Exploring Barriers to Remaining Physically Active: A Case Report of a Person with Multiple Sclerosis

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Abstract: Physical therapy intervention for those with chronic disabling conditions typically follows an episode of care approach: therapists provide services when a decrement in functional performance occurs such that individuals require intervention to return to baseline performance. Attention to the psychosocial supports required for successful transition can be unintentionally minimized when the focus of an episode of care follows a change in physical function. The purpose of this case report is to present and discuss the challenges to successful community reintegration following physical therapy intervention with an emphasis on developing independent exercise habits in management of a person with multiple sclerosis. RW, presented in this case study, is a 52-year-old man diagnosed with progressive multiple sclerosis five years before self-referral to a pro bono physical therapy clinic.

Key words: multiple sclerosis, exercise adherence, barriers to exercise

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INTRODUCTION

As part of a national goal of improving health, the Office of Disease Prevention and Health Promotion has identified regular participation in physical activity as one of the leading health indicators used to measure the health of the nation.[1] Participation in aerobic exercise for persons with multiple sclerosis (MS) appears to improve aerobic capacity (independent of level of disability),[2–4] improve maximum isometric strength, change mood (including perception of fatigue),[2,4,5] and lower participants' self-perception of the impact of their disease in everyday life.[3] Importantly, participation in exercise appears to improve quality of life.[2,3,5,6] Physical activity recommendations for persons with MS include strength training two times per week and participation in aerobic activity three or more times per week for 20–30 minutes at 65% of peak aerobic capacity as measured by VO_{2max}.[7] These studies exploring exercise for persons with MS provided interventions closely supervised by skilled personnel. Support personnel evaluated within and between session dose response, in addition to providing encouragement and physical assistance as needed. These supports maintained exercise adherence during the protocol.

Consulting a physical therapist is recommended to assist in the design and adaptation of an exercise program to meet the individualized needs of persons with MS, with the intended outcome of independent exercise without therapist supervision.[5,7] However, continued independent participation in a structured exercise program appears to come with challenges. Mostert and Kesselring[2] report overall compliance in a four-week training program to be only 65% when incidence of symptom exacerbation due to physical activity is very low (6%). This suggests barriers other than the physical exist may limit continued participation in regular physical activity for persons with MS.

Many factors influence physical activity participation as a lifestyle habit. Those factors include availability of support, finances, and community resources.[8] External factors likely interact with factors internal to the participant including readiness for change, concurrent stressors, physical condition, energy level, and physical ability.[9] Physical therapy recommendations addressing physical access barriers alone may not be sufficient to induce long-term behavioral change. A critical review of the effectiveness of cognitive and social interventions to increase physical activity suggested that among other successful interventions, addressing social supports in community settings and policy examination might optimize the environment for change.[9] No studies exploring these interaction effects influencing success of physical activity interventions in people with MS are known.

Exercise adherence is not a new challenge. A review of the social cognitive factors that influence exercise adherence suggests that confidence in one's ability to engage in physical activity and outcome expectations can predict or support participation in physical activity.[10–14] Varied activity interventions have been examined, with behavioral and social intervention strategies as well as policy-based interventions (eg, improved access to exercise environments) improving activity participation among otherwise healthy adults and children.[9] One study, specifically exploring prevalence of physical inactivity in older women with mobility restrictions, found that 14.4% of the participants were physically inactive.[15] Severity of the mobility challenge predicted risk of inactivity with those more challenged being less active.[15] Interestingly, however, although few of the participants met the recommended activity guidelines, most were not classified in this study as "inactive," suggesting that the presence of physical limitation alone is not adequate to explain activity

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participation. Important to activity participation is mental health. Those with depressive symptoms may have additional challenges to activity participation. In a large survey of men and women, Galper and colleagues[16] found an inverse dose-response relationship between cardiorespiratory fitness and scores on a standardized test for depression and a second standardized test for general well-being.

This case report describes the benefits of a physical therapy intervention delivered with the goal of developing the skills and supports necessary to meet the recommended activity dose through independent exercise. Specific attention is paid to the barriers and challenges attendant to successful exercise outcomes that were experienced in this case and that may be similar to those witnessed by other therapists and their clients. This case report highlights the challenges and the failures of the lead therapist, the community, and the model of rehabilitation delivery familiar to many therapists serving those with chronic disabling conditions.

