

PROGRESS ON MS REHABILITATION: EVIDENCE & RIMS ACTIVITIES

EMSP Annual conference 2014

Peter Feys, Hasselt, Belgium

Ass. Prof. Rehabilitation Sciences & Physiotherapy
RIMS president



multiple sclerosis
international federation



Programme co-funded by the
EUROPEAN UNION



Part I. Evidence update

Part II: RIMS activities



UNDER PRESSURE

Living with MS in Europe

EMSP 2013

Controversies in Multiple Sclerosis

Rehabilitation therapy in MS: a short-term, expensive, placebo: Commentary

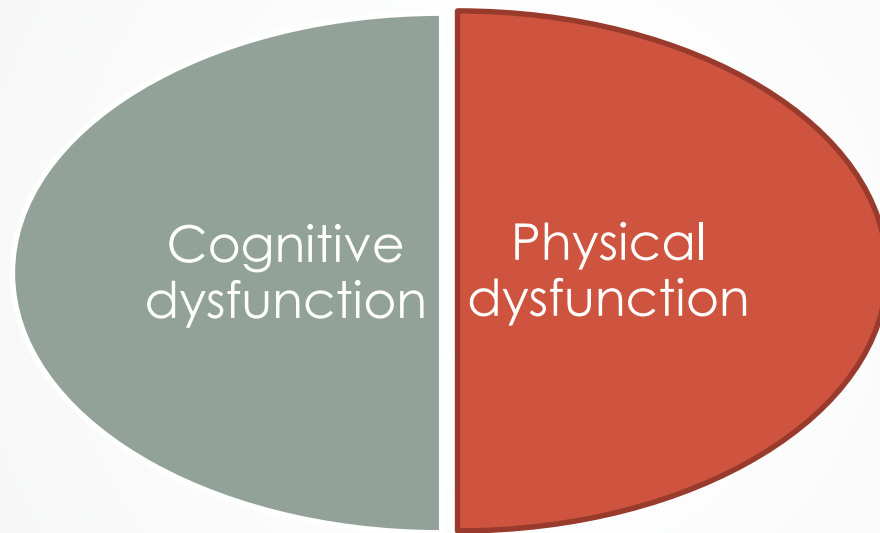
Michael Hutchinson

- *October 2012, Multiple Sclerosis Journal*
- *See also Ravnborg & Freeman*

PROGRESS IN REHABILITATION

- **Rehabilitation effects** --- Review papers
 - Cognitive rehabilitation
 - Exercise therapy (& cognition)
 - Spasticity management
 - Information provision (patient education)
- **Outcome measures** --- Increased consensus
 - Cognition (BICAMS)
 - Walking tests & scales
 - Arm function
 - Balance
- **Important papers** addressing community behaviour
 - Community-based training
 - Tele-coaching/rehabilitation in the community

Part I. Evidence update



TREATMENT OF COGNITIVE IMPAIRMENT IN MULTIPLE SCLEROSIS: POSITION PAPER

Cognitive
dysfunction

Maria Pia Amato
Dawn Langdon
Xavier Montalban
Ralph HB Benedict
John DeLuca
Lauren B. Krupp
Alan J Thompson
Giancarlo Comi

Journal of Neurology, 2013

LEARNING & MEMORY INTERVENTION FORMAT

Computerized interventions		Behavioral interventions	
Mendozzi, 1998	RehaCom	Jonsson, 1993	NP rehab
Solari, 2004	RehaCom	Allen, 1998	Story memory Tech
Tesar, 2005	RehaCom	Chiaravalloti, 2002	Generated learning
Hildebrandt, 2007	VILAT-G 1.0	Chiaravalloti, 2005	Story memory Tech
Brenk, 2008	Brain Gym	Basso, 2006	Generated learning
Vogt, 2009	Brain Stim	Goverover, 2008	Generated learning
Shatil, 2010	CogniFit Personal Coach	Goverover, 2009	Spaced learning
		Sumowski, 2010	Spaced retrieval
		Goverover, 2011	GE/SE

Courtesy to M Amato

TREATMENT FOR LEARNING AND MEMORY IN MS

Support

12

No Support

5

1 weak support

Courtesy to M Amato

Cognitive
dysfunction

Cognitive dysfunction

Multiple Sclerosis: Effects of Cognitive Rehabilitation on Structural and Functional MR Imaging Measures—An Explorative Study¹

Massimo Filippi, MD
Gianna Riccitelli, PhD
Flavia Mattioli, MD
Ruggero Capra, MD
Chiara Stampatori, PhD
Elisabetta Pagani, MSc
Paola Valsasina, MSc
Massimiliano Copetti, PhD
Andrea Falini, MD
Giancarlo Comi, MD
Maria A. Rocca, MD

