Understanding Engagement Decisions to Maximize Gait and Balance:

Persons' with Multiple Sclerosis and Physical Therapists' Perspectives

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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; [4]Myhr et al. Mult Scler 2001; [5]Bennett et al. IJMSC 2014; [6]Motl et al. Mult Scler 2005; [7]Kohn et al. Curr Med Res Opin 2014; [8]Rhodes & Fiala Physiother Theory Pract 2009; [9]Finlayson et al. Am J Occup Ther 2001;

Identifying & Addressing Gaps in the Literature

1.Content 2. Context 3. Methodology

1. PwMS behaviors	PT Recommend behaviors	Decision-making processes
2. Life after "discharge"	3. Multi-methods approach	

Study Overview

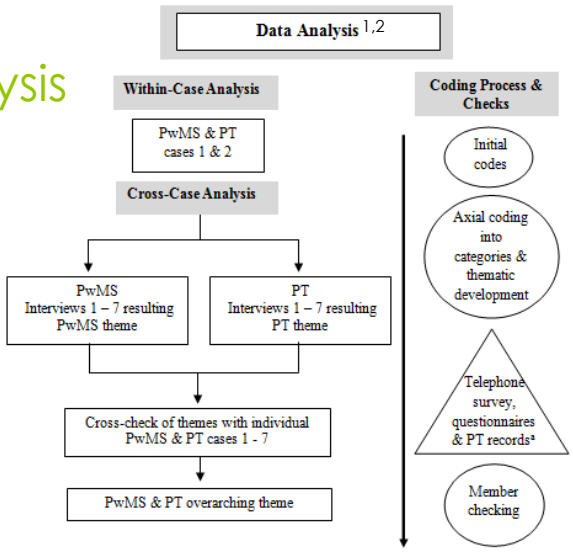
Multi-Method Case Series with Matched Pairs

PwMS Discharge from PT	PwMS Screened/Enrolled
2-4 Weeks PwMS	PwMS Survey & Questionnaires^
	PwMS Quota Matrix PT Matched & Enrolled
	PT Records
6- 8 Weeks PwMS & PT	PwMS & PT Interviews Questionnaires^

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



[1]Stake RE. Multiple case study analysis. New York: The Guilford Press; 2006.
[2]Brewer J, Hunter A. Foundations of multi-method research: synthesizing styles. Thousand Oaks, Calif.: Sage Publications; 2006.

PwMS-PT Characteristics

Table 1 Matched Pair (PwMS–PT) Characteristics

	PwMS						PT[a]			
Pair	Age	Yrs since Dx	PDDS	PT visits/ Time	ABC[c] %	Exercise Status[d] SQUASH[e]	Age	Degree, Specialty	Yrs in Clinical Practice	Clinical Practice %Neuro/ MS
1	41	< 1.0	4	11 / 3 mo	83.8	Meeting/ 7640	27	DPT	2	2 / 1
2	66	1.5	3	7 / 1 mo	80.0	Not Meeting/ 2695	45	BS, NCS	23	99 / 10
3[a]	60	22	4	7 / 3 mo	56.9	Meeting/ 6960	35[a]	MPT, MSCS	12	100 / 75
4	37	6.5	4	16 / 2 mo	35.0	Meeting/[d] 9630	33	MPT	9	40 / 5
5[a]	55	4.5	4	10 / 2.5 mo	32.5	Not Meeting/ 16,440	—	—	—	—
6	55	19	5	14 / 3 mo	38.1	Not Meeting/ 844	56	BS, MSCS	34	100 / 80
7[a]	67	8	6	19 / 6 mo	55.6	Meeting/ 4980	—	—	—	—

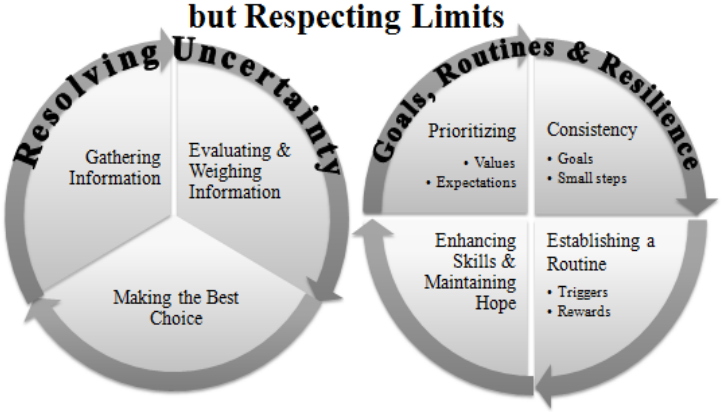
[1]Latimer-Cheung et al. Arch Phys Med Rehabil 2013