CASE DESCRIPTION

History and Examination

At the time of this intervention, RW (not his real initials) was a 58-year-old man diagnosed with progressive MS five years before self-referral to a pro bono physical therapy clinic. RW reported that his onset of MS was sudden and debilitating; while at work as an electrician, RW experienced a sudden "electrical flash" that resulted in inability to use his legs. He believed he had been electrocuted in completing his work and was taken immediately to the hospital for evaluation. Through consult and follow-up with a neurologist, he was informed that the symptoms experienced were not related to a possible electrocution, and he received his diagnosis of MS. RW reported that he never recovered fully after that initial attack and that although he had experienced no other sudden decrements in function, he reported his change in ability as slow but consistent. RW stopped working due to his disabilities three years before his referral to the clinic.

At initial examination, RW scored 6.5 on the Kurtzke Expanded Disability Status Scale, a ranking defined as requiring "constant bilateral assistance (canes, crutches, braces) required to walk 20 m without resting."[17] He reported a strong commitment to exercise and had recently been instructed by his physician to participate in an exercise program as a way of managing his MS symptoms. RW described himself as a runner before his diagnosis of MS and reported completing two marathons and averaging participation in three 10-km competitive events each year for the past 15 years. He had not run or engaged in any other form of fitness activity since his diagnosis of MS.

RW stated that he used a wheelchair as his primary means of household and community mobility primarily because his walking speeds were too cumbersome for others. He was independent with transfers including those in and out of the car. RW had stopped driving approximately six months before his initial examination. RW was consistently completing a home program of lower extremity stretching (self-designed from his running experience) with his wife providing assistance as needed. RW stated a strong preference to be independent with his exercise.

RW was married with an active and involved spouse who was the primary wage earner for the family. He had two grown children and four grandchildren who did not live in the immediate area but who visited on a regular basis. RW lived in a single-story home that had been adapted to be fully accessible. RW qualified for Supplemental Security Income six months before his admission to the clinic. As RW no longer drove, he was transported to the clinic for his sessions by either his spouse or a close friend.

At the time of his participation, RW was on a waiting list for a trial of plasmapheresis to treat his MS. RW's medications included interferon-β1a (Rebif) injections three times per week, baclofen (80 mg/day), ceftazidime (Tazidime) (10 mg/day), oxybutynin (Ditropan) (40 mg/day), paroxetine (Paxil) (40 mg/day), and dextroamphetamine (Adderall) (60 mg/day). In addition, RW took an over-the-counter multivitamin (four per day), vitamin C (600 mg), ginseng (unknown dose), and flaxseed oil (two tablespoons per day). RW reported himself as healthy with the exception of his challenges due to MS, and had no history of cardiac disease, metabolic disease, premorbid musculoskeletal trauma, or psychiatric illness. RW considered himself very healthy before the diagnosis of MS.

RW's goal was to participate in regular exercise, with the desire of improving walking performance primarily in the home. Because RW was motivated by running, a fitness activity that included a running/walking intervention was stated as a preference. Baseline functional performance measures quantifying ambulatory status and quality of life were chosen to document functional change as a result of the intervention. The measures included the Timed Up and Go (TUG),[18] comfortable gait speed (CGS), and fast gait speed (FGS) (Fig. 1), collected in that order. The TUG has high intrarater reliability and moderate test-retest reliability in a population of healthy adults.[19] Intrarater reliability and test-retest reliability of CGS is good to excellent.[20,21] Although no

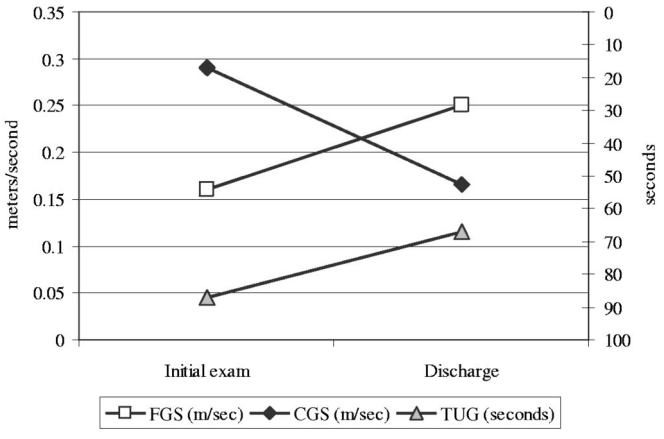

FIGURE 1. Change in functional performance during intervention. Normative values for men aged 60–69 years[24]. Timed Up and Go (TUG): eight seconds; Comfortable Gait Speeds (CGS): 1.59 m/s; Fast Gait Speeds (FGS): 2.05 m/s.

