Role changes related to multiple sclerosis: a case study

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Abstract

Multiple Sclerosis (MS) is a chronic, progressive disease that causes the demyelinating of the central nervous system (Silcox, 2003). MS typically affects those in their 20’s to 50’s, often the most productive years of one’s life. Little is known about how MS affects the roles of people dealing with the disease, and how these changes affect society in general. By understanding the role changes that occur in patients with MS, occupational therapists and healthcare professionals can offer a plan of care that focuses holistically on the patient and his or her needs. With MS being the largest debilitating disease of young people, the implications of understanding the life roles of individuals with MS is significant (Holland, Hurray & Reingold, 2002).

Just as no two people with MS will have the same symptoms and severity, no two people with MS will experience the same role changes in life. This case study serves as just one example of how MS can affect the life of an individual and the lives of those around that individual. Ultimately the goal of this case study is to bring awareness to the life dynamics that are affected by MS.
Introduction

Multiple Sclerosis (MS) is the most common neurological cause for debilitation in younger people. MS has an age of onset between 10 and 50 years of age, with the average onset at age 34 (Silcox, 2003). While the age of diagnosis of MS can range, the overwhelming majority of diagnoses occur between 20 and 40, which tend to be an individual’s most productive years. Only 5 percent of all diagnosis occur below the age 16. The age of onset is particularly important because this is a time when individuals typically fill many roles in life. Those in their 30’s and 40’s typically have families of their own, and in some cases may also be responsible for the care of their own parents. MS happens to occur more in the female population, with approximately 73 percent of all diagnosed being female.

In the United Kingdom, Miden (1994) found that only 29 percent of people with MS were employed, primarily working white collar jobs. While MS can lead to impaired function, it typically does not shorten the life expectancy of those with the disease. Compston et al. (1993) found that roughly 50 percent of those diagnosed with MS would require walking aids within 15 years, and only 10 percent of those diagnosed having no significant disability.

It is important to understand that no two people will experience the same MS symptoms. MS has many physical and cognitive impairments that can potentially develop (Sharon & Schonfeld, 1995). Freal et al., (1984) found fatigue to be the most common symptom of MS, affecting 75 to 95 percent in a particular study, with 50 to 60 percent reporting fatigue as one of their worst symptoms. The impact of fatigue over an individual’s life is important to understand. Fatigue can exacerbate impairment and disability and is intimately related to one’s feeling of control of the disease. Of those who experience fatigue, 40 to 70 percent of those individuals experience it on a daily basis, typically up to 6 hours a day with onset in the afternoon (Schapiro, 2003). In order to manage MS one must learn to plan ahead to get the most out of their day. A
mother who works during the day and also manages a house hold will usually not be able to fulfill both roles without serious modifications to her routine, and lifestyle.

Spasticity is a common debilitating symptom occurring in about 80 percent of people with MS. The spasticity is a hypertonicity of the muscles causing a shortening of the soft tissue. Spasticity is most common in the lower extremities which can hamper gait and functional performance (Finlayson, 2003).

Of all MS diagnoses, 95 percent are Caucasian, it is possible for other ethnic minorities to develop MS but it is not very common (Silcox, 2003). To truly understand the impact of MS one must view the disease from the perspective of those that live with the disease, and the life changes that occur because of the MS progression.

Client Background Info

Angela is a forty eight old African American woman who was diagnosed with Relapsing Remitting Multiple Sclerosis at the age of forty one. She currently lives with her husband in a three bedroom apartment in Charlottesville, Virginia. The husband Ed is the primary caregiver of the family and is currently the individual who supplies an income and benefits for the family. It is important to understand Angela’s family dynamics because this shows how the disease of multiple sclerosis has affected the roles of this woman’s life.

Angela and Ed have two sons, ages eighteen and twenty one. Prior to being diagnosed with multiple sclerosis in September 2003, Angela was the primary home manager, was heavily involved in the parent teacher association, and worked as an administrator for a large church in Fairfax, VA, a busy suburb of the District of Columbia. The impairments brought on by multiple sclerosis dramatically changed the lives of the entire family.

Angela was not only serving a role as the primary provider for her and Ed’s children, she was also beginning to be burdened by the care needs of both her and Ed’s parents. Angela and
Ed take the needs of their family seriously, and made an early decision to be the primary care providers if need be to their parents. Angela’s parents lived in North Carolina, while Ed’s parents lived in Maryland. Angela’s two older sisters live outside the United States, and are unable to assist in their parent’s care.

Angela’s disease progressed quickly early on, which is not uncommon in African American woman. To assist in providing care to his wife and family, Ed retired in 2003 from his ministry position while still in his forties. Fortunately Ed had served in the United States military prior to ministry work and had a solid pension and flow of good benefits. The cost of living in Northern Virginia is very high and continues to grow, demanding a high income to accommodate the costs. Angela and Ed decided it was in their best interest to move to an area more suitable to the new lives and lifestyles the two of them had. Angela and Ed’s oldest child just graduated and was going to school at Virginia Tech University. While Angela’s parents were in need of care in North Carolina, the two could not afford to pay out of state tuition at this time.

With Angela’s parents living in North Carolina, the two would routinely drive down State Route 29 to check in on her parents outside Winston-Salem, N.C. Along the drive the two would always pass through the quaint beautiful town of Charlottesville, VA. Angela and Ed had always thought it would be great if they found themselves in this historic peaceful town. Now it just so happened that the conditions were right and the two decided to make the dream a reality. Charlottesville was more than just a quaint, historic town, it was the home to the University of Virginia. The University has long been one of more prestigious schools on the east coast, and happened to have the one of the best MS support systems in the state. Angela used this resource and was connected to a local neurologist who provided the referral to the UVA-HealthSouth Neurology Outpatient Rehabilitation Center.
Pre-Intervention Assessment

Angela was first evaluated at the University of Virginia HealthSouth Neurological Outpatient Rehabilitation Center on February 17th, 2010. Angela’s husband Ed pushed Angela in the wheelchair up to the table where Angela answered questions about past medical history and was formally assessed. It was clear from the initial meeting that Angela had a very supportive husband, often he chimed in with questions, or answer questions throughout the session. On the initial evaluation it was apparent that Ed was assisting or completing much of Angela’s activities of daily living and independent living skills. The formal assessment involved the 9-hole peg test (Holser & Fuchs, 1957) and box and blocks (Kellor et al., 1971) to obtain a quantitative value for bilateral hand dexterity (See Appendix A) Grip and pinch strength were evaluated using a diamometer on the second setting. Angela identified having blurred vision (sometimes double vision) in the left eye when fatigued. From the interview, fatigue was identified as a limiting factor of function, to quantify this, two assessments were given, the “Modified Fatigue Scale”, and the “Fatigue Impact Scale” (See Appendix B). The Modified Fatigue Scale presented a score of 47/63, which is indicative of high fatigue, the Fatigue Impact Scale presented a physical fatigue score of 21/36, which supports the claim made by the first fatigue assessment. Fatigue questionnaires are one of the easiest ways to get an idea of a patient’s level of fatigue (Tipping, 1996).

Angela presents functionally as a subject with left side hemiplegia. She demonstrated a flexor spasticity pattern in the upper extremity, with an extensor spasticity pattern in the lower extremity. To help combat the spasticity and fatigue, Angela was taking Baclofen once a day coupled with a Tysabri infusion once a month. The Bobath NDT model of practice (Bobath, 1970), was chosen because it addressed spasticity, the reported primary limiting factor in Angela’s function.
NDT is a model of practice that is primarily concerned with the quality of movement patterns and its influence on selective functional activities (Bobath, 1990). During an NDT evaluation the first step is to understand the ability of the subject through passive range at the joints. The idea is that knowing how a joint moves passively will give reliable information on how the joint will move actively, provided the muscle strength is there to perform the movement. Evaluation of the joint movements passively can be done in conjunction with functional assessment. The degree and distribution of spasticity is inconsistent and should not be taken into account when determining passive range. It is important to understand that NDT looks more at the subject’s abilities as opposed to the subject’s level of function. A joint in isolation may have full range when tested, but have limitations when the joint is involved in patterns of movement.

