Understanding Engagement Decisions to Maximize Gait and Balance: Persons’ with Multiple Sclerosis and Physical Therapists’ Perspectives

Elissa C. Held Bradford, PT, PhD, NCS, MSCS
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Platform Presentation – June 3rd, 2016
Rehabilitation Intervention Track – RH01

Objective
- To describe the behaviors and underlying processes used by PwMS and recommended by PT to maximize gait and balance following discharge from out-patient PT.
- To discuss implications to practice & research in MS
Background & Significance

Gait & balance limitations
- Common\(^1\),\(^2\)
- Falls\(^3\)
- Healthcare costs ($5,700 to $11,114-26,365 USD/year)\(^4\)
- Function and quality of life\(^1\)

Current practice\(^5\)
- Exercise
- Mobility aids
- Medications
- Multidisciplinary rehabilitation

Low engagement
- Exercise & physical activity\(^6\),\(^7\),\(^8\)
- Mobility aids\(^9\)

\(^1\)Larocca The Patient 2011;\(^2\)Souza et al J Rehabil Res Dev 2010;\(^3\)Matsuda et al. PMR 2011;

Identifying & Addressing Gaps in the Literature


1. PwMS behaviors
2. Life after “discharge”
3. Multi-methods approach

PT Recommend behaviors
Decision-making processes
Study Overview

Variables of interest: Behaviors, levels of engagement, decision making processes, barriers & facilitators

^Questionnaires [SQUASH, ABC, CARE, MSWS-12, RS, FSS, MSIS-29, BHADP]

Data Analysis

Overarching PwMS-PT Theme

- Keeping their lived world large.
- Ultimate aim - PwMS stay engaged in meaningful and valued life roles
PwMS Core Theme

Challenging Self by Pushing but Respecting Limits

Resolving Uncertainty
Gathering Information
Evaluating & Weighing Information
Making the Best Choice

Goals, Routines & Resilience
Prioritizing
• Values
• Expectations

Enhancing Skills & Maintaining Hope
Consistency
• Goals
• Small steps

Establishing a Routine
• Triggers
• Rewards

Stay active & stay positive


PT Core Theme

Finding the Right Fit

Similarities & Differences
PT Toolbox
Evaluating & Weighing Information
Making the Best Choice

Develop a Partnership & Plan
Information Sharing
Expectation & Decision-Making
Confidence & Hope
Building Skills
Opportunity & Resources
Confidence & Consistency

Compare & Contrast PwMS-PT

- Differences in roles & beliefs
- Risk tolerance
- Independence
- Informational benchmarking

- Discrepancies between perceptions and stated actions

In Her Own Words -

“Well, I think it went much better this time than it did the first time I’ve had therapy... So that therapy was fine. I did the exercises. I did what they wanted....

This time getting to know them better, having interacted through the MS exercise class, them getting to learn my personality and me getting to learn theirs, it made the transition at the end of this therapy much easier and we came up with a working plan to continue to use that therapy, the things that we learned and covered in therapy more on a daily basis.” -PwMS
Clinical Implications

1) Find the Right Fit
- See similarities and get to know differences
  - PwMS expertise and uncertainty
- Develop a partnership & plan for empowerment & self-management
  - Support PwMS in learning to challenge themselves but respect limits
  - Promote confidence, consistency, & hope

2) Self-reflect on personal toolbox and beliefs¹-⁵
- Shared decision making
- Behavior change & self-management

Scholarly Implications & Future Directions

- Greater multi-method, collaborative & longitudinal research
- Solid theoretical framework & attention to framing the question
- PT/Healthcare provider role, responsibility & ability to impact engagement rates
  - Decision making processes → behavior → outcomes

Thank You to Collaborators & Mentors

Dr. Joanne Wagner\textsuperscript{1,2}, Dr. Marcia Finlayson\textsuperscript{3} & Dr. Andrea White Gorman\textsuperscript{4}

\textsuperscript{1}Saint Louis University, St. Louis, MO, USA
\textsuperscript{2}Acorda Therapeutics, Inc, Ardsley, NY, USA
Joanne Wagner is an employee and stock holder of Acorda Therapeutics, Inc
\textsuperscript{3}Queen’s University, Kingston, Ontario, Canada
\textsuperscript{4}Rocky Mountain University of Health Professions, Provo, UT, USA

Thank you.

