Participation in and Adherence to Physical Activity in People With Physical Disability

Ka Chuen Lui, MSc; Stanley S.C. Hui, EdD

Abstract: It is a challenge for physiotherapists and fitness instructors to promote adherence to regular physical activity/exercise in people with physical disabilities. Although there has been emerging awareness of this in recent years, this topic remains relatively underexplored. The literature has shown that multiple factors affect the initiation and maintenance of participation in regular physical activity in this population, and relevant behavioural strategies are useful in this regard. The main theme of the present review is to provide frontline exercise professionals a wide picture for understanding participation in and adherence to physical activity for people with physical disabilities. The objectives are as follows: (1) to explore the need for regular physical activity/exercise for people with physical disability; (2) to sum up the correlates between people with disabilities and physical activity participation, as well as physical activity adherence; (3) to review strategies for increasing physical activity participation and adherence in people with disabilities; and (4) to point out the practical difficulties and implications from the reviewed papers concerning the improvement of physical activity/exercise participation and adherence.

Key words: adherence, correlates, participation, physical activity, physical disabilities

Introduction

According to Nagi’s disablement model, disability is the expression of a physical or a mental limitation in a social context. In this review, the term physical disabilities (PD) refers to those who suffered from a pathological impact on a cellular level (e.g. spinal cord injury [SCI]), which led to anatomical and physiological impairment (e.g. paralysis) and caused functional limitations (e.g. difficulty in transfer or walking), and finally resulted in limitations in socially defined roles (e.g. inability to work) [1].

Participation and Adherence Rates

Various reports and surveys have shown the low participation rate in physical activity and the high prevalence of secondary conditions among adults with disabilities. One report [2] found that a smaller proportion of adults with a disability met the national recommendations for physical activity (37.7% vs. 49.4%) when compared with adults without disability. In addition, 25.6% of people with a disability reported being physically inactive during an average week compared with 12.8% of those without a disability. In another survey conducted in 2001 [3], almost 70% of older adults with disabilities did not obtain the recommended amount of physical activity for receiving health benefits. Kinne et al [4] reported that the prevalence of secondary conditions (e.g. chronic pain, isolation, periods of depression) in the disability group was two to three times higher than among adults without disabilities.

In a healthy population, the exercise drop-out rate was found to be about 50% within half a year [5]. For people with disabilities, the drop-out rate is similar. In a randomized controlled study of people with SCI, the drop-out

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rate in a 9-month structured exercise programme (exercise twice per week) was found to be 19.4%. However, the drop-out rate at the 3-month follow-up after the 9-month exercise programme increased to 57.3% [6,7]. A similar exercise non-adherence rate was found in people with chronic disease; Davis et al [8] reported that about 50% of people with chronic obstructive pulmonary disease would stop exercising in just 6 months. Although both populations share a similar drop-out rate, people with PD may need more attention, because it is relatively easier for them to develop secondary conditions as a result of their primary disability, and they have been reported to be comparatively inactive compared with healthy populations as cited above.

**Consequences of Lack of Physical Activity**

The mortality rate is higher in people with PD, because these people present with more risk factors (physical inactivity, obesity, lipid disorders, metabolic syndrome, and diabetes) for developing cardiovascular disease [9]. In their study of prospective assessment of mortality in chronic SCI, Garshick et al [10] found that the most common underlying and contributing causes of death in chronic SCI patients were circulatory diseases, which accounted for 40.5% of the 37 deaths out of 361 subjects. In addition, Garshick et al identified diabetes and heart disease as two risk factors for death. The authors suggested that the results provided evidence that mortality following SCI is related to treatable or preventable factors. Another recent prospectively study on the mortality rate of people who suffered from multiple sclerosis (MS) conducted by Torkildsen et al [11] also showed that cardiovascular disease is the second most common cause, accounting for 13.1% of death in a total of 198 cases. The authors explained that the lower frequency of deaths caused by cardiovascular diseases was probably because of the reduced life expectancy of patients with MS, who died from other conditions (e.g. infection) before they eventually developed cardiovascular diseases. Frugoli et al [12] also identified physical inactivity, diabetes, high cholesterol, and hypertension as the risk factors for cardiovascular disease development in an amputee population, and the rates of the last three factors were higher than those seen in the general United States population. Modan et al [13] evaluated the 24-year mortality rates of male traumatic lower limb amputees (n = 201) of the Israeli army wounded between 1948 and 1974, compared with a cohort sample representing the general population (n = 1,832). Mortality rates were significantly higher (21.9% vs. 12.1%; p < 0.001) in amputees than in controls. They found that amputees who survived had hyperinsulinemia, increased coagulability, and increased sympathetic and parasympathetic responses, and these risk factors may explain the excess mortality due to cardiovascular disease in traumatic amputees.

