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Additional Information

Title: Rehabilitation for multiple sclerosis, in adults (II). An overview.

Authors: Amparo Martinez-Assucena, PhD¹, Sven-Uno Marnetoft, PhD², Teresa Roig Rovira, PhD³, Javier Hernandez-San-Miguel⁴, Montserrat Bernabeu, MD⁵, Montserrat Martinell⁶.

¹ MDPhd. Specialist in Physical Rehabilitation Medicine (PRM), PRM Department of Hospital Requena, Requena, Spain, ²Associate Professor in Rehabilitation Science, Department of Health Sciences, Mid Sweden University, Östersund, Sweden, ³PhD specialist in Psychology and Neuropsychology, Acquired Brain Injury Department of Guttmann Institut, Barcelona, Spain, ⁴Associate Professor in Department of History of Science and Documentation, University of Valencia, Spain, ⁵MD. Specialist in PRM, Acquired Brain Injury Department of Guttmann Institut, Barcelona, Spain, ⁶Speech Therapist, Acquired Brain Injury Department of Guttmann Institut, Barcelona, Spain.

First author's e-mail: amparo.assucena@gmail.com

Abstract: Multiple Sclerosis (MS) may lead to different severity and progression of impairment and disability and to dissimilar levels of limitation in activities and participation in different social domains, with impacts on quality of life (QoL) of persons with MS (PwMS). Results have shown that PwMS prioritizing goal-setting may enhance adherence to treatment; that interdisciplinary rehabilitation may prolong PwMS' functional status level, display transient improvement in the aspects of impairment features, increase their participation in activities, and improve their QoL, despite not modifying disease progression; that single rehabilitation packages of comprehensive care components have proven beneficial, such as physiotherapy, enhancing aerobic capacity, strength, pain,

mood, mobility, and QoL; occupational therapy, reducing the impact of impairment on QoL, especially fatigue; neuropsychological interventions, such as learning and memory remediation; psychological intervention for depressive disorders; coping, self-management techniques, helping to adjust to disease and disability; speech therapy, improving intelligibility; swallowing techniques, preventing material from entering the airway; clean intermittent self-catheterism, avoiding urinary tract infections; power wheelchairs, enhancing occupational performance and energy conservation. Further Vocational Rehabilitation settings and research are required for more appropriate interventions due to high unemployment rates among PwMS. Comprehensive information should include planning for future independent living and long-term care needs.

Key words: Multiple Sclerosis, Rehabilitation, Physical Therapy, Occupational Therapy, Neuropsychology, Speech Therapy.

Introduction

A review of the literature has shown controversial results regarding the impact of relapses on disability progression among patients with relapsing remitting MS type (RR MS). Relapses in the first 2¹-5² years after onset of the disease may have no impact on disability progression^{3,4} or may influence this^{1,2,5}, in the short, not long term². There was general agreement that disease progression and disability progression were correlated³⁻⁵. The pathophysiological mechanisms underlying the relationship between the early and second phase of the course of the disease have remained unclear⁴. No definitive markers have been stated to predict long-term disability outcome in PwMS ⁶.

Interpheron β, glatiramer acetate, natalizumab and mitoxantrone are approved immunomodulatory agents in the United States (US), Canada and Europe, and have been recommended as escalating immunomodulatory treatment for RR MS⁶. Interpheron β-1b in Europe and mitoxantrone were approved for secondary progressive MS type (SP MS)⁷. Evidence from controlled randomized clinical trials (RCT) with immunomodulatory agents has suggested that all currently approved agents for treating PwMS have decreased the rate of clinical isolated syndrome (CIS) individuals turning into clinically definite MS (CDMS)⁸, reduced clinical relapse rate by about 30 %⁹, and accompanying inflammation within the central nervous system (CNS)⁷, and limited the sequelae of acute relapses⁹. A list of immunomodulatory agents, including expected benefits and reported adverse effects, is given in Appendix. Mesenchymal stem cell (MSC) therapy has been advocated as a potential treatment for MS¹⁰. MSC therapy has been shown to modulate immune responses that correlate with the inflammatory process in PwMS, and may eventually contribute to repair in the neurodegenerative process¹⁰. Research on MSC is being developed to examine this treatment's safety and effectiveness among a mild-moderate MS sample, excluding patients without relapses 10. Symptomatic pharmacological therapy has been provided aiming at treating the impairment during relapses and progression of the disease. Corticosteroids at 5 weeks have been most effective at relieving symptoms in PwMS with an acute exacerbation requiring treatment¹¹. Gastrointestinal symptoms, psychiatric disorders (insomnia, elevated mood, dysphoria), weight gain and edema were reported as adverse effects¹¹. Amantadine has been prescribed for fatigue. The adverse effects have been sleep disorders, anxiety and headaches¹¹. Baclofen, for spasticity, may induce weakness and mania¹². Cannabinoids, for spasticity and pain, may induce psychosis¹³, euphoria,

difficulty concentrating and mania¹¹. Drugs' adverse effects have often overlapped MS impairment, requiring ongoing assessment of pharmacological interventions.

In the context of a presence of transient, residual, and irreversible and progressive disability, with multiple impairment, Rehabilitation (RHB) interventions intended to enable people with disabilities, such as PwMS, have been proved to be necessary and appropriate ¹⁴⁻¹⁶. **RHB** is described as the health strategy applied by specialists in Physical and RHB Medicine (PRM) and professionals in the sector and across other sectors, aiming to enable people with health conditions experiencing or likely to experience disability to achieve and maintain optimal functions in interaction with the environment ¹⁷.

Interdisciplinary RHB (IRHB) has been the health strategy that may be provided across different care agencies¹⁸, and linked to counseling, applied under an interdisciplinary team approach¹⁹, and requiring a multiprofessional team²⁰. In an IRHB team approach, professionals with different backgrounds trust each other as important members of the team, work towards agreed goals, share strategies, in individual or in joint sessions, underpinned by the necessary skills for effective interaction, and knowledge of how to transfer integrated group activities towards the goal¹⁹⁻²¹. The multiprofessional team assessing and delivering the appropriate RHB interventions for PwMS and their caregivers has included PRM, Neurology, Ophthalmology, and Urology physicians, neuropsychologists, clinical psychologists²⁰, physio, occupational and speech and language therapists²⁰, dieticians²⁰, nurses with RHB expertise²⁰, assistive technology (AT) specialists^{20,22}, social workers (SW)²⁰, and case managers²³. This broad multiprofessional team may even require other medical and paramedical professionals with expertise in the different problems that may affect PwMS.

Broad RHB services with multiple packages of comprehensive care components delivered by multiprofessional teams, usually at acute and/or RHB hospitals, may provide IRHB interventions.

Care agencies have delivered RHB services for PwMS with different packages of comprehensive care in the inpatient, outpatient and community services, depending on patients' needs¹⁸ and local availability and affordability. These packages have been delivered in different facilities, such as inpatient and outpatient services, at acute hospitals, and at RHB hospitals, inpatients at long-term hospitals, at nursing homes, and at respite centers, at community-based services, and at home^{18,24}. Case management (CM) interventions reflected the link between healthcare and non-healthcare, in a continuum. The paramedical RHB packages of comprehensive care components have included Physiotherapy (Ph)^{18,24}, Occupational Therapy (OT)^{18,24}, Neuropsychological (NeuroPsy) interventions, Psychological (Psy) interventions, Speech and swallowing (Sp) therapy, Dietary interventions, expertise RHB nursing, AT, Social, and Vocational RHB (VR). Extensive RHB services with multiple packages of comprehensive care components delivered by multiprofessional teams, usually at acute and/or RHB hospitals, may provide IRHB interventions. CM interventions reflected the link between healthcare and non-healthcare, in a continuum.

IRHB interventions and single packages have been delivered at different points and timing, such as long or short term. "Long term" was considered for some authors as longer than 3 months²⁵ and by others, as longer than 6 months²⁶, and thus "short term" was considered as under that time frame. Packages have been delivered at different intensities, such as high or low intensity programs. Khan²⁶ (2007) considered high-intensity programs as those with at least two different components of care package, at least 30 minutes per session, for two to three hours a day, four days a week ²⁶. Low-

intensity programs involved a shorter duration of treatment and fewer RHB resources²⁶. Information provided by stakeholders has been considered crucial for PwMS' participation, empowerment, self-management²⁷, planning measures²⁸, and as a part of RHB care¹⁵ and counseling delivery.

It was recommended that RHB services should be delivered in pathways of care, according to a consistent "whole systems" approach of care delivery¹⁸, in order to ensure continuity of care¹⁸. Accessibility to and use of comprehensive care packages, and to information and education by PwMS may reflect the adequacy or the fragmentation of delivery of RHB services to this population.

Aim

The aim of the study was to report on the effectiveness of RHB planning (RHBP) and of global IRHB interventions; of paramedical RHB packages of comprehensive care components for PwMS; to report the impact of MS information and education for PwMS, their significant others and caregivers; to describe CM's main features; to report the impact of IRHB interventions and paramedical RHB packages of comprehensive care components on PwMS; and to describe the accessibility and use of RHB services in different countries.

Methods

A literature search using multiple literature databases (CINHAL, Cochrane Library, Current Contents, EMBASE, MEDLINE, PEDro, PsycINFO, OT seeker) was conducted. A manual search was also conducted in relevant journals, such as *Multiple Sclerosis*, related to the main topic and to RHB. The search was limited to articles, including items in electronic format, chapters of books, and webpages of MS organizations available in English, from January 1995 to June 2011. The search was undertaken using *MS* as main keyword, and combining this with other keywords, such

as *RHB*, *Ph*, *OT*, *NeuroPsy*, *Psy*, *Sp*, *Dietetics*, *Nursing*, *AT*, *Social Work*, *VR*, *CM*, and different body function and body structure impairment, and related terms. The development of each heading was structured in an introduction, aim and results format. A summary summed up results. In the *Ph* heading there was a common introduction and aim, while results and summary were described under each subheading. CM texts presented a description of CM's features and summary, since no evidence-based results about its effectiveness on MS were found. *Refworks* was used as reference management to index and cite the references in the text. In this manuscript, medical therapeutic interventions, such as pharmacological and non-pharmacological therapy, and interventions for caregivers have not been included. Original authors' expressions, such as "multidisciplinary RHB", were accepted.

I. Rehabilitation planning and interdisciplinary Rehabilitation interventions

1. Rehabilitation planning

Introduction

RHBP for PwMS has been a customized framework to assess patients' health condition, including any relevant clinical features and functional status using outcome measures (OM)¹⁴; to assess his/her contextual factors, such as environmental and personal factors; goal setting (GS); delivering goal-oriented strategies and services¹⁴; to assess functional follow-up; evaluating OM; and defining discharge destination. It has aimed at improving OM and enhancing the patient's autonomy²⁹, and has required PwMS' participation and adherence to their RHBP. Physicians' role included the development of RHBP, identifying its time frame¹⁴, and scoring according to defined OM³⁰.

According to bodies representing PRM specialty documents in Europe, RHBP is a PRM

physicians' role¹⁴. In different countries, this function has been assumed by Neurologists. Features of its goals have been described as specific, measurable, achievable, realistic and timed (SMART)¹⁶. PwMS and their significant others, and multiprofessional teams did not necessarily agree on GS and on expectations as to the amount of improvement and the likelihood of achieving their goals³¹ Achieving goals could be measured by means of Goal Attainment Scaling³².

Aim

The aim was to report on the effectiveness of RHBP, applied to PwMS.

Results

The effectiveness of RHBP has focused on GS. GS could be prioritized by PwMS and their significant others or it could be agreed between them and the multiprofessional team¹⁶ or GS can even be applied by the multiprofessional team without agreement with PwMS²⁹. No differences in functional OM were reported between PwMS prioritizing GS and the PwMS agreeing with multiprofessional teams for GS¹⁶. There is however general agreement that PwMS should participate in GS^{16,31}. There was significantly better adherence to RHBP and more satisfaction with GS among PwMS that prioritized GS¹⁶. A systematic review about goal planning's effectiveness in clinical RHB, which included CNS disorders and injuries, was seen to have some positive effect on patient motivation and treatment adherence²⁹. No generalizable therapeutic effects could be found with goal planning²⁹.