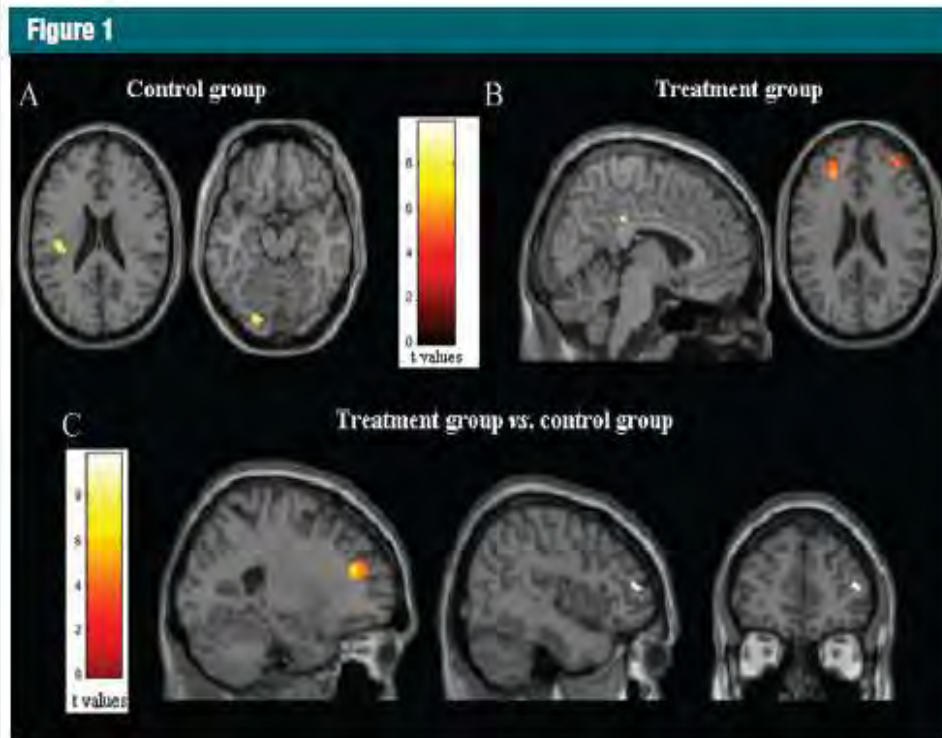
Purpose:

To evaluate brain changes after cognitive rehabilitation in patients with clinically stable relapsing-remitting (RR) multiple sclerosis (MS) by using neuropsychologic assessment and structural and functional magnetic resonance (MR) imaging techniques.

Materials and Methods:

The study was conducted with approval of the involved institutional review boards. Written informed consent was obtained from each participant. Twenty patients with RR MS and cognitive deficits at baseline were randomly assigned to undergo treatment ($n = 10$), which entailed computer-assisted cognitive rehabilitation of attention and information

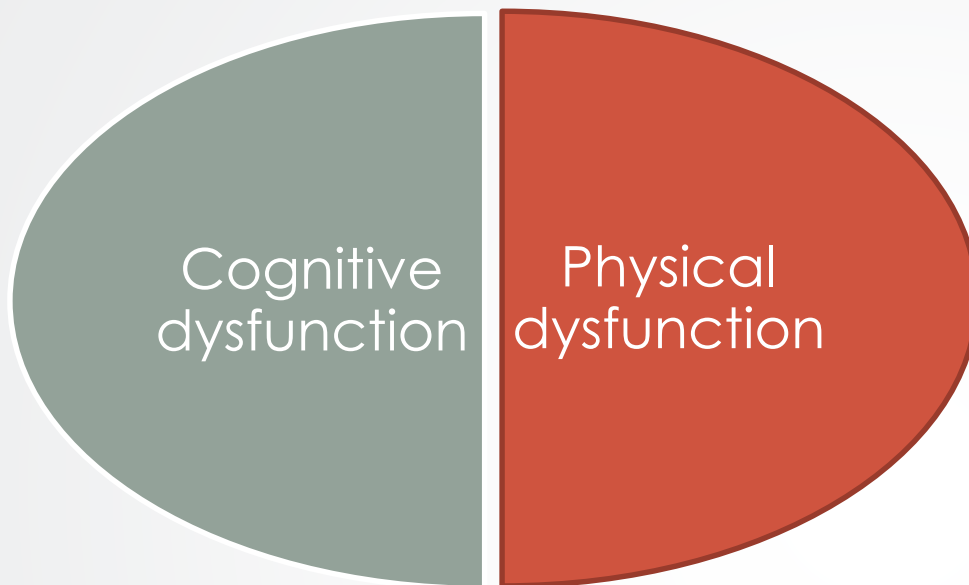
MRI changes following 12w Cognitive Rehabilitation



Increased Dorsolateral PFC bilaterally in Treatment group after treatment

In treatment group,
*Functional MRI changes
Correlated with cognitive
improvement*

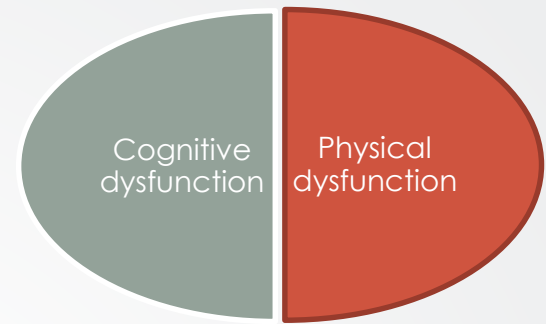
No structural MRI changes
In GM volume or NAWM
observed with treatment



WALKING WHILE TALKING

Attentional-cognitive resources

DUAL TASKING PARADIGMS DURING WALKING



Topical review by Leone, Patti, Feys

- 11 studies in recent 2 years
- WALKING & COGNITIVE TASKS
 - Word generation list
 - Alfabet
 - Calculating (100 97 94 91 88)
 - Sustained attention
 - ...
- Persons with MS **slow down** more than healthy controls
- DUAL TASK COST
- Potential ecologically valid outcome measure



Exercise therapy

Physical
dysfunction



Resistance training

Body building

Basketball

Soccer

Swimming

Rowing

Running
Cycling



Endurance training

EXERCISE THERAPY IS OVERALL EFFECTIVE BUT LESS KNOWN IN PROGRESSIVE MS & MORE ADVANCED DISABILITY

- Endurance & Resistance training

Reviews

- Rietberg et al (2005)
- Dalgas et al (2008) MSJ
- Motl et al (2008) MSJ
- Snook & Motl (2009) NNR
- Andreasen et al (2011) MSJ
- Latimer-Cheung AE (2012) APMR
- Sa et al (2013)
- ...

