Physical Activity Behavior Change in Persons With Neurologic Disorders: Overview and Examples From Parkinson Disease and Multiple Sclerosis

Terry Ellis, PT, PhD, NCS, and Robert W. Motl, PhD

Persons with chronic progressive neurologic diseases such as Parkinson disease (PD) and multiple sclerosis (MS) face significant declines in mobility and activities of daily living, resulting in a loss of independence and compromised health-related quality of life over the course of the disease. Such undesirable outcomes can be attenuated through participation in exercise and physical activity, yet there is profound and prevalent physical inactivity in persons with PD and MS that may initiate a cycle of deconditioning and worsening of disease consequences, independent of latent disease processes. This Special Interest article highlights the accruing evidence revealing the largely sedentary behaviors common among persons living with physically disabling conditions and summarizes the evidence on the benefits of physical activity in persons with PD and MS. We then examine the social cognitive theory as an approach to identifying the primary active ingredients for behavioral change and, hence, the targets of interventions for increasing physical activity levels. The design and efficacies of interventions based on the social cognitive theory for increasing physical activity in persons with PD and MS are discussed. Finally, a rationale for adopting a secondary prevention approach to delivering physical therapy services is presented, with an emphasis on the integration of physical activity behavior change interventions into the care of persons with chronic, progressive disabilities over the course of the disease.

Video Abstract available (see Video, Supplemental Digital Content 1, http://links.lww.com/JNPT/A42) for more insights from the authors.

Department of Physical Therapy & Athletic Training, College of Health and Rehabilitation Sciences: Sargent; Boston University, Boston, Massachusetts (T.E.); and Department of Kinesiology and Community Health, University of Illinois at Urbana-Champaign (R.W.M.).

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Correspondence: Terry Ellis, PT, PhD, NCS, Department of Physical Therapy & Athletic Training, College of Health & Rehabilitation Sciences: Sargent, Boston University, 635 Commonwealth Ave, Boston, MA 02215 (tellis@bu.edu).

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INTRODUCTION

Parkinson disease (PD) and multiple sclerosis (MS) are examples of common and life-altering neurologic diseases among adults in the United States and worldwide. The estimated prevalence of PD is nearly 10 per 1000 older adults, with MS affecting approximately 1 per 1000 adults in the general population of the United States.[1] Persons with chronic progressive neurologic diseases such as PD and MS face significant declines in mobility and activities of daily living, resulting in a loss of independence and compromised health-related quality of life over the course of the disease.[2-4] Another important consequence prevalent both in persons with PD and in persons with MS is physical inactivity; this inactivity may initiate a cycle of deconditioning and worsening of disability, independent of latent disease processes.[5] In both these conditions, however, numerous studies have revealed the significant benefits of physical activity, in the form of exercise training, in reducing disability and improving health-related quality of life.[6-8] This suggests that increasing physical activity and engaging in exercise should be part of the standard management of PD and MS. Although physical therapists recognize the importance of physical activity and routinely prescribe exercise programs, there may be limited long-term adherence to exercise and many persons with PD and MS adopt a sedentary lifestyle over the course of time.

We suggest that physical therapists have much more to offer people with chronic progressive diseases such as PD and MS. This is important, considering the consequences associated with physical inactivity in persons with PD and MS and the research demonstrating benefits of exercise and physical activity in reducing disability. More than a decade ago, Rimmer[9] proposed a paradigm shift from disability prevention to health promotion for people with disabilities. Physical therapists could play an important role in the integration of health promotion into the fabric of the community by partnering with fitness professionals to extend exercise programs from rehabilitation centers to fitness centers and into the home.[9] This paradigm shift should further emphasize a change in the way physical therapy services are provided to persons with PD,

MS, and potentially other chronic progressive disorders. This involves moving away from a tertiary prevention approach, in which the emphasis is on restoring function and reducing disease-related complications, and toward a secondary prevention approach, in which treatment is initiated early in the disease state, before the onset of significant morbidity. This secondary prevention approach would include the application of evidence-based behavioral change interventions emphasizing sustained exercise and physical activity over the course of the disease.

There is a need to increase physical activity levels among persons with PD and MS, given the staggering levels of inactivity despite the recognized benefits of exercise. The current challenge is to identify effective, theory-based approaches to increase long-term adherence to exercise in persons with chronic physical disabilities. For example, studies of healthy adults and persons with PD and MS have identified self-efficacy as a primary correlate of physical activity. *Self-efficacy* is defined as a situation-specific belief in one's ability to successfully undertake a course of action.[10] The social cognitive theory (SCT) offers a theoretical framework for examining and targeting correlates of behavioral change.[11] This framework can be applied to persons with PD and MS, with the goal of developing targeted interventions aimed at changing physical activity behavior.

