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Review

Barriers and Motivators to Engage in Exercise for Persons with Parkinson's Disease

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Abstract. Exercise is increasingly being recognized as a key element in the overall management of persons living with Parkinson's disease (PD) but various (disease-specific) barriers may impede even motivated patients to participate in regular exercise. We aimed to provide a comprehensive review of the various barriers and motivators for exercise in persons with PD. We scrutinized data on compliance-related factors published in cross-sectional studies, randomized controlled trials and reviews. We classified the barriers and motivators to exercise from a patient perspective according to the International Classification of Functioning, Disability and Health. We present an overview of the large range of potential motivators and barriers for exercise in persons with PD. Healthcare professionals should consider a wide and comprehensive range of factors, in order to identify which specific determinants matter most for each individual. Only when persons with PD are adequately motivated in a way that appeals to them and after all person-specific barriers have been tackled, we can begin to expect their long-term adherence to exercise. Such long-term compliance will be essential if exercise is to live up to its expectations, including the hope that prolonged engagement in regular exercise might help to modify the otherwise relentlessly progressive course of PD.

Keywords: Exercise, Parkinson's disease, aged, motivation, attitude to health, self efficacy, wearable electronic devices

INTRODUCTION

Exercise is increasingly being recognized as a key element in the overall management of persons living with Parkinson's disease (PD). In addition to its generic health benefits (e.g., reduction in risk

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for cardiovascular diseases) [1], exercise also has PD-specific symptomatic effects: it attenuates motor symptoms and, although not confirmed by many studies, possibly also non-motor symptoms (e.g., apathy, cognition, depression) [2–8].

High-intensity exercise, such as aerobic workout, appears particularly promising to achieve both these generic and disease-specific effects. Two recent high-quality randomized controlled trials showed an attenuation of motor symptoms measured in the practically defined *off* medication state in persons with PD who had performed high-intensity aerobic exercise. These studies illustrate that a sufficient dose of exercise by ascertaining a good compliance is key to achieving results [2, 6]. However, this is not achieved automatically, because unlike oral intake of medication (where compliance is also known to be suboptimal) [9], engaging in and complying with exercise requires much time and effort from persons with PD themselves, and various disease-specific barriers may impede even motivated patients to participate in regular exercise.

Achieving a good compliance with prescribed exercise regimens in clinical trials, where supervision is typically optimal, and where participants are often well motivated to participate, does not mean that this can automatically translate into a similar compliance during everyday life. It is certainly a common experience that the exercise dose tested in trials cannot be achieved easily as part of routine clinical interventions outside the research setting. Consequently, persons with PD often remain sedentary in everyday life and achieving a good adherence to an active lifestyle remains a great challenge [10, 11]. In order to motivate persons with PD to become and stay physically active beyond the setting of a clinical trial, it is pivotal to gain a better knowledge of the many barriers (but also the various motivators) for exercise. Previous exercise studies provided some insight into the barriers and motivators that persons with PD encounter, although one must consider the possibility of selection bias here, as exercise studies typically tend to recruit people who are already most motivated to increase their physical activities [10–16]. Here, we summarize the various barriers and motivators for exercise in persons with PD by applying a comprehensive review of the literature. We hope that this overview can be used by healthcare professionals (e.g., physiotherapists) when they plan to prescribe exercise to their patients as part of routine clinical care.

BARRIERS AND MOTIVATORS TO ENGAGE IN EXERCISE

We scrutinized data on compliance-related factors published in cross-sectional studies, randomized controlled trials and reviews that we retrieved with the search strategy specified in Box 1. Table 1 provides an overview of the barriers, while Table 2 provides an overview of the motivators to engage in exercise. When prescribing an exercise program to a person with PD, both these barriers and motivators should be considered.

Search strategy and classification of barriers and motivators

We searched for references in PubMed with the terms "Parkinson disease", "Parkinson", "Exercise", "Physical Activity", "Locomotion", "Motivation", "Motivator", "Enabler", "Facilitator", "Barrier", "Experience", "Attitude to Health", "Attitude". We scrutinized data on compliance-related factors published in cross-sectional studies, randomized controlled trials and reviews.

