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INTRODUCTION

Mobility impairment impacts the majority of multiple sclerosis (MS) patients, yet quantified assessment of walking ability is limited to the clinical setting. Consumer devices can measure number of steps and distance walked on a continuous basis in a patient's home environment. These data could provide potentially important information about the impact of MS on patient mobility over time to supplement office physician assessments.

The availability of accurate but low-cost consumer fitness devices that are designed to capture and transmit activity data from one's daily routine makes it practical to monitor gross levels of patient activity remotely in a non-intrusive way. Patient acceptance and adherence to wearing the devices is key to capturing useful data. In this study we considered the practicality of deploying activity monitoring devices, user acceptance and adherence to wearing devices, and the collection of data.

METHODS

PatientsLikeMe (PLM) is an online platform for people to track their health data (conditions, symptoms, labs, treatments, etc), and exchange experiences with other patients.

248 members of the PLM MS community were recruited to participate in a study deploying Fitbit One™ activity trackers. Devices were mailed to participants with instructions on activation and authorization of data sharing between the manufacturer and PLM. Patients were asked to wear the devices during their daily activities and charge the devices as needed. These devices automatically transmit activity data to Fitbit servers when in proximity of the patient's Bluetooth®-enabled computer or smartphone. The daily activity data was downloaded by PLM from Fitbit through their public web service.

Daily step and altimeter data were collected for a period of 3 weeks. For patients that chose to record it, sleep quality data was also collected. For each patient, basic demographic and self-reported functional disability Multiple Sclerosis Rating Scale (MSRS) scores were gathered from the participant's PLM profile. At the close of the study, patients were asked to complete a survey to provide feedback on their experiences with the device.

RESULTS

PLM users with MS (N=1600) were sent invitations to be part of this study and 385 responded. 248 respondents were selected on the basis of their responses to a brief survey that asked about their access to a computer or smart phone with Internet access, and if they used a wheelchair. Those in a wheelchair or without ability to connect the device to the web were excluded. Of the 248 participants that received fitness trackers, 213 (82%) activated the device with the Fitbit website and authorized PLM to access their activity data. 203 of those that authorized sharing of the data synchronized the device with the service and produced tracking data.

Only 5% of participants had used a fitness tracker before. Those that did not sync their devices reported higher MSRS score (mean=40) than those that did sync (mean=31) (see Table 1). Participants synced an average 18.21 days of data over the 21-day study (87% adherence) and walked an average of 4671 steps per day (SD=2639).

Figure 1. Step Activity Versus Walking Ability

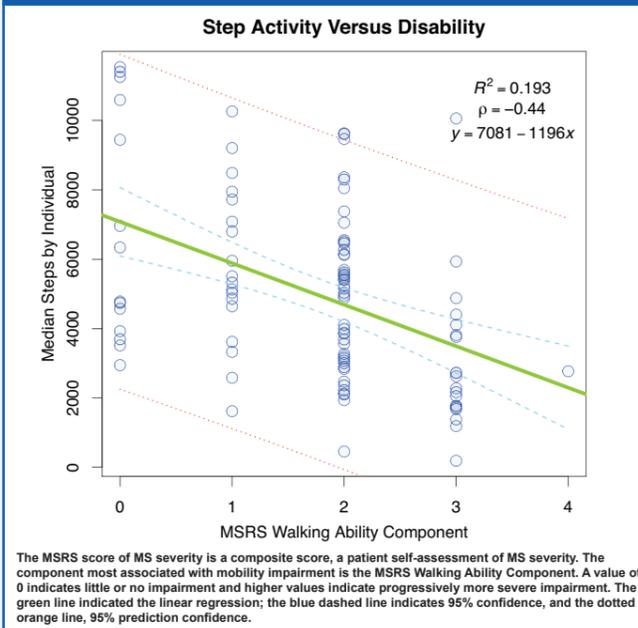


Table 2. Correlation of Demographic and Activity Data

	Mean	Median	Std. Dev.	CORRELATION								
	BMI	Days Since Diagnosis	Floors	Gender	Height	MSRS (walking ability)	Steps	Weight				
BMI	28.95	27.31	7.23	1.00								
Days Since Diagnosis	3784	2799	2946	-0.19	1.00							
Floors	9.11	5	18.48	-0.15	-0.15	1.00						
Gender	81.25% Female			-0.10	-0.03	-0.01	1.00					
Height (cm)	168.60	167.70	9.75	-0.16	0.11	0.01	0.55	1.00				
MSRS (walking ability)	1.73	2	0.96	0.15	0.08	-0.26	0.10	0.03	1.00			
Steps	4921	4181	3509	-0.27	-0.17	0.56	0.10	-0.04	-0.44	1.00		
Weight (kg)	82.29	79.77	21.16	0.90	-0.15	-0.14	0.14	0.28	0.16	-0.27	1.00	
Age	51.36	52	9.69	-0.12	0.35	-0.33	0.04	-0.02	0.34	-0.12	-0.13	1.00