Summary

GS are an important part of RHBP to evaluate OM. GS would rather be prioritized by PwMS or agreed with the multiprofessional team, and be SMART-based. RHBP was effective at improving PwMS' motivation and treatment adherence.

2. Interdisciplinary Rehabilitation interventions

Introduction

IRHB interventions for PwMS, as for other persons with disability, were recommended to be goal-oriented, task-specific, and timed¹⁶.

Aim

The aim was to report the effectiveness of IRHB interventions, applied to PwMS.

Results

IRHB interventions were reported to be effective at improving PwMS in different activities, participation, and HRQoL and QoL^{26,33,34}. There was strong evidence of improvement in activity and participation, at inpatient service delivery, for short-term gains^{26,35}. Controversial results were reported by Storr³⁶ (2006) who found no significant results. There was limited evidence that outpatient service delivery and home care with high-intensity programs would improve body function and body structure impairment, and disability for short-term gain²⁶. There was strong evidence that long-term intervention and low-intensity programs improved health-related QoL (HRQoL) and QoL²⁶. The effectiveness of IRHB intervention has been proved to be higher in PwMS affected with RR MS type¹⁶. No changes in progression were reported, despite IRHB intervention^{16,26}. PwMS with mild to moderate impairment were able to improve in activities and participation during IRHB intervention³⁴. At the other end of the range, less benefit with IRHB intervention³⁵ was seen in PwMS with severe impairment

associated with long disease duration. presented less benefit with IRHB intervention³⁴. Cognitive disorders, especially verbal intelligence, and ataxia were variables accounting for broad variance in the patients' improvements³⁷. However, HRQoL, especially mental and vital components, was associated with IRHB interventions in samples of PwMS with mild to severe impairment^{33,38}. The benefit of IRHB intervention lasted for a period of time after therapeutic intervention ceased, and later faded away³³. Freeman³³ (1999) reported that QoL lasted for a longer period, followed by emotional well-being, and disability and handicap³³.

Summary

Evidence of the benefit of IRHB intervention in activities, participation, HRQoL and QoL and scarce improvement in impairment has been reported. Controversial results not evidencing significant effectiveness could be for methodological reasons. Specific levels of service delivery, timing and intensity of programs have given different results, regarding improvement in activities, participation and QoL. PwMS with cognitive dysfunction and/or ataxia displayed greater variance in their improvement after IRHB intervention. QoL proved to remain longer than physical features.

II. Paramedical Rehabilitation packages of comprehensive care components

1. Physiotherapy

Introduction

a. Therapeutic exercise (TE). TE was defined as the prescription of a physical activity program that involves the client performing voluntary muscle contraction and/or body movement with the aim of relieving symptoms, improving functions or enhancing, retaining or slowing deterioration of health³⁹. TE included endurance and/or resistance

exercise, and flexibility⁴⁰. TE may be undertaken by means of motorized-supportedrobotics⁴¹ or be implemented within a virtual reality environment. For many years, PwMS were advised to avoid exercise because of the risk of heightened symptoms⁴². A minority of Pw MS has been engaged in regular exercise⁴³, with 71.4 % endorsing none at all, this being even less common with increasing age⁴⁴. It has been shown that physical activity in PwMS with Expanded Disability Status scale (EDSS) scores higher than 7 decreased dramatically⁴². PwMS with fatigue, depressive disorders and pain have been less committed to exercise 45. Exercise tolerance was considered as being an important component of physical function and mobility, and could be an early marker of functional limitation⁴⁶. **Assessment.** Assessment of baseline exercise tolerance condition⁴⁷, and of autonomic functioning, including heart rate response to a dynamic exercise test, and of blood pressure adaptation to orthostatic changes was recommended^{47,48}, and monitoring during the TE training program as well. Should the response be delayed or attenuated, referral for more formal autonomic laboratory testing was advisable⁴⁸. Autonomic laboratory testing was recommended in thermo-sensitive PwMS, whenever prescribing TE or if exposed to high temperature^{42,48}. TE should be prescribed on an individual basis, due to impairment heterogeneity among PwMS, and according to recommended guides⁴⁷.

b. Hydrotherapy (HT). HT is physical therapy performed in the water. HT's components include buoyancy, viscosity, and temperature⁴⁹. HT settings should control the environmental temperature and humidity, and the water temperature. The use of warm pools may be appropriate for carefully selected individuals but it was not included as a recommendation in the Spasticity Management Guidelines of the MS Council for Clinical Practice Guidelines (MSCCPG)⁵⁰. HT therapeutic elements were used to assist, resist or support movement^{49,51}. Accessibility settings should include ramps and lifts,

locker room facilities, and professional care for specific mobility needs and cognitive and mood impairment. Further material that should be available was water-safe footwear, walking aids, flotation devices, flippers and hand paddles for resistance exercises.

- c. Environmental condition control. This manuscript refers to water temperature and air humidity rate. White⁵²(2003) reported an adequate environmental temperature of 71.60 F or 22°C and relative humidity of around 20 %, at HT setting during a study of exercise with precooling immersion. Therapy with heat and cold has included heat and cold devices and cold water.
- **d. Electrotherapy** (ET), such as transcutaneous electrical nerve stimulation (TENS), functional electrical stimulation (FES), ultrasounds, and low grade laser were reported as being of therapeutic use for PwMS^{12,50,53,54}. FES consists of a stimulator unit mounted on a cuff, and electrodes⁵⁵. It provided muscle contraction and functional movement to compensate for focal weakness. FES stimulated the common peroneal nerve as a substitute intervention, in PwMS with foot drop⁵⁵.
- **e. Other types of Ph interventions** have referred to specific Ph techniques, exercises for increasing range of motion (stretching), and packages of exercises with or without ET or other Ph techniques, for specific body functions and body structure impairment.

Aim

The aim was to report on the effectiveness of **TE**, **HT**, of **environmental condition control**, and therapy with **heat** and **cold**, **ET**, and of **other types of Ph interventions** in PwMS; and to describe the adverse effects of TE and its prevention.

Results

a. TE. Target population. Women were more frequently included in samples of TE studies in MS, in accordance with their prevalence among patients with RR MS, and

they showed more benefit with TE than men⁵⁶. Individuals with PP MS have been more limited in engaging TE than those with RR MS ⁴³. Male PwMS have presented PP MS rather than RR MS ⁴³. There may be an age limit for inclusion at 65 years⁵⁷. Samples were of mild-moderately impaired PwMS, in most of the studies of TE (EDSS <7)⁵⁷⁻⁶². Fewer studies have included PwMS with EDSS > 7 in its samples⁶³. TE was applied to PwMS in most of the studies in remission⁵⁸⁻⁶². To our knowledge, only one study included PwMS during relapse⁶⁴. Individuals with PP MS type have been more limited in engaging TE than those with RR MS type⁴³. Male PwMS have presented PP MS type rather than RR MS type ⁴³. Research studies included PwMS with fatigue⁶⁵, spasticity⁶⁶, ataxia, depression⁶⁵, and other associated symptoms⁶⁷.

There was general agreement on the improvement of different OM in mild-moderately impaired PwMS during remission engaged in TE^{60,61,68-70}.

Types of exercise training. Dalgas⁷¹ (2008) reported that there was evidence that endurance exercise training at low to moderate intensity resulted in enhancement of cardio-respiratory and neuromuscular systems, inducing improvement in aerobic capacity, and moderately in ADL⁷¹, and it was well tolerated in PwMS with EDSS's scores lower than 7⁷¹. Resistance training increased muscle mass, including increased muscle fiber size, predominantly in type II fibers⁷², This resulted in major improvement in gait parameters⁷³, and in ADL performance, included walking, and was also tolerated well by PwMS within a sample of similar impairment^{47,71}. Flexibility exercises were required to avoid contractures, which were common among PwMS with spasticity or with reduced physical activity⁴⁷. PwMS with mild muscle weakness and no thermosensitivity would benefit more from endurance training⁷¹. Pw MS suffering from major strength deficits would rather undergo resistance exercise training⁷¹.

Motorized-supported-robotic exercise. Motorized devices such as treadmills could be used by PwMS in walking condition for endurance exercise training^{74,75}. This exercise training was tolerated well and increased gait speed and endurance^{74,75}. It was suggested that task-oriented body weight-supported treadmill training with robotic assistance was of benefit, regarding gait speed, walking distance and knee-extensor strength, for moderate-severely impaired PwMS (EDSS 6.0-7.5)⁴¹.

Virtual reality. This has been proposed as a potentially useful tool for motor assessment and RHB⁷⁶. An Internet intervention based on social cognitive theory improved physical activity and GS⁴⁵.

Psychological and motivational aspects. Endurance training was associated with improved psychosocial functioning, including mood^{59,71}. Benefits from non-physical inputs have been reported during TE, as a consequence of the physiotherapist's action. These could be PwMS' coaching, promoting self-efficacy and self-learning strategies through verbal engagement that could lead to a major impact on perceived QoL and health status⁷⁷. Cognitive behavioral techniques applied by other professionals could also increase self-efficacy⁷⁸. PwMS endorsing TE actually reported better mental health^{44,59}.

Compliance and adherence. Guidance and supervision were reported to be necessary for ensuring compliance and adherence⁵⁸, and to induce a positive influence on walking mobility²⁵. DeBolt⁷⁹(2004) nevertheless found improvement not only in mobility but also in QoL in a home-exercise program with little supervision.

Adverse effects. Worsening of symptoms after TE included visual acuity abnormalities, fatigue and weakness^{39,42,80}, which have been reported in up to 40 % of PwMS⁷¹. This symptom instability was reported to reverse after 30 minutes from

exercise cessation in about 85 % of PwMS⁷¹. Most of the authors reported no adverse effects related to TE^{39,57,58,62,68,81}.

Prevention of autonomic dysfunction (AD) adverse effects. PwMS displaying an autonomic cardiovascular (CV) response to exercise should avoid exertion during its performance⁴². PwMS with thermo-sensitivity should include cooling measures during exercise training, under controlled environmental conditions⁵² (See *Environmental condition control, therapy with heat and cold*).

TE training period duration. Both long-term TE programs^{68,69,82} and short-term ones^{61,79,83} have improved functional capacity and/or walking mobility in PwMS. Short-term TE programs have been reported to be more effective at improving walking mobility for PwMS than long-term ones²⁵, with a statistically significant influence on the average effect size²⁵.

Duration of benefit. In several studies it was reported that the duration of an exercise program's benefit was maintained for 3-10 months^{33,68,84} exercise capacity being lost sooner than QoL⁷⁷. The duration of benefit lasted no longer than two months after cessation of TE among PwMS with ataxia⁸⁵.

Service delivery. Improvement in exercise capacity and motor function occurred among PwMS in different service delivery situations, such as hospital, as inpatients, at a community setting, as outpatients, and at home^{68,79,82}.

Summary

Women have shown better results than men during a TE program, most probably related to the type of MS. TE has been reported to be prescribed basically for PwMS with mild-moderate impairment, and in remission. Those with PP MS showed less benefit from TE than those with RR MS, probably in relation to a more disabling status. Tolerance to

exercise and CV AD should be monitored prior and during exercise programs. Different authors concluded that there were no significant differences in effectiveness between types of exercise training. However, low-moderate intensity endurance TE has recently been reported as being tolerated well and beneficial for mild-moderately impaired PwMS to improve aerobic condition. Resistance exercise proved to be more suitable for moderately impaired PwMS to gain strength. Task-oriented TE with treadmill and body weight-supported treadmills were suggested to improve gait speed. Psychological and motivational aspects as a consequence of the physiotherapist and/or other professionals' work may be an added value to improve symptoms and functional results. Guidance and supervision were recommended for ensuring compliance and adherence, and obtaining better results in QoL. Adverse effects of TE appeared to be infrequent. Exertion during TE should be avoided by PwMS with CV AD. Thermo-sensitive PwMS were advised to wear pre-cooling garments or to body pre-cool before TE. Short-term interventions have shown benefits. Duration of benefit has been reported to last for up to 3-10 months after cessation of intervention. No consistent results have been reported regarding significant benefit between different service deliveries.

b. HT.

