Catherine Jacobs & Audrey Osinski

Assignment 3- Project Description/Approach

**Statement of Need:**

Multiple Sclerosis (MS) is a chronic and unpredictable immune mediated disease that affects the central nervous system. Individuals are affected in diverse ways. Symptoms may include weakness or paralysis, changes in vision, numbness and tingling, pain, spasticity, fatigue, bowel and bladder dysfunction, cognitive and emotional changes. As a consequence of these various symptoms, patients often experience reduced physical, mental and/or social well-being. These aspects of well-being are interconnected: as physical changes may lead someone to question their career choice, ability to start a family, or participate in previous hobbies and social activities, this also affects the individual’s mental and social wellbeing.1 It is common to be diagnosed between the ages of 20-50, with women diagnosed more than men (2-3:1). Individuals this age typically don’t anticipate physical challenges, which may affect mental and social well-being.

According the National Multiple Sclerosis Society (NMSS), more people are being diagnosed with MS today than in the past.2 There are estimated to be over 400,000 in the US who have MS.3 The Greater Carolinas Chapter serves over 14,400 individuals with MS and their families in 82 counties in NC and SC.4 Receiving a diagnosis of MS can be life changing. With such an unpredictable disease, there are inevitably questions and concerns. At the time of diagnosis an individual may not be emotionally ready to take in a lot of new information, and they may not know what questions to ask. Studies have shown patients desire more information, especially in the early stages of MS.5 The NMSS (and other larger organizations) offer many educational resources for those with MS, but this information can still be overwhelming. Resources include website links, intermittent teleconferences, chapter meetings, and self-help groups, but there are few consolidated resources (especially for those who are newly diagnosed). Other chapters of the NMSS have offered retreats, but no such program is offered through the Greater Carolinas Chapter. Individuals need a reliable and consolidated source of comprehensive information when they are newly diagnosed.

The World Health Organization defines health as, “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”6 We are proposing a three-day wellness retreat emphasizing the physical component of health, but also including the mental and social well-being aspects of health, for newly diagnosed individuals.

Physical:

* Individuals may be unaware of treatment options and strategies for management of physical symptoms of MS.5
* Individuals may not yet understand the importance of physical activity throughout the disease course. Any uncertainties should be addressed, both for those who are already active, as well as for those who need guidance to become more active.5
* Physiological changes can begin early with the diagnosis of MS (eg. change in gait and balance).7 Individuals should be educated about what these potential changes are and how to address them.
* Evidence demonstrates that physical activity can reduce the impact of MS and slow the disease progression.8
* Physical activity can positively affect disease activity, functional status, mental and physical health, and overall quality of life (QOL).9

Mental:

* Individuals’ emotional reactions will vary (eg. denial, anger, uncertainty, relief) at initial diagnosis, and throughout the course of the disease.1
* Individuals with MS may experience cognitive changes.10
* As physical changes can be unpredictable, individuals with MS may question their ability to be active, independent, and provide for others which leads to negative self-concepts.11

Social:

* + Individuals may have concerns about employment, their family and/or having a family, relationship challenges, etc.1

A diagnosis of a chronic disease can impact all areas of a person’s life, potentially decreasing self-efficacy and quality of life. The goal of this program is to help individuals in the Greater Carolinas who are newly diagnosed with MS to have a healthy and well informed adjustment to their diagnosis by improving self-efficacy and outcome expectation.

**Background:**

Finlayson et al identified that health promotion (both physical and social) is an important unmet health-related service need for individuals with MS.8 This is especially significant because evidence has shown people with chronic, disabling conditions may be less likely to demonstrate health-promoting actions, which consist of “behavioural, cognitive, and emotional efforts to sustain health and well-being.”12,13 Additionally, studies demonstrate that there is a disconnect between the amount of information people with MS desire and receive; people want more reliable information.5 This need is even more significant for those who are newly diagnosed.5

Several studies have demonstrated the connections between self-efficacy, QOL, and health-promotion, and suggest the importance for individuals with MS.9,14,15 Bandura explores the concepts of self-efficacy and outcome expectations in his Social Cognitive Theory.16 Self-efficacy is defined as “the belief or confidence that a person can carry out in a behavior necessary to reach a desired goal.”16 This is distinct from outcome expectation, which is “a personal judgment that a particular task or behavior will result in a specific outcome.”16 If an individual has high self-efficacy and high outcome expectation, they are more likely to demonstrate productive change and have an improved QOL.16 These concepts are especially important for self-management of a chronic disease such as MS. Self-efficacy influences how an individual adapts to physical, mental, and social changes, as well as their determination when facing challenges of MS. When a person understands the potential effect of various interventions, they are more likely to have positive outcome expectations, and demonstrate health promotion behaviors. Our goal is that self-efficacy and outcome expectation will be improved through the knowledge gained through attending this wellness retreat.