Cochrane Reviews
Function, Activity

QoL

Walking

Fatigue

J Neurol



MULTI-CENTER STUDY II: 2012-13



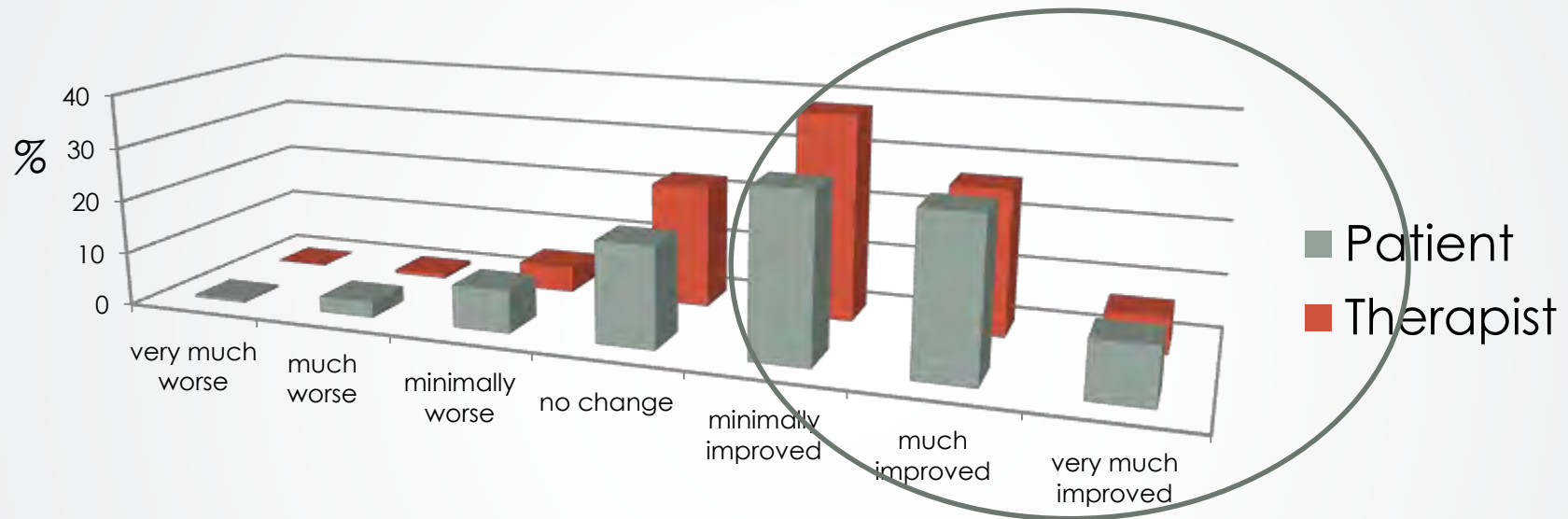
290 pwMS*
from
17 European centres
in 9 countries

**cerebellar ataxia excluded*



*Baert, Gebara, Knuts, Maertens-de-Noordhout, ..., Feys, Dalgas &
RIMS workgroup Mobility (NNR, 2014)*

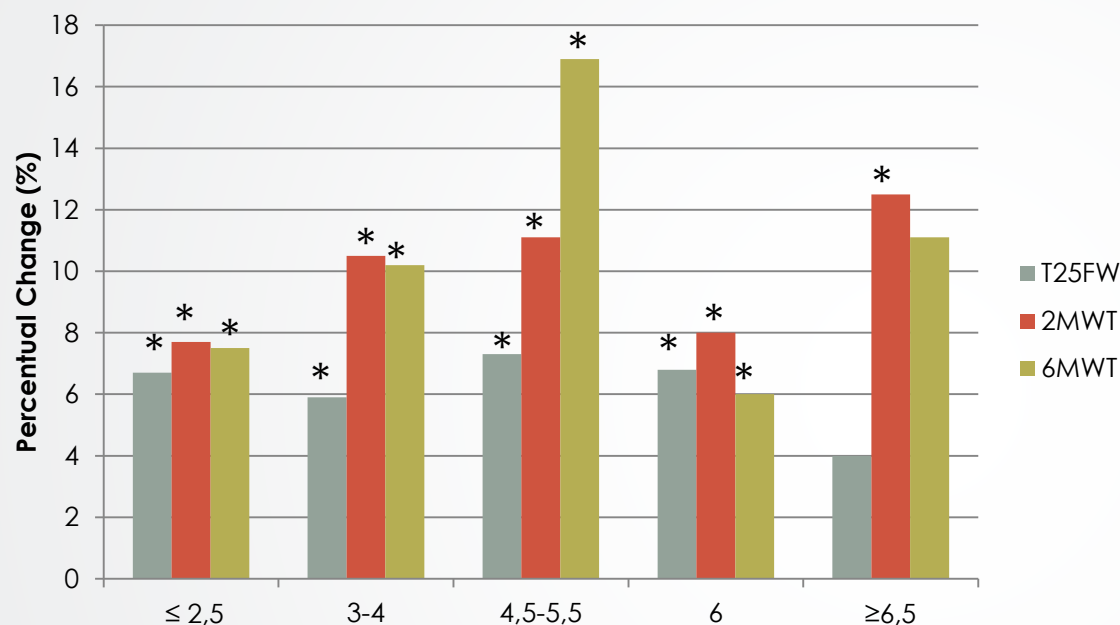
GLOBAL IMPRESSION OF CHANGE



75% pwMS reported improvement

Similar results between pwMS & therapist

EFFECTS OF REHABILITATION ACCORDING **DISABILITY LEVEL**



EDSS	N
≤2,5	36
3-4	62
4,5-5,5	78
6	65
≥6,5	41

EDSS

Effects across

- Different centers
- Disability level (up to 6)

2MWT & MSWS-12
most recommended
outcome measures

TABLE 1: Group physiotherapy exercises and their progressions.



