Preventing Falls in MS: An International Approach

Disclosures

- Marcia Finlayson has no conflicts to disclose
- Patricia Matsuda has no conflicts to disclose
- Susan Coote has no conflicts to disclose
- Hilary Gunn has no conflicts to disclose
This symposium is being presented on behalf of:

Core members of the International MS Falls Prevention Research Network:

- Davide Cattaneo, Italy
- Michelle Cameron, USA (*participant in Q & A period*)
- Susan Coote, Ireland (*speaker*)
- Marcia Finlayson, Canada (*moderator*)
- Jenny Freeman, UK
- Hilary Gunn, UK (*speaker*)
- Patricia Matsuda, USA (*speaker*)
- Elizabeth Peterson, USA
- Jacob Sosnoff, USA (*participant in Q & A period*)

Symposium Objectives

- Summarize current state of knowledge regarding:
  - Fall risk factors among people with MS;
  - Interventions that reduce fall risks and prevalence in people with MS;
- Describe strategies and tools for clinical practice based on current evidence;
- Discuss next steps to advance science and practice in MS falls prevention.
Outline of the Symposium

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00 – 9:20</td>
<td>Introduction to the symposium and the panel</td>
<td>Finlayson</td>
</tr>
<tr>
<td>9:20-10:00</td>
<td>Fall Risk Factors among People with MS</td>
<td>Matsuda</td>
</tr>
<tr>
<td>10:00 – 10:40</td>
<td>Interventions for reducing falls among people with MS</td>
<td>Coote</td>
</tr>
<tr>
<td>10:40-10:50</td>
<td>break</td>
<td></td>
</tr>
<tr>
<td>10:50-11:30</td>
<td>Application to current clinical practice</td>
<td>Gunn</td>
</tr>
<tr>
<td>11:30 – 12:00</td>
<td>Question and Answer Panel Wrap-up</td>
<td>All speakers; joined by Cameron and Sosnoff</td>
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</table>

Vision: International MS Falls Prevention Research Network

- Connect researchers focused on MS falls prevention
- Collaborate to develop and test multifactorial MS falls prevention interventions that build on our individual areas of expertise
- Ultimate goals:
  - Advance knowledge on MS falls prevention – pursue work we cannot do alone
  - Disseminate effective MS prevention protocols that are feasible in community-based settings worldwide.
Our Initial Aims: CIHR funded Planning Grant

- Build collaborative partnerships among researchers, clinicians, consumers, and other key stakeholders committed to strengthening evidence for MS falls prevention.
- Begin work on a protocol for a MS falls prevention intervention trial that could be replicated by each co-applicant on the research team in his/her own jurisdiction.
- Create an infrastructure (mission, goals, core principles) that will support the long-term sustainability of the IMSFPRN, including multi-site studies and data harmonization.

Inaugural Meeting
Queen’s University – March 3-5, 2014
Issues Discussed & Debated

- What can we learn from related research?
- What outcomes should we target?
  - What do we know or believe about how these outcomes come about?
- Who should we target?
- What factors should we consider during planning to maximize uptake later on?
- What would the intervention look like?

Work since the meeting

- Intentionally and strategically working together
  - Theme issue
  - Several small initiatives to develop elements of the protocol and/or select and evaluate outcomes
- Seeking more funding
- Gathering intellectual property and multi-site study agreements
- Investigating options for data harmonization
Fall risk factors among people with MS

Objectives

- Explore the current definition of falls
- Examine the prevalence and incidence of falls in people with MS
- Discuss falls in the ICF model
- Identify the risk factors for and consequences of falls
- Identify non-modifiable and modifiable risk factors
Research Review Part I: Falls in People with MS

Definition of a fall
  • Different types of falls

Current statistics
  • Older adults and other neurologic populations

Consequences of falls

Risk factors

Definition of a Fall

Do you ask your patient about falls?

Do you define falls for your patient?

How do you think your patient(s) defines a fall?
  • Landing on the floor
  • Associated with injury
Definition and Types of Falls in the Literature

- Fall
- Recurrent Falls
- Injurious Falls

Definition of a fall

“An event which results in a person coming to rest inadvertently on the ground or other lower level and other than as a consequence of the following: Sustaining a violent blow, loss of consciousness; sudden onset of paralysis, as in a stroke; or an epileptic seizure.”