We classified the barriers and motivators to exercise from a patient perspective according to the International Classification of Functioning, Disability and Health (ICF) [41]. The ICF framework is commonly used by healthcare professionals and involves factors related to body function and structure, activities and participation, environmental factors and personal factors.

First, factors in the category of body structure and function can be related to general health issues [10, 15, 17–20]. Barriers related to motor symptoms and common non-motor symptoms of PD, such as depression and apathy, which are often not considered when studying exercise adherence, can have a major impact and should be addressed carefully [15–18, 20–25]. Second, although only few factors related to activities and participation were identified, assessing a person's (in)ability to integrate exercise into daily life routines is key [10, 11, 25, 26]. Third, one should always assess the personal factors which may underlie adherence. Self-efficacy (i.e. a person's belief in having enough capacity to perform a task) [27] and a person's outcome expectations are important examples of such personal factors. Sufficient self-efficacy plays a pivotal role in the likelihood that persons

Table 1
Barriers to start with exercise or to remain engaged in exercise, as these have been described for persons with PD. References are grouped according to the type of study (randomized clinical trial – RCT, cohort study, qualitative study or review)

	RCTs	Cohort studies	Qualitative studies	Reviews
Factors related to body structure and function				
General health barriers (not related to PD)		[17–20]	[10, 15]	
Physical discomfort with exercise		[17]		
PD motor symptoms		[20]	[25]	[16]
PD non-motor symptoms				
Fluctuations in motivation	[12]			[24]
Anxiety			[23, 25]	[24]
Depression		[17, 18, 21, 22]	[23]	[16, 24]
Fatigue		[21]	[15, 25]	[16]
Apathy			[15]	[16]
Factors related to activities and participation				
Low previous physical activity level or sport participation		[21]		
Personal factors				
Low self-efficacy		[19, 22]	[23]	[11, 16, 24, 26]
Reduced balance self-efficacy or fear of falling		[17, 18, 20]		[24]
Low outcome expectations from exercise		[17]		[11, 16]
Lack of time		[17]	[10]	[16]
Environmental factors				
Lack of social support		[21]		
Lack of an exercise partner		[20, 21]		
Discomfort of seeing advancing symptoms of peers when exercising in a group			[23]	[16, 24]
Poor accessibility of the exercise location and lack of transportation to this location		[21]	[10]	[16]
Bad weather		[17, 20]	[25]	
Cultural challenges				[16]
Financial burden of exercise				[16]
Wariness of moving in a crowded environment			[25]	

with PD will start engaging in exercise and remain engaged [11, 16, 19, 22–24, 26]. Also, it is well known that having low outcome expectations can be a major barrier to initiate exercise [11, 16, 17]. It is therefore crucial to educate persons with PD about the accumulating and convincing evidence of the positive effects of exercise, thereby transforming this barrier into a key motivator [10, 11, 15, 18, 23, 24]. The aforementioned personal factors can be highly influenced by the (course of the) disease, but personal factors that are unrelated to PD, such as educational background, should also be addressed [21, 22]. Lastly, environmental factors such as one's social environment (i.e., family or friends) or professional support from a trainer can be crucial [10–12, 16, 18, 19, 21, 23, 28]. The abilities of a skilled trainer to monitor progression, to offer feedback, to share mastery experiences (i.e. accomplishments) and to offer encouragement are likely components of an exercise program that successfully motivates people with PD [11–15, 23, 24, 26]. Finally, medical specialists (usually neurologists or geriatricians) play an important role in the education of persons with PD about the benefits of exercise and should address exercise uptake regularly during their outpatient consultations, so that persons with PD take the exercise prescription seriously [10, 11, 14, 16, 21, 24, 26].