NDT has a unique way of viewing muscle strength. When testing muscle strength it is important to understand that the result may not give a true representation of the individual’s abilities for the following reasons:

Muscle weakness may not be real, but rather the result of opposition by spastic antagonists. If the antagonist’s spasticity is reduced, the testing muscle might show to be of relatively normal strength. In hemiplegic patients the traditional idea of reciprocal relaxation of the non-contracting muscle group does not always exists. Instead a patient may have opposing muscle groups firing into contraction at the same time. This is reinforced by the tonic stretch reflex that makes elongation of the antagonist muscles contract even more for sustained periods of time. This co-contracture shows how the prime movers can be measured as weak by a functional output assessment; but in fact could be very powerful muscles. Angela does not appear to have sensory deficits (tactile or proprioceptual), that could cause poor prime mover contraction. Instead her lack of strength appears to be a related to opposition of spastic antagonists in external rotation, and lack of neuro-muscular innervations in the distal extensors.
Abnormal coordination is often seen as the main limitation in hemiplegia, therefore assessment of coordination is the highest priority. Angela’s poor performance in the dexterity tests, and inability to type or write are observed primarily as issues of coordination. It is appropriate to follow the NDT model of practice and view Angela’s joint range limitations, and muscle strength as secondary problems to the lack of coordination. While Angela has a general left upper extremity flexor spasticity issue, she demonstrates flaccid wrist and digits. Flaccidity is the result of the lack of postural reflex against gravity (Bobath, 1978). Tone can be to low resulting in no patterns of activity (normal or abnormal).

Angela’s initial NDT assessment is used to provide a baseline to compare abilities at a future time. Once the therapist has an idea of the subject’s abilities, these abilities must be continuously assessed throughout the following treatments. While Angela reported spasticity as a primary limiting factor to her function, under NDT spasticity in itself is not assessed. The reason for not specifically assessing spasticity is that spasticity is always changing, the strength varying with the constant changing state of the patient’s central excitation (Bobath, 1990). The close association of spasticity with the typical abnormal postural patterns of the subject make a separate spasticity assessment unnecessary (Bobath, 1970).

Throughout the NDT evaluations and treatments it was not noticed that Angela had difficulty with sensory tactile or proprioceptive issues of distal parts of the body, but did seem unaware of her postural positioning, along with proximal movements in space. NDT testing was not done in one day but rather over a period of treatment days. Typically treatment sessions are forty five minutes which does not allow enough time to get everything assessed at one time. NDT evaluations were made through observations and position testing in occupational therapy sessions, and through my observations from Angela’s physical therapy sessions. Testing can be done in three positions, standing, sitting, or supine for most NDT evaluations. Typically sitting
gives better results (Sullivan & Schmitz, 2007), however Angela preferred supine, and results seemed to be better with movement from this position (see Figure 3). Angela, like many hemiplegic patients has lost her normal automatic postural reactions against gravity (Richer & Bhasin, 1999) When Angela leans forward in sitting, her trunk flexors contract instead of her erectors spinae and she tended to fall forward. Angela spasticity in her limbs tended to increase as they were pulled in the direction of gravity, which made straightening her left arm for standing support difficult. Left arm movement during assessment was uncontrolled and jerky towards the end of the movements. The subject reported that her arms felt like dead weight.

From the assessment it was found that Angela’s patterns of spasticity produced retraction, fixation and depression of the scapula. The arm was in internal rotation, with a flexed elbow and slight pronation. The side flexors seemed tight and the subject appeared to lean forward to the left side slightly (see Figure 3).

Angela was upbeat during the interview and assessment, to get a caregiver perspective I talked to Ed during the physical therapy evaluation. After talking to Ed, it became apparent that Angela was depressed by the MS related impairments and the changes in life it presented. The theme expressed was that this was “no part of the plan”, which can be a common thought among those with MS (LaRocca, 2006). Angela had been diagnosed 6 years earlier, but still had difficulty adapting to the changes. Ed discussed that he felt he created a system of dependency on him. After the diagnosis and Angela’s impairments in function, he volunteered to take on all of the home management roles of the house. He felt that this was a mistake because it did not help facilitate Angela’s independent living. Patient perceived independence has been shown to improve life satisfaction (Lundmark & Branholm, 1996). As I learned more about the dynamics and roles of this family it became apparent that the Mosey Role Acquisition Model (Mosey,
would be an appropriate fit with the NDT model for a holistic approach to Angela’s rehabilitation.

The Role Acquisition Model is appropriate for those who are experiencing role transitions, or those like Angela who must learn to participate in social roles in a different manner because of their current life situations (Mosey, 1996). It is suggested that this should not be used as the initial frame of reference for those individuals with severe deficits in motor function, this is why this frame of reference is being used alongside NDT. The theoretical base of this frame of reference consists of five parts: the nature of the individual, what needs to be learned, how learning takes place, typical and atypical development, and appropriate tools.

The nature of the individual addresses how the subject explores his or her environment, identifies a desire to be competent, this desire then is structured into a goal. Angela was once the manager of a household, a key player in the local PTA, and a church administrator. Each of these roles has changed form drastically, and Angela has found a strong desire to get these roles back. Her stated goals are rather direct and function related, but the desire for this function is to be able to assume the past roles that she held for a number of years.

What needs to be learned addresses what education must occur before these goals can be carried out. Without any doubt Angela is a bright woman who knows what is required to be a home manager, administrator, and caregiver, but getting back to these roles with physical impairments is something that requires learning. Angela must learn to manage her time from a fatigue stand point. She must learn principles of rehabilitation, and her home exercise program to increase the potential for regained function. Angela is heat sensitive and must learn to manage her environment and activities to get the best results and avoid increased MS symptoms. Angela has indentified goals, and her success also relies on how she acts on the knowledge provided.
How learning takes place consists of socialization, and the psychological perspective. Socialization is the process of acquiring a particular social role. Mosey lists sixteen concepts as the psychological dimension of the learning process:

1. Learning is influenced by the individual’s inherent capacities, current assets and limitations, age, sex, interests, and past and present cultural group membership.
2. Attention and perception influence learning.
3. The learner’s motivation is important.
4. Learning goals set by the individual are more likely to be attained than goals set by someone else.
5. Learning is enhanced when the individual understands what is to be learned and the reason for learning.
6. Learning is increased when it begins at the individual’s current level and proceeds at a rate that is comfortable for the individual.
7. Active participation in the learning process facilitates learning.
8. Reinforcement and feedback as the consequence of action are important parts of a learning experience.
9. Learning can be enhanced through trial and error, shaping, and imitation of models.
10. Frequent repetition or practice facilitates learning.
11. Planned movement from simplified wholes to more complex wholes facilitates integration of what is to be learned.
12. Inventive solution to problems should be encouraged as well as more usual and typical solutions.
13. The environment in which learning takes place is an important factor.
14. There are individual differences in the ways anxiety affects learning.
15. Conflicts and frustrations, inevitable in the learning situation, must be recognized and provision made for their resolution or accommodation;

16. There needs to be continuity between the learning situation and experience for which the learning constitutes preparation.

It is within the framework of the sociological and psychological perspective of learning that the acquisition of basic skill, social roles, and temporal adaptation take place in this frame of reference (Mosey, 1996).

*Typical and atypical development* describes the relationship between the subject and her environment. If the environment is not conducive for learning, or if role patterns are disrupted or altered, atypical development can occur. If the environment is not conducive for learning it may be necessary for the individual to a. Reorganize role priorities, b. learn new skills so the individual is able to participate in new roles, c. redefine one or more roles in a way that is more comparative with present abilities; or d. give up a particular role.