Results

HT therapeutic elements that were reported to be useful for PwMS were buoyancy and viscosity⁴⁹. Buoyancy allowed movements that would otherwise be significantly more difficult on land for PwMS with mobility limitation⁴⁹. Viscosity allowed TE against water resistance, as the faster the motion, the greater the resistance⁴⁹. This type of exercise allowed for heightened flexibility⁴⁹. Benefits from HT were reported to be improved movement in water, increased flexibility, strength, muscular and CV endurance, reduced pain mainly due to spasticity¹², improved mood and self-esteem^{49,51}.

Enjoyment as a consequence of HT was reported ⁸⁶, which could lead to improved motivation. More social interaction involving leisure activities undertaken in an aquatic environment meant increased participation ^{49,51,86}. There has been limited evidence of HT effectiveness on MS.

Summary

An aquatic environment allowed TE using some water properties such as buoyancy which facilitated mobility; and viscosity, useful for TE against water resistance.

Improvement in mobility during immersion, improved mood, enhancing participation in leisure activities were found during HT programs for PwMS.

c. Environmental condition control, therapy with heat and cold.

Results

PwMS with thermo-sensitivity should undergo TE in a cool environment, such as an air-conditioned gym or in a swimming pool at a temperature ranging from 80 to 84 F or from 26.70 to 28.90°C, for exercise⁸⁷. Heat could increase spasticity in thermo-sensitive PwMS⁵⁰. However, evidence to support cold treatment, either as cold-water baths (70-80°F or 21.10-26.70°C) or cold packs or garments, for spasticity in PwMS, was equivocal⁵⁰. Water immersion before exercise (precooling), either of the whole body or lower body, preferably the latter, could attenuate core heat measured by rectal temperature⁵². After precooling, core temperature decreased, and did not increase or rose only slightly after exercise ⁵². Precooling allowed 30 minutes of submaximal exercise⁵², and led to TE performance with less perceived fatigue^{47,87}.

Summary

Controlled temperature and humidity environment, and water temperature are important environment conditions, in order to avoid adverse effects in thermo-sensitive PwMS.

Body cooling has been shown to reduce body core temperature and allow TE performance with less perceived fatigue.

d. ET.

Results

Dysaesthesic limb pain or burning pain was reported to improve with cryotherapy and electrotherapy⁸⁸. It was reported that TENS increased tactile sensitivity of the fingers. measured with Semmes Weinstein monofilaments, in an MS intervention group with low tactile sensitivity⁸⁹. Painful tonic spasms and pain associated with spasticity, especially if spasms interfered with sleep⁵⁰, improved with TENS^{50,88}.Other musculoskeletal pain, such as calcified tendinopathy, improved with ultrasound, according to guidelines^{12,90}. For other unresolved musculoskeletal pain, NICE guidelines⁹¹ recommended ET, such as TENS, ultrasounds and low grade laser. Limited evidence was however reported about TENS treatment variables, study design or OM⁹². TENS appeared to be effective for spasticity treatment, at an optimal frequency of 100 Hz⁹². The electrode placement and application time were still not clearly identified⁹². FES showed an orthotic effect (clearing the foot over the ground while using FES), and a therapeutic effect (clearing the foot over the ground after having used FES in the long term), that lasted for 3 months 93 to 4 months and 2 weeks 94 (See Assistive Technology). It was also associated with an increase in walking speed and endurance^{93,94} and a decrease in physiological cost index 9493. Further research is required for the assessment of benefits to functions.

Summary

TENS has been recommended for painful spasms and for spasticity. Ultrasound has been of benefit for calcified tendonitis. FES has shown an orthotic and a therapeutic

effect in clearing the foot over the ground in PwMS with drop foot. There is limited evidence about ET in PwMS.

e. Other type of Ph interventions.

Results

Specific Ph techniques, such as Bobath's, or Vojta's, or propioceptive neuromuscular facilitation were reported as having positive results for GPD in spastic PwMS, with no significant differences regarding efficacy between them¹².

Positioning and weight transfer were of benefit for painful tonic spasms and pain associated with spasticity⁵³. Ph for back pain was recommended according to Philadelphia Panel guidelines^{12,54,90}. Ph for other unresolved musculoskeletal pain was recommended according to NICE guidelines⁹¹. Ph for spasticity was recommended according to MS Therapy Consensus Group (MSTCG) of the German MS Society¹² and to the MS Consortium of MS Centers (CMSC)⁵⁰. These recommendations included stretching. There was some evidence of positive effects of stretching, in the short term, but no evidence in the long term for spasticity in PwMS⁹⁵. PwMS with ataxia could benefit from exercises that would improve balance⁹⁶. It was suggested that TE based on coordinated movements and bilateral muscle actions using a Swiss ball would improve balance⁸⁷. These exercises could be useful for balance disorders (BD) and postural control disorders (PCD).

Pelvic floor training and neuromuscular stimulation could be suitable for PwMS with urgency and urinary incontinence (UI)⁹⁷. The goal was a volunteer "hold on" for longer periods of time. It needed to be assessed whether there were intact neural pathways to the pelvic floor muscles and that these contracted voluntarily prior to initiating treatment⁹⁷. Reflex pelvic floor contractions obtained by stimulating pudendal afferents, by means of an electrical device, would lead to the same goal⁹⁷. Biofeedback could be

included as part of the treatment⁹⁷. These techniques were reported either as specific tasks of specialist continence advisors or included in the Ph scope⁹⁷. Neurogenic bowel dysfunction (NBD), such as constipation, has proved to benefit from colon massage⁹⁸, increasing the frequency of defecation; pelvic floor training for relaxation of sphincter muscles and for incontinence showed some benefit¹².

Regarding respiratory (Resp) dysfunction, an appropriate assessment and TE program, including inspiratory, and especially expiratory, muscle strength training, has been effective at improving PE_{max} , PI_{max} , and maximal voluntary cough in PwMS with different levels of disability⁹⁹⁻¹⁰¹.

Summary

Specific Ph techniques appeared to be useful for spasticity. It was recommended to follow guidelines for back pain, for spasticity and for other unresolved musculoskeletal pain. Specific techniques for continence problems were recommended. Specific Ph exercise for Resp dysfunction proved to be effective.

2. Occupational Therapy

Introduction

The main aim of OT was reported to be maintaining, restoring or creating a match that was beneficial to the individuals between their abilities, and occupational and environmental demands¹⁰², thus aiding them to participate in society¹⁰³. MS scientific literature has shown OT as a cross-discipline that has included cognitive and/or behavioral-based interventions, such as energy conservation strategies, self-efficacy for self-management programs, synergistically with suitable AT. Fewer studies nevertheless looked at activities and task effects¹⁰⁴. Energy conservation strategies include analyzing and modifying activities to reduce energy expenditures, balancing

work and rest, delegating some activities, examining and modifying standards and priorities, using the body efficiently, organizing workspaces, and using assistive technologies to conserve energy¹⁰⁵. Fatigue management education courses have conveyed social learning, peer support, and energy conservation management¹⁰⁶⁻¹⁰⁸. These strategies have been taught in an individual or in a group format, either face-to-face or telephone-delivered¹⁰⁶⁻¹⁰⁸. Coping styles have been related with a better adaptation to living with the disease¹⁰⁹. Self-efficacy has been considered as the individual's confidence in being able to perform a given activity, or perceived self-control¹¹⁰. Self-management programs have included the following goals: caring for the disease, engaging in one's previous life activity, coping with the disease and disability emotionally, and developing self-efficacy¹¹⁰.

Aim

The aim was to report the effectiveness of OT in PwMS.

Results

OT was reported to be effective at capacity, ability, activity and task levels, but less effective at the life role level¹⁰⁴. However, in a systematic review of RCT, it was concluded that there were no studies that could evidence any improvement of outcomes in MS after OT interventions¹⁰². Some benefit in improving fatigue was nevertheless reported ¹⁰². Intervention studies have shown that energy conservation courses and fatigue management education courses have led to significant reduction in MS-related fatigue^{106,108}. Mathiowetz^{105,111,112} has reported that an energy conservation techniques course has improved fatigue in PwMS with moderate-severe fatigue and mild or no cognitive deficit. The benefit meant that there was improvement in fatigue, in the three areas measured with the Fatigue Impact Scale – physical, cognitive and psychosocial;

and in HRQoL measured with SF-36, in vitality, social functioning and mental health subscales ^{105,111,112}. The carry-over lasted for 12 months and the cognitive results gave even better scores in the long term than 6 weeks after the course ^{105,112}. "Several studies about a fatigue management program based on energy conservation techniques supported these results ^{108,113}, despite former controversial results ¹¹⁴. Steultjens ¹⁰² had previously reported no evidence based on the energy conservation techniques course, for methodological reasons. This type of strategies have been recommended by the Spasticity Management in MS CMSC⁵⁰ to minimize the effort associated with completion of a task, for PwMS with spasticity, or to ensure their safety ⁵⁰. Several studies have supported that fatigue management education programs, either face—to-face or telephone-delivered, have improved self-efficacy ¹⁰⁶⁻¹⁰⁸.

Summary

Although there have been controversial results, OT was reported to be effective at reducing the impact of impairment, especially fatigue, at improving capacities, abilities, activities and tasks, and QoL. Energy conservation courses and techniques have proven to be effective at minimizing the effort associated with completion of tasks. Fatigue management education programs, either face—to-face or telephone-delivered, have vouched for being effective at improving fatigue impact, self-efficacy and HRQoL.

3. Neuropsychological and psychological interventions

Introduction

NeuroPsy interventions included cognitive and behavior RHB, aimed at improving memory, attention¹¹⁵, executive functions and communication skills¹¹⁵. Treatment was reported to follow the common principles of cognitive RHB programs that include

cognitive structuring, compensation and substitution strategies, and mnemonic approaches ^{13,115,116}. Modified story memory technique was a compensatory strategy for learning and memory ¹¹⁵. It was recommended that cognitive programs would adjust to a hierarchical complexity order, from basic processes, such as attention and perception, to more complex ones, such as memory and executive functions ¹¹⁷. These programs would be better applied within an interdisciplinary team approach ¹¹⁷. NeuroPsy interventions were often delivered together with pharmacological treatment ¹³. Some NeuroPsy interventions could be delivered for goals with an OT's approach ¹¹⁸.

Psy interventions have been based on therapeutic strategies that allow treating affective symptoms and increasing coping mechanisms in order to improve adaptation¹¹⁹. Psy interventions were reported as part of a therapeutic intervention for fatigue^{13,119}.

Different Psy interventions were reported, such as cognitive behavioral interventions^{13,119-121}, coping styles¹²¹⁻¹²³, insight-oriented groups^{120,123}, a supportive-expressive group¹²⁰, supportive emotion-focused therapy¹²⁴, relaxation techniques^{13,121}, and self-efficacy^{78,110,125,126} (See *Occupational Therapy*), and counseling¹²¹. Programs including cognitive self-management strategies for helping PwMS to solve problems and perform Psy-based tasks could be administered either on an individual basis^{13,120}, or in group format^{13,120}, and even telephone/video-administered^{121,124}. Psy interventions were often combined with pharmacological symptomatic therapy, especially antidepressants^{13,120,123}.

Aim

The aim was to report the effectiveness of NeuroPsy and Psy interventions in PwMS.