normative data in people with MS are known for the TUG, the population used to evaluate reliability of the CGS included persons with MS.[21] No reliability or validity data are known for the FGS, which was included to examine capacity for varying functional gait. Normative values for TUG, CGS, and FGS are provided in Figure 1. Baseline examination of quality of life was evaluated using the subscale scores of the Medical Outcomes Study 36-item short-form health survey (SF-36) (Fig. 2). Although the SF-36 physical and psychological subscales correlate with well with other measures of physical and psychological health in persons with MS,[22] there are concerns about responsiveness to change[17] and floor effects in the physical subscales.[22,23]

Intervention

RW participated in eight weeks of supervised exercise. Weeks 1 through 6 consisted of lower extremity stretching of bilateral quadriceps and hip flexors (two stretches of each muscle group held for 60 seconds each stretch with 30 seconds between stretches) followed by aerobic training completed by treadmill walking at speeds of 0.4–0.6 miles per hour. Initially, RW self-limited his walk to eight minutes based on fatigue, but increased walk time to 20 minutes at the end of the eight-week session. Walking intensity was graded using the 20-point rate of perceived exertion (RPE) scale. RW was instructed to maintain his perceived exertion between 10 and 14 on the scale. The intervention was based on recommendations in the literature,[25] modified by goals of the patient who preferred a treatment emphasis on aerobic conditioning. Given a choice of varied techniques, RW felt treadmill walking most closely reflected his past interests as a runner. Assuming eccentric muscle activity might reduce the muscle fatigue of walking exercise,[25] the treadmill was adapted such that RW was walking on a 10% downhill grade using a custom-designed block to lift the back end of the treadmill. In addition, because RW had balance challenges that made walking on a treadmill a behavior risky for injury due to falls, a body support system was used as a safety device. RW supported his full body weight during the training program. RW completed all sessions of the exercise program.

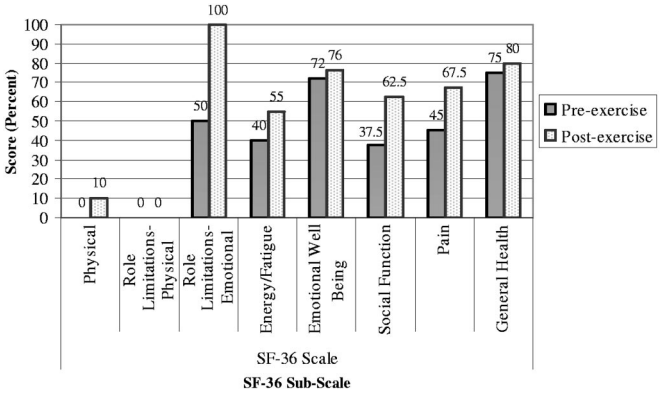

FIGURE 2. Pre-/postexercise change in quality of life as measured by the SF-36.

In weeks 6 through 8, the intervention was designed to begin cross-training on a recumbent bike and to develop a self-stretching program. RW was expecting to continue his training at the YMCA. Because of the need for a body support harness for treadmill safety (not available at RW's local YMCA) cross-training to another piece of equipment was necessary to ensure safety with aerobic exercise. The goal of the intervention was to provide RW with the training strategies and supports to be successful with the transition to independent exercise given the relatively new physical, medical, and psychological challenges associated with his diagnosis of MS. A follow-up phone call to evaluate success with aerobic intervention was scheduled at four months post-discharge.

At discharge, RW was independent with a standing lower extremity stretching program but required assistance to secure his feet in the recumbent bike foot pedals. RW reported he had assistance from either friends who would accompany him in his exercise or other support staff at the YMCA who could provide the needed assistance with the recumbent equipment. RW was independent at grading his exercise program using the RPE as a guide to manage intensity.

Outcomes

Activity Change During the Intervention Phase

As presented in Figure 1, RW improved his TUG score by 23% and his FGS score by 36%. His CGS score decreased by 41%.

Quality of Life Change During the Intervention Phase

Baseline and postexercise scores on the seven subscales of the SF-36 are presented in Figure 2. Improvements were noted in RW's perception of his role limitations due to emotional problems (100% improvement), reports of low energy or fatigue interfering with quality of life (37.5% improvement), improved social function (66.7% improvement), and reduced perception of pain altering his quality of life (50% improvement).

