

“MovetoSport” in Belgium: an organizational model to facilitate skilled guidance of persons with multiple sclerosis during exercise and sport in the community

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P. Van Asch¹, K. Tytgat², L. de Groote², B. O. Eijnde³, P. Feys³

Abstract

This paper describes the non-profit organization “MovetoSport”, which has recently been established in Flanders, Belgium. Founding members are both practitioners and academic physiotherapists and exercise physiologists well experienced with specific neurological problems in persons with multiple sclerosis. The organization regularly provides educational courses and workshops for health care professionals including sport instructors working in rehabilitation centers, neurological units, but also in the community and sport facilities. Certified professionals are visible on a website, which is accessible for persons with MS. “MovetoSport” also collaborates with the MS Society for information transfer as well as for the teaching of persons with MS attending specific educational days. The overall vision is to provide affordable and accessible exercise therapy programs for all persons with MS.

Key words: education, multiple sclerosis, exercise and sport, health care professionals, community

¹Fit Up, fitness and physiotherapy center Kontich, Belgium;
²MS Society Flanders, Belgium;
³REVAL Rehabilitation Research Center, BIOMED, Hasselt University and PHL University College, Diepenbeek, Belgium

Background

Research in the last decade has demonstrated that exercise therapy is potentially effective to improve function, activity, and quality of life in persons with MS (PwMS) [1, 8, 10]. Importantly, no increased risk for relapses was found during these studies [12], although temporarily decreased sensory function has been reported [9]. Only few studies have performed follow-up measurements and indicated a potential for sustained benefits at three months after training [2]. In general rehabilitation research, it is known that physical improvements do not outlast six months [4, 11].

However, not all patients have equal access to specialized rehabilitation units. Availability of specialized MS services and health care professionals, skilled in exercise therapy, varies strongly within Europe while also distance to central services may impede making use of it regularly. For an overview, we refer to the MS Barometer project (previously MS-ID, MS information dividend) of the European MS Platform (EMSP, see <http://www.emsp.org/projects/ms-id>). Data are available for 33 European countries and were collected in 2008 and 2011. One of the domains relates to the estimation of access to treatment and therapies, and reimbursement of costs. Large differences can be found between Germany (207 of 225 points) in a questionnaire summary scale about MS health care, see <http://www.emsp.org/attachments/>

[article/160/MS_Barometer_2011.pdf](http://www.emsp.org/attachments/article/160/MS_Barometer_2011.pdf)) and for example Portugal (124/225) and Belarus (46/225). Given the context of varying health care for MS, it is a challenge to get PwMS active themselves in their own living community. But even in countries having established multi-disciplinary rehabilitation centers, PwMS should adapt a healthy lifestyle and incorporate physical activity and exercise in their daily life. MS societies are increasingly aware of this importance and have started to promote exercises on their websites (for an example, see <http://www.mstrust.org.uk/information/exercises/>).

Regarding physical rehabilitation, also the education level of physiotherapists varies greatly within Europe from a professional Bachelor to an academic Master program of five years [7]. In some, but not all countries, specialization programs in neurological rehabilitation exist within or additional to the basic education program. Physical rehabilitation can also be performed by exercise physiologists and sport instructors if they focus on physical activity and health; however their standard education programs only limitedly address neurological pathologies. In this regard, the International Master in Adapted Physical Activity (http://onderwijsaanbod.kuleuven.be/opleidingen/e/CQ_50811449.htm) is worth mentioning. For regular community health care professionals, post-graduate courses on MS are occasionally available (now also on-line, see the MS PRO / MS NEED project, <http://www.emsp.org/projects/ms-need>), espe-

cially for MS nurses, but they do not focus on exercise and sport for MS.

To enable PwMS to adapt a physically active lifestyle, we are convinced that education at two levels, both patient and professional/therapist level, is a key factor for success. Sport is a powerful vehicle for bringing about positive changes in the lives of PwMS. Sporting activities strengthen physical and emotional health resources. Sport is a significant aspect of life-long well-being and is an essential way to improve mobility and increase self-confidence and specific skills. Professional guidance can help to convince PwMS to engage in exercise, to choose the right type of exercise and sport based on their preferences, to keep PwMS motivated and guide them to “success” with respect for each PwMS own possibilities and capacities [5].