This article will begin with a review of research on the apparently profound levels of inactivity in persons with PD and MS and the benefits of physical activity in these populations. This will serve as a prelude for the subsequent focus on the use of the SCT[10,11] for identifying agents or targets of behavior change and the existing research on its application for understanding engagement in physical activity in persons with PD and MS. This will be followed by a discussion of the design and efficacy of interventions based on the SCT for increasing physical activity in persons with PD and MS. Finally, we present ideas on subsequent directions and implications for integrating these approaches to promote physical activity behavior change into clinical practice.

PHYSICAL INACTIVITY

Physical inactivity was recently described as a pandemic and the fourth leading cause of death worldwide.[12] Although the lack of physical activity is a problem for all people, those with physical disabilities are at a much higher risk of developing serious health problems as a result of physical inactivity.[13] This is important, considering that persons with PD and MS are largely sedentary and engage in less physical activity than healthy adults—this might account for many of the negative consequences of these disabling conditions.

There is evidence of prevalent physical inactivity in persons with PD and MS. For example, one recent study compared physical activity levels in older adults (N = 1,959) with that in persons with PD (N = 699) and revealed that persons with PD were approximately one-third less active than older adults.[14] Using the Hoehn and Yahr scale, a marker of disease severity in persons with PD, this study highlighted the decline in physical activity that occurred with disease progression. A 13% decrease in physical activity was observed from Hoehn and Yahr stages I to II, a 21% decrease from stages I to III, and an 84% decrease from stages I to IV.[14] Similarly, a study examining walking behavior by using a step activity monitor over a 7-day period at baseline and 1 year later revealed a significant decline in daily steps (12%) and a substantial reduction in moderate intensity steps (40%) over the course of a year in persons with PD.[15] Other studies have noted reductions in daily energy expenditure, poorer physical conditioning, and longer bouts of sedentary behavior in persons with PD compared with healthy older adults.[16-18] One meta-analysis quantified the difference in physical activity among individuals with MS compared with that in healthy and diseased populations.[19] Overall, 53 effects were retrieved from 13 studies with 2360 MS participants and yielded a weighted mean effect size of -0.60 (95% confidence interval, -0.44, -0.77).[19] This overall effect indicates that individuals with MS are significantly and moderately less active than the overall comparison group. This observation has been confirmed in more recent research involving persons with MS and matched healthy controls, using validated objective and self-report measures of physical activity.[20] Overall, these findings of substantially reduced physical activity levels in persons with both PD and MS compared with healthy persons without disabilities are alarming, given the well-documented prevalence of physical inactivity among adults in the general population.

IMPORTANCE OF PHYSICAL ACTIVITY

Over the last decade, evidence has accumulated for significant and clinically meaningful benefits of physical activity in the form of exercise training for persons with PD and MS. One systematic review of the literature indicated that persons with PD who participated in exercise interventions had better strength, flexibility, cardiovascular fitness, balance, walking ability, and quality of life than those who did not exercise.[21] A recent Cochrane review, including 33 randomized controlled trials with more than 1500 participants with PD, indicated significant improvements in gait velocity, functional mobility, balance, and activities of daily living following therapeutic exercise (ie, physical therapy) compared with no intervention.[6] Similarly, there are several literature reviews and meta-analyses documenting the benefits of exercise training in persons with MS for improving muscle strength, aerobic capacity, and walking performance, and some additional evidence revealing the beneficial effects on fatigue, balance, and quality of life.[22-24] Overall, the existing evidence is sufficiently strong to underscore the importance of physical activity for managing many of the consequences of PD and MS.