Sit to stand



Squat



Heel raises

Clinical Study

The Effect of Community Exercise Interventions for People with MS Who Use Bilateral Support for Gait

Positive effect of
balance & strengthening exercises
on balance



Step ups



Side stepping

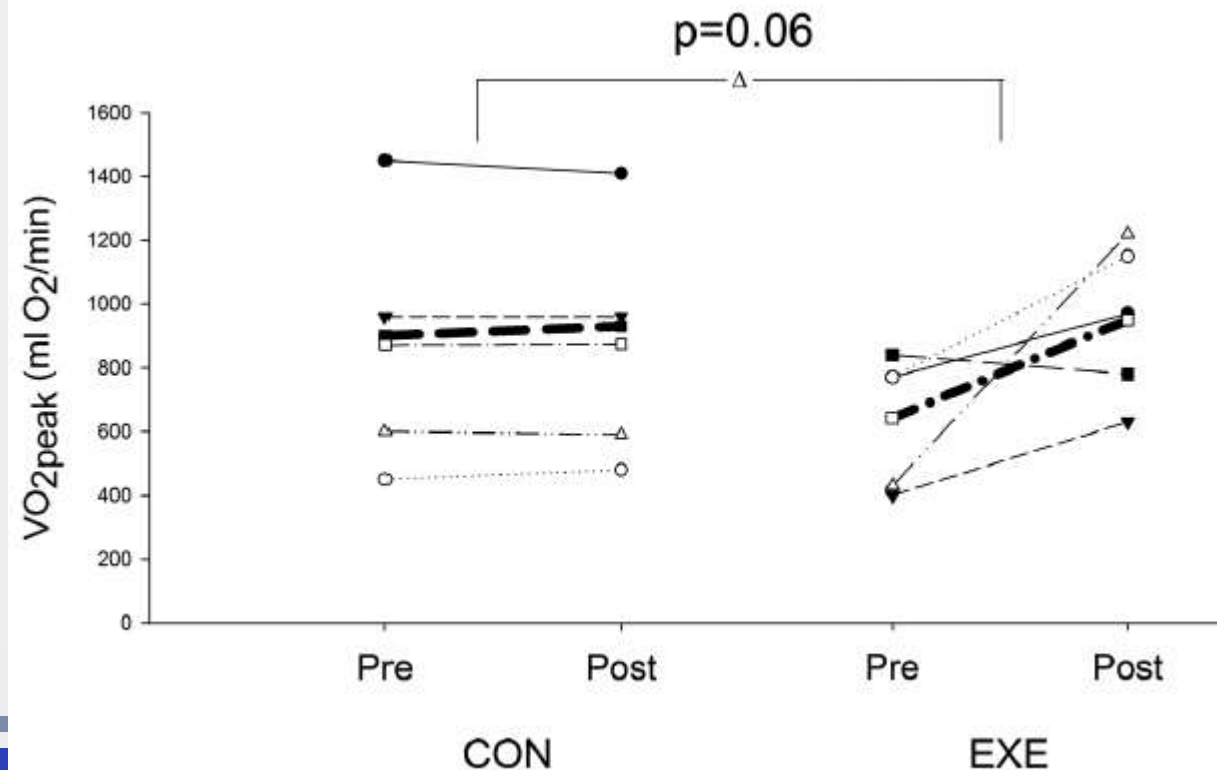


Tandem



Endurance training is feasible in severely disabled patients with progressive multiple sclerosis

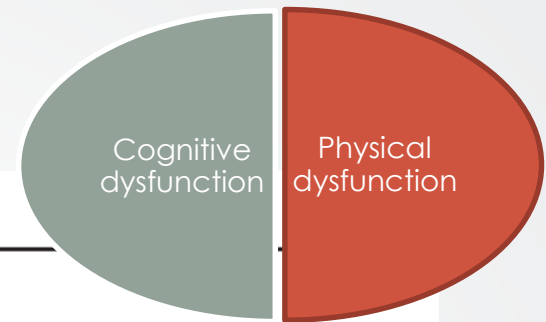
AG Skjerbæk¹, M Næsby¹, K Lützen¹, AB Møller^{2,6}, E Jensen¹, I Lamers⁵, E Stenager^{3,4} and U Dalgas²



- 11 pwMS
- **EDSS 6,5-8,5**
 - CON (n=5)
 - EXE (n= 6)
- 10 sessions ergometry during 4 weeks