(Kellogg International Working Group, 1997)
Definition of a Fall

Many different definitions exist in the MS literature
• As many as 8

Commonly used:
• “Unexpected event in which a participant comes to rest on ground, floor, or lower level”

Definition of Recurrent Falls

Experiencing 2 or more falls
• “Multiple”
• Different time frames are used
  • 2 to 12 months
• Frequent falls
  • Experiencing more than occasional falls
    • Three+ or unable to recall
Definition of Injurious Falls

Fall that leads an individual to seek medical attention
- Cuts, scrapes, contusions to head injury or broken bones

Falls in People with MS Compared with Other Populations
## Falls in Neurologic and Special Populations

<table>
<thead>
<tr>
<th>Population</th>
<th>Prevalence estimates</th>
<th>Reference(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke (chronic)</td>
<td>Around 50%</td>
<td>Harris et al., 2005</td>
</tr>
<tr>
<td>Parkinson’s Disease (PD)</td>
<td>Range from 40-70%</td>
<td>Ashburn et al., 2007; Wood et al., 2002</td>
</tr>
<tr>
<td>Spinal Cord Injury (SCI)</td>
<td>Range from 39-75%</td>
<td>Phonthee et al., 2013; Brotherton et al., 2007</td>
</tr>
<tr>
<td>Older adults (65+ or &gt;)</td>
<td>33% 50%</td>
<td>CDC, Campbell et al., 1981; Lord et al., 1993</td>
</tr>
<tr>
<td>Middle age (50-60 y.o.)</td>
<td>somewhat higher</td>
<td>Painter et al., 2009</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>2X that of cognitively intact older adults, 71.9%</td>
<td>Allan et al., 2009; Taylor et al., 2012; Taylor ME et al., 2012</td>
</tr>
</tbody>
</table>

## Falls in Medicare Population Compared to People with MS

**Fewer than half (48%)** Medicare beneficiaries reported talking to their health care provider (HCP) following fall
- 60% of these reported receiving fall prevention information
  - Shumway-Cook et al., 2002

**This number is similar in persons with MS (50%)**
- 94% reported receiving fall prevention strategies from their HCP
  - Matsuda et al., 2011
Falls in People with MS: Retrospective & Prospective Studies

<table>
<thead>
<tr>
<th>Fall Category</th>
<th>Prevalence/Proportion reporting falls</th>
<th>Fall Rates</th>
</tr>
</thead>
<tbody>
<tr>
<td>People reporting falls</td>
<td>30-80%</td>
<td>40-71%</td>
</tr>
<tr>
<td>Proportion recurrent fallers (2+)</td>
<td>19-64%</td>
<td>14-53%</td>
</tr>
<tr>
<td>People reporting injurious falls</td>
<td>12-34%</td>
<td>48-53%</td>
</tr>
</tbody>
</table>

Method of Collecting Fall Rates: Prospective

- Fall diary or calendar
  - Most common: monthly
  - Time frames: from 3 – 12 months
  - With or without telephone reminders
Consequences of Falls

Consequences to the Individual

- Injury and hospitalization
- Loss of independence
- Fear and loss of confidence
- Limiting your activity
  - Reduced strength
  - Reduced balance
  - Reduced stamina
  - Increases your chance of falling

Fall → Fear of falling
Restricted Activity → Decreased Strength
Gait
Risk Factors: What we know

Risk Factors in the ICF Framework

Body Structure & Function (Impairments)
- Strength
- Flexibility
- Sensation
- Perception
- Cognition
- Balance
- Gait

Functional Activities (Limitations)
- Sitting
- Standing
- Walking
- Transfers
- Reaching

Participation (Disability)
- ADLs/IADLs
- Work
- Recreation
- Mobility (Community)

Personal
- Fear/Self-confidence
- History of falls

Environmental
- Home/Work/Community

6/29/2015
Risk Factors Associated with Falls in the ICF Framework: Retrospective Studies