THEORY OF BEHAVIOR CHANGE AND CORRELATES OF PHYSICAL ACTIVITY

As described in preceding sections, there is an urgent need for increasing physical activity levels in persons with PD and MS to mitigate disability and improve overall health; theory should inform the development of approaches (ie, interventions) for changing any behavior, including physical activity.[25] Theory guides the search for variables that are associated with a focal behavior (ie, correlates) and provides insight into the design of programs that successfully change the behavior.[25] Ideally, an examination of these variables should be rooted in a well-developed theory that identifies correlates, strategies,

and pathways of behavior change,[25,26] such as the SCT of Bandura.[10,11] One of the primary active agents for behavior change in the SCT is self-efficacy.[10] Research has supported self-efficacy as a primary correlate of physical activity in the general population[26,27] and in persons with both PD[28] and MS.[29-31] The importance of self-efficacy operating as a correlate of physical activity is that there are sources of information that can be targeted for changing this variable and consequently behavior.[10] Many other models of health behavior (eg, Health Belief Model, Theory of Planned Behavior, Protection Motivation Theory) include predictors that are overlapping with the SCT, but those theories identify predictors of health behaviors rather than both predictors and principles for targeting change.[11]

Bandura[11] has recently offered a model whereby self-efficacy has both direct and indirect pathways with health behaviors (Figure). The indirect pathway, in particular, includes physical, social, and self-evaluative outcome expectations, sociostructural factors (ie, impediments and facilitators), and goal setting as possible intermediate variables between self-efficacy and health behavior. As noted by Bandura,[11] those with high self-efficacy expect more favorable physical, social, and self-evaluative outcomes, view impediments as more surmountable, and set higher goals for themselves. Bandura[11] further notes that those with more favorable outcome expectations, fewer impediments, and higher goals engage in more positive health behaviors. Variables within the SCT, including self-efficacy and outcome expectations, have been identified as correlates of physical activity in persons with PD and MS. For example, one cross-sectional study of 260 persons with PD indicated that the participants with high self-efficacy were more likely to engage in regular exercise than those with low self-efficacy (adjusted odds ratio [OR] = 2.34).[28] Additional analyses indicated that low outcome expectations (OR = 3.93), lack of time (OR = 3.36), and fear of falling (OR = 2.35) were further associated with the lack of participation in exercise.[32] One study of 196 persons with MS reported that self-efficacy and enjoyment were primary determinants of physical activity participation.[33] Another study of 80 individuals with MS indicated that both overall symptoms and motor symptoms had indirect effects on physical activity by way of self-efficacy.[34] Similarly, a study of 218 persons with relapsing-remitting MS demonstrated that self-efficacy had an indirect, rather than direct, relationship with physical activity by way of goals, impediments, and outcome expectations, providing additional support for the SCT.[35] Collectively, these studies suggest that components of the SCT are important correlates of physical activity participation and should be the targeted components of interventions.

BEHAVIOR CHANGE INTERVENTIONS

Researchers have begun designing and testing interventions based on the SCT for increasing physical activity in persons with PD and MS. The Parkfit Trial, currently in process in the Netherlands, is a 2-year multicenter randomized controlled trial comparing physical therapy with a specific emphasis on promoting a physically active lifestyle (Parkfit Program) with a matched physical therapy with specific emphasis on safety and quality of performing activities of daily living (ParkSafe Program).[36] The Parkfit Program, based on models of behavioral change, including the SCT, specifically focuses on inducing a lasting change in exercise behavior through goal setting, overcoming barriers to engaging in exercise, recruiting social support, coaching by the physical therapist, and use of an activity monitor with visual feedback regarding daily activity levels.[36] Results of this trial will provide important new knowledge about the effects of a behavioral change intervention, provided face-to-face by physical therapists, on improving activity level over the long term in persons with PD.

Among persons with MS, researchers have demonstrated, in a randomized controlled trial, that a SCT-based intervention delivered face-to-face increases exercise adherence across a 3-month period.[37] The sample included 26 persons with MS who were randomized into either intervention or standard care conditions within the context of a 3-month exercise training program. The intervention condition involved workshops (ie, lectures and mini–homework assignments) that focused on the provision of information, based on the SCT, about physical activity participation. The participants randomized to the intervention condition attended more exercise sessions over the 3-month period than did participants randomized to the standard care, control condition ($d = 0.47$). This translated into 6 more days of exercise over the trial (ie, 2 more of the 12 weeks) and a total of approximately 150 additional minutes of exercise over the 3-month period. There were no adverse or serious adverse events recorded during this trial.