Development of a non-profit organization in Flanders: “MovetoSport”

In Flanders, a collaboration was set up by a team of professional physiotherapists and researchers in MS rehabilitation and research focusing on exercise therapy on the one hand, and the Flemish MS Society on the other hand. The driving health care professionals and researchers were Paul Van Asch (PT, Fit Up Kontich, B), Peter Feys (PT, PhD) and Bert Op ‘t Eijnde (Sport Sciences, PhD). All persons had long-standing experience in MS rehabilitation and research while actively participating in international networks such as RIMS, the European Network for Best Practice and Research in Rehabilitation (www.euRIMS.org). A formal non-profit organisation was formed, in collaboration with the Flemish MS Society, and was called “MovetoSport” (see www.movetosport.be), implicitly also referring to the acronym of MS. This initiative has been primarily taken in 2010 in order to organize courses for health care professionals interested in guiding PwMS during exercise and sports.

The ultimate vision is that persons in Flanders have, for guidance in an individual exercise and/or sport program, access to health care professionals who are familiar with the particular condition of MS and related functioning problems. The rationale for this vision was multifold. First, on patient level, it was experienced that a substantial number of PwMS did not report positive experiences with performance of sports activities in the community. Coaches or personal trainers mostly do not have extended knowledge about MS in general and more specific about possible workouts for this group adapted to their capacities and taking into account typical MS functioning problems as hypertonia/spasticity or fatigue. A lack of sufficient knowledge was also reported in generic physiotherapists, who have not treated many persons with neurological disability. Secondly, even if a PwMS deliberately wants to contact a specialized health care professional or a sport facility familiar with MS, it is difficult to identify them. Also

»MovetoSport« in Belgien: Ein organisiertes Konzept zur Förderung der qualifizierten Anleitung von Multiple-Sklerose-Patienten bei Training und Sport in der Gemeinde

P. Van Asch, K. Tytgat, L. de Groote, B. O. Eijnde, P. Feys

Zusammenfassung

Diese Arbeit beschreibt das Konzept der gemeinnützigen Organisation »MovetoSport«, die kürzlich im belgischen Flandern etabliert wurde. Zu den Gründungsmitgliedern zählen sowohl praktische Ärzte als auch akademische Physiotherapeuten und Sportphysiologen, die über viel Erfahrung mit den spezifischen neurologischen Problemen von Patienten mit Multipler Sklerose verfügen. Die Organisation bietet regelmäßig Ausbildungskurse und Workshops für Berufstätige im Gesundheitsbereich und Sportlehrern an, die in Rehabilitationseinrichtungen und neurologischen Abteilungen, aber auch in der Gemeinde und in Sportvereinen tätig sind. Patienten mit MS finden zertifizierte Experten auf einer Website. »MovetoSport« kollaboriert hinsichtlich des Informationstransfers auch mit der Flämischen MS-Gesellschaft und organisiert gemeinsam mit dieser spezielle Schulungstage für Menschen mit Multipler Sklerose. Die Grundidee des Konzeptes ist es, kostengünstige und leicht zugängliche therapeutische Sportprogramme für alle MS-Betroffenen zu schaffen.

Schlüsselworte: Ausbildung, Multiple Sklerose, Training und Sport, Gesundheitsberufe, Gemeinde

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therapists and medical doctors in rehabilitation centers reported that there was a lack of an updated list or website with names and contact details of specialized community workers. Thirdly, it was realized that the number of community professionals with knowledge about exercise and sport was low, also explaining the difficult referral.

“MovetoSport” has the mission to promote and actively support exercises (moving) and sport for PwMS, based on the following principles:

1. accessible (open for all – infrastructure)
2. affordable
3. certified professional supervision
4. outside the medical environment

Accessible

If a sportsclub or a fitnesscenter is proposing to provide services to PwMS (or other disabled people), an adapted infrastructure should be available. Depending on the functional status of the PwMS (measured with the Expanded Disability Status Scale (EDSS), see <http://www.mult-sclerosis.org/expandeddisabilitystatusscale.html>) this can be different. PwMS with EDSS 1–5 are able to participate in normal, not adapted facilities. Otherwise, when people are using a wheelchair, not only the sport facilities and equipment needs to be adapted, but also adapted sanitary facilities must be available.