Perceived Barriers to Physical Activity: Long-Term Outcomes

RW was successful in meeting a therapy goal of achieving independence with a physical activity program. To evaluate whether transition to community involvement was successful, a follow-up survey was conducted four months after discharge from physical therapy. The follow-up survey was based on the Barriers to Bing Active Quiz (Appendix A).[26] In the interview, RW stated he had not returned to physical activity at the YMCA. RW also stated that he felt he had lost some mobility since discharge from the supervised services provided.

To attempt to quantify where challenges to successful participation arose, a modified version of the Barriers to Being Active Quiz (Appendix A)[20] was administered. Although no validation of this quiz was found, this tool is available from the Centers for Disease Control and Preven-

tion on a Web site designed to assist people in self-identifying barriers to physical activity participation. At RW's request, the survey was sent to RW in the mail and returned by RW within the week. A second phone call was made to elaborate on findings. The quiz results suggested that RW's greatest perceived barrier to regular exercise is "lack of willpower" followed by "lack of skill." Discussion with RW suggested his perceived lack of willpower comes from exercise not being as "fun as it was before getting MS." RW stated he was particularly motivated to ambulate on the treadmill because he saw a direct link to his preferred sport (running) before his diagnosis and because he viewed the one-to-one supervision provided in the formalized pro bono intervention a social opportunity organized around a meaningful activity. He reported that he did not find this same fulfillment in the setting at the YMCA where independent use of equipment provided less opportunity for social interaction.

An attempt to reintroduce RW to the pro bono clinic at the four-month follow-up, with the goal of addressing the lack of success at community reintegration, found RW requesting the opportunity to defer until the completion of his plasmapheresis trials.

DISCUSSION

RW's case presents an opportunity to examine outcomes to interventions. At first glance, RW appears to have exercise related changes in physical performance and psychological function during the eight-week intervention. Interventions were provided based on needs identified in an initial examination, which was completed in a single session. The practice model followed intervention immediately from the initial examination, a model typical of most practice settings. However, this scheduling did not allow for the therapist to identify whether the baseline observed at initial examination was indeed a stable baseline reflecting average performance. A single-subject case design with multiple examination points before the start of the intervention would clarify the concern of an unstable baseline. Therapists, however, rarely have opportunity to establish baseline performance before initial examination.

Since training at 0.4–0.6 miles per hour translates to walking practice with gait speeds of 0.18–0.27 m/s, improvements in FGS might be a function of practice. This does not explain the decline of CGS, nor does it explain the fact that at initial examination RW's CGSs were actually faster than his FGSs. As such, improvements noted in FGS and the TUG as well as decrements in CGS are better interpreted as variability in baseline performance in an individual with significant activity limitations and a progressive chronic disease. There is no clearly observable effect of intervention on functional performance in this case.

Whether the same interpretation can be made of SF-36 scores is a little more difficult. Since RW felt supported and motivated to participate in the intervention provided, the changes in how he viewed his disability may actually have been a direct result of intervention. However, because RW did not continue participation in the community after discharge, it is presumed that these changes were not retained.

Importantly, although the therapy was successful at meeting the outcome of RW achieving the skills for independent exercise, it failed to actually get RW exercising. In the case of RW, barriers to physical activity appear to be related to those internal to the participant. RW's desire to participate in a specific walking activity, might have overcome the will power barrier because of its reward characteristics. However, when supports (both the social support of supervision and the safety of the body support system) for that walking activity were removed, the reward offered by participation in other safe, seated activities apparently was insufficient to maintain change. To establish a supportive physical environment that optimizes successful continuation of behavioral change initiated in a formal therapeutic relationship, external supports need to be available, accessible, affordable, acceptable, and appropriate.[20] In this particular instance, a person with limited disposable income with physical limitations was unable to find acceptable services. The social void filled by participation in physical activity must be considered when transitioning to community environments. This reflection was lacking before discharge of this client. Services were, however, available, accessible, appropriate, and affordable through his local YMCA.

The question raised by this case is whether the services of the general community are adequate to maintain an exercise behavior developed in formalized physical therapy intervention. As physical therapists regularly provide interventions for those with chronic, disabling, and often progressive conditions, the interventions we deliver cannot and should not be organized around a care model that emphasizes physical rehabilitation at the expense of considering the psychosocial issues surrounding successful outcomes. As approximately 60% of adults in the United States are not sufficiently active to achieve the health benefits of exercise,[26] it is likely that many of our patients present to rehabilitation without the exercise history that may optimize success of a community transition. Relapse to sedentary behavior is likely.[8] We do note that the exercise history of our client should have optimized successful community transition. We do note the inverse relationship between physical activity participation and mental health[16] and suggest that perhaps a formal screening for mental health challenges may have been a recommendation overlooked.