Many studies evaluate the outcomes of wellness programs on health promotion for individuals with MS. Stuifbergen et al note recent evidence demonstrates that health promoting behaviors, including physical activity and stress management, may positively affect “disease activity, functional status, mental and physical health, and overall QOL.”9 A wellness intervention should address barriers, resources available, and self-efficacy, which can influence health promoting behaviors.9 Ultimately the goal is to improve QOL.9 113 women with MS participated in 8 weeks of “lifestyle-change classes” and had telephone follow-up for 3 months; results demonstrated significant improvements in self-efficacy for health behaviors, health-promotion behaviors, and the mental health and pain scales of the SF-36.9

Ennis et al emphasize the important correlation between self-efficacy and health promotion activities in both general population, as well as those diagnosed with MS.13 Interventions therefore should focus on increasing self-efficacy, for example through a group program. 62 adults with MS participated in an 8 week multi-disciplinary education program “aimed at increasing knowledge, skills and confidence in undertaking health promotion activities.”13 This led to increasing health promotion activity and self-efficacy, both of which were maintained for 3 months after the program ended.13 Additionally, other studies have demonstrated the long-term benefits of health promotion programs, including improved QOL up to 5 years after the wellness program.14

CAN DO is an established wellness program which also uses the format of a multi-day multi-disciplinary program to address self-efficacy, although they do not specifically focus on individuals who are newly diagnosed with MS. Ng et al review self-efficacy in MS as it relates to psychological adjustment, QOL and perceived health status, and physical activity.15 Ng et al note that self-efficacy is critical for an individual to be their own self advocate.15 Ng et al studied the CAN DO program and found improvements in self-efficacy, health related QOL and physical activity, which were maintained up to 6 months after intervention.15

These studies demonstrate the effectiveness of a wellness intervention specifically for individuals with MS. They also address the importance of self-efficacy on health promotion activities. We hope to build on this body of evidence by specifically focusing on those who are newly diagnosed with MS. As we are proposing a three-day retreat, self-efficacy is critical for success in implementing health-promotion changes after the program. We believe the wellness program we are proposing builds from this current evidence and will continue to improve the health-promoting behaviors and overall QOL of those newly diagnosed with MS.

**Project Description/Approach:**

*Objectives:*

The goal of the wellness program is for individuals to gain extensive knowledge of MS in areas related to physical, mental, and social well-being in order to improve self-efficacy and outcome expectations. In order to measure the effectiveness of the program, the following objectives will be assessed. The specific objectives are listed below.

* + *Participants will demonstrate 25% improvement on the Multiple Sclerosis Self-Efficacy survey at conclusion of wellness retreat and will be maintained at 3 month follow up*. Self-efficacy influences how an individual adapts to physical, mental, and social changes, as well as their determination when facing challenges of MS. High self-efficacy will enable individuals to implement long lasting healthy behaviors after the brief wellness program. The Multiple Sclerosis Self-Efficacy survey has been validated for this population, and measures the perception of ability to perform physical and psychological behaviors related to the management of MS.15,17
	+ *Participants will increase physical activity measured by the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) by 15% at 3 month follow up.* *Additionally, participants will report 80% confidence in implementing individualized wellness plans at conclusion of wellness retreat, measured by a post wellness program survey.* Physical activity can positively affect disease activity, functional status, mental and physical health, and overall QOL.9 The PASIPD tracks the time individuals spend on recreational, household, and occupational activities throughout the week.18
	+ *Participants will improve overall score on Multiple Sclerosis Quality of Life-54 (MSQOL-54) by 10% at 3 month follow up*. The MSQOL-54 was built from the SF-36, with additional questions specific to MS.19 It has been validated in populations with MS.19 MSQOL-54 measures multiple subscales include emotional well-being, health perceptions, social function, cognitive function, health distress, and overall quality of life.19 This measure will help assess physical, mental, social well-being and overall quality of life.
	+ *Participants and their partner (eg. family member, friend) will demonstrate increased knowledge of MS as measured by at least a 15% score improvement on a questionnaire distributed pre and post wellness program.* This score will help measure effectiveness of the wellness program in providing a consolidated source of information for the individual with MS and their partner who is specifically helping them adapt to life with MS.
	+ *Participants’ partners will improve confidence by 15% measured by a pre and post questionnaire regarding confidence levels, to indicate an improved ability to support their loved one throughout this chronic diagnosis, particularly in implementing the participant’s individualized wellness plan.* Improvement in this area has the potential to improve participants’ quality of life as well as decrease psychosocial demands on the caregiver.20

*Methods:*

 The wellness program will consist of a three day retreat offered twice a year for individuals newly diagnosed with MS and their partners. The spring program will be held in Chapel Hill, NC, and the fall retreat will be held in Asheville, NC. Individuals will be responsible for transportation and lodging, but participation in the event will be free of charge. As sponsors, Asheville Retreat Center and Chapel Hill Lodge will offer reduced room rates. Target audience will be 15-20 individuals with MS.