Throughout much of this role acquisition Ed is the primary role partner. If anything were to happen, for example he needs to pick up some part time employment, this may cause the environment what is difficult for role development, in this case, it may be needed for Angela to give up her role of career building and focus on accomplishing ADLs independently so her husband can work.

*Appropriate tools* are the legitimate tools of occupational therapy used in this frame of reference. The tools include: Emphasize doing. Active participation by Angela is important for her learning process. While knowledge can be acquired through verbal interaction, skill needs physical practice. Vary on a continuum from conscious to unconscious: The conscious level of learning is stressed early on in this frame of reference. Angela needs to give careful attention to the environmental stimuli, to responses of self, and the effect of those responses on the
environment. As competency is achieved, Angela would need to spend less attention on the particulars of a given interaction. Vary on a continuum from real to symbolic: Some patients respond more to symbolic components of an exercise, however overtime the therapist should draw the client towards the realistic dimensions of an activity. Vary on a continuum from simulated to natural: Simulated activities can be easier to facilitate if the appropriate environment or resources are not available, however natural activities are better suited for learning social roles. However natural activities should not be used until Angela is able to engage in activities with a degree of comfort.

*Angela’s roles pre-MS diagnosis*

**Mother:** Angela’s most valued role is one as mother and manager of the house hold. In this role Angela would pick her son’s up from school, cook meals, clean the house, pay bills, and maintain an active role in the Parent Teach Association for Reston, Virginia Public Schools. The role required Angela to be able to drive, have sustained energy levels to carry her through the long days, the bilateral coordination to type, fine motor coordination and dexterity to write and engage in cooking and office work tasks. Angela’s kids were now in middle school and beginning high school, the need for her to run to and from athletic practices and games became quite a demand.

**Wife:** There was a thin line between Angela’s role of wife and Church Administrator. Angela’s husband Ed was a minister and her supportive role transcended the traditional 9-5 schedule. Ed would spend many of his evenings preparing sermons and working on bible study materials while Angela did much of the administrative work for the church. Tasked included balancing budgets, contacting members, working on large projects and delegating responsibility. The church they worked for was a large church in Northern Virginia of over 500 members. Angela had to be independent with transportation, and all ADLs/IDS.
**Athlete:** Prior to being diagnosed with MS in 2003 Angela was a highly athletic individual in high school, college, and in adult life. After college Angela continued to run for leisure on a daily basis, competing in local 5 kilometer races, half marathons and even two full marathons. This lifestyle required a high energy level, and an excellent overall physical condition. Running was part of her daily regiment, squeezed into her day along with employment, motherly duties and house management.

**Caretaker:** Just prior to Angela’s diagnosis of MS in 2003, both of her parents were diagnosed with cancer. Her parents lived in North Carolina and her father was able to provide care to her mother as much as he could early on. Angela’s two other sisters lived outside of the United States, so it was up to her to take on the responsibility of managing her parents care. This role came at a difficult time in Angela’s life because she was already involved with her own family, employment, and now another straw was added to the camel’s back. Running was Angela’s way of blowing off steam, but it was becoming apparent that this would have to take a backseat.

**Therapy Goals**

While the therapists involved in Angela’s treatment had ideas of what would be good goals, a client centered approach was taken. Angela was asked what she would like to work on, and what she saw as a priority. The interdisciplinary team expressed what they would like to work on, and a general consensus was made.

Physical therapy identified the following goals during the initial evaluation:

**STG:** To be met in 3 weeks
1. Pt will identify locations in house for adaptive equipment. (Met)
2. Pt will ambulate 10 feet in parallel bars. (Met)
3. Pt will stand 5 minutes at kitchen counter. (Met)
4. Pt will explore ability to participate in bodyweight assisted treadmill training. (Met)

**LTG:** To be met in 12 weeks
1. Pt will be Mod I in bed using adaptive equipment. (Met)
2. Pt will transfer to w/c, commode with Mod I. (Met)
3. Pt will increase functional standing tolerance to 10 minutes. (Met)
4. Pt will increase functional walking tolerance to 20 feet with rolling walker. (in progress, currently at 11 feet as of 4-26-2010)
5. Pt will be independent with Home Exercise Program (HEP). (Met).

Occupational therapy identified the following goals during the initial evaluation:

STG: To be met in 4 weeks
1. Pt will increase right grip strength to norm for compensation purposes. (Met)
2. Pt will increase right pinch strength to norm for compensation purposes. (in progress)
3. Pt will have left pinch strengths assessed. (Met)
4. Pt will be independent with HEP. (Met)
5. Pt will increase left shoulder external rotation (AROM) to 20 degrees. (in progress)
6. Pt will increase L elbow AROM to WFL. (Met)

LTG: To be met in 12 weeks
1. Pt will be independent with shower/toilet transfers. (Met)
2. Pt will increase balance for home/community mobility. (Met)
3. Pt will increase AROM of LUE to increase ADL performance. (Met)
4. Pt will demonstrate practices of energy conservation and home management. (Met)
5. Pt will increase FMC for handwriting, typing. (in progress)
6. Pt will demonstrate modified household ADLs for increased independence. (Met)
7. Pt will increase right hand speed and dexterity for compensation purposes. (in progress)
8. Pt will be able to oppose left digits 1 and 2. (Met).
9. Pt will be able to feed self 3 bites with Mod I. (Met)

Angela’s main focus was to become as independent as possible and to get her “life back”.

This expression of goals is one of the biggest reasons that the Role Acquisition Frame of Reference was chosen to use in this case study. Bobath NDT was chosen to help address the many physical deficits that presented as a hemiplegia secondary to the lesions from MS. A neuro-motor re-education model had to be used to help stop the abnormal patterns of movement, and recreate the naturalistic patterns. Through this NDT model of practice it was thought that left AROM, coordination, and finally strength could be increased, which it was. A home exercise program was created for occupational therapy and physical therapy to help speed the recovery process. Angela’s husband was educated on how to assist her with transfers, positioning, stretching, and her hand over hand occupations. Ed came to every treatment and would usually watch the entire treatment except for about the last 15 minutes, during that time he would go into
the lobby, grab a coffee, surf the web and enjoy a little time to himself. If we wanted Ed to know something, we knew his routine, and would inform him early in the treatment. Typically the end of the sessions was when Bioness was used, during that time there was little he could learn for application at home anyways.

Intervention

Since Angela presents as a hemiplegic, the goal of her treatment was to inhibit her abnormal patterns of movement, since normal patterns of movement cannot be superimposed on to abnormal patterns. Angela’s spasticity was not confined to one particular muscle or set of muscles, but rather was coordinated in definite synergic patterns. During treatments addressing left side upper extremity flexor spasticity the key was to get Angela to move her trunk while I stabilized the distal left hand. In this treatment Angela would have her wheelchair parallel with the adjustable height table. The table was adjusted to a comfortable height where she could extend and abduct her left arm so that it was over the table. In order for this extension and abduction to occur, I would have Angela use hand over hand with her right arm to slowly passively stretch the left arm. I would help stabilize her trunk and she would slowly flex at the waist, while using her right hand to pull down the left hand so that the left arm was extended. From this point, I would help abduct the left arm onto the table. Often a seat cushion would have to be used to elevate Angela since the table would only go down so far. Once Angela’s left arm was over the table, I would hold the arm down while she slowly moved her trunk against the arm and hand to inhibit the flexor spasticity. The first movement would be a slow and constant movement of the trunk towards the arm, this would last about 30 seconds to a minute. Next, Angela would move her trunk away from her left arm in the same type of stretch as before. I would provide resistance on the left hand to keep the hand in place so that she could move against her spasticity as much as her own comfort would allow her. Angela would then move
sideways from the left arm in the same fashion. In the final stretch the goal would be for me to hold the left hand as she moved forward, then repeat the stretch without needing me to hold the hand. Patient caregiver education was provided to husband throughout most of the treatment sessions so that he could help at home.