Beyond face-to-face interventions, Internet-delivered interventions based on the SCT have been successful at increasing physical activity levels. For example, 54 subjects with MS were randomly allocated into either a 12-week Internet intervention condition or a waitlist control condition.[38] The intervention provided electronic content (eg, text, pdf, video files) based on the SCT and the article about the aforementioned study in MS.[37] The intervention group reported a large effect size (ie, Cohen *d*) and statistically significant increase in physical activity over time ($d = 0.72$; $P = 0.01$), whereas the control group had a small and nonsignificant change in physical activity ($d = 0.04$; $P = 0.71$). The intervention group further reported a large and significant increase in goal setting over time ($d = 0.97$; $P = 0.001$), whereas the control group had a small and nonsignificant change ($d = -0.13$; $P = 0.17$). The authors concluded that the change in goal setting over time mediated the effect of the Internet intervention on physical activity behavior.

Video coaching has been used to supplement an Internet-delivered, SCT-based behavioral intervention as an approach for increasing comprehension and penetration of the interventional materials and for supportive encouragement with behavior change.[39] Physically inactive, ambulatory persons with MS (n = 45) were randomly assigned to intervention (n = 22) or control (n = 23) conditions and completed a battery of questionnaires before, after, and 3 months after a 12-week intervention period. Effect sizes indicated that the intervention group had a large increase in physical activity after the 12-week trial ($d = 0.98$) that was sustained over a 3-month follow-up ($d = 0.79$). That study supported the efficacy of a behavioral intervention that combines the Internet and video

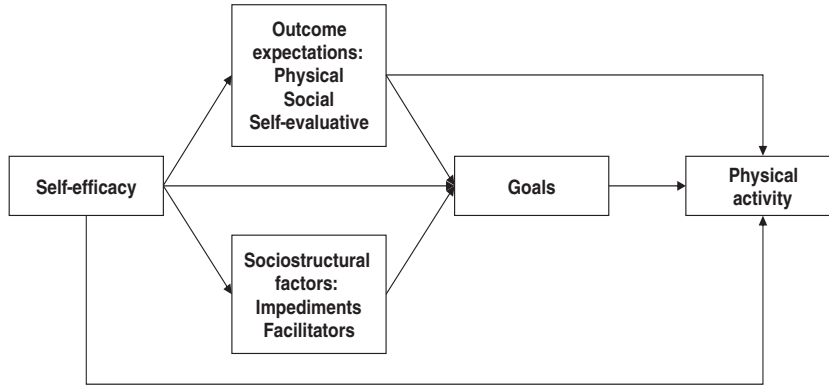

Figure. Model of the direct and indirect relationships between self-efficacy and behaviors such as physical activity (based on Bandura[11]).

chats for increasing and sustaining physical activity by using the SCT components in a sample of persons with MS.

Studies using virtual coach systems have demonstrated significant improvements in behavioral outcomes in trials of exercise promotion among healthy older adults, persons in underserved communities, and overweight adults but have only recently been applied to persons with disabilities.[40-42] Virtual exercise coaches are human-like computer characters that deliver a theoretically based behavioral change intervention by simulating complex human interactions.[43] The feasibility, acceptability, and preliminary evidence of effectiveness of a virtual exercise coach to promote daily walking in community dwelling persons with PD were examined in a phase I single-group, nonrandomized clinical trial.[44] Twenty sedentary subjects with PD were instructed to interact with the virtual exercise coach for 5 minutes, wear a pedometer, and walk daily for 1 month. At study completion, there was a 100% retention rate and the mean adherence to daily walking was 85%, suggesting that interacting with a virtual exercise coach in the home environment may be a viable method of increasing adherence to exercise in sedentary persons with PD.

IMPLICATIONS FOR PHYSICAL THERAPY: MORE SUPPORT FOR A PARADIGM SHIFT

Physical therapy, often including exercise and physical activity, is frequently provided to persons with PD and MS but often not until the middle and later stages of the disease or after a discrete period of disease exacerbation (eg, a relapse in MS). In this tertiary prevention approach, the focus is mainly on restoring function after an acute event (ie, a fall) or following a substantial decline in functional status (ie, loss of independence). Patients typically receive a short-term episode of physical therapy services that initially lead to improvements in physical function. After this episode of care, patients are frequently discharged with a home exercise program, with the expectation of long-term, independent adherence. However, the evidence suggests that adherence to exercise is poor following discharge from physical therapy,[45] leading to a loss of the initial gains, resumption of a sedentary lifestyle, and worsening levels of disability over time.[46]

In a secondary prevention approach, persons with PD and MS would be referred to a physical therapist upon diagnosis, even in the absence of obvious disability. The physical therapist could then administer a series of standardized outcome measures to establish a baseline status related to participation restrictions, activity limitations, impairments, and physical activity level. An exercise program tailored to the unique needs of the individual would be prescribed, with an emphasis on promoting and sustaining at least moderate levels of physical activity over the long term. Behavioral approaches or interventions based on a well-established and tested theoretical framework such as the SCT would be incorporated into the plan of care to teach skills, resources, and techniques for sustained participation in exercise. Follow-up visits would be scheduled on a regular basis over the course of the disease to increase patient accountability related to exercise adherence, to identify changes in disability level, to set new goals, and to progress the exercise program with the goal of reducing disability and optimizing health and wellness over the long term.