 Information at the wellness retreat will focus on physical well-being, but will be supplemented by presentations to also promote social and mental well-being. Each participant will meet one on one with a physical therapist to establish an individualized wellness plan that provides specific guidelines to promote physical activity after the completion of the wellness program. Wellness plans will include an individualized home exercise program building off of their previous level of activity. Additionally, the physical therapists will provide recommendations for appropriate community based resources for each participant depending on their access to resources. This will meet the needs of those who are beginning to exercise as well as those who have already established exercise routines. Physical therapists will only help initiate the wellness plans; therefore it is important that participants have a high sense of self-efficacy to successfully implement the plans. Therapists will call participants one month after the retreat to address any barriers faced by the participants. Individuals will be contacted again via phone at three months to assess progress towards objectives and goals. Written outcome measures will also be mailed to participants at one and three month follow ups. A detailed itinerary is below.

Weekend Itinerary:

|  |  |
| --- | --- |
| Friday  | **Morning:**Check In Complete all assessment measures and individual meetings with physical therapists.**Afternoon**:Lunch and get to know you PT Information Session: *General knowledge of MS, early changes in MS* Break Group Exercise: *Yoga led by local fitness instructor* **Evening:** Dinner and Social Event  |
| Saturday  | **Morning:** Breakfast PT Information Session: *Importance of Physical Activity: Resistance and Aerobic Training* Break Participants’ Group Exercise: *Resistance Training led by PT* Partner Activity: *Caregiver well-being led by PT*  **Afternoon:** Lunch Interdisciplinary Information Session (Neurologist): *Medical management and Open Forum* **Evening**: Social Event  |
| Sunday  | **Morning:** Breakfast PT Information Session: *Importance of Physical Activity: Balance and Flexibility* Break Participants’ Group Exercise: *Balance and flexibility exercises led by PT and local Tai Chi Instructor* Partner Activity: *Forum with Neuropsychologist: coping, supporting your loved one* **Afternoon:** Roundtable Lunch with Interdisciplinary Professionals (Neuropsychologist, Nutritionist, Vocational Rehab): *Coping, Nutrition, Employment* Complete all closing assessment measures Closing Ceremony  |

**Evaluation:**

*Assessment*

To assess the specific program goals we will utilize the outcome measures stated in the objectives section above. As described, various measures will be distributed at the conclusion of the event as well as at one and three months follow up. In addition, we will distribute a satisfaction survey to participants and their partners at conclusion of the retreat to assess the program overall and specific details. These details may include logistics such as location and time as well as materials covered and presenters at the retreat.

*Limitations*

 There are potential limitations with this proposed wellness retreat. Logistics of running this event twice a year could be challenging. It is important that multi-disciplinary providers attend this retreat so that participants have a comprehensive experience that addresses physical, mental, and social well-being. Additionally, recruitment of participants is important for success. While we have established a need for this program, some individuals who are newly diagnosed may cope differently and are not ready to actively address their diagnosis. Transportation may be problematic, although varying the location of the retreat will help address this issue. We believe three days allows for a thorough and relaxed experience, although some peoples’ schedules may not permit for this time commitment.

 While we believe the design of this program is appropriate for the stated objectives, there are potential limitations in interpreting certain outcomes. Due to the brevity of the program, we are limited in our ability to assist participants over time as well as assess long-term lifestyle changes. We hope to facilitate success through improved self-efficacy, and two follow up phone calls. Finally, the lack of a control group limits the quality of the evidence. These results will still add to the current literature regarding wellness programs for individuals with MS.

*Relevance*

The evaluation results will provide support for early intervention for individuals newly diagnosed with MS. Additionally this retreat can be a model of early intervention both for individuals newly diagnosed with MS, as well as other chronic diagnoses such as Parkinson’s disease. Receiving information and promoting health is a challenge for individuals with many chronic conditions.21 This program design helps to promote self-efficacy and taking an active role in managing one’s health. This will be beneficial for anyone newly diagnosed with a chronic condition.