While Angela was diagnosed with MS in September 2003, it was apparent that she had not received adequate therapy since her diagnosis. Many of the tasks done, from transfers to ADLs were being done by the husband. The first step to regaining her lost roles was to regain aspects of her independence. From interviewing the couple it was clear that Ed was positioning Angela in bed and getting her out of bed, these were goals physical therapy decided to address early in treatment to begin the road to independence.

Angela on February 17, 2010 was a Max Assist for transfers by mid March she had learned to use hand over hand techniques to change position in bed from supine to side lying, she had learned how to get in and out of bed with modified independence using a bed side “super pole” and had become independent with transfers. Angela had a consistent standing tolerance of ten plus minutes and was beginning gait training.

With a consistent standing tolerance developed, Angela was ready to put function into her standing. Occupational therapy began to utilize the left arm as a stabilizer in standing, so that the right arm could engage in reaching, and various tasks. Angela would begin by stretching the left arm by flexing at the trunk, using hand over hand with the right hand to pull the left arm into extension (Eggers, 1984). Once the spasticity in the left arm decreased, she was then able to stand up, and weight bare into the left hand at the kitchen counter while the right arm would engage in sorting of shelves, rinsing plates, putting dishes away, all functional former tasks involved in the role of house manager. Angela would engage in seated occupations of sorting objects on the adjustable therapy mat. During these occupations, Angela would sit with both feet
flat on the floor, and use the left arm to support herself while also inhibiting associated reactions. Affected arms used for support have been found to help inhibit associated reactions (Davies, 1985). The right arm would then transfer towels to the affected side to mimic a laundry task. Hand over hand engagement was useful in Angela’s hobby of “scrabble”. Angela could use this commonly played game as a method of therapy at home. In one case she could use the left hand as a method of stabilization of the board. She laughed when the idea was introduced and stated “yea, I see where you’re coming from”. Hand overhand placement of scrabble pieces was introduced as another way to incorporate the left hand through bilateral activities. It was stressed that the left hand could be involved in many common tasks around the house. Angela was given the challenge to make a list of ways to involve the left hand at home (Haselkorn, Richer, Welch, Herndon, Johnson, Little, et al., 2005). Angela saw the usefulness of therapy in this aspect of “getting back to where she was”, even if it meant modifications would have to be made.

Angela was not satisfied with the idea of strictly using the left hand as a method of stabilization or simply in hand over hand occupations. NDT activities could be used as therapeutic occupations to help regain the home manager role. Weight bearing with the right hand was done, while the left hand engaged in “dusting table”. Angela had difficulty with this occupation secondary to lack of external rotation with the left arm. Ed was advised to be nearby during the exercises at home for safety precautions. To facilitate neuro-motor re-education the Bioness electrical stimulation unit was introduced as a way to practice and retrain the left arm in functional occupational engagement. At first, the Bioness was set to “open exercise” to assist Angela in digit extension. It was found that Angela had the ability to make a fist, but lacked the digit extension to release objects. The Bioness was used in household activities such as “pouring a glass of water”. In this occupation the Bioness was used to open the left hand, while sliding the arm along the table to grasp an empty cup. The right hand would then pour a pitcher of water.
into the cup. Angela was astonished at her ability to do this occupation. Angela did need minimal assistance in sliding the left arm, to avoid her hiking the left shoulder in compensation technique to elevate the left arm.

To help facilitate good posture during the occupations, a beanie baby was placed on Angela’s left shoulder to bring attention to her compensation. Angela was instructed not to let the beanie baby fall off her shoulder. Another change to the occupation was the use of a large wheeled mirror. During the occupations the mirror would be brought out to serve as a visual cue to correct her posture, these cues worked well with her. Other forms of compensation included trunk movement to make up for lack of distal movement in the left upper extremity. Instead of gliding her left arm to reach, it appeared that she would “push” the arm forward with her core.

Feeding and drinking became Angela’s favorite occupations with the Bioness. During these occupations Angela would be seated at a table, usually in her wheelchair. Functional reach, grasp, and release would occur with cups, utensils, or finger foods as targets. The tasks once again required assistance on part of the occupational therapist to help lift the arm to avoid unwanted compensation. Bioness tolerance increased over time. Initially Angela was only able to tolerate about 5 minutes of stimulation, by mid April she was tolerating 15 plus minutes of continual stimulation. There appears to be a slow carry over affect of the Bioness assisting her with left hand use. In a retest of pinch strength she was able to increase her lateral, 2 point, and 3 point pinch strengths by about a pound each. She has also noticed some increases in left hand opposition, although the increases are small. Angela likes the Bioness treatments because it gives her hope that she will be able to one day use that arm again. While she understands that her disease is progressive, she is rather optimistic. Typically after the Bioness I would attempt hand over hand grasp and release in an attempt to retrain the brain.
Treatments with the Bioness were always done sitting. In the future it would be beneficial to incorporate standing occupations such as standing while opening a door with the left hand (difficult now because of standing balance and slight trouble with supination). Other re-synthesize options would be to involve the Bioness in dressing. Currently she has enough flexion on her own that she does not need the Bioness to assist in flexion. For occupations such as dressing, she might require more grip strength, thus the Bioness may have to be used to provide flexion assist as well.

Interventions also took place in helping Angela change roles. From the Pre-Intervention Assessment the following basic roles were identified: Mother, Wife, Athlete, and Caretaker. Below each of the following roles are discussed in terms of functional impairments, and treatments which occurred.

**Mother:** Since being diagnosed with MS Angela’s children have begun college. Her oldest son goes to Virginia Tech two and a half hours away in Blacksburg, VA. Her youngest son lives in an apartment in Northern Virginia, works, and goes to a Community College. The role mother has changed and become less demanding with the children moved away. Her husband has taken on the responsibilities of cooking, cleaning, and assisting with Angela’s ADLs. Angela presents as a hemiplegic, therefore typing, computer work, and paying bills had become especially challenging. To assist with typing, voice recognition software called “Dragon” was purchased and installed by her husband. This modification was one that her husband independently thought off just prior to her coming to outpatient therapy. The software allows Angela the ability to maintain part of her “house management” role with paying bills and managing assets online. Angela’s involvement as mother and house manager has taken on a new role with the voice recognition software. The family is in the process of selling her parent’s old house in North Carolina, and she works in the office contacting real estate agents and researching
the market via the web. The concept of using the internet as a leisure/employment tool has sparked interest in finding the next house to move into after the children graduate and out of state tuition is no longer an issue. Angela now is fulfilling the family manager role as the one who pays the bills, looks for a new “accessible house”. She uses the internet to keep up with her two kids and has learned to become more independent. After a home evaluation on March 24, 2010, Angela is in the process of getting a power chair so that she can maneuver throughout the house with modified independence. Grab bars in the bathrooms have been installed so that in the future she will be able to operate at home for long periods of time without having to rely on her husband. Angela was instructed to plan meals and make her own “to-do” lists, along with “to-do” lists for her husband so that she does what she can around the house, and identifies what still must be done. The to-do lists and meal prep lists have helped regain her a sense of the role.

_Wife:_ After Angela’s diagnosis of MS her husband retired to take care of his wife who had become max assist or dependent on many ADLs and transfers. With his wife’s progress Ed is able to begin the process of gaining freedom in his own right which has helped make life easier for both. Ed has been planning going back to ministry which has opened a new door to Angela in a role that was once lost, employment. Angela has set a goal of volunteering with the local MS National Society Blue Ridge Chapter, in addition to helping with her husband ministry work. She plans on volunteering a few hours a week answering phones and doing what she can at the society. With both of her kids off at college, there is more time to assume these roles of helping her husband, and doing her own work with the MS society. Fatigue management concepts such as planning an activity guide have helped Angela strategize her daily routines.