Results

In the NeuroPsy field, Thomas¹¹⁹ (2006) reported that there were inconclusive results regarding the evidence of NeuroPsy interventions' effectiveness for cognitive disorders. Some techniques showed benefits in cognitive impairment, however. O'Brien¹¹⁵ (2008) reported that modified story memory technique could be recommended for learning and memory remediation. Self-generation (a learning strategy where persons are asked to generate their own words or items, to improve their learning and memory) applied to tasks, was shown to enhance memory performance¹²⁷. Cognitive intervention, including exercises for executive functioning and feedback, was demonstrated to improve executive functioning and verbal learning, and the carry-over effect lasted for one year¹²⁸. Learning new motor skills could adaptively drive motor abilities in PwMS¹²⁹. Regarding learning tasks, it was suggested that spaced learning trials (when trials are distributed over time), as a learning technique for cognitive impaired PwMS, were useful to enhance recall and performance of activities of daily living (ADL) for verbal task stimuli 130, as happens among healthy individuals examining acquisition of novel material. There was limited evidence in the area of remediation of attention, and communication skills. It was suggested that a cognitive intervention program including compensatory strategies within functional activities, problem-solving techniques and self-management training could increase levels of self-efficacy to manage cognitive difficulties^{125,126}. Psy interventions combined with pharmacological symptomatic therapy were shown to be of benefit for PwMS with depressive disorders, being the gold standard at least for the most severe depressive disorders ¹²⁰. Psy interventions including coping skills, either problem-focused or emotion-focused¹²², were observed to be more effective than the insight-oriented group ¹²³. Supportive-expression Psy interventions displayed lower efficacy than cognitive behavior interventions and antidepressant sertraline¹²⁰. Relaxation was reported to decrease levels of anxiety¹²¹. Group

psychotherapy efficacy was not proven for methodological reasons¹²¹. Nicholas¹¹ (2007) and Thomas¹¹⁹ (2006) found no direct information from RCTs that could support cognitive behavioral therapy for fatigue, in systematic reviews. However, Haussleiter¹³ (2009) reported that it appeared to be an effective treatment for fatigue, as well as relaxation techniques. Self-efficacy has been reported as being a useful framework for psychosocial adjustment in chronic diseases, such as MS^{78,131,132}.

Summary

There is limited evidence of NeuroPsy and Psy interventions' effectiveness for PwMS. There was some evidence that several learning and memory remediation techniques, cognitive interventions for executive deficits to improve executive functioning and verbal learning, were effective. Specific learning techniques for cognitive impaired PwMS could be useful to enhance recall and performance of ADL.

Cognitive behavior techniques were recommended for depressive disorders. Coping skills looked encouraging for adjusting to disability status. Cognitive, self-efficacy strategies within programs for self-management have been shown to offer some benefit for psychosocial adjustment.

4. Speech and swallowing therapy

Introduction

The acquisition of specific skills, rather than a focus on specific impairment, has been the trend, in order to improve communication, swallowing, and thus social participation¹³³, and preventing Resp complications. Experienced physicians assessing speech and swallowing disorders, managing percutaneous gastrostomy (PG) and possibly even tracheotomy were required for these problems. Speech therapists have most commonly been the professionals instructing PwMS and caregivers in restitution

and compensating maneuvers for dysphagia (Dysph)¹³⁴. Other professionals, such as nurses with RHB expertise, have also been engaged in these therapeutic interventions, educating PwMS and caregivers in compensation interventions.

Aim

The aim was to describe Sp and to report the effectiveness of Sp in PwMS.

Results

Dysarthrophonia (DysA)

Several recommendations have been drawn from a review of the literature on dysarthria in MS. It was advisable to inform the patient from the onset of the disease of possible occurrence of speech-language disorders, as they have an impact on QoL¹³⁵. It was wiser to ensure early assessment and treatment in community-based individual or group programs, whenever there were any signs of speech mechanism dysfunction (tongue, laryngeal), even in non-dysarthric PwMS¹³⁶. The reason was that early intervention has been proven to be more successful in maintaining function and in learning alternative augmentative communication (AAC) techniques before functional, cognitive limitations and fatigue become more severe^{137,138}. How early speech intervention should be has remained unclear.

The type of intervention and goals should be determined on an individual basis, aiming at the acquisition of specific skills to achieve activities – intelligible verbal speaking, communicating – and to increase participation – at home, in the community^{138,139}. Retaining and improving intelligibility and naturalness are main goals in speech therapy for dysarthria in PwMS¹³⁹. It may be required to improve speech production and/or develop speech supplementation strategies in order to improve speech intelligibility¹³⁸.

It was reported that Resp and/or phonatory dysfunction improved with speech production in PwMS. Improving breath support in PwMS was usually intended for increasing force of expiration¹³⁹. This produced more syllables in one breath and talk for longer periods of time, provided that laryngeal, velopharyngeal and upper articulator valving were adequate 140. Increasing expiratory forces could be developed by means of exercises, biofeedback (for patients with low to moderate levels of response to stimuli), or prosthetic devices, if the former cannot be performed¹⁴⁰. For those with non-speech activity, programs for improving Resp support were available, such as the Lee Silverman Voice Treatment program, that has established behavior in a non-speech activity, followed by speech production¹⁴⁰. Improving Resp/phonatory coordination was especially suitable for ataxic PwMS or with involuntary Resp//phonatory movements, being unable to manage their Resp/and phonatory systems appropriately during speech. There were numerous strategies available for increasing the coordination and control of the Resp/phonatory system. Many of them entailed the patient's awareness about his/her speech- Resp/pattern and some form of auditory, visual or, occasionally, tactile feedback¹⁴⁰.

Enhancing phonatory functioning included treating hyper-adduction and hypo-adduction. The former aimed at enhancing harsh voice quality, which was often difficult to modify. The latter aimed at improving soft, breathy, whispered voice quality¹³⁹. The Lee Silverman Voice Treatment program aimed at increasing phonatory effort, and thus, vocal loudness, with an impact on improved intelligibility¹³⁹. This program has shown variable results in hyper-adduction phonatory functioning¹³⁹.

Reducing speaking rate is aimed at improving intelligibility. Controlling the rate could be achieved by means of external aids, such as finger tapping, a pacing board or a

metronome¹³⁹; or by using biofeedback systems. This system improved also speech naturalness. Exaggerating articulation was intended to enhance intelligibility¹³⁹. Increased loudness, in hypo-adduction phonatory dysfunction, and reduced rate were associated with increased articulator and acoustic working space, thus leading to an overall enhancement of articulation precision and acoustic distinctiveness¹³⁹.

It proved to be necessary to ensure ongoing evaluation of communicative function and teaching compensatory strategies for periods of exacerbation¹⁴¹. Some compensatory approaches considered were speech supplementation strategies, such as alphabet, and semantic or topic supplementation, gestures and syntactic supplementation; and AAC. In alphabet supplementation, the speaker identified the first letter of each word on an alphabet board. In topic supplementation, the topic was provided to listeners just before the message. Gestures or illustrators were movements that visually represented what was spoken verbally and may be made concurrently while speaking¹⁴¹. Syntactic supplementation provided information about the grammar or the word class (e.g., noun, verb, adjective) associated with each word spoken¹⁴¹. The best candidates for supplementation strategies were the patients with severe dysarthria that interfered with communication function in natural settings, had adequate pragmatic language skills and cognitive skills and sufficient motor function to generate cues¹⁴¹. A speaker's reduced cognitive function could be compensated by listeners' cognitive skills, in some circumstances¹⁴¹. The listener must be viewed as an active participant and his/her information and training were considered critical¹⁴¹. AAC required specific AT (See Assistive Technology) and should be conducted within the interdisciplinary team, taking into account all the factors implied: physical, sensorial and cognitive status, motivation and social context¹². There is little evidence on Sp for PwMS with DysA¹⁴².

Dysphagia

Dysph management was reported to be focused on impairment, and according to its pathophysiology¹⁴³. Swallowing therapy could be divided into methods of restitution, compensation and adaptation¹⁴³. At a mild stage, informing PwMS and their caregivers about how to identify swallowing in risk situations and its management was a required therapeutic step¹³⁴. PwMS with Dysph should be instructed about cough modulation and specific maneuvers to prevent material entering the airway. Hence, exercises aiming at the restitution of the different physiological phases of swallowing, such as tongue exercises and Masako maneuver (tongue holding) for impaired tongue base retraction; or exercises to increase reduced laryngeal closure, or exercises to maximize the hyoid or laryngeal elevation, such as the Shaker maneuver (repetitive head-raising exercise) should be taught to the patient¹⁴³. Instruction on compensation maneuvers should be included, such as head ante flexion, in the case of impaired tongue base retraction; and Mendelsohn maneuver (holding the upward movement of the larynx during swallowing for a few seconds), in the case of dysfunction of the upper esophageal sphincter¹⁴³. Staying in an upright position for one hour after feeding was intended to prevent material from entering the airway¹³⁴. Adaptation strategies to improve the swallowing process may include thickening of liquids, whenever there is diminished lingual control and laryngeal closure¹⁴³. Prolonged chewing was intended to avoid changes in food consistency¹³⁴.

Progression of Dysph leading to choking episodes, food retention in the pharynx, obstructive apnea and acute pneumonitis due to aspiration of bolus into the bronchial tree would signify a moderate level of Dysph¹³⁴. Besides the maneuvers described above this situation may require sensorial tactile and thermal stimulation of mouth and

faucial isthmus to improve PwMS' awareness of pharyngeal swallowing¹³⁴. Transient naso-gastric tube (NGT), or PG were indicated to preserve the patients' adequate caloric intake, if there were more than three consistencies of food penetration, or aspiration of more than one¹³⁴. In the event of NGT being needed for longer than 30-40 days, PG should be considered¹³⁴. PG did not totally prevent the risk of aspiration, as there was still the risk of saliva aspiration through insufficient suction of this. Caregivers should be instructed about safety strategies such as the Heimlich maneuver, in cases of choking¹⁴³. Tracheotomy was rarely indicated. It should be considered if the patient develops more than one episode of pneumonitis, due to saliva aspiration, or if he/she was threatened by choking, and the Heimlich maneuver had been unsuccessful¹⁴³. Tracheotomy itself showed different management difficulties for caregivers, in the long term¹⁴³. Sp for PwMS with Dysph both for liquids and solids, but in whom functional deglutition was achievable using compensatory strategies, has been useful to avoid aspiration¹⁴⁴.

Summary

There has been no general agreement about the most suitable stage to apply Sp for PwMS with DysA. There has been agreement that Sp should not be delayed in symptomatic PwMS, with speech activity. The type of intervention depends on the characteristics of the patient's impairment and disability. It is aimed at acquiring skills that may lead to improving speech intelligibility and naturalness, or to enhancing non-verbal communication. For PwMS with speech activity, the goal may include more intelligible and natural speech. This may require improvement of breath support, Resp/phonatory coordination, phonatory function, managing speaking rate and exaggerating articulation. For PwMS with non-speech activity, compensatory strategies

such as speech supplementation strategies and AAC are suitable. The listener is a key participant for improving communication among PwMS with non-speech activity, and informing and training him/her is critical for achieving this goal.

Dysph management includes informing and instructing PwMS and their caregivers about Dysph events and exercises, maneuvers, positioning, and dietetics, already at a mild level of Dysph. The goal is to prevent material entering the airway and Resp complications. At increased levels of swallowing dysfunction, a transient NGT or a PG may be required to ensure adequate feeding. There is evidence of the usefulness of Sp for PwMS to avoid aspiration.

5. Dietary interventions

Introduction

Dietary interventions could be broadly classified as dietary intake and supplementation. There has been extensive literature on dietary intervention for PwMS, especially supplementation with polyunsaturated fatty acids, allergen (gluten and milk)-free diets, vitamins, micronutrients and antioxidants, such as selenium, Ginko biloba extracts, and coenzyme Q10¹⁴⁵. There has been discussion about the role of vitamin D, either as dietary intake or as a supplement¹⁴⁶. Dieticians were reported as part of the multiprofessional team for PwMS²⁰ with the role of assessing special dietary needs for PwMS, planning dietary interventions, and providing nutrition counseling¹⁴⁷.

Aim

The aim was to report the effectiveness of dietary interventions in PwMS.

Results

Healthy eating recommendations, including advice for constipation, similar to those made to the general population were reported¹⁴⁸. Dietary supplements with high saturated fat content¹⁴⁸ and with proteins were recommended, as in other patients with malnutrition. Thickened fluids and a consistency-modified diet was necessary in case of dysphagia¹⁴⁸.

A systematic review on dietary interventions in MS did not reveal any effectiveness of the aforementioned dietary supplements at reducing disease progression and recurrence of exacerbations¹⁴⁵. It could not be proved that total vitamin D intake during adolescence would be associated with risk of MS in adulthood¹⁴⁶. Little evidence supports a therapeutic role for vitamin D in the treatment of multiple sclerosis¹⁴⁹.

Summary

Healthy eating similar to recommendations for the general population; dietary supplements for persons undergoing malnutrition, and consistency adaptation in case of Dysph were recommended.