Honor Code: *I have neither given nor received unauthorized aid on this assignment.*

*– Catherine Jacobs and Audrey Osinski*

References:

1. Halper J. The psychosocial effect of multiple sclerosis: The impact of relapses. Journal of the Neurological Sciences. 2007;256:S34-S38.
2. National Multiple Sclerosis Society: Who Gets MS? <http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/who-gets-ms/index.aspx>.  Accessed 10/9/13.
3. Multiple Sclerosis Foundation: Facts About MS. <http://www.msfocus.org/Facts-About-MS.aspx>.  Accessed 10/11/13.
4. National Multiple Sclerosis Society: Greater Carolinas. <http://www.nationalmssociety.org/chapters/NCT/index.aspx>.  Accessed 10/9/13,13.
5. Matti AI, McCarl H, Klaer P, Keane MC, Chen CS. Multiple sclerosis: Patients' information sources and needs on disease symptoms and management. *Patient Prefer Adherence*. 2010;4:157-161.
6. World Health Organization: WHO definition of Health.<http://www.who.int/about/definition/en/print.html>.  Accessed 10/11/13.
7. Martin CL, Phillips BA, Kilpatrick TJ, et al. Gait and balance impairment in early multiple sclerosis in the absence of clinical disability. *Mult Scler*. 2006;12(5):620-628.
8. Plow M, Cho C, Finlayson M. Utilization of health promotion and wellness services among middle-aged and older adults with multiple sclerosis in the mid-west US. *Health Promot Int*. 2010;25(3):318-330. doi: 10.1093/heapro/daq023; 10.1093/heapro/daq023.
9. Stuifbergen AK, Becker H, Blozis S, Timmerman G, Kullberg V. A randomized clinical trial of a wellness intervention for women with multiple sclerosis. *Arch Phys Med Rehabil*. 2003;84(4):467-476. doi: 10.1053/apmr.2003.50028.
10. Jonsson A, Andresen J, Storr L, Tscherning T, Soelberg Sorensen P, Ravnborg M. Cognitive impairment in newly diagnosed multiple sclerosis patients: A 4-year follow-up study. J Neurol Sci. 2006;245(1-2):77-85. doi: 10.1016/j.jns.2005.09.016.
11. Irvine H, Davidson C, Hoy K, Lowe-Strong A. Psychosocial adjustment to multiple sclerosis: exploration of identity redefinition. Disability and Rehabilitation. 2009;31(8):599-606.
12. Stuifbergen AK, Roberts GJ. Health promotion practices of women with multiple sclerosis. *Arch Phys Med Rehabil*. 1997;78(12 Suppl 5):S3-9.
13. Ennis M, Thain J, Boggild M, Baker GA, Young CA. A randomized controlled trial of a health promotion education programme for people with multiple sclerosis. *Clin Rehabil*. 2006;20(9):783-792. doi: 10.1177/0269215506070805.
14. Hadgkiss EJ, Jelinek GA, Weiland TJ, et al. Health-related quality of life outcomes at 1 and 5 years after a residential retreat promoting lifestyle modification for people with multiple sclerosis. *Neurol Sci*. 2013;34(2):187-195. doi: 10.1007/s10072-012-0982-4; 10.1007/s10072-012-0982-4.
15. Ng A, Kennedy P, Hutchinson B, et al. Self-efficacy and health status improve after a wellness program in persons with multiple sclerosis. *Disabil Rehabil*. 2013;35(12):1039-1044. doi: 10.3109/09638288.2012.717586; 10.3109/09638288.2012.717586.
16. Rea BL, Hopp Marshak H, Neish C, Davis N. The role of health promotion in physical therapy in california, new york, and tennessee. *Phys Ther*. 2004;84(6):510-523.
17. Schwartz CE, Coulthard-Morris L, Zeng Q, Retzlaff P. Measuring self-efficacy in people with multiple sclerosis: a validation study. Arch Phys Med Rehabil. 1996;77(4):394-8.
18. Washburn RA, Zhu W, McAuley E, Frogley M, Figoni SF. The Physical Activity Scale for Individuals With Physical Disabilities: Development and Evaluation. Arch Phys Med Rehabil. 2002;83:193-200.
19. National Multiple Sclerosis Society. MSQOL-54. Clinical Study Measures. <http://www.nationalmssociety.org/ms-clinical-care-network/researchers/clinical-study-measures/msqol-54/index.aspx>. Accessed 11/12/13.
20. Kouzoupis AB, Paparrigopoulos T, Soldatos M, Papadimitriou GN. The family of the multiple sclerosis patient: A psychosocial perspective. International Review of Psychiatry. 2010;22(1):83-89.
21. Stuifbergen AK, Rogers S. Health Promotion: An Essential Component of Rehabilitation for Persons with Chronic Disabling Conditions. *Advances in Nursing Science*. 1997;19(4):1-20.