Health Condition: MS
- Deteriorating
- Disability

Body Structure and Function
- Cognition
- Balance
- Bladder incontinence

Contextual Factors

<table>
<thead>
<tr>
<th>Environmental</th>
<th>Personal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility aids/assistive devices</td>
<td>Male</td>
</tr>
<tr>
<td>No to occasional use of w/c</td>
<td>Fear or concern about falling</td>
</tr>
<tr>
<td>Use of cane or walker</td>
<td>Financial/Socioeconomic status (&lt;$25,000)</td>
</tr>
<tr>
<td>Increased number of mobility aids used</td>
<td>Sense of coherence</td>
</tr>
</tbody>
</table>
### Risk factors in the ICF Framework: Prospective Studies

#### Body Structure and Function (Impairments)

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking/Gait</td>
<td></td>
</tr>
<tr>
<td>Strength</td>
<td></td>
</tr>
<tr>
<td>Sensation</td>
<td></td>
</tr>
<tr>
<td>Increased postural sway (with eyes closed)</td>
<td></td>
</tr>
<tr>
<td>Coordinated stability</td>
<td></td>
</tr>
<tr>
<td>Center of pressure/center of mass</td>
<td></td>
</tr>
<tr>
<td>Spasticity</td>
<td></td>
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</tbody>
</table>

#### Personal Factors

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of falls</td>
<td></td>
</tr>
<tr>
<td>Fear of falling/falls self-efficacy</td>
<td></td>
</tr>
<tr>
<td>Self-perceived walking ability</td>
<td></td>
</tr>
</tbody>
</table>
Risk factors for injurious falls: Retrospective & prospective studies

- Health condition
  - Osteoporosis

- Body Structure and function
  - Walking/Gait

- Personal
  - Fear or concerns about falling
  - Falls history
  - Self-reported walking ability

Risk factors for recurrent falls
(Coote et al., 2014)

- Mobility status

- Major findings:
  - Non-linear association between mobility limitations and fall status
  - Bilateral assistance for gait category greatest prevalence of fallers
  - Use of w/c somewhat protective
  - Those who did not use a mobility aid/assistive device had the highest proportion of multiple fallers
Proposed relationship

Potential Risk Factors Through Qualitative Studies

- Participation
  - Divided attention
  - Walking in crowds (Community mobility)
  - Taking care of the home
  - Driving

- Environment
  - Unsuitable physical environment
    - Carpets, slippery surfaces, doorsteps
  - Climate
    - Snow, ice, heat

- Personal
  - Stress

Matsuda et al., 2012

Niisagard et al., 2009, Peterson et al., 2010
Summary of Fall Risk Factors

Common Risk Factors Between Retrospective and Prospective Studies

- Fear or concern about falling
- Mobility, including assistive devices used
- Balance/Gait
- Falls History

Risk Factors: Non-modifiable

- Gender (male)
- Falls history
- Cognition
- Financial/Socioeconomic Status
  
  Disease progression
  
  e.g., bladder incontinence
**Risk Factors: Modifiable**

- Strength
- Balance
- Gait/Mobility disability/Assistive Devices
- Fear of falling/falls self-efficacy

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**Importance of Understanding Risk Factors**

- Helps us to understand the factors
  - Impacting falls and falls self-efficacy
  - Identify factors that may predict future falls
  - Select appropriate outcome measures
- Target population
- Develop more effective interventions
Interventions for reducing falls among people with MS

Susan Coote, PhD, MISCP
Lecturer in Physiotherapy
University of Limerick
Objectives

- To outline the current evidence for falls prevention interventions for people with MS
  - To consider the outcomes of interest
  - To review the evidence for fall prevention in MS

- To outline the learning from falls prevention literature in other populations

- To consider what theories should be used to inform the development and delivery of new interventions

1a - Outcomes from Fall Prevention Interventions in MS

- Number of falls, number of fallers

- Falls risk reduction
  - Balance, fear of falling, use of fall prevention strategies

- Reduce the consequences of falling
Outcomes from Fall Prevention Interventions in MS – Number of falls