**Benefits of Regular Physical Activity**

It has been well-documented that regular physical activity can enhance health-related fitness, functional independence, and quality of life for people with various PD [14–16]. To cite some examples, Hicks et al [6] reported in their 9-month randomized control trial that twice weekly supervised exercise training could produce positive effects on perceived quality of life and muscle power of SCI patients. White and Dressendorfer [17] have reported that aerobic exercise training in MS is associated with increased maximal oxygen uptake and functional capacity as well as increased muscle and endurance. McCartney et al [18] also showed 11–50% improvement in leg strength after a 9-week strength training programme for people with spinal muscular atrophy.

In addition, regular physical activity or exercise has been reported to improve or have a negative correlation with the secondary conditions of people with disabilities [16]. The term secondary conditions refers to a number of preventable health problems that may be indirect results of lifestyle (physical inactivity), environment or behaviour originating from the primary disabling condition [19]. Moreover, it has been found that increased levels of physical activity appear to lead to higher high-density lipoprotein in the blood among people with SCI [20]. Hicks et al [6] also showed significantly less stress and depression in a group of people with disabilities after a 9-month period of weekly exercise. Kaplan et al [21] reported that regular weight-bearing training in people with SCI could reduce hypercalciuria and make the calcium balance more positive. In addition, Santiago and Coyle [22] have reported that physical deconditioning and social isolation are inversely related to the ability of women with disabilities to participate in leisure time physical activity. A recent study also showed that not engaging in weekly exercise is a significant predictor of subsequent occurrence of urinary tract infections in people with SCI [23].

**Correlates Between Physical Activity and People With PD**

Studies or surveys investigating correlates associated with exercise or physical activity are twofold. On the one hand, some studies used samples with single diagnosis, such as cerebral palsy (CP) [24], stroke [25], MS [26,27] and rheumatoid arthritis [28]. On the other hand, there are studies whose samples included mixed diagnoses (e.g. SCI, MS, muscular dystrophy, mobility impairment) [29–33] or which used disability classification questions [34].

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Samples With Single Diagnosis

Heller et al [24] found in 83 adults with CP that the caregiver’s perceived benefits of exercise for people with CP and the type of residence were the most significant determinants of exercise participation. They found that when caregivers perceived greater benefits of exercise, adults with CP were likely to exercise more frequently. In addition, non-nursing home residents were more likely to exercise than nursing home residents; however, this difference was not related to personal factors of the residents or access to an exercise facility but instead to the perceived benefits of the caregiver. Damush et al [25] identified three barriers (physical impairments from stroke, lack of motivation, and environmental factors) and three facilitators (motivation, social support, and planned activities to fill empty schedules) in their qualitative study, which investigated factors affecting physical activity among 13 stroke survivors. Motl et al [26] also reported that there were statistically significant direct relations between physical activity and enjoyment as well as self-efficacy in people with PD. Furthermore, they also found that self-efficacy had direct relations to enjoyment, social support, and disability limitation. A year later, Motl et al [27] further indicated that increasing age, use of a cane for ambulation, unemployment, and primary and secondary progression of MS were independently associated with less physical activity participation in 196 MS patients. Eurenius and Stenstrom [28] also showed that there was a statistically significant correlation between physical activity and general health perception, pain or disease activity in a group of people with rheumatoid arthritis.