Dietary supplements' effectiveness at decreasing the risk of disease progression and/or relapses could not be proven, and neither did full-fat milk intake reduce MS risk. There is no evidence for vitamin D supplements reducing risk of MS.

6. Expertise RHB Nursing interventions

Introduction

The nurse's role included providing support and information for PwMS and their significant others about body functions and body structure impairment, and its assessment and treatment pathways¹⁵⁰, shortly after the diagnosis and throughout the course of the disease; initiating preventive measures¹⁵¹; educating PwMS and their

caregivers about specific procedures, including social issues, about the acute and the long-term condition and related disability¹⁵¹, together with SW; promoting adjustment to the disease process, self-awareness and coping skills¹⁵², together with psychologists; handling technical aspects of care¹⁵¹; either in the hospital or community settings or home-based¹⁵² or over a webpage¹⁵¹. The following have been specific nursing care tasks, in the field of RHB: providing PwMS and caregivers with information and support on NLUTD's management⁹⁷, prevention and treatment of NBD impairment¹², counseling on sexual dysfunction¹⁵³, and education on compensatory strategies for Dysph.

Aim

The aim was to report the effectiveness of Expert RHB Nursing interventions in PwMS.

Results

It was reported that a nurse-led social RHB program, which included social education and home care, improved patients and caregivers' social life¹⁵². Regarding technical aspects, management of neurogenic lower urinary tract dysfunction (NLUTD) has required urine testing for excluding urinary tract infection (UTI), checking that post-voiding residual volume should not exceed 100 ml⁹⁷, while NLUTD was present, fluid schedule control, voiding techniques, including catheterization and clean intermittent self- catheterization (CISC) every 4 to 6 hours¹⁵⁴. Education and support by nurses with expertise in continence or by continence advisors should be provided in order for PwMS to perform CISC whenever post micturition residual volume exceeded 100 ml, according to guidelines⁹⁷.

Summary

Providing support and information in the early disease stage and during the course of the disease, promoting prevention measures, education of PwMS and caregivers as regards specific procedures, long-term conditions, disability and adjustment to disability status were tasks directly related to Nursing.

7. AT

Introduction

AT was defined as items, pieces of equipment or product systems used to maintain or improve functional capabilities of individuals with disabilities ^{22,155}. Taken from a broad perspective it could include orthotics²². AT that have been reported to be used by PwMS included ankle foot orthosis (AFO), dynamic AFO, power-harvesting ankle-foot orthosis (PhAFO)¹⁵⁶, which is a self-controlled, pneumatic power orthosis; and lightweight hip flexion-assist orthosis (HFAO), which was developed to compensate unilateral hip flexor weakness¹⁵⁷. FES could be considered an AT, besides a Ph tool, due to its orthotic effect¹⁵⁸ (See *Electrotherapy*). Mobility AT (MAT) included canes, crutches, walkers and/or wheeled walkers, manual wheelchairs, power-assist pushrimactivated wheelchairs, scooters, power wheelchairs 158. The Segway Personal Transporter is a self-balancing electric-powered transportation device that has been marketed as an alternative transportation device that can replace the automobile on short trips¹⁵⁹. It was suggested that it could be useful as a means of transport for PwMS with limitation in mobility¹⁵⁹. Devices for cognitive compensation included prompts, day timers and memory books, high-tech electronic devices, such as digital audio memory key fobs, smart phones with calendars, integrated task lists, electronic memory aids¹⁵⁵, personal digital assistants, and personal computers²². AT for ADL included AT for feeding, for self-care and adapting everyday life tools, such as scoop plates and weighted utensils^{22,96}. Visual image aids should have the magnification and contrast enhancement approach, as for other people with limited central vision 160. AAC required

specific material, such as voice amplifiers, with either digital or synthetic electronic voice output ²², and computer software that could replace some verbal skills.

Adaptations in the house included grab bars in the bathroom, bedroom modifications and environmental control systems²². Computer-based technologies were designed to enable PwMS to continue to work, learn and create²².

Aim

The aim was to reporting the utilization and effectiveness of AT for PwMS.

Results

AFO compensated for drop foot¹⁵⁸, but could stiffen the ankle joint, result in contractures of the plantar flexors⁹³, and decrease gait speed¹⁶¹. Further research is required about the effectiveness of PhAFO. HFAO improved gait speed and endurance ¹⁵⁷. The most frequent AT that PwMS used were mobility AT, mobility equipment¹⁶² and bathroom modifications^{155,162}. Wheelchairs, mainly manual wheelchairs, have been reported as being the most common MAT used by PwMS¹⁶³, and were positively correlated with duration of disease, age and awareness of the diagnosis¹⁵⁸. PwMS showed less efficacy using manual wheelchairs, leading to a lower speed of wheelchair propulsion and increased energy expenditure during wheelchair propulsion¹⁵⁸. There were controversial results regarding the efficiency of wheelchair use among PwMS. The arcing wheelchair propulsion pattern could be considered an energy conservation technique, and thus preferred by wheelchair–bound PwMS, despite being the least efficient propulsion pattern ¹⁶⁴. On the other hand, reduced efficacy of wheelchair propulsion could mean a problem among a population suffering from muscle weakness

and fatigability. The use of power wheelchairs was reported to enhance occupational performance, adaptability, increased self-esteem and energy conservation¹⁵⁸.

Image processing for visual RHB could be adapted from the systems used for people with central vision impairment. A Fresnel lens placed over the screen, either TV, computer or portable display could provide magnification, but with reduced clarity and contrast¹⁶⁰. Reduced contrast could be compensated with image enhancing¹⁶⁰. As for computer screens and some portable devices, an increased font size and additional light could be useful²².

Memory strategy devices, especially electronic memory aids, were reported as very frequently used, mainly by PwMS with fatigue and difficulty thinking¹⁵⁵.

Communication and cognitive aids proved very useful as compensating cognitive treatment, in different daily life activities, mainly at the place of work¹⁵⁵. However, O'Brien¹¹⁵ (2008) reported no significant benefits for using calendars, notebooks, diaries and lists, regarding memory or other cognitive impairment improvement with these devices¹¹⁵. Training in PC-based techniques could be used to treat permanent and selective alertness or activation of alertness, and it was reported to be useful to improve attention³⁰.

Service-delivery to provide suitable assessment about AT to PwMS and their caregivers required an interdisciplinary approach, addressing the user's skill, goals, support, resources and context¹⁵⁸, training PwMS and their caregivers and the appropriate professionals to use AT properly, and ensuring maintenance, repair or replacement of devices¹².

A survey reported that AT were used by 50 % of a MS sample¹⁶². PwMS that used AT showed a greater extent of disability and more frequentation of OT settings than PwMS

not using AT¹⁶². PwMS who were working did not use AT as much as those not working¹⁶². Johnson¹⁵⁵ (2009) reported that PwMS who were not using AT for cognitive compensation included older PwMS, less educated ones, those with higher disability and more depressive symptoms.

Summary

AT may help to substitute and compensate specific impairments and disabilities, either in mobility, cognitive dysfunction, ADL, instrumental ADL, at work, or others. Manual wheelchairs are the most common MAT among PwMS. However, power wheelchairs appear to be more suitable in order to improve activities and energy conservation.

Cognitive compensation has been of benefit, but it requires skills to use it. Visual compensating adaptations to TV, computer or portable display could be useful to improve vision.

8. Social Work interventions

Introduction

Social reintegration was defined as an individual's ability to do what he or she wants or has to, to his/her own satisfaction¹⁶⁵. Social support included the emotional, appraisal, informational and instrumental support provided to a person in need of support¹⁶⁶. SW could involve different approaches regarding disabled people, such as PwMS. SW could be considered as an expert guiding disabled people's problems towards a solution^{167,168} and helping people to adjust to society¹⁶⁹. Another approach supports SW's role of empowering people with disabilities to attain their own capacities and resources in the environment¹⁶⁹. Both approaches could be related to a SW's role of enhancing his/her clients' QoL¹⁶⁶. SW could be embedded in the healthcare system or act as counselors in

the community¹⁷⁰. Social reintegration and clients' empowering were reported in the literature by nurses and by SW as part of proactive services in which both professionals had competences^{152,169}. Social workers were envisioned by PwMS as agents of information of the resources available to the community¹⁶⁹.

Aim

To report on the effectiveness of interventions impacting on PwMS' social life.

Results

To achieve social RHB, it was reported that educational programs were required ¹⁵². These educational programs should include self-care resources, social contacts-activities, independence vs. disability, burden of care, adjustment, satisfaction communication, and behavior, and family functioning ¹⁵². The effectiveness of a social RHB program for neurological patients and their caregivers at improving their social life was reported ¹⁵². This effectiveness was due to promoting the increase of awareness and recognition of social needs, helping to cope through social education and information, and it took environmental factors into consideration ¹⁵².

Coping strategies that were used to deal with financial hardship significantly predicted psychological well-being beyond the prediction provided by economic parameters¹⁷¹. Proactive problem-solving coping strategies proved to be more effective than emotion-focused approaches to adjust to economic pressure and to improve QoL¹⁷².

Perceived social support occurred in PwMS with a higher level of mental health and QoL¹⁶⁶, interacted with uplifts to predict depression¹⁷³ and was related to positive rather than negative life events.

Summary

Proactive interventions, such as social RHB programs including education, information, self-care, social activities, and communication, were seen to be effective at enhancing patients' and caregivers' social life. Problem-solving strategies proved to be more effective for adjusting to economic pressure. Problem-solving strategies and perceived social support led to higher QoL.

9. Vocational Rehabilitation interventions

Introduction

VR has been used to refer to a multi-professional approach provided to individuals of working age with health-related impairments, limitations, or work-functioning restrictions and whose primary aim has been to optimize work participation¹⁷⁴. Since adult PwMS have undergone significant disruption in work participation, VR has been consistent with return to work (RtW) in this manuscript. VR was reported to be delivered jointly by health professionals, such as physicians, nurses; and non-health professionals, such as case managers or RHB counsellors¹⁷⁴.

Although around 90 % of PwMS had work histories¹⁷⁵, unemployment rates ranged from 23 to 80 % ¹⁷⁶⁻¹⁷⁹. Approximately 70% to 80% of PwMS were unemployed after diagnosis¹⁸⁰. Employed PwMS were reported to be two to threefold lower than the remaining general population¹⁶³. MS displayed a negative impact on the ability to remain in the workforce, since MS occurred among people during the peak years of employment¹⁸¹. It has however been reported that PwMS wish to RtW^{182,183}. The reasons could be that RtW meant material benefits and the maintenance of a preferred identity^{184,185}. Being engaged in desired occupations in a competitive employment has

being¹⁸⁷, and thus, to a better QoL when compared to those who leave the labor market¹⁸⁸. It thus proved to be important to RtW shortly after MS diagnosis¹⁸⁹. Despite this reality, few VR settings were available, as reported by Khan¹⁹⁰ (2006). To remain at work or RtW for PwMS has been observed to require physical, social and policy support, such as flexible working, rest periods, the necessary work adaptations and a social protection safety net that respond effectively to PwMS' needs and ensure

positive outcomes for health¹⁸⁶ and could lead to improvement in emotional well-

Aim

both accessibility and dignity¹⁶³.

The aim was to report on the effectiveness of VR interventions in PwMS, and factors influencing employment, work or work retention for PwMS.

Results

A systematic review of RCT³⁵ about the effectiveness of VR intervention on RtW and employment of PwMS found no conclusive evidence to support preventive or therapeutic, job retention or job re-entry VR programs for employed or unemployed PwMS, for methodological reasons. Further research is needed to identify which individuals are most likely to benefit from VR, and the most suitable VR type of intervention.

The factors that have a negative influence on RtW have been older age¹⁹¹, fatigue^{179,192-197}, cognitive^{180,198-201}, and mood disorders¹⁹⁰. There were controversial results regarding cognitive disorders and RtW. Smith¹⁷⁹ (2005) reported no significant association of cognitive disorders and RtW. The factor that showed positive influence on RtW was higher education level^{202,203}. Regarding the environment, attitudes of

people in positions of authority²⁰⁴, employers' attitudes toward employees with MS and co-workers' misconceptions about MS have affected PwMS RtW^{180,205}, acting as barriers. Availability of products and technology for education could act as a facilitator²⁰⁴. Employment policies facilitating RtW instead of disability pensions, and adapted transport could act as a facilitator²⁰⁴.