_Athlete:_ While this role has been lost in terms of running, Angela’s home exercise program has helped to fill a void and keep her active in her own rehabilitation. Initially it was
thought that a MS oriented Yoga program would work to help promote general flexibility while taking a holistic approach. Instead it was decided that floor stretches with an exercise ball would be the most beneficial and most practical approach. In collaboration with physical therapy a ball exercise program was created to address Angela’s spasticity, core strength, and flexibility. The exercises are done independently and require max/mod assistance to get Angela to the floor and back into her chair. This has become part of her daily morning routine. After working out and getting dressed, her husband heads down to the apartment complex gym to get his own workout in.

*Caretaker:* Angela’s mother past away in January 2010, one month prior to her coming to outpatient rehab. Her father still continues to smoke despite his cancer. Angela has since January helped her father locate and enroll in an assistive living facility easing the burden of care on her and Ed, and allowing her to have a piece of mind. Her roll of care taker has change, but is still present. Angela keeps contact with her father and is involved in handling the estate.

Since coming to outpatient therapy Angela has become more independent and has taken on more responsibility. While MS is a progressive disease, the family is hopeful that therapy and environmental modifications will keep Angela active in her roles. Once Angela has her power chair she will be able to get out of bed, transfer with modified independence, and engage in her tasks with little assistance from her husband, allowing him to go back to work, and for their lives to somewhat get back to normal. The debate over power assist chair and the power chair ended with the power chair having a superior turning radius, allowing Angela to maneuver easier inside her house. She has begun to ambulate with a walked to and from the closest bathroom and back to her office. Figure (D) shows the office listed as the 11’ by 14’ 2” bedroom with the bathroom attached.
In order to make the environment facilitate independence with task skills such as ADLs, a number of modifications had to be done. Currently there are no grab bars in the bathrooms which make transfer unsafe to and from the toilet. In bathroom one it was suggested that a grab bar be installed to the right of the toilet between the toilet and bathtub. A loop rail would be ideal so that the lower rail can be used to assist in standing while the upper rail can be used when doing the transfer to the toilet. The recommended height of the lower rail would be 30-31 inches and the upper rail would be 36 to 38 inches. In bathroom two a grab bar is needed in front of the toilet about 35 to 36 inches from the floor. Ideally the horizontal grab bar should be long enough to reach from the shower, and extend the entire distance in front of the toilet. Elevating the toilets of both bathrooms by 4 inches would help make transfers easier on Angela as well as help her to conserve energy.

In the bedroom it was decided that the bed should be lowered to a range of about 20 to 23 inches off of the floor to make transfers easier to and from her chair. A super pole was installed with an adjustable swinging arm that assists her in all transfers. The super pole has placed 28 inches from the head of the bed.

To help facilitate role development, temporal aspects of one’s life must be discussed and prioritized. Angela has severe fatigue occurring in the late afternoon which inhibits concentration and limits physical activity, which is common in patients with MS (Bol, Dutis, Hupperts, Vlaeyen & Verhey, 2009). Angela has stated that afternoon fatigue also slows her thought and processing speed of cognition, while a nap can help, typically she feels she is done “working her brain at this time”. Cognitive fatigue can take longer to recover from in patients with MS, than those in the general population (Gingold, 2006). Below Angela’s daily routine was evaluated to determine if there was a way to maximize her day so that she could achieve more before the fatigue set it.
A typical daily routine for Angela was the following:
• 8:00 am – wake up, bathroom
• 9:00am – eat breakfast, floor stretches
• 10:00 am – get dressed
• 10:30 am – work at computer
• 12:00 pm – lunch, bathroom
• 1:30 pm – work at computer
• 4:30 pm – computer work is done for the day, fatigue sets in.
• 6:00 pm – dinner
• 8:00 pm – scrabble or game with husband
• 9:30 pm – shower, prepare for bed
• 11:00 pm – in bed

When asked, “what is the most important thing you must do day to day”, she expressed that her computer work is the most important because that is how she contributes to the family by paying bills, managing her and Ed’s parent’s financial business, keeping in touch with family. Angela does this at 10:30 in the morning because that is the time of day that she has the most energy. Angela fit her floor stretches and ball exercises into the morning so that she knows she has the energy to get them done. This time of day also works well for Ed to assist her with getting on the floor.

Angela receives a Tysabri transfusion every month as part of her disease modifying therapy. In the two weeks following the transfusion Angela feels great with less fatigue. However in the weeks leading up to the transfusion she feels like a car running on empty. It was suggested that Angela not only prioritize her day, but also her month, so that she gets the most done when she has the most energy.

Discussion

As a result of intervention four of six short term occupational therapy goals have been met. The remaining short term goals that have not been met focus on strengthening the right side pinch for compensation purposes, and left shoulder AROM external rotation. Seven of nine long term goals have been met. The remaining long term goals that have not been met are strictly
related to the right upper extremity (right UE fine motor coordination, and right UE hand dexterity and speed).

Angela typically is only able to be seen for forty five minute treatments three times a day. Since Angela could only be seen for short periods of time, the focuses of the treatments dealt with the left side hemiplegic. Right side strengthening and dexterity were rarely addressed. Angela has made progress with left shoulder external rotation in regards to PROM, which we hope will lead way to gains in AROM.

Since initial evaluation Angela has gone from a dependent/max assist transfer to an independent transfer. AROM left side shoulder flexion has increased to 120 degrees, PROM has increased to 135 degrees. Left side shoulder abduction AROM has increased to 85 degrees, PROM has increased to 90 degrees. Left UE external rotation has increased to 30 degrees PROM. Left grip strength has increased to 12 lbs.

While Angela is aware that her condition is progressive, these results keep her confident that progress can be made. It is important to point out that she is a strong Christian woman who takes comfort in the fact that she is not getting worse. There has been discussion that Angela could talk to another MS patient at our facility to offer encouragement. This other MS patient was a possible candidate for my capstone project, and in all honesty, would have been a better candidate for the “Role Acquisition Frame of Reference”. Angela was a great subject, and a joy to be around, but she was highly motivated and needed little occupational therapy intervention in the way of role and task creation and modification. Angela and her husband had the insight to foresee future challenges, the ability to accept modifications, and the creativity to seek and pursue new roles. There were many times when I thought I had a good suggestion to introduce to Angela in regards to role acquisition, only to discover that she and her husband had already began pursuing the task skills needed to obtain the role.
While Angela and her husband were insightful about role acquisition, they did need help with the physical impairments that Angela was suffering from. This is an example of how occupational and physical therapy helped improve task skill performance. Angela’s goals for therapy are rather simple, to become as independent as possible and get back to her life as she knew it. I believe I have taught Angela a good deal about neuro rehabilitation, but in the process she has taught me so much. Angela has offered me an insight into the world of MS that I never imagined. As a Christian she has shown me strength and faith that is unmatched by other patients I have encountered in my short occupational therapy career.

Angela is currently not ready for discharge as she is progressing well. My recommendations for her discharge will vary depending on her condition. Angela does well socializing, however it would be nice to expand this social task in leisure from a “role acquisition” perspective while working towards fitness. One idea is for her and her husband to join a gym called “ACAC” or Albemarle County Athletic Club. This facility is a nice large gym unlike another I’ve seen. They have physical therapists and athletic trainers on staff. The gym is similar to a YMCA but offers much more in regards to equipment, space, classes, and environmental comfort. The building is newer and subdivided into sections, with the architecture dampening sounds so that it is a quite naturally lit place. Large windows maximize natural lighting, and parking would be easy with a spacious parking lot. The building is built under concepts of “universal design” so that it could be easily accessible to Angela. The only drawback to ACAC is the price of membership. Roughly, Angela and Ed as a couple would be looking at $160 a month, which is not in the budget. However the MS Blue Ridge chapter may be able to help reduce that cost. While it may sound far fetch, I view this as a sound idea. Over the course of the 16 week capstone I have worked with the MS Blue Ridge chapter on a regular basis. Angela is a member and will be volunteering for them in June. ACAC is about a mile away from
the MS Blue Ridge Chapter on the same side of the street, County Road 29. Typically the MS Blue Ridge chapter tries to limit their cost per individual to about one thousand dollars, however this is commonly broken. Angela herself in the MS walk rose close to a thousand dollars by receiving pledges. I know the case workers, and this seems like a good option. Throughout this capstone experience I have learned to use resources to advocate for patients and clients. I have gotten to work first hand with social workers and appreciate what they bring to the table.

