of this study was less than the time it took to receive approval for the original Project GEMS program (i.e., 41 days). Total personnel time to complete the study equaled 102 hours. The development and implementation of this program largely benefited from the exhaustive development of the original exercise program which may have contributed to the decrease in personnel time among other reasons (e.g., smaller staff, smaller sample size). The original exercise program took a total of 263 hours to complete. Of note, the modification of online assessments versus mailed assessments expedited the time necessary to enter participant data. Participants that completed the baseline assessment left 6 individual questions unanswered, and no questions were left unanswered during the post-assessment. Future studies may utilize the “require to answer question” setting for each question on electronically delivered assessments with the addition of a “skip question” answer choice so that participants are unable to submit the assessment without providing an answer but given the opportunity to skip all questions they do not wish to answer. Regarding safety and adverse events, four participants had mild adverse events (i.e., falls unrelated to the study and increase in MS symptoms) over the three-month period of time and careful consideration of modifications to their current exercise prescription were taken by the behavioral coach. The number of adverse events reported during the three-month exercise program aligns with what is typically reported in other exercise programs delivered in this population (Pilutti et al., 2014). This result supports the safety of this exercise program in inactive black individuals living with mild-to-moderate MS.

The outcome of scientific feasibility concerned safety, burden, compliance, experience, and treatment effect of the study. The addition of an external auditor provides additional credibility to the safety of this program. There were no reports of the assessments being burdensome, unlike what has been reported in previous studies (Learmonth et al., 2017).

However, a couple of participants indicated that the exercise guidelines were too time consuming. Participant compliance was higher for resistance exercise sessions (77%) than with aerobic exercise sessions (63%). These results are contrary to what was observed in the previous iteration of this exercise program which indicated that participant's complied with more aerobic exercise session (75%) than resistance exercise sessions (68%). The participants of the previous version of the exercise program voiced the importance of more variety in the resistance training exercise prescription, which was taken into consideration in the exercise prescription of the current program. It is possible that the ability to choose which exercises the participant would complete for each exercise session satisfied the previous concern and resulted in better compliance of the resistance sessions. Alternatively, this may have been a result of the nature of the sample. There were improvements in mean duration (76% increase) and mean steps (75% increase) over the three-month period of time. Further, the mean number of resistance exercises completed (83% increase) over the three-month period increased as well. Collectively, these data suggest that the progressive exercise prescription increased exercise behavior towards the physical activity guidelines over the three-month period.

Participant experience was measured via feedback surveys which 14 participants elected to complete. Overall, the exercise program was received well and indicated a high level of acceptability, which is important to consider when making adjustments for a larger trial. Further, participants indicated that they were satisfied with the racial consideration. The results of this survey highlighted the importance of a patient informed approach as well as representation in the media of all program materials, as those were the two most common points made by participants. However, these results should be taken with consideration that only 58% of the participants who completed the post assessment elected to complete the formative evaluation.



This study quantified the efficacy of the exercise program for increasing exercise participation as measured by the GLTEQ HCS. There was a statistically significant increase in exercise participation reported over the three-month period of time. Indeed, the results of this feasibility study suggest that this program may improve exercise participation in black persons living with MS. However, they should be considered in light of a relatively small cohort and that six participants did not complete the post assessment.

Of particular note, this study is the first patient informed and racially tailored exercise program delivered in the black MS population. Understanding the correlates (Kinnett-Hopkins & Motl, 2016), wants of an exercise program (Kinnett-Hopkins & Motl, in preparation), and specific needs to engage in an exercise program (Kinnett-Hopkins et al., in preparation), is essential for designing and testing behavioral interventions to increase exercise participation in black individuals with MS. Additionally, as a feasibility study, this project provides great insight into the process, resources, management, and scientific metrics of delivering this exercise program, which may provide valuable insight for the development of large scale RCTs.

Despite these strengths, this study is not without limitations. This study had a relatively small sample size, the sample consisted of primarily women, and there was no control group. Including a control group in future trials will aid in understanding if the attention from a behavioral coach, completing the self-report questionnaires threaten the conclusions of this study. Additionally, exercise participation was measured via self-report survey and therefore the improvement in exercise participation may have been the result of repeated administration effects or response bias. Further, interpretation of the data should be taken cautiously given the number of individuals who did not complete the post assessment (N=6).