Physical therapists are well versed in prescribing exercise programs with particular attention to ensuring that patients correctly perform the exercises with the appropriate technique. Yet, more time spent on arming patients with the skills needed to sustain an exercise program over the long term is necessary. The SCT variables appear to be important determinants of exercise adherence in both persons with PD and MS, and evidence indicates that patients would benefit if physical therapists were to adopt methods to improve self-efficacy, goals, and resources during treatment sessions. Explicitly discussing the barriers to exercise with each individual patient and problem solving to overcome these barriers is an important initial step in the process. Providing experiences of mastery is one of the most effective ways to improve self-efficacy. For example, goals related to physical activity level must be challenging yet attainable. Success raises self-efficacy, whereas failure lowers it. Using a pedometer, for example, with a goal of increasing the number of steps walked per day over the course of a week or a month to attain a mutually agreed upon goal allows the patient to work hard, monitor progress, and experience success while achieving several incremental goals over time.

Self-efficacy can also be increased through modeling—when a person with a disability sees others with a similar disability achieve a relevant goal or successfully engage in a behavior. Treatment in a group setting may serve as a mechanism to provide these modeling experiences. Social persuasion in the form of direct encouragement from another person, particularly an "expert" in the field or peer coach, can increase self-efficacy and outcome expectation. By sharing the results of studies demonstrating the benefits of exercise in persons with PD or MS, physical therapists can further increase the patient's outcome expectations.

In a secondary prevention model, persons with chronic progressive disabilities would be monitored and treated periodically by a physical therapist, beginning early and continuing over the course of the disease. Between episodes of care, theory-based behavioral interventions administered by using Internet-based mechanisms, virtual coaches, and other means of technology may be useful to increase physical activity levels in persons with chronic progressive disabilities. Advances in the technology used to deliver these types of interventions may also include mechanisms by which data on exercise adherence is remotely sent to physical therapists, who could then monitor progress over time. Alternatively, alerts could be sent to therapists when a patient fails to adhere to an exercise program over a given period of time. This may indicate a decline in status, triggering a return to the physical therapist for further intervention. Methods such as these offer exciting opportunities that could change the way physical therapists provide services to persons with chronic, progressive disorders over the course of the disease.

Although a paradigm shift proposing a secondary prevention model was proposed more than a decade ago,[9] this shift has not been fully realized. Barriers limiting progress must be considered and overcome. Restrictions in direct access to physical therapy services, lack of awareness among consumers and physicians regarding the role of physical therapy in health promotion in those with chronic disabilities, time constraints within physical therapy sessions, reimbursement restrictions from third-party payers, and limited research revealing superior outcomes and cost-effectiveness of a secondary prevention approach are some of the potential barriers to change. Physical therapists are well positioned to meet the health and wellness needs of persons with chronic disabilities; however, changes in policies and practices are necessary to overcome these barriers so that persons with disabilities can realize their potential.[47] In conclusion, recurrent physical therapy intervention that incorporates behavioral change interventions and is provided over the course of the disease may help to improve the physical activity levels and health outcomes of those with chronic progressive diseases such as PD and MS.

SUMMARY

Regular participation in exercise and physical activity improves function and reduces disability in persons with PD and MS. Nevertheless, persons with PD and MS are strikingly physically inactive even when compared with a largely sedentary healthy adult population. Self-efficacy, outcome expectations, goals, and facilitators have been identified as important determinants of exercise and physical activity behavior in persons with PD and MS. There is an emerging body of literature revealing that behavioral change interventions based on principles of the SCT may be effective in increasing physical activity in persons with PD and MS by targeting those determinants. Accordingly, we propose a paradigm shift in the physical therapist management of PD and MS, away from a tertiary model and toward a secondary prevention model. Physical therapy intervention and practice that embraces behavioral change interventions to promote greater levels of physical activity through sustained exercise over time through the SCT constructs may result in a reduction in the accumulation and progression of disability in persons with PD and MS across the life span.

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