Samples With Mixed Diagnoses or Classified by Disability Questions

For samples using mixed diagnoses or classified by disability questions, Boslaugh and Andresen [34] revealed that physical activity was associated with race, an age of 50 years or older, higher income and general health, whereas sex, education level and years of disability were not associated. Warms et al [29] recently identified the correlation of physical activity in adults with mobility limitations by using both objective (by actigraphy) and subjective measures (physical activity scale) of physical activity. They found that objectively measured activity correlated significantly with body mass index and subjectively measured activity correlated significantly with age, stage of change, health, and healthcare providers discussing exercise and social support. In 2004, Rimmer and colleagues [31] identified eight categories of barriers and facilitators (e.g. accessibility of exercise and recreation equipment, cost, information access) of physical activity participation among people with disabilities, which were derived from four sets of perspectives obtained from focus groups, including people with disabilities, architects, fitness and recreation professionals and city planners. They concluded that the degree of participation in physical activity among people with disabilities was affected by a multifactorial set of barriers and facilitators that were unique to them. In the following year, Rimmer et al [32] continued to investigate the accessibility of 35 fitness clubs to people with disabilities. They found deficiencies in the environmental infrastructure and the availability of adaptive exercise equipment, power-assisted doors, and professional behaviour. Their findings were in line with a recent study, which found that inadequate access to certain primary preventive services for individuals with PD was likely a product of structural–environmental and process barriers [30].

Other studies also showed that maintenance of and belief in physical activity in people with disability were associated with various factors. Kinne et al [33] pointed out that adults with mobility impairment who had barriers associated with low motivation (e.g. tiredness [personal characteristics] and higher exercise self-efficacy [attitude to exercise]) showed a higher probability of exercise maintenance. Their study also showed that there were no relations of exercise maintenance to demographic and disability variables (e.g. sex, age, education, general health, degree, type of disability, income, and body mass index). Taylor et al [35] found that emotional and physical support from family members, provision of equipment, provision of an exercise log-book, and having a programme with a small number of exercises were the environmental factors optimizing exercise adherence. Motivation, autonomy, the effort involved in completing the exercises, health issues, and time management were the personal factors affecting people with PD. Forkan et al [36] pointed out that lack of interest, poor health, depression, weakness, weather, shortness of breath, and low outcome expectation were associated with a lack of post-discharge participation in regular home exercise. They also found that change in health status was the primary reason for poor adherence for the older adults with balance impairment. Motivation was further related to age, and the goals inventory was related to body mass index. Ellis et al [37] also found that health issues, such as pain, soreness, time consumption and tiredness, were identified as the most common behavioural disadvantages of exercise across 223 adults with PD.

Factors Categories

Associating factors for PD and physical activity and activity adherence generally fall into one of the following categories: (1) the personal aspect, e.g. motivation, autonomy, lack of interest, goal orientation, low outcome expectation, enjoyment, self-efficacy, race, income, age,
stage of change in exercise behaviour, attitude to exercise, and tiredness; (2) disability and health factors, e.g. pain, depression, weakness, general health, change in health status, disability limitation, disease activity, and body weight; (3) programme or activity variables, e.g. quantity of exercise in a programme, the effort involved in completing the exercises and time (exercise duration); and (4) environmental influence, e.g. family support, equipment support, provision of an exercise log-book, weather, social support, healthcare providers support and their behaviour, caregivers’ perceived benefits of exercise, accessibility of exercise equipment and environment, cost and information access.

In short, previous explorations of factors associated with exercise and physical activity among people with PD suggest an interaction between personal factors, disability and health variables, programme content, and environment effects. All of these may contribute to the disparity in physical activity in this population.

Strategies to Increase Physical Activity/Adherence

With identification of factors that correlate with physical activity, there have been some interventions or strategies suggested to enhance the level of participation among this population, e.g. TTM, social cognitive theory (SCT), achievement goal theory [15].

Transtheoretical model

TTM originated in studies of addictive behaviour, but the model has since incorporated areas relating to physical activity adherence. It is a contemporary and integrative motivational theory specifying behaviour change within a stage framework. Specifically, individuals are classified into certain stages based on their readiness to change a behaviour (e.g. increase or decrease of physical activity). Individuals within the same stages of change experience similar facilitators and barriers toward physical activity initiation and/or enhancement. In this way, the development of cognitive, behavioural and emotional strategies (e.g. processes of change) is directed to the individual stages of change. The stages of change and processes of change (including behavioural and cognitive processes), together with self-efficacy and decisional balance, have formed the theoretical roots of this theory. Self-efficacy is the confidence a person feels about performing a particular activity, including confidence in overcoming the barriers to performing that behaviour. Decisional balance is an individual’s perception and evaluation of the relative costs (cons) and benefits (pros) associated with behaviour change [38,39].