Affordable

Often, the costs for inscription fees, for memberships etc. are a barrier for PwMS to get access to sport- and/

or fitnessclubs given that PwMS already have a lot of disease-related costs [6]. This is the point where the engagement of the MS Society plays a crucial role in this concept (see below). For activities provided by certified “MovetoSport” therapists, the MS Society proposes a financial reimbursement of 25 Euro on a yearly base to their members with MS.

Certified professional supervision

The aims of “MovetoSport” are to educate health care professionals working in the community regarding physical rehabilitation of PwMS, and to form a network in which updated information and experiences can be shared. With health care professionals, we primarily focus on physiotherapists, sport instructors and fitness experts. “MovetoSport” regularly organizes a series of courses, which lead to a formal certificate. We distinguish an introductory full-day course and thematic workshops as prerequisite for certification and related visibility (see below).

Outside the medical environment

An important objective of “MovetoSport” is to integrate sport participation of PwMS within their own living community, together with family and friends. This is important to induce a behavioral change with active participation in society. Different local group projects, led by “MovetoSport” coaches were started in different regions in Flanders. Sometimes, sport classes are organized within rehabilitation centers as a follow-up of a more intensive training program, and attended as ambulatory patients.

Formation program of “MovetoSport”

Key activities of “MovetoSport” are the formation of health care professionals and sport/fitness instructors in adapted exercise and sport activities for PwMS. Formation activities include an introductory education day and workshops in smaller groups (n=up to 20)

Location	Date	N	Topic
Kontich	5/06/2010	30	How to set up exercise and fitness programs for PwMS? Assessment of walking ability and fatigue
Nieuwpoort	5/06/2010	21	Assessment of physical activity and community walking. Adapted sports for PwMS (zumba, aquatics, nordic walking, yoga, spinning etc).
Sijsele	4/02/2011	12	Endurance tests and analyses for PwMS
Kontich	7/05/2011	21	Adaptation of fitness programs and assessment of walking ability and fatigue
Hasselt	10/09/2011	20	Muscle strength measurements, analyses and development of resistance training programs

Table 1: Overview of workshops in 2010 and 2011

to allow for direct interaction and discussion among participants and teachers. Education days and workshops are repeatedly organized in different locations in Flanders.

Introductory education day

A full day of education is provided as a start of an education cyclus, and contains following elements:

- Pathophysiology, overall MS symptoms and state-of-the-art of symptomatic treatment and disease modifying drugs; presented by a neurologist or rehabilitation physician.
- Typical functioning problems and features of underlying motor disorders and other symptoms (e.g. fatigue), presented by a physiotherapist.
- Scientific findings and evidence related to exercise and sport interventions in PwMS; presented by academics in rehabilitation sciences, physiotherapy as well as exercise physiology.
- Practical points of attention when guiding and coaching PwMS in exercise and sport; presented by a physiotherapist and fitness instructor.
- Testimonies of PwMS that practice exercises and sports, varying from exercises to be able to play golf, to cycling to the Mont Ventoux or running.
- Presentation of relevant synergic activities of the MS Society in Flanders (see below) by the director or project coordinator.

For example, in 2010, up to three education days (Hasselt, 27/2/2010: n=89; Deinze, 13/03/2010: n=79 and Elewijt, 04/12.2010: n=41; Diegem, 05/05/2012: n=45) were organized reaching a total of 209 professionals (physiotherapists, physicians, fitness instructors, sport scientists, provincial sports policy makers etc).

Workshops

During thematic workshops, practical and interactive hands-on sessions are organized in small groups (max. n=20) and with active involvement of PwMS to create a real-life situation. The information provided is always directly implementable in the daily work with PwMS. Workshop leaders vary at different locations, but are always specialists in their domain with large experience. In the future, also certified “MovetoSport” professionals with an unique expertise or facilities will be involved as teachers to share their experience. An overview of topics in 2010 and 2011 is presented in table 1.

