



**THE INTERACTIVE, FATIGUE
SELF-MANAGEMENT RESOURCE:**

**THE ROAD FROM...
DEVELOPMENT TO TESTING TO HOPE
FOR A POTENTIAL NEW FATIGUE
MANAGEMENT TOOL**

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30th CMSC Annual Meeting – June 3, 2016



DISCLOSURES

- Karen Turpin – Multiple Sclerosis Medical Science & Education Liaison for Hoffmann-LaRoche, Western Canada (04APR16).



RESEARCH TEAM

- Nadine Akbar, PhD,
Post-doctoral Fellow,
Kessler Foundation
- Julie Petrin, MSc, PhD Student,
Queen's University
- Penny Smyth, MD, MS Specialist,
University of Alberta
- Marcia Finlayson, PhD, OT Reg (Ont),
OTR, Queen's University



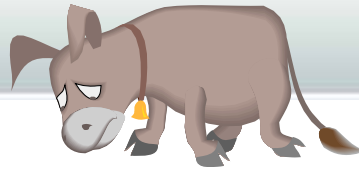
LEARNING OBJECTIVES



- Describe the utility of an interactive, fatigue self-management resource for people with MS
- Describe the key outcomes experienced by people with MS who used the resource over a 3-month period



MS FATIGUE



- "It is constant tiredness. I wake up tired; I go to bed tired. I'm tired all of the time."



- "It's a constant heaviness; like walking in cement."

- "I feel like I'm bloodless. I just feel so drained, just drained. It's a feeling like you've just lost everything. You're an empty shell."



MANAGING FATIGUE

Is NOT...



Is...





SELF-MANAGEMENT & SELF-MONITORING

- Allows for better communication with healthcare provider
- More individualized and specific to individual life circumstances
- More self-directed and empowering, more motivating
- Gives patients more control



MS Fatigue:

An Interactive
Education Resource
for Persons with MS

Use *“Enter”* to
advance the
slides

What would you like to learn about first?

- Main Menu
 - [Ways to track your fatigue](#)
 - The factors that might be influencing your fatigue and strategies to manage them
 - [Poor sleep](#)
 - [Medication side effects](#)
 - [Lack of exercise](#)
 - [Mental exertion](#)
 - [Depression](#)
 - [General fatigue management strategies](#)
 - [Communicating to others about your fatigue](#)
 - [Finding more information](#)



PILOT STUDY

- Study Aim - Evaluate the extent to which the resource...
 - Increases knowledge, confidence about managing fatigue
 - Increases self-efficacy
 - Reduces impact of fatigue
- Screening – Fatigue Severity Scale (FSS)
 - Average score between 2.0 – 5.4 (mild to moderate fatigue)
- Study Design
 - Single-group, **mixed-method**, time-series design (baseline, 3 weeks, 3 months)
- Study Measures
 - Modified Fatigue Severity Scale (MFIS)
 - Lorig Self-management Efficacy Scale (SMES)
 - Perceived Deficits Questionnaire (PDQ)
 - Semi-structured interviews
- Data Analysis
 - Quantitative – paired t-tests
 - Qualitative – interpretive description analysis



SAMPLE

- Recruited from 2 Canadian Sites (N=35)



Gender	Female	27 (77%)
	Male	8 (23%)
Average Age		49.1
Average Disease Duration		12.1
Average Disability (PDSS)		2.6
Type of MS	Relapsing	24 (69%)
	Progressive	11 (31%)