The use of the TTM to change physical activity behaviour among people with disabilities has been recommended, and its relevance within a population with PD has been studied [15,38,40,41]. Cardinal et al [40] have used the full transtheoretical model (TTM) to investigate the most important psychosocial predictors of the exercise stages of change among mainly active adults with PD. They found that the most important predictors of physical activity stages of change were the behavioural process of change, self-efficacy, the cognitive processes of change, and perceived pros and perceived cons. Another applied study done by the same authors [41] applied the full TTM and focused on inactive adults with PD and showed that the behavioural processes of change were the most important to the physical activity stage of change distinction, followed by the cognitive processes of change, self-efficacy, and decisional balance. In recent years, Kosma et al [38] further investigated the theorized relationships among the stages of changes, the TTM predictors, and physical activity among adults with disabilities, and found that linear patterns of associations between stages of change and the behavioural processes of change, as well as the cognitive processes of change, were observed. In addition, they also revealed that there were positive relationships between decisional balance and physical activity behaviour.

Several studies had reported on the recent trend and positive outcome of utilizing the constructs or whole model of TTM for change of physical activity behaviour in people with PD or chronic illness [39,42–44] (Table 1). The trend has shifted from cross-sectional study design to longitudinal designs with randomized control to assess the constructs of TTM with the implementation of individual physical activity/exercise programmes across time.

Social cognitive theory

Another strategy used to change physical activity behaviour for ordinary people is SCT. According to Bandura [45,46], SCT not only is a theory for describing factors that affect and determine behaviour, but also specifies mechanisms through which the determinants work and how they may be translated into effective health practice. The constructs of SCT are goals, perceived self-efficacy, outcome expectancies, facilitators, and impediments. Goals guide the specific behaviour. Perceived self-efficacy is the same as that in the TTM (i.e. the belief that one is able to perform the goal behaviour despite obstacles). Outcome expectancies are the perceived costs and benefits of the behaviour. Facilitators and impediments are the social structural factors that include environmental aspects that potentially predict goals and behaviour.

Until now, the use of SCT in studying the behaviour of physical activity domains in people with PD has been extremely limited. In contrast, a little more is known about populations with chronic illness (e.g. diabetes). Therefore, we will examine the diabetic population in this review as an introduction to SCT, because diabetes is a common secondary complication for PD [9].

A recent literature search revealed that investigation of the full constructs of SCT in single studies is still lacking.
Most of the diabetes studies focus on the examination of one or a few of the constructs of the theory [47] (Table 2). However, the overall results showed positive outcomes on physical activity participation and adherence to controls for SCI in people with type II diabetes, the exception is McKay et al [48], who showed that there were no significant differences in physical activity level found between groups if interventions were mainly delivered through computer assessment.

Table 1. Studies that applied the transtheoretical model intervention on change of physical activity behaviour in people with physical disabilities or chronic illness

<table>
<thead>
<tr>
<th>Study</th>
<th>Subjects</th>
<th>Design</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warms et al [44]</td>
<td>n=16 (SCI)</td>
<td>Pre- and post-test; no control group</td>
<td>Stage-matched education materials; home visit by nurse; personal plan to increase activity; phone call (lifestyle physical activity)</td>
<td>Significant changes in motivational barriers, exercise self-efficacy, and self-rated health</td>
</tr>
<tr>
<td>Guillot et al [39]</td>
<td>n=40 (cardiac and pulmonary patient)</td>
<td>Pre-, mid- and post-test</td>
<td>Hospital cardiopulmonary programme alone; 36 sessions; 2–3 per week</td>
<td>Self-efficacy and cognitive process differentiated completers and drop-out</td>
</tr>
<tr>
<td>Kosma et al [43]</td>
<td>n=75 (mixed diagnoses including SCI, MS, and CP)</td>
<td>Experimental design with control group; pre- and post-test</td>
<td>Treatment group with 4-week stage-matched Web-based motivational materials; control group with 4-week non-specific motivating materials, e.g. friendship</td>
<td>Self-efficacy was the best predictor of adherence</td>
</tr>
<tr>
<td>McAuley et al [42]</td>
<td>n=26 (MS)</td>
<td>Randomized controlled trial; pre- and post-test</td>
<td>Treatment group with 3-month efficacy enhancement exercise condition; control group with 3-month standard exercise condition</td>
<td>Treatment group attended more exercise sessions, and reported greater levels of well-being Both groups reported stronger self-efficacy</td>
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</tbody>
</table>