DISCUSSION

Role of healthcare professionals

Some of the factors that we discussed involve personal attitudes and attributes, but some other factors—such as education about the beneficial effects of exercise—are more universal. The role of healthcare professionals, especially medical specialists (neurologists, geriatricians), specialized

Table 2
Motivators to start with exercise or to remain engaged in exercise, as these have been described for persons with PD. References are grouped according to the type of study (randomized clinical trial – RCT, cohort study, qualitative study or review)

	RCTs	Cohort studies	Qualitative studies	Reviews
Factors related to body structure and function				
Perceived positive effect of exercise on PD motor- and non-motor symptoms once started with exercise			[10]	[16]
Factors related to activities and participation				
Ability to incorporate exercise in daily routine			[10, 25]	[11, 26]
Personal factors				
Sufficient self-efficacy			[19, 22]	[16, 24]
Belief that				
physical activity is beneficial for health in general		[18]	[10]	
physical activity can impact disease manifestation				
persons with PD can have control over PD motor- and non-motor symptoms with exercise		[18]	[11, 23]	[16]
			[10, 15]	
Desire to				
maintain independence				[16]
delay progression of PD			[10]	
re-frame one's identity as 'active'			[15]	
Program individually tailored to				
abilities and interest	[13, 14]	[19, 20]		[11, 16]
personal goals	[13]		[10, 15]	[16, 24]
Perceived positive effect of exercise on health or performance in general once started with exercise			[23]	[26]
High educational level		[22]		
Environmental factors				
Social support by family or friends	[12]	[18, 19, 21]	[10, 23, 25, 28]	[11, 16]
Professional support (e.g., by a trainer for coaching)	[12–14]	[21]	[15, 28]	[16, 24, 26]
Education about benefits of exercise or recommendation of exercise by neurologist	[14]	[21]	[10]	[11, 16, 24, 26]
Social interaction with peers during exercise		[21]	[15, 23]	[11, 16, 26]
Drawing strength from comparison to peers with more advanced symptoms during group exercise				[16, 24]
Mastery experiences	[13]		[23]	[24]
Feedback on performance	[13, 14]		[15]	[11, 26]
Rewards				[11]

Parkinson nurses and physiotherapists, in educating persons with PD about the importance of exercise is key. Medical specialists have a high credibility and, as mentioned earlier, their role in education about the benefits of exercise is an important motivator for many persons with PD [10, 11, 14, 16, 21, 24, 26]. The educational program should convey to persons with PD how exercise can have beneficial effects on general health [29], but also emphasize that beyond this, exercise can attenuate the motor symptoms of PD [2, 4, 6] and improve balance, gait, general mobility and quality of life [3–5, 8]. Medical specialists should advise persons with PD to initiate exercise immediately after the diagnosis, and should uphold a low threshold for referring their patients to a physiotherapist who is specialized in PD [30]. More of these specialized therapists are needed, since care by experts is associated with better outcomes than care delivered by generically trained therapists, and is also more cost-effective [31]. Just like medication, exercise should be considered as a standard part of the overall management plan for persons with PD. Even after referral to a physiotherapist, actual exercise status should be evaluated in the follow-up consultations by the neurologist and Parkinson nurse. Advice from such experts enhances the credibility, which may aid persons with PD in taking an 'exercise prescription' seriously.

Optimizing dosing of exercise

It is the role of a specialized physiotherapist to determine, within the framework of the motivators and barriers, what the optimal type and dose (in

terms of frequency and intensity) of exercise is for any person with PD. Determining the appropriate dose of exercise is essential, but remains a considerable challenge. High intensity exercise is likely more effective than moderate-intensity exercise, but more evidence supporting such a dose-response relationship is needed [6, 32]. What is the minimum dose needed for exercise to be effective? Is more exercise always better, or is there perhaps a plateau? Can excessive exercise be deleterious, as is suggested by anecdotal stories by individual patients who engaged in running a marathon every day? While high-intensity exercise can be performed safely and attenuates motor symptoms [2, 6], exercise as performed currently in clinical practice is not always of sufficient intensity. Especially when exercising at home, persons with PD often do not dose their exercise objectively (for example, using heart rate to titrate the dose of exercise—although we should note that not all Parkinson patients are able to increase the heart rate beyond certain levels, possibly due to defects and autonomic innervation of the heart) [33]. These factors make it difficult to both determine and monitor the actual exercise intensity. It is also expected (but hitherto not very widely studied) that a higher frequency of exercises is more effective than just occasional bouts of exercise. This assumption is illustrated by an adequately powered study that did not find a positive effect of a community physiotherapy intervention, which probably resulted from underdosing [34]. Dosing in terms of frequency and intensity clearly needs further investigation.