This case has implications for research in regards to treatment techniques. It is common practice at UVA-HealthSouth to use an NDT type approach to MS patients who present as a hemiplegic. However, there is little research on this type of model of practice with this population. Further research is needed in regards to the Bioness functional electro stimulation device with this population. While Angela was enthusiastic and optimistic about this intervention, not all patients will be easily sold on the idea of using this without seeing studies showing its results.

This case is innovative because it looks at how MS affecting an individual in their most productive years changes the roles and lifestyle dynamics one has. As an occupational therapist we not only treat the impairment, we treat the person holistically. Before this capstone, I never spent the time to think about how this common disease interrupts the life of the individual, and the lives of those around the individual. It is common for those in their thirties, forties, and fifties to have numerous generations relying on them for care or financial support. Often those in their middle ages are “sandwiched” between two generations needing someone to provide for them. This is the case with Angela and Ed who have two children in college, and parents in poor health. This case study helps one view patients holistically, and helps contribute to occupational therapy by serving as an example of what occurs behind the scenes in a patient’s life after they leave your treatment session.
Acknowledgements

I would like to acknowledge my site mentor and faculty advisor for the resources, wisdom, and creativity they provided throughout the capstone process. I would like to thank my capstone subject Angela and her husband Ed for their openness, and insight into the disease. Last but not least I would like to thank my classmates and other professors who have helped me develop clinically and in my professional demeanor.
References


Holser, P., Fuchs, E. (1957). *Box and block test.* Bolingbrook, IL: Sammons Preston


Appendix A

Strength and Dexterity Results:

<table>
<thead>
<tr>
<th></th>
<th>Right Side</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Grip</strong></td>
<td>55 lbs.</td>
<td>62 lbs.</td>
</tr>
<tr>
<td><strong>Lateral pinch</strong></td>
<td>12 lbs.</td>
<td>17.6 lbs.</td>
</tr>
<tr>
<td><strong>Strength</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 point pinch</td>
<td>7 lbs.</td>
<td>13 lbs.</td>
</tr>
<tr>
<td>3 point pinch</td>
<td>12 lbs.</td>
<td>17.9 lbs.</td>
</tr>
<tr>
<td><strong>9- hole peg</strong></td>
<td>31.56 seconds</td>
<td>15.5 seconds</td>
</tr>
<tr>
<td><strong>Box and Blocks</strong></td>
<td>45 blocks/min</td>
<td>82 blocks/min</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Left Side</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Grip</strong></td>
<td>7 lbs.</td>
<td>56 lbs.</td>
</tr>
<tr>
<td><strong>Lateral pinch</strong></td>
<td>2 lbs.</td>
<td>16.6 lbs.</td>
</tr>
<tr>
<td><strong>Strength</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 point pinch</td>
<td>Unable</td>
<td></td>
</tr>
<tr>
<td>3 point pinch</td>
<td>Unable</td>
<td></td>
</tr>
<tr>
<td><strong>9- hole peg</strong></td>
<td>Unable to initiate</td>
<td></td>
</tr>
<tr>
<td><strong>Box and Blocks</strong></td>
<td>Unable to initiate</td>
<td></td>
</tr>
</tbody>
</table>
Appendix B

**Modified Fatigue Impact Scale**

The following is a list of statements that describe the effects of fatigue. Please read each statement carefully, then circle the number that best indicates how often fatigue has affected you in this way during the past 4 weeks. Please answer every question. If you are not sure which answer to select, choose the one answer that comes closest to describing you.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Because of my fatigue during the past 4 weeks...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have been less alert.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I have had difficulty paying attention for long periods of time.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I have been unable to think clearly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I have been clumsy and uncoordinated.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I have been forgetful.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I have had to pace myself in my physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I have been less motivated to do anything that requires physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I have been less motivated to participate in physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I have been limited in my ability to do things away from home.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I have trouble maintaining physical effort for long periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I have had difficulty making decisions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
### Appendix B

<table>
<thead>
<tr>
<th>Because of my fatigue during the past 4 weeks...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. I have been less motivated to do anything that requires thinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 C</td>
</tr>
<tr>
<td>13. My muscles have felt weak.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I have been physically uncomfortable.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. I have had trouble finishing tasks that require thinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 C</td>
</tr>
<tr>
<td>16. I have had difficulty organizing my thoughts when doing things at home or work.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I have been less able to complete tasks that require physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 P</td>
</tr>
<tr>
<td>18. My thinking has been slowed down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 C</td>
</tr>
<tr>
<td>19. I have had trouble concentrating.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I have limited my physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 F</td>
</tr>
<tr>
<td>21. I have needed to rest more often or for longer periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4 F</td>
</tr>
</tbody>
</table>

**Instructions for Scoring the MFIS**

Items on the MFIS can be aggregated into three subscales (physical, cognitive, and psychological), as well as into a total MFIS score. All items are scored so that higher scores indicate a greater impact of fatigue on a person’s activities.

**Physical Subscale**
This scale can range from 0 to 36. It is computed by adding raw scores on the following items: 4+8+7+10+13+14+15+16+21.

21/36

**Cognitive Subscale**
This scale can range from 0 to 40. It is computed by adding raw scores on the following items: 1+2+3+5+7+12+13+16+18+19.

13/40

**Psychosocial Subscale**
This scale can range from 0 to 8. It is computed by adding raw scores on the following items: 8+9.

3/8

**Total MFIS Score**
The total MFIS score can range from 0 to 84. It is computed by adding scores on the physical, cognitive, and psychosocial subscales.

37/84
Fatigue Severity Scale

The fatigue severity scale is a method of evaluating the impact of fatigue on you. The questionnaire contains nine statements that rate the severity of your fatigue symptoms. Read each statement and circle a number from 1 to 7, based on how accurately it reflects your condition during the past week and the extent to which you agree or disagree that the statement applies to you.

A low value (eg, 1) indicates a strong disagreement with the statement, whereas a high value (eg, 7) indicates a strong agreement.

It is important that you circle a number (1 to 7) for every question.

During the past week, I have found that:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Circled Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My motivation is lower when I am fatigued</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>2. Exercise brings on my fatigue</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>3. I am easily fatigued</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>4. Fatigue interferes with my physical functioning</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>5. Fatigue causes frequent problems for me</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>6. My fatigue prevents sustained physical functioning</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>7. Fatigue interferes with my carrying out certain duties and responsibilities</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>8. Fatigue is among my three most disabling symptoms</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>9. Fatigue interferes with my work, family, or social life</td>
<td>1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>

Total Score: 47

Scoring: Add all the numbers that you circled to get your total score.

Key: A total score of less than 36 suggests that you may not be suffering from fatigue. A score of 36 or more suggests that you may need further evaluation by a physician.

Your next step: This scale should not be used to make your own diagnosis. If your score is 36 or more, please share this information with your clinician.

Fatigue Severity Scale © Lauren B. Krupp. Reproduced with permission from the author.
Appendix C

I. TESTS FOR THE QUALITY OF MOVEMENT PATTERNS

Patterns to be tested

Tests for Arm and Shouldergirdle (to be tested separately in supine, sitting and standing, as the result will be different in these positions.)