Future researchers would do well to conduct formative evaluations to better understand how to reduce attrition and the best way to support continued participation in exercise despite barriers that may occur. Furthermore, the examination of moderators in a larger sample size would be helpful in understanding if some of the program components led to an increase in exercise participation. For example, if participants who engaged in the secret Facebook group, completed the online log book, or complied with all six behavioral coaching calls experienced a greater increase in exercise participation.

This study extended the available literature on exercise in black persons living with MS. Future studies should utilize the comprehensive assessment provided to investigate the actual efficacy and effectiveness of this exercise program in a larger sample on outcomes of MS (e.g., walking impairment, quality of life, depression). Additionally, researchers may utilize a similar feasibility approach to target other racial minority populations living with MS. Finally, follow up testing may be helpful in assessing the long-term effects of a home-based exercise trial.

## **Chapter 6 - Conclusion**

The findings of the current study are encouraging given that the novel exercise program proved feasible and increased exercise participation in a sample of inactive black individuals living with MS. This research was specifically developed for black individuals with MS as a progressive, inexpensive, exercise program that could be modified to an individual's specific abilities, performed at home, and it has great potential for wide dissemination. This research further supports the importance of encouraging exercise participation and tailoring exercise trials in black individuals with MS. Future researchers would do well to utilize the comprehensive assessment of this feasibility study to develop a large scale RCT.

## Chapter 7 – Figures and Tables

Figure 1. Consort Diagram of participant flow.

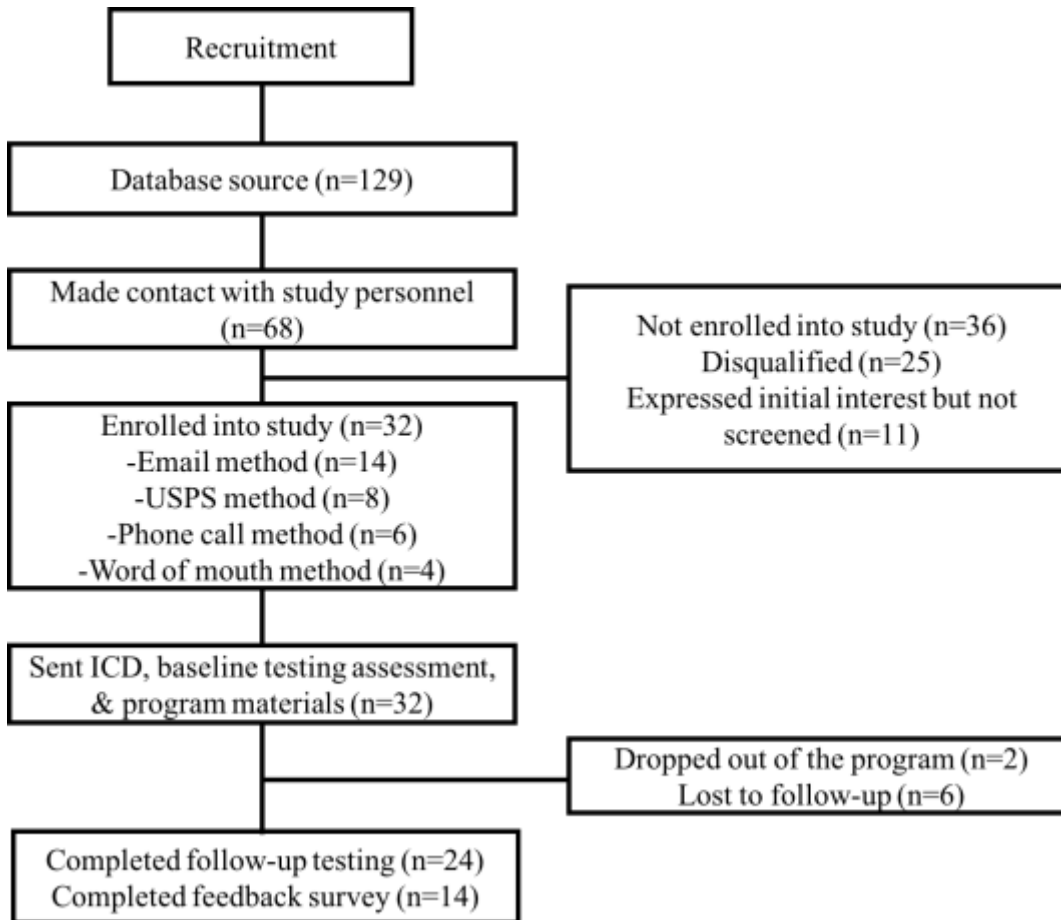


Figure 2. Average steps per weekly aerobic exercise sessions with standard error bars for the participants (N=18) during the three-month exercise program.