Summary

Although there is little conclusive evidence to support different types of VR interventions for methodological reasons, several issues could be drawn from evidence. Age, fatigue, cognitive and mood dysfunction were determining factors for decreasing RtW. A high education level is a positive influencing factor. Different environmental factors may act as facilitators for PwMS RtW, such as availability of products and technology for education, and employment policies, or as barriers, such as attitudes of people in positions of authority, employers, and co-workers.

III. Comprehensive information and education for patients, their significant others, and caregivers.

Introduction

Information for PwMS, their significant others and caregivers has a preeminently educational approach, with self-management implications, besides an ethical purpose. PwMS have shown that they wish be fully informed about their disease, especially those with minimal and mild disease impact²⁰⁶, irrespective of their participation role preference²⁰⁷. Significant others are also involved in the management of the disease and disability impact and thus require being informed²⁰⁸. Caregivers may need information and education on specific tasks to support adequately and to avoid injury to people they

care for and to themselves^{28,209}. Information is required for planning measures regarding needs for PwMS and their significant others²⁸. Initial delivery of information does not automatically entail understanding²⁰⁸, especially in the peri-diagnostic period, leading to an added psychological burden, impact on disease management²⁰⁸, and additional consultation²⁰⁷.

Information could be delivered as educational material, such as books, booklets, articles, guidelines, webpages, videotapes, reports; as direct information from the multiprofessional team⁷⁷; and included in health promotion education programs²¹⁰. The National Institute for Health and Clinical Excellence (NICE) guideline for MS⁹¹ (2004) is in agreement with the information process, since it has indicated that an educational program should be provided within 6 months of diagnosis, and its information is aimed at PwMS, besides health professionals. Webpages of international associations of national MS societies, such as the European Union MS Platform (EUMSP)¹⁶³, or federations, such as the MS International Federation (MSIF)²¹¹, professional organizations, such as CMSC²¹², different MS Societies, at national level, such as the National MS Society (NMSS), from the US²¹³, from Canada²¹⁴, and from the United Kingdom²¹⁵ are available. Documents in pdf format from international organizations, such as the Pocket guide of Code of Good Practice in MS¹⁶³, from the EUMSP, and Principles to Promote the Quality of Life, from the MSIF²¹¹ can be downloaded over the Internet.

Aim

The aim was to report on the impact of MS information and education delivered to PwMS, their significant others and caregivers.

Results

It was reported that optimizing the information process with relevant and understandable information was important as it may induce coping styles 109, be useful for planning possible future needs²¹⁶, to enhance PwMS' participation in healthcare²¹⁷, and satisfaction with care²⁰⁷. An information aid added to usual practice in communicating the MS diagnosis revealed good disease knowledge and satisfaction with care after the first month among PwMS in the intervention group²⁰⁷. There was agreement that information should be delivered in early stages 109,217, even for PwMS with cognitive impairment²¹⁷. It was reported that PwMS with perceived cognitive impairment found that information on cognitive deficits was relevant and did not increase fears²¹⁷. This information was found not so relevant by the PwMS without cognitive impairment²¹⁷. A study about the impact of information on PwMS' planning of future measures for care needs showed that PwMS with more severe impairment and of an older age took more measures for care needs than those in early stages²¹⁶. These were results of a survey about available information on MS and future needs, among PwMS from a US MS society²¹⁶. PwMS answered that most of them had received information on MS and future needs from formal sources²¹⁶. However, only a small proportion of them had received information about independent living and long-term care needs²¹⁶. Results from a prospective study, using a questionnaire, at an outpatient setting in Sweden, showed that PwMS considered that information on social insurance/VR was something needed and insufficient²¹⁸. Health promotion education programs were seen to improve mental health and general health, and certain domains of HRQoL and QoL^{210,219}, either in group format²¹⁰or as scheduled telephone counseling sessions²²⁰.

Summary

Educational material, direct information from the multiprofessional team, and information included in health promotion education programs has been reported. Specific educational material, such as information aid added to usual practice in communicating the MS diagnosis, has been observed to improve PwMS knowledge about their disease and satisfaction about care. Early information delivery should be provided and no psychological adverse effects have been reported, even among those with perceived cognitive impairment. PwMS with more severe impairment and of older ages appear to be more engaged with measures for long-term care needs than those in early stages of the disease. Information about independent living and long-term care needs, social insurance and VR may be insufficient. Health promotion education programs have enhanced mental and general health and certain domains of HRQoL and OoL, but no direct relationship of information to the results has been defined.

IV. Case management.

CM is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes²²¹. CM has been viewed as a type of intervention that may be suitable for people with complex and disabling health processes and that may require different service delivery across the health services, since it is a case manager's role to facilitate accessibility to services and continuity of care²³. This role included both the acute phase¹⁴⁷ and the long term stage²²² of chronic diseases, such as MS. The case manager was considered as the professional helping the individual to obtain community resources and information from the community²²³. CM could be delivered by organizations²²⁴ or by individuals, and these could come from a variety of disciplines, especially from nursing^{23,225}, social

work 169,225, RHB counseling 225, and OT. The patient and the case manager were expected to establish an employer-employee relationship, where the former decided from the options that the latter could offer him/her. The case manager's role has included the patient's pre-admission evaluation to assess the most suitable service delivery and RHB setting according to the patient's needs¹⁴⁷. This assessment was described as a review of the patient's medical record and health history¹⁴⁷, highlighting the patient's impairment, disability, age, and co-morbidity¹⁴⁷. Complex treatment plans with attainable timed goals should be developed by the case manager¹⁴⁷ in agreement with the patient and his/her significant others and should be established in the admission process¹⁴⁷, according to guidelines²²². The patient's discharge potential could be previewed in order to plan the discharge process. Financial management of the stay in the RHB setting was reported as part of the managerial role¹⁴⁷. Discharge planning and further interventions on an ongoing basis, including information and education for the patient, his/her significant others, and caregivers, as well as environment adaptations¹⁴⁷, and vocational counseling were part of the case manager's role. CM included providing delivery of health promotion programs by forming partnerships with other organizations in the community, if needed²²². It was also its commitment to assist patients and their significant others in negotiating with the healthcare system through transitions²²². Ongoing follow-up should be part of the case manager's role in order to detect new needs and plan appropriate interventions, in the framework of a healthcare and counseling continuum²²². CM was reported to require information on and accessibility to healthcare and counseling providers, availability of clinical information systems in order to coordinate care and counseling across settings, within the healthcare system, and in the community²²², in order to provide the most appropriate resources at the right time. Related to this broad spectrum of roles, there

has been a lack of standardization which may lead to role conflict and ambiguity, overload, and effects on their role performance²²⁵. This collaborative process has not been fully integrated in MS RHB healthcare and counseling in different geographic areas. The former two issues may be some of the reasons for the lack of relevant publications on effectiveness of case management's interventions in MS.

Summary

CM has been considered a process aiming to provide the most suitable accessibility to healthcare and community resources for people with acute and especially, chronic diseases, in a continuum management. The case manager is expected to assess, plan and provide information, education and resources to the patient, who is promoted to be a self-managed and proactive client deciding from the options that the case manager can offer him/her. CM for PwMS across healthcare continuum and counseling, in different geographical areas, is not yet fully provided. Research on effectiveness of CM interventions on PwMS outcomes and their accessibility to suitable resources and ongoing requirements is needed.

V. Impact of interdisciplinary Rehabilitation interventions and paramedical Rehabilitation packages of comprehensive care components on body function and body structure impairment, on activities, participation, and health-related quality of life and on quality of life.

Introduction

IRHB interventions and paramedical RHB packages of comprehensive care components have aimed at decreasing impairment, and improving PwMS' level of activities and

participation, and also at having an impact on HRQoL and on QoL. . Body function and body structure impairment included in this manuscript consistent with a previous publication (Martinez-Assucena 2010 pending of editor's acceptance).

Aim

The aim was to report the effectiveness of IRHB interventions and paramedical RHB packages of comprehensive care components at improving body function and body structure impairment, activities and participation, and on HRQoL and on QoL of PwMS.

Results

1. Impact on body function and body structure impairment

Fatigue. There were controversial results regarding modification of fatigue after RHB programs that were exercise training-based. PwMS neither underwent increased fatigue in a mild-moderate MS group taking a short-term exercise program⁶¹ nor was physical fatigue modified by TE^{57,71,75,226,227}. However, some authors reported that fatigue improved after endurance exercise training^{66,68}, after a resistance exercise training program⁵⁹, after an endurance and resistance exercise training program^{56,68,81}, and after a multidisciplinary RHB program that included TE^{65,228}. Improvement in fatigue during or after TE was associated with improvement in depressive disorders⁶⁵. A multidisciplinary RHB program including strength and mobility exercises, aquatic therapy and balance training did not produce any improvement in Fatigue Severity Scale (FSS) scores³⁸. Energy conservation courses showed promising results, regarding improvement in fatigue^{105,111-113} (See *Occupational Therapy*). Some authors have reported improvement of fatigue after self-management interventions^{108,113}, despite

previous controversial results¹¹⁴. An education and self-management-based multidisciplinary RHB program proved to improve FSS scores⁶⁵.

Weakness. This improved with endurance exercise in mild-moderate impaired PwMS (EDSS < than 7)^{25,38,57,60,68}. Resistance exercise programs have been shown to improve strength, increasing leg extensor power^{57,79,229}. There was no evidence supporting electrical stimulation for increasing voluntary muscle strength in PwMS^{229,230}. Despite these results, exercise training may neither reverse nor stabilize weakness as a consequence of altered central motor drive²³¹.

Decreased tolerance to exercise and cardiovascular and respiratory dysfunction

TE improved tolerance to exercise^{57,70}, maximal aerobic capacity^{69,70}, muscle strength^{57,69,71,232} and muscle endurance^{57,74}. Endurance exercise improved maximal aerobic capacity^{69,70} and muscle endurance^{57,74}. Resistance exercise improved muscle strength^{57,69,71,232}. A short-term moderate exercise program improved peak oxygen consumption (V'O_{2peak}) and anaerobic threshold (physical fitness), among PwMS with mild disability (EDSS < 4)⁵⁸. A long-term exercise course improved exercise tolerance, in a mild-moderate disabled MS group⁶⁸. PwMS decreased anaerobic threshold in a mild-moderate MS group undergoing a short-term exercise program⁶¹, reaching the same levels of recovery as healthy untrained people.

Sensory disorders

Further research is required to define which RHB interventions are effective at improving sensory disorders.

Pain syndromes

Positioning and weight transfer were beneficial for painful tonic spasms and pain associated with spasticity⁵³.

Spasticity and other signs of upper motor neuron syndrome

Spasticity was reported neither to improve nor to worsen after endurance exercise training⁶⁶, while there was some evidence of benefit with range of motion exercises⁵⁰. There was some evidence of positive effects of stretching, in the short term⁹⁵.

Ataxia and tremor. Ph was found to be safe and improved outcomes by small amounts, although treatment effects might not be sustained^{83,85}.

Balance disorders and postural control disorders. A systematic review by Rietberg⁵⁷ (2005) reported that balance time improved with exercise training in a systematic review. PCD has improved with endurance exercise in mild-moderate impaired PwMS (EDSS < than 7)^{25,38,57,60,68}.

Gait disorders. Gait speed improved after a long-term resistance exercise program, in mild-moderate PwMS⁶². Other authors have reported that gait has improved with endurance exercise, in mild-moderate impaired PwMS (EDSS < than 7)^{25,38,57,60,68}.

Visual impairment.

Further research is required to define which RHB interventions are effective at improving visual impairment in PwMS.

Pelvic floor muscle dysfunction.

PFM training in women with MS led to an improvement in endurance²³³, and in voiding and storage symptoms, and thus to reducing the number of incontinence episodes^{233,234}.

No changes in urodynamics were detected regarding maximum flow rate and post-void residual volume^{233,234}.

Neurogenic lower urinary tract dysfunction.

A comprehensive multidisciplinary RHB program²³⁵, consistent with recommended continence management guidelines^{97,236}, has been shown to significantly improve urogenital distress in the intervention group, while those in the control group deteriorated in these conditions²³⁵.

