International Journal of Medical Informatics 100 (2017) 26–31

Contents lists available at ScienceDirect

International Journal of Medical Informatics

journal homepage: www.ijmijournal.com

Remotely engaged: Lessons from remote monitoring in multiple sclerosis

Matthew M. Engelhard[a,*], Stephen D. Patek[b], Kristina Sheridan[c], John C. Lach[d], Myla D. Goldman[e]

[a] Department of Systems and Information Engineering, University of Virginia, P.O. Box 400747, Charlottesville, VA, 22904, USA
[b] Department of Systems and Information Engineering, University of Virginia, Charlottesville, VA, USA
[c] MITRE Corporation, McLean, VA, USA
[d] Department of Electrical and Computer Engineering, University of Virginia, Charlottesville, VA, USA
[e] Department of Neurology, University of Virginia, Charlottesville, VA, USA

ARTICLE INFO

Article history:
Received 15 August 2016
Received in revised form 6 January 2017
Accepted 7 January 2017

Keywords:
Multiple sclerosis
Patient engagement technology
Patient empowerment
Patient-provider communication
Patient-reported outcomes
Personalized medicine

ABSTRACT

Objectives: Evaluate web-based patient-reported outcome (wbPRO) collection in MS subjects in terms of feasibility, reliability, adherence, and subject-perceived benefits; and quantify the impact of MS-related symptoms on perceived well-being.
Methods: Thirty-one subjects with MS completed wbPROs targeting MS-related symptoms over six months using a customized web portal. Demographics and clinical outcomes were collected in person at baseline and six months.
Results: Approximately 87% of subjects completed wbPROs without assistance, and wbPROs strongly correlated with standard PROs ($r > 0.91$). All wbPROs were completed less frequently in the second three months ($p < 0.05$). Frequent wbPRO completion was significantly correlated with higher step on the Expanded Disability Status Scale (EDSS) ($p = 0.026$). Nearly 52% of subjects reported improved understanding of their disease, and approximately 16% wanted individualized wbPRO content. Over half (63.9%) of perceived well-being variance was explained by MS symptoms, notably depression ($r_s = -0.459$), fatigue ($r_s = -0.390$), and pain ($r_s = -0.389$).
Conclusions: wbPRO collection was feasible and reliable. More disabled subjects had higher completion rates, yet most subjects failed requirements in the second three months. Remote monitoring has potential to improve patient-centered care and communication between patient and provider, but tailored PRO content and other innovations are needed to combat declining adherence.

1. Introduction

Patient-centered care has helped patients and providers find common ground [1], and electronic symptom monitoring can improve health-related quality of life [2]. When care providers use a patient-centered approach, patients utilize health care services less often [3] with reduced associated cost [4,5]. For these reasons, both elements are part of a consensus vision for the future of MS care [6]. Internet and mobile health technologies (mHealth) can facilitate symptom reporting and patient-centered care by regularly gathering health-related information at low cost, changing the patient role through unprecedented data access and control. As a result, over 500 studies have assessed mHealth interventions, with remote monitoring of chronic conditions being one of the most common and consistent targets [7]. On average, these interventions have had a small but significant positive effect on targeted behaviors [8].

MS is a promising target for mHealth because of the progressive nature of the disease, the unpredictability of relapses, and the importance of ongoing assessment. Over 80% of persons with MS use the internet on a weekly basis and 90% can navigate an electronic health record [9], making internet-based interventions technically feasible in MS. Consequently, a growing number of mHealth studies have focused on the MS population. An informational website for MS patients and their families received positive feedback [10], and *MSDialog*, a mobile and web-based patient-reported outcome (PRO) platform, was well-received by patients and care providers [11]. Data collected through novel modalities

* Corresponding author.
E-mail address: mme@virginia.edu (M.M. Engelhard).

http://dx.doi.org/10.1016/j.ijmedinf.2017.01.006
1386-5056/

can be presented via interfaces such as the *MS Bioscreen*, a clinical data visualization tool developed specifically for MS [12].

Despite these successes, proving the real-world effectiveness of mHealth remains a top priority of the field [13,14]. Most studies have recruited highly motivated subjects, so positive results may not generalize to a broader population [15]. Moreover, participant interest seems to decline over time, casting doubts on long-term feasibility. For instance, a phone-based diabetes management intervention had a 50% dropout rate [16], and call completion for an interactive voice response service decreased over a three to six month period [17]. In a mobile-enabled weight loss intervention, adherence to dietary self-monitoring declined from roughly 70% to less than 20% over the course of the study [18]. Further, a mobile intervention for irritable bowel syndrome found a 25% decline in meal entries between weeks one and two [19]. In contrast, comparatively little is known regarding sustained mHealth compliance in MS.

The current study addresses mHealth engagement and adherence in MS by evaluating web-based PRO (wbPRO) collection in terms of feasibility, reliability, adherence, and subject-perceived benefits. While our wbPROs are similar to those used in other studies, we have conducted a detailed exploration of the dynamics of remote monitoring in persons with MS. As a secondary objective, the question "How are you feeling today?" (HAYFT) was used to study the influence of MS-related symptoms on perceived well-being. This relationship is complicated by symptom co-occurrence [20], so sustained and repeated PRO collection is required for accurate analysis.