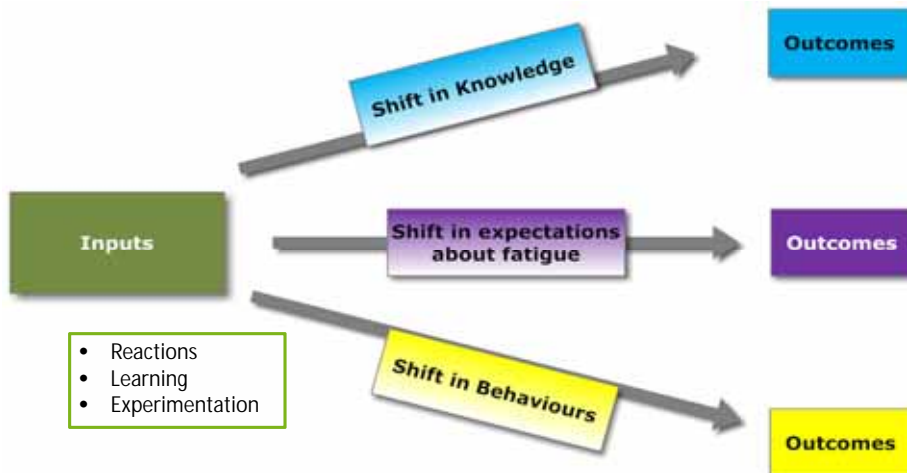
DATA COLLECTION

	Baseline (in person)	3-Week (phone)	3-Month (phone)
Quantitative	<ol style="list-style-type: none"> Demographic & Clinical Info Fatigue – MFIS Self-efficacy – SMES Perceived deficits - PDQ Usage log 	<ol style="list-style-type: none"> Usage log 	<ol style="list-style-type: none"> MFIS SMES PDQ
Qualitative	<ol style="list-style-type: none"> Current fatigue management knowledge & strategies How to use the resource 	<ol style="list-style-type: none"> Ease of use Relevance Application Facilitators Barriers 	<ol style="list-style-type: none"> Ease of use Relevance Application Facilitators Barriers Fatigue mgmt knowledge & strategies

QUANTITATIVE RESULTS

Measure (mean, SD)	Baseline	3-Months	Paired t-test	p-Value
MFIS				
Total Score	48.6 (17.5)	42.8 (16.5)	2.64	.012*
Physical Subscale	24.1 (8.8)	21.5 (7.8)	1.95	.059
Cognitive Subscale	20.3 (9.3)	17.7 (9.2)	2.89	.007**
Psychosocial Subscale	4.2 (2.4)	3.6 (2.5)	2.84	.008**
SMES	6.6 (1.6)	7.0 (1.8)	-1.91	.065
PDQ	1.7 (0.9)	1.5 (0.8)	2.68	.011*
Knowledge about MS fatigue	6.5 (2.7)	7.6 (2.4)	-3.02	.005**
Confidence in managing MS fatigue	5.5 (2.9)	7.1 (2.6)	-3.68	.001**

DATA ANALYSIS





CHANGES IN...



KNOWLEDGE:

"I'm so much better now just with that information that I've learned. It just makes me more aware. I can manage myself better. I'm more proactive with my health..."

- ❖ Clearer thinking
- ❖ Greater awareness
- ❖ Less frustration
- ❖ Normalization

EXPECTATIONS:

"Now I am more at ease with myself in not always trying to help or not always trying to keep up to others or in doing less than I used to, and I still feel alright with it."

- ❖ Less worry and fear
- ❖ Personal permission
- ❖ Trust in self



CHANGES IN BEHAVIOURS

- *"So now what I'm doing is I'm walking on each of my breaks at work. I will walk the entire 15-minute break. Yeah, I've essentially incorporated a lot more exercise instead of sitting."*

- Achieving important tasks / goal
- Greater sense of control





CHANGES OVERALL

- ✓ Better communication with others
- ✓ Improved quality of life
- ✓ Increased self-confidence
- ✓ More proactive



CONCLUSIONS



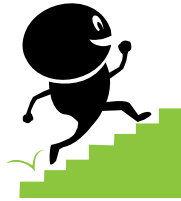
- The results from this pilot suggest this resource holds strong potential to be an effective and valuable fatigue self-management support tool.
- Self-guided fatigue management tools may aid in achieving successful outcomes when added to established treatment strategies for MS fatigue



FINAL THOUGHTS

- Next Steps:

- Randomized controlled trial
- Versions – mobile app, web-based



- Acknowledgements:

- This work was supported fully by a Pilot Research Award from the CMSC. Thank you!



- Thank you to the MS Society of Canada for the endMS SPRINT program.



THANK YOU

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