- **Number or rate of falls and injurious falls**
  - Falls rate (PPY) = (total number of actual falls/total number of person days (all participants)) x 365

- **Number of fallers**

- **Prospective or Retrospective?**
  - Retrospective 36%, prospective 63% (Nilsagard et al 2009)
  - Retrospective 57%, prospective 70.3% (Gunn et al 2013)
  - 6 month recall 17% accurate, 63% underestimated, 12 month recall 23% accurate, 47% underestimated (Dibble et al 2013)
Outcomes from Fall Prevention Interventions in MS – Number of falls

- Falls diary prospectively recorded before and after the intervention
  - Reminders every 2 weeks
  - Returned every 4 weeks
  - Context and consequences for first 2 falls
- “an unexpected event in which the participants come to rest on the ground, floor, or lower level.” (Lamb et al 2005, ProFaNE Network)
- Future – fall sensors, online reporting, smart phone/app data?

Balance as an outcome

- 42% of falls attributed to balance (Peterson et al 2013)
- Static or dynamic? When do people with MS fall?
  - Physical and leisure pursuit activities (Nilsagard et al 2009)
  - Double no. of falls during transitions than standing (Matsuda et al 2012)
  - Home, during the day, turning, walking, stair climbing, or transitions between body postures (Gunn et al 2014)
- Dual tasking element?
Participation level Outcomes

- Reduce consequences of falling
  - Fear of falling and activity curtailment
  - Improve participation
- N=1064, 45 to 90 years, 63.5% reported fear of falling & 82.6% reported curtailing activity (Peterson et al 2008)
- 70.5% of 546 pwMS limited activity due to falling (Matsuda et al 2012)

How do we capture “participation”? 

1b - What do we know about fall prevention interventions in MS? Number of falls/fallers

- Prospective fall diaries

  Nilsagard et al 2014 – Single group
  - 7 week diaries, n=29
  - 7 week tx, groups, CoDuSe,
  - Significant reduction in falls and fallers after the intervention (53% - 31%)

  Gandolfi et al 2015 – RCT
  - Diary 1 month pre and post
  - 5 week tx, 3x per week, individual
  - Sensory integration balance training v usual care
  - Significant reduction in number of falls
1b - What do we know about fall prevention interventions in MS?
Number of falls/fallers

Diary during study period

Drop foot stimulator

- *Esnouf et al 2010* – RCT
- Drop foot stimulator v exercise
- 18 week intervention
- ODFS group had fewer falls during intervention period

Mixed reporting

- *Sosnoff et al 2013* – RCT – self report 3/12 prior, phone call twice weekly,
- Balance, LL strength, core strength, stretching
- Greater proportion of fallers in control (94%- 50%)
- Improvements in PPA, T25FW, balance confidence

- *Sosnoff et al 2014* – RCT - self report 3/12 prior, phone call twice weekly during, monthly diary afterwards
- Exercise, Education, Exs + Ed, control
- Trend reduced fallers in exs and exs and ed groups
- Exercise reduced PPA score


**1b - What do we know about fall prevention interventions in MS? Number of falls/fallers**

**Self report**
- *Cattaneo et al 2007* – RCT - 1/12 self report
  - Motor, motor and sensory strategies, tx as usual
  - Better outcomes than motor only and control on BBS, DGI, DHI and number of fallers

  - Strength and balance exercises, group physio, 1:1 physio, yoga, control
  - Group physio improved BBS and reduced number of falls and fallers

**1b - What do we know about fall prevention interventions in MS? Fall risk reduction**

**Balance**
- *Prosperini et al 2010* – cross over design
  - Visuoproprioceptive training
  - Fall risk - % time using hand support during single and bilateral balance tasks

**Use of fall prevention strategies**
- *Finlayson et al 2009* – single group design
  - Improved falls control, falls management, use of fall prevention strategies, falls efficacy and fear of falling
2 – What can we learn from other populations?