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

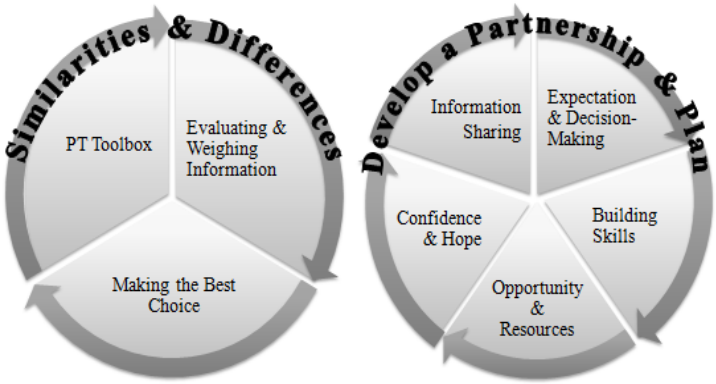


Stay active & stay positive

Thorne et al. Qual Health Res 2003; Lawden et al. J Neurosci Nurs 2014

PT Core Theme

Finding the Right Fit



Confidence & Consistency

Jensen et al. Phys Ther 2000; Schenkman et al. Phys Ther 2006

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 beliefs[1-5]
   - Shared decision making
   - Behavior change & self-management

[1]Jensen et al. Phys Ther 2000; [2]Dierckx et al. Phys Ther 2013; [3]Heesen et al. J Neurol Sci 2013; [4]Lorig & Holman Ann Behav Med 2013; [5]Lorig et al. Chronic Ill 2014

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[1,2], Dr. Marcia Finlayson[3] & Dr. Andrea White Gorman[4]

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

Thank you.

QUESTIONS?

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Extra slides for anticipated/ potential questions

PwMS Behaviors

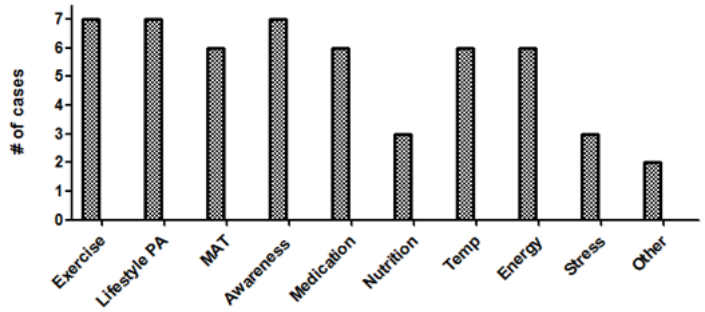


Figure 3.3a. PwMS Engagement in Gait- and Balance-Enhancing Behaviors Following Discharge from PT

PT recommendations & PwMS Patterns of Behavior

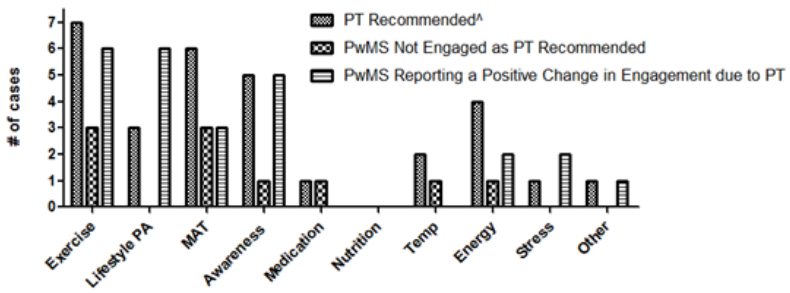
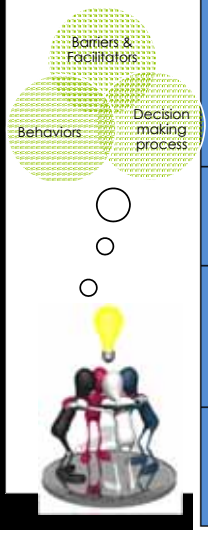