Neurogenic bowel dysfunction.

Abdominal massage was reported to be effective at increasing frequency of defecation 98.

Sexual dysfunction

Educational written material improved primary sexual dysfunction among women with mild-moderate MS, while this material plus face-to-face and telephone support brought about an improvement in persons with tertiary sexual dysfunction¹⁵³. Further research is required to define which RHB interventions are effective at improving sexual dysfunction in PwMS.

Autonomic dysfunction

External cooling, including cooling-garment technology, was developed to compensate thermosensitivity^{237,238}. Cooling-garment technology in PwMS performing physical exercise allowed HR variability similar to the healthy control group²³⁷, avoiding incremental core temperature. It may help to improve weakness, walking and dexterity²³⁷.

Neuropsychological and neuropsychiatric impairment

Thomas¹¹⁹ (2006) reported that there were no conclusive results on NeuroPsy and Psy interventions, due to methodological issues. More recently cognitive interventions for learning and memory and for executive functioning have proven to be of benefit for tasks performance^{127,128}.

The purpose of Psy interventions was either to treat depressive disorders or to enhance PwMS' strategies to cope with disease and disability¹¹⁹. It was suggested that PwMS with depressive disorders could improve after a cognitive behavior-based adjustment intervention²³⁹. Coping strategies have been of benefit to deal with MS and related disability¹²², while self-efficacy strategies have been recommended to adjust to the changing health status⁷⁸. TE^{57,59,69}, short-term Ph program⁸³, and HT^{49,51} showed some benefit on mood.

Dysarthrophonia

Little information has been found as to the outcome of Sp interventions with PwMS¹⁴².

Dysphagia

PwMS with unsteady aspiration, or with Dysph both for liquids and solids, but functional deglutition achievable using compensatory strategies, prevented aspiration using compensatory strategies such as postural changes, modification of the amount and speed of food presentation, and change in food consistency¹⁴⁴.

Respiratory dysfunction

Expiratory muscle training tended to enhance both inspiratory and expiratory muscle strength and significantly improved the objectively and subjectively rated cough efficacy, which lasted for 3 months after training cessation²⁴⁰.

Sleep disorders

Further research is required to define which RHB interventions are effective at improving sleep disorders.

1. Impact on activities:

There has been strong evidence that increased levels of activity and participation have taken place during inpatient multidisciplinary RHB, albeit of short duration²⁶. Khan³⁵(2008) showed that PwMS in the intervention group of a long-term inpatient comprehensive multidisciplinary RHB program improved significantly in transfers, locomotion and self-care, measured with Functional Independence Measurement (FIM)³⁵. Freeman³³ (1999) reported that a short-term inpatient RHB program improved disability and handicap, and that the gains lasted for up to 6 months in both disability and handicap³³. Mild-moderate disability PwMS in the intervention group of a short-term, inpatient multidisciplinary RHB program showed an improvement in ADL and mobility, comparing functional status at admission and at discharge, measured with Barthel Index and Rivermead Mobility Index³⁴. Despite most of the authors' agreement on the effectiveness of short-term inpatient multidisciplinary RHB, in a systematic review, Khan²⁶ (2007) showed that there was limited evidence that high-intensity outpatient and home-based RHB programs improved impairment, disability, and participation²⁶. Storr³⁶ (2006) found no beneficial effect of multidisciplinary RHB

program with mild-severe PwMS (EDSS < 9) on activity measured with Guy's Neurological Disability Scale.

A comprehensive multidisciplinary RHB program²³⁵ consistent with recommended continence management guidelines^{97,236} was seen to improve participation restriction in the intervention group²³⁵.

Fig. 1. Impact of IRHB interventions on impairment, activities, participation, HRQoL and on QoL.

A short-term Ph program was found to significantly improve FIM scores for self-care and mobility in a MS mild-moderate group, with 15 weeks carry-over⁸⁴. On the other hand, Romberg^{62,82} (2004, 2005) reported that PwMS in the intervention group of a short-term inpatient RHB program combined with a long-term home-based exercise program improved in gait speed⁸², but no changes in disability were found scored with EDSS or with FIM⁸².

Increases in exercise behavior correlated to less accumulation of functional limitations²⁴¹. There were controversial results regarding the impact of exercise training on improving **mobility**. Most of the authors reported that exercise training improved mobility^{44,57,67,83}, although improvement might be small in walking mobility and over a brief period of time²⁵. Romberg⁸² (2005) reported improvement in impairment but no correlation with improvement in disability after a long-term resistance and aerobic exercise program⁸². In agreement with these findings, Broekmans²²⁹ (2010) reported that improvement in leg extensor power did not lead to enhanced mobility²²⁹. However, PwMS undergoing a short-term Ph program gained improved mobility⁸³. HT facilitated mobility during immersion and increased participation in leisure activities^{49,51}.

Fig.2. Impact of Ph and TE on impairment, activities, and HRQoL and on QoL.

Fig.3. Impact of Ph on impairment.

Educational material alone or added to counseling improved interpersonal relationships with partners among women with mild-moderate MS with primary and tertiary sexual dysfunction¹⁵³.

Self-efficacy improved after self-management education interventions^{78,108} leading to increased adjustment (Psy, social, and physical)⁷⁸.

2. Impact on health-related quality of life and on quality of life

A short-term inpatient RHB program improved emotional well-being and HRQoL, and the gains lasted for up to 7 months for emotional well-being, and up to 10 months for HRQoL³³. Improvement in HRQoL concerning general health and vitality was reported in a group of moderate PwMS, in a short-term inpatient neurorehabilitation program³⁸. There was limited evidence that high-intensity outpatient and home-based RHB programs improved QoL²⁶. On the other hand, there was strong evidence that low-intensity and long-term outpatient programs increased longer-term gains in QoL^{26,69}. A comprehensive multidisciplinary RHB program aimed at improving continence self-management²³⁵ has been shown to improve OoL significantly ²³⁵.

There was general agreement that TE training improved QoL among mild to moderate PwMS^{58,69,241,242}, and even, severe PwMS⁶³. A short-term moderate exercise program among mild PwMS⁵⁸, and a long-term exercise course, in a mild-moderate disabled MS group⁶⁸ improved QoL. On the other hand, Romberg⁸² (2005) found no impact on QoL after a long-term exercise program. Inpatient Ph interventions improved fatigue during and shortly after delivery²⁴³. This improvement was suggested to be related to factors

other than improvement in physical performance, such as psychosocial factors²⁴³.

Improved health-related fitness after TE has a positive correlation with HRQoL²⁴¹.

Energy conservation courses have improved HRQoL (physical, mental health and social functioning)¹⁰⁵. Decreased fatigue impact after self-management education interventions have led to increased HRQoL¹⁰⁶.

Self-efficacy led to adjustment to the disease and adjustment was associated with subjective well-being. 244,245. Social support has been observed to improve PwMS' and caregivers' QoL²⁴⁴. Social support has proved to decrease the negative impact of NeuroPsy impairment on HRQoL²⁴⁴. Healthcare information on disease was positively correlated with QoL, among a sample of Japanese PwMS²⁴⁶. Education for self-management 106 and health promotion programs 210 have been associated with an increase in HRQoL, in mental and general health domains. Limitations to accessibility and use of healthcare providers and facilities have had a detrimental impact on QoL²⁴⁵.

Fig. 4. Impact of IRHB interventions, Ph, OT, NeuroPsy and Psy interventions, Social interventions, Information and education, and limitation in accessibility on HRQoL and OoL.

Summary:

There are controversial results regarding whether RHB programs with TE improve fatigue. Energy conservation courses and multidisciplinary education and self-management-based RHB programs have improved PwMS' fatigue impact. Endurance and resistance exercise have been shown to improve weakness in mild-moderate PwMS. Nonetheless, whenever weakness becomes a consequence of altered central motor drive, exercise may not improve weakness. Either short or long-term TE improves tolerance to

exercise and some components of physical fitness among mild-moderate PwMS. Endurance exercise improves maximal aerobic capacity and muscle endurance, and resistance exercise improves muscle strength. Stretching has been useful for spasticity in the short term. There was a modest improvement in ataxia with Ph, in the short term. Gait speed is shown to improve with exercise training. A comprehensive multidisciplinary RHB program, consistent with current continence management guidelines for PwMS with continence disorders, has been shown to improve urogenital distress, while its absence has been shown to be detrimental for these patients. Pelvic floor training and neuromuscular stimulation improved UI. Abdominal massage has proven to be useful for increasing the frequency of defecation. Primary and tertiary female sexual dysfunction improved with counseling that included educational material and face-to-face and telephone support. External cooling and cooling garments have been useful for compensating thermosensitivity among PwMS with AD. NeuroPsy interventions have given promising results regarding improvement in executive functioning, verbal learning, and memory performance; there were controversial results regarding the benefit of cognitive behavior techniques to improve fatigue. Psy interventions combined with drugs are the gold standard for severe depressive disorders. Psy interventions to increase self-efficacy have been useful for psychosocial adjustment, and have given promising results for fatigue management. Compensatory strategies, including postural changes and dietetic measures for Dysph have proven to be effective for avoiding aspiration. Expiratory muscle training improves cough efficacy. There are controversial results as regards improvement of mobility with multidisciplinary RHB programs, with Ph, and with exercise training. An RHB program for continence management improves participation. Educational material and counseling improved interpersonal relationships among women with sexual dysfunctions. A comprehensive

multidisciplinary RHB program for continence management, and exercise training among mild to severe PwMS has led to enhanced QoL. Energy conservation courses, coping strategies, self-efficacy strategies, social support, information, education for self-management and health promotion courses have a positive association with HRQoL and QoL. Limitation to accessibility and use of healthcare providers and facilities is negatively associated with QoL.

VI. Accessibility and use of Rehabilitation services

Introduction

Use of health services is, according to the International Classification of Functioning (ICF), an environmental factor that might have an impact on functioning and disability, as a facilitator or as a barrier²⁴⁷.

Aim

The aim was to report on the accessibility and use of RHB services by PwMS

Results

In Finland, local authorities are mainly responsible for the arrangement of RHB services, in accordance with the Disability Service Act. The Social Insurance Institute is responsible for severely disabled individuals under 65 years of age, regarding inpatient services. The Service Act includes services such as RHB guidance, adaptation training, and personal assistance. Non-governmental service providers, as stakeholders, are cooperating with the regional authorities in the social welfare and health sector through their inpatient and outpatient centers. One of the main service providers is the Finnish MS Association with its Masku RHB Centre. The municipalities have to provide

transportation services, if needed. People who require round-the-clock assistance for housing are entitled to access housing services (personal communication with Professor J Wikström 2011). In the United Kingdom (UK), the National Health Service in each nation is a publicly-funded healthcare system, though there are charges associated with many aspects of personal care. Despite NICE guidelines for MS recommendations, it was reported that over 50 % of PwMS in England and Wales were unable to access RHB services²⁴⁸. This data confirmed the results of a study in England on accessibility to community services, showing that 45 % of PwMS received healthcare assistance only from the General Practitioner and 39 % of PwMS with moderate and 12% with severe disability failed to receive community services²⁴⁹. These results were in agreement with those of a survey in the US, where 53 % of the respondents had unmet needs for RHB services²⁵⁰. In the US, it was reported that healthcare funding sources provided disparate coverage for physical RHB services to persons with chronic and disabling conditions, including MS²⁵⁰. People with chronic and disabling conditions such as MS were more likely to receive physical RHB services depending on the following aspects: having Medicaid funding, higher household incomes and better health status²⁵⁰. A survey in the Midwestern US showed that PwMS living in urban or suburban areas, suffering from spasticity that interfered with ADL, involving difficulties with moving around inside the house, experiencing hospitalization in the past 6 months, and having a family physician, had a higher predisposition to use physical therapy services²⁵¹. Cost and physical accessibility were the primary factors making it difficult for PwMS to access physical therapy services²⁵¹. Canada has a predominantly publicly-financed health system with delivery effected through private (profit-making and non-profit-making) and public (arm's length and direct) channels, also affecting RHB services²⁵². Healthcare in Australia is provided by both government and private institutions. The public health

system ensures free universal access to hospital treatment and subsidized out-of-hospital medical treatment. The private health system is funded by a number of private health insurance organizations. Insufficient RHB opportunities, gaps in the continuity of care and assistance with transport to RHB have been reported ²⁵³. In Pakistan, there has been no government-sponsored health insurance scheme, but private health insurance has been available for the few who could afford it. PRM services were scarce, situated in urban areas, and there was a lack of transport for disabled patients. However, military hospitals have fostered RHB services within their settings, and local initiatives developing multidisciplinary programs were also reported ²⁵⁴.