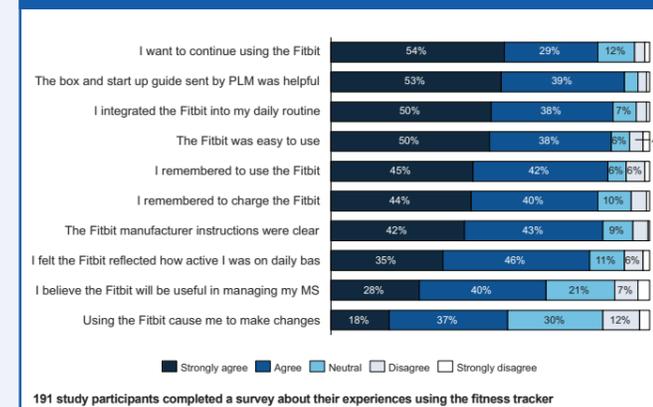
Pearson correlation coefficients for all pairs of demographic and observation parameters. Correlations with p < 0.01 are indicated in blue, and correlations with p < 0.0001 are indicated in bold-red (excluding self-comparisons).

Demographic parameters such as age, height, weight, gender, and estimated computed body mass index showed some correlation with step and stair-climbing activity (see Table 2). Younger participants tended to climb more stairs, and those with higher body mass indices tended to take fewer steps. Older patients tended to have higher walking ability scores (indicating more impairment). Higher walking ability scores (greater impairment) also correlate with less stair climbing. There was little observed correlation between gender and step activity.

The correlation between the participants' self-reported walking ability (a component of the MSRS composite score) and number of steps taken had a correlation of -0.44 (p < 0.0001); note that a higher MSRS "walking-ability" component score represents increased impairment). Age significantly correlated with the number of floors climbed, but little correlation overall step activity (Table 2).

191 participants responded to a post-study survey about their experience with the fitness tracker device (see Table 1 and Figure 2). 88% reported the device was easy to use and incorporate into their daily routine. 83% agreed that they would continue to use the device after the study. 68% believed that device would be useful to them in managing their MS.

Figure 2. Post-study Survey Summary Results



CONCLUSIONS

This study established a framework for the rapid and effective deployment of activity tracking devices to MS patients and subsequent data collection. The patients for this study were recruited in less than 24 hours of sending out the invitation to participate. Those that responded to the invitation were more than twice as likely as non-respondents to have accessed the PLM service a week prior to their invitation. Few participants had issues in setting up their devices – most indicating the device was easy to use. Each recipient received a kit containing the tracker, and a step-by-step guide for configuring the device provided by PLM, as well as a contact for assistance, if any was required. Adherence to wearing and charging the devices was high, as reflected by the amount of data synced by users. Overall user experience was extremely positive and MS patients found the Fitbit One device a useful aid in helping quantify their walking

Correlation between the observed number of steps and patient-reported walking ability score suggests that gross measures of daily can be used to quantify walking ability in the patient's home environment. Further study is needed to determine whether changes in walking activity would correlate with MS progression over time.

References

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- PatientsLikeMe survey data for Biogen Idec Devices Experience Survey; "Use of Activity Tracker in MS: Your Experience"

Disclosures

This study was supported by Biogen (Cambridge, MA, USA). JM, SD, JR: employees of Biogen; hold stock/stock options in Biogen.

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Table 1. Participation Details

	Participants		Device Activity		Survey Response	
	All (n=248)	Syncs (n=203)	Non-Syncs (n=45)	Completes (n=191)	Incompletes (n=57)	
Age, Mean (SD)	51 (9)	51 (9)	52 (9)	51 (9)	51 (8)	
Gender (n, % Female)	194 (78%)	159 (78%)	35 (78%)	155 (81%) ^b	39 (68%) ^b	
MSRS, Mean (SD)	32 (17)	31 (17) ^a	40 (15) ^a	31 (17) ^c	37 (18) ^c	
Prior Fitbit Use (n, %)	12 (5%)	12 (6%)	0 (0%)	10 (5%)	2 (4%)	
Sync (n, %)	203 (79%)	-	-	178 (93%) ^d	25 (44%) ^d	
Median Step Count (n, %)	-	-	-	-	-	
< 4,000		116 (57%)		102 (57%)	14 (56%)	
4,000-10,000		81 (40%)		72 (41%)	9 (36%)	
> 10,000		6 (3%)		4 (2%)	2 (8%)	

The term "sync" here refers to a participant that uploaded their activity data through the Fitbit service; "completes" refers to participants that responded to the post-study questionnaire about user experience. Letter superscripts designate pairs of observations that show significant difference.