Certification

Attendance of the introductory education days and two workshops leads to an official certification signed by the “MovetoSport” president and the Flemish MS Society. By the certification system, we are able to identify motivated professionals and to form an active network

of persons, who meet during workshops, but also at MS exercise and sport-related events in Flanders. As well, we facilitate knowledge exchange by this network. Some of the certified professionals are involved in future formation activities or projects. However, only individuals can be certified – not institutions (rehabilitation centers) or enterprises (fitness centers). This regulation prevents that one is profiling an institution or company as skilled in MS guidance in exercise and sports, if not all professionals followed the course.

This certificate is valid for three years, after which it expires when no participation to an additional workshop is made. The duration of the certificate was limited as certified professionals are shown with their coordinates on the website of “MovetoSport” (www.movetosport.be) to allow responsible health professionals (PwMS, MS Society, neurologists, general practitioners, etc.) to find them for referral. An illustration of visualization of regions with certified professionals is shown in figure 1.

Collaboration with the MS Society

The realization of “MovetoSport” and continuous activities is established thanks to the collaboration with stakeholders. Primarily, we collaborated with the Flemish MS Society, who decided to co-organize events for PwMS regarding the topic of exercise and sports, and to stimulate local initiatives to provide guided exercise and sport in the community.

Sport and information days for PwMS

In 2010 and 2011, so-called sport and information days were organized for PwMS in different Flemish regions (Table 2). These days were composed of a theoretical part in the morning, where education on MS symptoms, functioning problems, exercise and sport programs were provided with strong involvement of “MovetoSport” instructors. Here as well, also testimonies of persons concerned were given. In the afternoon, a practical part was organized during which PwMS could choose out of three different exercise types and sport activities to gather first experiences and to become motivated. The offer was manifold: cycling (also with adapted cycles), zumba classes (in sitting position as well), Tai Chi and yoga classes, aquarobics, archery, nordic walking etc. These sport activities were professionally guided with adaptation to individual capacities, boosting the self-confidence of the participants.

These days were advertised in press as well, as young PwMS and recently diagnosed persons are often not yet member of the MS Society, while this group is importantly targeted with these events. These events are considered important as they serve as a trigger for PwMS to engage in a physically active lifestyle.



Fig. 1: Logo of “MovetoSport” and visualisation of certified “MovetoSport” professionals by region in Flanders

Location	Date	N
Kortrijk	07/11/2009	38
Tongerlo	14/11/2009	55
Nieuwpoort	26/9/2010	100
Herselt	28/05/2011	25
Leuven	26/5/2012	45

Table 2: Overview of sport and information days in 2010 and 2011

Facilitation of exercise and sport in the community setting

The MS Society also facilitated both the engagement of PwMS in exercise and sports by providing financial support for members in their expenses (25 Euro/year, if expenses exceed 50 Euro; 101 PwMS were reimbursed in 2010, 95 in 2011) as well as stimulating local professionals to offer services and activities for PwMS. Examples are fitness centers, who provide group lessons and adapted programs with affordable prices in various places in Flanders. As well, there started zumba, yoga and swimming groups. As PwMS stated that mobility impairment had a substantial impact on their lives, including working life, social life and family life [3], a program like “MovetoSport” will help to overcome these difficulties.

Research

A cooperative of “MovetoSport”, the Belgian MS Society and the University of Hasselt enabled to also perform research within the context of the sport and information days. Participants were asked to complete questionnaires at the event, as well as three and six months later. Domains of interest were physical activity and perceived walking ability, self-efficacy level, fatigue, quality of life. Forty-two persons answered all questionnaires at all timepoints. It appeared that a one-day education program had, depending on perceived disability level, some long-standing effects on physical activity and perceived impact of MS [3].