Kendrick et al 2014 Cochrane review
- Exercise for reducing fear of falling
- 30 trials
- Small to moderate reduction in fear of falling

Gillespie 2012 Cochrane review
- Interventions for preventing falls for older people living in the community
- 159 trials
- Single intervention n=59, multifactorial n=40

<table>
<thead>
<tr>
<th>Gillespie et al 2012</th>
<th>Rate</th>
<th>Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple component group exercise</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Multiple component home based exercise</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Tai Chi</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Exercise</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Multifactorial interventions with individual risk assessment</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>Vitamin D</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Home safety assessment and modification</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Tx for vision problems</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Pacemakers</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>Cataract surgery</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Psychotropic meds reduction</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>GP prescribing</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Antislip devices</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Podiatry</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Cognitive behavioural interventions</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
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Note: √ indicates effectiveness, X indicates lack of effectiveness.
2 – What can we learn from other populations?

Verheyden et al 2015

- Stroke
- 10 trials n=1004
- Exercise – acute/subacute, chronic – no effect on fall rate OR number of fallers
  - Noted High intensity functional exercises & Agility programmes warrant further investigation
- Medication – 2 studies, Vit D, Alendronate – rate and number reduced
- Single lens glasses – no effect

2 – What can we learn from other populations?

- Exercise
- Home/environmental modifications
- Multifactorial or Multicomponent Interventions
- Pharmacological management (drug-drug & drug-disease interactions)
3 - Intervention content development

MRC Framework for Complex Interventions

Dynamic balance impairments

- Cameron & Lord (2010)
  - Increased sway
  - Delayed responses to perturbation
  - Reduced ability to move to limits of stability

- Comber, Connell, Galvin, Coote in preparation
  - N=16 papers, pwMS vs healthy controls
  - Gait - decreased speed, cadence, stride length, increased double support time
  - Functional movements, decreased distance, speed and timing of CoP displacement, greater variability
    - Worsened with visual and cognitive challenges
  - External perturbations - latencies and reaction, increased CoP displacement
Cognitive Motor Interference

- Significant reductions in balance and walking speed with addition of a cognitive task (Wajda & Sosnoff 2015)

Other Person factors.....

- Fatigue
  - Single predictor of falls in walking aid users (Coote et al 2013)
  - Perceived cause of falls (Gunn et al 2014)
    - 27.8% falls participants ‘somewhat more fatigued’
    - 13.3% ‘much more’ than usual (n=74).

- Fear of falling (Peterson et al 2007)
- Sense of coherence (Ytterberg et al 2013)
- +++++
**Task & Environment**

- Models for task analysis
- Walking aid use
  - Multiple device use predictive of falls (Finlayson et al 2013)
  - Safe, effective, efficient walking aid use
- Vision
- Built environment – surface, other demands etc

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**Summary**

- Falls rate, and number of fallers as primary outcome
  - Prospective measurement NB
- Reduction of risk factors & consequences of falls as secondary outcomes
- Very few MS studies to date
  - Sensory inputs during dynamic balance
- Extensive literature from elderly fallers
  - Multicomponent and multifactorial interventions, medications
- Need to develop falls prevention interventions
  - Identifying evidence base
  - Identifying/Developing Theory
  - Modelling process and outcome
- Implementation
Falls in MS- Application to practice

Plan

- Aim of this part of the symposium is to consider the factors impacting on the successful application of falls programmes in the real world
- Utilise evidence from our work to date, with our experiences from trials and studies in MS; plus evidence from other areas (e.g. falls practice with older people)
Managing falls in MS - what do we need?

- A programme that addresses key modifiable risk factors
  - Likely to include education/exercise components
- A programme that is acceptable to service users
- A programme that fits with funding/service delivery models

Sources of evidence

- Systematic review (n=16)
- Nominal Group study (n=36)
- Research and experience from other IMSPFRN members
- Research from related areas

(Gunn et al 2015, 2015a)
Application of an MS falls programme in practice

- Programme structure and format
- Sustainability
- Programme support and facilitation

Programme structure and format
Programme structure and format

- Group vs individual
- Setting
- Approach

Group vs individual: Groups are viewed positively....