Figure 3.3b PT Gait- and Balance-Enhancing Behavioral Recommendations at and PwMS Patterns of Behaviors Related to PT following Discharge

Study Limitations

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



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

Quota Sample Results

	Exercise Levels	
Use of MAT	**Meeting Guidelines**	**Not Meeting Guidelines**
Yes	**MS1** (Ex >5x/wk: 30 mins aerobic ex 3x/wk moderate intensity, strength ex 5x/wk; indep aquatics 1-2x/wk, Amb with quad cane in community **MS3**(Ex > 5x/wk: 30 mins aerobic ex 2x/wk moderate intensity and strength ex 5x/wk, Amb with st. cane and bioness L300 in community **MS7**(Ex > 5x/wk: 31-45 mins water aerobic 2x/wk and strength ex 3-4x/wk; Amb with rollator walker in home and community	**MS5** (Ex 2x/wk: 20 mins aerobic moderate intensity 1x/wk, strength ex 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 **MS6**(Ex 3-4x/wk: <10 mins aerobic ---intensity, no strength ex, Amb with st. cane or 2 wheeled walker in community
No	**MS7** (Ex >5x/wk; 30-60 mins aerobic ex 2x/wk (by phase 2) hard intensity, strength ex 5x/wk.; AFO inconsistently, otherwise no device, wall walks in home, and use of person assistive when needed in community	**MS2** (Ex 3-4x/wk; 20 mins aerobic ex 3-4x/week moderate intensity; strength ex inconsistent 1-2x/wk; No device

*Cutoff between meeting and not meeting Ex guidelines was ≥ 30 minutes moderate intensity aerobic 2x/week and strength training of major muscle groups 2x/week, in addition to usual daily PA.[12]
*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

Methods

Recruitment & Data Collection

Design & Data Collection

PwMS recruitment from OP-PT & NMSS n=13

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

Telephone screen

Time Post Discharge from PT

0-2 Weeks

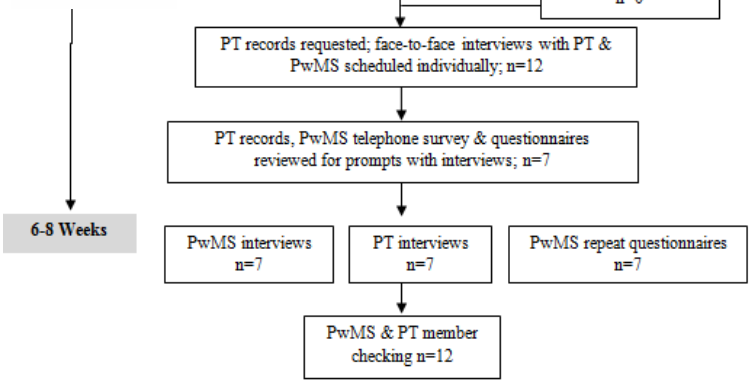
Questionnaires, informed consent, medical record release, privacy consent mailed to those enrolled, n=7

PwMS questionnaires & forms completed; returned via mail n=7

2-4 Weeks

Informed consent questions answered over the telephone; PwMS telephone survey completed n=7