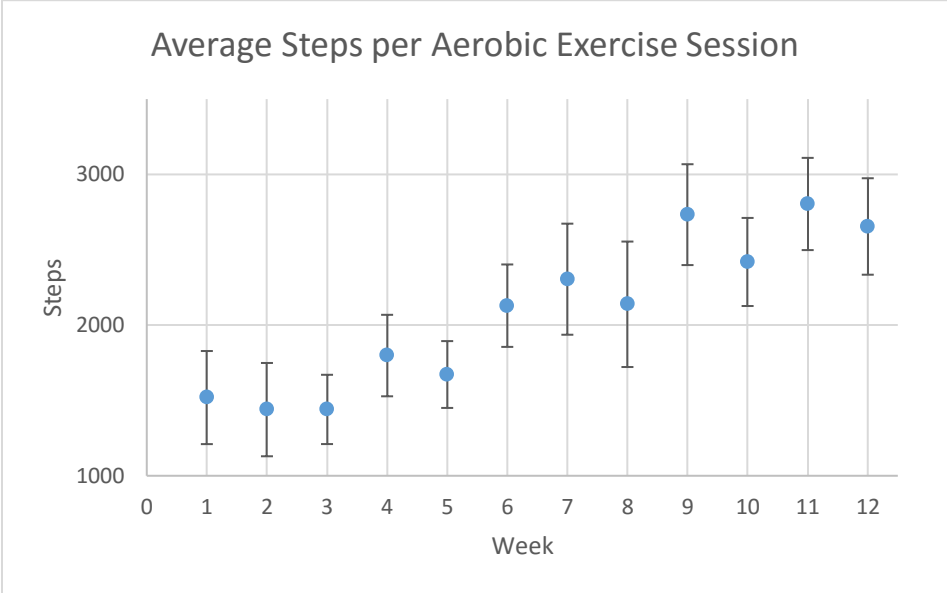


Figure 3. Average RPE per weekly aerobic exercise sessions with standard error bars for the participants (N=18) during the three-month exercise program.

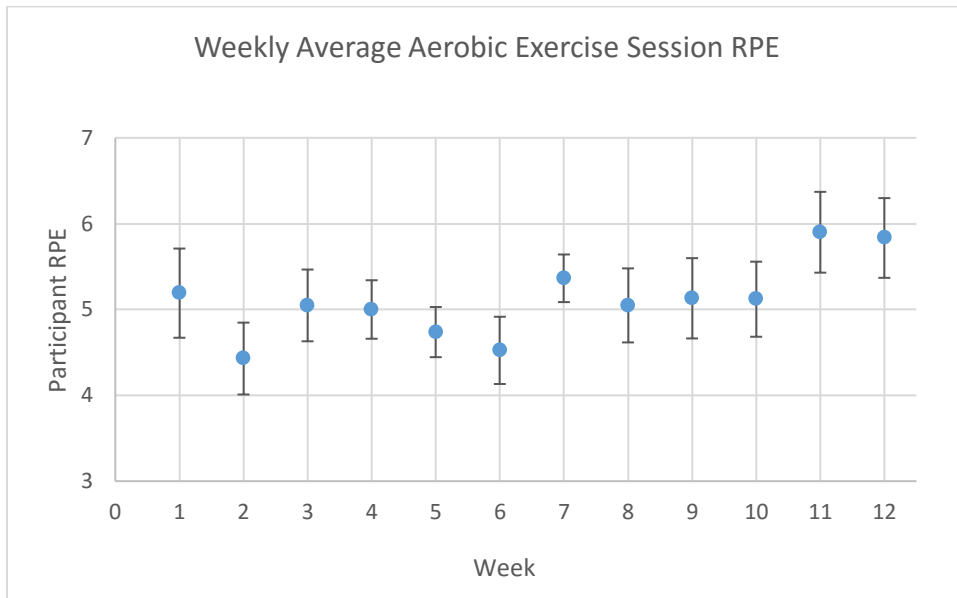


Figure 4. Average number of exercises performed per weekly resistance exercise sessions with standard error bars for the participants (N=18) during the three-month exercise program.