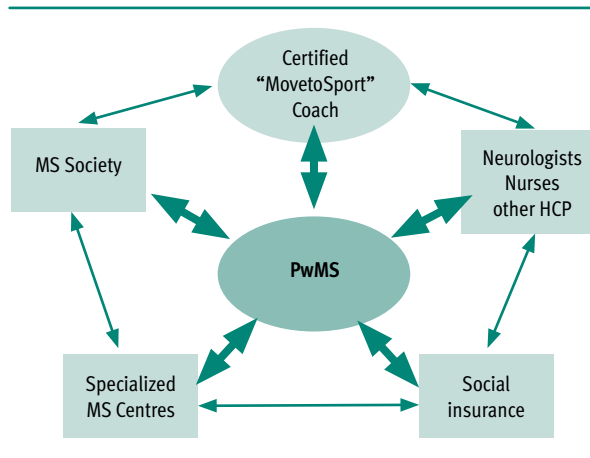


Fig. 2: Network with all stakeholders and different possible relations (MS = multiple sclerosis, PwMS = persons with MS, HCP = health care professionals)

Conclusion

We presented an organizational model where the active physical lifestyle of PwMS is envisaged, with certified “MovetoSport” coaches and professionals interacting with them in the community. The MS Society is an important partner, but also others as neurologists and MS nurses, as well as rehabilitation centers and health insurance systems are of high relevance (Figure 2). Together, the overall capacities of PwMS can be changed more positively and effectively.

References

- Dalgas U, Stenager E, Ingemann-Hansen T. Multiple sclerosis and physical exercise: recommendations for the application of resistance-, endurance- and combined training. *Mult Scler* 2008; 14 (1): 35-53.
- Dalgas U, Stenager E, Jakobsen J, Petersen T, Hansen HJ, Knudsen C, et al. Resistance training improves muscle strength and functional capacity in multiple sclerosis. *Neurology* 2009 Nov 3; 73 (18): 1478-1484.
- Feys P, Tytgat K, Gijbels D, De Grootte L, Baert I, Van Asch P. Effects of an 1-day education program on physical functioning, activity and quality of life in community living persons with Multiple Sclerosis. *Journal of Neurological Physiotherapy* (in review).
- Freeman JA, Langdon DW, Hobart JC, Thompson AJ. Inpatient rehabilitation in multiple sclerosis: do the benefits carry over into the community? *Neurology* 1999; 52 (1): 50-56.
- Hale LA, Smith C, Mulligan H, Treharne GJ. “Tell me what you want, what you really really want...”: asking people with multiple sclerosis about enhancing their participation in physical activity. *Disabil Rehabil* 2012 Apr 5.
- Kobelt G. Costs and quality of life for patients with multiple sclerosis in Belgium. *Eur J Health Econ* 2006; 7 (Suppl 2): S24-S33.
- Rasova K, Feys P, Henze T, van TH, Cattaneo D, Jonsdottir J, et al. Emerging evidence-based physical rehabilitation for multiple sclerosis – towards an inventory of current content across Europe. *Health Qual Life Outcomes* 2010; 8: 76.
- Rietberg MB, Brooks D, Uitdehaag BM, Kwakkel G. Exercise therapy for multiple sclerosis. *Cochrane Database Syst Rev* 2005; (1): CD003980.
- Smith RM, Deney-Steel M, Fulcher G, Longley WA. Symptom change with exercise is a temporary phenomenon for people

with multiple sclerosis. *Arch Phys Med Rehabil* 2006; 87 (5): 723-727.

- Snook EM, Motl RW. Effect of Exercise Training on Walking Mobility in Multiple Sclerosis: A Meta-Analysis. *Neurorehabil Neural Repair* 2009; 23 (2): 108-116.
- Solari A, Filippini G, Gasco P, Colla L, Salmaggi A, La Mantia L, et al. Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. *Neurology* 1999; 52 (1): 57-62.
- Tallner A, Waschbisch A, Wenny I, Schwab S, Hentschke C, Pfeifer K, et al. Multiple sclerosis relapses are not associated with exercise. *Mult Scler* 2011 Jul 6.

Conflict of interest

In the preparation of “MovetoSport”, initial courses for health care professionals and PwMS have been supported by Bayer Schering Pharma Belgium (2009–10).

Contact

Paul Van Asch
Fit Up – Fitness and physiotherapy center Kontich
Mechelsesteenweg 192A
2550 Kontich
Belgium
E-Mail: info@fitup.be