- Anthony Feinstein, MSJ 2013

Editorial



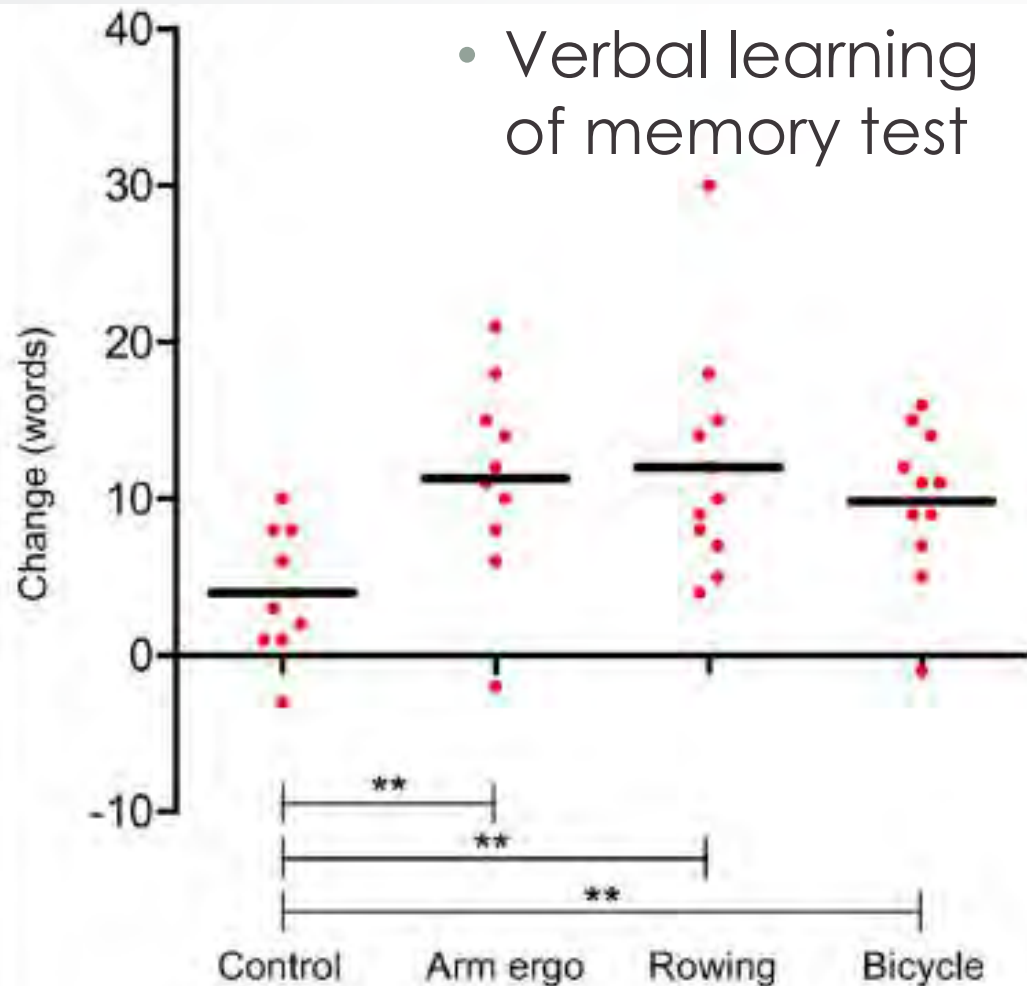
Multiple sclerosis, cognitive dysfunction and the potential benefits of exercise

- Briken, Heesen et al , MSJ 2014

Effects of exercise on fitness and cognition in progressive MS: a randomized, controlled pilot trial

S Briken^{1,2}, SM Gold¹, S Patra³, E Vettorazzi⁴, D Harbs³, A Tallner⁵, G Ketels⁶, KH Schulz^{3,7} and C Heesen^{1,2}

EFFECT OF EXERCISE ON COGNITION IN PERSONS WITH PROGRESSIVE TYPE OF MS



- 42 pwMS
- EDSS 4-6
- 8-10 weeks training (10% drop-out)
- Improved fitness, walking, mood, energy & cognitive function!

PROGRESSIVE MS ALLIANCE (PMSA)



New Perspectives

Setting a research agenda for progressive multiple sclerosis: The International Collaborative on Progressive MS

Fox, Thompson, Comi, Baneke et al (2012) MSJ

- SECTION

'Symptomatic treatment & Rehabilitation'

Submission of projects (January 2014)

Preparation of a large exercise trial (phys/cognitive)

CARE & CURE



Topical Review

MULTIPLE
SCLEROSIS
JOURNAL

MSJ

Lifestyle physical activity in persons with multiple sclerosis: the new kid on the MS block

Robert W Motl

Multiple Sclerosis Journal
1–5


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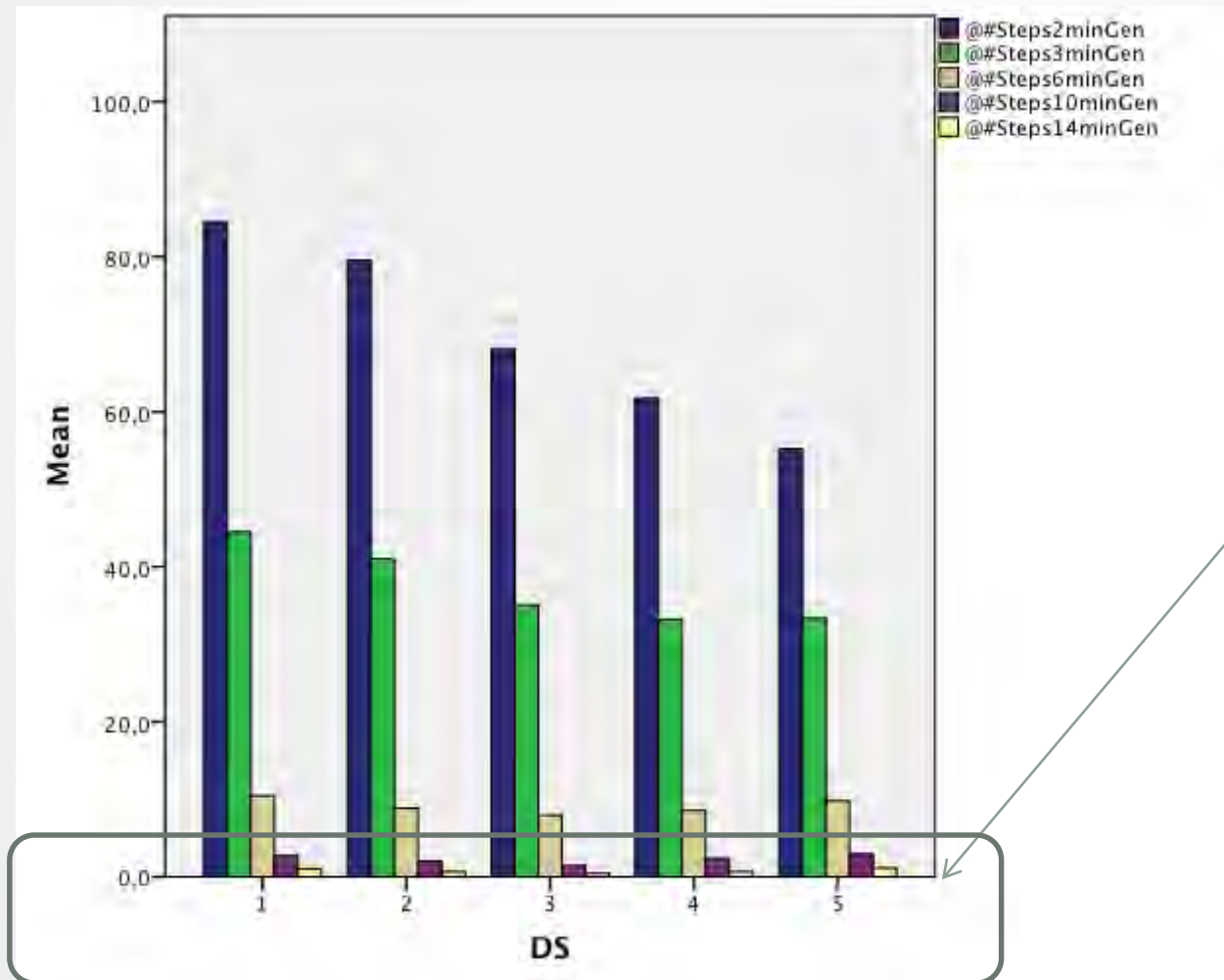
DOI: 10.1177/1352458514525873