- With regard to exercise groups that I've been a participant in, somehow there is some kind of, um, 'group energy' that comes about ....there definitely is something there in the group. NG3MS15

Verbal comment

Falls Self-Efficacy Among Adults With Multiple Sclerosis: A Phenomenological Study

Elizabeth W. Peterson, Gary Kielholzer, Kerstin Tham, Lena von Koch

A qualitative exploration of the impact of a 12-week group exercise class for those moderately affected with multiple sclerosis

However…..

• I met a lady last week, she is terrified, she hates seeing people in wheelchairs and people who are struggling…she just gets so upset; she says it’s not worth it. And I can’t argue, what can I say? NG2MS12 Verbal comment

Frequency may be important

• If you’re an MS person there is no guarantee you can be there one week and the next week, it’s a day on day thing…. You would like to be there for that time, but there’s no guarantee you will be. NG2MS10 Verbal comment

• From my experience of the things I’ve put in place, people struggle to do it [attend on a weekly basis] for that period of time. That isn’t to say they shouldn’t have the choice, but maybe we need to just be more flexible. NG3P14 Verbal comment
Programme setting

- I wouldn’t want sessions to be in a hospital... We’re not ill as in ill, we are finding it difficult to cope but nevertheless not needing hospitals. NG3MS18 Verbal comment
- The idea of a hospital setting for me gives it some validity. I’ve got MS, I don’t want to just turn up to a random place not knowing...... I’d like to think that somebody is a professional, and you know, has got a plan in mind. NG2MS12 Verbal comment

Programme setting

Fall prevention in the community: what older people say they need

Angela Dickinson, Ina Machen, Khim Horion, Deepak Jain, Ted Maddox, Jenny Core

Negotiating Participation: How Women Living With Disabilities Address Barriers to Exercise

Danielle E. Rolfe a, Karen Yoshida b, Rebecca Renwick b & Carrie Bailey c

The lived experiences of people diagnosed with multiple sclerosis in relation to exercise

ERIKA BORKOLES1, ADAM R. NICHOLLS1, KATE BELL1, RON BUTTERLY1, & REMCO C. J. POLMAN2
Approach

- People with MS have very separate needs to ‘average’ users of falls services (e.g. over 65’s) NG3P17 Verbal comment

- By the nature of it it will tend to be older people who go [to the falls service], and then if you’re someone young with say progressive MS, you may be grieving for your former self anyway without having it thrust in your face that you are falling around like your Gran. NG3MS16 Verbal comment

Programme approach

Daily, in the form of exercises at home—if you want me to do two hours of exercise you can forget it, I have better things to do even though it may help me self-manage my condition. NG3MS16 Verbal comment

Integration of balance and strength training into daily life activity to reduce rate of falls in older people (the LIFE study): randomised parallel trial

Lindy Clemson professor of occupational therapy and ageing, Maria A Fliastone Singh john sutton chair of exercise and sport science, professor of medicine, Anita Bundy professor of occupational therapy, Robert G Cumming professor of epidemiology and geriatric medicine, Kate Manollaras research assistant, Patricia O’Laughlins physiotherapist, Deborah Black biostatistician, professor, and chair of health data management
Programme Approach

• Referral makes it sound like it’s a patient being referred, you know I don’t “refer” myself to the gym, you choose and you just go. NG3P14 Verbal comment

Programme support and facilitation
Programme support and facilitation

The leader is pivotal to the success of the programme

- I think the relationship between the therapist, the enabler, whatever we want to call this wonderful being who is leading this group, and the people of the programme is utterly paramount. Because unless that sense of trust, respect, friendliness is there, the opportunity isn’t going to be exploited to the full.

NG3MS16 Verbal comment

Role of the leader/ facilitator
Need for training and support

- Role and expectations
- Paradigm shift

Sustainability
Sustainability

- Maximising outcome- ‘value for practice’
- Maintaining engagement
- Funding and ongoing support

Maximising outcome- value for practice of exercise: Evidence in other groups

Challenge

Exercise in standing involving:
- movement of the centre of mass
- narrowing of the base of support
- minimising upper limb support

24%
RR 0.76
(95%CI =0.62 to 0.93)

Sherrington et al., JAGS 2008
Maximising outcome-value for practice of exercise: evidence in other groups

**Dose**
- 50+ hours
  - At least 2 hours a week of exercise for at least 6 months
  - Home or group-based or a combination of both