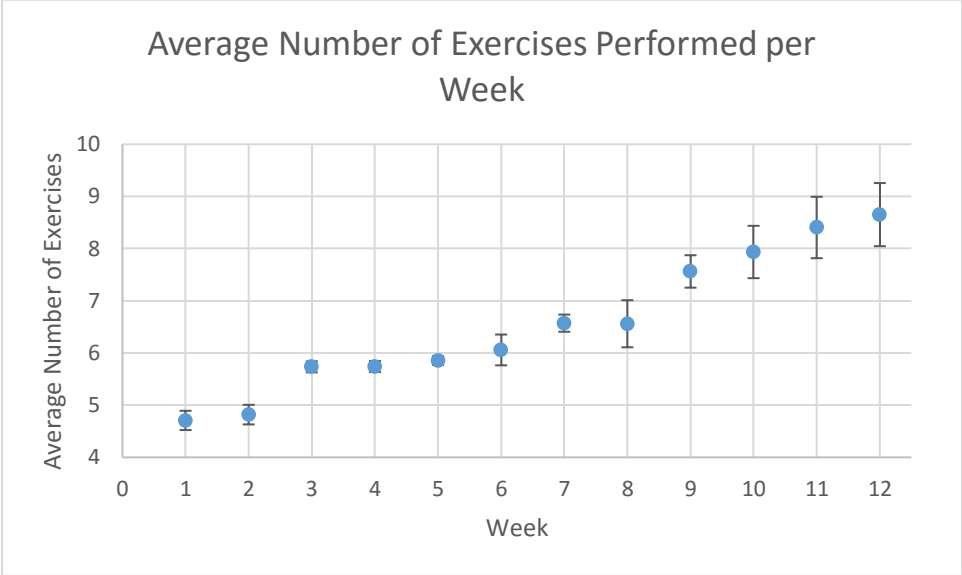


Figure 5. Average RPE per weekly resistance exercise sessions with standard error bars for the participants (N=18) during the three-month exercise program.

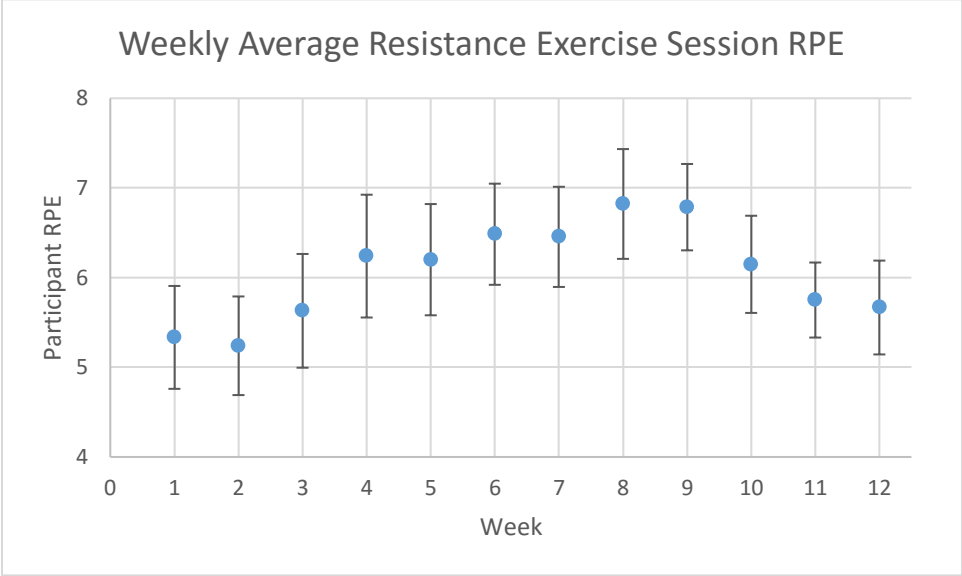




Table 1. Feasibility Metrics: Monitoring and assessment strategy and methodology.