2. Methods

2.1. Recruitment and study procedures

All study procedures were approved by the University of Virginia (UVA) Institutional Review Board for Health Sciences Research. Interested subjects were recruited from the University of Virginia James Q. Miller MS Clinic outpatient population. Written consent was obtained prior to initiation of study procedures. Recruited subjects had clinically definite MS [21] with Expanded Disability Status Scale (EDSS) $\leq$6.5. Subjects with EDSS above 6.5 were excluded to ensure that all subjects were ambulatory, as several of the selected assessments (below) are not appropriate in a non-ambulatory population. Internet access via desktop or tablet (not phone) was also required.

Subjects participated over a period of six months, with in-person assessment at baseline and six months. These baseline and six month assessments included collection of demographic information; neurologic exam by Neurostatus-certified staff; and completion of several PROs, including the MS Walking Scale (MSWS-12) [22], Modified Fatigue Impact Scale (MFIS) [23], Godin Leisure Time Exercise Questionnaire (GLTEQ) [24], Patient-Determined Disease Steps (PDDS) [25], and Performance Scales (PS) covering 11 distinct symptom domains such as mobility and vision [26].

2.2. Web-based patient-reported outcome (wbPRO) collection

A UVA-hosted web portal allowed subjects to report symptoms from home and view their symptom history. The web portal was created specifically for this study. Its navigation page features the "How are you feeling today?" (HAYFT) question, scored from 1 to 10, and links to the following four questionnaires: MSWS-12, MFIS, GLTEQ, and PS. The 11 PS were adapted for the portal and labeled as the "Symptom Tracker". The history of responses to HAYFT, MSWS-12, MFIS, GLTEQ, and each PS could be viewed as a graph or a table.

Table 1
Demographics and Selected Outcome Measures at Initial Visit.

N (Female/Male)	31 (29/2)
Age, median (range) [IQR]	48 (27–61) [44–56]
Years since onset, median (range) [IQR]	15.5 (4–37) [10.25–19.75]
Years since diagnosis, median (range) [IQR]	12 (3–31) [9.25–15]
MS Subtype:	
Relapsing-remitting disease	21
Progressive disease	10
EDSS, median (range) [IQR]	3.5 (2–6.5) [2.5–6]
PDDS, median (range) [IQR]	3 (0–7) [1–4.5]
IADL Score, median (range) [IQR]	2 (0–9) [0–4]
MSWS-12 Score, median (range) [IQR]	31.3 (0–100) [8.9–79.7]
MFIS Total, median (range) [IQR]	36 (0–67) [23–49]
T25FW, median (range) [IQR]	4.95 (3.3–67.4) [3.9–12.7]

IQR: Inter-Quartile Range; MS: Multiple Sclerosis; EDSS: Expanded Disability Status Scale; PDDS: Patient Determined Disease Steps; IADL: Instrumental Activities of Daily Living; MSWS-12: MS Walking Scale; MFIS: Modified Fatigue Impact Scale; T25FW: Timed 25-Foot Walk.

A dedicated "Symptom Tracker" page allowed subjects to compare severity between symptoms and view recent trends. Subjects were oriented to the web portal at baseline visit with a 15-min, face-to-face tour and tutorial.

Subjects were required to complete each of the five questionnaires at least once per month. Additional use of the web portal was encouraged but not required. Subjects rated the utility of the web portal and provided free-response feedback at the six month visit.

2.3. Data analysis

Data were analyzed in Matlab R2015b. Groups have been compared by *t*-test or Mann-Whitney rank sum test as appropriate for interval and ordinal variables, respectively. Spearman correlations have been used, as Pearson correlations are not appropriate for ordinal data. Subject-adjusted correlations were calculated by subtracting subject-specific mean values from all measurements before computing the correlation. Thus the mean-adjusted correlation measures the association between changes in one measurement and changes in the other while allowing for subject-specific offsets. A linear mixed-effects model was used to achieve a similar effect, but it is less appropriate for ordinal data, and clinical interpretation of model coefficients is limited by correlations between predictors. The linear mixed-effects model has been used solely to estimate the total HAYFT variance explained jointly by the predictors.

3. Results

3.1. Subject demographics and disability outcome measures

Thirty-one subjects completed all study requirements. By design, recruited subjects were evenly dispersed across the disability spectrum up to an EDSS of 6.5. Nine had mild disability (EDSS 0–2.5), 11 had moderate disability (EDSS 3–4.5), and 10 had severe disability (EDSS 5–6.5). All subjects were ambulatory, but 13 used assistive devices inside the home (7 cane; 4 walker; 2 hand bars), and three additional subjects used a cane outside of the home. Demographics and outcome measures at baseline visit are summarized in Table 1. Subjects were 93.5% female (29/31), with a median