20%

RR 0.80
(95%CI = 0.65 to 0.99)

Maximising outcome-value for practice of exercise: Evidence in MS

**Volume:**
Positive correlation between intensity (documented mins/wk) and effect size
\[ r = 0.70 \] (p=0.009).

**Duration:**
Negative correlation between programme duration (in weeks) and effect size
\[ r = -0.62 \] (p=0.03)
Maximising outcome: Education programmes

Pilot study of a fall risk management program for middle aged and older adults with MS
Marcia Finlayson*, Elizabeth W. Peterson and Chi Cho
Department of Occupational Therapy, University of Illinois at Chicago, Chicago, IL, USA

Fall risk and incidence reduction in high risk individuals with multiple sclerosis: A pilot randomized control trial
Jacob J Sosnoff1, Yaejin Moon1, Douglas A Wajda1, Marcia L Finlayson1, Edward McAuley1, Elizabeth W Peterson1, Steve Morrison1 and Robert W Motl1

Supporting engagement

- The input needs to be given in such a way that we enjoy it; we remember it or we have prompts to remember it, and we go away and we do it. So that is, whether it’s a group or individual, those rules must apply because the only way it’s going to work is with the time, motivation and energy that we find to put into it. NG3MS16 Verbal comment
Supporting engagement

Web-based physiotherapy for people moderately affected with Multiple Sclerosis; quantitative and qualitative data from a randomized, controlled pilot study
Lorna Paul, Elaine H Coulter, Linda Miller, Angus McFadyen, Joe Dorfman and Paul George G Mattison
Clin Rehabil 2014 28: 934 originally published online 1 April 2014
DOI: 10.1177/0269215514527995

Randomized controlled pilot study of customized pamphlets to promote physical activity and symptom self-management in women with multiple sclerosis
Matthew Plow, Francois Bouthoux, Corey McDaniel, Mark McGlynn and Bess Marcus
Clin Rehabil published online 17 July 2013
DOI: 10.1177/0269215513494229

Internet intervention for increasing physical activity in persons with multiple sclerosis
Robert W Matt, Gereta Diagonikli, Thomas R Hazzard, Edward McIntyre and David C Mohr
Mult Scler 2011 17: 116 originally published online 4 October 2010
DOI: 10.1177/1352458510383148

The Efficacy of Telephone Counseling for Health Promotion in People With Multiple Sclerosis: A Randomized Controlled Trial
Charles H. Baumgartner, PhD, Mary Causino, MSW, Robini Wadhroni, BA, Laura E. Gibson, PhD, Kimberly D. Blake, PhD, George H. Kraft, MD

Supporting engagement

Randomized controlled trial of an energy conservation course for persons with multiple sclerosis
Virgil G Mathiowitz, Marcia J Finlayson, Kathleen M Mataska, Hun Yan Chen and Ping Luo

Randomized trial of a teleconference-delivered fatigue management program for people with multiple sclerosis
Marcia Finlayson, Katharine Preissner, Chi Cho and Matthew Plow
Funding and ongoing support

You need to do it properly...

- It needs to have its own resources because you get fed up trying to run everything on a shoestring and rushing in and doing a group and then rushing off again to the next thing. NG2P8 Verbal comment

- There’s just not enough time to do anything properly. It would just be depressing if we spent a lot of time developing a really lovely quality service to start off, and they wouldn’t have the time anyway.... NG2P13 Verbal comment

Take home messages....

- Intensity of practice and maintaining engagement is critical
- Participants need support and facilitation delivered by skilled and experienced staff
- Programme needs to support self-efficacy/ lifestyle/ behaviour change
- Individual flexibility within evidence-based limits is important
- We need to do this right!
Thank you for listening

Challenges moving forward
(a few of them.....)

- Developing an intervention that can work across countries, systems and disciplines
  - Finding common language
  - Getting past our own biases about what is ‘most important’ and who should deliver intervention
- Balancing what is ideal with what has the greatest chance of long term knowledge translation
- Integrating new ideas and people without starting from the beginning again
Question and Answer Period

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For more information about the Network.....

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