<b>Feasibility Metric</b>	<b>Monitoring/Assessment Strategy</b>	<b>Methodology</b>
<b>Process</b> Recruitment and retention	a. Recruitment and refusal rates	a. Recruitment occurred via email, USPS, and telephone calls. All contact with potential participants was recorded in Microsoft Excel.
	b. Retention, attrition, and adherence rates	b. All participants' flow through the recruitment and program sections of the study was recorded in Microsoft Excel. Adherence with the program was measured via online log books and behavioral coaching calls.
<b>Resources</b> Communication and monetary requirements of the study	c. Communication with participants	c. All communication with participants was recorded in Microsoft Excel. There were no communication problems throughout the three-month program.
	d. Monetary costs of research	d. A record of all monetary costs for the study incurred by the research staff was calculated.
<b>Management</b> Data management and safety reporting during the study	e. IRB approval procedures	e. All communications between University IRB and staff, and time from submission of IRB application to approval was recorded.
	f. Staff preparation and report time for participant communication	f. All preparation, call time, attempted call time, and report-taking time for each participant during the program was recorded in Microsoft Excel.
	g. Time and accuracy in data collection/entry	g. Data completeness, record time to collect, enter, and check data was recorded in Microsoft Excel.
	h. Reporting and handling of adverse events (AE), serious adverse events (SAE) and clinical emergencies	h. There were four mild incidences of AEs reported to the behavioral coach during the exercise program.
<b>Scientific</b> Safety, burden, compliance, experience, and treatment effect	i. AEs, SAEs and clinical emergencies	i. Participants were asked to report and record all medical concerns via log-books, phone chats, and to the external auditor. There were four mild AEs reported.
	j. Participants burden, compliance, and experience during the program	j. Participants were asked to complete a voluntary feedback survey concerning their experience with the GEMS-T program. All answers were analyzed in Microsoft Excel. Participant self-reported their exercise sessions via log books and discussed them during the behavioral coaching calls.
	k. Treatment effect	k. Effect size and clinical meaningfulness of any change in physical activity was determined.

Note: S=set, R=repetition, E=exercise. \*=meeting guidelines

Table 2: Progression of three arms of the physical activity program.

Wk	Orange		Blue		White	
	Aerobic Training	Resistance Training	Aerobic Training	Resistance Training	Aerobic Training	Resistance Training
1	10 min	1S, 10R, 5E	10 min	1S, 10R, 5E	10 min	1S, 10R, 5E
2	10 min	1S, 12R, 5E	10 min	1S, 10R, 5E	10 min	1S, 10R, 5E
3	15 min	1S, 15R, 5E	15 min	1S, 12R, 5E	10 min	1S, 12R, 5E
4	20 min	2S, 10R, 5E	15 min	1S, 15R, 5E	15 min	1S, 12R, 5E
5	25 min	2S, 15R, 5E	20 min	2S, 10R, 5E	15 min	1S, 15R, 5E
6	30 min*	2S, 15R, 6E*	20 min	2S, 15R, 5E	20 min	2S, 10R, 5E
7	30 min*	2S, 15R, 6E*	25 min	2S, 12R, 6E	20 min	2S, 12R, 5E
8	30 min*	2S, 15R, 7E*	30 min*	2S, 15R, 6E*	25 min	2S, 15R, 6E
9	30 min*	2S, 15R, 7E*	30 min*	2S, 15R, 7E*	25 min	2S, 15R, 7E
10	30 min*	2S, 15R, 8E*	30 min*	2S, 15R, 8E*	30 min*	2S, 15R, 8E*
11	30 min*	2S, 15R, 9E*	30 min*	2S, 15R, 9E*	30 min*	2S, 15R, 9E*
12	30 min*	2S, 15R, 10E*	30 min*	2S, 15R, 10E*	30 min*	2S, 15R, 10E*

Table 3: Details of racial tailoring modifications.

Program Component	Original Program	Patient Informed/Tailoring Modification
Manual	The manual is a training guide that provided a detailed description of the exercises to be performed in a progressive manner over a four-month period. The exercise prescription is based on the physical activity guidelines for persons with MS	<ul style="list-style-type: none"> <li>- All images are of a middle aged black woman</li> <li>- Inspirational quotes rooted in faith and/or famous quotes were included in the manual</li> </ul>
Log Book	The log book is a self-monitoring tool that allowed participants to record each aerobic and resistance training session. It further served as a measure of compliance	<ul style="list-style-type: none"> <li>- Inspirational quotes rooted in faith and/or famous quotes were included in the log book</li> <li>- More room for notes was provided</li> </ul>
Exercise Progression & Choices	The exercise progression consists of three arms (i.e., white, blue, and orange) which reach the physical activity guidelines at various paces over the course of the four-month program. There are 10 resistance training exercises that must be followed as prescribed that are included as part of this program	<ul style="list-style-type: none"> <li>- The three arms of the program remained, however participant's progressed to the physical activity guidelines over a three-month period of time (see Table 2)</li> <li>- Participants self-selected the specific exercises from the list of 10 exercises but were asked to incorporate all three target areas (i.e., upper body, lower body, or core) during each session</li> </ul>

Table 3 (Cont.)