*Grade 1*

a. Can he hold the extended arm in elevation
   after having it placed there?............................
   With internal rotation?.................................
   With external rotation?.................................

b. Can he lower the extended arm from the position of elevation to the horizontal plane and back again to elevation?.........
   Forwards-downwards?.................................
   Sideways-downwards?.................................
   With internal rotation?.................................
   With external rotation?.................................

*Grade 2*

a. Can he lift his arm to touch the opposite shoulder?.................................

<table>
<thead>
<tr>
<th></th>
<th>Supine Yes</th>
<th>No</th>
<th>Sitting Yes</th>
<th>No</th>
<th>Standing Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>b</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>c</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
With palm of hand?.................................

With back of hand?.................................

b. Can he bend his elbow with his arm in
elevation to touch the top of his head?..

With pronation?.................................

With supination?.................................

c. Can he fold his hands behind his head with
both elbows in horizontal abduction?...........

With wrist flexed?.................................

With wrist extended?.................................

Grade 3

a. Can he supinate his forearm and wrist?.....

Without side-flexion of trunk on the
affected side?............................................

With elbow and flexed fingers?.................

With extended elbow and extended fingers?

b. Can he pronate his forearm without
adduction of arm at shoulder?..................

c. Can he externally rotate his extended arm?
(i) in horizontal abduction?.....................
(ii) by side of his body?.........................
(iii) in elevation.................................

d. Can he bend and extend his elbow in
supination to touch the shoulder of the

<table>
<thead>
<tr>
<th></th>
<th>Supine</th>
<th>Sitting</th>
<th>Standing</th>
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<td>With palm of hand</td>
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<td>With back of hand</td>
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<td>Can he bend his elbow with his arm in</td>
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<td>elevation to touch the top of his head?</td>
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<td>With pronation?</td>
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<td>With supination?</td>
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<td>Can he fold his hands behind his head with</td>
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<td>both elbows in horizontal abduction?</td>
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<td>With wrist flexed?</td>
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<td>With wrist extended?</td>
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<td>Can he supinate his forearm and wrist?</td>
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<td>Without side-flexion of trunk on the</td>
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<td>affected side?</td>
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<td>With elbow and flexed fingers?</td>
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<td>With extended elbow and extended fingers?</td>
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<td>Can he pronate his forearm without</td>
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<td>adduction of arm at shoulder?</td>
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<td>Can he externally rotate his extended arm?</td>
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<td>(i) in horizontal abduction?</td>
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<td>(ii) by side of his body?</td>
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<td>(iii) in elevation</td>
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<td>Can he bend and extend his elbow in</td>
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<td>supination to touch the shoulder of the</td>
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same side? Starting with:

(i) Arm by side of his body?.......................... X X X

(ii) horizontal abduction of the arm?............. X X X

Tests for Wrist and Fingers

Grade 1

a. Can he place his flat hand forward down on the table in front?......................... X
   Can he do this sideways when sitting on plinth?.............................................. X
   With fingers and thumb adducted?................................................................. X
   With fingers and thumb abducted?................................................................. X

Grade 2

a. Can he open his hand to grasp?................................................................. X
   With flexed wrist?............................................................................................ X
   With extended wrist?........................................................................................ X
   With pronatation?............................................................................................. X
   With supination?............................................................................................... X
   With adducted fingers and thumb?................................................................. X
   With abducted fingers and thumb?................................................................. X

Grade 3

a. Can he grasp and open his fingers again?..................................................... X
   With flexed elbow?.......................................................................................... X
With extended elbow? .................................................................
With pronation? .................................................................
With supination? .................................................................
b. Can he move individual fingers? .................................................................
  Thumb? ..........................................................................
  Index finger? ..........................................................................
  Little finger? ..........................................................................
  2nd and 3rd finger? ..........................................................................
c. Can he oppose fingers and thumb? .................................................................
  Thumb and index finger? ..........................................................................
  Thumb and 2nd finger? ..........................................................................
  Thumb and little finger? ..........................................................................

Tests for Pelvis, Leg and Foot Prone Tests

Grade 1
Can he bend his knee without bending his hip? .................................................................
With foot in dorsiflexion? ..........................................................................
With foot in plantiflexion? ..........................................................................
Foot inverted? ..........................................................................
Foot everted? ..........................................................................

Grade 2
Can he lie with both legs externally rotated and extended,
Feet dorsiflexed and everted, heels touching? .................................................................

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Hold position when placed?......................................................................................................................... X

Turn affected leg out again to touch heel of sound leg
after it has been internally rotated by therapist?........................................................................................................ X

Perform internal and external rotation unaided?........................................................................................................ X

Grade 3

a. Can he keep heels together and touching while bending both knees to right angle?............................................................ X

Affected foot inverted?........................................................................................................................................ X

Affected foot everted?........................................................................................................................................ X

b. Can he hold knee of affected leg flexed at right angle and alternately dorsiflex and plantiflex ankle?.................................................. X

Foot inverted?........................................................................................................................................ X

Foot everted?........................................................................................................................................ X

Without moving his knee?...........................................................................................................................................

Tests for Pelvis, Leg and Foot Supine

Grade 1

a. Can he bend affected leg?................................................................................................................................. X

With sound leg flexed, foot off support?................................................................................................................. X

Without bending affected arm?................................................................................................................................. X

b. Can he bend hip and knee with foot remaining on the support from the beginning of extension until the foot is near his pelvis?................. X

Can he extend his leg by degree, his foot remaining on the support?................................................................................. Yes No


**Role Changes Related to Multiple Sclerosis**

**Grade 2**

Can he lift his pelvis without extending his affected leg, both feet on the support?.................................................................

Can he keep his pelvis up and lift his sound leg?..........................

Without dropping pelvis on the affected side?..........................

Can he keep pelvis up and adducted and abduct knees?...............

**Grade 3**

a. Can he dorsiflex his ankle?.....................................................

Can he dorsiflex his toes?..........................................................

With flexed leg, foot on the support?...........................................

With extended leg?..................................................................

With foot inverted?.................................................................

With foot everted?.................................................................

b. Can he bend his knee when he lies near the edge of plinth, his leg over side of plinth? (hip extended).................................

**Test for Pelvis, Leg and Foot**

**Sitting on Chair**

**Grade 1**

a. Can patient adduct and abduct affected leg, foot on ground?..............

b. Can he adduct and abduct affected leg, foot lifted off ground?..............

**Grade 2**

a. Can he lift affected leg and place foot on sound knee? (without use of hand to lift leg)?.................................

b. Can he draw affected foot back under chair, heel on the floor?..............

**Grade 2- continued**
c. Can he stand up with sound foot in front of affected one?

(without use of hand?)........................................................................................................

**Standing Tests**

**Grade 1**

Can he stand with parallel feet, feet touching?.................................................................

**Grade 2**

a. Can he stand on affected leg, lifting sound one?....................................................

b. Can he stand on affected leg, sound one lifted, and bend

and extend standing leg?....................................................................................................

c. Can he stand in step position, weight forward on affected leg,

sound leg behind on his toes?............................................................................................

d. Can he stand in step position, sound leg forward with weight on it, affected

leg behind and bend knee of affected leg without taking toes off ground?........

**Grade 3**

a. Can he stand in step position, weight forward on sound leg, affected leg

behind and lift foot forward without bending hip of affected leg?........................

Foot in inversion?..............................................................................................................

Foot in eversion?.............................................................................................................

b. Can he stand on affected leg and transfer weight over it to make step with

sound leg?.........................................................................................................................

Forward?.........................................................................................................................

Backward?......................................................................................................................

