MS Wearables 101 Course

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Objectives

Building on the self-experimentation concept, we recruited a pilot sample of MS patients to explore the following research questions:

- under free living conditions, how do people with MS utilize and incorporate wearable devices and behavior change principles into their daily activity; and
- can patients with MS utilize data from a consumer activity monitor to manage their daily activity using personal rules

Phase I Qualitative Study and Course Development: interviews with MS patients who were currently using a wearable activity device informed the development of a brief behavior change course with simple self-experimentation rules (n=7)

Phase II Pilot Study: test the feasibility of applying daily personal rules for activity with a small sample of MS patients (n=12)

Wearable Use & Behavioral Adaptations

Patient Behavioral Adaptations

Planning – accounting for days of rest after a more taxing or treatment day

Schedule shifting – changing timing of strenuous activities because of the effects of heat on MS symptoms

Environmental adaptations – avoiding the heat by finding environmentally controlled settings such as malls and large stores (e.g., Costco)

Pacing - reducing activity intensity, slowing down, and not pushing beyond indicators of worsening symptoms (e.g., reduction in range of motion)

Wearables 101 Course

Session 1: Sweet Spot Concept

- "Sweet Spot" - number of self-perceived maximum steps that a participant can complete based on their condition each day without overtaxing themselves

- track their steps for one week, determine most troublesome symptoms, rate their overall daily status using the online PLM InstantMe ("How are you feeling now?") on a five-point rating scale ("very good' to "very bad")

**Session 2: Develop Personal Rule**

- Review Week 1 Fitbit tracking data - determine the most impactful symptom affecting on their daily activity, and then develop a "sweet spot" matching rule

    - When my pain level reaches "very bad", I will reduce my step goal by 200

- patients selected a behavior change technique (e.g., self-reward) that would be applied when they matched the sweet spot

- For the next two weeks, rate InstantMe, set step goal based on rule, rate InstantMe at end of day, apply self-reward if met goal

Session 3: Review Self-Experimentation

- participants reviewed perceived effectiveness in applying rules ("matches")

- assessed of the overall experience with the course

- provided recommendations for course changes

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Results

- ❑ Adherence to personal daily match rules "sweet spot" was variable
- ❑ Positive reports about activity awareness, pacing, links between symptoms and activity levels

Box-plots grouped by participants. Circles indicate daily step count
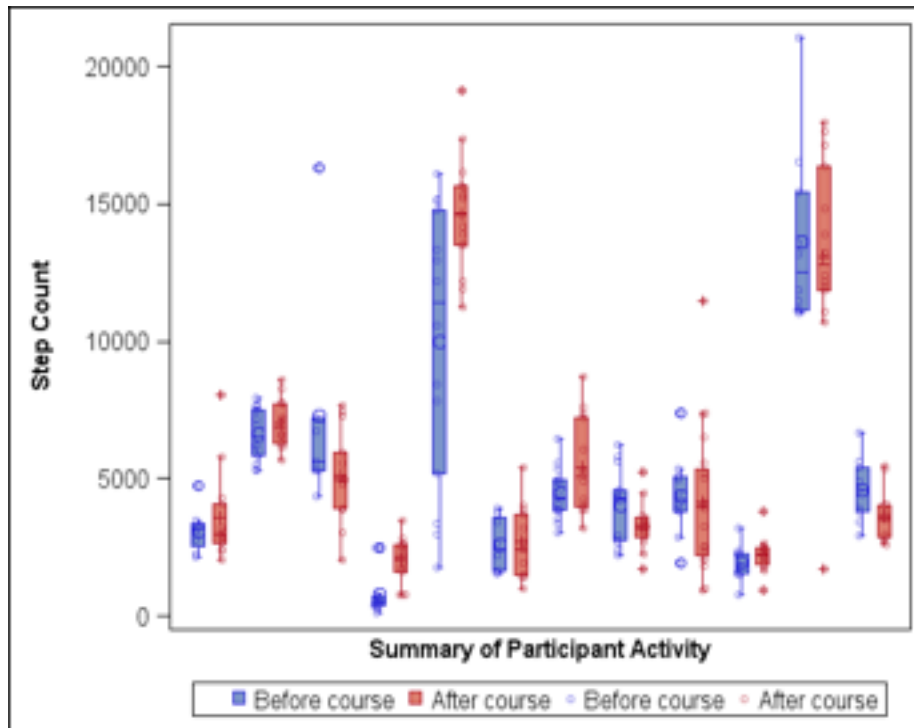
Participant	Before course		After course			
	Mean	CV[a]	Mean	CV[a]	Match[b]	Adherence[c]
1	3111	26	3589	47	9/13	69%
2	**6619**	**14**	**6978**	**12**	**12/14**	**86%**
3	7269	56	5117	33	3/12	25%
4	802	102	2019	40	4/13	31%
5	9981	50	14625	15	9/14	64%
6	**2698**	**38**	**2694**	**48**	**1/10**	**10%**
7	4448	21	5400	32	4/9	44%
8	4039	33	3290	26	9/14	64%
9	4371	34	4163	62	2/13	15%
10	1949	34	2225	29	9/14	64%
11	13621	24	13063	31	5/6	83%
12	4580	26	3644	25	3/11	27%
Aggregate statistics[d] (Mean)	**5291**	38	**5567**	33	.	49% Range **10% to 86%**

a: CV (Coefficient of variation) = Standard deviation (SD)/mean a measure of variability in relation to the mean
b: Match shows concordance between daily goals with device measured activity within a ± 20% range. Data presented show total match days (numerator)/total course days (denominator). Note: Total course days may not equal total days in session 2 due to skipped course days.
c: Adherence is the percentage of match days during the course
d: Aggregate statistics reflect the mean of the variables for all 12 participants

Implications for Data Donation/Citizen Science

- Consider the role of data within the context of a broader disease self-management plan (actionability)

- Engagement methods utilized for wellness context may not work in chronic disease context, e.g., social competitive features (more is not necessarily better)

- Leverage existing behavior change methods that utilize PHD ("health hacks")

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