<p>Newsletters</p>	<p>Participants receive newsletters periodically throughout the program on a tapering basis that provide information on outcome expectations, self-monitoring, self-efficacy, overcoming barriers, and identifying facilitators. As well as a resource for information on additional resources, testimonials of individuals with MS who have benefitted from engaging in exercise, and exercise tips.</p>	<ul style="list-style-type: none"> <li>- An additional emphasis on self-efficacy, outcome expectations, functional limitations as impediments, and goal setting and planning as it relates to the specific outcome expectations, motivations, barriers, and facilitators expressed by black individuals with MS (Kinnett-Hopkins, Adamson, &amp; Motl, in preparation) was made throughout the newsletters</li> <li>- Testimonials were from black individuals with MS to solicit feelings of vicarious experience as a means of increasing self-efficacy</li> <li>- Resources were provided that detailed information for black individuals with MS</li> <li>- Tips for exercise included ways to overcome specific barriers to black individuals with MS ( Kinnett-Hopkins, Adamson, &amp; Motl, in preparation)</li> </ul>
<p>Coaching Calls</p>	<p>There were 8 one-on-one, semi-structured, skype/FaceTime chats with an MS exercise specialist over the four-month period. The calls coincide with the newsletters, complement their content, and any additional concerns the participant may have had</p>	<ul style="list-style-type: none"> <li>- There were 6 semi-structured phone chats (i.e., standard telephone calls) over the three-month period (i.e., weeks 1,2,3,4,6, and 9)</li> </ul>
<p>Coach</p>	<p>The behavioral coach was a trained research staff member of the Exercise Neuroscience Research Laboratory at the University of Illinois at Urbana-Champaign</p>	<ul style="list-style-type: none"> <li>- In addition to being a trained research staff member of the Exercise Neuroscience Research Laboratory, the coach also identified as a black individual</li> </ul>
<p>Assessments</p>	<p>Participants completed all a battery of questionnaires via USPS</p>	<ul style="list-style-type: none"> <li>- All assessments were delivered via Google Forms in attempts to alleviate participant burden</li> </ul>

Table 4. Participant demographics and clinical variables.

Variable	MS (N=31)
Mean age (SD)	51.6 ± 9.4
Sex (n, % female)	29 (94%)
Income (n,%)	14 (44)
<\$40,000 USD	17(55%)
>\$40,000 USD	14 (44%)
Contraindications (n)	
Diabetes	1
Hypertension	14
High Cholesterol	3
PDDS (median, range)	1.5 (4)
MS Type (n) N=30	
RRMS	26
PPMS	3
SPMS	1
Mean duration of MS (SD)	15.7 ± 7.5

*Note:* PDDS=Patient Disease Determined Steps; RRMS=Relapsing Remitting Multiple Sclerosis ; PPMS=Primary Progressive Multiple Sclerosis; SPMS=Secondary Progressive Multiple Sclerosis

Table 5. Formative Evaluation ( $n=14$ ) of the Three-Month Exercise Program.

Variable	Mean (SD)
Satisfaction:	
Overall program	4.9 (0.4)
Program manual	4.4 (0.7)
Paper log book	4.5 (0.7)
Online log book	4.7 (0.5)
Calendars	4.6 (.8)
Exercise video demos	4.9 (0.4)
Resistance bands	4.8 (0.4)
Pedometer	4.5 (0.8)
Newsletters	4.5 (0.7)
Phone calls	4.8 (0.4)
Facebook group	4.25 (0.7)
Racial tailoring of this program	4.6 (0.7)
Agreement:	
I would recommend the GEMS-T program to others with MS	4.9 (0.3)
I would participate in a program like this again	4.9 (0.3)
I will continue using the GEMS-T materials to keep exercising	4.9 (0.3)
Considering how MS affects me, the GEMS-T program was appropriate	5.0 (0.0)
GEMS-T was suitable for someone of my fitness level	4.6 (0.7)
The time commitment was reasonable	4.6 (0.8)
The progression of the exercise program was appropriate	4.9 (0.3)
The materials of this program represented me well	4.2 (0.6)
I noticed that this program was racially tailored	3.0 (1.3)

Note. Satisfaction was measured on a 1-5 Likert scale (1=completely unsatisfied, 5=completely satisfied); Agreement was measured on a 1-5 Likert scale (1=completely disagree, 5=completely agree); GEMS-T=Guidelines for Exercise in Multiple Sclerosis-Tailored.

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