QUESTIONS?
Elissa Held Bradford
eheld@slu.edu
Extra slides for anticipated/potential questions
**Results: Behaviors & Decision Making**

### PwMS Behaviors

![Bar Chart](image)

*Figure 3.3a. PwMS Engagement in Gait- and Balance-Enhancing Behaviors Following Discharge from PT*

### PT recommendations & PwMS Patterns of Behavior

![Bar Chart](image)

*Figure 3.3b. PT Gait- and Balance-Enhancing Behavioral Recommendations at and PwMS Patterns of Behaviors Related to PT following Discharge*
Study Limitations

- Lack of prospective clinician reported/objective outcomes
- Short time frame for follow-up
- Small sample
- No observation of behaviors

<table>
<thead>
<tr>
<th>Phase</th>
<th>Specific Aim</th>
<th>Strategy/Tool</th>
<th>Sample</th>
<th>Focused Area</th>
<th>Analysis</th>
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<tbody>
<tr>
<td>1</td>
<td>1,2</td>
<td>DC phone survey</td>
<td>7 pwMS</td>
<td>Identify behaviors, levels of engagement, barriers &amp; facilitators</td>
<td>Descriptive</td>
</tr>
<tr>
<td>1</td>
<td>1,2</td>
<td>Standardized questionnaires</td>
<td>7 pwMS</td>
<td>Identify functional status, barriers &amp; facilitators</td>
<td>Descriptive</td>
</tr>
<tr>
<td>2</td>
<td>1,2</td>
<td>Standardized questionnaires repeated</td>
<td>7 pwMS</td>
<td>Assess change &amp; stability of measures over 1 month</td>
<td>Descriptive, change scores will be analyzed through content and comparative analysis</td>
</tr>
<tr>
<td>1,2</td>
<td></td>
<td>PT records</td>
<td>7 pwMS</td>
<td>Gather information on goals, outcomes, interventions &amp; DC recommendations</td>
<td>Descriptive, Content and comparative analysis</td>
</tr>
<tr>
<td>1,2,3</td>
<td></td>
<td>PwMS interview</td>
<td>7 pwMS</td>
<td>Detailed information on behaviors, levels of engagement, barriers, facilitators, function, change &amp; stability over 1 month</td>
<td>Descriptive, Content and constant comparative analysis</td>
</tr>
<tr>
<td>1,2,3</td>
<td></td>
<td>PT interview</td>
<td>5 PT</td>
<td>Detailed information on pwMS, PT experience, PT recommendations, barriers, facilitators &amp; pwMS G&amp;B function</td>
<td>Descriptive, Content and constant comparative analysis</td>
</tr>
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</table>
### Exercise Levels

<table>
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<tr>
<th>Use of MAT</th>
<th>Meeting Guidelines</th>
<th>Not Meeting Guidelines</th>
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<tbody>
<tr>
<td>Yes</td>
<td>MS1 (Ex &gt;5x/wk): 30 mins aerobic + 3x/wk moderate intensity, strength 5x/wk</td>
<td>MS1 (Ex ≥2x/wk): 20 mins aerobic moderate intensity 1x/wk, strength 1x/wk, and 1x/wk 60 min PT lead MS ex. class combination of strength, balance, aerobic, and stretching. Amb with st. cane in community</td>
</tr>
<tr>
<td></td>
<td>MS2 (Ex &gt;5x/wk): 30 mins aerobic + 2x/wk moderate intensity and strength 5x/wk</td>
<td>MS2 (Ex ≥3-4x/wk): &lt;10 mins aerobic — intensity, no strength ex. Amb with st. cane or 2 whaled walker in community</td>
</tr>
<tr>
<td></td>
<td>MS3 (Ex &gt;5x/wk): 31-45 mins water aerobic 2x/wk and strength 3-4x/wk</td>
<td>MS3 (Ex ≥3-4x/wk): 20 mins aerobic ex 3-4x/wk moderate intensity, strength ex inconsistent 1-2x/wk. No device</td>
</tr>
<tr>
<td>No</td>
<td>MS7 (Ex &gt;5x/wk): 30-60 mins aerobic + 2x/wk (by phase)</td>
<td></td>
</tr>
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</table>

* Cutoff between meeting and not meeting Ex guidelines was ≥30 minutes moderate intensity aerobic 2x/wk and strength training of major muscle groups 2x/wk, in addition to usual daily PA.  
* Use of MAT was either a cane or walker used at least sometimes at home and or in the community.  
* Ex = exercise, x/wk = days per week, mins = minutes, amb = ambulation