Data Collection



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

Results

Supplementary table 3.3 Level of Engagement in Behaviors and Functional Outcomes

		MS1	MS2	MS3	MS4	MS5	MS6	MS7
Ex: Days/wk	P1 P2 C	5 or > 5 or>, ↑Weight	3-4 3-4, ↓Strength	5 or > 5 or > -	5 or > 5 or >, ↑Aerobic	1-2 1-2, ↑Weight	3-4 3-4 -	5 or > 5 or > -
PA: SQUASH& (DC survey)	P1 P2 C	7970 7640 333 ↓ (A little more)	2295 2695 -400↑ (A little more)	5310 6960 -1650 ↑ (Same)	8400 9630 -1230↑ (A little more)	3960 16,440 -12,480↑ (A little more)	190 844 -654↑ (Same)	7140 4980 2160↓ (A little less)
Awareness Home	*	Often	Sometime	Routine	Sometime	Routine	Often	Often
Awareness Community	*	Routine	Routine	Routine	Routine	Routine	Routine	Often^
MAT Use Home	*	Never	Never	Bioness: Sometime	AFO: Sometime	Never	Never	AFO, 4WR: Routine
MAT Use Community	*	Cane: Often	Never	Bioness: Routine, Cane: Sometime	AFO: Routine; Changed to Often in P2	Cane: Routine, Foot lifter: Never	Cane Routine; 2WR: Often	AFO Never; 4WR Often; 2WR: Sometime
Walking Status: MSWS-12& (DC survey)	P1 P2 C	66.7 59.5 7.3↑ (A little better)	14.3 21.4 -7.1↓ (A lot better)	81.o 81.0 0 - (Same)	76.2 85.7 -9.5↓ (Unsure)	81.0 66.7 14.3↑ (A little better)	31.0 42.9 -11.9↓ (Same)	59.5 57.1 2.4↑ (Same)
Balance Status: ABC& (DC survey)	P1 P2 C	77.5 83.8 -6.3↑ (Same)	77.5 80.0 -2.5↑ (A little better)	63.1 56.9 6.3↓ (Same)	45.6 35.0 10.6↓ (Unsure)	24.4 32.5 -8.1↑ (A little better)	26.9 38.1 -11.25↑ (A lot better)	65.0 55.6 9.4↓ (Same)

Results

Supplementary table 4.4. Barriers and Facilitators

		MS1	MS2	MS3	MS4	MS5	MS6	MS7
PwMS Importance	P1 P2 C	10 8-10 -2↓	10 10 -	10 10 -	10 9 -1↓	10 10 -	10 10 -	9 10 +1↑
PwMS Confidence	P1 P2 C	10 10 -	10 8 -2↓	10 10 -	10 10 -	10 10 -	7 4 -3↓	8 9 +1↑
PT Confidence	P2	7	7	10	3	9	5	5-7
Support Living Situation Resource Needs	P1	Pet, Social	Alone, None	Partner, None	Son, Physical and Social	Partner, None	Partner, Physical and Social	Pet, None
Resilience	P1 P2 C	166 152 14↓	170 167 3↓	157 146 11↓	119 130 -11↑	146 141 5↓	67 40 27↓	151 153 -2↑
BHADP	P1 P2 C	36 30 6↓	27 23 4↓	21 20 1↓	32 34 -2↑	26 27 -1↑	51 35 16↓	22 26 -4↑
FSS	P1 P2 C	4.4 3.6 0.9↓	5.1 2.1 3.0↓	5.8 6.9 -1.1↑	5.4 4.1 1.3↓	6.1 6.3 -0.2↑	2.8 2.3 0.5↓	4.8 4.3 0.5↓
MAT pre PT	P1	Yes	No	Yes	No	Yes	Yes	Yes
Ex Enjoyment*	P1	5	8	7	8	8	4	9
PwMS #1 barrier*	P1-P2	G&B, Fall risk	Denied-Maybe Fatigue	Other priorities	G&B, Fall risk	Denied - Potential Relapse	Other priorities	Fatigue
PwMS #1 facilitator*	P1-P2	Impt - Function Benefit	Resilience - Determination	Support – Knowledge from PT	Support-Knowledge from PT & others	Impt-Long-term Benefit	Impt-Long-term Benefit	Resilience - Determination
Positive Change	P1-P2	Ex, PA	Ex, PA, Aware	PA, MAT, Aware, Energy	Ex, PA, MAT, Aware	Ex, PA, Aware	Ex, PA, MAT	Ex, Energy, Aware
Not doing as recommended	P1-P2	None	Ex	Temp	Ex, MAT, Medication	MAT	Ex, MAT	Aware, Energy
Ex History (SOC pre-PT)	P1	5	3	5	3	4	5*	5
Mood	P1 P2	Optimist Optimist	Neutral Optimist	Neutral Neutral	Optimist Optimist	Optimist Optimist	Neutral Optimist	Optimist Optimist

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 = sensiormotor-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