msj.sagepub.com

 SAGE

 RIMS

MINUTES OF UNINTERRUPTED COMMUNITY WALKING ACTIVITY



6, 10, 14'
Walking
without
interruption

- Neven, Vanderstraeten, Ilsbrouckx, Van Asche, Willekens, Truyens, Feys (U Hasselt)

COMMUNITY-BASED EXERCISE THERAPY

- Smith et al (2011) Disabil & Rehab
- N=10
- Qualitative research
- Patient education & guidance
 - health believes
 - choice of exercise
 - feel safe
 - Self-integrity

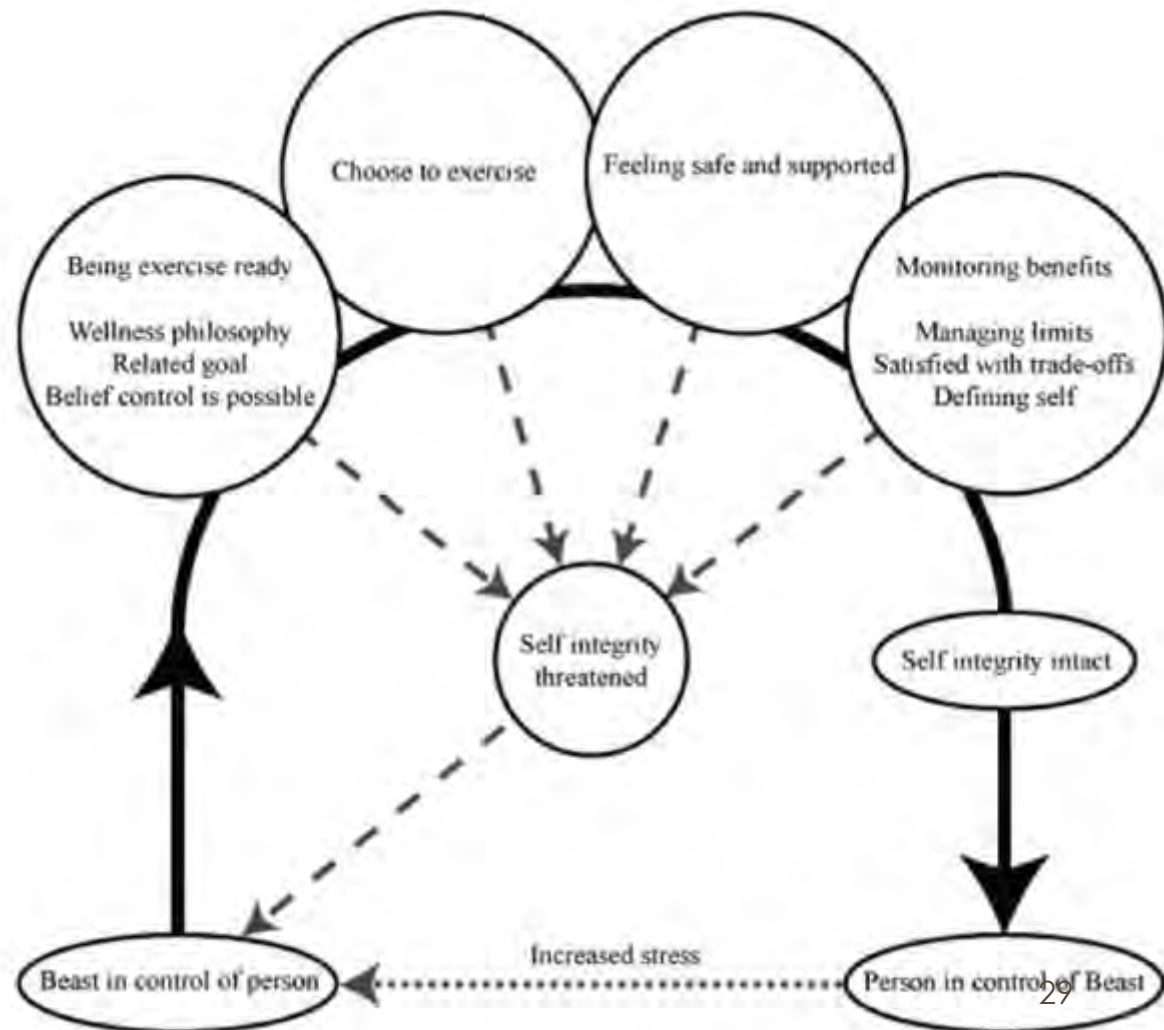


Figure 1. How fatigue influences community-based exercise choices in women with MS.

Information provision for people with multiple sclerosis (Review)

Köpke S, Solari A, Khan F, Heesen C, Giordano A

2013



Patient
relevant
information

When
needed

Tailored

Evidence-
based



Blue Prescription

Facilitating self-directed increases in physical activity for people with multiple sclerosis.