RECOMMENDATIONS

We recommend that physical therapists with expertise in neurological rehabilitation advocate for development of community-based physical activity programs. These can serve as an adjunct to and complement of traditional therapy services to effectively manage clients throughout the disease process. Therapy delivered before participation in these community-based programs can emphasize teaching the activities necessary for independent exercise including instruction on the use of equipment as well as teaching participants how to self-regulate exercise intensity to maintain doses effective for safety and fitness improvement. Therapists can schedule regular re-evaluations for the purposes of monitoring and updating exercise prescriptions as well as to address barriers

to continued exercise participation. Finally, as this case suggests, the community-based programs must fulfill some of the social needs that those with chronic disabling conditions face in order to increase the probability of successful long-term participation. It is not clear whether a different approach to community-based exercise would have been effective in allowing RW to meet his independent exercise goals; it is clear that the traditional approach to therapeutic management did not.

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APPENDIX. Barriers to Being Active Quiz

NAME/DATE: _____ Directions: Listed below are reasons that people give to describe why they do not get as much physical activity as they think they should. Please read each statement and indicate how likely you are to say each of the following statements. (There are no right or wrong answers.)

How likely are you to say?	Very likely	Somewhat likely	Somewhat unlikely	Very unlikely
1. My day is so busy now; I just don't think I can make the time to include physical activity in my regular schedule.	3	2	1	0
2. None of my family members or friends like to do anything active, so I don't have a chance to exercise.	3	2	1	0
3. I'm just too tired after work (or at the end of the day) to get any exercise.	3	2	1	0
4. I've been thinking about getting more exercise, but I just can't seem to get started.	3	2	1	0
5. I'm getting older, so exercise can be risky.	3	2	1	0
6. I don't get enough exercise because I have never learned the skills for any sport.	3	2	1	0
7. I don't have access to exercise equipment, jogging trails, swimming pools, bike paths, etc.	3	2	1	0
8. Physical activity takes too much time away from other commitments like work, family, etc.	3	2	1	0
9. I'm embarrassed about how I will look when I exercise with others.	3	2	1	0
10. I don't get enough sleep as it is. I just couldn't get up early or stay up late to get some exercise.	3	2	1	0
11. It's easier for me to find excuses not to exercise than to go out and do something.	3	2	1	0
12. I know of too many people who have hurt themselves by overdoing it with exercise.	3	2	1	0
13. I really can't see learning a new sport at my age.	3	2	1	0
14. It's just too expensive. You have to take a class or join a club or buy the right equipment.	3	2	1	0
15. My free time during the day is too short to include exercise.	3	2	1	0
16. My usual social activities with family or friends do not include physical activity.	3	2	1	0
17. I'm too tired during the week and I need the weekend to catch up on my rest.	3	2	1	0
18. I want to get more exercise, but I just can't seem to make myself stick to anything.	3	2	1	0
19. I'm afraid I might injure myself or have a heart attack.	3	2	1	0
20. I'm not good enough at any physical activity to make it fun.	3	2	1	0
21. If I had exercise equipment at home or work, then I would be more likely to exercise.	3	2	1	0

Researcher comments:

Scoring key [for researcher use only]:

- Enter the circled number in the spaces provided, putting the number for statement 1 on line 1, statement 2 on line 2, and so on.
- Add the three scores on each line. The barriers to physical activity fall into one or more of seven categories: lack of time, social influences, lack of energy, lack of will power, fear of injury, lack of skill, and lack of resources. A score of ≥5 in any category shows that this is an important barrier to overcome.

____	+ ____	+ ____	= _____	
1	8	15		Lack of time
____	+ ____	+ ____	= _____	
2	9	16		Social influence
____	+ ____	+ ____	= _____	
3	10	17		Lack of energy
____	+ ____	+ ____	= _____	
4	11	18		Lack of willpower
____	+ ____	+ ____	= _____	
5	12	19		Fear of injury
____	+ ____	+ ____	= _____	
6	13	20		Lack of skill
____	+ ____	+ ____	= _____	
7	14	21		Lack of resources

Reference: U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Nutrition and Physical Activity. (1999). *Promoting Physical Activity: A Guide for Community Action.* Champaign, Ill.: Human Kinetics; 1999:100–101. Available in pdf form from the Centers for Disease Control and Prevention at http://www.cdc.gov/nccdphp/dnpa/physical/life/overcome.htm.