SCI = spinal cord injury; MS = multiple sclerosis; CP = cerebral palsy.

There is no evidence indicating how much physical activity is beneficial for people with disabilities. The current most frequently used recommendation for a healthy physically active lifestyle in the general population is 30 minutes of cumulative, moderate intensity physical activity at least 5 days a week [52]. However, this recommendation may not fit the disability population. In a very recent study, Bassett et al [53] investigated the relationship between minutes of wheeling and aerobic fitness in 48 individuals with SCI. They showed that cumulative bouts of wheeling greater than 10 minutes in duration were generally not strong correlates of aerobic fitness compared with the sum of all wheeling. This finding might be contrary to physical activity guidelines for the general population in that it might be suitable to encourage cumulative short bouts of wheeling. Therefore, there is an urgent need to define the recommended healthy levels of physical activity for different types of disability.

In addition, for every person with a disability, there is probably a certain amount of physical activity beyond which a further increase is no longer beneficial or may even be contraindicated [54]. For some disability types, this amount will be quite low (e.g. people with MS may be easily fatigued or excessive physical activity may lead to a recurrent relapse attack [55]). Therefore, there may be a psychological burden associated with performing regular physical activity. For people with SCI, there was a twofold or more increase in the probability of emotional disorders compared with the general population [56]. For people with MS, both depression and anxiety were found to be significantly more prevalent than in the general population [57]. It has been reported that physical activity levels are negatively associated with depressive symptoms [29]. Therefore, a strategy for tackling psychological problems may need assistance from their caregivers.
**Table 2. Studies that applied partial social cognitive theory constructs on change of physical activity behaviour in diabetic patients**

<table>
<thead>
<tr>
<th>Study</th>
<th>Construct(s) tested or enrolled</th>
<th>Subjects</th>
<th>Design</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>McKay et al [48]</td>
<td>Goal setting, impediments, social support</td>
<td>$n = 78$ (average age of 52.3 years with type 2 diabetes)</td>
<td>Randomized controlled trial with experimental designs (pre and post) among two groups</td>
<td>Two groups: Experiment group assigned with Diabetes Network Active Lives PA intervention Control group with internet information only, e.g. PA safety precautions</td>
<td>After 8 weeks, there was no significant difference in PA level between the two groups</td>
</tr>
<tr>
<td>Keyserling et al [49]</td>
<td>Social support as facilitator</td>
<td>$n = 167$ (age ≥ 40 years with type 2 diabetes)</td>
<td>Randomized controlled trial with experimental designs (pre, mid and post) among three groups</td>
<td>Three groups: Group A—clinic (four visits by a nutritionist provide PA counselling) and community (three group sessions and 12 monthly phone call by peer counselling) Group B—clinic only (as in Group A) Group C—minimal intervention (educational pamphlets mailed to participants)</td>
<td>Comparing Group A with Group C, average adjusted mean for PA was 44.1 kcal/d Comparing Group B with Group C, average adjusted mean for PA was 33.1 kcal/d The intervention was associated with a modest enhancement of PA</td>
</tr>
<tr>
<td>Di Loreto et al [50]</td>
<td>Self-efficacy, impediments, family support as facilitator</td>
<td>$n = 340$ (type 2 diabetes)</td>
<td>Randomized controlled trial with experimental designs (pre and post) among two groups</td>
<td>Two groups: Experimental group treated by physician who used behaviour strategy for PA promotion (one phone call and 15-minute clinic appointment every 3 months) Control treated with the usual care (general advice on PA) PA level measured with Modified Activity questionnaire</td>
<td>After 2 years, 69% in experiment group and 18% in control group reached target (energy expense &gt; 10 METs-h/wk via voluntary PA ($p &lt; 0.001$) Significant improvements in BMI and HbA$_{1c}$ ($p &lt; 0.001$)</td>
</tr>
<tr>
<td>Gleeson-Kreig [51]</td>
<td>Self-efficacy</td>
<td>$n = 58$ (type 2 diabetes)</td>
<td>Randomized controlled trial with experimental designs (pre and post) among two groups</td>
<td>Two groups: Experiment group was interviewed about the moderate PA and assigned a PA daily record and requested to send back the records every 2 weeks Control group only had interview</td>
<td>After 6 weeks, subjects had to complete the habitual physical activity index and the self-efficacy for exercise scale again Significant difference was shown in self-efficacy improvement between the groups Both groups had a significant increase in PA level</td>
</tr>
</tbody>
</table>