Assoc. Prof.
Leigh Hale
School of Physiotherapy



Dr Hilda Mulligan
School of Physiotherapy



Dr Cath Smith
School of Physiotherapy



Dr Gareth Treharne
Dept. of Psychology



What is Blue Prescription?

An innovative physical therapy approach to enable development of self-efficacy in order to sustain participation in physical activity.

Derived from 3 evidence-based factors:

- Choice of activity
- Control over level of engagement
- Support in choice of activity with advice and encouragement

It offers:

- 1-3 home visits or accompanying visits to a physical activity environment
- Facilitation for preferred physical activity
- Setting of own goals using motivational interviewing
- Realistic expectations
- Appropriate advice and encouragement
- Support on a regular basis via communication of choice
- Volitional help sheets to assist with maintaining level of activity

Approach

Long term participation in physical activity is challenging for people with multiple sclerosis.

Using questionnaires and in-depth interviews (uncontrolled before-after design), we investigated short term benefits of Blue Prescription in encouraging adherence to physical activity.

27 adults with multiple sclerosis (4M, 23F, mean age 51 years (range 34-71), mean duration of MS 15 years (range 1-40), wide range of disability levels), were assessed at baseline and at

Qualitative Themes

Motivation to participate

It's great for people like me to have somebody...show any interest

Support

The Blue Prescription approach

...really love and it you, you do it!

The therapist

...that somebody's along the line...care...I mean to their job...they and how you are...something I

The approach

...the value of this: we were invited and challenged to consider...activity...I found at the beginning it was quite exciting but over a period of three months there was sort of no contact. It was just sort of left low and I think I sort of fell off the wagon a wee bit just through that. Started off with a hiss and a roar and sort of...died off

Conclusion

BP had a favourable impact on the lives of our participants; they felt supported and motivated to engage in physical activity. Participants valued PT expertise and advice. Exercise self-efficacy might be a better construct to measure than MS self-efficacy.

'BLUE PRESCRIPTION'
New Zealand
1-3 sessions
at pwMS home/community

- Importance of own choice
- Realistic Feedback
- Accompanying visits to physical activity environment

Hale et al (2012) Disability & Rehabilitation

internet-delivered interventions to promote ph.Act

e-therapy

e-interventions

online therapy

Computer-mediated
interventions

e-health

web-based therapy

Tele-healthcare

cybertherapy

Tele-rehabilitation



Courtesy to
Tallner (Erlangen)

ON-LINE MONITORING & FEEDBACK

Motivation by Facebook-friends

The image is a screenshot of the Nike+ website. On the left is a navigation sidebar with links for RUN, SEARCH, SHOP, Features, Men, Women, Get Geared Up, Nike+, NIKEiD, TRAINING, EVENTS, NEWS, SUPPORT, VIDEO, NIKE+, and LOGIN. The main content area has a red background with the heading "Get Cheered On". Below the heading is a paragraph: "Post the start of your run to Facebook and hear a real-time cheer for each like or comment." To the right of this text is a large smartphone displaying a Facebook comments page for a post about a run with Nike+ GPS. A yellow ribbon graphic starts from the left, loops around the phone, and ends on the right. A female runner is shown running along this ribbon. Several red speech bubbles with white thumbs-up icons are floating around the runner. In the top right corner of the main area is a "Download the App Nike+ GPS" button. In the bottom right corner is a Facebook "Vind ik leuk" button. Below the main content area is a "FEATURES" section with five icons: a runner (labeled "NIKE+ GPS APP"), a red circle with a white "TAG" (labeled "DON'T BE IT"), a thumbs-up and speech bubble (labeled "GET CHEERED ON" and highlighted with a red border), a musical note (labeled "POWERSONG"), and a trophy (labeled "CHALLENGE YOURSELF").

Get Cheered On

Post the start of your run to Facebook and hear a real-time cheer for each like or comment.

Download the App Nike+ GPS

Facebook Comments:

- Jessica Crane: I just started a run with Nike+ GPS... (Apr 20 11:42 AM via text message)
- Christine Spencer: Way to go, rock start! (Apr 21 11:05 AM)
- Jennifer S. Leventhal: Yay! keep going Jodi! (Apr 21 11:07 AM)
- Jennifer S. Leventhal: Are you training for a marathon? (Apr 21 11:08 AM)
- Daniel Kainer: keep up the fast pace! (Apr 21 11:08 AM)

FEATURES

- NIKE+ GPS APP
- DON'T BE IT
- GET CHEERED ON
- POWERSONG
- CHALLENGE YOURSELF

Part I. Evidence update

Part II: RIMS activities



UNDER PRESSURE

Living with MS in Europe

MS THRUST LONDON
&
NATIONAL HOSPITAL OF
NEUROLOGY

RIMS 2014

REHABILITATION IN MS

SUPPORTING BEHAVIOUR CHANGE
LINKING SCIENCE TO CLINICAL PRACTICE



6-7 JUNE 2014 **BRIGHTON**



REHABILITATION IN
MULTIPLE SCLEROSIS

IN PARTNERSHIP WITH



University College
London Hospitals



PLUS MS MASTERCLASS LONDON 5 JUNE

- Supporting behavioural change
- Linking science to clinical practice
- Masterclasses & Seminars (also in research skills)
- www.rims2014.org



ADAMS PROJECT INITIATED BY NOVARTIS IN 2013



MULTIPLE
SCLEROSIS
JOURNAL

MSJ

Meeting Review

Adherence in multiple sclerosis (ADAMS): Classification, relevance, and research needs. A meeting report

Multiple Sclerosis Journal

1-4

DOI: 10.1177/
1352458514531348

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Christoph Heesen, Jared Bruce, Peter Feys, Jaume Sastre-Garriga, Alessandra Solari, Lina Eliasson, Vicki Matthews, Bettina Hausmann, Amy Perrin Ross, Miho Asano, Kaisa Imonen-Charalambous, Sascha Köpke, Wendy Clyne and Paul Bissell