Non-motor symptoms

Our review also emphasizes that non-motor symptoms can create a barrier to engage in exercise [12, 15–18, 21–25]. For example, people might need to overcome negative thoughts (e.g., "exercise will make me feel more tired") when they start with exercise. In this regard, fatigue and apathy [15, 16, 21, 25] are extremely important factors for many persons with PD. Fatigue is highly prevalent in persons with PD (about 50% of patients experiences this) and is moderately associated with the non-motor symptoms apathy, anxiety and sleep [35]. Although there is some evidence of a beneficial effect of exercise on non-motor symptoms such as apathy [8], non-motor symptoms have thus far been studied infrequently as an outcome in exercise trials in persons with PD. This warrants careful assessment of these symptoms by health professionals and inclusion of non-motor outcomes in future trials [8, 19, 21].

Promoting exercise adherence

Further studies are needed to define optimal strategies to improve long-term adherence to exercise. For example, the question whether exercise could have a disease-modifying effect in persons with PD is still controversial, and can only be demonstrated in studies with long-term follow-up, thus requiring optimal compliance by participants. Research in rodents, using several disease models, suggests that exercise potentially has disease-modifying effects in animal models of PD [36, 37] but whether this translates to humans with PD remains unclear [11]. Having high-quality evidence on disease modification would obviously be a major motivator for persons with PD to engage in exercise. Studies on this important subject are beginning to emerge [38].

Another important area for further study is how recent advances in mobile technology [39] can be used to further promote compliance to exercise. Intuitively, individually tailored and intensively supervised exercise programs provide the largest benefit. Moreover, patients participating in exercise trials often report that the idea that their data is being monitored by someone else, motivates them. Recent advances in mobile technology are increasingly recognized as a scalable alternative for human monitoring and supervision [13, 40]. Apps, which can measure motor symptoms and its progression [39], can provide feedback and reinforce mastery experiences through rewards, while also allowing for interaction with peers and the social environment [11, 13, 24]. Although few studies have thus far implemented such an approach [2, 13], mobile technologies show great promise to help people integrate exercise into daily life. One particularly interesting strategy is to use technology such as a smartphone to implement exercise regimens (a motivational app) and to monitor their long-term effects in research and clinical practice (using the movement sensors embedded within a smartphone). Whether a motivational app that incorporates those features through gamification and social network engagement can effectively and entirely replace a traditional (human) trainer remains to be established—a blended approach may well be needed in the long term. Removing the dependence on a physical trainer would certainly be interesting in terms of scalability to loosely populated or economically underdeveloped countries where access to care

is still very difficult. As such, use of technology may greatly expand access to the benefits of exercise in PD well beyond Western societies.

Limitations

A limitation of this overview is that many issues on perceived barriers and motivators are still unclear. For example, numerous relevant factors have been poorly studied, including issues such as age, gender, genetics and cultural background of the participants. The overview presented here therefore serves as a temporary framework for both future research and perhaps to guide clinical practice, acknowledging that various gaps in knowledge will have to be addressed by future research. Moreover, we were unable to quantify the barriers and motivators, given the diversity of the various barriers and motivators investigated in the included studies, and also because of the variety of research methods that were used (both qualitative and quantitative). We propose that, based on this first inventory, a framework for quantifying these barriers should be developed.

CONCLUSION

Here, we offer a comprehensive review of the barriers and motivators to engage in exercise for persons with PD. For this purpose, we compiled an extensive list of positive and negative influences, acknowledging that not all factors are equally relevant for all persons with PD. Nonetheless, it is important for healthcare professionals to consider a wide and comprehensive range of factors, in order to identify which specific determinants matter most for each individual. While all healthcare professionals, including the medical specialist, should be aware of this large range of potential motivators and barriers, (specialized) physiotherapists are probably best equipped to identify (and then address) the specific personal barriers and motivators for each individual person with PD. Only when persons with PD are adequately motivated in a way that appeals to them - which requires motivational interviewing skills of the healthcare professionals, built sufficient self-efficacy for exercise and after person-specific barriers have been ameliorated, we can begin to expect their long-term adherence to exercise. Such long-term compliance will be essential if exercise is to live up to its expectations, including the hope that prolonged engagement in regular exercise might help to modify the otherwise relentlessly progressive course of PD.

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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