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### Methods

#### Recruitment & Data Collection

**Design & Data Collection**

- **Indigible or decline n=6**
  - 3 Indigible (PT type, time since discharge, depression)
  - 3 Declined

- **Time Post Discharge from PT**
  - 0-2 Weeks
    - Telephone screen
    - Questionnaires, informed consent, medical record release, privacy consent mailed to those enrolled, n=7
  - 2-4 Weeks
    - PwMS questionnaires & forms completed, returned via mail n=7
  - Informed consent questions answered over the telephone, PwMS telephone survey completed n=7
Data Collection

Methods

Steps to maximize rigor...

Reliability & Validity
- Single researcher for all data collection
- Reliable & valid standardized questionnaires
- Formative feedback on DC survey for face validity, readability and clarity from PTs and pwMS

Dependability & Credibility
- Triangulation
- Audit trail
- Member checking
- Formative feedback on interviews for credibility, clarity and dependability from PTs and pwMS
- Negative case analysis
- Thick descriptions
- Reflexive memos
### Supplementary table 3.3: Level of Engagement in Behaviors and Functional Outcomes

<table>
<thead>
<tr>
<th></th>
<th>MS1</th>
<th>MS2</th>
<th>MS3</th>
<th>MS4</th>
<th>MS5</th>
<th>MS6</th>
<th>MS7</th>
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<tbody>
<tr>
<td></td>
<td>P1</td>
<td>P2</td>
<td>C</td>
<td>P1</td>
<td>P2</td>
<td>C</td>
<td>P1</td>
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<tr>
<td>Ex:</td>
<td>Days/week</td>
<td>5 or &gt;</td>
<td>1.2</td>
<td>5 or &gt;</td>
<td>1.2</td>
<td>5 or &gt;</td>
<td>1.2</td>
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<td>PA:</td>
<td>SQUASH (DC survey)</td>
<td>7970</td>
<td>2945</td>
<td>335</td>
<td>335</td>
<td>(A little more)</td>
<td>8400</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Same)</td>
<td></td>
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<tr>
<td>Awareness</td>
<td>Home</td>
<td>Often</td>
<td>Sometimes</td>
<td>Routine</td>
<td>Sometimes</td>
<td>Routine</td>
<td>Often</td>
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<tr>
<td>MAT Use</td>
<td>Home</td>
<td>Never</td>
<td>Never</td>
<td>Biosensor: Sometimes</td>
<td>AFO: Sometimes</td>
<td>Never</td>
<td>Never</td>
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<tr>
<td>MAT Use</td>
<td>Community</td>
<td>Rare</td>
<td>Often</td>
<td>Biosensor: Rare</td>
<td>AFO: Sometimes</td>
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<td>Walking Status:</td>
<td>MDWI-12k (DC survey)</td>
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<td>7.1</td>
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<td>(A little better)</td>
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<td>Balance:</td>
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<td>75.5</td>
<td>80.0</td>
<td>63.1</td>
<td>45.6</td>
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<td>P2</td>
<td>61.5</td>
<td>63.1</td>
<td>45.6</td>
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### Supplementary table 4.4: Barriers and Facilitators

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<th>MS6</th>
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<tr>
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<td>P1</td>
<td>P2</td>
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<td>Support Living Situation Resource Needs</td>
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<td>C</td>
<td>P1</td>
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<td>C</td>
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<td>MAT prePF</td>
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<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
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<td>Ex Enjoyment</td>
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</table>
Take Away - PwMS

1) Challenge & respect self
2) Seek and share information – build teams & partnerships
3) Use specific & general behaviors:
   - Ex, lifestyle PA, awareness, MAT, Temp, Energy, Stress, Nutrition, plus...
4) Start small building routines & flexible
5) Stay active and stay positive

Operational definitions

- Exercise = structured planned physical activity, with primary intent to improve underlying physiological systems and associated impairments
- Physical activity = any bodily movement produced by skeletal muscles resulting in energy expenditure.
- Engagement = the purposeful, voluntary selection and execution of an action by an individual.
Operational definitions

- **Movement awareness** = sensorimotor-cognitive strategies focused on either the kinematics of movement or the specific cognitive strategies that ultimately assist with movement decisions
- **Resilience** = or the process of positive adaptation, or coping, in face of adversity, also represented a personal attribute consisting of a positive can do attitude