ADAMS

ADHERENCE IN MS --- MEETING REPORT 2013

- ADHERENCE --- concordance ⇔ compliance
- NON-ADHERENCE (15-50% of pwMS regarding drugs)
 - Intentional
 - Non-intentional
 - Forgetness
 - Fatigue
 - Emotional distress
 - Incomplete (fe, 20% drugs missing)
Interruption of therapy, stopping

ADAMS

ADHERENCE IN MS --- 2014

- ADHERENCE --- concordance ⇔ compliance
- Focus on REHABILITATION
 - exercise, physiotherapy, cognitive training, fatigue management, ...
 - Patient characteristics (fatigue, depression, disability, dependency etc)
- Strategic Meeting in June (RIMS conference) including different health care professions
- Literature review & study preparation
- Follow-up symposium in autumn

SPECIAL INTEREST GROUPS: MEETINGS 2014



MS Norwegian Multiple Sclerosis COMPETENCE CENTRE

Special Interest Group on Mobility

RIMS REHABILITATION IN MULTIPLE SCLEROSIS
European network for best practice and research

Challenges in physical rehabilitation in MS – integrating qualitative and quantitative approaches

Hosted by Norwegian Multiple Sclerosis Competence Centre, Haukeland University Hospital and collaborators

SIG Mobility Chairs:
Anders Romberg
and Paul Van Asch

Local organizer: Tori Smedal

**26th and 27th
September 2014**

Call for abstracts is open.
Deadline: April the 15th 2014.
Please submit abstracts to:
tori.smedal@helse-bergen.no and
anders.romberg@ms-liitto.fi
For practical arrangements,
please contact: the local organizer.
See the RIMS website www.euRIMS.org

- NORWAY

- MOBILITY

Chairs

Paul Van Asch,
Anders
Romberg

Organisation:
Tori Smedal



SPECIAL INTEREST GROUPS: MEETINGS 2014

- **SIG Occupation :**

‘Implementing science into practice’

November 28-29th 2014

Barcelona, CEMCAT, Spain

local organiser: N. Filio

- New group on ‘**health service quality indicators**’
Leads: Tom Meurrens (Belgium) & Astrid Huissaerts (NL)

EDUCATION PROGRAM (IN DEVELOPMENT)

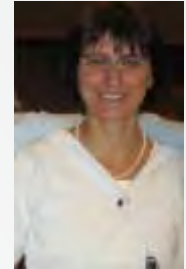
- PEER VOICE --- sessions on rehabilitation during RIMS/ECTRIMS
support of Biogen Idec
- E-book on physical rehabilitation
(Kamila Rasova, CR)
- Webcasts
- State-of-the-art modules in different domains
Support of regional meetings
- Booklets
(new booklet from the SIG communication & swallowing)

RIMS GRANTS

- **2012: CONTENT OF PHYSICAL REHABILITATION**

a survey

Lead: Kamila Rasova (CR)



- **2012: ADL PERFORMANCE multi-center trial**

Leads: Daphne Kos (Belgium)
& Jelka Jensa (Slovenia)



- **2013: BALANCE TRAINING : multi-center trial**

Lead: Davide Cattaneo (Italy)

- **2014: PSYCHOLOGY OF SEXUAL DYSFUNCTION**

a systematic review

Lead: Ana Ožura (Slovenia)

ONGOING MULTI-CENTER DATA COLLECTION PROJECT 2014-15 EFFECTS OF PHYSICAL REHABILITATION

- **On Mobility (beyond walking speed) & Arm function**
systematic review: Lamers et al MSJ & APMR
- **In >20 European centers & >5 US centers as well**
- Data collection starts in summer 2014
- Coordination: University of Hasselt (Ilse Baert, Belgium)

Sponsoring of NOVARTIS



RIMS PARTNER WORK:

ENDORSEMENTS

- **EMSP**
 - MS PRO
 - Patient Survey (project 2014)
 - Annual Conference 2014
- **IMSCOG**
 - International MS Cognition Society
 - Conference 2014 in Barcelona (June 9-13th)
- **Serono Symposia**
 - Preceptorship on Rehabilitation
 - Klinik Valenz, September
- **Scientific Journals**
 - International Journal of MS Care (IJMSC) with CMSC
 - Multiple Sclerosis Journal (MSJ) – 2014 conference abstracts
- **MS Climbing** in the Netherlands (ao, Nationaal MS fonds)



ANNUAL REPORTS



NEWSLETTER VIA WWW.EURIMS.ORG



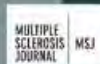
European network for best practice and research

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RIMS present in the Multiple Sclerosis Journal –Network

The Multiple Sclerosis Journal has launched an on-line MSJ network that aims to connect researchers and professionals working in the field of MS. Discussions can be initiated based on scientific papers or self-initiated, besides announcement of events or jobs and other reflections. Also RIMS is present as a group in the MSJ network. We invite you to join the network and to become a member of our organization, where rehabilitation topics can be discussed. See <http://multiplesclerosisjournal.ninq.com/group/rims>.

MSJ NETWORK



SaGAS now available as I-phone app

The SAGAS, an acronym for Short and Graphic Ability Score, was developed by Dr. C. Vaney (Berner Klink Montana, CH), former president of RIMS and chair of the special interest group on Mobility. It summarizes and visualizes the scores on the motor components of the Multiple Sclerosis Functional Composite scores, being the Timed 25 Foot walk and the Nine Hole Peg test. With this application, one can add the scores to a database in a mobile way, and compare with previous performances. See <http://itunes.apple.com/us/app/sagas-20-10/id520129522?ls=1&mt=8> for more information.



RIMS NEWSLETTER

Register here if you want to receive our RIMS newsletter!