Specific utilization of services among PwMS with specific features was reported. PwMS with mild disability and fatigue used more outpatient care, primary care and RHB than those without fatigue²⁴⁷, fatigue being related to more utilization of overall healthcare services²⁴⁷. Moderate-severe disabled PwMS without fatigue used OT services in primary care more frequently than those with fatigue²⁴⁷.

Women with education levels over high school, with inadequate income, experiencing pain, and less ability to perform ADL than the previous year were likely to report unmet need for health promotion and wellness services²⁵⁵.

Summary

Different reasons may underlie the fact that accessibility to RHB services by PwMS has not been universal in different countries. Different coverage of public healthcare, availability of RHB services, adequacy of RHB resources, continuity of assistance, availability of transport to RHB services among countries like Finland, the UK, the US,

Canada, Australia or Pakistan have marked inequalities among PwMS, as with other chronic and disabling conditions, these being much huger in the developing countries.

The fact that moderate-severely disabled PwMS without fatigue used more OT services at primary care was encouraging. It could be due to the fact that these patients were more able to benefit from the RHB modality in primary care than those with fatigue.

PwMS with mild disability and fatigue proved to be high healthcare service consumers.

VII. Conclusions

The results support IRHB interventions and single RHB packages of comprehensive care' components reported in this review as effective strategies and tools for some features of body function and body structure impairment, activities and participation, and for enhancing HRQoL and QoL for clients with MS.

The clients' profile that has shown most benefit from IRHB interventions is an individual with RR MS, and mild-moderately impaired. On the other hand, the profile that has shown least benefit from these interventions in improving activities and participation has been an individual with cognitive dysfunction and/or ataxia, with severe impairment and/or long-term disease duration.

Some RHB interventions cannot fail to implement RHB programs for PwMS, due to the detrimental effect that would be caused by excluding these, despite insufficient evidence-based literature demonstrating their effectiveness. This is the case of CISC to prevent UTI and of compensatory strategies, including dietetic measures, to prevent aspiration, as for other chronic neurological conditions.

The results defeat the conclusion that RHB interventions improving specific impairments lead to improvement in activities and participation and on HRQoL and on

QoL. They furthermore fail to indicate that improvement in specific activities is underpinned by improvement of all specific impairments related to that activity.

Other interventions, such as symptomatic pharmacological treatment and visuo-propioceptive RHB programs, are considered to fall under the medical scope in most countries, and are delivered either by PRM physicians¹⁴, Neurologists or others. These have been reported elsewhere ^{12,15,256-258}, and fulfill many of the gaps in RHB interventions for body function and body structure found in this overview.

We may conclude that there are very different numbers of articles written on RHB interventions for different body function and body structure impairments, different activity limitation and participation restriction, and on their impact on HRQoL and on QoL. This may in some aspects reflect the areas of researchers' interest rather than clients' and their significant others' most important perceived problems and needs. Actions on environmental factors may be a key to enhancing the effectiveness of RHB interventions for clients with MS, and continue to be an opportunity for the authors to further review this issue.

The importance of the different professionals within the RHB team, and the importance of stakeholders, delivering services and policies in an interdisciplinary approach may be inferred from the results. We may gather that there is a need in healthcare and non-care systems to deliver services in a client-oriented direction, which means changing the clients' role from object to subject, and placing customers and their significant others in the center of these services.

We may conclude that the accessibility of clients with MS to the broad frame of healthcare and non-care resources is still a challenge in the so-called developed countries, this accessibility to resources remaining very far off for the enormous group of individuals with special needs in the developing countries.

Strengths of this study: This overview is supported by a review of the literature that has included 6 Cochrane systematic reviews, 4 meta-analysis, 4 systematic reviews, 3 consensus guidelines, 6 consensus documents, and 18 RCTs. Most of the RHB interventions suitable for PwMS, their impact on activities and participation, and on HRQoL and QoL, have been reported from a broad perspective.

Limitations of this study: Not being a systematic review, the selected database and language may have induced bias regarding included and excluded articles' relevance. Actions on environmental factors have not been thoroughly reported.

Implications for research. Further research is needed on neuroprotection and repair therapy²⁵⁹, such as mesenchymal stem cell transplantation¹⁰.

Further research is needed in order to determine the most suitable RHB interventions for sensory disorders, ataxia and tremor, visual impairment, sexual dysfunction, DysA, and sleep disorders among PwMS. There is a need to detect the effectiveness of HT, ET and Sp for PwMS. It is necessary to detect the impact of NeuroPsy and Sp interventions on improving communication, HRQol and Qol; the impact of compensating interventions for Dysph on HRQoL and QoL, the impact of TE on reducing Resp complications and related QoL; the impact of interventions for depressive disorders on social participation; the impact of AT on activities and QoL; the impact of VR and CM on RtW, and on detrimental financial issues; the impact of HT, Psy, and of Social interventions on social participation, including leisure and social relationships, and on HRQoL and on QoL; of information and education on decision-making; and of CM on continuum of care among

PwMS. Further research on MS risk factor intervention, such as lack of vitamin D₃ with

dietetics or with other therapy, is required.

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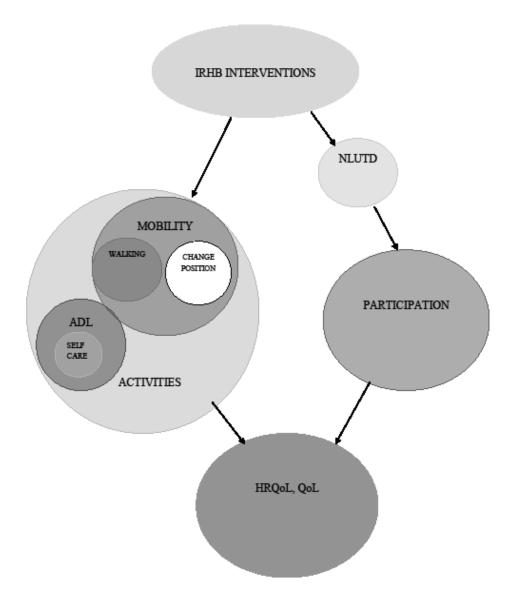
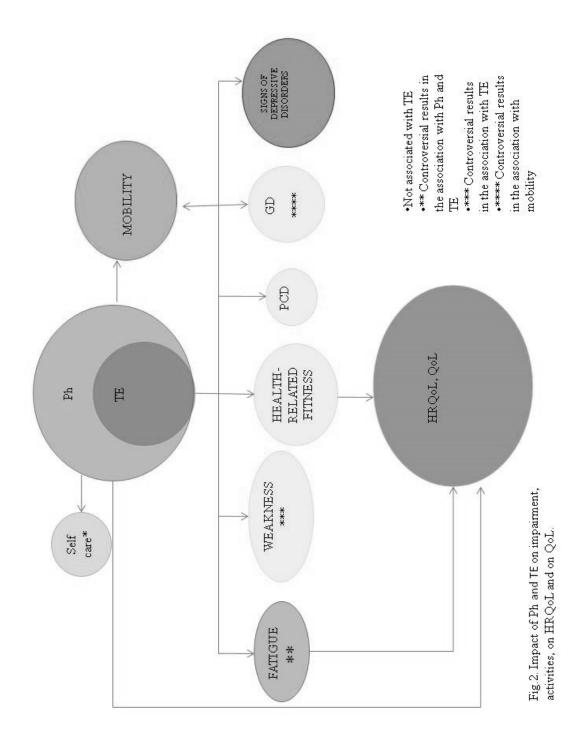


Fig. 1. Impact of IRHB interventions on activities, participation, on HRQoL and on QoL.



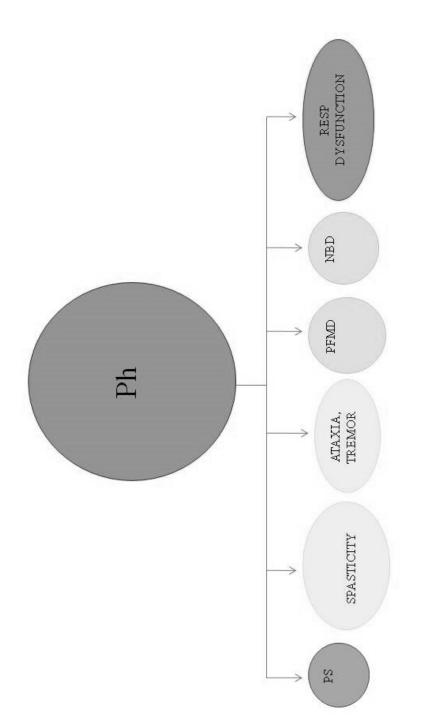


Fig. 3. Impact of Ph on impairment.

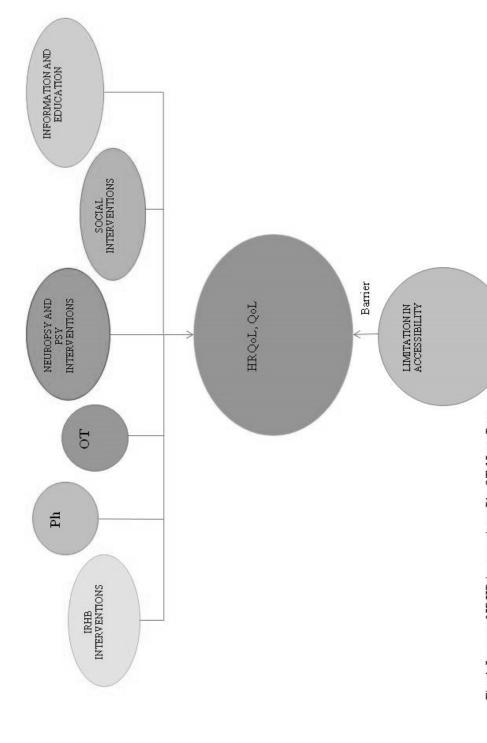


Fig. 4. Impact of IRHB interventions, Ph. OT, NeuroPsy and Psy interventions, Social interventions, Information and education, and limitation in accessibility on HRQoL and on QoL.

APPENDIX

IMMUNOMODULATOR AGENTS, ADDRESSED TO PwMS WITH DIFFERENT PROFILES, EXPECTED BENEFITS FOR PwMS, AND ADVERSE EFFECTS

Source: based on Nicholas¹¹ (2007) and Wiendl⁶ (2008).

Interferon β (IF), hepatotoxicity (HepT), alergic reactions (AlR), progressive multifocal leukoencephalopaty (PML), opportunistic infections (OI), aseptic meningitis (AM), cardiomyopathy (CardM), treatment-related leukemia (TRL), autoimmune disorders (AID)

PHARMACEUTICAL	PROFILE	EXPECTED	ADVERSE
NAME	GROUP	BENEFITS	EFFECTS
Interferon β (IF)	PwMS at risk of	Reduces this risk	HepT, flu-
	CIS resort to		syndrome
	CDMS		
Glatiramer acetate	RR MS	Similar to IF	Self-limiting AlR
Natalizumab	Highly active	Significant	PML, OI
	RR MS non-IF-	reduction of lesions	
	responding	in MRI	
IV immunoglobulins	During	Reduction in annual	AM, AlR
	pregnancy	relapse	
Mitoxantrone	Highly active	Reduction in annual	CardM, TRL
	RR MS, PR MS	relapse, in sustained	
		disease progression,	
		reduced disability	
		scores	
Azathioprine	2nd line for RR	Reduction of lesions	PML, OI, other
	MS	in MRI	AID
Plamapheresis	Highly active	If other drugs have	No serious adverse
	RR MS non-IF-	failed. not	effects
	responding	recommended as	
		permanent therapy	

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