PA = physical activity; MET = metabolic equivalents; BMI = body mass index; HbA$_{1c}$ = glycated haemoglobin A$_{1c}$.
(e.g. transfer or transportation). However, studies have shown that caregivers also suffer under the pressure of having to look after a person with a PD and having to perform daily tasks as well \[58,59\]. The consideration of caregivers’ perspectives is another important focus in promoting physical activity and its adherence in people with disabilities.

Another clinical concern is the change in health status of people with PD. Some types of chronic illness or disability (e.g. muscular dystrophy and rheumatoid arthritis) show progressive deterioration, and certain physical activity or exercise may thus be possible at a given time but not after a few months or years \[55\]. In addition, people with disabilities may develop other severe chronic illnesses (e.g. cancer). Courneya et al \[60\] reported that cancer sufferers who received multimodal adjuvant therapy (radiotherapy plus chemotherapy) have lower exercise adherence rates than participants receiving unimodal adjuvant therapy (chemotherapy) or no adjuvant therapy (i.e. surgery alone.).

Implications of Improving Physical Activity Participation and Adherence

Frontline exercise/physical activity promoters must understand the correlates of both physical activity/exercise participation and adherence strategies in the specific population to be compliant with regular physical activity (i.e. improve physical functions and prevent secondary complications in the long term). People with PD should be assessed not only on their physical functions, but also on their cognitive and behavioural states concerning exercise/physical activity (e.g. stages of change, self-efficacy or decision balance). With reference to the correlated factors between physical activity and people with disabilities and from systematic approaches (e.g. TTM or SCT) to enhancing physical activity of disabled people or those with chronic illness, the framework for exercise/physical activity participation and adherence development are suggested as follows (Figure).

![Figure. Framework for exercise/physical activity participation and adherence development for people with physical disabilities. The two-directional arrows indicate the interrelationship and the dynamics among the four boxes.](image-url)
Suggestions for Future Research

There is a need to conduct various types of research related to physical activity and people with PD. In this review, we emphasize four areas of urgent concern.

1. There is a need for more prospective longitudinal studies on the effects of physical activity enhancement approaches (e.g. TTM and SCT) on people with PD.
2. We need to further examine the effect of individual construct to full construct of TTM and SCT on physical activity for various kinds of people with PD.
3. There must be more research aimed at establishing appropriate amounts of physical activity/exercise for people with different PD.
4. We need to integrate, develop and validate a comprehensive approach in a clinical situation (e.g. community rehabilitation setting) for the promotion of regular physical activity in a population of people with PD.

Conclusion

The promotion of physical activity participation and maintenance in people with PD is difficult. The primary disabling condition, secondary complications, programme factors, and personal and environmental influences create a multifactorial condition, leading to the complexity of solving this problem. A validated method (TTM) for this population is one way to solve this challenging issue. Another approach (SCT) is an alternative and is still under exploration in this population. With the collaboration of physical activity researchers and frontline physical activity promoters (e.g. physical therapist and exercise professionals), a better level of health and quality of life for people with different PD will be achieved.

References