**Grade 3- continued**

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c. Can he stand on sound leg and make step forwards with affected leg
   without hitching pelvis up?................................................................. X

d. Can he stand on sound leg and make step backwards with affected leg
   without hitching pelvis up?................................................................. X

e. Can he stand on affected leg and lift toes?........................................ X

II. TESTS FOR BALANCE AND OTHER AUTOMATIC PROTECTIVE REACTIONS

1. Balance Reactions

   (Patient in prone lying, supporting himself on his forearms).

   a. His shouldeergirdle is pushed toward affected side. Does he remain
      supported on affected forearm?............................................................. X

   b. His sound arm is lifted forward and up, as when reaching out with one hand.
      Does he immediately transfer weight towards the affected arm?............... X

   c. His sound arm is lifted and moved backwards and he is turned to his side,
      support on affected arm.
      Does he remain supported on affected arm?........................................ X

Tests for Balance Reactions- contd.

   (Patient sitting on the plinth, his feet unsupported)

   a. He is pushed towards the affected side. Does he stay upright?.............. X
      Does he laterally flex his head towards the sound side?........................... X
      Does he abduct his sound leg?................................................................. X
      Does he use the affected forearm for support?......................................... X
      Does he use the affected hand for support?............................................. X
b. He is pushed forward.

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<td>Does he bend affected hip and knee?</td>
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<td>Does he extend his spine?</td>
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<td>Does he lift his head?</td>
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c. Both his legs are lifted up by the therapist, knees flexed,

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<td>Does he stay upright?</td>
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<td>Does he support himself backwards with affected arm?</td>
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**Tests for Balance Reactions- contd.**

(Patient in four-foot kneeling)

a. His body is pushed towards the affected side.

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<td>Does he abduct the sound leg?</td>
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<td>Does he remain on all fours?</td>
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b. His sound arm is lift and held up by the therapist.

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<td>Does he keep affected arm extended?</td>
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c. He sound leg is lifted

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<td>Does he keep affected leg flexed and transfer weight on to it?</td>
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d. His sound arm and affected leg are lifted

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<td>Does he keep affected arm extended?</td>
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e. His affected arm and his sound leg lifted.

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<tr>
<td>Does he remain on affected flexed leg?</td>
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f. His sound arm and leg are lifted.

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<td>Does he transfer his weight towards the affected side and maintain position?</td>
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**Tests for Balance Reactions- contd.**
(Patient in kneel-standing)

a. He is pushed towards the affected side.

Does he abduct the sound leg?................................................................. X

Does he bend head laterally towards the sound side?................................. X

Does he use his affected hand for support?............................................... X

b. He is pushed towards the sound side.

Does he abduct the affected leg?.............................................................. X

Does he extend the affected arm sideways?............................................. X

c. He is pushed backwards and ask not to sit down.

Does he extend the affected arm forwards?............................................ X

d. He is pushed gently forwards, his sound arm held backwards by the therapist.

Does he use affected arm and hand for support on the ground?.................. X

Does he lift affected foot off the ground?.................................................

Tests for Balance Reactions- contd.

(Patient half kneeling, sound foot forwards. He should not use sound hand for support).

a. His sound foot is lifted up by the therapist.

Does he remain upright?........................................................................... X

Does he keep affected hip extended?........................................................ X

b. His sound foot is lifted by the therapist and placed sideways.

Does he remain upright?........................................................................... X

Does he show balance movements with his affected arm?.........................

c. His sound foot is placed from the above position back to kneel-standing.
Does he keep upright?.................................................................................................. X

Does he keep affected hip extended?........................................................................ X

**Tests for Balance Reactions- contd**

(Patient standing, feet parallel, standing base narrow)

a. He is tipped backwards and not allowed to make step backwards with sound leg. (Therapist puts her foot on his sound one to prevent step.)

Does he step backwards with affected leg?............................................................... X

b. He is tipped backwards and not allowed to make steps with either leg.

Does he dorsiflex toes of affected leg?................................................................. X

Big toe only?........................................................................................................ X

Dorsiflex ankle and toes of affected leg?............................................................. X

Does he move affected arm forwards?................................................................. X

c. He is tipped towards sound side.

Does he abduct affected leg?............................................................................... X

Does he abduct and extend affected arm?.......................................................... X

Does he make steps to follow with affected leg across sound leg?....................

d. He is tipped towards the affected side.

Does he abduct the sound leg?.............................................................................

Does he bend head laterally towards the sound side?.......................................


Tests for Balance Reactions- contd.

(Patient standing on affected leg only, he is not allowed to use sound hand for support).

a. His sound foot is lifted by the therapist and moved forwards as in making a step, extending his knee.
   Does he keep the heel of affected leg on the ground?..........................
   Does he keep the knee of the affected leg extended?..........................
   Does he assist weight transfer forward over affected leg with extended hip?....

b. His sound foot is lifted by therapist and moved backwards as in making a step backwards.
   Does he keep the hip of affected leg extended?..............................
   Does he assist weight transfer backwards over affected leg?.............

c. His sound foot is lifted by the therapist and held up while he is push gently sideways towards the affected side.
   Does he follow and adjust his balance, moving the foot of the affected leg sideways by inverting and everting his foot alternately?.............
   The same manoeuvre is done pulling him towards the affected side.
   Does he follow and adjust his balance by moving his foot as above?........

2. Tests for Protective Extension and Support of the Arm

(When testing these reactions the patient’s sound arm should be held by his hand so that he cannot use it. It is advisable to hold the sound Arm in extension and external rotation because this facilitates the Extension of the affected arm and hand).

a. The patient stands in front of a table or plinth. His sound arm is held backwards and he is pushed forwards towards the table.
Does he extend his affected arm forward? ............................................................... X

Does he support himself on his fist? ................................................................. X

On the palm of his hand? ................................................................................. X

His thumb adducted? ....................................................................................... X

His thumb abducted? ....................................................................................... X

b. The patient stands facing a wall, at a distance which allows him to reach it with his hand. He is pushed forward against the wall, his sound arm held backwards.

Does he lift his affected arm and stretch it out against the wall? ......................... X

Does he place his hand against the wall, fingers flexed, thumb adducted? ............. X

Fingers open, thumb abducted? ......................................................................... X

c. The patient is sitting on the plinth. His sound arm is held sideways by the therapist. He is pushed towards the affected side.

Does he abduct the affected arm and support himself on his forearm? ................... X

On his extended arm? ....................................................................................... X

Does he support himself on his fist? .................................................................... X

On his open palm? ................................................................................................ X

Thumb and fingers adducted? ............................................................................ X

Thumb and fingers abducted? ............................................................................ X

d. The patient stands sideways to a wall, at a distance which allows him to reach it with his affected hand.

Does he abduct and lift the affected arm? ......................................................... X

With flexed elbow? .................................................................................................. X
Does he reach out for the wall with extended elbow?.......................... X
Does he support himself with his fist against the wall?......................... X
With open hand?................................................................................... X
With adducted thumb and fingers?......................................................... X
With abducted thumb and fingers?......................................................... X

The patient lies on the floor on his back, His sound hand is placed under his hip so that he cannot use it. The therapist takes a pillow and pretends to throw it towards his head.

Does he move his affected arm to protect his face?.............................. X
With flexed elbow?............................................................................... X
With extended elbow?......................................................................... X
With internal rotation?.......................................................................... X
With external rotation?......................................................................... X
With fisted hand?.................................................................................. X
With open hand?................................................................................... X
Can he catch the pillow?....................................................................... X
Appendix D:

Home Layout

3 Bedroom 2 Bath
- 11'0" x 13'8" Master Bedroom with Private Bath
- Oversized Bath Tub
- Large 11'0" x 14'2" 2nd Bedroom
- 3rd 10'0" x 12'2" Bedroom
- Walk-In Closets
- Second Full Bathroom
- 15'8" x 14'8" Living Room
- Separate Dining Area
- 15'0" x 6'8" Patio/Balcony
- Full Size Washer & Dryer
- Dishwasher
- Garbage Disposal
- 18 Cu. Ft. Refrigerator with Icemaker
- Storage Room
- Utility Room
- Mini - Blinds
- French Doors
- Ceiling Fans

1220 sq. ft.